

Media Watch...

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

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Guiding best practice in end-of-life care: Scroll down to [Specialist Publications](#) and 'Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences' (p.14), in *Palliative Medicine*.

Canada

Homeless deserve end-of-life care, but aren't getting it

BRITISH COLUMBIA | *The Times-Colonist* (Victoria) – 14 August 2016 – While life expectancy for British Columbians averages between 80 and 84 years, homeless people die at a median age of only 40 to 49. Between 2007 and 2013, Victoria had the highest *per capita* number of deaths of homeless people in the province. Dealing with chronic illnesses and isolation means good health is rarely attainable, yet homeless people feel unworthy of care; biases, both societal and from health workers, tell homeless people that they are undeserving. Shelter staff who are well-equipped to work with this population can't always recognize a dying person. Someone with advanced lung cancer who comes to a shelter for the night would not necessarily look or sound different than any other client to a medically untrained eye. The final injustice for homeless people is to have no palliative or end-of-life care available. If you or I want to register for hospice care, we provide a home address where we can receive an assessment. We get a referral from a doctor, oncologist or healthcare provider who knows we have a progressive, life-threatening

illness. A homeless person has no address and rarely has access to a professional to provide a diagnosis or transportation to appointments. <http://goo.gl/c0zbwo>

Specialist Publications

'Hospice care in Calgary: Survey of family physicians on their knowledge, experience, and attitudes' (p.9), in *Canadian Family Physician*.

'A family way of dying: The story of a residential palliative care facility' (p.9), in *Canadian Family Physician*.

'Ultimate journey of the terminally ill: Ways and pathways of hope' (p.9), in *Canadian Family Physician*.

'Revisiting the use of "place" as an analytic tool for elucidating geographic issues central to Canadian rural palliative care' (p.11), in *Health & Place*.

Cont.

Noted in Media Watch, 8 August 2016, #474 (p.12):

- *SOCIAL WORK & SOCIETY*, 2016;14(1). ‘**Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work.**’ In attempting to support the dignity and worth of the patients, social workers should advocate for better discharge practices, and should gain more direct familiarity with the needs of serious and chronically ill homeless individuals. <http://goo.gl/UiG8EB>

N.B. Additional articles on end-of-life care for the homeless noted in Media Watch 14 March 2016, #453 (pp.14-15).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News – 17 August 2016 – ‘**Palliative care home in Trois-Rivières latest to refuse to offer doctor’s help to die.**’ A patient seeking medical help to die had to be transferred out of the Maison Albatros, a palliative care (PC) home in Trois-Rivières, because staff at the hospice weren’t willing to assist him... The incident happened earlier this summer. In accordance with Quebec’s law on doctor-assisted death which went into effect last December, with no doctor on staff willing to carry out the procedure, the patient was transferred to the Centre hospitalier de Trois-Rivières. The Maison Albatros isn’t the only PC establishment to take this position: of the 31 such centres in Quebec, only two – the Maison René Verrier in Drummondville, and the Maison Aube-Lumière in Sherbrooke – offer medical assistance to die. <http://goo.gl/bBKlX9>

U.S.A.

Hospice teams may be overlooking teenaged family members

REUTERS HEALTH | Online – 19 August 2016 – Teens with dying parents don’t benefit as much from hospice services as older members of the family do, a new study suggests.¹ The needs of teenagers with parents in hospice are often not met or even assessed, the study found – even though the hospices take a team approach to care delivery that’s designed to manage the physical, psychosocial and spiritual concerns of dying patients and their families. Most of the surveyed adolescents with a parent in hospice had zero or limited contact with staff, researchers reported... “In hospice, the unit of care is to the patient and family, but kids are being overlooked,” said study author M. Murray Mayo of Ursuline College’s Breen School of Nursing in Pepper Pike, Ohio. Mayo’s team in-

terviewed 30 adolescents between the ages of 12 and 18, living in the mid-west U.S., who had a parent receiving hospice care. The team asked open-ended questions about how the youngsters learned their parent was dying and how they navigated the stress with ongoing responsibilities inside and outside of school. Twelve teens reported they had no interaction at all with hospice staff. Timing of providers’ visits was largely to blame. <http://goo.gl/llfjm9>

Specialist Publications

‘Talking to children with cancer: Sometimes less is more’ (p.12), in *Journal of Clinical Oncology*.

1. ‘An examination of interactions between hospice health care providers and adolescents with a parent in hospice,’ *Journal of Hospice & Palliative Nursing*, 2016;18(4):302-309. <http://goo.gl/QNR23r>

Related

- *THE NEW YORK TIMES* | Online – 18 August 2016 – ‘**Talking to children when a patient is dying.**’ Studies show that levels of anxiety are lower in children who are told of their parent’s diagnosis, even if it’s cancer. However, we also know that the risk of post-traumatic stress disorder is high in children who have lost a parent. These forces impact our desires to tell children the facts and make us ask, how much is too much and how much is just right. <http://goo.gl/ZzM9gO>

“A dangerous conversation”: Medical interpreters need extra training to help dying patients

CALIFORNIA | *Kaiser Health News* – 17 August 2016 – Interpreters routinely help people who speak limited English – close to 9% of the U.S. population, and growing – understand what’s happening in the hospital. They become even more indispensable during patients’ dying days. But specialists say interpreters need extra training to capture the nuances of language around death. Many doctors and nurses need the assistance of interpreters not only to overcome language barriers but also to navigate cultural differences. Opportunities for miscommunication with patients abound. Words don’t always mean the same thing in every language. Medical staff, already nervous about delivering bad news, may speak too quickly, saying too much or too little. They may not realize patients aren’t comprehending that the team can no longer save their lives. <https://goo.gl/G6xDgv>

