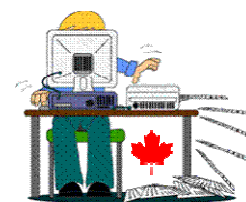


Media Watch...

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

Researchers and funding bodies should develop new strategies to ensure meaningful participation of palliative care patients and families, building in structures and processes to account for the vulnerability often present within this population.

'International palliative care research priorities: A systematic review' (p.6), in *BMC Palliative Care*.

Canada

Palliative care in Canada: Harsh facts, sad realities

THE CATHOLIC REGISTER | Online – 5 February 2020 – The cry for more palliative care (PC) continues to grow louder in Canada. While protesting the introduction of legislation expected to expand access to assisted suicide next month, Canada's bishops joined many advocates in decrying stalled plans to give Canadians the alternative of PC. "As citizens, we see all levels of government, abetted by regulatory bodies and the media, give priority to those who want to choose euthanasia and assisted suicide while providing minimal funding and support for PC, home care and hospices," said the bishops' 31 January letter to Prime Minister Justin Trudeau, signed by Canadian Conference of Catholic Bishops president Archbishop Richard Gagnon. A guaranteed right to doctor-assisted death in Canada has still not been matched with a right to PC as the vast majority of Canadians continue to die among strangers in institutions, either without PC or with too little PC delivered too late in their disease trajectory, PC experts told *The Catholic Register*. Of Canadians who died at home in 2016-2017, even though two-thirds (66%) received home care during their last year, less than one-in-six (15%) received PC at home, according to a 2018 Canadian Institutes of Health Information report.¹ Only 6% of people in long-term care (LTC), and just 22% of LTC residents with less than six months to live, received PC. Only 15% of Canadians die at home, even though 75% say they would prefer to spend their final hours with family at home. In contrast, over 40% of medical aid in dying procedures provide death at home. <http://bit.ly/3bgP1Mk>

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, Ottawa, Ontario, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view at:** <http://bit.ly/2MqmCYO>



Would this article be of interest to a colleague?

As the prison population ages, parolees with age-related illnesses struggle to find support

ONTARIO | *The Toronto Star* – 3 February 2020 – Cliff Strong just spent two weeks in the hospital with his latest bout of pneumonia. He has a litany of illnesses now, at 78, including the Parkinson's disease that requires him to use an electric wheelchair to get around. Strong is also on day parole for second-degree murder, living at a halfway house in Peterborough that is specifically designed to provide supportive and palliative care to former inmates on parole. It's the kind of place you wouldn't hear about until you – or someone you care about – needed it. Resources for elderly parolees is one part of a new guidebook released by the Provincial Human Services & Justice Coordinating Committee that provides a crash course in navigating the criminal justice system for people with age-related illnesses and their caregivers.¹ "There really isn't a lot of information out there for family members or caregivers of people that are caught up in the justice system, or are getting out. What supports or resources are available in the community on their release?" said Jeff Morgan, a case manager at Haley House, the halfway house where Strong has lived for the past four years. There is a growing number of inmates over the age of 50 in the prison system – now 25% of the population, according to a 2019 report from the Office of the Correctional Investigator.² Prisons are increasingly being called on to care for inmates who have serious age-related illnesses, or require end-of-life care, and there are not enough community-based options. <http://bit.ly/2ttKplc>

1. 'Older Adults and the Justice System: A navigational guidebook for caregivers and service providers,' the Provincial Human Services & Justice Coordinating Committee, February 2020. **Download/view at:** <http://bit.ly/3927nim>
2. 'Aging and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody,' Correctional Investigator of Canada & Canadian Human Rights Commission, 28 February 2019. [Noted in 4 March 2019 issue of Media Watch (#604, p.1)] **Download/ view at:** <http://bit.ly/2GP4aZr>

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>

U.S.A.

An inmate serving 50 years for attempted murder is an unlikely caretaker for dying prisoners

MAINE | *The Bangor Daily News* – 8 February 2020 – Prison might be the worst place you can think of to die. Isolated from the outside world, perishing behind concrete walls and metal locking doors because death caught up with you while you were serving a sentence. That is the reality for inmates housed in Maine State Prison's infirmary because they are suffering from a terminal illness and are not expected to live longer than six months. But a group of inmates has made it their mission to make sure no prisoner dies alone. The prison began offering hospice services when its new facility opened in 2001 through a partnership with the Maine Hospice Council. In 2008, the council began training inmates to provide end-of-life care to their fellow inmates. Over the past decade, this group of incarcerated hospice volunteers has worked hand-in-hand with prison medical staff to provide

comfort care to terminal inmates. Maine State Prison is the only facility in the Maine Department of Corrections system with an infirmary where inmates can be held and treated for extended periods of time, so it serves patients from other state prisons, too. <http://bit.ly/39nBHUD>

Specialist Publications

'A call for epidemiology and thanatology to address the dying, death, and grief pipeline among Blacks in the U.S.' (p.7), in *Death Studies*.

'The lived experiences of family caregivers of persons dying in home hospice: Support, advocacy, and information urgently needed' (p.8), in *Journal of Hospice & Palliative Nursing*.

