Palliative care nurses’ considerations, insights and competence when performing end-of-life care in the diverse environments of private homes can contribute to the development of clinical practice. Knowledge about strategies can be used in nursing practice during everyday work, in nursing education and in the organisation of care, and can inform policy to ensure future high-quality palliative home care.

‘Palliative care nurses’ strategies when working in private homes: A photo elicitation study’ (p.8), in Journal of Clinical Nursing.

Canada

Pilot project offers home care to Nova Scotia palliative patients through iPad

NOVA SCOTIA | CBC News (Halifax) – 26 September 2019 – A pilot project that used an iPad and a cell phone connection to care for dying patients could soon help people across Nova Scotia receive the same sort of care in their homes. The project began as an idea between Dr. Robert Horton, an associate professor of palliative medicine at Dalhousie University in Halifax, medical student Claire Slavin-Stewart, and registered nurse Amber Phillips. Horton and Phillips were already delivering palliative care (PC) to patients in the Windsor, Nova Scotia, area when they began the eight-month experiment in 2017. “Many of them live in rural areas that don’t have regular access to PC expertise and some of them don’t even have regular access to a family physician,” During the pilot project, Phillips carried an iPad with a cell phone connection, and she was able to set it up so that everyone in the room could see and talk to the doctor in Halifax. “They were all very comfortable with it and thought it was fantastic,” Phillips said. “And the key was they were able to get their symptoms addressed and didn’t have to leave their homes, which is huge.” Horton said there are some drawbacks to telemedicine, such as physicians not being able to do a physical exam. http://bit.ly/2m3znPQ

Specialist Publications

‘Palliative care for homeless patients: A practical approach for medical students’ (p.14), in University of Toronto Medical Journal.

Cont. next page

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Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 18 September 2019 – ‘A feasibility study of home-based palliative care telemedicine in rural Nova Scotia, Canada.’ This study evaluated the use of the FaceTime application on an Apple iPad to improve timely access to physician consultation for home-based palliative care (PC)... Results indicated that using FaceTime through cellular data networks is feasible in rural areas of the province. The results add to the limited literature exploring the application of telehealth in PC, demonstrating the utility of low-cost commonly used technology to improve access to PC in underserviced areas. Abstract: [http://bit.ly/2miPV5L](http://bit.ly/2miPV5L)

- **THE CONVERSATION** | Online – 26 September 2019 – ‘Why people choose medically assisted death revealed through conversations with nurses.’ Current legislation guards the right of healthcare providers to conscientiously object to participation in medical assistance in dying (MAID). Nurses who do so have a professional obligation to inform their employers of that objection, to report requests for MAID, and to not abandon their clients. They also must ensure that their choices are based on “informed, reflective choice and are not based on prejudice, fear or convenience.” The nurses who surround the process of medically assisted dying are an important source of insight into the complex and nuanced conversations our society needs to have about what it is like to choose, or be involved with, this new option at the end of life, and to be involved in supporting patients and their families toward death with compassion. The authors’ most recent research involved interviews with 59 nurse practitioners or registered nurses across Canada who accompanied patients and families along the journey of medically assisted dying or who had chosen to conscientiously object. Nurses worked across the spectrum of care in acute, residential and home-care settings. [http://bit.ly/2mdxhgV](http://bit.ly/2mdxhgV)


- **THE LAWYER’S DAILY** | Online – 23 September 2019 – ‘Landmark ruling on medically-assisted death may set stage for more challenges.’ A landmark ruling that invalidated the “reasonably foreseeable” death clause of both the federal and Quebec laws on medical assistance in dying may lay the groundwork for further legal challenges seeking to broaden its coverage, according to legal experts. In a ruling hailed as an “elegant demonstration of sense and sensibility,” Quebec Superior Court Justice Christine Baudouin on struck down the end of life (EoL) requirement under s. 26 of Quebec’s End-of-Life Care Act and the reasonable foreseeability of natural death requirement under the Criminal Code, holding that it breached s. 15 of the Canadian Charter of Rights & Freedoms, prerequisites that prevented some people from accessing the EoL procedure. The federal law also contravened s. 7 of the Charter. The ruling, which suspends application of the judgment for six months to allow legislators an opportunity to amend the laws, will likely be used as a springboard to extend the criteria to encompass groups who currently are prohibited from requesting medical aid in dying... There is growing debate over allowing people under the age of 18 ... and people with a severe and debilitating mental disorder as their sole underlying medical condition to gain access to medically assisted dying. Also under consideration is allowing people to issue advance directives. [http://bit.ly/2mCUxUU](http://bit.ly/2mCUxUU)

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**Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: [http://bit.ly/2RPJy9b](http://bit.ly/2RPJy9b)
Hospice outreach to minorities could save Medicare $270 million

HOSPICE NEWS | Online – 27 September 2019

Addressing long-standing racial disparities in hospice care could save Medicare as much as $270 million annually, new research has found. Outreach to underserved communities can ensure more patients receive quality care at the end-of-life... "We all know the quality of life benefits but seeing the economic potential can be helpful," researcher Courtney Hughes, associate professor at Northern Illinois University, told Hospice News. "We looked at the Medicare population and found that if we close that gap between white individuals who elect hospice and racial ethnic minorities it would result in an additional $270 million in savings in a year." Nearly 87% of Medicare decedents in 2016 were Caucasian, according to the National Hospice & Palliative Care Organization. Comparatively, slightly more than 8% were African American; 2.1% Hispanic, and 1.2% Asian. That year, only 0.2% of Medicare decedents were Native American. Due in part to lower rates of hospice utilization, Medicare spends nearly 20% more for care in the last year of life among African American and Hispanic patients than white patients. Increasing hospice election among those communities would save approximately $2,105 per Medicare hospice enrollee... http://bit.ly/2lKSxdc