Noted in Media Watch, 20 June 2016, #467 (p.15):

- *PSYCHO-ONCOLOGY* | Online – 15 June 2016 – ‘Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters.’ Language barriers and underuse of medical interpreters have been widely identified as obstacles to equitable and quality care; however, the rate of professional interpreter use remains unknown. Further, no known study has explored patients’ reasons for refusing interpreter assistance, rather, existing studies have largely focused on physician and parental barriers. <http://goo.gl/VSe2l8>

N.B. Additional articles on patients with limited English proficiency in the context of end-of-life care are noted in this issue of Media Watch.

We doctors see death all around us, but we don’t like to think about our own

THE WASHINGTON POST | Online – 15 August 2016 – Physicians, like most people, do not want to discuss the implications of their own mortality. We forgo difficult conversations, assuming that our wishes would somehow be innately known by our friends and families. Haven’t we always been told that all doctors want the same thing? Indeed, a 2014 survey confirmed that an overwhelming majority of physicians – almost 90% – would choose no resuscitation.¹ Most doctors also report wanting to die at home rather than in a hospital. Perhaps it is these general assumptions that make physicians not feel the need to explicitly discuss and outline their end-of-life preferences. In a survey of almost 1,000 physicians whose mean age was 68, almost 90% thought that their family members were aware of their wishes for end-of-life care.² Almost half of those surveyed did not think their doctor was aware of their end-of-life choices, with 59% of those participants having no intention of discussing these wishes with their doctor in the next year. But we know that conversations about proxies and advance directives should happen long before they need to be utilized. A 2016 study found that physicians were as likely to be hospitalized in the last six months of life as were non-physicians.³ On average, they also spent

more days in intensive care units at the end of life and were as likely as others to die in a hospital. So why are doctors dying in hospitals and in intensive care units instead of at home, when we know that their wishes tend to align with avoiding extreme measures at the end of life? <https://goo.gl/urTxcO>

Specialist Publications

‘Facing death: A critical analysis of advance care planning in the U.S.’ (p.7), in *Advances in Nursing Science*.

‘Place of death of individuals with terminal cancer: New insights from Medicare Hospice Place-of-Service Codes’ (p.13), in *Journal of the American Geriatrics Society*.

‘Defining high-quality palliative care in oncology practice: An American Society of Clinical Oncology/American Academy of Hospice & Palliative Medicine guidance statement’ (p.12), in *Journal of Oncology Practice*.

‘Populations and interventions for palliative and end-of-life care: A systematic review’ (p.13), in *Journal of Palliative Medicine*.

Cont.

1. 'Do unto others: Doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives,' Plos One, 28 May 2014. [Noted in Media Watch, 2 June 2014, #360 (p.11)] <http://goo.gl/3M0BF1>
2. 'Life-sustaining treatments: what do physicians want and do they express their wishes to others?' Journal of the American Geriatric Society, 2003;51(7):961-969. <http://goo.gl/aLD91z>
3. 'How U.S. doctors die: A cohort study of healthcare use at the end of life,' *Journal of the American Geriatrics Society*, 16 May 2016. [Noted in Media Watch, 23 May 2016, #463 (p.12)] <http://goo.gl/dKCZ2a>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Economist* – 16 August 2016 – '**Colorado will be the next state to vote on doctor-assisted dying.**' The issue is a tough one for legislators, since it arouses strong passions and well-organised opposition. Sometimes, therefore, campaigners have sought to "let the people decide." The latest place to take this route is Colorado. A bill supporting doctor-assisted dying was quashed last year by the state legislature. But in April a draft statute was filed with the secretary of state, an elected constitutional officer, to place Initiative 145, the 'Colorado End-of-Life Options Act,' on the ballot in November. <http://goo.gl/CTlhJs>
- WASHINGTON STATE | Department of Health – 16 August 2016 – '**2015 Death with Dignity Act Report.**' In 2015, medication was dispensed to 213 individuals. Prescriptions were written by 142 different physicians and dispensed by 49 different pharmacists. Of the 213 participants in 2015, 202 are known to have died, 166 died after ingesting the medication, and 24 died without having ingested the medication. For the remaining 12 people who died, ingestion status is unknown. <http://goo.gl/qvcG7h>
- CALIFORNIA | *WorldNetDaily* (Washington DC) – 11 August 2016 – '**California OKs assisted suicide for disabled, but not prisoners.**' The California bureaucracy proposed a dramatic policy last week. It was essentially unreported. The Department of Corrections issued new regulations proposing that no prisoner shall be allowed to avail of the so called Death With Dignity Act. The law itself, currently under litigation, has been allowed to remain in effect for all other Californians until a ruling expected later next month. But in the meantime it is proposed that no prisoner, no matter how ill, may avail of the "right" that other ill people have been offered; the supposed "right to be dead." <http://goo.gl/ualcP2>