Crisis of care in hospice industry

FLORIDA | 12 News (West Palm Beach) – 7 February 2020 – Hospice can be a great comfort for a person with a terminal illness living their final days. It is supposed to be a way to die with dignity in as little pain as possible. But, a CBS12 News I-Team investigation found widespread issues in the hospice industry including care failures that left patients untreated and in agony. The CBS12 News I-Team examined hundreds of state and fire marshal inspections and complaint investigations for the eight hospice facilities in ... Palm Beach County and the Treasure Coast. Every hospice in this area was cited for deficiencies, a total of 241 over the past 10 years. The most common issue is what patients are not getting: nursing care, medications, and medical equipment were often lacking. A different report states bereavement services were dropped. These findings were almost identical to the cases highlighted in an Inspector General Report on hospice throughout the country...¹ <http://bit.ly/39fNVig>

1. 'Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity: An OIG Portfolio,' Office of Inspector General, U.S. Department of Health & Human Services, July 2018. [Noted in 6 August 2018 issue of Media Watch (#575, p.3)] **Download/view at:** <http://bit.ly/2YKJreH>

Medical cannabis side effect could send hospice patients to the hospital

HOSPICE NEWS | Online – 4 February 2020 – As the use of medicinal cannabis among hospice patients grows, researchers have identified side effects of chronic use that could lead to increased emergency room visits and hospitalizations, known as cannabis hyperemesis. This condition is characterized by cyclical vomiting and abdominal pain. If not recognized quickly it can lead to severe dehydration, acute renal failure, other organ complications, and death, as well as raising the incidence of costly, high-acuity medical care, according to a recent study...¹ Presently, incidents of cannabis hyperemesis are rare, but will likely rise as the number of patients using the substance increases. The use of cannabis among hospice patients is growing more prevalent. A 2019 study ... included a survey of 310 hospice and palliative care clinicians from 40 states on practice, experience and opinions on medical cannabis, the largest such survey to date.² Nearly three quarters of the respondents indicated that they had cared for a patient who was using medical cannabis, which has shown some promise in treating pain, nausea, seizures and anxiety, according to the survey. <http://bit.ly/39iUSyS>

1. 'Cannabis hyperemesis syndrome in palliative care: A case study and narrative review,' *Journal of Palliative Medicine*, published online 30 September 2019. **Full text:** <http://bit.ly/31yoigq>
2. 'A survey of hospice professionals regarding medical cannabis practices,' *Journal of Palliative Medicine*, published online 30 September 2019. **Full text:** <http://bit.ly/2veEFfo>

Noted in Media Watch 30 December 2019 (#646, p.6):

- CANADIAN AGENCY FOR DRUGS & TECHNOLOGIES IN HEALTH | Online – Accessed 24 December 2019 – '**Medical cannabis use in palliative care: Review of clinical effectiveness and guidelines...**' Two evidence-based guidelines are included in this report. Their recommendations reflect the known high risk of adverse events of medical cannabis, coupled with uncertain benefit for palliative care (PC) patients and the availability of other treatment options. Canadian guidelines provide a strong recommendation against use of medical cannabis as first or second-line option for pain in PC. Both guidelines suggest that cannabis could be considered after other options and failed and with careful consideration of risks versus benefits. **Download/view at:** <http://bit.ly/2Qrg2wr>

N.B. The two articles cited in the *Hospice News* report above were published in a special issue of the *Journal of Palliative Medicine* on medical cannabis in palliative care noted in 14 October 2019 issue of Media Watch (#635, p.10). **Journal contents page:** <http://bit.ly/30UdroB>. Additional articles on medical cannabis in PC noted in 18 November 2019 issue of Media Watch (#640, pp.11-12).



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

International

Urgent need for end of life care volunteers to play a critical role in our National Health Service say Helpforce and Marie Curie

U.K. | Helpforce & Marie Curie – 5 February 2020 – Almost three in every ten patients in hospital are in their last year of life, yet many of them will die alone on a busy ward, spend long periods on their own, or have little company in hospital or at home. This is set to change with a new collaboration between Helpforce, a charity inspiring National Health Service Trusts to work with more volunteers in innovative roles, and terminal illness charity Marie Curie. With funding from The National Lottery Community Fund, The Peter Sowerby Foundation, the Welsh Government, and Marie Curie they are launching seven innovative projects across England, Scotland, Wales and Northern Ireland, which will mean more end-of-life care volunteers working in hospitals and in the community to provide much needed extra support to patients, families and friends, and staff. The volunteers will be trained to support terminally ill people and their families, and be there for them at a very difficult time. They will provide emotional and practical support, companionship and alleviate social isolation. They will ensure fewer patients die alone, bring comfort and help relieve the stress and

guilt that staff sometimes feel when they can't be with dying patients as much as they'd like. <http://bit.ly/2OyoEYS>

Specialist Publications

'International palliative care research priorities: A systematic review' (p.6), in *BMC Palliative Care*.

'Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?' (p.7), in *HRB Open Research*.

'Drivers of care costs and quality in the last 3 months of life among older people receiving palliative care: A multinational mortality follow-back survey across England, Ireland and the U.S.' (p.13), in *Palliative Medicine*.

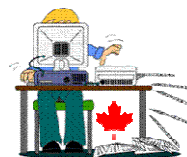
'British Medical Association launches first-ever survey of doctors' views on assisted suicide' (p.14), in *Pulse*.

