

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.

22 January 2018 Edition | Issue #547



Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

Prioritizing the fundamental needs of patients in the technical and data-driven environment of modern health care: Scroll down to [Specialist Publications](#) and ‘Palliative care assessment in the surgical and trauma intensive care unit’ (p.12), in *JAMA Surgery*.

Canada

When it comes to end-of-life care, options for Halifax’s homeless are few

NOVA SCOTIA | CBC News (Halifax) – 18 January 2018 – More options are needed to ensure homeless people in Halifax can die in a safe and comfortable environment, advocates say, and a hospice is a good place to start. It’s unrealistic for shelters to hire staff to assist with end-of-life care, said Patti Melanson, executive director of Mobile Outreach Street Health, which provides primary health care to those who are homeless or street-involved. This means the hospital is usually the only option for a homeless person who is dying, even if it’s not the place where they want to spend their final days. A hospice for the homeless in Halifax – a home designed to provide residential care for the terminally ill – would be “really, really helpful,” said Melanson. Claudia Jahn, program director for the Affordable Housing Association of Nova Scotia, said a Halifax charity called Hope Cottage ... purchased the parking lot next to the cottage in recent years. Its goal was to build a facility that would include residential palliative care. Jahn, who helped compile a report on the health status of Halifax’s homeless population in 2012, said the final days for a homeless person with a terminal illness can be especially difficult.¹ The report found many people refused treatment outright because they knew they wouldn’t have anywhere to recuperate, and they couldn’t handle the side effects while living in a shelter or on the street. <https://goo.gl/4kHCmn>

1. ‘Health & Homelessness in Halifax,’ Nova Scotia Housing & Homeless Network, November 2012. **Download/view at:** goo.gl/syowbQ

Specialist Publications

‘Staying out of the closet: Lesbian, gay, bisexual, and transgender older adults’ hopes and fears in considering end-of-life’ (p.11), in *Canadian Journal on Aging*.

‘Going it alone: A scoping review of unbefriended older adults’ (p.11), in *Canadian Journal on Aging*.

‘Social isolation in later life: Extending the conversation’ (p.11), in *Canadian Journal on Aging*.

‘Associations between home death and the use and type of care at home’ (p.14), in *Journal of Palliative Care*.

‘Community pharmacists’ attitudes on suicide: A preliminary analysis with implications for medical assistance in dying’ (p.18), in *Canadian Pharmacists Journal*.

Cont.

Noted in Media Watch 10 July 2017 (#520, p.9):

- *CURRENT ONCOLOGY*, 2017;24(3):187-191. **‘Palliative care as a public health issue: Understanding disparities in access to palliative care for the homeless population living in Toronto based on a policy analysis.’** The authors identify how the current palliative care (PC) system is structurally unable to meet the complex needs of the homeless population. In advocating for a public health approach to improve PC delivery, they illustrate the ethical need for health prevention and promotion to be developed hand-in-hand with good PC. Care integration and partnerships with homeless shelters and various service providers are crucial in bringing PC services to the places where homeless people feel most comfortable – in their home communities, as defined by them. <https://goo.gl/KdJ72K>

Noted in Media Watch 23 January 2017 (#496, p.7):

- *BULLETIN OF EUROPEAN HEALTH PSYCHOLOGY SOCIETY*, 2016;Suppl. **‘Challenges and recommendations in increasing homeless persons’ access to palliative care: An international systematic review.’** This review of qualitative literature identifies challenges to and recommendations for the provision of palliative care (PC) for homeless people. Twelve articles were eligible for review. Challenges and recommendations for the provision of PC for homeless people encompassed three core themes: 1) The unique circumstances of homeless people; 2) The structure of health care systems; and, 3) Limitations of temporary accommodation systems. The importance of the development of trusting relationships and flexible, joined-up services were highlighted. <https://goo.gl/9ecWXy>

In denial about death: Our aversion to the inevitable will only prolong our pain

ONTARIO | *The Hamilton Spectator* – 17 January 2018 – Death lurks in the corners of our lives, threatening to emerge from the shadows at any moment. When it bursts into our day-to-day existence – sometimes unexpectedly, occasionally anticipated – it is almost always unwelcome. In Canada and the western world, we have reached a point where we will do almost anything to convince ourselves that death doesn’t exist. But experts who work in the field of death and dying say our increasing tendency to ignore death, no matter the cost, is hurting us. Our death illiteracy means we are woefully unprepared to handle the growing number of aging people in our society, says Denise Marshall, associate professor of palliative care at McMaster University and the Medical Director of the Niagara West Palliative Care Team and McNally House Hospice. According to Marshall, unless we begin to talk about death ... we will see suffering on a massive scale. “This is like the perfect storm in North America,” said Marshall. “There will be too many people with too many needs, and not enough of us able to support them. We won’t know what to do with all of these dying people in frailty. <https://goo.gl/CZzrJD>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | Global TV News (Calgary) – 14 January 2018 – **‘37 Albertans transferred after faith-based facilities refused medically assisted deaths.’** Since medically assisted death became legal in Canada in June 2016, 268 people in Alberta have died with assistance up to 31 December 31 2017 according to figures from Alberta Health Services. The Alberta model is being called a success by supporters of assisted death. It’s an integrated service where patients can contact one navigator in their area and be accompanied through the whole process. [The policies of faith-based centres have created barriers.] Thirty-seven patients in Alberta have had to be transferred from those centres. Among them are hospitals operated by Catholic-based health agency Covenant Health. Covenant prohibits medical aid in dying in all its facilities, which requires patients to be transferred elsewhere when the time comes. From June 2016 to 30 November 2017, 105 patients who requested a medically assisted death did not meet the federal criteria. Ineligibility reasons include: a mental health diagnosis, loss of competency, and that death is not reasonably foreseeable. The most cited health conditions included: cancer, MS, ALS and advanced lung disease. <https://goo.gl/JecYy9>

N.B. Additional articles, reports, etc., on faith-based hospitals *vis-à-vis* medical assistance in dying are noted in the 15 January 2018 issue of Media Watch (#546, pp.1-2)]

U.S.A.

Cancer patients who tell their life story find more peace, less depression

WISCONSIN | *News* (University of Wisconsin-Madison) – 19 January 2018 – Fifteen years ago, University of Wisconsin-Madison researcher Meg Wise began interviewing cancer patients nearing the end of life about how they were living with their diagnosis. She was surprised to find that many asked for a transcript of the interview, saying that they had not talked about these issues with family or friends. “I would think, wait a minute,” Wise recalls. “You’ve had stage 4 lung cancer for eight months, and this is the first time you’ve talked about it?” The *Journal of Palliative Medicine* recently published the latest study in Wise’s exploration of resilience in advanced cancer – what she calls “mortal time.”¹ It found that delivering an edited life and cancer story elicited by a phone conversation measurably enhances the sense of peace in the face of looming death. An advanced-stage cancer diagnosis often brings chaos and stress. Managing pain, exhaustion, medical appointments and finances make it hard for patients to reckon with questions of legacy and stave off depression. When Wise ... began studying what could help people cope with cancer, she became fascinated by an incidental finding: “The pause after describing how cancer sucks. Some people say, ‘You know, in some ways, my life is better since I was diagnosed. Family is more important. I don’t sweat the small stuff,’” Wise says. <https://goo.gl/PeChi7>