International

End-of-life care in Spain

It takes a village: Expert calls for community involvement in palliative care

SPAIN | Australian Ageing Agenda – 18 August 2016 – European experience has confirmed that community-based palliative care (PC) reduces unnecessary and costly hospital treatment, an international PC specialist has told Australian aged care providers. Dr. Emilio Herrera, a Spanish PC specialist, recently presented a financial analysis that showed a home-based PC approach was saving health systems millions where it has been introduced. Dr. Herrera has developed the We're All With You (Todos Contigo) movement in Spain and throughout other European cities and South America to meet the rapid increase of chronic illness facing countries with an ageing population. Speaking at the recent Palliative Care Victoria conference, Dr. Herrera said that rather than looking for miracles when a loved one was dying at the end of a long-term chronic illness, people needed to plan to meet the person's emotional and physical needs, with the support of their community and not just health professionals. Dr. Herrera said that for every Euro invested in the community-based PC program, five to six Euro was saved in alternative more intensive acute and emergency hospital care. His approach saw the person placed at the centre, surrounded by family, carers and the community, and then social and health services – all working together to ensure quality end-of-life care. <http://goo.gl/dH0BDD>

End-of-life care in Australia

Proposed new drug guidelines for the Pharmaceutical Benefit Scheme put cost-cutting before patients

AUSTRALIA | *The Guardian* (U.K.) – 17 August 2016 – For decades, Australia led the world in recognising the importance of assessing the value new medicines provide to its citizens and ensured the prices Australians paid for these medicines reflected their value. As a result, the health of Australians has been among the best in the world, a feat achieved at levels of health-care spending that have fallen well below nations such as the U.S. Indeed, within the U.S., health policy scholars have frequently viewed Australia’s healthcare system as a model of how care can be delivered efficiently to an entire population. Meanwhile, the notion drug prices can reflect value has escaped the U.S. health marketplace. But Australia’s dominant position at the forefront of public health policy innovation and therefore its global health advantage lie in question. Healthcare treatments are quickly evolving, as is our understanding of how treatments affect society at large, an issue is particularly important with an ageing population that must be cared for by others. This rapid evolution means Australia’s system for determining which drugs are available to the population will need to adapt to ensure treatments that provide value to society continue to be accessible to Australians. <https://goo.gl/SfGFxB>

Extract from *The Guardian* article

The guidelines, as proposed, do not go far enough in specifying and including direct input from patients and clinicians into the coverage recommendations. It should come as no surprise then that a failure to systematically incorporate these important views has led some drug assessments, particularly in cancer, to not meet best practices globally. For instance, in end-of-life care, where patient preferences are paramount, other nations have led the charge in better assessing how treatments affect quality of life near its end.

Photo series captures death and dying in palliative care unit

AUSTRALIA (New South Wales) | *The Daily Telegraph* (Sydney) – 17 August 2016 – Captured in a series of emotive black and white photos, Western Sydney Local Health District’s Carlos Furtado captures “precious moments” as patients resting uneasily, family members reflecting on the impending finality of life, and hospital staff doing their challenging jobs with gentleness and grace. <http://goo.gl/TzjL61>

Report: Scotland’s home care sector in crisis

U.K. (Scotland) | *The Herald* (Glasgow) – 17 August 2016 – A damning report into Scotland’s home care service claims the sector is at breaking point, with vulnerable people failing to receive the care they need.¹ The UNISON report reveals claims from many carers that they are given too little time to properly care for clients, with some receiving less than 15 minute slots because travel times are not accounted for. Staff also claim budget cuts and privatisation mean that the emphasis in the sector is now on “quantity rather than quality.” The report ... also shows carers often go without pay for travelling time between visits and regularly have to work longer than their contracted hours. The report, which surveyed home carers across the country, states that 9 in 10 carers are limited to specific times for client visits. Many contradicted the claim by councils that 15 minute time slots are only allocated to those with minimal needs, while some also claimed that scheduling often does not consider travel time between visits. Freedom of information requests by UNISON reveal that 25 councils pay staff for travelling expenses, but four only pay their own staff, not contracted workers. Three councils confirmed they do not pay at all, while one said it varied. <http://goo.gl/bPOHlx>

1. ‘We Care, Do You? A Survey of Care Workers in Scotland,’ UNISON, July 2015. <http://goo.gl/J0SpWR>

N.B. UNISON is one of the U.K.’s largest trade unions. Additional articles on end-of-life care in Scotland noted in Media Watch, 21 March 2016, #454 (pp.5-6).

How can care homes ensure a good death for residents?

U.K. (England) | *The Guardian* – 16 August 2016 – No one goes into a care home with the express intention of dying. At the same time, most residents have a limited life expectancy and the majority will die within two or three years of moving to a home. There is a long list of challenges facing all those involved in providing the best possible support for the 460,000 people living in U.K. care homes. They become even greater when it comes to caring for the eight out of 10 residents likely to suffer from dementia. They are also compounded by the fact that as many as 27 different National Health Services services can visit to provide care and treatment for residents. Add a variably qualified care home workforce with inconsistent access to clinical support and what you get is a lot of uncertainty. The furore around ... the Liverpool Care Pathway illustrated many flaws in assumptions about how people die and who makes decisions regarding treatment options. Even the term “pathway” has been branded misleading, with its implications of

known direction, shared goals and the ability to standardise care. <https://goo.gl/Fhe2Ey>

Extract from *The Guardian* article

Research ... tracked the care of older people in 29 care homes over a 12-month period.¹ End-of-life interventions were characterised by uncertainty in three key areas:

Which is the “right” treatment?

Who should do what and when?

In which setting should end-of-life care be delivered and by whom?