Specialist Publications


America’s Care of Serious Illness: 2019 State-by-State Report

CENTRE TO ADVANCE PALLIATIVE CARE & NATIONAL PALLIATIVE CARE RESEARCH CENTRE | Online – 26 September 2019 – America’s health care delivery system does not currently meet the needs of patients and families living with a serious illness. Our nation’s focus on disease-specific treatments, rather than on the needs of the whole person and their family, has resulted in unnecessary suffering, fragmented, burdensome – often futile – and costly interventions, untreated pain and symptoms, lengthy and repeated hospitalizations and emergency department visits, overwhelmed family caregivers, and clinician burnout. This is an unsustainable system in terms of both poor quality and high cost. Sweeping changes in standards of care for the most seriously ill are required if we are to provide appropriate and effective, value-driven care. Palliative care (PC) is a solution. The new report demonstrates that access to PC continues to remain variable and depends more upon accidents of geography, whether a hospital is for-profit or non-profit, and hospital size than it does upon the needs of patients living with a serious illness, and their families. The U.S. shows continued growth in the overall number of hospital PC teams: 72% of U.S. hospitals with fifty or more beds report a PC team. This is up from 67% in 2015, 53% in 2008, and 7% in 2001. These hospitals currently serve 87% of all hospitalized patients in the U.S., yet the overall grade for the U.S. in 2019 is a B, unchanged from 2015. Download/view at: http://bit.ly/2IrJOWl
Modernizing the Medicare Hospice Benefit

HOSPICE NEWS | Online – 24 September 2019 – The Medicare Hospice Benefit is aging along with the patients it is designed to serve. Nearly 40 years since its inception, it may be time to re-examine aspects of the program in light of the ways that patient populations and the larger health care system have changed. The hospice benefit was established as a demonstration project in 1970 and became a formal part of Medicare in 1983. At the time, nearly all of the patients who enrolled in hospice were suffering from cancer, and the U.S. Centers for Medicare & Medicaid Services and its collaborators designed the program around the needs and illness trajectory of those patients. Though cancer remains the most prevalent diagnosis among hospice patients, the proportion it represents has shrunk. Of the 1.49 million Medicare decedents who enrolled in hospice during 2017, cancer patients represented only 30%. Patients with cardiac conditions, such as congestive heart failure, accounted for nearly 18% of enrollees. For more than 15% of patients, their principal diagnosis was dementia... One aspect of the program that some stakeholders would like to see revised is the requirement that a patient must have a terminal prognosis of six months or less in order to access hospice care. Hospice providers and advocates have called for the loosening of the six-month limitation to allow patients to access interdisciplinary, person-centered care earlier in the course of their illnesses, be it through an expanded hospice benefit or via a new palliative care benefit. http://bit.ly/2n9ZBAr

International

People with terminal illness “trapped in homes,” charity report finds

U.K. (England, Northern Ireland & Wales) | Charity Today – 27 September 2019 – The Motor Neurone Disease Association has launched a new report highlighting the challenges facing terminally ill people when adapting their homes to suit their needs.¹ The charity surveyed 850 people, including those living with motor neurone disease (MND), carers, health and social care professionals and the charity’s own volunteers for the report, Act to Adapt. It found terminally ill people are becoming trapped in inaccessible homes due to a failure to deliver essential home adaptations. Some are living for months, and in some cases dying, before even the most basic adaptations can be made to their homes to meet their changing needs. The report found significant differences in the services provided by authorities across England, Wales and Northern Ireland, with varying levels of funding available and no nationally agreed response timescale, creating a postcode lottery. The report calls for a range of measures to ensure steps are taken at both national and local levels to ensure ‘housing matters’ for people with MND and other terminal illnesses. http://bit.ly/2mufr9a

Specialist Publications


‘Refractory psycho-existential distress and continuous deep sedation until death in palliative care: The French perspective’ (p.12), in Palliative & Supportive Care.

‘Assisted suicide in Switzerland’ (p.15), in Deutsches Arzteblatt International.


Closing the Gap Between Knowledge & Technology

People to get stronger rights to refuse life-saving treatment

IRELAND | *Irish Independent* (Dublin) – 22 September 2019 – “Do not resuscitate” requests will get a stronger legal basis when a new law comes into force. People who declare they do not want cardiopulmonary resuscitation, or further medical procedures as they near the end of their lives, will have firmer legal backing for their wishes when the Assisted Decision Making (Capacity) Act 2015 finally commences. The new law, signed by President Higgins almost four years ago, continues to undergo legislative work. It is now hoped it will be ready to commence near the end of next year. People already have the right to make an advance healthcare directive (AHD) indicating what medical treatment they do not want, in the event of them losing their capacity to make such decisions later in their lives. AHDs will be simpler to operate under the new law. Deirdre Shanagher … of the Irish Hospice Foundation, told the *Independent* that for years doctors have been dealing with legal fears about the limits of what they can do, and not do, regarding AHDs and “do not resuscitate” requests. [http://bit.ly/2kWnsCP](http://bit.ly/2kWnsCP)


**Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- ITALY | *The Guardian* (London, England) – 25 September 2019 – ‘Assisting a suicide is not always a crime, rules Italian court.’ Italy’s constitutional court has ruled it was not always a crime to help someone in “intolerable suffering” kill themselves, opening the way for a change of law in the Catholic country. Parliament is now expected to debate the matter, which was highlighted by the Milan trial of an activist who helped a tetraplegic man die in Switzerland. Anyone who “facilitates the suicidal intention … of a patient kept alive by life-support treatments and suffering from an irreversible pathology” should not be punished under certain conditions, the top court ruled. The court was asked to rule on the case of Fabiano Antoniani, known as DJ Fabo, a music producer, traveller and motocross driver left tetraplegic and blind by a 2014 traffic accident. [http://bit.ly/2lmZd0Y](http://bit.ly/2lmZd0Y)

**Specialist Publications**

Withholding and withdrawing life-support in adults in emergency care: Joint position paper from the French Intensive Care Society and French Society of Emergency Medicine

*ANNALS OF INTENSIVE CARE* | Online – 23 September 2019 – For many patients, notably among elderly nursing home residents, no plans about end-of-life (EoL) decisions and palliative care are made. Consequently, when these patients experience life-threatening events, decisions to withhold or withdraw life-support raise major challenges for emergency healthcare professionals. Emergency department premises are not designed for providing the psychological and technical components of EoL care. The continuous inflow of large numbers of patients leaves little time for detailed assessments, and emergency department staff often lack training in EoL issues. For prehospital medical teams … implementing treatment withholding and withdrawal decisions that may have been made before the acute event is not the main focus. The challenge lies in circumventing the apparent contradiction between the need to make immediate decisions and the requirement to set up a complex treatment project that may lead to treatment withholding and/or withdrawal. Laws and recommendations are of little assistance for making treatment...
Implementing primary palliative care best practices in critical care with the Care & Communication Bundle

**BMJ OPEN QUALITY** | Online – 6 September 2019 – Clinician-family communication is a central component of medical decision-making in the intensive care unit (ICU) and the quality of this communication has a direct impact on decisions made regarding care for patients who are critically ill. The purpose of this project was to standardize the approach to primary palliative care (PC) in the ICU by using the nationally recognized and published Care & Communication Bundle (CCB) tool to improve the quality in the ICU and in the hospital overall. The demand for PC specialists is growing rapidly, since timely PC consultations have been shown to improve the quality of care, reduce overall costs and, in some populations such as outpatient lung cancer, increase longevity. This project increased primary PC in the intensivist teams engaging in basic PC processes such as goals-of-care conversations, basic symptom management, discussion of advance directives and code status. PC was consulted for the more complex cases of conflict between team members, family, uncontrolled symptoms or cases of near futility. Sustainability of the CCB will be impacted by: 1) The creation of policies and procedures related to its use; 2) Intermittent evaluation of compliance – as a unit performance measure; 3) Creating the CCB as a standard of care in every ICU; 4) Including education of the CCB to all new hires and new resident physicians during orientation; 5) Use of Early Integration of Palliative Care/Electronic Medical Record processes to encourage easy access to information and documentation of meetings; and, 6) Providers’ ability to find meaningful outcomes with its utilization in relation to time, effort and potential discomfort regarding this sensitive topic. **Full text:** [http://bit.ly/2mNaRCT](http://bit.ly/2mNaRCT)

**Family outcomes and perceptions of end-of-life care in the intensive care unit: A mixed-methods review**

**JOURNAL OF PALLIATIVE CARE** | Online – 23 September 2019 – Five synthesized themes were identified: 1) Distressing emotions; 2) Shared decision-making; 3) Proactive communication; 4) Personalized end-of-life (EoL) care; and, 5) Valuing of nursing care. For quantitative results, study methodologies and interventions were heterogeneous and did not always improve family members’ perceived quality of care and family members’ psychological distress. Configuration of qualitative and quantitative data revealed intensive care unit (ICU) EoL interventions were ineffective because they were not guided by family members’ reported needs and perceptions. To fulfill the family members’ needs for the patients’ EoL care in the ICU, researchers should develop a theory to explicitly explain how the family members experience ICU EoL care and implement a theory-based intervention to improve family psychological outcomes. **Abstract:** [http://bit.ly/2kFg0fm](http://bit.ly/2kFg0fm)

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

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

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 24 September 2019 – Although clinicians are unlikely to accurately pinpoint when death is likely to occur in the people they care for, the death in a person with a diagnosis of malignant and nonmalignant tends to involve a period of predictable progressive clinical and functional deterioration. During this time, it is common for death rattle to occur. Due to its presentation, death rattle can cause stress and distress to caregivers. This often prompts clinicians to consider medical interventions that are not only ineffective in treating the problem but may also do harm. There is a dearth of research related to the management of death rattle. This article discusses the existing evidence in the management of death rattle, considerations for clinicians in the absence of reliable evidence and suggests areas for future research. Abstract: http://bit.ly/2n6seOM

N.B. Additional articles on the death rattle noted in 12 December 2016 issue of Media Watch (#491, p.12).
Selected articles on imminent or impending death noted in 23 September 2019 (#632, pp.12-13).

