

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'Supporting the support system: How assessment and communication can help patients and their support systems' (p.14), in *Professional Case Management*.

Canada

More families are choosing to have their child's end-of-life care outside of critical care units

ONTARIO | The Perspective (The Hospital for Sick Children) – 6 June 2017 – Paediatric end-of-life care (EoLC) is just as likely, if not more so, to occur in hospital. But differences between children and adults begin to emerge when one looks closer at the specific location of death within the hospital – studies consistently show that most children die in the intensive care unit (ICU). Many of these deaths are the result of unexpected acute processes, including trauma, which understandably result in an intensive care admission. But the ICU is also the most likely location of EoLC for children whose death might be considered expected or foreseeable. And yet there's been a sense that a new shift in the location of death might be taking place within the hospital; it seems like more families are choosing to have their child's EoLC on the wards. The hospital's research group is the first to study this hypothesis on the general paediatrics wards...¹ They examined all "general pediatric" inpatient deaths at the hospital over three time periods – 1998, 2005 and 2012 (patients were included if their underlying diagnosis would have normally resulted in an admission to a general paediatrics ward; patients were excluded if they were admitted for cancer; primary cardiac, renal or respira-

tory disease; trauma; transplant; surgical conditions; or otherwise requiring intensive care). The research group found a seven-fold increase in the proportion of patients who died on general paediatrics wards between 1998 and 2005, from 5.7% to 40.7% (there was no significant change from 2005 to 2012). This shift coincided with a significant increase in the proportion of children with a "no CPR" order at the time of death and earlier decisions to put such an order in place. Finally, while less than 10% of the children who died in hospital in 1998 had palliative care consultations, this had increased to just under 74% by 2012. <https://goo.gl/XJqXqg>

Specialist Publications

'The validity of using health administrative data to identify the involvement of specialized pediatric palliative care teams in children with cancer in Ontario, Canada' (p.12), in *Journal of Palliative Medicine*.

'Does the pediatric emergency department have a role in pediatric palliative care?' (p.11), in *Paediatrics & Child Health*.

1. 'General paediatric inpatient deaths over a 15-year period,' *Paediatrics & Child Health*, published online 17 April 2017. <https://goo.gl/p4xY7f>

Nunavut struggles to care for elders closer to home

NUNAVUT | CBC News (Iqaluit) – 5 June 2017 – Rankin Inlet Members of the Legislative Assembly are calling on the premier and health minister to find solutions to care for elders closer to home instead of sending them thousands of kilometres away to residential care facilities outside of Nunavut. There are 27 long-term care beds in Nunavut, including three designated for respite or palliative care. No facilities in the territory provide care for dementia. That means a growing number of elders are sent to residential care facilities in the south... “Elders establish the backbone of Nunavut culture and language and the Inuit fabric across the communities,” said Rankin Inlet South’s Alexander Sammurtok, quoting the government’s strategy on caring for seniors. <https://goo.gl/hJGy5j>



Noted in Media Watch 13 February 2017, #499 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 February 2017 – ‘**Inuit experiences, current realities, and ways forward.**’ End-of-life care, once the domain of Inuit families and communities, has come to include professionalized healthcare providers with varying degrees of awareness of factors to consider in providing care to Inuit populations. <https://goo.gl/HMbbgO>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | ‘White Coat, Black Art’ – Accessed 5 June 2017 – ‘**A clearer path to medically-assisted death.**’ If death is not reasonably foreseeable, then you’re not eligible for medical aid in dying (MAiD). Doctors who perform MAiD and those who might want to do it, but are reluctant say, this part of the law is problematic because of differences of opinion on how to interpret the phrase reasonably foreseeable. Interpretations may vary from hospital to hospital and from province to province, which means not every Canadian has equal access. The Canadian Association of MAiD Assessors & Providers (CAMAP) believes the resulting confusion means that some patients who are eligible made be denied access to medically assisted death. The CAMAP guidelines recommend replacing the term *reasonably foreseeable* with *reasonably predictable*. <https://goo.gl/rqhQqi>

Specialist Publications

‘**Organ donation and medical assistance in dying (MAiD): Ethical and legal issues facing Canada**’ (p.15), in *McGill Journal of Law & Health*.