1. ‘End of life care interventions for people with dementia in care homes: Addressing uncertainty within a framework for service delivery and evaluation,’ *BMC Palliative Care*, 17 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.10)] <http://goo.gl/FS5ZtI>

Related

- U.K. (England | LocalGov – 18 August 2016 – ‘**First county to back Dying to Work campaign.**’ Nottinghamshire has become the first county council to sign up to a new charter helping employees with terminal illnesses stay in their job. The Trade Union Council’s Dying to Work Voluntary Charter gives employees a “protected period” in which they can not be dismissed from their role as a result of their terminal illness. <http://goo.gl/Y2Nlvu>

N.B. Additional articles on job protection for people living with a terminal illness are noted in Media Watch, 28 March 2016, #455 (p.5).



[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.¹ 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>

1. Ashpole BR. ‘Communications with the Public, Politicians, and the News Media,’ *Oxford Textbook of Palliative Medicine*, 5th Edition (pp.357-359), Oxford University Press, 2015. <https://goo.gl/Vi07RS>.



Media Watch: Behind the Scenes
<http://goo.gl/XDjHxz>

New “dementia atlas” reveals disparity in care across England

U.K. (England) | *The Guardian* – 16 August 2016 – People with dementia are being let down by local services across the country, according to new government data that critics say has revealed a postcode lottery in care for the chronic and degenerative brain disease. An interactive “dementia atlas”¹ ... exposes wide differentials in aspects of dementia care: while in some parts of England, 85.8% dementia patients have their care looked at every year, in others just 49.3% receive the same service. Those checks are seen as important because, as dementia is a long-term and degenerative condition, “reviewing those with a diagnosis at least annually will ensure that the needs of people with dementia and their carers are discussed and appropriate care plans can be implemented”, the atlas says. Similarly, while some areas have as many as 8,000 “dementia friends” available to help patients, others have none at all. There is also a more than three-fold variation in the number of those

with dementia being admitted to hospital as an emergency. <https://goo.gl/1pJhHe>

Extract from dementia map “on dying well”

In England, approximately 480,000 people die each year. One in 10 of these people will have dementia. One in three people who die after the age of 65 have dementia. All health and care staff who support dying people must be capable and compassionate in treating people with dementia.

[Specialist Publications](#)

‘What is important at the end of life for people with dementia? The views of people with dementia and their carers’ (p.12), in *International of Journal of Geriatric Psychiatry*.

1. Interactive Dementia Map, Department of Health, August 2016. <https://goo.gl/3gVqag>

[Specialist Publications](#)

Facing death: A critical analysis of advance care planning in the U.S.

ADVANCES IN NURSING SCIENCE | Online – 11 August 2016 – Studies have shown that advanced care planning (ACP) improves communication and reduces suffering for patients and their bereaved caregivers. Despite this knowledge, the rates of advance care plans are low and physicians, as the primary gatekeepers, have made little progress in improving their rates. Through the lens of critical social theory, the authors examine these forces and identify the ideologies, assumptions, and social structures that curtail completion of advanced care plans such as preserving life, ageism, paternalism, and market-driven healthcare system. <http://goo.gl/ilfWrB>

Related

- *JOURNAL OF PATIENT-CENTERED RESEARCH & REVIEWS*, 2016;3(3):167-168. **‘Advance care planning practices in caring for vulnerable elders: An analysis of electronic health record data and interviews with physicians.’** Among 65,253 patients [i.e., the patient population studied] with no advance care plan (ACP) prior to 2013, 11.6% had ACP documentation by the end of 2014 and 88.4% did not. Among those with serious illness, at the end of 2 years 21.13% had ACP and 78.87% had no ACP. Interviewees suggested three stages of ACP: 1) Initial patient-physician conversations; 2) Patient investigates/discusses with family; and, 3) Follow-up with physician. <http://goo.gl/sW5Kbv>

Noted in Media Watch, 11 July 2016, #470 (p.13):

- *HEC FORUM* | Online – 8 July 2016 – **‘Failure of the current advance care planning paradigm: Advocating for a communications-based approach.’** The intersection of end-of-life (EOL) medical technology, ethics of EOL care, and state and federal law has driven the development of the legal framework for advance directives (ADs). From an ethical perspective the current legal framework is inadequate to make ADs an effective EOL planning tool. <http://goo.gl/QvZLSo>

Cont.

Noted in Media Watch, 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment programs despite the absence of compelling evidence that they improve patient outcomes. <http://goo.gl/9gFs4X>

Experiences and expressions of spirituality at the end of life in the intensive care unit

AMERICAN JOURNAL OF RESPIRATORY CRITICAL CARE MEDICINE | Online – 15 August 2016 – The austere setting of the intensive care unit (ICU) can suppress expressions of spirituality. Participants [in this study] characterize dying as a spiritual event. Spirituality is an integral part of the life narrative of the patient before, during, and after death. Experiences and expressions of spirituality for patients, families and clinicians during end-of-life care in the ICU are supported by eliciting and implementing wishes in several ways. Eliciting wishes stimulates conversations for people of diverse spiritual orientations to respond to death in personally meaningful ways that facilitate continuity and closure, and ease emotional trauma. Soliciting wishes identifies positive aspirations, which provide comfort in the face of death. The act of soliciting wishes brings clinician humanity to the fore. Wishes may be grounded in spiritual goals such as peace, comfort, connections and tributes; they may seek a spiritually-enhanced environment, or represent specific spiritual interventions. <http://goo.gl/oUD9IL>

Related

- *JOURNAL OF HEALTH PSYCHOLOGY* | Online – 15 August 2016 – ‘**The interface between psychology and spirituality in palliative care.**’ In palliative care, a biopsychosocial-spiritual model is essential to address the patient in its totality. Spirituality is often a relevant issue in such settings, yet there is a need to differentiate spirituality from religion. <http://goo.gl/ZMmQKN>

N.B. Additional articles on spirituality in the context of end-of-life care noted in Media Watch 27 Jun 2016, #468 (pp.9-10), 4 April 2016, #456 (p.7), and 8 June 2015, #413 (pp.10-11).