Some 85,000 terminal patients opt to die with dignity over two years: Data

ASIA (South Korea) | Yonhap News Agency (Seoul) – 4 February 2020 – More than 85,000 terminally ill South Koreans have chosen to forgo life-prolonging treatment since the legalization of the right to die with dignity two years ago... The law allows terminal patients to sign up to forgo a “meaningless extension of life” by stopping or postponing four life-sustaining treatments. The four treatments – cardiopulmonary resuscitation, artificial respiration, hemodialysis and anti-cancer drug administration – are only meant to prolong the lives of terminally ill patients without giving any treatment from the start. Slightly over 37,300 terminally ill patients have so far registered with authorities to die with dignity without receiving further treatment. A total of 577,000 people have registered a letter of intent with hospitals and public organizations to stop receiving treatment once they became terminally ill. <http://bit.ly/2SfToi8>

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

Supportive care and palliative care: A time for unity in diversity

ANNALS OF ONCOLOGY, 2020;23(8):1932-1934. The current issue of *Annals of Oncology* highlights a number of articles that deal with topics related to the supportive and palliative care (PC) of cancer patients.¹ What is the difference between these two aspects of patient care? Where does “palliation” end or “support” start? This has been an area of debate for a long time, but as in all sub-specialties of oncology, one has to realize that there is a continuum. Today’s management of patients with cancer is of a multidisciplinary nature... Historical reasons have led to the development of specialist groups that have dedicated their expertise more towards issues frequent at the end of life (EoL) – often called PC – or more towards issues around treatment management and post-treatment issues – supportive care. According to the Multi-national Association for Supportive Care in Cancer, supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side-effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and EoL care are integral to supportive care. Supportive care alleviates symptoms and complications of cancer, reduces or prevents toxic effects of treatment, supports communication with patients about their disease and prognosis, allows patients to tolerate and benefit from active therapy more easily, eases emotional burden of patients and caregivers, helps can-

cer survivors with psychological and social problems. **Full text:** <http://bit.ly/2RZFnWX>

Models of palliative care delivery for patients with cancer

JOURNAL OF CLINICAL ONCOLOGY | Online – 5 February 2020 – This review provides a state-of-the-science synopsis of the literature that supports each of the five clinical models of specialist palliative care (PC) delivery, including outpatient clinics, inpatient consultation teams, acute PC units, community-based PC, and hospice care. The roles of embedded clinics, nurse-led models, telehealth interventions, and primary PC also will be discussed. Outpatient clinics represent the key point of entry for timely access to PC. In this setting, patient care can be enhanced longitudinally through impeccable symptom management, monitoring, education, and advance care planning. Inpatient consultation teams provide expert symptom management and facilitate discharge planning for acutely symptomatic hospitalized patients. Patients with the highest level of distress and complexity may benefit from an admission to acute PC units. In contrast, community-based PC and hospice care are more appropriate for patients with a poor performance status and low to moderate symptom burden. Each of these five models of specialist PC serve a different patient population along the disease continuum and complement one another to provide comprehensive supportive care. Additional research is needed to define the standards for PC interventions and to refine the models to further improve access to quality PC. **Abstract:** <http://bit.ly/2Ov9Rhk>

N.B. Access the *Journal of Clinical Oncology*’s special series of articles titled “Palliative care: Science and practice” at: <http://bit.ly/2Sn6REV>

1. Journal contents page: <http://bit.ly/2UtO5OO>

Related:

- *CURRENT TREATMENT OPTIONS IN ONCOLOGY* | Online – 5 February 2020 – ‘**How effective is palliative care in improving patient outcomes?**’ As studies and data proliferate ... questions persist about [the] who, what, why, when, and how [of] palliative care (PC) as well as the ideal time for a PC consult and length of involvement. When comparing outcomes from chemotherapy trials, it is important to consider the dosing regimens used in the various studies. In the same way, it is important to account for the “dose” of the PC interventions utilized across studies, and apples to apples comparisons are needed in order to draw accurate conclusions about PC’s benefits. The ultimate question is: Does PC indeed improve outcomes? **Opinion statement (w. list of references):** <http://bit.ly/37cnFnG>



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Shared decision-making with oncologists and palliative care specialists effectively increases the documentation of the preferences for do not resuscitate and artificial nutrition and hydration in patients with advanced cancer: A model testing study

BMC PALLIATIVE CARE | Online – 4 February 2020 – The SOP (Shared decision-making with Oncologists and Palliative care specialists) model significantly increased the rate of do not resuscitation documentation in patients with advanced cancer in this pilot study. The functional status of patients is the most important influencing factor on the documentation rate in this model. The coordination of oncologists and palliative care specialists in the SOP model demonstrated a feasible strategy to facilitate the decision-making process of the patients. The model might help patients with advanced cancer to receive end-of-life treatments concordant with their wishes. **Full text:** <http://bit.ly/2v3xEy6>

International palliative care research priorities: A systematic review

BMC PALLIATIVE CARE | Online – 3 February 2020 – The authors call attention to the need for more end users in research priority setting exercises, therefore, researchers and funding bodies should develop new strategies to ensure meaningful participation of palliative care (PC) patients and families, building in structures and processes to account for the vulnerability often present within this population. Findings of this review provide an initial blueprint for PC research funders and policymakers to contribute to the future research agenda for PC from a patient and healthcare professional perspective. Given that funding resources are limited the importance of collaboration and international approaches to PC is growing, these findings may help to inform this debate. Methodologically, a standardised approach and reporting for priority setting is advocated allowing for increased validity and comparability of findings from across PC settings. Due to varied methods and analytical techniques, an additional challenge was presented for the authors of this review when trying to compare and weight studies. Future attempts to set research priorities should involve a multidisciplinary representation of stakeholders, such inclusion will provide credibility and enhance the feasibility of the developed priorities. Whilst it is outside the remit of this review to specify an appropriate priority setting methodology, the conduct of any such exercises should be governed by methodological guidelines, clear objectives and defined criteria and concepts, for identifying and ranking priorities. Doing so, will aid the transparency of the process and credibility of the results. **Full text:** <http://bit.ly/37VsJxS>