A brief history of death and American psychiatry

HARVARD REVIEW OF PSYCHIATRY, 2019; 27(4):260-267. The author ... argues that American psychiatrists – both clinicians and scholars – were instrumental in framing the mid-twentieth-century debate on the “taboo of death.” This debate concentrated on the argument that death had been silenced as a consequence of advances in biomedicine – in particular, intensive care medicine – and its quest to prolong life. Psychiatrists’ contribution to that discussion was to explain dying as a psychological process, or “psychic event.” Furthermore, the “experience of dying” became a key topic for mental health professionals. More broadly then, American psychiatrists in the mid-twentieth century pooled insights about death and dying from different fields and epochs – as far back as antiquity – to make their main claim: dying should happen consciously and without agony. To demonstrate this development, the author first provides contextual elements to explain how and why psychiatry played a central role in the American “rediscussion of death.” She then focuses on two examples to illustrate ways in which psychiatrists, based on their observations of terminally ill patients and survivors, described dying pro-cesses: first, pain management with LSD, and second, investigations of near-death experiences. Finally, the author examines how psychiatrists linked these clinical insights to historical notions of an “easy” and “good death.” In conclusion, she reflect on the legacy of psychiatrists’ contributions to the study of death, and question their relevance today. Full text: http://bit.ly/2m83zZy

Extract from Harvard Review of Psychiatry article

...when it comes to death, the key issues are not only the fears of the patient and his or her problems in confronting them, but also the ways in which practitioners can approach these issues with their patients. For instance: Is it important to explore one’s own fears in the process of accompanying a patient with death-related anxieties? Should one make a universal claim about the meaningfulness of dying? If so, based on what data and convictions? How does one decide to tell (and at what stage does one tell) a patient that there is no cure, and how does that decision ultimately affect the psychotherapeutic process?

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

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

*HEART* | Online – 19 September 2019 – Most patients [i.e., focus group participants] could imagine deciding to have their implantable cardioverter defibrillator (ICD) deactivated, for instance because the benefits of an active device no longer outweigh the harm of unwanted shocks, when having another life-limiting illness, or when relatives would think this would be in their best interest. Some patients expressed a need for advance care planning (ACP) conversations with a healthcare professional about deactivation, but few had had these. Others did not, saying they solely focused on living. Some patients were hesitant to record their preferences about deactivation in advance care directives, because they were unsure whether their current preferences would reflect future preferences. Although patients expressed a need for more information, ACP conversations about ICD deactivation seemed to be uncommon. Deactivation should be more frequently addressed by healthcare professionals, tailored to the disease stage of the patient and readiness to discuss this topic. **Full text:** [http://bit.ly/2mt1qYP](http://bit.ly/2mt1qYP)

**Related**

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2019;74(13). ‘Improving communication in heart failure patient care.’ Although implantable cardioverter-defibrillators (ICDs) reduce sudden death, these patients die of heart failure (HF) or other diseases. To prevent shocks at the end of life, clinicians should discuss deactivating the defibrillation function. The authors discuss an intervention that increased conversations about ICD deactivation and goals of care. HF clinicians [i.e., study participants] were able to apply new communication techniques based on patients’ severity of illness. **Abstract:** [http://bit.ly/2kKYy98](http://bit.ly/2kKYy98)

Noted in Media Watch 10 December 2018 (#593, p.7):

- *AMERICAN JOURNAL OF THE MEDICAL SCIENCES* | Online – 29 November 2018 – ‘Managing implantable cardioverter-defibrillators at end of life: Practical challenges and care considerations.’ Cardiopulmonary arrest serves as the final common pathway of natural death, and the appropriate management of an implantable cardioverter-defibrillators (ICD) near the end of life (EoL) is crucial to ensure that a patient’s death is not marked by further suffering due to ICD shocks. The tenets of palliative care at the EoL include addressing any medical intervention that may preclude dying with dignity; thus management of ICDs during this phase is necessary. **Abstract:** [http://bit.ly/2kNxc2n](http://bit.ly/2kNxc2n)

**Palliative care nurses’ strategies when working in private homes: A photo elicitation study**

*JOURNAL OF CLINICAL NURSING* | Online – 19 September 2019 – The private home as a physical work environment for nurses is explored, with both positive and negative aspects being described. To ensure future high-quality end-of-life care (EoLC), there is a need to describe how palliative care (PC) nurses work in private homes. The authors identify four constructed themes, presented as strategies used by PC nurses: 1) Adjusting interactions and actions depending on the environment when entering each unique private home; 2) Supporting patients and family members in finding a balance between self-care, independence and safe care; 3) Guiding patients and family members towards and through environment-
tal changes supporting EoLC at home; and, 4) Using transitions between homes to reflect, recuperate and prepare. PC nurses’ considerations, insights and competence when performing EoLC in the diverse environments of private homes can contribute to the development of clinical practice. Knowledge about strategies can be used in nursing practice during everyday work, in nursing education and in the organisation of care, and can inform policy to ensure future high-quality palliative home care. Abstract: http://bit.ly/2kMEGmg