1. ‘Suffering in advanced cancer: A randomized control trial of a narrative intervention,’ *Journal of Palliative Medicine*, published online 14 November 2017. <https://goo.gl/GyYmQg>

Home care agencies often wrongly deny Medicare help to the chronically ill

KAISER HEALTH NEWS | Online – 18 January 2018 – Medicare does cover home care services for patients who qualify, but incentives intended to combat fraud and reward high quality care are driving some home health agencies to avoid taking on long-term patients ... who have debilitating conditions that won’t get better, according to advocates for seniors and the home care industry. Rule changes that took effect this month could make the problem worse. Federal law requires Medicare to pay indefinitely for home care – with no co-payments or deductibles – if a doctor ordered it and patients can leave home only with great difficulty. They must need intermittent nursing, physical therapy or other skilled care that only a trained professional can provide. They do not need to show improvement. Those who qualify can also receive an aide’s help with dressing, bathing and other daily activities. The combined services are limited to 35 hours a week. Medicare affirmed this policy in 2013 when it settled a key lawsuit brought by the Center for Medicare Advocacy and Vermont Legal Aid. <https://goo.gl/GrxGUz>

Stanford’s artificial intelligence predicts death for better end-of-life care

IEEE SPECTRUM | Online – 16 January 2018 – Many physicians often provide overly rosy estimates about when their patients will die and delay having the difficult conversations about end-of-life (EoL) options. That understandable human tendency can lead to patients receiving unwanted, expensive and aggressive treatments in a hospital at their time of death instead of being allowed to die more peacefully in

Specialist Publications

‘End-of-life training in U.S. internal medicine residency programs: A national study’ (p.13), in *Journal of Medical Education & Training*.

‘Characterizing cause of death in U.S. Veterans Affairs medical centers’ (p.14), in *Journal of Palliative Care*.

‘Perinatal palliative care: Integration in a U.S. nurse midwifery education program’ (p.15), in *Midwifery*.

Cont.

relative comfort. The alternative being tested by a Stanford University team would use artificial intelligence to help physicians screen for newly-admitted patients who could benefit from talking about palliative care (PC) choices. Past studies have shown about 80% of Americans would prefer to spend their last days at home if possible. In reality, up to 60% of Americans end up dying in an acute care hospital while receiving aggressive medical treatments, according to research cited by the Stanford group.¹ PC experts usually wait for the medical team in charge of a given patient to request their services, which typically include providing relief for patients suffering from serious illnesses and possibly recording EoL treatment preferences in a living will. But Stephanie Harman, an internal medicine physician and founding medical director of Palliative Care Services for Stanford Health Care, saw an opportunity to flip that routine around by giving PC physicians the ability to identify and proactively reach out to patients. <https://goo.gl/hEsL4D>

1. 'Improving Palliative Care with Deep Learning,' IEEE International Conference on Bioinformatics & Biomedicine 2017. **Abstract:** <https://goo.gl/2pJi5k>

Functionality, usability cited as barriers to adoption of caregiver digital health tools...

MEDCITY NEWS | Online – 16 January 2018 – In 2014, research by the American Association of Retired Persons (AARP) estimated that 40 million Americans provide unpaid care to an adult.¹ About 68% of family caregivers have no paid help and by 2020, 45 million family caregivers will care for 117 million people, according to a new report on caregivers that is part of AARP's Project Catalyst.² Given that caregivers are overworked, frequently isolated and stressed, technology could theoretically help them manage their loved ones better. And most of the caregivers in a previous survey by the AARP expressed interest in these tools. But when caregivers were given the opportunity to test drive these tools over a six week period, they often found that the functionality and usability left something to be desired. <https://goo.gl/ot12w3>

1. 'Family Caregivers Providing Complex Chronic Care to People with Cognitive & Behavioral Health Conditions,' American Association for Retired Persons Public Policy Institute, 2014. [Noted in Media Watch 25 August 2014 (#372, p.4)] **Download/view at:** <https://goo.gl/d8zpFJ>
2. 'Designing Technology for Caregivers: Understanding what works and what doesn't,' American Association of Retired Persons, November 2017. **Download/view at:** <https://goo.gl/xEBq7c>

N.B. The National Alliance for Caregiving this week published 'From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Issue.' **Download/view at:** <https://goo.gl/oxMWTk>

Understanding grief

THE NEW YORK TIMES | Online – 15 January 2018 – Although many of us are able to speak frankly about death, we still have a lot to learn about dealing wisely with its aftermath: grief, the natural reaction to loss of a loved one. Relatively few of us know what to say or do that can be truly helpful to a relative, friend or acquaintance who is grieving. In fact, relatively few who have suffered a painful loss know how to be most helpful to themselves. We can all benefit from learning how to respond to grief in ways that don't prolong, intensify or dismiss the pain. Likewise, those trying to help need to know that grief cannot be fit into a preordained time frame or form of expression. Too often people who experience a loss are disparaged because their mourning persists longer than others think reasonable or because they remain self-contained and seem not to mourn at all. <https://goo.gl/W8ALvq>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

International

End-of-life care in Japan

Planned revision to end-of-life care guidelines include at-home treatment

JAPAN | *The Mainichi* (Tokyo) – 18 January 2018 – The health ministry has unveiled a plan to revise guidelines for end-of-life care (EoLC) to cover terminally ill patients who wish to die at their homes or nursing care facilities. The Ministry of Health, Labor & Welfare referred the plan to a panel of experts for deliberations. The ministry will complete the revision plan by the end of the current fiscal year in March. This will be the first time for the guidelines to be amended since their introduction in 2007. The ministry's guidelines explicitly provide for patients' decision-making procedures in the assumption that they would be used at medical facilities. As 10 years have passed since the guidelines were compiled, however, the aging of Japan's population has progressed and more than 1.3 million people now die each year. As an increasing number of terminally ill patients wish to die at home rather than at medical institutions, the ministry plans to revise the guidelines so that they can be used for EoLC at homes or nursing care facilities.

Specifically, a clause stipulating that medical professionals such as doctors and nurses should discuss patients' decisions on whether to discontinue life-prolonging treatment and how they want to take their last breath will be rewritten to involve care managers and care workers in the process. Moreover, since the will of patients could change as time passes and their illnesses progress, the revision plan underscores the need to repeatedly talk to patients to confirm their decisions. <https://goo.gl/WvpZBp>

End-of-life care in Korea

Government to give patients the right not to be resuscitated

SOUTH KOREA | *Korea Joongang Daily* (Seoul) – 17 January 2018 – The Ministry of Health said its three-month trial of a “do not resuscitate” policy, whereby patients or their relatives can ask for life support to be shut down, has resulted in 43 ending their lives by choosing not to rely on medicine or medical equipment. The policy ran ... at 15 hospitals. It will be formally launched on 4 February as the ‘Act on Decisions on Life-sustaining Treatment for Patients in Hospice & Palliative Care or At the End of Life.’ The wishes of the 43 patients were either voiced in person or by their families. Medical staff confirmed the wishes of patients by speaking with as many relatives as possible. <https://goo.gl/CyZyW4>

Elder care in the U.K.