Supporting bereaved parents at the time of a child’s death

ARCHIVES OF DISEASE IN CHILDHOOD: EDUCATION & PRACTICE EDITION | Online – 12 August 2016 – If you are facing a discussion with parents whose child has died, your humanity is as important as your clinical knowledge and skill. Nothing you can say will ever take away the emotional pain they are facing but your involvement on a very human level will make a difference. Listening builds a trusting relationship and is essential if families are to be responded to effectively. The key components needed for good support are honesty, information, choices and time. Parents need to be guided through what will happen next and to know who to turn to when they leave the hospital. They should be

offered a follow-up appointment. Staff working with bereaved families need support for themselves. <http://goo.gl/glAhNV>



Related

- *INTENSIVE & CRITICAL CARE NURSING* | Online – 12 August 2016 – ‘**Parents’ experience of a follow-up meeting after a child’s death in the paediatric intensive care unit.**’ The parents [i.e., study participants] found it meaningful that the follow-up meeting was interdisciplinary, since the parents could have answers to their questions both about treatment and care. It was also important that the staff involved in the follow-up meeting were those who had been present through the hospitalisation and at the time of the child’s death. <http://goo.gl/mGtbCP>

“Sometimes I’ve gone home feeling that my voice hasn’t been heard”: A focus group study exploring the views and experiences of health care assistants when caring for dying residents

BMC PALLIATIVE CARE | Online – 19 August 2016 – Participants confirmed that health care assistants (HCA) provide the majority of hands on care to dying residents and believed they had a valuable role to play at this time due to their unique “familial” relationship with residents and families. However, it was apparent that a number of barriers existed to them maximising their contribution to supporting dying residents, most notably the lack of value placed on their knowledge and experience by other members of the multidisciplinary team. Whilst a need for additional palliative and end-of-life care education was identified, a preference was identified for hands on education delivered by peers, rather than the didactic education they currently receive. Given ageing populations internationally coupled with a constrained health budget, the role of HCA in most developed countries is likely to become even more significant in the short to medium term. This study makes a unique contribution to the international literature by identifying the barriers to caring for dying residents experienced by this valuable sector of the aged care workforce. These data have the potential to inform new, innovative, interventions to address the urgent need identified to improve palliative and end-of-life care management in aged care internationally. <http://goo.gl/dlsZT4>

End-of-life care in Canada

Hospice care in Calgary: Survey of family physicians on their knowledge, experience, and attitudes

CANADIAN FAMILY PHYSICIAN, 2016;62(8):e484-e494. Family physicians (i.e., survey respondents) agreed palliative care (PC) in a hospice setting can greatly improve quality of life for patients, but only 2 of 6 knowledge questions about hospice care were answered correctly by most. Family physicians with special areas of interest or sub-specialties were more likely to feel well-informed about hospice referrals, indicated a higher comfort level discussing hospice and PC, and were less likely to defer discussing it with patients. Physicians with a special interest in palliative medicine were more likely to correctly answer the knowledge questions and to be familiar with the referral process, patient eligibility, and the palliative home care program. Qualitative analysis revealed support for palliative home care and consultation services, but concerns about caregiver coping and family issues. Concerns about disengagement of family physicians and uncertainty about the referral process are obstacles to referral. <http://goo.gl/n1BC3V>

N.B. Also in this issue of *Canadian Family Physician*, ‘A family way of dying: The story of a residential palliative care facility’ (pp. 660-663). <http://goo.gl/sFojs>

Ultimate journey of the terminally ill: Ways and pathways of hope

CANADIAN FAMILY PHYSICIAN, 2016;62(8):648-656. This study sheds further light on what hope represents for patients with a terminal illness, their loved ones, and their physicians. 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. It is important for clinicians to understand and remember that hope is a dynamic phenomenon to which they must adapt from one day to the next. <http://goo.gl/imsB4g>

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Selected articles on hope in the context of end-of-life care

- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 21 April 2016 – ‘**Hope dies last ... A qualitative study into the meaning of hope for people with cancer in the palliative phase.**’ Palliative patients may have strong hope, even hope for a cure, despite knowing their prognosis. Health professionals do not always understand patients who have this kind of hope. The meaning of hope is related to the importance of the object it is attached to, rather than to a real chance of achieving this object. [Noted in Media Watch, 2 May 2016, #460 (p.5)] <http://goo.gl/gixJE3>
- *HUISARTS EN WETENSCHAP*, 2016;59(1):14-16. ‘**Managing hope in palliative care.**’ Patients and their caregivers approach the concept of “hope” not only from a realistic perspective, but also from a functional perspective (hope helps to cope with the situation) or a narrative perspective (hope fits with someone’s narrative). [Noted in Media Watch, 1 February 2016, #447 (p.12)] <http://goo.gl/QxcjeO>

