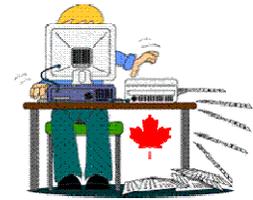


Media Watch...

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

Formal bereavement program evaluation appears to be *ad hoc* and sporadic, and potentially unlikely to provide the type and quality of information needed to retain, improve, expand, or abandon programs.

'A research literature review to determine how bereavement programs are evaluated' (p.11), in *Omega – Journal of Death & Dying*.

Canada

Lawsuit against Toronto doctors accused of ignoring man's wishes to stay alive dismissed

ONTARIO | CTV News (Toronto) – 23 August 2019 – Two doctors were acting within the rules and providing adequate care to an elderly patient when they imposed a “do not resuscitate” order on the man without notifying him or his substitute decision maker, an Ontario judge has ruled. Ontario Superior Court Justice Peter Cavanagh defended the actions of Dr. Donald Livingston and Dr. Martin Chapman as he dismissed a \$2.2 million lawsuit against the two physicians who treated Douglas DeGuerre. Cavanagh’s ruling found both sides largely agreed on DeGuerre’s medical history in the months before his death, noting the man had diabetes, kidney failure and gangrene among other conditions. Both parties also agreed DeGuerre had at one point signed a document saying he did not wish to be resuscitated if death seemed imminent. The suit, filed by Ontario resident Joy Wawrzyniak, accused the doctors of negligence and malpractice in the death of her father, a 88-year-old veteran of the Second World War. Wawrzyniak said that while her father was contending with several serious conditions at the

time of his death in September 2008, he had repeatedly expressed a wish to keep pursuing treatments and had empowered her to continue advocating for him. Her suit alleged Livingston and Chapman changed her father’s status from “full code” – meaning make all reasonable efforts to keep the patient alive – to “do not resuscitate,” without asking either her or her father. <http://bit.ly/2MBIwvA>

Specialist Publications

'Organizing end of life in hospital palliative care: A Canadian example' (p.13), in *Social Science & Medicine*.

'But it's legal, isn't it? Law and ethics in nursing practice related to medical assistance in dying' (p.14), in *Nursing Philosophy*.

Cont.

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

- ONTARIO | CTV News (Toronto) – 24 March 2019 – ‘**Toronto doctors sued for allegedly ignoring veteran’s wishes to stay alive.**’ A trial is set for two doctors accused of ignoring an elderly man’s wishes to stay alive, allegedly imposing a “do not resuscitate” order without consulting him or his substitute decision-maker. It is alleged the doctors changed his status from “full code” to “do not resuscitate,” without asking the patient. The patient’s daughter twice filed complaints to the College of Physicians & Surgeons of Ontario, neither of which resulted in any action being taken. <http://bit.ly/2UUSRII>

Noted in Media Watch 22 June 2015 (#415, p.1):

- ONTARIO | *The Toronto Star* – 17 June 2015 – ‘**Watchdog cautions doctors in Sunnybrook end-of-life case.**’ After twice exonerating two Sunnybrook Health Sciences Centre doctors for their conduct in a controversial 2008 end-of-life case, Ontario’s medical watchdog has had what experts are calling an unprecedented change of heart. The College of Physicians & Surgeons has issued written cautions against Drs. Martin Chapman and Donald Livingstone after previously rejecting a formal complaint and two appeals by the daughter of a man they treated. <http://bit.ly/2TpsK4Y>

[U.S.A.](#)

Effective comprehensive assessments prevent hospice survey deficiencies

HOSPICE NEWS | Online – 20 August 2019 – Hospices are taking stock of their comprehensive patient assessment processes in the wake of two government reports on quality deficiencies that received widespread media coverage. The U.S. Department of Health & Human Services Office of the Inspector General released the reports in July, indicating that more than 87% of the 4,563 hospices operating in the U.S. between 2012 and 2016 had at least one deficiency identified during a regulatory or accreditor survey. The U.S. Centers for Medicare & Medicaid Services (CMS) Conditions of Participation require hospices to conduct and document in writing a patient-specific comprehensive assessment that identifies the patient’s need for hospice care and services, and the patient’s need for physical, psychosocial, emotional, and spiritual care. This assessment must include all areas of hospice care related to the palliation and management of the terminal illness and related conditions. These assessments must be conducted at admission and repeated every 15

days or as frequently as the patient requires it. Nearly 42% of hospices had a deficiency related to patient assessments between 2012 and 2016. Some common issues that CMS identified during surveys include failure to document key information such as medication profiles or the patient’s history of pain. In many cases, hospices failed to update the assessments within the required 15 days. <http://bit.ly/2P7Snul>

[Specialist Publications](#)

‘**Health literacy matters more than experience for advance care planning knowledge among older adults**’ (p.9), in *Journal of the American Geriatrics Society*.

‘**Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network Workshop**’ (p.12), in *Journal of Pain & Symptom Management*.

N.B. Links to the Office of the Inspector General reports, noted in 15 July 2019 issue of Media Watch (#622, p.2), embedded in the *Hospice News* article.