Related:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 February 2020 – ‘**Economics of palliative care for cancer: Interpreting current evidence, mapping future priorities for research.**’ Early research studies on the economics of palliative care (PC) have reported a general pattern of cost savings during inpatient hospital admissions and the end-of-life phase. Recent research has demonstrated more complex dynamics, but expanding PC capacity to meet clinical guidelines and population health needs seems to save costs. Quantifying these cost savings requires additional research, because there is significant variance in estimates of the effects of treatment on costs, depending on the timing of intervention, the primary diagnosis, and the overall illness burden. **Abstract:** <http://bit.ly/3beeGW5>

Noted in Media Watch 27 January 2020 (#650, p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2020 – ‘**Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data.**’ Research is important internationally, impacting on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication, and be sub-optimal for healthcare development. **Abstract (w. list of references):** <http://bit.ly/3aCr8i5>

Palliative care needs of direct care workers caring for people with intellectual and developmental disabilities

BRITISH JOURNAL OF LEARNING DISABILITIES | Online – 31 January 2020 – Direct care workers (DCWs) caring for people with intellectual and developmental disabilities (PWIDD) provide palliative care (PC), but research indicates DCWs are ill-equipped to do so. Staff trained as DCWs in organisations that serve PWIDD were surveyed in suburban and rural areas of a U.S. Midwestern state. Participants reported limited experience in legal matters, yet had substantial experience in assisting PWIDD with pain, distress and bereavement. Training was inadequate but desired for cultural competence, effective communication, post-death logistics and legal matters. Rural DCWs reported less PC experience and training than suburban counterparts. The results of this survey demonstrate the need for specific types of PC training among DCWs caring for PWIDD and that such training should be prioritised in rural agencies. Future research can explore ways to maximise training effectiveness. **Abstract:** <http://bit.ly/31taXzp>

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

A call for epidemiology and thanatology to address the dying, death, and grief pipeline among Blacks in the U.S.

DEATH STUDIES | Online – 6 February 2020 – Dying, death, and grief are significant events that impact individuals, families, and communities. In the U.S., Blacks historically have higher morbidity and mortality rates than other racial-ethnic groups. While death is a normal and natural phase of the life-course process, high incidents of infant mortality, premature death, and preventable death are not. The disproportionate burden of dying, death and grief among Blacks have detrimental consequences which demand interdisciplinary interventions from public health and death study researchers. The authors explores dying, death and grief from three distinct fields of study: 1) Epidemiology of death; 2) Social epidemiology of death; and, 3) Thanatology. **Abstract:** <http://bit.ly/2S7e8K6>

Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?

HRB OPEN RESEARCH | Online – 3 December 2019 – The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.¹ The difference primarily reflects Ireland's relatively young population. Projected increases are underpinned by two factors: increasing absolute numbers of people dying (68% increase, 2016-2046), and increasing proportion of all deaths that are from a disease indicating PC need (from 76% in 2016 to 80-83% in 2046). Increases are most observable in the 85+ age group. The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis by 12:1, and this ratio is projected to remain fairly constant as both groups increase in absolute size over the next 30 years. People living and dying with a disease associated with PC need account disproportionately for disability burden, pain prevalence and health care utilisation. Per person burden is highest among those who are in the last year of life; total burden is larger among those with life expectancy of more than a year because they are a much larger group. Both groups, and so their associated health burdens and care needs, will increase significantly in size to 2046. **Full text:** <http://bit.ly/2OzrhJJ>

1. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services,' *BMC Medicine*, published online 18 May 2017. [Noted in 22 May 2017 issue of Media Watch (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>

The overlap between geriatric medicine and palliative care: A scoping literature review

JOURNAL OF APPLIED GERONTOLOGY | Online – 2 February 2020 – With an increasing aging population worldwide, there is a growing need for both palliative care (PC) and geriatric medicine (GM). It is presumed in medical literature that both specialties share similar goals about patient care and could collaborate. To inform future service development, the objective of this review was to identify what is currently empirically known about overlapping working practices. This article provides a scoping literature review on the relationship between GM and PC within the U.K.. The review encompassed literature written between 1997 and 2019... Three themes were identified: 1) Unclear boundaries between specialties; 2) Communication within and between specialisms; and, 3) Ambiguity of how older people fit in the current healthcare system. The authors suggest that more empirical research is conducted about the overlap between PC and GM to understand how interprofessional working and patient care can be improved. **Abstract:** <http://bit.ly/31pTQib>

N.B. Additional articles on the potential overlap of GM and PC noted in 6 January 2020 issue of Media Watch (#647, pp.6-7).