N.B. Canadian Association of MAiD Assessors & Providers website: <https://goo.gl/aZi7R3>

U.S.A.

A lesser known advanced directive – “do-not-hospitalize”

U.S. NEWS & WORLD REPORT | Online – 8 July 2017 – Toward the end of life – particularly for some frail, older individuals with chronic conditions – hospitalizations can become more frequent. While commonly these admissions are warranted, experts say, in some cases they don’t improve comfort and can instead be stressful, expose patients to more tests and procedures and, while possibly nominally increasing the length of a person’s life, not improve their quality of life. For that reason, some, particularly nursing home residents – as part of advanced care planning – now seek to reduce hospitalizations. Though the number with do not hospitalize orders (DNH) is still small, a recent study finds the orders may be helpful to prevent unwanted hospitalizations.¹ The research ... evaluated nursing home residents in New York, including those with dementia. It found that overall, 6% of residents had DNH orders, and those individuals had significantly fewer hospital stays – 3%, compared to 6.8% for those without the orders – in the last

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90 days. Residents with dementia who had DNH orders also had fewer hospital stays, at 2.7%, compared with 6.3% who didn't. Put another way, the researchers noted those without DNH orders were more than twice as likely to be hospitalized. <https://goo.gl/9t09hg>

1. 'Are hospital/ED transfers less likely among nursing home residents with do-not-hospitalize orders? *Journal of Post-Acute & Long-Term Care Medicine*, 2017;18(5):438-441. [Noted in Media Watch 22 May 2017, #513 (p.13)] <https://goo.gl/EZ11u6>

Noted in Media Watch 25 November 2013, #333 (p.3):

- *THE NEW YORK TIMES* | Online – 20 November 2013 – '**A misunderstood directive.**' Dr. Michael Rothberg and colleagues in Pennsylvania and Massachusetts have written a new paper on a little known, poorly understood medical directive.¹ The key findings? Often, proxies are confused about how "do not hospitalize" orders work. Several proxies believed, mistakenly, that such an order was equivalent to a request to withhold medical intervention altogether. And a physician's willingness to recommend it makes a difference. <https://goo.gl/lxJOUS>

1. 'Do-not-hospitalize orders for individuals with advanced dementia: Healthcare proxies' perspectives,' *Journal of the American Geriatrics Society*, 2013;61(9):1568-1573. <https://goo.gl/AuqgbT>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- DELAWARE | *Delaware State News* (Dover) – 7 June 2017 – '**Assisted suicide bill sent to House floor.**' A House committee released to the full chamber a controversial proposal that would legalize physician-assisted suicide. The bill now awaits a floor vote. House Bill 160, also known as the Delaware End of Life Options Act, would allow an individual with a terminal disease – defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months" – to end his or her life with the aid of a doctor. The proposal requires the individual be judged by a doctor as being capable of making a decision to die, and it mandates a waiting period between the request and the implementation. The person wishing to end his or her life would have to self-administer the medication, and a physician could not prescribe the drugs if the patient is believed to be affected by "a psychiatric or psychological disorder or depression causing impaired judgment." <https://goo.gl/PWGxVo>
- *THE WASHINGTON TIMES* | Online – 7 June 2017 – '**Abusing assisted suicide laws.**' With the passage of assisted-suicide laws, there are new reports that health insurance companies are refusing to cover lifesaving medical care and are offering to pay patients to kill themselves instead. The debate surrounding legalizing assisted suicide is largely cast as one focusing on an individual who genuinely wants to end his or her life because of the pain and suffering they're experiencing due to a terminal medical condition. But this issue is wholly different – the possible cold-blooded and brutal abuse of those laws by bureaucrats in insurance companies against patients whom they determine are too expensive to keep alive. <https://goo.gl/ctjYb3>

International

Doctors film elderly patients to show they should be left to die: Judge warns against "invasive" tactics and fears footage could be edited to mislead the courts