Forgiveness as a factor of adjustment in bereaved parents

JOURNAL OF LOSS & TRAUMA | Online – 24 September 2019 – The aim of this study was to focus on the relationship of forgiveness toward others, self-forgiveness, and anger toward God after the loss of a child. A sample of 84 grieving parents completed a battery of questionnaires. Self-forgiveness was found to be the strongest predictor of avoiding negative psychological adjustment after the loss (defined by the variables of normative and complicated grief, depression, anxiety, and anger) and the strongest predictor of positive psychological adjustment after the loss (defined by the variables of life meaningfulness, sense-making, benefit finding, and meaning reconstruction). Abstract: http://bit.ly/2kMKj3B

Lessons learnt: Examining the use of case study methodology for nursing research in the context of palliative care

JOURNAL OF NURSING RESEARCH | Online – 6 September 2019 – An empirical social research approach, facilitating in-depth exploration of complex, contemporary contextualised phenomena, case study research has been used internationally in healthcare studies across clinical settings, to explore systems and processes of care delivery. In the U.K., case study methods have been championed by nurse researchers, particularly in the context of community nursing and palliative care (PC) provision, where its applicability is well established. Yet, dogged by conceptual confusion, case study remains largely under utilised as a research approach. Drawing on examples from nursing and PC studies, the authors clarify case study research, identify key concepts and consider lessons learned about its potential for nursing research within the unique and complex palliative and end-of-life context. A case study approach offers nurse researchers the opportunity for in-depth, contextualised understanding of the systems and processes which influence their role in PC delivery across settings. However, philosophical and conceptual understandings are needed and further training in case study methodology is required to enable researchers to articulate and conduct case study. Abstract: http://bit.ly/2mxPiWk

Using implementation science to further the adoption and implementation of advance care planning in rural primary care

JOURNAL OF NURSING SCHOLARSHIP | Online – 23 September 2019 – In this scoping review of the literature, four steps to advance care planning (ACP) were specified: 1) Identification; 2) Conversation; 3) Documentation; and, 4) Follow-up. Determinants were identified for each step, but studies largely focused on the conversation step. Professional role and identity, environmental context and resources, and emotion were the most frequently cited determinants in initiating conversations. The identification step was largely determined by behavioral regulation. For documenting ACP, environmental context and resource determinants were most prevalent. In the few studies that addressed follow-up, providers expressed a desire for electronic reminders as a behavioral regulator to follow-up. While ACP has been shown to have patient, family, and societal benefits, its uptake in primary care has been minimal. Because ACP is a complex process that is highly context dependent, implementation science is critical to inform its successful adoption and implementation. Smaller healthcare networks, adaptable professional roles, trusted relationships, and tight-knit community might be important facilitators of ACP in rural primary care. Findings from this study can be used to accelerate ACP implementation in rural primary care. Abstract: http://bit.ly/2mXm3g1
Top ten tips palliative care clinicians should know about physical medicine and rehabilitation

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 September 2019 – Physical medicine and rehabilitation (PM&R) is a specialty of medicine focused on optimizing function and quality of life for individuals with physical impairments, injuries, or disabling illnesses. Given the sometimes acute nature of the loss of function and even loss of independence, there are significant palliative care (PC) needs within patients seen by PM&R. This article, written by a team of PM&R and PC specialists, aims to help the PC team better understand the world of post-acute care, expand their toolkit for treating musculoskeletal and neurological symptoms, improve prognostication for patients with brain and spinal cord injuries, and decide when patients may benefit from PM&R consultation and support. There is significant overlap between the populations treated by PM&R and PC. Better integration between these specialties will help patients to maintain independence as well as advance excellent patient-centered care. **Abstract:** http://bit.ly/2lxH54o

Psychosocial interventions for patients with severe chronic obstructive pulmonary disease: An up-to-date literature review

*MEDICINE* | Online – 16 September 2019 – Chronic obstructive pulmonary disease (COPD) is a life-limiting condition with a long list of serious psychosocial consequences, aggravating with illness progression. In advanced stages, chronic respiratory failure often develops, which might undermine mental health and reduce activity. Thirty-four studies were identified and divided into four thematic groups: 1) Home medical support 2) Exercise; 3) Self-management; and, 4) Mental health. The number of studies that focused on mental health preservation in severe COPD is very limited... Improving patients’ self-efficacy gave promising effects to the acceptance of palliative care, pulmonary rehabilitation completion and mental health. Physical activity might be recommended to be included in interventions for mental health enhancement, although little is known about the role of the particular forms of exercise. An increasing beneficial use of new technologies for psychosocial interventions is noted. Psychosocial interventions applied in advanced COPD underline the roles of self-efficacy, telehealth and physical activity in physical and mental health preservation. **Abstract:** http://bit.ly/2krTwOE

N.B. Additional articles on palliative care for people living with COPD noted in 5 August 2019 issue of Media Watch (#625, pp.7-8).