Self-compassion and healthcare chaplaincy: A need for integration into clinical pastoral education

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 3 February 2020 – Clinical chaplains are exposed to varying degrees of suffering and are not exempt from suffering themselves. This study took a phenomenological approach to examining self-compassion among 11 clinical chaplains, all of which had suffered from personal and/or professional hardships while providing spiritual care to medical staff, patients, and families. The three elements of self-compassion are mindfulness, self-kindness, and common humanity. Results showed that clinical chaplains' understanding of the aspects of self-compassion are limited or non-existent. Participants in this study ardently shared their experiences as they related to self-care activities during times of personal hardship. However, the intentional implementation of self-compassion practice was not displayed in these narratives. The need for education in this area would prove to enhance self-awareness and overall self-care within the profession of clinical chaplaincy. **Abstract:** <http://bit.ly/2GV1JCw>

N.B. Additional articles on the role of chaplaincy in palliative and end-of-life care noted in 13 January 2020 issue of Media Watch (#648, p.4).

The lived experiences of family caregivers of persons dying in home hospice: Support, advocacy, and information urgently needed

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 1 February 2020 – Death in America is changing from hospital to home, which demands complex skills by family caregivers (FCGs). However, information from family members about the challenges of providing home hospice care until death is scant. To understand the challenges a family caregiver confronts when he/she decides to deliver hospice care and during the actual delivery of the hospice care, the authors used descriptive phenomenology methods to document the experience of 18 FCGs as they delivered home hospice care. They learned the decision to begin home hospice was made by a physician, followed frequently by family resistance and refusal to assist. Family caregiver burden is enormous, compounded by fatigue, sleeplessness, and confusion on issues such as morphine dosage and administration. The stages and process of dying, such as transition, baffled FCGs. All FCGs agree financial and emotion support, empathic advocacy, and affirmation of their worth are needed to sustain them to care for the dying. The peacefulness following offering a home death comes at a high price to FCGs. Evidence is needed from a randomized controlled trial as to effectiveness of advocacy support for FCGs to increase their resiliency and higher probability of a good death for the dying. **Abstract:** <http://bit.ly/2v64Pkp>

N.B. Additional articles on home hospice care in the U.S. noted in 3 February 2020 issue of Media Watch (#651, p.2).

Palliative care needs of individuals with cystic fibrosis: Perspectives of multiple stakeholders

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 February 2020 – Studies suggest palliative care (PC) may be different in cystic fibrosis (CF) than in other conditions. To provide quality PC to individuals with CF, unique needs must be understood. A total of 70 adults with CF, 100 caregivers, and 350 care team members completed surveys. While care team members reported they introduce PC to patients a majority of the time, adults with CF and caregivers rarely recalled learning about it. Very few reported having seen a PC specialist. A majority of participants reported that PC is valuable in CF care. Over 80% of participants felt PC is different in CF, most often citing the unpredictable disease course. Top PC needs identified include emotional support, emotional symptom management, and communication about treatment decisions. Major barriers to PC identified include perception that it is for dying people and lack of CF care team knowledge and training in PC. The authors' findings will be used to develop interventions targeting specific needs and inform guidelines to enhance provision of PC in CF. **Abstract:** <http://bit.ly/2Uq6BaW>

Noted in Media Watch 30 December 2019 (#646, p.9):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 17 December 2019 – **'Prevalence of unmet palliative care needs in adults with cystic fibrosis.'** Physical and emotional burdens impair quality of life (QoL) in many adults with cystic fibrosis (CF). Palliative care (PC) improves QoL in other serious illnesses, yet the full array of palliative needs amenable to PC are unknown in CF. Unmet physical and psychological palliative needs are prevalent in adults with CF. Symptoms are a stronger predictor of needs than physiologic measures. Routine screening of unmet PC needs using tools such as the Supportive Care Needs Survey-34 may enable CF care teams to optimize the provision of primary and specialist PC. **Abstract:** <http://bit.ly/2sUrQpg>

N.B. Additional articles on the PC needs of people living with CF noted in 9 September 2019 issue of Media Watch (#630, p.8).

Dying online: An analysis of end-of-life narratives

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 3 February 2020 – This study utilized publicly available online narratives (vlog postings) written by individuals diagnosed with a terminal illness to explore themes on what dying individuals wished to say about their experiences. While the content of the messages varied, universally all postings provided advice for living a good life. The implications of these narratives are still unknown. Questions remain about the role online peer support plays in the dying process and the extent to which sharing one's digital story can affect others online. The act of being introspective at the end of life (EoL) and the desire for social connection is similar to other forms of social work intervention such as dignity therapy suggesting an opportunity for further exploration. Additionally, these EoL narratives could also serve as a tool for educating future social work professionals about the experiences of those diagnosed with a terminal illness. **Abstract:** <http://bit.ly/31oAaLm>

Nurses' knowledge of law at the end of life and implications for practice: A qualitative study

PALLIATIVE MEDICINE | Online – 7 February 2020 – Some patients do not receive adequate pain and symptom relief at the end of life, causing distress to patients, families and healthcare professionals. It is unclear whether undertreatment of symptoms occurs, in part, because of nurses' concerns about legal and/or disciplinary repercussions if the patient dies after medication is administered. While many study participants had no personal experiences with legal or professional repercussions after a patient had died, the fear of hastening death and being held accountable was frequently discussed and regarded as relevant to the provision of inadequate pain and symptom relief. Concerns included potential civil or criminal liability and losing one's job, registration or reputation. Two-thirds of participants believed that pain relief was sometimes withheld because of these legal concerns. Less than half of the interviewed nurses demonstrated knowledge of the doctrine of double effect, the legal protection for health professionals who provide EoL pain and symptom relief. **Abstract (w. list of references):** <http://bit.ly/2OEwPTh>

Cont.