U.K. (Wales) | *The Daily Mail* – 9 June 2017 – A senior judge has condemned hospitals that film desperately ill patients to use as evidence that they should be allowed to die. Mr. Justice Hayden rebuked doctors after an National Health Service board used a video of an 81-year-old man to persuade the Court of Protection that his life support should be withdrawn. In a landmark ruling, the judge told the health service to stop making videos of patients unless they could show "strong and well-reasoned justification." The Abertawe Bro Morgannwg health board in South Wales submitted the film to gain legal permission to withdraw a patient's ventilation and other life-sustaining treatment, and only provide him with palliative care. <https://goo.gl/iZ2QeC>

Appeal Court judges publish Charlie Gard rulings

U.K. (England) | BBC News – 5 June 2017 – Three Court of Appeal judges who ruled doctors should stop treating a baby at the centre of a legal fight have published their ruling on the case. It comes four days before the parents of Charlie Gard are to challenge the decision in the Supreme Court. Chris Gard and Connie Yates want their 10-month-old son to undergo specialist treatment in the U.S. But doctors at Great Ormond Street Hospital in London say the treatment is experimental and will not help. In April, a High Court judge ruled against the parents' wishes and in favour of Great Ormond Street doctors. Mr. Justice Francis concluded that life support treatment should end and said Charlie should be allowed to die with dignity. Three Appeal Court judges upheld that ruling...

Lord Justice McFarlane, Lady Justice King and Lord Justice Sales have published the reasoning behind their ruling.¹ <https://goo.gl/u1ZChh>

Charlie Gard's treatment must continue, European Court of Human Rights says

U.K. (England) | *The Daily Telegraph* – 9 June 2017 – Doctors in London must continue to treat a terminally-ill baby at the centre of a life-support legal battle until midnight on Tuesday [13 June], judges in the European Court of Human Rights have said. A spokeswoman for the Court in Strasbourg, France, said judges wanted treatment to continue while they looked at paperwork in the case. <https://goo.gl/t2ZwDI>

1. England & Wales Court of Appeal (Civil Division) Decisions, British & Irish Legal Information Institute: <https://goo.gl/Wkfl7n>

Noted in Media Watch 17 April 2017, #508 (p.5):

- U.K. (England) | BBC News – 11 April 2017 – **'Charlie Gard case: Doctors can withdraw baby's life support.'** Doctors can withdraw life support from a sick baby with a rare genetic condition against his parents' wishes, a High Court judge has ruled. Specialists at Great Ormond Street Hospital said eight-month-old Charlie Gard has irreversible brain damage and should be moved to palliative care. His parents Connie Yates and Chris Gard, from London, had wanted to take him to the U.S. for a treatment trial. <https://goo.gl/nzOZCr>

Specialist Publications

What did Latino family caregivers expect and learn from education intervention 'Caregivers Like Me'?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 June 2018 – U.S. Latinos historically have underutilized end-of-life resources. An educational intervention 'Caregivers Like Me' was offered to family caregivers of Latino elders from three different communities. A pre-test, open-ended question on expected learning identified two themes: 1) Care for the sick; and, 2) Self-care. It included five sub-themes and the most common one was how to help the sick. The post-test question on actual learning identified the same two themes and four sub-themes that were similar, but different from the pre-test. Accepting help and knowledge of services available were the most common. 'Caregivers Like Me' was able to improve attitudes toward end-of-life care because participants who wanted to help their loved ones realized that they need to accept professional help and were made aware of the services available. <https://goo.gl/5CLgtS>

Noted in Media Watch, 1 June 2015, #412 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 May 2015 – **'Education intervention 'Caregivers Like Me' for Latino family caregivers improved attitudes toward professional assistance at end-of-life care.'** This study explores the ability of a culturally sensitive and case-based education intervention to improve knowledge and attitudes regarding end-of-life resources among Latino caregivers. <http://goo.gl/0yeH0Y>

Care of the critically ill burn patient: An overview from the perspective of optimizing palliative care

ANNALS OF THE AMERICAN THORACIC SOCIETY | Online – 7 June 2017 – Burn specialists have long recognized the need for and role modeled a comprehensive approach incorporating relief of distress as part of care during critical illness. More recently, palliative care (PC) specialists have become part of the healthcare team in many U.S. hospitals, especially larger academic institutions that are more likely to have designated burn centers. No current literature describes the intersection of PC and burn care or integration of primary and specialist PC in this unique context. This authors gives an overview of burn care; focuses on pain and other symptoms in burn ICU settings; addresses special needs of critically ill burned patients, families, and clinicians for high-quality PC; and highlights potential benefits of integrating primary and specialist PC in burn critical care. American Burn Association guidelines lay the foundation for a robust system of PC delivery, embedding PC principles and processes in intensive care by burn providers. Understanding basic burn care, challenges for symptom management and communication, and culture of the particular burn unit, can optimize quality and integration of primary and specialist PC in this distinctive setting. <https://goo.gl/RRjnlN>