More stroke patients seeking hospice care

HOSPICE NEWS | Online – 20 August 2019 – Hospice utilization among stroke patients is on the rise as an increasing number choose to end their lives in their homes, according to a recent study...¹ More than 2 million people in the U.S. died as a result of cerebrovascular disease during the study period, which ran

Cont.

from 1 January 2003 to 31 December 2017. Deaths among stroke patients in hospitals dropped nearly 10% from 72,691 to 53,467. The number of stroke patients who died in a nursing facility saw a similar decline, from 35% of all stroke decedents to 25.4%. “While the majority of patients who had a stroke die in the hospital, our data suggest that the proportion of patients who had a stroke die at home, a location preferred by patients, has increased substantially,” the study’s authors noted. “However, the experience of patients who had a stroke dying at home, and that of their caregivers, remains under-investigated. Furthermore, we demonstrate that hospice facility use has also increased.” <http://bit.ly/2Mq1Dz>

1. ‘Trends in location of death for individuals with cerebrovascular disease in the U.S.,’ *JAMA Neurology*, published online 19 August 2019. **Abstract:** <http://bit.ly/2Z5jNFu>

International

Dying in dignity behind bars

SWITZERLAND | Swissinfo (Bern) – 23 August 2019 – Swiss prisons were designed for 20-to-30-year-old offenders who are released after serving their sentences. However, the number of older inmates is steadily increasing. In 2017, there were 828 prisoners over the age of 50. Yet most prison facilities lack the necessary infrastructure to meet their needs. For some people, prison is not just a place to live, but also a place to die. “No one should have to die in prison against their will,” says anthropologist Ueli Hostettler. The question of death is one that brings us all together in a way. Hostettler is a researcher at Bern University’s Institute of Criminal Law & Criminology, and led the project ‘End of life in prison: Legal context, institutions and actors.’¹ The study found Swiss prisons, designed for offenders between 20 and 30 years old, are not ready to meet the different needs of the growing group of over-50s. <http://bit.ly/2TWuTXG>

1. Prison Research Group, Institute for Penal Law & Criminology, University of Bern: <http://bit.ly/33SPznX>

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



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>

Specialist Publications

‘Rural palliative care to support dying at home can be realised: Experiences of family members and nurses with a new model of care’ (p.5), in *Australian Journal of Rural Health*.

‘Ethical issues when working with terminally ill people who desire to hasten the ends of their lives: A western perspective’ (p.8), in *Ethics & Behavior*.

‘When is the appropriate time to integrate palliative care?’ (p.10), in *Klinicka Onkologie*.

‘Palliative care in Tajikistan’ (p.10), in *The Lancet*.

‘Construction of meanings during life-limiting illnesses and its impacts on palliative care: Ethnographic study in an African context’ (p.13), in *Psycho-Oncology*.

Out-of-hours specialist and generalist palliative care service provision. An evidence review

IRELAND | Health Research Board (Dublin) – 21 August 2019 – Inadequate community supports and deficiencies in access to services outside of regular office hours have been linked to poor outcomes for patients with life-limiting illness. Policymakers, researchers, providers, patients, and carers in Ireland have all identified out-of-hours care as



An Roinn Sláinte
Department of Health

a key deficit in current service provision. The Department of Health commissioned this review to inform the revision of national palliative care (PC) policy and address the recognised challenges in providing out-of-hours palliative care. Therefore, the purpose of this evidence review was to synthesise evidence regarding the provision of out-of-hours palliative care for adults. This systematic review of both peer-reviewed and grey literature identified no studies of sufficient quality that evaluated the effect of out-of-hours PC on patient and caregiver outcomes nor on cost and cost-effectiveness. The grey literature review included policy and practice documentation for 16 high-income countries, selected due to their well-integrated PC services. The authors identified widespread consensus about the importance of integrated, 24-hour PC in principle; however, descriptions of out-of-hours care were very limited. Specific examples of innovative care models were described in some documents. Only one set of performance measures specifically for out-of-hours PC was identified, but these indicators had not been assessed for validity or usefulness. The authors identified more barriers than facilitators regarding challenges to implementation. Barriers included insufficient resources, inadequate knowledge among practitioners and patients, a lack of guidance for non-specialists, inadequate communication between out-of-hours services and other parts of the healthcare system, and insufficient knowledge or confidence among unpaid caregivers. The findings of this review indicate that Ireland's current position is typical among high-income countries with well-established services. That is, the importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged, but details on how to organise, provide, and evaluate out-of-hours services are scant. The need for ongoing evaluation of the feasibility and effectiveness of new and existing services is critical in the context of very limited international evidence. **Download/view at:** <http://bit.ly/2L4gPYh>

End-of-life care in the U.K.

Hospices to get £25 million cash boost to secure future...

U.K. (England) | ITV News (London) – 21 August 2019 – The government has pledged £25 million to help struggling hospices and palliative care services following an ITV News and Hospice U.K. investigation into funding for end-of-life care (EoLC). In an ITV News exclusive, the Prime Minister Boris Johnson announced the cash injection “to alleviate the everyday pressures” faced by the sector. Boris Johnson said he hopes there will be more money next year too before adding: “It’s absolutely clear the work [hospice workers] do is crucial for our society.” It is hoped the new investment will improve the quality of EoLC for around 200,000 people being cared for in hospices and help keep many of the struggling facilities open. In May an exclusive [ITV] survey with Hospice UK¹ found one in three hospices are being forced to cut services, while more than half (55%) either have, or plan to, delay or cancel the roll out future plans to provide EoLC. For 89% of hospices who responded to ITV News’ survey, the cost of providing EoLC had risen in the past two years, but has not been matched by increased funding from central government. 73% have seen their funding from their local Clinical Commissioning Group had been frozen or cut. <http://bit.ly/30mvpkg>