Related:

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

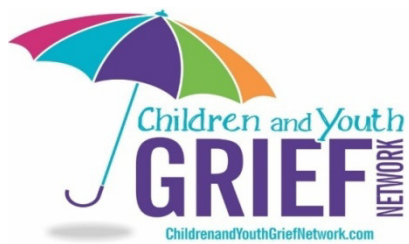
Healthcare providers’ views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis

PALLIATIVE MEDICINE | Online – 5 February 2020 – Healthcare providers working in hospitals are frequently exposed to patients with palliative care (PC) needs. For most patients, these reflect non-specialist rather than specialist PC needs. Embedding PC principles early in patients’ disease trajectories within acute care delivery in hospitals, however, is a challenge. How to best understand the experiences of those providing non-specialist PC in hospitals has not been systematically assessed. Thirty-nine papers of 37 studies were included in this review, representing 985 hospital healthcare providers’ views and experiences. Four major analytical themes emerged; 1) Understanding of PC; 2) Complexities of communication; 3) Hospital ecosystem; and, 4) Doctors and nurses – a different lens. Non-specialist PC in hospitals is operationalised as care in the last weeks and days of life. The organisation of acute care, interdisciplinary working practices, clinician attitudes, poor communication structures and lack of education and training in PC principles exacerbates poor implementation of this care earlier for patients in hospitals.

Abstract: <http://bit.ly/2RZx1OW>

Regret and unfinished business in parents bereaved by cancer: A mixed methods study

PALLIATIVE MEDICINE | Online – 5 February 2020 – Research has demonstrated the presence of regret and unfinished business is associated with poorer adjustment in bereavement. Though there is a growing literature on these constructs among caregivers of adult patients, the literature on regret and unfinished business in bereaved parents has been limited. Results showed that 73% of the parents [i.e., study participants] endorsed regret and 33% endorsed unfinished business, both of which were more common among mothers than fathers. Parents were on average moderately distressed by their regrets and unfinished business, and both regret-related and unfinished business-related distress were associated with distress while caregiving and prolonged grief symptoms. Findings of this study have implications for how providers work with families, including increasing treatment decision-making support, supporting parents in speaking to their child about illness, and, in bereavement, validating choices made. Grief interventions that use cognitive-behavioral and meaning-centered approaches may be particularly beneficial. **Abstract:** <http://bit.ly/2S18c5k>



The Crossroads of Grief:
Understanding Grief & Diversity
<http://bit.ly/2OB4Y6C>

Of related interest:

International Association for Hospice & Palliative Care
Newsletter, February 2020. <http://bit.ly/3blzifk>

N.B. Scroll down to ‘Media Watch: Grief & Bereavement.’

Cont.

Noted in Media Watch 17 December 2018 (#594, p.8):

- *DEATH STUDIES* | Online – 12 December 2018 – ‘**Bereavement-related regrets and unfinished business with the deceased.**’ Unresolved relational issues with the deceased have been considered a prominent risk factor for negative bereavement outcomes. However, this area of study has suffered from a lack of conceptual clarity, with some commentators focusing on bereavement-related regret and others focusing on “unfinished business,” or lingering or unspoken conflicts with the deceased. This study examined the two concepts in a sample of 229 bereaved individuals, finding them to be overlapping but distinct constructs. Unfinished business occurred more frequently with immediate family and friends and in cases of sudden and violent death of loved ones. **Abstract:** <http://bit.ly/2UsS1Q4>

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

- *DEATH STUDIES* | Online – 4 December 2018 – ‘**The Unfinished Business in Bereavement Scale: Development and psychometric evaluation.**’ The scale composed of two related factors. Items tapping into “unfulfilled wishes” pertained to unspoken affirmations or missed opportunities with the deceased. These experiences often emerged in loving relationships and only became problematic when accompanied by high levels of distress. In contrast, “unresolved conflict” pertained to unaddressed disputes or indiscretions. Other findings strongly supported the internal consistency, concurrent validity, and incremental validity of the scale. Unfinished business and meaning made of loss together accounted for 50-60% of the variance in prolonged grief symptoms. **Abstract:** <http://bit.ly/2GXBAmF>

Components of palliative care interventions addressing the needs of people with dementia living in long-term care: A systematic review

PALLIATIVE MEDICINE | Online – 4 February 2020 – People with dementia requiring palliative care (PC) have multiple needs, which are amplified in long-term care settings. The European Association for Palliative Care (EAPC) White Paper offers recommendations for optimal PC in dementia integral for this population, providing useful guidance to inform interventions addressing their specific needs.¹ The aim of this study is to describe the components of PC interventions for people with dementia in long-term care focusing on shared decision-making and examine their alignment to the EAPC domains of care. Fifty-one papers were included, reporting on 32 studies. For each domain (1-10), there were interventions found aiming to address its goal, although no single intervention addressed all domains. Domain 7 (symptom management), 6 (avoiding overly aggressive treatment) and 10 (education) were the most commonly addressed; Domain 5 (prognostication) and 4 (continuity of care) were the least addressed. Almost all domains were addressed across all interventions currently offered for this population to various degrees, but not within a singular intervention. Future research optimally needs to be theory driven when developing dementia-specific interventions at the end of life, with the EAPC domains serving as a foundation to inform the best care for this population. **Abstract:** <http://bit.ly/2Os4vU7>



1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, published online 4 July 2013. [Noted in 8 July 2013 issue of Media Watch (#313, p.10)] **Full text:** <http://bit.ly/2P53RLM>

Related:

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 7 February 2020 – ‘**Appropriateness of end-of-life care in people dying with dementia: Applying quality indicators on linked administrative databases.**’ In Belgium in 2015, 10,629 died with dementia. The authors of this study found indications of appropriate as well as inappropriate end-of-life care in people with dementia, including high rates of family physician contact, as well as high percentages of diagnostic testing, and emergency department and hospital admissions. They also found high risk-adjusted variation for multiple quality indicators, indicating opportunity for quality improvement in end-of-life dementia care. **Abstract (w. link to references)** <http://bit.ly/378WaLI>

Cont.