Elderly dying amid National Health Service wrangles over who pays for care...

U.K. | *The Telegraph* (London) – 17 January 2018 – Elderly patients are dying amid National Health Service (NHS) wrangles over who pays for care, with thousands denied help which should have been given, a new report suggests.¹ The Public Accounts Committee said patients suffering devastating health conditions such as Alzheimer's disease were being forced into long battles for funding, with some waiting as

Specialist Publications

‘Benefit or harm? A study on impact of collusion on the quality of life among palliative care patients’ (p.12), *Indian Journal of Palliative Care*.

‘Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature’ (p.14), in *Palliative & Supportive Care*.

Cont.

long as three years and others dead by the time a decision was reached. Under NHS rules, patients with significant ongoing healthcare needs – such as a diagnosis of Parkinson’s disease, or dementia - should have their care funded, whether it takes place in hospital or at home. But the report found the vast majority of patients were not told about their entitlement until “very late in their journey through the health and social care system.” In some cases, assessors only knocked on patients’ doors, the day after their death, MPs heard. Just 3% were told by GPs that the NHS should be paying for their care, and even once an assessment began, one third of patients waited at least a month for a decision. <https://goo.gl/oGoc5E>

1. ‘13th Report – National Health Service continuing healthcare funding,’ Public Accounts Committee, January 2018. **Download/view at:** goo.gl/A2NgNc

Related

- U.K. (England) | *The Telegraph* (London) – 13 January 2018 – **‘National Health Service crisis fuelled by closure of 1,000 care homes housing more than 30,000 pensioners.’** The growing National Health Service (NHS) crisis has been fuelled by the closure of almost 1,000 care homes housing more than 30,000 pensioners, research suggests. The report by industry analysts shows that in the last decade, 929 care homes housing 31,201 pensioners have closed, at a time when the population is ageing rapidly. Research shows care homes going out of business at an ever increasing rate, with 224 care homes closed between March 2016 and March 2017, amounting to more than 2,000 beds. <https://goo.gl/KgRAJG>

Specialist Publications

‘Identifying who lives in a care home: A challenge to be conquered’ (p.7), in *Age & Ageing*.

Noted in Media Watch 18 December 2017 (#543, p.7):

- U.K. | *The Economist* – 14 December 2017 – **‘Care homes are struggling. Blame the odd structure of the market.’** In the past decade profitability in the industry has plunged. That has limited investment in the care homes of tomorrow – sorely needed, since the population is ageing. Since 2015 the number of beds has in fact fallen slightly. That puts pressure on other services. <https://goo.gl/YffGDr>

Inside the world of dealing with someone who has died alone

AUSTRALIA (Victoria) | *The Courier* (Ballarat) – 14 January 2018 – Isolation and an ageing population have combined to leave rising numbers of our population at the risk of dying alone. A police officer, coronial undertaker and two funeral directors all spoke openly about the growing frequency of being called to homes where someone has died alone and undiscovered, sometimes for weeks, sometimes months, occasionally years. In some cases it’s a person who has no nearby or living relatives. In others, it’s mental illness. Sometimes it is suicide. Often they find themselves in the detritus of someone’s life: in the house of hoarder, or someone whose existence hasn’t changed for decades; the home of an alcoholic or a person who has lived in modern poverty. Each of them describe with astounding detail and compassion the work that they do in these frequently difficult and distressing conditions. <https://goo.gl/rRBMQw>

Noted in Media Watch 18 December 2017 (#543, p.17):

- **MORTALITY** | Online – 13 December 2017 – **“‘I’ve no fear of dying alone’”: Exploring perspectives on living and dying alone.** Dying alone is portrayed as undesirable in terms of policy, health and social care provision, the wishes of family and friends, and in popular culture. Despite this, people do often die alone, both in institutional and domestic settings. This article suggests that dying alone may be a problem for survivors, rather than for the person who is dying. **Abstract:** <https://goo.gl/4CmtRU>

See ‘For some people dying alone is not such a bad thing – here’s why,’ *The Conversation*, 19 January 2018. <https://goo.gl/GNR1gH>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | *The New Zealand Herald* (Auckland) – 20 January 2018 – ‘**End-of-life choice bill sparks debate about euthanasia and Māori values.**’ The Rotorua Māori are discussing how euthanasia fits with their values, as a bill legalising euthanasia makes its way through parliament. While some kaumatua [i.e., elders] said the thought of euthanasia did not sit well with them culturally, they saw no need to stop a tangi [i.e., traditional Maori funeral] of someone who chose euthanasia from being held on a marae [i.e., meeting ground]. Parliament voted 76-44 to pass the first reading and the bill has been referred to the Justice Select Committee which has to report back within nine months. <https://goo.gl/mPRDqH>
- U.K. (England) | BBC News – 18 January 2018 – ‘**Terminally ill man granted assisted dying appeal.**’ A terminally ill man who wants to be helped to die has been granted permission to take his case to appeal. Two judges from the Court of Appeal said there should be a full hearing of 68-year-old Noel Conway's case. Mr. Conway, a retired lecturer from Shropshire who has motor neurone disease, was too ill to attend court. Last October, the High Court rejected his challenge to the Suicide Act 1961 which he argues breaches his right to a “peaceful and dignified death.” Mr. Conway wants a doctor to be allowed to prescribe him a lethal dose of drugs. The Appeal Court granted permission for him to challenge the ruling and will give its reasons later. But the full appeal will not be heard until a later date. <https://goo.gl/A86APm>

Specialist Publications

Elder care in the U.K.

Identifying who lives in a care home: A challenge to be conquered

AGE & AGEING | Online – 16 January 2018 – Care home residents in the U.K. outnumber hospital inpatients threefold and yet our knowledge about their needs, care and outcomes is staggeringly poor, not least because there is no central register of care home residents. Identifying who lives in a care home is therefore difficult. Large care data collection systems which have been adopted by care home providers in North American and Europe for service evaluation and research ... are not routinely used in the U.K. These data can be extracted and linked to hospital data to evaluate outcomes. Why is identifying those who live in care homes so challenging? Primarily because care home residency is not systematically recorded by the National Health Service or any other public body. There are no U.K. registers of all care home residents, even though such registers would be technically straightforward to create as part of GP registration and change of address. **Full text:** <https://goo.gl/rUW79V>

Physicians’ perceptions of hope and how hope informs interactions with patients: A qualitative, exploratory study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 January 2018 – Today some studies of physicians’ perceptions of hope are available, but not studies of how hope informs patient care. Hope was defined [by participants] as an abstract, evolving concept characterized by future-oriented wishes; offering possibilities for reframing and shaping new meaning; an attitude of positivity or optimism; an attribute of the human condition with emotional and relational roots; and, as a response to the existential inevitability of suffering and death. Three themes describing hope emerged: “assessing hope,” “fostering and sustaining hope,” and “attributes and outcomes of hope.” The findings show how physicians conceptualize hope and how these conceptions differ in the empirical light of the study. Physicians’ perceptions of “hope” may evolve when entering into a therapeutic relationship exploring the needs and desires of patients. Physicians’ perspectives about “hope” may at times not be solely their own, but are those of their patients and thus resulting in an amalgamation, or a rebuilding/rekindling of hope amidst hopelessness, that suits a particular relationship. **Abstract:** <https://goo.gl/TV53fC>

Cont.