Prediction system found to be effective at increasing palliative care consultations

*NEWS MEDICAL* | Online – 25 September 2019 – Palliative Connect, a trigger system developed at Penn Medicine and powered by predictive analytics, was found to be effective at increasing palliative care (PC) consultations for seriously ill patients, according to a new study from researchers in the Perelman School of Medicine at the University of Pennsylvania.¹ After the system was implemented, PC consultation increased by 74%. Palliative Connect draws on clinical data from the electronic health record and uses machine learning to develop a score based on 30 different factors of a person’s likely prognosis over six months – the timeframe doctors are asked to use when making a decision on whether PC consultation would be beneficial. However, primary team physicians were able to decline triggered consultations, and the researchers found that about 43% did so. The authors note that there were several reasons provided by the primary teams for declining a triggered consult. These include the primary team feeling that they are already meeting the patient’s needs, or that the patient doesn’t have any PC needs at the time. These explanations ... highlight the fact that prognosis isn’t a perfect measure of PC needs for every patient – it’s just one aspect of serious illness. **Full text:** http://bit.ly/2ns8pSj


Cont.
Predicting survival in patients with advanced cancer in the last weeks of life: How accurate are prognostic models compared to clinicians’ estimates?

PALLIATIVE MEDICINE | Online – 28 September 2019 – The authors compared the prognostic accuracy of Palliative Performance Scale, Palliative Prognostic Index, Palliative Prognostic Score, and clinician prediction of survival in this setting. A total of 204 patients were included with a median overall survival of 10 days. In patients with advanced cancer with days of survival, clinician prediction of survival and Palliative Performance Scale alone were as accurate as Palliative Prognostic Score and Palliative Prognostic Index. Abstract: http://bit.ly/2oc9sq1

Impact of the caregiver burden on the effectiveness of a home-based palliative care program: A mediation analysis

PALLIATIVE & SUPPORTIVE CARE | Online – 27 September 2019 – The growing aging population and the high prevalence of several comorbid chronic diseases have contributed to the elevated rates of caregiver burden and suffering in patients. In turn, intending to relieve unnecessary pain in patients, there has been a rapid growth of outpatient palliative care (PC) programs. Little has been studied about caregiver burden as a relevant factor potentially affecting the effectiveness of these programs. This study aimed to determine the extent of caregiver burden as a possible mediator on the effectiveness of a home-based PC program. The association between caregiver burden and palliative outcomes was corroborated with a categorical regression model. Caregiver burden was found to be a significant mediator in the relationship between outcome measures for PC at baseline and after 1 month of enrollment in the program. To the authors’ knowledge, this is the first study to assess the role of caregiver burden in the effectiveness of a home-based PC program. Although further work is required, the results indicate that a patient-focused intervention does not have the same beneficial effect if the caregiver burden is not addressed. Future home-based PC programs should focus on care givers as well as patients, with particular attention to psychosocial intervention on caregivers. Abstract (w. list of references): http://bit.ly/2lDwk0t

Family Caregiving

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE | Online – September 2019 – The growing recognition of the importance of family and loved ones as members of the palliative care team is mirrored by increased attention given to this issue in the literature. http://bit.ly/2UANOL
Related

- **JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE** | Online – 26 September 2019 – ‘Cartography of factors influencing caregivers’ experiences of loss: A promising tool to help social workers support caregivers.’ The authors introduce a cartography tool to help social workers work with and support family caregivers (FCGs). This tool aims to determine: 1) Which FCGs are likely to need additional support during bereavement; and, 2) What resources the FCG has that care teams can rely on for decision-making and planning. The purpose of this article is to present a preliminary assessment of the cartography based on the feedback collected from potential users regarding the tool’s content and usage. **Abstract:** [http://bit.ly/2lDMya1](http://bit.ly/2lDMya1)

- **PALLIATIVE & SUPPORTIVE CARE** | Online – 27 September 2019 – ‘Impact of the caregiver burden on the effectiveness of a home-based palliative care program: A mediation analysis.’ The growing aging population and the high prevalence of several concomitant chronic diseases have contributed to the elevated rates of caregiver burden and suffering in patients. In turn, intending to relieve unnecessary pain in patients, there has been a rapid growth of outpatient palliative care programs. However, little has been studied about caregiver burden as a relevant factor potentially affecting the effectiveness of these programs. A patient-focused intervention does not have the same beneficial effect if the caregiver burden is not addressed. **Abstract:** [http://bit.ly/2lDwk0t](http://bit.ly/2lDwk0t)

**Refractory psycho-existential distress and continuous deep sedation until death in palliative care: The French perspective**

**PALLIATIVE & SUPPORTIVE CARE** | Online – 25 September 2019 – Since February 2016, French Claeys-Leonetti law has recognized patients’ right to confront incurable diseases with short-term prognosis and refractory physical or psychological or existential symptoms by requesting continuous deep sedation until death (CDSUD). Determining when psychological or existential distress is refractory and unbearable remains complex and controversial. This review provides a comprehensive thought on CDSUD for advanced incurable patients with refractory psychological and/or existential distress in palliative care (PC) settings. It offers guidance on psychiatric or psychological diagnosis for explaining patients’ requests for CDSUD. Before implementing CDSUD, palliative healthcare professionals should seek input from psycho-oncologists in PC. Mental health professionals should analyze and assess the reasons for psychological and/or existential distress, consider the intentionality processes of requests, and explore alternative diagnoses, such as depressive or adjustment disorders, demoralization syndrome, desire to hasten death, and desire for euthanasia. Therapeutic responses … should be implemented before deciding that psycho-existential distress is refractory. **Abstract:** [http://bit.ly/2l2CWVT](http://bit.ly/2l2CWVT)

**N.B.** Selected articles on patient rights and the doctor obligations under France’s Claeys-Leonetti Law noted in 14 January 2019 issue of Media Watch, #597, pp.6-7.