1. ‘U.K. hospices face funding crisis as one in three forced to cut end-of-life services,’ ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] <http://bit.ly/3071bSA>

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Related

- U.K. (Northern Ireland) | *Belfast Telegraph* – 22 August 2019 – ‘**Hospice users in Northern Ireland miss out on £25 million English funding boost.**’ Hospice users in Northern Ireland are suffering a “huge shame and injustice” because they are not receiving the same financial support as elsewhere in the UK, the charity said. The region will not benefit from the £25 million cash boost announced by Prime Minister Boris Johnson to protect charitable hospices and palliative care services. Each year it costs £15.5 million to provide specialist palliative care to infants, children and adults, with only 30% of that received through statutory funding. <http://bit.ly/2NqNdqB>

The healer: In Rohingya camps, a local response reaches untreated refugees

BANGLADESH | *The New Humanitarian* (Geneva, Switzerland) – Accessed 19 August 2019 – There are nearly 100 non-governmental organizations, United Nations’ agencies, or government bodies working on the massive refugee response in Bangladesh’s Rohingya camps. But only one – a tiny local organisation – is focused on the neglected field of palliative care (PC). The Dhaka-based Fasiuddin Khan Research Foundation treats people with life-threatening or severe chronic illnesses in their homes – finding hard-to-reach patients who can’t access hospitals or clinics in the sprawling camps. Proponents say it’s the first PC programme in any humanitarian response. The group’s founder, Farzana Khan, says the needs of the dying – or of people with chronic illnesses – are frequently overshadowed in humanitarian emergencies, where responders rush to save lives and concentrate on traumatic injuries like gunshot wounds. “In a humanitarian context, the patients who need PC [are] deprioritised,” says Khan, a doctor and PC specialist. Like those working for many local groups, Khan is fighting to keep her own operations afloat. Unable to secure long-term funding,

she’s had to cut back her specialised programme. Today, the bulk of the PC work is done by a team of three: an assistant and a consultant who roam the camps, advised by Khan herself from her Dhaka base. <http://bit.ly/2TK0ziZ>



Media Watch: On humanitarian crises

Palliative care is entering the “culture” of humanitarian organizations. Morbidity and mortality caused by non-communicable diseases are about to overtake infectious diseases in adults, and the epidemiology of diseases is shifting toward chronic conditions even in low-income countries where disasters and armed conflicts are common. <http://bit.ly/2G8FVUb>

N.B. Scroll down to ‘Media Watch: On Humanitarian Crises’

N.B. Additional articles on integrating PC and symptom relief into responses to humanitarian emergencies and crises noted in 5 August 2019 issue of Media Watch (#625, p.12).

Specialist Publications

Rural palliative care to support dying at home can be realised: Experiences of family members and nurses with a new model of care

AUSTRALIAN JOURNAL OF RURAL HEALTH, 2019;27(4):336-343. Families in a rural environment feel particularly unsupported in fulfilling this last wish of their loved one, which reflects the general shortage of healthcare workforce and resource allocation to institutions. This study describes the experience of families and nurses with extended rural palliative care (PC) to support dying at home. All patients in the project died at home. The families were very positive about the extended PC; it increased their familiarity with dying, and had a positive impact on bereavement. The nurses were equally positive, but also com-

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mented on the need to debrief and on the heavy emotional toll the work takes. Rural care support for dying at home can be realised. This study has demonstrated the positive impact of an end-of-life (EoL) service, while at the same time pointing to concerns of the nursing staff on the suitability of the model of care. Healthcare workers and communities alike need to be educated and have conversations on EoL care. **Abstract:** <http://bit.ly/2NIWCQk>

Noted in Media Watch 1 July 2019 (#620, p.5):

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 26 June 2019 – ‘**Living, loving, dying: Insights into rural compassion.**’ Participants in this study discussed the challenges they experienced during end-of-life (EoL) caring, including transport into the city for treatment, and access to basic and specialised services. However, they also reported positive aspects of formal and informal palliative care, and described experiences of personable, expert, flexible and innovative caregiving. The rural location enabled personalised and innovative expressions of care. This research adds new insight into rural EoL palliation, as a complex intersection of supererogation, innovation and place-driven care. **Abstract:** <http://bit.ly/31VFHZE>
- *BMC PALLIATIVE CARE* | Online – 25 June 2019 – ‘**End-of-life care in rural general practice: How best to support commitment and meet challenges?**’ Few studies have specifically assessed the scope, nature and challenges of palliative and end-of-life care (P&EoLC) in rural general practice. These knowledge gaps limit the development of evidence-based policies and services for patients in the last months of life. This study aimed to explore the perspectives of general practitioners (GPs) and other stakeholders on rural GPs’ involvement and challenges in providing P&EoLC in regional Australia. The rural GPs’ central role in EoLC was recognized by the majority of participants but multiple challenges were also identified. **Full text:** <http://bit.ly/2X2ViDd>

N.B. Additional articles on the provision and delivery of P&EoLC in rural and remote regions of Australia noted in 4 March 2019 issue of Media Watch (#604, p.11).