Noted in Media Watch 16 October 2017 (#534, p.11):

- *JOURNAL OF ONCOLOGY PRACTICE*, 2017;13(10):675-677. ‘**Hope, Phase I trials, and palliative care: So you’re telling me there’s a chance?**’ In its modern form, palliative care (PC) is no longer reserved for situations where treatment options are exhausted; rather, high-quality specialty PC can and should be provided along with a clinical trial or any other active cancer treatment in patients with advanced disease. In this context, PC is another vehicle through which to maintain and facilitate realistic hope and to help patients to plan for all possible outcomes, including those that receive comparatively less attention in our discussions about clinical trial participation: symptoms, quality of life, distress, and suffering. **Full text:** <https://goo.gl/4w6h7H>

Noted in Media Watch 22 May 2017 (#513, p.17):

- *BEHAVIORAL SCIENCES* | Online – 15 May 2017 – ‘**Communicatively constructing the bright and dark sides of hope: Family caregivers’ experiences during end-of-life cancer care.**’ The current study examines the bright and dark sides of how hope is communicated across the cancer journey from the vantage point of bereaved family caregivers. Two overarching patterns of hope emerged. Those who experienced hope as particularized (focused on cure) cited communication about false hope, performing (“faking it”), and avoidance. Those who transitioned from particularized to generalized hope (hope for “a good death”) reported acceptance, the communication of hope as social support, prioritizing family, and balancing hope and honesty. **Abstract:** <https://goo.gl/bQLEbl>

Noted in Media Watch 22 August 2016 (#476, p.9):

- *CANADIAN FAMILY PHYSICIAN*, 2016;62(8):648-656. ‘**Ultimate journey of the terminally ill: Ways and pathways of hope.**’ The attributes of hope focus initially on cure, then shift toward prolonging survival, and then to improving quality of life. As the illness advances, this hope might evolve into a form of acceptance or, conversely, give way to despair, phenomena that can alternate over time in either direction. This study also highlights the need to avoid oversimplifications, both in clinical interactions and in research, as it provides valuable insights from both the clinical and research perspectives. Family physicians clearly need to maintain some degree of hope in their patients while remaining as realistic as possible, even if this balance is tenuous. **Full text:** <http://goo.gl/imsB4g>

N.B. Additional articles on hope in the context of palliative and end-of-life care are noted in this issue of Media Watch.

What are the ethical questions raised by the integration of intensive care into advance care planning?

ANNALS OF TRANSLATIONAL MEDICINE, 2017;5(4). A major goal of intensive care units (ICUs) is to offer optimal management, but for many patients admitted to the ICU they are unlikely to yield any lasting benefit. In this context, the ICU physician remains a key intermediary, particularly when a decision regarding possible limitation or withdrawal of life-sustaining therapy becomes necessary. The possibility of admission to the ICU, and the type of care the patient would like to receive there, should be integrated into the healthcare project in agreement with the patient, regardless of the stage of disease that the patient suffers from. These dispositions should be recorded in the patient’s file, and should respect the progressive nature of both the disease itself, and the discussions necessary in such complex situations. The ICU physician can serve as a valuable consultant for the treating physician, in particular to guide patient choices when formalizing their healthcare preferences in the form of advance care planning (ACP) or advance directives (AD). Ideally, the best time to address this issue is before the patient’s clinical situation deteriorates towards an acute emergency, and providing complete and transparent information to inform the patient’s choices. **Full text:** <https://goo.gl/oLNGEW>

Cont. next page

Related

- *ANÄSTHESIOLOGIE UND INTENSIVMEDIZIN NOTFALLMEDIZIN SCHMERZTHERAPIE*, 2018;53(1):62-70. '**Advanced care planning and its relevance for emergency and intensive care medicine.**' Like in other countries, advance care planning (ACP) is currently being implemented in Germany as a new concept to realise valid and effective advance directives. This concept comprises processes to explore and document individual preferences for future treatment, and to honour them at a time when the person is incapacitated. ACP aims to ensure that patients will be treated according to their preferences when they are no longer capable due to acute health crises or chronic diseases. This paper gives an overview of the concept of ACP with a focus on relevant issues for emergency and intensive care medicine. **Abstract:** <https://goo.gl/j4jnex>

N.B. German language.
- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2018;24(1):17-24. '**A retrospective study of end-of-life care decisions in the critically ill in a surgical intensive care unit.**' Singapore law believes in the "individual autonomy" model whereby patients themselves have the right to know about their conditions and make their own decisions. However locally, families (especially of elderly patients) expect to be the first to know, and they will subsequently decide how much information to disclose to the patient. While this generally stems from good intentions, in the case of end-of-life care, collective decision-making by the family may not always be in concordance to the patient's true wishes. It is startling to know that one-third of surrogates' decisions run discordant to patients' wishes and up to 60% of physicians would overrule incompetent patients' previously documented wishes. **Full text:** <https://goo.gl/XcSwXb>
- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 16 January 2018 – '**Should capacity assessments be performed routinely prior to discussing advance care planning with older people?**' Clinicians should routinely explain advance care planning (ACP) to older people and ensure they fully understand it prior to an ACP discussion. If there is any concern about their understanding, further exploration and documentation of their capacity using the capacity assessment framework would be necessary. However, capacity assessment is a complex iterative process that does not easily lend itself to screening methodology and requires a high level of clinical judgment. **Abstract (w. list of references):** <https://goo.gl/wBwt44>
- *JAMA INTERNAL MEDICINE* | Online – 16 January 2018 – '**Using chaplains to facilitate advance care planning in medical practice.**' Rather than waiting for an urgent health crisis, regular office visits are a preferred time for advance care planning (ACP) discussions. With the new Centers for Medicare policy [in the U.S.], lack of reimbursement for time spent in ACP discussions should no longer be a barrier to conducting them. However, other structural (e.g., competing demands) and professional barriers (e.g., lack of training) remain. These persistent barriers suggest consideration of non-physicians for such discussions. The aim of this pilot quality improvement project was to determine whether having a board-certified chaplain conduct ACP conversations with patients in the physician's office would be feasible, effective, and acceptable to all stakeholders. **Abstract:** <https://goo.gl/PAUcLw>
- *JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH SERVICES*, 2018;56(1):32-35. '**End-of-life conversations as a legacy.**' It is important that nurses in hospitals, long-term care facilities, and the community become confident in initiating end-of-life (EoL) conversations with individuals of various ages. Without these important conversations about life goals and wishes, patients across gender, ethnic, and age lines may receive unwanted treatments at the end of their lives. In addition, family members and patients may lose the chance to share the intimacy and peace of a goodbye. Thoughtful and respectful planning and conversations in which a provider or family member listens and attempts to understand individuals' unique experiences, beliefs, and values can help break through the reluctance that has silenced these EoL conversations. **Full text:** <https://goo.gl/oyC5i6>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Systematic review of general practice end-of-life symptom control