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

- **BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 3 September 2019 – ‘Physicians’ perceptions of palliative sedation for existential suffering: A systematic review.’ The authors’ literature search yielded 17 publications published between 2002 and 2017. Physicians do not hold clear views or agree if and when palliative sedation for existential suffering (PS-ES) is appropriate. There is still no consensus regarding criteria to distinguish between necessary and sufficient conditions for invoking PS-ES. Further research is necessary to understand factors that influence physicians’ perceptions and philosophical-ethical presuppositions underlying this perceptions. **Abstract:** [http://bit.ly/2lwZRsm](http://bit.ly/2lwZRsm)

Noted in Media Watch 18 February 2019 (#602, p.14):

- **JOURNAL OF PALLIATIVE CARE** | Online – 13 February 2019 – ‘The use of palliative sedation to treat existential suffering: A scoping review on practices, ethical considerations, and guidelines.’ Four themes were identified as key findings: 1) Ethical considerations; 2) The role of the healthcare provider; 3) The need for multidisciplinary care teams; and, 4) Existential suffering’s connection to religiosity and spirituality. Palliative sedation to treat existential refractory symptoms was labelled a controversial practice. A shortage of evidence-based resources limits the current literature’s ability to inform policy and clinical practice. **Abstract:** [http://bit.ly/2UUHZ7d](http://bit.ly/2UUHZ7d)
Pediatric rheumatology and palliative care for children: A most relevant match

RESIDÊNCIA PEDIÁTRICA, 2019;9(2):189-192. The severity and significant morbidity characteristically seen in pediatric rheumatic diseases call for the early introduction of palliative care (PC) to preserve the quality of life of patients and their families. Multi- and interdisciplinary teams with specific training in pediatric PC must be assembled to address the needs of pediatric patients and children with rheumatic diseases in particular. While a few centers have adopted practices from PC to treat children with rheumatic diseases, in most healthcare institutions the issue has been given insufficient attention. This study sheds light on the urgent need to introduce notions of PC to healthcare providers involved in pediatric rheumatology and in managing patients with chronic diseases. Full text: http://bit.ly/2kKS7Ts

N.B. English language article.

“Just lie there and die”: Barriers to access and use of general practitioner out-of-hours services for older people in rural Ireland

RURAL & REMOTE HEALTH | Online – 24 September 2019 – For an older person living in rural Ireland, becoming ill outside GP surgery hours is complex. The obstacles encountered are both real and personal when deciding if and how to seek help. As the social networks of rural-dwelling older people shrink, and available neighbours and friends also become older and less available for transportation and other support, the impact of these challenges on use of Accidents & Emergency (A&E) and ambulance services may need to be examined. If ill, out-of-hours, A&E may be an appropriate healthcare choice for many older people, given the illness severity deemed necessary before they would call for help in the first place. Whether older people choose A&E over Doctor on Call (DOC) because they have accurately assessed the urgency of their healthcare need, because their lack of understanding about DOC has resulted in delayed help-seeking until A&E was required, because it was an easier or more expedient option, or for some other reason, requires further consideration. The findings of this study have shown that rural-dwelling older people are reluctant to use DOC and that lack of direct experience with DOC is linked with reluctance to use the service. Examining the nature of this connection, measuring the extent to which concerns expressed would ultimately prevent a call to DOC and comparing the barriers for older people in both urban and rural areas warrant further research. When experiencing severe illness, increased vulnerability can undermine even the strongest resolve, best-laid plans and depths of self-sufficiency. An absence of neighbours or family to call for assistance leaves some feeling they have little option other than to “wait it out” or “lie there and die.” Reducing reluctance and worry about calling for help requires addressing the challenges of rurality identified in this study and empowering older people in rural communities to access and use existing general practitioner out-of-hours services. Full text: http://bit.ly/2litZb2

Noted in Media Watch 26 August 2019 (#628, p.4):

- HEALTH RESEARCH BOARD (Dublin, Ireland) | Online – 21 August 2019 – ‘Out-of-hours specialist and generalist palliative care service provision. An evidence review.’ 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 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. Download/view at: http://bit.ly/2L4qPYh
Palliative care in the emergency department as seen by providers and users: A qualitative study

SCANDINAVIAN JOURNAL OF TRAUMA, RESUSCITATION & EMERGENCY MEDICINE | Online – 18 September 2019 – Much effort has been made to explore how patients with advanced chronic illness and their families experience care when they attend the emergency department (ED), and many studies have investigated how healthcare professionals perceive palliative care (PC) provision in the ED. Various models exist, but nonetheless incorporating PC into the ED remains challenging. Considering both healthcare professionals’ and users’ perspective on problems encountered in delivering and receiving appropriate PC within this context may provide important insight into meaningful targets for improvements in quality of care. This study explored issues in delivering PC in the ED from the perspective of both providers and users, as part of a larger project on the development and implementation of a quality improvement program in Italian Emergency Departments. Five themes were identified: 1) Shared priorities in ED among healthcare professionals and patients; 2) The information provided by healthcare professionals and that desired by relatives; 3) Perception of environment and time; 4) Limitations and barriers to the continuity of care; and, 5) The contrasting interpretations of giving and receiving PC. This study provides insights into targets for changes in Italian EDs. Room for improvement relates to training for healthcare professionals on PC, the development of a shared care pathway for patients with PC needs, and the optimization of ED environment. Full text: [Link](http://bit.ly/2moqaRP)

Noted in Media Watch 26 August 2019 (#628, p.8):

- **EMERGENCY MEDICINE JOURNAL** | Online – 13 August 2019 – ‘End-of-life care in the emergency department.’ 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 literature 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 EoLC in the ED noted in 5 August and 16 September 2019 issues of Media Watch (#625, pp.9-10 and #631, p.12, respectively)).