Managing uncertain recovery for patients nearing the end of life in hospital: A mixed-methods feasibility cluster randomised controlled trial of the AMBER care bundle

BMC TRIALS | Online – 16 August 2019 – In recent years the number of feasibility trials conducted in palliative care has increased and they have become an important requirement for funding bodies as well as being of high value to researchers in justifying study designs (to both funders and ethics committees). However, noticeably absent from many feasibility studies reported are those that conform to the recommendation that clear feasibility objectives are in place beforehand to inform whether the study protocol is ultimately feasible. This feasibility study conformed to this recommendation and concluded that whilst the study was indeed technically possible, based on the challenges reported and the number of design modifications required, it would be impractical to use the protocol tested to guide a full trial of the AMBER care bundle. This study has, therefore, accomplished an important positive objective of a feasibility trial: the de-risking of funding of a full clin-

ical trial estimated to cost £1.2 million that would be unlikely to meet the necessary patient recruitment and retention rates necessary to identify a clinically meaningful outcome. Meanwhile, however, the AMBER care bundle continues to be used extensively in many hospitals and endorsed in policy. **Full text:** <http://bit.ly/2zbDQTj>

Extract from *BMC Trials* article

Effective timely participant recruitment is essential, since it has a significant impact on findings. Health professionals and research nurses involved in studies of this nature, therefore, require specific training to give them the right skills and to make them feel confident in identifying and then recruiting potential patient participants. Some may feel hesitant and on occasion upset, given the focus of the study. Training should, therefore, be accompanied by regular debriefings that openly discuss instances of study-invoked distress.

N.B. The AMBER (Assessment, Management, Best Practice, Engagement, Recovery Uncertain) care bundle is a complex intervention used in U.K. hospitals to support patients with uncertain recovery.

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Noted in Media Watch 22 July 2019 (#623, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 July 2019 – ‘**Optimised clinical study recruitment in palliative care: Success strategies and lessons learned.**’ Recruitment challenges to clinical research studies in palliative care (PC) settings, particularly in hospices, are well documented. However, a recent study performed across five hospices in the U.K. recruited above target and on time. The authors describe strategies that aided successful recruitment in this study, and the lessons learnt for improving future studies. A recent review suggested that the ‘Social Marketing Mix Framework’ could help researchers with recruitment strategies in PC. **Abstract:** <http://bit.ly/2YRBqoj>

Noted in Media Watch 15 July 2019 (#622, p.11):

- *MORTALITY* | Online – 10 July 2019 – ‘**The performance of researching sensitive issues.**’ Comparatively little attention has been paid to the emotional labour and emotion work researchers perform and how it is shaped by the need to behave appropriately and in ways that are in keeping with the demands of the study setting. The authors draw on two research experiences, an ethnographic study into end-of-life care in care homes and an exploration into the role of the anatomical pathology technologist in a hospital mortuary to explore the tensions between conducting sensitive research and managing emotions. **Abstract:** <http://bit.ly/2Y6ydnS>

Home care and end-of-life hospital admissions: A retrospective interview study in English primary and secondary care

BRITISH JOURNAL OF GENERAL PRACTICE, 2019;69(685):e561-e569. Enabling death at home remains an important priority in end-of-life care (EoL) policy. However, hospital continues to be a more prevalent place of death than home in the U.K., with admissions at the EoL often negatively labelled. Admissions are frequently attributed to an unsuitable home environment, associated with inadequate family care provision and insufficient professional care delivery. In this qualitative study, home-based EoL care appeared precarious. Hospital admission was considered by healthcare staff when there was insufficient nursing provision, or where family support, which was often extensive but under supported, was challenged. In these circumstances, home was not recognised to be a suitable place of care or death, justifying seeking care provision elsewhere. Home EoL care depended on substantial input from family and professional carers, both of which were under-resourced. Where either care was insufficient to meet the needs of patients, home was no longer deemed to be desirable by healthcare staff and hospital care was sought. **Full text:** <http://bit.ly/2Tb2Jrs>

Noted in Media Watch 15 July 2019 (#622, p.10):

- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY RESEARCH & PRACTICE*, 2019;1(1):e3. ‘**Navigating the path to care and death at home – it is not always smooth: A qualitative examination of the experiences of bereaved family caregivers in palliative care.**’ Understanding the complexities of end-of-life care and the support needs of family caregivers in the home setting could improve services. Relationships where families and patients are partnered with, mentored, empowered, and feel comfortable with clinicians and volunteer caregivers are valued. Flexible practical assistance is valued highly and care arrangements that are not flexible may be more harmful than helpful for some families. Models of care that are based on the assumption that home death is straightforwardly beneficial may cause unintended consequences. **Full text:** <http://bit.ly/2xJ6YRq>

Noted in Media Watch 6 May 2019 (#613, p.12):

- *PALLIATIVE MEDICINE* | Online – 3 May 2019 – “‘**It all depends!**’: **A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers.**’ It is often suggested terminally ill patients favour end-of-life care at home. Yet, it is unclear how these preferences are formed, if the process is similar for patients and family caregivers, and if there are discrepancies between preferences for place of care and place of death. The process of forming location preferences by the participants in this study was shaped by uncertainty relating to the illness, the caregiver and the services. Patients and caregivers dealt with this uncertainty on a level of thoughts, emotions, and actions. At the end of this process, patients and caregivers expressed their choices as contextual, personal, relational, conditional and flexible preferences. **Abstract:** <http://bit.ly/2IWKALQ>

End-of-life care in the emergency department

EMERGENCY MEDICINE JOURNAL | Online – 13 August 2019 – The importance of end-of-life care (EoLC) for patients and their families is well documented, however, the skills and knowledge of emergency clinicians in delivering EoLC is not widely understood but it is clear from the existing literature that we fall short in delivering consistently good EoLC although there is recognition of the need to improve. The author acknowledges the challenges of delivering good EoLC in the emergency department (ED) but more importantly considers practical ways of improving EoLC in the ED in line with best practice guidelines on EoLC. **Abstract:** <http://bit.ly/2ZaD4km>

N.B. Additional articles on palliative and end-of-life care in the ED noted in 5 August 2019 issue of Media Watch (#625, pp.9-10).