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 20 January 2018 – From 6,209 journal articles, 46 papers reported general practitioner (GP) performance in symptom management. There was no reference to the performance of general practice nurses (GPNs) in any paper identified. Most GPs expressed confidence in identifying end-of-life care (EoLC) symptoms. However, they reported lack of confidence in providing EoLC at the beginning of their careers, and improvements with time in practice. They perceived emotional support as being the most important aspect of EoLC that they provide, but there were barriers to its provision. GPs felt most comfortable treating pain, and least confident with dyspnoea and depression. Observed pain management was sometimes not optimal. More formal training, particularly in the use of opioids was considered important to improve management of both pain and dyspnoea. **Abstract:** <https://goo.gl/9dW161>

Related

- *INNOVAIT* | Online – 16 January 2018 – ‘**End-of-life care in non-malignant conditions.**’ End-of-life care (EoLC) refers to the care of patients with progressive, incurable conditions and considered to be in the last year of life. Approximately 75% of EoL patients will die from non-malignant conditions. There are significant challenges in the identification of patients with chronic disease who are nearing the EoL and in the provision of high-quality palliative care in this group. This article explores the role of GPs in the management of EoLC in the most common non-malignant conditions, including management of symptoms and advance care planning. **Abstract (w. list of references):** <https://goo.gl/YWuHGg>

Noted in Media Watch 15 January 2018 (#546, p.15):

- *PALLIATIVE MEDICINE* | Inprint – Accessed 13 January 2018 – ‘**Patients’ and carers’ perspectives of palliative care in general practice: A systematic review with narrative synthesis.**’ GPs have overall responsibility for community care, including towards end-of-life. Current policy places generalists at the centre of palliative care (PC) provision. However, little is known about how patients and carers understand the GP’s role. Five key themes were identified: 1) Continuity of care; 2) Communication between primary and secondary care; 3) Contact and accessibility; 4) Communication between GP and patient; and, 5) Knowledge and competence. **Abstract:** <https://goo.gl/CoHX77>

Tackling hearing loss to improve the care of older adults

BRITISH MEDICAL JOURNAL | Online – 18 January 2018 – The World Health Organization estimates that disabling hearing loss affects nearly a third (32.8%) of people aged 65 years and over around the world. The prevalence of hearing loss is growing; it is now the fourth leading cause of years lived with disability globally. But the implications tend to be overlooked. Clinical care is often delivered in settings where people with hearing loss struggle to understand speech. Communication is key for healthcare quality and safety, so people with hearing loss are at risk of receiving poor care. Simple steps can improve communication in clinical encounters. Changes in practice environments, processes, and policies could substantially improve the quality of medical care. But first, we need greater awareness. Typically, hearing loss isn’t a problem of hearing sounds, but rather of understanding speech. People with mild to moderate presbycusis (age related hearing loss) can often detect sound well and have good speech understanding in ideal circumstances; for example, in rooms with little competing ambient noise, in conversation with one speaker who is facing them. Understanding can decrease when the setting is less than ideal – when the speaker turns away, when there are multiple simultaneous speakers... **Abstract:** <https://goo.gl/yWdDS8>

N.B. Additional articles on the implications of hearing loss in the context of elder and end-of-life care are noted in the 28 August 2017 issue of Media Watch (#527, p.5).

Going it alone: A scoping review of unbefriended older adults

CANADIAN JOURNAL ON AGING | Online – 17 January 2018 – Older adults who have reduced decision-making capacity and no family or friends to compensate for these deficiencies are known as “unbefriended” and require a public guardian. The purpose of this study was to review the peer-reviewed and grey literature to determine the scope of available research on unbefriended older adults in Canada and the U.S. They found limited research examining unbefriended older adults. No Canadian studies or reports were located. Unbefriended older adults were childless or had fewer children, were more cognitively impaired, and were older than older adults who were not unbefriended. These findings demonstrate a stark scarcity of studies on unbefriended older adults. Research is urgently needed using standardized data collection of guardianship status in order to enable studies of the prevalence of public guardianship in Canada. **Abstract:** <https://goo.gl/KehmsZ>

N.B. Additional articles on decision-making for “unbefriended” or “unrepresented” patients are noted in the 18 September 2017 issue of Media Watch (#530, p.14).

Related

- *CANADIAN JOURNAL ON AGING* | Online – 8 January 2018 – ‘**Social isolation in later life: Extending the conversation.**’ Although much is known about individual-level risks and negative health outcomes associated with social isolation in later life, the impact of life course trajectories and the more collective experiences are seldom considered. Current definitions and program responses tend to rely on individualized approaches to social isolation. The authors argue that the conversation be extended to consider the social and cultural aspects of social isolation among older people. Specifically, they suggest that definitions and approaches consider three particular dimensions: temporal factors, spatial factors, and the relationship between social isolation and exclusion. **Abstract:** <https://goo.gl/XfD8Jy>

Staying out of the closet: Lesbian, gay, bisexual, and transgender older adults’ hopes and fears in considering end-of-life

CANADIAN JOURNAL ON AGING | Online – 16 January 2018 – Canada is experiencing population aging, and given the heterogeneity of older adults, there is increasing diversity in late life. The purpose of this study was to help fill the research gaps on lesbian, gay, bisexual, and transgender (LGBT) aging and end-of-life (EoL). Through focus groups, the authors sought to better understand the lived experience of older LGBT individuals and to examine their concerns associated with EoL. Their analysis highlights the idea that identifying as LGBT matters when it comes to aging and EoL care. In particular, gender identity and sexual orientation matter when it comes to social connections, in the expectations individuals have for their own care, and in the unique fear related to staying out of the closet and maintaining identity throughout aging and EoL. This study underscores the need to consider gender identity and sexual orientation at EoL. In particular, recognition of intersectionality and social locations is crucial to facilitating positive aging experiences and EoL care. **Abstract:** <https://goo.gl/Sbw1q8>

Noted in Media Watch 1 January 2018 (#544, p.20):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 18 December 2017 – ‘**End-of-life preparations among lesbian, gay, bisexual, and transgender people: Integrative review of prevalent behaviors.**’ Lesbian, gay, bisexual, and transgender (LGBT) people often experience discrimination from health care providers that will detrimentally affect their ability to communicate their care preferences. Structural barriers, such as those based on sexual orientation and gender identity, may impede timely and quality care when one is most in need. The aim of this study was to examine the prevalence of EoL preparatory behaviors among LGBT people, with particular focus on transgender individuals. **Abstract:** <https://goo.gl/N9XTzR>

N.B. Additional articles on palliative and end-of-life care for LGBTQ communities are noted in this issue of Media Watch.