Art of sensitive communication in patient and family centered care

BAOJ PALLIATIVE MEDICINE | Online – Accessed 10 June 2017 – Sensitive communication with the patients and the family members is based on a continuous healing relationship interleaved with empathy, compassion, honesty and respect. Both oral speaking and receptive listening skills are necessary for effective communication between the health care provider and the patient and caregivers. The verbal communication based on the use of relevant spoken words, interlaced with the appropriate non-verbal communication, including body language, eye contact, mindful gestures, a calming tone of voice can all play a major role in developing a bonding relationship infused with trust. When conducting, the family meeting any disputes or differing opinions on goals of care between family members, should be approached sensitively and judiciously, always keeping the patient at the center, to reach the common goal. Listening to family members and being respectful of their viewpoints fosters a culture of trust and enables reaching a shared plan of care. Tailoring to the individual needs of the patient and the family members and acknowledging the patient's socio-economic and cultural background along with fostering a culture of trust and transparency, can be the guiding principle in patient and family centered care of a critically ill patient. <https://goo.gl/B6AAYW>

First do no harm: Changing culture surrounding ceilings of treatment in end-of-life care

CLINICAL MEDICINE | Online – 1 June 2017 – The [U.K. (England & Wales)] National Institute of Health & Care Excellence quality standard for end-of-life care (EoLC) for adults provides a far-reaching vision of how high quality EoLC should appear.¹ Unfortunately, patients approaching the end of life may receive inconsistent care as their condition deteriorates. Failure of the team providing normal medical care to communicate patients' wishes, and clearly document a personalised care plan for current and future support and treatment, can expose patients to burdensome medical investigations and increase anxiety among nursing staff and "on call" medical teams, should an acute deterioration occur outside of normal working hours. Ninety percent of doctors and 73% of nurses [i.e., survey respondents] have witnessed patients undergoing treatments they consider to be futile or burdensome. Seventy-one percent of doctors and 77% of nurses have been left unsure what active interventions a patient is still considered for. After educational events and the addition of the ceiling of treatment (COT) form, the number of patients with a clear COT identified has risen from 12% to 53%, while those patients documented as "do not attempt CPR" have had improved COT identification from 35% to 92%. Structural reform at hospital level is vital to enable optimum EoLC and we hope the introduction of "ceiling of treatment" forms coupled with education, will provide a clearer direction for hospital staff as to what is important as patients approach EoLC. <https://goo.gl/2MPpsQ>

1. 'End of life care for adults: Quality standard,' National Institute of Health & Care Excellence, 2011. [Updated April 2017; noted in the 6 March 2017 issue of Media Watch (#502, p.4)] <https://goo.gl/rD2XPC>

Related

- *CHEST*, 2017;151(6):1404-1406. **'Palliative care, spiritual care, and clinical ethics: Widely available, but underused.'** With expansion of hospital-based care come increasingly complex needs inviting palliative care (PC), clinical ethics (CE) and spiritual care (SC) collaboration. Commonly encountered situations include withdrawal of life-sustaining therapies, surrogate decision-making, provider conflict, and spiritual/religious distress, all of which overlap among PC, CE, and SC domains of expertise. Nevertheless, although hospitals commonly use these three clinical services, little guidance exists regarding which service to consult, how they might best collaborate, and their effect on quality benchmarks. <https://goo.gl/NTnkDv>

“High-risk” patients with chronic obstructive pulmonary disease have a poor prognosis and need to be able to access palliative care services

CLINICAL MEDICINE | Online – 1 June 2017 – There are many patients with obstructive pulmonary disease (COPD) who have a “high risk” of deterioration and death. The prognosis for this group is poor, with almost half dying within a year, yet only 37% [of the patient group studied] had accessed palliative care (PC) services (50% in those who died during follow-up). More PC input is needed for patients with severe COPD, especially those discussed at multidisciplinary team or with multiple admissions to hospital. <https://goo.gl/MZfRNc>

N.B. Additional articles on palliative care and patients living with chronic obstructive pulmonary disease are noted in the 2 January 2017 issue of *Media Watch* (#493, p.9).