Ethical issues when working with terminally ill people who desire to hasten the ends of their lives: A western perspective

ETHICS & BEHAVIOR | Online – Accessed 19 August 2019 – Terminally ill people might want to discuss the options they have of hastening their deaths with their psychologists who should therefore know the law that regulates euthanasia in the jurisdictions where they practice. The legal, and therefore ethical, situation that influences psychologists' position and terminally ill people's options, however, differs notably across jurisdictions. The authors' aim is to provide a brief moral-legal historical context that explains how the law reform processes in different jurisdictions created these different legal contexts and options that, in turn, influence psychologists' ethical position. They conclude by considering eight specific ethical issues at a conceptual level that might confront psychologists irrespective of where they practice. **Abstract:** <http://bit.ly/2P4mdjd>



Noted in Media Watch 27 May 2019 (#615, p.8):

- *BIOETHICS*, 2019;33(4):439-447. 'Self-perceived burden to others as a moral emotion in wishes to die. A conceptual analysis.' Patients at the end of their life who express a wish to die sometimes explain their wish as the desire not to be a burden to others. This feeling needs to be investigated as an emotion with an intrinsically dialogical structure. Two key meanings of the feeling of being a burden to others as a reason for a wish to die are identified. First, it is an existential suffering insofar as it contains the perception of a plight so desperate that it can only be relieved by the end of the patient's existence. Second, it is an empathic concern that implies caring about those who bear the burden of caring for the person at the end of their life. **Abstract:** <http://bit.ly/2wrq2Db>

N.B. The focus of this special issue of *Bioethics* is on "being a burden to others and wishes to die." Journal contents page: <http://bit.ly/2W22ljH>. Additional articles on wishes to hasten death noted in 4 February 2019 issue of Media Watch (#600, p.15).

Overriding advance directives: A 20-year legal and ethical overview

JOURNAL OF HEALTHCARE RISK MANAGEMENT | Online – 21 August 2019 – Health professionals have been known to override patients' advance directives (ADs). The most ethically problematic instances involve a directive's explicitly forbidding the administration of some life-prolonging treatment like resuscitation or intubation with artificial ventilation. Sometimes the code team is unaware of the directive, but in other instances, the override is done knowingly and intentionally with clinicians later pleading that it was done "in the patient's best interests." This article surveys a twenty-year period extending back to 1997 when ethicists began to question the legitimacy of overriding ADs despite clinicians believing they had compelling reasons to do so. A legal and ethical analysis of advance directive overrides is provided as [in the U.S.] no court to date has awarded damages to plaintiffs who alleged their loved one suffered "wrongful life" following a successful life-prolonging intervention. A hypothetical scenario is especially discussed wherein a patient's DNR status is overridden because her cardiac arrest was caused by error whose effects might be reversible. The authors conclude with a strategy for mitigating certain vagaries associated with overriding ADs, but suggest that until courts provide clinicians with clear guidelines and protections, violations of patients' ADs are likely to continue. **Abstract:** <http://bit.ly/2MxzWNU>

Facilitating timely advance care planning: Discussions in the ambulatory setting with a heart failure population

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 16 August 2019 – This quality improvement project utilized a risk stratification process and an advance care planning (ACP) tool to identify patients at high risk of death and prompt ACP discussions and documentation of healthcare preferences in the electronic health record. Inherent uncertainty in heart failure (HF) prognostication and provider time constraints impede initiation of timely ACP discussions. In an effort to mitigate these obstacles, the Seattle Heart Failure Model was utilized to calculate mortality risk for 195 patients in an ambulatory HF clinic. Next, a HF-specific ACP tool, developed for this project, was used to prompt and guide ACP discussions with patients determined to have a prognosis of life expectancy of 3 years or less. Post implementation surveys suggest clinic staff believe a comprehensive and systematic approach to ACP services facilitates timely ACP discussions and decision making in the outpatient setting. **Abstract:** <http://bit.ly/2z8urvN>

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 19 August 2019 – ‘**Health literacy matters more than experience for advance care planning knowledge among older adults.**’ Advance care planning (ACP) engagement is low among vulnerable populations, including those with limited health literacy. Health literacy and socio-demographics are stronger predictors than prior ACP experience of ACP knowledge. This study suggests that providing easy-to-understand ACP materials is paramount and should be offered even if patients have previous experience with the ACP process. **Abstract:** <http://bit.ly/2TRtJNk>