Noted in Media Watch 25 November 2019 (#641, p.14):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 18 November 2019 – ‘**A systematic review of the integration of palliative care in dementia management.**’ Four key themes were identified: 1) Goals-of-care and end-of-life conversations; 2) Symptom management; 3) Emergency room visits; and, 4) Prescribing behavior. In each domain, palliative care consultation either showed benefit or was postulated to have benefit if implemented. Although the literature to support or refute thematic conclusions is not large, there was a trend toward patient care benefit across several domains. Large randomized controlled trials with longer follow-up across different settings should be undertaken to solidify the themes and trends outlined in this review. **Abstract (w. list of references):** <http://bit.ly/2NZD4RL>

Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review

PALLIATIVE MEDICINE | Online – 3 February 2020 – This review aimed to identify the implementation strategies used in organizational level interventions to improve palliative care (PC) in long-term care facilities (LTCFs). It explored four implementation strategies: 1) Facilitation; 2) Education/training; and, 3) Internal and 4) External engagement; however, the extent to which each strategy supports successful implementation is unclear. Nine themes were identified as potential facilitators and/or barriers to successful implementation of these interventions, which were then grouped into three development stages: 1) Establishing conditions to introduce the intervention; 2) Embedding the intervention within day-to-day practice; and, 3) Sustaining ongoing change. The findings of the review have highlighted that the feasibility of implementing PC interventions is largely dependent on the context, and the extent to which delivery can be tailored to the individual needs of the facility, its staff and its residents. In addition, successfully implemented interventions were able to either improve or adapt to relatively poor existing conditions. These included poor communication between health professionals, LTCFs staff and families, high staff turnover and unsupportive management or a lack of leadership. In previous systematic reviews on interventions that attempted to change staff practice to improve LTCFs resident outcomes and on implementing

advance care planning in nursing homes, similar barriers and facilitators to implementing interventions were identified as those found in this review. **Full text:** <http://bit.ly/385z3mc>

The role of the palliative care registered nurse in the nursing facility setting

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 1 February 2020 – There is a growing recognition of significant, unmet palliative care (PC) needs in nursing facilities, yet limitations in the workforce limit access to PC services. Attention to palliation is particularly important when there are efforts to reduce hospitalizations to help ensure there are no unintended harms associated with treating residents in place. A specialized palliative care registered nurse (PCRN) role was developed [in the U.s.] as part of the OPTIMISTIC (Optimizing Patient Transfers, Impacting Medical quality, and Improving Symptoms: Transforming Institutional Care) program, a federally funded project to reduce potentially avoidable hospitalizations. Working in collaboration with existing clinical staff and medical providers, the PCRN focuses on managing symptoms, advance care planning, achieving goal concordant care, and promoting quality of life. The PCRN serves as a resource for families through education and support. The PCRN also provides education and mentorship to staff to increase their comfort, knowledge, and skills with end-of-life care. **Abstract:** <http://bit.ly/2txJgZW>

Noted in Media Watch 25 November 2019 (#641, p.8):

- *BMC PALLIATIVE CARE* | Online – 19 November 2019 – ‘**Palliative care nurse specialists’ reflections on a palliative care educational intervention in long-term care: An inductive content analysis.**’ The overall impression of palliative care (PC) nurse specialists was that the implementation of a PC education intervention supports the building of a strong relationship between the hospice nurse specialists and facilities, facilitates improved communication between registered nurses (RNs) and residents and RNs and families and alerts RNs to be vigilant in assessing the PC needs of their residents. The more the PC nurse specialists interacted with long-term care registered nurses and health-care assistants, the better the knowledge base for both sides. **Full text:** <http://bit.ly/35ooKbr>

Cont.

Noted in Media Watch 18 November 2019 (#640, p.6):

- *BMC PALLIATIVE CARE* | Online – 12 November 2019 – ‘**Hospice use and one-year survivorship of residents in long-term care facilities in Canada: A cohort study.**’ The assessed use rate of hospice care in long-term care facilities (LTCFs) was very low (i.e., less than 3%), while one in five residents died within 3 months and one in three died within 1 year. Most deaths occurred 3 months after the assessment regardless of hospice use. Among those who did not receive hospice care, more than a quarter died within 1 year. This indicates over one in four residents in LTCFs who had potential to benefit from hospice care may not have received it. The actual use of hospice care among residents in LTCFs is critically low in Canada... **Full text:** <http://bit.ly/2KoDIGg>

N.B. Additional articles on hospice and PC in LTCFs noted in 11 November 2019 issue of Media Watch (#639, pp.11-12). See also the October 2019 issue of the International Association for Hospice & Palliative Care’s newsletter (scroll down to ‘Media Watch: Long-Term Care’) at: <http://bit.ly/2p0p68g>

Drivers of care costs and quality in the last 3 months of life among older people receiving palliative care: A multinational mortality follow-back survey across England, Ireland and the U.S.