Benefit or harm? A study on impact of collusion on the quality of life among palliative care patients

INDIAN JOURNAL OF PALLIATIVE CARE, 2018;24(1):61-66. In India, roughly one-half of patients undergoing cancer treatment are unaware of their diagnosis or treatment. A cross-sectional study was conducted among 100 palliative care (PC) patients to assess the extent of knowledge about their diagnosis and prognosis. The caretakers and the treating doctors were interviewed. The prevalence of collusion was 37%, i.e., in more than one-third of the PC patients; caregivers restrained doctors from disclosing the diagnosis. The prevalence of collusion was less among patients with higher educational qualification and professionals. Collusion was not associated with gender, type of family, place of residence, and socio-economic status. In multivariate regression, collusion was independently associated with poor quality of life (QoL) when adjusted for age, gender, place of residence, religion, educational status, family type, and socio-economic status. Collusion is fairly prevalent and it worsens the QoL among cancer patients. Since the main driver for collusion is the strong desire among caregivers to protect the physical and psychological well-being, the findings of the study could motivate the caregiver for a more open and honest communication. **Full text:** <https://goo.gl/k5mPpr>

Noted in Media Watch 9 January 2017 (#494, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2017 – ‘**Collusions between patients and clinicians in end-of-life care: Why clarity matters.**’ Two archetypal situations of collusion ... and means of working through collusion are presented. The theoretical framework of collusion is described and the conceptual shortcomings of the palliative care literature in this respect discussed, justifying the call for more clarity. Cultural aspects and societal injunctions on the dying, contributing to the development of collusion in end-of-life care, are discussed. **Abstract:** <https://goo.gl/uLkTDS>

Palliative care assessment in the surgical and trauma intensive care unit

JAMA SURGERY | Online – 10 January 2018 – How can we prioritize the fundamental needs of patients in the increasingly technical and data-driven environment of modern health care, especially in the intensive care unit (ICU)? Palliative care (PC) is a relatively new specialty that focuses on the most basic and human elements of medicine... The innovation is incorporating a PC assessment into the daily rounding metrics in the surgical and trauma ICU. The PC assessment is a simple question – does this patient have any PC needs? – that the team understands to include symptom management challenges, issues of psychosocial support, and disparities in perception of treatment plan and prognosis. Incorporating this question into the daily rounds allows these aspects of patient care to be given equal priority as issues such as hemodynamics and infection in the daily rounding discussion. **First page view:** <https://goo.gl/3jFyXo>

Qualitative analysis of palliative care for pediatric patients with cancer at Bugando Medical Center: An evaluation of barriers to providing end-of-life care in a Resource-limited setting

JOURNAL OF GLOBAL ONCOLOGY | Online – 16 January 2018 – Palliative care (PC) remains an urgent, neglected need in the developing world. Global disparities in end-of-life care (EoLC) for children, such as those with advanced cancers, result from barriers that are complex and largely unstudied. This study describes these barriers at Bugando Medical Center, one of three consultant hospitals in Tanzania, to identify areas for PC development suitable to this context. Data from interviews as well as participant observation revealed several barriers to PC: financial, infrastructure, knowledge and cultural (including perceptions of pediatric pain), and communication challenges. Although this study focused on barriers, what also emerged were the unique advantages of EoLC in this setting, including community cohesiveness and strong faith background. This study provides a unique but focused description of barriers to PC common in a low-resource setting, extending beyond resource needs. This multidisciplinary qualitative approach combined interviews with participant observation, providing a deeper understanding of the logistical and cultural challenges in this setting. **Full text:** <https://goo.gl/rBkNb5>



End-of-life training in U.S. internal medicine residency programs: A national study

JOURNAL OF MEDICAL EDUCATION & TRAINING | Online – 14 December 2018 – End-of-life (EoL) care is a required and important component of medical training for internal medicine residents; many of whom will go on to provide care for adults at the EoL stage. Although a body of past research suggests that physician training in EoL care needs significant improvement, a comprehensive national study of EoL education within U.S. internal medicine residency programs has never been published. [See sidebar] More than half (52%) of all program directors completed the survey. Although directors strongly believed in the benefits of residents integrating EoL care components into clinical practice, only 36% of programs reported having formal EoL curriculum in place for more than three years. Of those programs that taught EoL topics or skills, the majority did not formally evaluate residents' competence. Moreover, 24% of residency programs did not have an EoL curriculum; 34% did not offer a rotation in hospice care; and, 31% did not have structured conference teaching on topics dealing with EoL. **Full text:** <https://goo.gl/uzBgbZ>

A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2016;34(6):559-565. The purpose of this longitudinal study of U.S. medical schools over a 40-year period was to ascertain their offerings on end-of-life (EoL) issues. At 5-year intervals, beginning in 1975, U.S. medical schools were surveyed via a questionnaire to determine their EoL offerings. Data were reported with frequency distributions. The Institute of Medicine has encouraged more emphasis on EoL issues over the past two decades. Findings revealed that undergraduate medical students in the U.S. are now exposed to death and dying, palliative care (PC), and geriatric medicine. The inclusion of EoL topics has definitely expanded over the 40-year period as findings reveal that U.S. undergraduate medical students are currently exposed in over 90% of programs to death and dying, PC, and geriatric medicine, with the emphasis on these topics varying with the medical programs. Such inclusion should produce future favorable outcomes for undergraduate medical students, patients, and their families. [First published online 10 March 2016; noted in the 14 March 2016 issue of *Media Watch* (#453, p.8)] **Abstract (w. list of references):** <http://goo.gl/pa3cCV>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 January 2018 – ‘**Medicine as it should be: Teaching team and teamwork during a palliative care clerkship.**’ Interprofessional education (IPE) is an important component of medical education. Rotations with palliative care interdisciplinary teams (IDTs) provide an optimal environment for IPE and teaching teamwork skills. Dominant themes identified [in this study] related to teams and teamwork. Eight specific themes were identified: 1) Value of IDT for team members; 2) Value of IDT for patient/family; 3) Importance of each team member; 4) Reliance on other team members; 5) Roles of team members; 6) How teams work; 7) Team communication; and, 8) Interdisciplinary assessment and care planning. **Abstract:** <https://goo.gl/pCYdv6>

Culture and palliative care: Preferences, communication, meaning, and mutual decision-making

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 January 2018 – Palliative care (PC) is gaining acceptance across the world. However, even when PC resources exist, both the delivery and distribution of services too often is neither equitably nor acceptably provided to diverse population groups. The goal of this paper is to illustrate tensions in the delivery of PC for diverse patient populations in order to help clinicians to improve care for all. The authors begin by defining and differentiating between culture, race, and ethnicity, so that these terms – often used interchangeably – are not conflated and are more effectively used in caring for diverse populations. They then present examples from an integrative literature review of recent research on culture and PC to illustrate both how and why varied responses to pain and suffering occur in different patterns, focusing on four areas of PC: 1) The formation of care preferences; 2) Communication patterns; 3) Different meanings of suffering; and, 4) Decision-making processes about care. For each area, the authors provide international and multi-ethnic examples of varia-

Cont.