Identifying systems barriers that may prevent bereavement service access to bereaved carers: A report from an Australian specialist palliative care service

COLLEGIAN | Online – 2 June 2017 – Access to a designated bereavement service (BS) can ensure that bereaved next-of-kin are contacted routinely and in a timely way. However the effectiveness of this type of service is dependent upon the BS having access to all relevant contact information. A retrospective medical audit, using process mapping, was undertaken within one Australian specialist palliative care (PC) service to identify the systems that linked BSs to a consecutive cohort of PC decedents next-of-kin. Bereavement records were located for 80% of decedents. Nearly all (98%) had a nominated next-of-kin, with just over half (54%) of those nominated contacted by BSs. Incomplete or missing contact details was the main reason (75%) that the BS was unable to contact the decedents' next-of-kin. <https://goo.gl/CakuJI>

Selected articles on hospital bereavement programs

- *BEREAVEMENT CARE*, 2015;34(2):69-75. **'Qualitative evaluation of a hospital bereavement service: The perspective of grieving adults.'** The Australian hospital bereavement service studied provides three consecutive tiers of support to palliative care patients and families including information and compassion, non-specialised bereavement support, and specialist intervention referral to external agencies. [Noted in *Media Watch* 24 August 2015, #424 (p.10)] <http://goo.gl/1WaLSq>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 August 2015 – **'Adding value to palliative care services: The development of an institutional bereavement program.'** The authors describe the development of the program at Dana-Farber Cancer Institute (Boston, Massachusetts) where they conceptualized bereavement services as a preventive model of care. [Noted in *Media Watch* 17 August 2015, #423 (p.16)] <http://goo.gl/3RA49H>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2014 – **'An evaluation of a bereavement program in a U.S. research hospital.'** The bereavement program at the National Institutes of Health Clinical Center (Bethesda, Maryland) makes contact with the next of kin on four occasions post-notification of death. [Noted in *Media Watch*, 17 November 2014, #384 (p.11)] <http://goo.gl/UXtwJT>

End-of-life care in Spain

Variability in professional practice among departments explains the type of end-of-life care, but not the difficulty of professionals with decision-making

ESTUDIOS DE PSICOLOGÍA | Online – 2 June 2017 – An observational, descriptive, cross-sectional, multicentre study was conducted to determine the perspectives and experience of physicians and nurses in regard to clinical, psychosocial and ethical actions at the end of life and to determine any variability among departments. A questionnaire was completed by 312 medical and nursing professionals in general and regional hospitals and primary care centres in Granada (Spain). Questionnaire results significantly differed as a function of the department in which participants worked. Lowest consideration was given to psychological actions, advance directives, and ethical dilemmas. Professionals in oncology, palliative care and primary care showed higher and less-variable scores in comparison to those in surgery, internal medicine or intensive care departments. Additional efforts are needed to improve the hospital care of these patients. <https://goo.gl/6HxTFU>

N.B. Spanish language article.

Noted in Media Watch 5 December 2016, #490 (p.4):

- SPAIN | Agencia Efe (Madrid) – 28 November 2016 – ‘**Spain’s low palliative care ranking in European Union due to lack of specialty.**’ The lack of recognition of palliative care (PC) as a medical specialty explains in part why Spain has fallen during the last decade in its ranking in Europe, according to Dr. Carlos Centeno, a member of the European Association of Palliative Care (EAPC) and a co-author of the EAPC’s 2013 ‘Atlas on Palliative Care in Europe.’¹ <https://goo.gl/cQRpD3>

1. Full edition: <https://goo.gl/XEltbC>

“What happens behind the curtains?” An exploration of ICU nurses’ experiences of post mortem care on patients who have died in intensive care