Opportunities to improve utilization of palliative care among adults with cystic fibrosis: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 August 2019 – Individuals with cystic fibrosis (CF) frequently survive into adulthood and many have multi-faceted symptoms that impair quality of life. The authors screened 652 article abstracts and 32 full text articles; 12 studies met inclusion criteria. All studies were published between 2000 and 2018. Pertinent findings include that while 43% to 65% of adults with CF had contemplated completing advance care planning (ACP), the majority only completed ACP during their terminal hospital admission. Patients also reported high prevalence of untreated symptoms, with adequate symptom control reported in 45% among those with dyspnea, 22% among those with pain, and 51% among those with anxiety and/or depression. Prevalence of in-hospital death ranged from 62% to 100%, with a third dying in the intensive care unit (ICU). The majority received antibiotics and preventative treatments during their terminal hospitalization. Finally, treatment from a palliative care specialist was associated with a higher prevalence of patient completion of advanced directives, decreased likelihood of in-ICU death and decreased use of mechanical ventilation at end-of-life. **Abstract (w. link to references):** <http://bit.ly/2Hu7ecn>

Noted in Media Watch 22 October 2018 (#586, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 October 2018 – ‘**Advance care planning experiences and preferences among people with cystic fibrosis.**’ Few subjects [interviewed] reported talking with their cystic fibrosis (CF) team about care preferences or completing advance directives detailing desired medical treatments. However, most worried about living with advanced disease (84%) and felt comfortable discussing care preferences with CF providers (92%). Subjects largely preferred that advance care planning conversations occur when they are generally healthy, in the outpatient setting, and with any familiar CF team member. **Abstract:** <http://bit.ly/2ZfnZSE>

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

Noted in Media Watch 11 June 2018 (#567, p.14):

- *PEDIATRIC PULMONOLOGY* | Online – 3 June 2018 – ‘Exploring knowledge and perceptions of palliative care to inform integration of palliative care education into cystic fibrosis care.’ While palliative care (PC) is a standard of care in serious illnesses, there are no guidelines for its incorporation into cystic fibrosis (CF) care. Patients with CF, caregivers, and CF care providers may lack knowledge about PC and perceive barriers to integrated care. The findings of this study warrant replication in a larger, multisite study to inform PC educational interventions as a step toward consistent integration of PC into routine CF care. **Abstract:** <http://bit.ly/2MsH11R>

N.B. Additional articles on PC for people living with cystic fibrosis noted in this issue of Media Watch.

When is the appropriate time to integrate palliative care?

KLINICKA ONKOLOGIE, 2019;32(4):303-305. Many patients with advanced, non-curable cancer experience disease progression to a stage requiring symptomatic care alone. The integration of palliative care (PC) into oncology practice is therefore important, with many studies showing the benefits of early introduction of PC. Although all oncologists provide basic PC, recent data indicate that the parallel involvement of a specialist palliative team that addresses the psychological, social, and spiritual needs of patients may be advantageous for both patients and their families. This mode of early integration of PC has been found to enhance patient quality of life and to provide more effective use of costly treatments. In Czech hospitals, however, this mode is rarely employed. PC is usually perceived as an end-stage approach, which is initiated only when all other anticancer treatment modalities have been exhausted. This case describes the challenges and missed opportunities when PC was initiated late during the dying phase of a young female patient with metastatic colorectal cancer, and it discusses the potential benefits of early integration of PC. **Summary:** <http://bit.ly/2Mvw7rW>



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

Palliative care in Tajikistan

THE LANCET, 2019;394(10199):P624-626. This service was launched in December, 2018, in Dushanbe, a city of 800,000 people, in the west of the country and also in the Gorno Badakhshan province in the Pamir mountains in the east of the country. The government gave its approval for the launch after pilots in each of the city's four districts were deemed successful. These pilots were funded by the Open Society Institute Assistance-Foundation, Tajikistan. More than 2,440 home visits have been made to date, offering interventions to improve quality of life, and access to oral and injectable morphine and support, which includes attendance by a psychologist or religious leader if desired. A parallel service funded by the government operates out of the Republican Oncological Scientific Center, the leading cancer hospital in Tajikistan, run by the Ministry of Health & Social Protection. Although palliative care (PC) at home is becoming increasingly common in the northern hemisphere, in Tajikistan, political and religious sensitivities have led to resistance to PC services for years – particularly to the provision of care at home. Zafar Huseynzade, director of the Republican Oncological Scientific Center, says that 15 years ago, there was no such thing as PC, with no special beds or budget allocation in the health system. In this mountainous country, where three-quarters of the 9.25 million people live in hard-to-reach remote rural areas, and where there are only 410 inpatient cancer beds and 75 outpatient oncology rooms in city and district health centres, the advances in PC are far-reaching. **Full text:** <http://bit.ly/31Qlp1U>



A research literature review to determine how bereavement programs are evaluated

OMEGA – JOURNAL OF DEATH & DYING | Online – 20 August 2019 – A review of 44 research reports ... on bereavement program evaluation was undertaken to identify evaluation methods and assess their apparent efficacy. Bereavement program evaluations varied considerably, with multiple data collection methods per study common (61.4%) over single methods (38.6%). Among these evaluation methods, a self-devised questionnaire was most often used (59.1%), followed by qualitative interviewing (36.4%), and the use of one or more of 35 data collection instruments such as grief inventories or depression scales (40.9%). Evaluative data were usually only collected once (77.3%), typically around program completion. Formal bereavement program evaluation appears to be *ad hoc* and sporadic, and potentially unlikely to provide the type and quality of information needed to retain, improve, expand, or abandon programs. Evaluation method developments including evaluation standards are needed to ensure recipients and others benefit as expected from bereavement programs. **Abstract:** <http://bit.ly/30mD9Tt>

Noted in Media Watch 15 July 2019 (#622, p.12):