Tions that emphasize the need for personalization of care and the avoidance of stereotyping beliefs and practices without considering individual circumstances and life histories. They conclude with recommendations for improving PC research and practice with cultural perspectives, emphasizing the need to work in partnerships with patients, their family members, and communities to identify and negotiate culturally meaningful care, promote quality of life, and ensure the highest quality PC for all, both domestically and internationally. **Abstract:** <https://goo.gl/UF6Eo4>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 January 2018 – ‘**Experiential learning to increase palliative care competence among the Indigenous workforce: An Australian experience.**’ Improving Indigenous people’s access to palliative care (PC) requires a health workforce with appropriate knowledge and skills to respond to end-of-life (EoL) issues. The Indigenous component of the Program of Experience in the Palliative Approach includes opportunities for Indigenous health practitioners to develop skills in the palliative approach by undertaking a supervised clinical placement of up to 5 days within specialist PC services. This paper presents the evaluative findings of the components of an experiential learning programme and considers the broader implications for delivery of successful PC education programme for Indigenous people. **Full text:** <https://goo.gl/D7Xibu>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 17 January 2018 – ‘**Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature.**’ Sub-optimal analgesic use, delays in receiving treatment, reluctance to report pain, and/or poor adherence to prescribed analgesics contributed to the patients’ inadequate pain control. Patient-related barriers included fatalism, desire to be good, low pain control belief, pain endurance beliefs, and negative effect beliefs. Patients and family shared barriers about fear of addiction and concerns on analgesic side effects and disease progression. Health professional-related barriers were poor communication, ineffective management of pain, and analgesic side effects. Healthcare system-related barriers included limited access to analgesics and/or after hour pain services and lack of health insurance. **Abstract (w. list of references):** <https://goo.gl/s25iJH>

End-of-life care in Canada

Associations between home death and the use and type of care at home

JOURNAL OF PALLIATIVE CARE | Online – 14 January 2018 – Despite wishes for and benefits of home deaths, a discrepancy between preferred and actual location of death persists. Provision of home care may be an effective policy response to support home deaths. Using the population-based mortality follow-back study conducted in Nova Scotia, the authors investigated the associations between home death and formal care at home and between home death and the type of formal care at home. They found 1) The use of formal care at home at the end of life was associated with home death; and, 2) The use of formal home support services at home was associated with home death among those whose symptoms were well managed. **Abstract:** <https://goo.gl/xqCpgF>

“They said on the death certificate...but, really what I think happened.”

Characterizing cause of death in U.S. Veterans Affairs medical centers

JOURNAL OF PALLIATIVE CARE | Online – 14 January 2018 – Cause of death information is a vital resource for family and public health, yet significant issues persist regarding its determination, documentation and communication. In this study, the authors aimed to characterize cause of death attribution process from the perspective of next-of-kin of veterans who died in Veterans Affairs medical centers. In over two-third of cases, next-of-kin’s understanding was not consistent with their recollection of physicians’ determination of cause of death. Discrepancies between official cause of death and lay understanding engendered confusion and distress. **Abstract:** <https://goo.gl/V6BJMX>

N.B. Additional articles on end-of-life care in the Veterans Affairs health care system are noted in the 15 January 2018 issue of Media Watch (#546, p.15).

How are young caregivers affected by family members with a chronic illness?

MEDICAL NEWS BULLETIN | Online – 16 January 2018 – The literature thus far indicates that there may be benefits as well as drawbacks to caring for family members with chronic illness at a young age. Some studies have found that young carers demonstrate a high sense of self-esteem, early maturity, and a close relationship with their parents. Other studies indicate that there may be harm to the physical, psychosocial, and educational development of these children. A recent review summarizes the current body of knowledge about young carers' lives, paying particular attention to their personal experiences, the impact of caring, and their needs and coping behaviours.¹ The study found that many of the children involved in caring for family members with chronic illness were highly involved in their care, and consequently spent the majority of their time at home. The studies indicated that the children tended to conceal their role of caregiver from others, including extended family members, not wanting to be identified as different, or as "young carers." **Full text:** <https://goo.gl/kj4yeQ>

1. 'Growing up with chronic illness in the family: A systematic review 2007-2017,' *Journal of Compassionate Health Care*, published online 10 November 2017. **Full text:** <https://goo.gl/o6wGsh>

Perinatal palliative care: Integration in a U.S. nurse midwifery education program

MIDWIFERY, 2018;58(3):117-119. Midwifery students with perinatal palliative care (PC) education develop a skill set to provide holistic midwifery care to women and families who are experiencing stillbirth or life-limiting fetal diagnoses. This paper presents a model of perinatal PC in a U.S. midwifery education program. By utilizing evidence based practices and national programs, perinatal PC can be threaded through midwifery curricula to achieve international standards of practice and competencies. Most importantly, enhancing perinatal PC education will better prepare future midwives for when a birth outcome is not what was expected at the outset of a pregnancy. **Abstract:** <https://goo.gl/KKw43q>

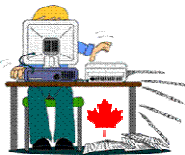
N.B. The latest issue of the Children's Project on Palliative/Hospice Services (ChiPPS) e-journal focuses on perinatal and neonatal palliative and hospice care. [Noted in the 27 November 2017 issue of Media Watch (#540, p.14)] **Download/view at:** <https://goo.gl/GPH48x>

Noted in Media Watch 18 September 2017 (#530, p.18):

- *SEMINARS IN FETAL & NEONATAL* | Online – 13 September 2017 – '**Ethics and palliative care in the perinatal world.**' The perinatal world is unique in its dutiful consideration of two patients along the lines of decision-making and clinical management – the fetus and the pregnant woman. The potentiality of the fetus-newborn is intertwined with the absolute considerations for the woman as autonomous patient. **Abstract:** <https://goo.gl/1A55qf>

Noted in Media Watch 10 August 2015 (#422, p.8):

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. '**Clinician perspectives of barriers in perinatal palliative care.**' Among the study participants, both nurses and physicians expressed similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. Participants in the study also reported a lack of societal support and understanding about perinatal palliative care. **Abstract:** <https://goo.gl/Tb44j8>



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://goo.gl/5CHoAG>

Forgoing life-sustaining treatments in the ICU. To withhold or to withdraw: Is that the question?

MINERVA ANESTESIOLOGICA | Online – 17 January 2018 – In the last decades, mortality from severe acute illnesses has considerably declined thanks to the advances in intensive care medicine. Meanwhile, critical care physicians realized that life-sustaining treatments (LST) may not be appropriate for every patient, and end-of-life care in the intensive care unit (ICU) started to receive growing attention. Most deaths occurring in the ICU now follow a decision to forgo life-sustaining treatments (DFLST), which can be implemented either by withdrawing (WDLST) or withholding (WHLST) life-sustaining treatments. Despite the broad consensus about the equivalence of the two practices from an ethical point of view, the issue of the best option between WDLST and WHLST constantly gives rise to controversies in clinical practice. This review is not intended to take a stand for or against WDLST or WHLST. Based on available evidence, the definitions of the two practices are first presented. Secondly, the preferences of ICU physicians towards WDLST and WHLST are examined. Finally, some arguments are offered outlining pros and cons of WDLST and WHLST, stressing that the clinician's attention should focus on an early and thorough recognition of patients in need of a DFLST, rather than on the theoretical strength and weakness of the two practices. **Abstract:** <https://goo.gl/8zwRXL>