INTENSIVE & CRITICAL CARE NURSING | Online – 5 June 2017 – Safeguarding the integrity and physical appearance of the dead body was the major finding and of the utmost priority for the participants in this study. Regardless of how the nurses felt about death, providing professional and quality care to the dead body and the family was seen as significantly important. The nurses, whilst performing post mortem care, experienced detachment from various relationships. This comprised of the nurse detaching him/herself professionally and emotionally from the dead patient, the family and him/herself from the death experience. This “unspoken” experience of thanatophobia became apparent when the nurses were confronted by the reality of their own deaths. In a technological society, where answers to many questions can be pursued through science, understanding the experience of death, as opposed to dying, may be logically incomprehensible. Death remains one of the most traumatic events experienced by the patient and their family, and in some instances nurses themselves. This study draws attention to the nurses’ experiences and in doing so; the emotional and educational needs have been identified, and in part, pedagogical offerings are recommended. <https://goo.gl/MNxECG>

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[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

Noted in Media Watch 2 January 2017, #493 (p.12):

- *HEALTH & SOCIAL WORK* | Online – 15 December 2016 – ‘**Involved in the business of death: The social work role in post-mortem care.**’ A comprehensive post-mortem program needs many different components, including support to families (e.g., viewing the dead, advising on next steps after a death, and providing bereavement support), consulting with and supporting multidisciplinary staffers, and coordinating with multiple medical center departments. This article examines a hospital’s use of social work principles and clinical training to provide leadership to an office of decedent affairs and describes the key elements and advantages of a successful program. <https://goo.gl/tt15Oj>

Analysis of common barriers to rural patients utilizing hospice and palliative care services: An integrated literature review

JOURNAL OF THE AMERICAN ASSOCIATION OF NURSE PRACTITIONERS | Online – 30 May 2017 – Although the healthcare system is continually advancing, healthcare providers may not be optimizing hospice care (HC) and palliative care (PC) referrals for the growing rural population who underutilize these services. There are several barriers that interrelate to decreased utilization of PC and HC for rural populations and there are many options for overcoming them to equalize care. Although advances to the general healthcare system are expediently rising, the rural patient population seems to fall short of these important life-changing services, especially in the realm of PC/HC. Beginning in primary care, this patient population can be affected and included in a positive manner. <https://goo.gl/j65XDn>

Related

- *BMC PALLIATIVE CARE* | Online – 4 June 2017 – ‘**Nurse-led navigation to provide early palliative care in rural areas: A pilot study.**’ Using a nurse navigator to facilitate a palliative approach to care for rural older adults living with advanced chronic illness is a promising innovation for meeting the needs of this population. The person-centred approach, whereby complex problems were addressed in an individualized and incremental manner, is typical of best practices for this population. The service provided continuity for patients and families who were seeing multiple healthcare providers and resulted in a high degree of satisfaction from participants. <https://goo.gl/LEZZS>
- *JOURNAL OF CLINICAL ONCOLOGY*, 2017;15_suppl:e6546. ‘**Telehospice: Implementation lessons from rural hospice care with mobile tablets.**’ Compared with early work, technology advances and a community-centered approach have increased Telehospice (TH) adoption. With decreasing budgets as well as rural hospice closures, innovative, cost-effective and community-driven approaches such as TH are needed to decrease disparities. As dissemination occurs in national hospice organizations, continued research is needed to understand best fit within frontier hospices, to inform future urban applications and to address reimbursement. <https://goo.gl/sdcSrM>

N.B. Additional articles on access to specialized end-of-life care in rural communities and remote regions are noted in the 5 June 2017 issue of Media Watch (pp.15-16, #515).

Agency, social and healthcare supports for adults with intellectual disability at the end of life in out-of-home, non-institutional community residences in Western nations: A literature review

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 6 June 2017 – The nature and quality of end-of-life care (EoLC) received by adults with intellectual disabilities in out-of-home, non-institutional community agency residences in Western nations is not well understood. More information is needed about where people with intellectual disabilities are living at the very end of life (EoL) and where they die. The support needs for adults with intellectual disabilities will change over time, particularly at the EoL. There are some areas, such as removing barriers to providing services, staff training, partnerships between agencies and palliative care providers, and advocacy, where further research may help to improve the EoLC for adults with intellectual disabilities. <https://goo.gl/EoaNXu>

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Noted in Media Watch 29 May 2017, #514 (p.9):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 25 May 2017 – ‘**Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach.**’ There is a strong relationship between organizational structure and culture, and both influence end-of-life practice in community living services. Organizational reorientation is crucial to achieving sustainable change that will support healthy dying. The authors outline an organizational model they have developed from public health principles to manage end-of-life care in community living services. <https://goo.gl/Dbb5qV>

N.B. Additional articles on end-of-life care for people living with intellectual and developmental disabilities are noted in the 22 May 2017 issue of Media Watch (#513, p.15).