N.B. Dutch language article.
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 January 2016 – ‘**Hope, symptoms, and palliative care: Do symptoms influence hope?**’ Anxiety, depression, fatigue, and pain are reported to impair hope. The objective of this study was to determine whether age, gender, marital status, duration of cancer, symptoms, or symptom burden correlated with hope... This study found a correlation between symptom burden and hope was not clinically relevant, but was so for depression. [Noted in Media Watch, 1 February 2016, #447 (p.12)] <http://goo.gl/zj7Mki>

End-of-life care in Australia

Intensive care specialists’ knowledge, attitudes and practice relating to the law about withholding and withdrawing life-sustaining treatment: A cross-sectional study

CRITICAL CARE & RESUSCITATION, 2016; 18(2):109-115. Participants included 867 medical specialists from seven specialties most likely to be involved in end-of-life decision-making in the acute setting (emergency, geriatric, palliative, renal and respiratory medicine, medical oncology, and intensive care). Intensivists performed above average in terms of legal knowledge, but important knowledge gaps remain. Intensivists had a more negative attitude to the role of law in this area than other specialty groups, but reported being seen as a leading source of information about legal issues by other medical specialists and nurses. Intensivists also reported as being the specialty most frequently making decisions about end-of-life treatment. Improved legal knowledge and open engagement with law can help manage the risk of harm to patients and to protect Intensivists from liability. <http://goo.gl/3WjHuw>

Defining futile and potentially inappropriate interventions: A policy statement from the Society of Critical Care Medicine Ethics Committee

CRITICAL CARE MEDICINE, 2016;44(9):1769-1774. The statement was developed to provide a clear definition of inappropriate interventions in the ICU environment. ICU interventions should generally be considered inappropriate when there is no reasonable expectation that the patient will improve sufficiently to survive outside the acute care setting, or when there is no reasonable expectation that the patient’s neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment. This definition should not be considered exhaustive. <http://goo.gl/IHTuq9>

N.B. *The Journal of Critical Care* recently published ‘What is an Intensive Care Unit: A Report of the Task Force of the World Federation of Societies of Intensive & Critical Care Medicine,’ <http://goo.gl/Ork2uu>

Related

- *JOURNAL OF ADVANCE NURSING* | Online – 10 August 2016 – ‘**An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care.**’ Greater understanding is needed of the language that can be used with families to describe death and dying in intensive care. Clearer conceptualisation of the relationship between the medically focussed withdrawal of life-sustaining treatments and patient/family centred end-of-life care is required making the nursing contribution at this time more visible. <http://goo.gl/xVM3jG>

Cont.

- *JOURNAL OF MEDICAL ETHICS* | Online – 16 August 2016 – ‘The role of law in decisions to withhold and withdraw life-sustaining treatment from adults who lack capacity: A cross-sectional study.’ Medical specialists [i.e., survey respondents] prioritised patient-related clinical factors over law when confronted with a scenario where legal compliance is inconsistent with what they believe is clinically indicated. Although legally knowledgeable specialists were more likely to comply with the law, compliance in the scenario was not motivated by an intention to follow law. Ethical considerations (which are different from, but often align with, law) are suggested as a more important influence in clinical decision-making. More education and training of doctors is needed to demonstrate the role, relevance and utility of law in end-of-life care. <http://goo.gl/vouwKp>

End-of-life preparations among lesbian, gay, bisexual and transgender older adults


GENERATIONS, 2016;40(2):46-48. Lesbian, gay, bisexual and transgender persons disproportionately reach later life without partners or children – the people most likely to provide support to older adults, and to engage them in conversations about advance care planning (ACP) and end-of-life issues. Friends often rise to the challenges of caregiving, but with limits imposed by family-centered social customs and family-first policies and practices. Friends often feel unqualified to discuss ACP, or are not invited into such conversations. This dynamic, these limits, and their consequences are the focus of this article, which summarizes the literature, with examples drawn from the authors’ qualitative study. <http://goo.gl/GSXQ8h>

N.B. In the U.K., Nottingham University, in cooperation with the the National Council for Palliative Care have published ‘Being Accepted Being Me: Understanding the end of life care needs for older LGBT people’ <http://goo.gl/rVX6qL>. Additional articles on end-of-life care for LGBT communities noted in Media Watch 23 May 2016, #463 (p.3), and 8 February 2016, #448 (p.16).

Revisiting the use of “place” as an analytic tool for elucidating geographic issues central to Canadian rural palliative care

HEALTH & PLACE, 2016;41(9):19-23. In 2010, Castleden and colleagues published a paper in this journal using the concept of “place” as an analytic tool to understand the nature of palliative care (PC) provision in a rural region in British Columbia, Canada.¹ This ... was based upon pilot data collected for a larger research project that has since been completed. With the addition of 40 semi-structured interviews with users and providers of PC in four other rural communities located across Canada, the authors revisit Castleden and colleagues’ (2010) original framework. Applying the concept of place to the full dataset confirmed the previously published findings, but also revealed two new place-based dimensions related to experiences of rural PC in Canada: 1) Borders and boundaries; and, 2)

“Making” place for PC progress. These new findings offer a refined understanding of the complex interconnections between various dimensions of place and PC in rural Canada. <http://goo.gl/13BJL1>



RURAL ONTARIO INSTITUTE

‘End-of-life care in rural communities.’ <http://goo.gl/WPjvBI>

‘National palliative medicine survey looks at urban versus rural.’ <http://goo.gl/GEJL4u>

1. “It’s not necessarily the distance on the map...”: Using place as an analytic tool to elucidate geographic issues central to rural palliative care,’ *Health & Place*, 2010;16(2):284-290. [Noted in Media Watch, 18 January 2010, #132 (p.6)] <http://goo.gl/6im5gm>

N.B. Additional articles on end-of-life care in rural communities and remote regions noted in Media Watch 16 May 2016, #462 (p.18), and 18 April 2016, #459 (p.4).