Related

- *CURRENT OPINION IN ANESTHESIOLOGY* | Online – 18 January 2018 – **‘Worldwide end-of-life practice for patients in ICUs.’** Recent observational and survey data shows a marked variability in the practice of withholding and withdrawing life sustaining therapy worldwide. Some evidence supports the view that culture, religion, and socioeconomic factors influence end-of-life (EOL) practice, and individually or together account for differences observed. There are likely to be commonly desired values and expectations for EOL practice, and recent attempts at establishing where worldwide consensus may lie have improved understanding of shared values and practices. **Abstract:** <https://goo.gl/iGPF2E>
- *CURRENT OPINION IN ANESTHESIOLOGY* | Online – 15 January 2018 – **‘Withdrawal of life-sustaining therapy.’** With the withdrawal of life-sustaining therapy (WLST), differences in perspectives exist between medical specialties, within one specialty at different levels of training, and in physicians' ethical and psychological responses to the WLST. The timing of WLST appears to be influenced by ICU strain and communication issues. Study outcomes differ regarding the functionally favorable survival of patients who have had WLST. Universal guidelines for the WLST may not address individual patient circumstances. **Abstract:** <https://goo.gl/pKKmWY>

Provision of palliative care for people with advanced dementia

DER NERVENARZT | Online – 11 January 2018 – As a result of a literature-based expert process, this review provides an overview about the principles of palliative care (PC) for people with advanced dementia that are relevant for clinical practice. In particular, the indications, impact and aims of PC for advanced dementia are described. Life-prolonging measures and management of symptoms at the end of life are discussed. Furthermore, the overview focuses on the legal basis of decision-making. **Abstract (w. list of references):** <https://goo.gl/1xYkaE>

N.B. German language article. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia are noted in the 1 January 2018 and 18 December 2017 issues of *Media Watch* (#544, p.12 and #543, p.18, respectively).

Related

- *PALLIATIVE MEDICINE* | Online – 18 January 2018 – **‘Caring for a family member or friend with dementia at the end of life: A scoping review and implications for palliative care practice.’** Carers' experience centred on relationships (with care recipients, family and friends and health care professionals) and the specific context of caring for someone with dementia. These broad categories of carers' experiences had clear influences on them personally, particularly in relation to their sense of self and their wellbeing. Tailoring services to the specific context of dementia would enable effective, personalised support throughout extended periods leading up to care recipient death as well as through the challenges faced beyond bereavement. **Abstract:** goo.gl/yq66fW

Reflection on curative treatment versus palliation of symptoms in end-of-life care

NURSING STANDARD, 2018;32(21):46-51. The conflicting tasks of treating or managing disease and preparing patients and their families for the end of life (EoL) are well documented in haematology and palliative care settings. This article is a reflection on practice by a nursing student who was in the fourth year of an internship, and discusses a case study involving a woman at the EoL. It considers the approach to palliative and EoL care adopted in an oncology and haematology ward where there was a reluctance to be realistic about the limitations of treatments among some healthcare practitioners, who did not want to dispel unrealistic expectations of the patient's recovery as a result of continuing treatment. This reflection focuses on the care of a patient at the EoL and the frustration experienced by the nursing student at their inability to alter the direction of treatment from curative treatment to the palliation of symptoms. **Abstract:** <https://goo.gl/KcJVbU>

The importance of parental connectedness and relationships with healthcare professionals in end-of-life care in the pediatric ICU

PEDIATRIC CRITICAL CARE MEDICINE | Online – 11 January 2018 – Support from healthcare professionals in a pediatric ICU (PICU) is highly valuable for parents of dying children. The way they care for the patients and their families affects the parents' initial mourning process. This study explores what interaction with hospital staff is meaningful to parents in existential distress when their child is dying in the PICU. Parents' narratives of their child's end-of-life stage in the PICU bespeak experiences of estrangement, emotional distancing, and loneliness. Significant moments shared with hospital staff that remained valuable even after 5 years primarily involved personal connectedness, reflected in frequent informational updates, personal commitment of professionals, and interpersonal contact with doctors and nurses. **Abstract:** <https://goo.gl/4krMXv>

N.B. Additional articles on end-of-life and bereavement care in pediatric intensive care units are noted in the 2 October and 28 August 2017 issues of *Media Watch* (#532, p.6 and #527, p.13, respectively).

Psychiatry and palliative care, collaboration for the benefit of the patient

LA REVUE DE L'INFIRMIÈRE | Online – 11 January 2018 – As palliative care units continue to develop, the provision of end-of-life care (EoL) for patients with a chronic mental illness needs to be addressed. Aside from the somatic comorbidities to which these patients are particularly exposed and in view of the specificity of psychiatric treatment, the forms of EoL support for a patient with schizophrenia are described here, based on the experience of a psychiatric unit in the Var region [of south-eastern France]. **Abstract :** <https://goo.gl/f7ptL4>

N.B. French language article.

Noted in *Media Watch* 9 June 2014 (#361, p.14):

- *JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH SERVICES*, 2014;52(8):32-38. '**Palliative care for terminally ill individuals with schizophrenia.**' Individuals with schizophrenia are often medically undertreated and experience symptoms that interfere with communication and the capacity to make medical decisions. These issues complicate quality end-of-life care for this population and are of particular concern for hospice and palliative care nurses and health care providers. **Abstract:** <https://goo.gl/13zi8r>

N.B. Additional articles on palliative and end-of-life care for people living with schizophrenia are noted in this issue *Media Watch*.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN PHARMACISTS JOURNAL*, 2018;151(1):17-23. ‘**Community pharmacists’ attitudes on suicide: A preliminary analysis with implications for medical assistance in dying.**’ Roles for pharmacists in suicide and medical assistance in dying (MAiD) are emerging and evolving as knowledge and understanding build around suicide and with recent changes in MAiD legislation. This preliminary survey analysis indicates that pharmacists perceive a low frequency of direct interaction with those at risk of suicide. Pharmacists may be underestimating those who are at risk for suicide and those who may seek MAiD in their care, given their likelihood of interacting with numerous groups of people known to have higher risk than the general population for suicide attempts, suicide and a desire to hasten death (e.g., those with serious mental illness, those with multi-morbidity aged 65 years, those with terminal diagnoses, etc.). Death by suicide occurs in approximately 1 in 10,000 (age-standardized) Canadians. Given that attempts are 10 to 40 times more frequent, up to 40 per 10,000 Canadians attempt suicide, and more experience suicidal ideation than attempt suicide. This preliminary finding has implications for education and training of pharmacists and the need for more research to explore what pharmacists require in individual practice settings and within the health system to support their care of those at risk of suicide as well as those seeking MAiD. **Full text:** <https://goo.gl/rKHSWY>

Noted in Media Watch 25 January 2016 (#446, p.16):

- *CANADIAN PHARMACISTS JOURNAL*, 2016;149(1):54-55. ‘**Canadian Pharmacists Association surveys pharmacists on physician-assisted dying.**’ In certain jurisdictions where assisted dying is legal, pharmacists are not only asked to dispense lethal drugs, but can be expected to offer advice to patients and physicians. Consistent with this approach, the Canadian Pharmaceutical Association’s survey found that Canadian pharmacists favour such a requirement for pharmacist counselling to the patient, physician or patient’s family as part of dispensing lethal medication. **Abstract:** <http://goo.gl/Npxtqi>

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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/VnqvXP>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK-e: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole'; see also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/sBTcJS>

[November/December 2017 issue (Scroll down to 'Vulnerable populations: From the homeless to the unbefriended)']

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net