Intensifying relational care: The challenge of dying in long-term residential care

JOURNAL OF CANADIAN STUDIES, 2017;50(2):396-421. Although the culture change movement has sought to transform residential care facilities from *warehouses of death* into homes for living, there is growing recognition of the need to address dying within these settings. Drawing on data from an international and interdisciplinary study, this paper explores the state of end-of-life care (EoLC) in residential care facilities, identifying barriers to the provision of compassionate care for the dying, as well as promising practices and areas for future inquiry. Interviews with staff and researcher observations at 20 nursing homes in Canada, Germany, Norway, Sweden, the United States, and the U.K. were analyzed. Six themes were identified: 1) The growing need for EoLC; 2) The challenge of identifying a dying phase; 3) The importance of open communication about death; 4) The need to address bereavement of both families and staff; 5) The need for additional training and resources; and, 6) The inadequacy of current models of care. Taken together, these findings suggest that dying intensifies the need for relational care, a type of care residential care facilities have been struggling to provide. However, while demands increase, there are also opportunities. The authors conclude with a reflection on the potential that the blurred boundaries between living and dying hold for experimentation in long-term residential care with visions of life and health that can include death. <https://goo.gl/f37VGM>

Noted in Media Watch 5 June 2017, #515 (p.13):

- *JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE*, 2017;18(6):465-469. ‘**International survey of end-of-life care in nursing homes.**’ This article reports the findings of a survey on end-of-life (EoL) care in nursing homes of 18 long-term care (LTC) experts across 15 countries. Overall, experts strongly agreed that hospice and palliative care should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears the experts felt that in most countries the reality fell short of what they believed would be ideal care. As a result, they call for increased training, communication, and access to specialized EoL services within the nursing home. <https://goo.gl/U3c3Xy>

N.B. Additional articles on palliative and end-of-life care in care homes and nursing homes are noted in the 24 April 2017 issue of Media Watch (#509, p.12).

How to better help cancer patients face their coming death?

JOURNAL OF CLINICAL ONCOLOGY, 2017;15_suppl:e21505. According to literature and medical experience, the doctor-patient relationship becomes strained when oncologists tell their patients that they have no more curative treatments to offer them. Patients often resist when they are told that it is in their best interest to meet with the palliative teams. Little is known about how to meet patients’ expectations at this advanced stage. The authors conducted a multicenter qualitative research in an oncology department, a hospital at home service and in an inpatient hospice care center. Qualitative analysis revealed four main results: 1) For respondents, palliative care (PC) introduction meant impending death; 2) PC introduction meant loss of hope. (Without hope, the cancer trajectory is impossible to sustain, they said); 3)

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Hope was intricately interwoven with the request for more chemotherapy, even if doctors had clearly refused to provide it; 4) The oncologist remained the referent physician, even for patients in hospice care. Patients for which the mean duration between cancer diagnosis and interview was 5 years or more, were more willing to talk about death and better accepted PC than patients for which the mean duration of cancer was inferior to 3 yrs. For patients with fast progressing cancer, 10 were not willing to talk about death and 7 strongly resisted PC introduction. <https://goo.gl/Hyi9pS>