‘Living and dying in pain: It doesn’t have to happen’
8 October 2016
<http://goo.gl/iKZH4k>

What is important at the end of life for people with dementia? The views of people with dementia and their carers

INTERNATIONAL OF JOURNAL OF GERIATRIC PSYCHIATRY | Online – 12 August 2016 – Research has consistently shown that improvements in care and services are required to support better quality and more person-centred care for people with dementia towards and at end of life. However, the views of people with dementia about what factors contribute to high-quality care at this time are a neglected area. Four distinct views were identified: 1) Family involvement; 2) Living in the present; 3) Pragmatic expectations; and, 4) Autonomy and individuality. Some areas of consensus across all views included compassionate care, decisions being made by healthcare professionals, and information availability when making decisions. The findings of this study reveal several different views on what is important about end-of-life care for people with dementia; therefore, a “one-size-fits-all” approach to care is unlikely to be most appropriate. <http://goo.gl/cTrhhC>

Noted in Media Watch, 1 August 2016, #473 (p.11):

- *DEMENTIA* | Online – 26 July 2016 – ‘**The extended palliative phase of dementia: An integrative literature review.**’ There was no consistent definition of advanced dementia. The extended palliative phase was generally synonymous with end-of-life care. A lack of understanding of palliative care among frontline practitioners was related to a dearth of educational opportunities in advanced dementia care. <http://goo.gl/ujukhx>

N.B. Additional articles on end-of-life care for people living with dementia noted in Media Watch 4 July 2016, #469 (pp.15-16).

Defining high-quality palliative care in oncology practice: An American Society of Clinical Oncology/American Academy of Hospice & Palliative Medicine guidance statement

JOURNAL OF ONCOLOGY PRACTICE | Online – 16 August 2016 – An expert steering committee outlined 966 palliative care (PC) service items, in nine domains, each describing a candidate element of primary PC delivery for patients with advanced cancer or high symptom burden. Using modified Delphi methodology, 31 multidisciplinary panellists rated each service item on three constructs: 1) Importance; 2) Feasibility; and, 3) Scope within medical oncology practice. Panellists endorsed the highest proportion of PC service items in the domains of end-of-life care (81%); communication and shared decision making (79%); and, advance care planning (78%). The lowest proportions were in spiritual and cultural assessment and management (35%), and psychosocial assessment and management (39%). In the largest domain, symptom assessment and management, there was consensus that all symptoms should be assessed and managed at a basic level, with more comprehensive management for common symptoms such as nausea, vomiting, diarrhoea, dyspnea, and pain. Within the appropriate PC and hospice referral domain, there was consensus that oncology practices should be able to describe the difference between PC and hospice to patients and refer patients appropriately. <http://goo.gl/uE91Sq>

Related

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 9 August 2016 – ‘**Talking to children with cancer: Sometimes less is more.**’ There are plenty of guidelines to guide prognostic conversations, but little to help us when a child opts not to know. Ask yourself, does the child truly not want to know? Because most adults and presumably most children in the U.S. want to know if their prognosis is poor, we should not take an initial request to withhold this information as a final answer. We should respect that request, but at the same time revisit and re-explore and not necessarily breathe a sigh of relief over a hard conversation diverted. Guidelines, musings, wisdom, pearls, and the counsel of others are invaluable when it comes to disclosure (or non-disclosure) of prognostic information, but it is not enough. <http://goo.gl/dtgZSm>

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

Populations and interventions for palliative and end-of-life care: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 August 2016 – Evidence supports palliative care (PC) effectiveness. Given workforce constraints and the costs of new services, payers and providers need help to prioritize their investments. They need to know which patients to target, which personnel to hire, and which services best improve outcomes. The objective of this study was to inform how payers and providers should identify patients with “advanced illness” and the specific interventions they should implement, the authors reviewed the evidence to identify: 1) Individuals appropriate for PC; and, 2) Elements of health service interventions (personnel involved, use of multidisciplinary teams, and settings of care) effective in achieving better outcomes for patients, caregivers, and the healthcare system. The majority of studies in cancer demonstrated statistically significant patient or caregiver outcomes, as did those in congestive heart failure, chronic obstructive pulmonary disease, and dementia. Most prognostic criteria used clinicians’ judgment. Most interventions included a nurse, and many were nurse-only. Social workers were well represented, and home-based approaches were common. Home interventions with visits were more effective than those without. Interventions improved communication and care planning, psychosocial health, and patient and caregiver experiences. Many interventions reduced hospital use, but most other economic outcomes, including costs, were poorly characterized. PC teams did not reliably lower healthcare costs. <http://goo.gl/gMGI6c>

Related

- *JOURNAL OF AGING LIFE CARE* | Online – Summer 2016 Issue – ‘**Beyond good deaths and angry families: Improving end-of-life care in the community.**’ The July 2015 White House Conference on Aging explored a range of important topics concerning how to structure and finance long-term care and related services to better meet the needs of our aging society. Missing from this policy-oriented agenda, and yet vital to effective policymaking in this area, was a deeper discussion about how policies and services should reflect and respond to the psychological and social realities of the end of life. This brief essay summarizes some of the ethical questions that ... people are grappling with and find it difficult to resolve. <http://goo.gl/DYOD0X>