Palliative care for homeless patients: A practical approach for medical students

UNIVERSITY OF TORONTO MEDICAL JOURNAL | Online – 31 August 2019 – In this article, Dr. Naheed Dosani, the founder of the Palliative Education & Care for the Homeless (PEACH) program, shares his insight on topics ranging from integrating structural vulnerability into clinical practice to engendering changes within the community through translation of an idea into a real-world program. PEACH is a community-based organization that aims to provide high-quality and easily accessible palliative care (PC) to individuals that are homeless. The authors of the article explore key tenants of PC such as harm reduction and trauma-informed care and their applicability for homeless or transiently housed patients. Dr. Dosani describes the unique elements of PEACH and the Journey Home Hospice, including accepting referrals from care workers, and the practical logistics of building this successful program in just a few short years. [Abstract](http://bit.ly/2myk2ab)

N.B. Click on pdf icon to access full text.
dying (PAD) in terminal illness combine to create a moral dilemma. If PAD in killing, but prohibit PAD for persons whose suffering is less severe.

The theme ‘My Care, My Right’ aims to communicate that palliative care (PC) can be demanded by the public – and that, together, every person impacted by a life limiting illness can influence their policy makers to prioritize PC financing under universal health coverage. http://bit.ly/2RMImQK

N.B. Additional articles on palliative and end-of-life care for the homeless in Canada noted in 23 September 2019 issue of Media Watch (#632, p.1).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- **DEUTSCHES ÄRZTEBLATT INTERNATIONAL, 2019;116(33-34):545-552. ‘Assisted suicide in Switzerland.’** Alongside a marked increase in the overall number of assisted suicides since the turn of the century, the number of people traveling to Switzerland from other countries – predominantly Germany – for this purpose has risen steadily. The proportion of women was 60%, and the age at death ranged from 18 to 105 years (median 73). The largest diagnostic category was malignancy overall, neurological disease for those from other countries. The next largest category was age-related functional limitation, e.g., sensory impairment (loss of sight and hearing), the consequences of which were stated in writing as the reason for the wish to die. Following the Swiss Federal Court’s promulgation of binding requirements in 2006, the documentation contained in the death records for the subsequent period up to 2014 is much more detailed, but still not uniform or even necessarily complete. The number of candidates for organized assisted suicide increased steadily during the study period, but no standard procedures were followed. **Abstract (via PubMed):** http://bit.ly/2nupaMu

- **JOURNAL OF AMERICAN BIOETHICS, 2019;19(10):29-39. ‘Physician aid-in-dying and suicide prevention in psychiatry: A moral crisis?’** Involuntary psychiatric commitment for suicide prevention and physician aid-in-dying (PAD) in terminal illness combine to create a moral dilemma. If PAD in terminal illness is permissible, it should also be permissible for some who suffer from non-terminal psychiatric illness: suffering provides much of the justification for PAD, and the suffering in mental illness can be as severe as in physical illness. But involuntary psychiatric commitment to prevent suicide suggests that the suffering of persons with mental illness does not justify ending their own lives, ruling out PAD. Since both practices have compelling underlying justifications, the most reasonable accommodation might seem to be to allow PAD for persons with mental illness whose suffering is severe enough to justify self-killing, but prohibit PAD for persons whose suffering is less severe. **Abstract:** http://bit.ly/2n82S37


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World Hospice & Palliative Care Day 12 October 2019

The theme ‘My Care, My Right’ aims to communicate that palliative care (PC) can be demanded by the public – and that, together, every person impacted by a life limiting illness can influence their policy makers to prioritize PC financing under universal health coverage. http://bit.ly/2RMImQK
Publishing Matters

Researchers tackle predatory publisher awareness

INSIDE HIGHER ED | Online – 26 September 2019 – Texas Tech University academics have been awarded funding to create a training program helping scientists identify and avoid predatory publishers. With support from the [U.S.] National Science Foundation, an interdisciplinary team of researchers will develop a free online training program that will help educate academics about predatory publishing. The training will be geared toward scientists, but applicable to all disciplines. The Texas Tech team will also conduct research into the awareness of this issue among academics. Predatory publishers often offer to publish authors’ work for a fee, but unlike credible open-access journals, they fail to follow accepted standards in scholarly publishing such as rigorous peer review. The rise of predatory publishing was closely tracked by librarian Jeffrey Beall, who for many years maintained a list of open-access publishers he believed to be illegitimate. Beall took down the list in 2017, reportedly as the result of legal threats. “One of the reasons predatory publishing has thrived is because it’s so easy to blast out information that seems legitimate,” said Amy Koerber, one of the Texas Tech professors who will lead the research. “Hopefully we’re providing a counterforce, because we are going to make our training available online and free.”

Media Watch: Editorial Practice

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

Distribution

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Something Missed or Overlooked?

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

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