PALLIATIVE MEDICINE | Online – 3 February 2020 – This large international study of older people known to palliative care (PC) services found that in the last three months of life, hospital care accounts for over 80% of total health and social care costs. Community and PC costs were low... Care costs differed between countries, being the lowest and most homogeneous in England. The 10% highest cost patients accrued four times the care costs of the remaining 90%. Being aged ≥ 80 years and having difficulty living on current income (indicating poverty) were significantly associated with higher total costs across all three countries. Clinical factors were not or only marginally influential. Care quality was highest in PC unit/in-patient hospices. Poor home care was associated with higher hospital costs. The findings of this first major study to compare costs and experiences of people in different countries near the end of life (EoL) suggest that improving PC access and intensity is an essential priority for healthcare policy, especially for non-cancer patients who had least access. Cost distributions in England (London) were more homogeneous and with lower mean costs than in the U.S. (New York, San Francisco) and Ireland (Dublin), which warrants further investigation. Poverty, increased age and poor home care were drivers of high costs and should be a target for future interventions to improve care quality and value at the EoL. **Full text:** <http://bit.ly/2SdD9SJ>

End-of-life care and the use of an integrated care pathway

THE QUALITATIVE REPORT, 2020;25(1):216-237. The Liverpool Care Pathway is an integrated care pathway (ICP) designed to ensure the provision of high-quality end-of-life care (EoLC). However, the ICP has come under substantial criticism, suggesting that its use is related to poor care. This study explores nurses’ use of the ICP to dying patients in Norwegian nursing homes. The authors conducted a qualitative study using an abductive, mystery-focused method to analyze the experiences of 12 registered nurses. Their findings show that the nurses experienced the ICP as a very useful tool in EoLC, although they were actually working independently of the ICP in the provision of ongoing bedside care for the dying patients. This can be understood as following: 1) The ICP is not compatible with the complex problems of dying patients; therefore, nurses must tinker with the ICP in order to give dying patients proper and dignified care; 2) The ICP is a myth with symbolic power, legitimizing care makes nurses positive towards the ICP; and, 3) Using the ICP as a loosely coupled system creates novel effects on nursing practice. The ICP creates a common culture through a process of individual and collective sense-making, which we labelled clinical mindlines. **Abstract:** <http://bit.ly/2GYMsAR>

N.B. Additional articles on the Liverpool Care Pathway noted in 23 September 2019 issue of Media Watch (#632, pp.13-14).

Cont.

Noted in Media Watch 4 February 2019 (#600, p.10):

- *HEALTHCARE* | Online – 1 February 2019 – ‘**The development of pathways in palliative medicine: Definition, models, cost and quality impact.**’ Just as end-of-life care pathways standardized symptom management at the time of death, similar care pathways should be developed for early palliative medicine (PM) consultations to address symptom control and cohesive disease management as part of multidisciplinary teams. Care pathway development should also involve support patterns for caregivers and management of the bereaved after hospice enrollment. Outcomes research involving integrated care pathways in PM is completely lacking and should be considered a prime area of future research efforts to support the management of PM programs... **Full text:** <http://bit.ly/2HNoUC7>

Noted in Media Watch 22 October 2019 (#586, p.10):

- *JOURNAL OF HOUSING FOR THE ELDERLY* | Online – 15 October 2018 – ‘**Care pathways for the dying patients: Physician perspective.**’ The overriding care philosophy in medicine is to prevent death, rather than focus on dying. However, increasing longevity in most parts of the world has resulted for many people in prolonged periods of declining health toward the end of life. This has complicated understanding of when the dying process begins. As a result, there has been a growing movement within society and among healthcare systems to focus on finding ways to contribute to the quality of life of patients just before they die. The hospice and palliative care movement has gained distinction as an alternative way of looking at healthcare. **Abstract:** <http://bit.ly/2RXG82J>

Noted in Media Watch 5 March 2018 (#553, p.7):

- *DEMENTIA*, 2018;17(2):252-257. ‘**The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia.**’ The Challenge Project has led to self-reported improvements in the knowledge, confidence and care skills of family carers and acts as an important source of emotional and respite support for patients and families. It seems that the service has also enabled more patients to be cared for at home. The Project has positively influenced the knowledge and practice of some local health and social care professionals, leading to earlier referrals, improved understandings, communication practices and more collaborative ways of working when caring for patients and families with dementia. **Full text:** <http://bit.ly/2v56PcY>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *PULSE* | Online – 6 February 2020 – ‘**British Medical Association launches first-ever survey of doctors’ views on assisted suicide.**’ The Association has launched a survey into members’ views on doctor-assisted dying for the first time. The survey is aimed at informing the doctors’ representative body regarding a potential update on its stance on the topic. Currently, the association’s position is to oppose all forms of physician-assisted suicide, but a vote at last year’s Annual Representative Meeting (ARM) instructed the association to launch the poll. Should the poll back a change in stance, this year’s ARM will have to ratify any change before it takes effect. Members will be asked: 1) Whether they believe the association should support, oppose, or take a neutral stance on a change in the law to permit doctors to prescribe drugs for eligible patients to end their own life; 2) About a stance to a change in the law to permit doctors to administer drugs with the intention of ending an eligible patient’s life; and, 3) Their personal opinions, the reasons behind them, and about how the association should respond in the event of any future proposals to change the law. **Full text:** <http://bit.ly/39h9vmG>

[Media Watch: Editorial Practice](#)

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Cont.

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