N.B. *The Gerontologist* published a special issue in advance of the 2015 White House Conference on Aging. One of the articles, ‘Public health imperative of the 21st Century: Innovations in palliative care systems, services, and supports to improve health and well-being of older Americans,’ was noted in *Media Watch*, 27 April 2015, #407 (pp.10-11): <http://goo.gl/5PFyV7>. Journal contents: <http://goo.gl/MjDNZP>.
BRA

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 18 August 2016 – ‘**Place of death of individuals with terminal cancer: New insights from Medicare Hospice Place-of-Service Codes.**’ Two-thirds of the beneficiaries used hospice. Younger, male, black, Asian, and unmarried beneficiaries and those enrolled in fee-for-service Medicare or from areas with lower income were less likely to use hospice. Thirty percent of the hospice users were not receiving home-based care at the time of death, and 17% were enrolled for less than 3 days. <http://goo.gl/rAsuqW>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 16 August 2016 – ‘**Association of practice-level hospital use with end-of-life outcomes, readmission, and weekend hospitalization among Medicare beneficiaries with cancer.**’ The purpose of this study was to determine the relationships between hospital use of treating oncology practices and patient outcomes. Total 30-day readmissions were 22.8% and 31.9% for patients in practices with the lowest versus highest quartiles of inpatient intensity, respectively; unplanned readmissions were 19.8% and 27.1%, respectively. The proportion of admissions that occurred on weekends was similar across quartiles. Patients of practices in the highest quartiles of inpatient intensity had higher rates of death in an ICU stay in the last month of life and a lower rate of hospice stay of at least 7 days. Medical oncology practices that seek to reduce hospitalizations should consider focusing initially on processes related to end-of-life care and care transitions. <http://goo.gl/PHJdGx>

End-of-life care in nursing homes: From care processes to quality

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 August 2016 – Nursing homes (NHs) are an important setting for the provision of palliative and end-of-life care. Excessive reliance on hospitalizations at end of life (EOL) and infrequent enrollment in hospice are key quality concerns in this setting. The authors examined the association between communication – among NH providers and between providers and residents/family members – and two EOL quality measures: in-hospital deaths and hospice use. Better communication with residents/family members was statistically significantly associated with fewer in-hospital deaths. However, better communication among providers was significantly associated with lower use of hospice. <http://goo.gl/aeXaYi>

End-of-life care in The Netherlands

Palliative care in mental health facilities from the perspective of nurses: A mixed-methods study

JOURNAL OF PSYCHIATRIC & MENTAL HEALTH NURSING | Online – 16 August 2016 – This explorative study is unique in offering an insight into current palliative care (PC) practice for psychiatric patients and showed that one in three nurses working in Dutch mental health facilities is involved in the provision of PC. In PC for psychiatric patients there is more attention for psychosocial and spiritual care compared to PC for patients without psychiatric disorders. Educating psychiatric nurses about PC and close collaboration between physical and mental health care are crucial to address the PC needs of this vulnerable patient group. <http://goo.gl/weSQVq>

Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences

PALLIATIVE MEDICINE | Online – 17 August 2016 – Constructs of sympathy, empathy, and compassion contain distinct themes and sub-themes. Sympathy was described [by study participants] as an unwanted, pity-based response to a distressing situation, characterized by a lack of understanding and self-preservation of the observer. Empathy was experienced as an affective response that acknowledges and attempts to understand individual's suffering through emotional resonance. Compassion enhanced the key facets of empathy while adding distinct features of being motivated by love, the altruistic role of the responder, action, and small, supererogatory acts of kindness. Study participants reported that unlike sympathy, empathy and compassion were beneficial, with compassion being the most preferred and impactful. Although sympathy, empathy, and compassion are used interchangeably and frequently conflated in healthcare literature, patients distinguish and experience them uniquely. <http://goo.gl/7vHa89>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *INTERNATIONAL JOURNAL OF HUMAN RIGHTS & CONSTITUTIONAL STUDIES*, 2016;4(2):166–175. 'Dying in dignity: The place of euthanasia in Kenya's legal system.' Euthanasia raises medical, legal, moral and ethical issues. One of the major ethical issues surrounding euthanasia concerns the value attached to human life... Opponents argue that individual autonomy should not be allowed to dictate the social policy regarding euthanasia. Proponents of euthanasia fashion their argument around quality or dignified life, saying when the quality of life falls below the threshold of dignity, a person has a right to die. <http://goo.gl/KcdiGz>

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Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.

<http://goo.gl/OTpc8l>

- *INTERNATIONAL JOURNAL OF HUMAN RIGHTS & CONSTITUTIONAL STUDIES*, 2016;4(2):153-165. ‘Euthanasia from Iran law and Islamic legislation perspective.’ Euthanasia is a permitted and even moral action from the view of its supporters since they believe in a person’s right to decide to die. Based on different verses of Quran, people are not allowed to commit suicide or kill others. Euthanasia is a taboo and an unlawful action. Abusing this word to achieve some humanistic goals is not acceptable; therefore, pain and suffering should not be used as an excuse or a legal and ethical permission to commit euthanasia. This study is aimed at studying permissibility or impermissibility of euthanasia based on Iran law and Islamic rules. <http://goo.gl/TIFHTR>

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/vjGQws>

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

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

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

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

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

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