- *DEATH STUDIES* | Online – 11 July 2019 – ‘**Developing a practice-based research agenda for grief and bereavement care.**’ Grief and bereavement care providers were invited to participate in a three-phase Delphi study to create expert consensus on the top priorities for grief and bereavement research. Ten research priorities form the basis of a practice-based research agenda for grief and bereavement care to enable researchers to respond to key issues in grief and bereavement care that will ultimately improve the lives of bereaved people. **Abstract:** <http://bit.ly/2xJUAAs>

Noted in Media Watch 8 July 2019 (#621, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 July 2019 – ‘**A systematic literature review of the current state of knowledge related to interventions for bereaved parents.**’ This review highlights the need for individualized, well-tested, and effective bereavement care interventions to support bereaved parents. The state of the science on interventions for bereaved parents is poor and much work needs to be done to effectively address the needs of bereaved parents, including both their physical and emotional health needs. **Abstract:** <http://bit.ly/2L2S2g2>

Hospital to home transport at end of life: Survey of clinician experience

PALLIATIVE MEDICINE | Online – 21 August 2019 – Palliative transport (PT) is transport home of patients requiring critical care transport support with expectation of imminent death. Many parents prefer their child’s death at home; evidence suggests death in the preferred location improves bereavement outcomes. Little is known about the clinical and demographic diversity of patients receiving PT or the perspectives of participating staff. The cohort of 12 patients [i.e., patient population studied] was 58% female, with a mean (range) age of 0.01-22 years; racial composition was not significantly different than the palliative care clinical census over the same time period. Distances under 30 miles accounted for 50% of PTs. The majority of patients (75%) died within 2 days of palliative transport. Six unanticipated events are described. Staff reported PT as a positive experience, regarding it as an important job component. However, 63% were dissatisfied or undecided about the plan should the patient die enroute, and 48% experienced some level of dissatisfaction with communication. **Abstract:** <http://bit.ly/2HKWv3A>



Would this article be of interest to a colleague?

IPCRC.NET International Palliative Care Resource Center

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Achieving beneficial outcomes for children with life-limiting and life-threatening conditions receiving palliative care and their families: A realist review

PALLIATIVE MEDICINE | Online – 21 August 2019 – Palliative care (PC) for children and young people is a growing global health concern with significant resource implications. Improved understanding of how PC provides benefits is necessary as the number of children with life-limiting and life-threatening conditions rises. An iterative literature search was conducted over two years. Empirical research and systematic reviews about the experiences of children and families in relation to palliative care were included. Sixty papers were included in this review. Narrative synthesis and realist analysis led to the proposal of context-mechanism-outcome configurations in four conceptual areas: 1) Family adaptation; 2) The child's situation; 3) Relationships with healthcare professionals; and, 4) Access to PC services. The presence of two interdependent contexts, the “expert” child and family and established relationships with healthcare professionals, triggers mechanisms, including advocacy and affirmation in decision-making, which lead to important outcomes including an ability to place the emphasis of care on lessening suffering. Important child and family out-

comes underpin the delivery of PC. This review provides in-depth understanding into important contexts in which child and family outcomes can be achieved so that they benefit from PC and should inform future service development and practice. **Abstract:** <http://bit.ly/33Hx1XM>

Quality of life of children in palliative context, how to document it? Can we measure it?

MÉDECINE PALLIATIVE | Online – 22 August 2019 – Pediatric palliative care aims to promote quality of life but measuring this highly individual and multidimensional construct remains challenging. Difficulties are linked to heterogeneity of diseases, ages, care trajectories and type of interventions provided. Often, measure instruments do not include children's perspectives through self-reporting of what matters to them. Furthermore, the psychometric properties of some existing standardized questionnaire were criticised in the field of pediatric palliative care. **Abstract:** <http://bit.ly/2MzSxZs>

N.B. French language article.

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 August 2019 – ‘**Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network Workshop.**’ Five common challenges were identified: 1) Patient diversity and small population size; 2) Interdependencies and dynamic interactions between child, family members, and disease processes over time; 3) Outcomes and measurement; 4) Workforce and infrastructure limitations; and, 5) Presumed burden of pediatric palliative care (PPC) research upon participants. Seven priorities emerged: 1) Bolster training and development of PPC investigators; 2) Develop core resources; 3) Advance symptom measurement (and measurements of other exposures and outcomes); 4) Improve symptom management and quality of life interventions; 5) Improve communication, elicitation of goals of care, and decision-making; 6) Understand family impact and facilitate or improve family adaptation and coping; and, 7) Analyze and improve systems of care, policy, and education. **Abstract (w. link to references):** <http://bit.ly/2MxvM8r>
- *MÉDECINE PALLIATIVE* | Online – 22 August 2019 – ‘**Pediatric palliative care in Cameroon: How to respond to the discontinuity of care?**’ At the Mother and Child Center of Chantal Biya Foundation in Cameroon, the annual incidence of pediatric cancers is 150 new cases. All childrens cancers are represented. Thirty percent are incurable at diagnosis, 20% of patients forsake treatment and 90% arrive at an advanced stage of the disease. The major reasons given by families in order to justify the interruption of care are: lack of financial means and the use of other therapies. However, between the very late diagnoses that are the consequence of the advanced stages of the disease and socio-cultural determinants, it is necessary to set up a system that is able to reduce these pitfalls. This article proposes pediatric palliative home care as a response to the discontinuity of care in pediatric oncology. **Abstract:** <http://bit.ly/2Hku2ei>

N.B. French language article.

Construction of meanings during life-limiting illnesses and its impacts on palliative care: Ethnographic study in an African context

PSYCHO-ONCOLOGY | Online – 20 August 2019 – Knowledge about how people make meaning in cancer, palliative and end-of-life care is particularly lacking in Africa, yet it can provide insights into strategies for improving palliative care (PC). This study explored ways in which cancer patients, their families and healthcare professionals construct meaning of their life-limiting illnesses and how this impact on provision and use of PC in a Nigerian hospital. Meaning-making in life-limiting illness was predominantly rooted in belief systems. Most patients and their families, including some healthcare professionals, perceived that cancer was caused by the devil, mystical or supernatural beings. They professed that these agents manifested in the form of either spiritual attacks or that wicked people in society used either poison or acted as witches/wizards to inflict cancer on someone. These beliefs contributed to either non-acceptance of, or late presentation for, PC by most of patients and their families, whilst some professionals depended on supernatural powers for divine intervention and tacitly supporting religious practices to achieve healing/cure. Findings of this study revealed that cultural and religious worldviews about life-limiting illnesses were used in decision-making process for PC. This, therefore, provided evidence which could improve the clinicians' cultural competence when providing PC to individuals of African descent, especially Nigerians, both in Nigerian societies and in foreign countries. **Abstract:** <http://bit.ly/31UnWJv>

Psychiatric referral in the terminally ill patient

RECENTI PROGRESSI IN MEDICINA, 2019:110(7):343-346. The distinction between physiological and dysfunctional emotions in end-of-life care may be hard, for a twofold reason: on the one hand, the patient as a subject, with specific clinical features, personality, system of values; on the other hand, the clinical judgment by involved health professionals, particularly their specific cut-offs in discrimination between normal suffering and psychopathology. Both excessive/untimely medicalization and underestimation of medical conditions such as anxiety, depression, suicidal ideation, and insomnia may be a risk while dealing with end-of-life patients. Prompt, reliable psychiatric diagnosing contributes significantly to the major goal of dignity in death. The aims of a psychiatric consultation for patients with end-stage diseases should be: controlling concomitant psychiatric symptoms, managing pain and physical symptoms, assisting patient and relatives in the crisis-management, mediating conflicts between patient, family and ward personnel, and planning advocacy. **Abstract:** <http://bit.ly/2MnWCjh>

N.B. Italian language article

Organizing end of life in hospital palliative care: A Canadian example

SOCIAL SCIENCE & MEDICINE | Online – 16 August 2019 – Hospitals remain the most common location of death in a significant number of countries, and specialist palliative care (PC) is positioned as a crucial resource for improving hospital care for those nearing end of life (EoL). Little is known, however, about a substantive aspect of this work: how hospital palliative clinicians anticipate and organize a patient's dying trajectory. The author draws from a larger original ethnographic research study of palliative specialists in two Canadian hospitals. Abductive analysis resulted in framing their work as affective labour, both reflecting and re-creating a larger affective economy shaping the affective states of everyone involved in the provision and uptake of care. The author articulates six analytically ideal outcomes of clinicians' affective labour that organize EoL, including: 1) Proactive co-authorship of disease trajectory; 2) Mutual acknowledgement of a dying trajectory; 3) Naturalizing direction and outcome of care; 4) Ensuring a minimum of social disruption; 5) Identification as compassionate and efficient care providers; and, 6) Increased specialist knowledge and interventions. In so doing, clinicians' practices become understandable as labour to meet a diversity of – at times conflicting – individual, societal, and organizational mandates that necessarily include, but extend well beyond, the patient and her immediate social network. This is the first study to consider hospital PC as an affective economy, and presents a theoretically innovative and empirically grounded model to advance new ways of conceptualizing hospital PC. The author concludes by considering how this model, and the unique insights it affords, can inform the future development of EoL care in hospital settings. **Abstract:** <http://bit.ly/2ZhvXun>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *NURSING PHILOSOPHY* | Online – 19 August 2019 – ‘**But it’s legal, isn’t it? Law and ethics in nursing practice related to medical assistance in dying.**’ In June 2015, the Supreme Court of Canada struck down the Criminal Code’s prohibition on assisted death. Just over a year later, the federal government crafted legislation to entrench medical assistance in dying (MAiD), the term used in Canada in place of physician-assisted death. Notably, Canada became the first country to allow nurse practitioners to act as assessors and providers, a result of a strong lobby by the Canadian Nurses Association. However, a legislated approach to assisted death has proven challenging in a number of areas. Although it facilitates a degree of accountability, precision and accessibility, it has also resulted in particular challenges negotiating the diverse perspectives of such a morally contentious act. One of these challenges is the tendency to conflate what is legal and what is moral in a modern liberal constitutionalism that places supreme value on autonomy and choice. Such a conflation tends to render invisible the legal and moral/ethical considerations necessary for nurses and nurse practitioners to remain ethical actors. The authors introduce this conflation and then discuss the process of lawmaking in Canada, including the legalization of MAiD and the contributions of nursing to that legalization. We then engage in a hypothetical dialogue about the legal and moral/ethical implications of MAiD for nursing in Canada. They conclude with an appeal for morally sustainable workspaces that, when implementing MAiD, appropriately balance patient choices and nurses’ moral well-being. **Full text:** <http://bit.ly/2ZnEQm7>

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