Implementation of advance care planning in oncology: A review of the literature

JOURNAL OF ONCOLOGY PRACTICE | Online – 6 June 2017 – Advance care planning (ACP) should be initiated early and be readdressed often for patients with cancer. This directive is expressed in the Institute of Medicine’s report, ‘Dying in America,’¹ and is a component of several quality metrics, including American Society of Clinical Oncology’s ‘Quality Oncology Practice Initiative’² and the Centers for Medicare & Medicaid Services ‘Oncology Care Model.’³ Although simple in concept, implementation in practice is challenging. A variety of patient education tools exist in several different forms, including pamphlets, guidebooks and question prompt lists, with the strongest data supporting the use of video decision aids that depict cardiopulmonary resuscitation. These tools should address topics that include anticancer treatment, cardiopulmonary resuscitation, and health care surrogates. Physician prompts in the electronic health record to discuss ACP should be considered. Health care provider training should be offered to meet the needs and comfort level of the practitioners who conduct the intervention. Intervention studies that assessed ACP documentation rates as the primary end point increased documentation from 15% to 30% to 40%. Additional well-conducted randomized studies are needed to understand the intervention characteristics that can further improve the completion and docu-

mentation of ACP. Further research is needed to determine if there is a difference in outcome based on which provider conducts ACP as well as how to maximize the benefits of the electronic health record, such as prompts to readdress ACP. <https://goo.gl/VO1IJB>

End-of-life care in Lithuania

Are advance directives helpful for good end of life decision making: A cross sectional survey of health professionals

BMC ETHICS | Online – 5 June 2017 – Issues in relation to advance directives (ADs) occur in clinical units in Lithuania; however, it remains one of the few countries in the European Union where the discussion on ADs is not included in the health-care policy-making agenda. To encourage the discussion of ADs, a study was designed to examine health professionals’ understanding and preferences related to ADs. In addition, the study sought to explore the views of health care professionals of the application of ADs in clinical practice in Lithuania. The study findings reveal a low level of knowledge on ADs among health professionals. Most agreed that ADs improved end-of-life (EoL) decision making while the majority of physicians appreciated AD as the best tool for sharing responsibilities in clinical practice in Lithuania. <https://goo.gl/VCq69J>

1. ‘Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,’ Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch 22 September 2014, #376 (p.4)] <http://goo.gl/6Q5VNY>
2. ‘Quality Oncology Practice Initiative,’ American Society of Clinical Oncology. <https://goo.gl/rrYo0F>
3. ‘Oncology Care Model,’ Centers for Medicare & Medicaid Services. <https://goo.gl/Miklq0>

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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.16.

Related

- *CLINICAL MEDICINE* | Online – 1 June 2017 – ‘**Recognising the need for innovation in digitalising urgent or advance care planning in adults aged 70 years and over following emergency admission.**’ An emergency admission over the age of 70 years could be used to aid recognition of the last years of life and to initiate urgent or advance care planning. The data highlight the need to innovate by sharing electronic, patient-accessible care plans across multiple sites and out-of-hours care providers to improve end-of-life care. <https://goo.gl/umLus4>
- *HEART, LUNG & CIRCULATION*, 2017;26(7):643–644. ‘**Advance care planning in cardiology.**’ As cardiologists are increasingly involved in treating elderly patients with multiple co-morbidities, there are frequent dilemmas as to the appropriate ceiling of care when such patients deteriorate. Respecting the wishes and dignity of the patient is of paramount importance when considering whether to escalate care, keep treatment in a “holding pattern” or, indeed, withdraw active care when treatment is deemed futile. <https://goo.gl/bQ3rVH>

European Association for Neuro-Oncology guidelines for palliative care in adults with glioma

THE LANCET ONCOLOGY, 2017;18(6):e330-e340. The multidisciplinary PC task force of the European Association of Neuro-Oncology did a systematic review of the available scientific literature to formulate the best possible evidence-based recommendations for the PC of adult patients with glioma, with the aim to reduce symptom burden and improve the quality of life of patients and their caregivers, particularly in the end-of-life phase. When recommendations could not be made because of the scarcity of evidence, the task force either used evidence from studies of patients with systemic cancer or formulated expert opinion. Areas of PC that currently lack evidence and thus deserve attention for further research are fatigue, disorders of behaviour and mood, interventions for the needs of caregivers, and timing of advance care planning. <https://goo.gl/A8efeV>

Noted in Media Watch 28 July 2014, #368 (p.8):

- *JOURNAL OF NEURO-ONCOLOGY* | Online – 20 July 2014 – ‘**End-of-life care in high-grade glioma patients in three European countries: A comparative study.**’ In The Netherlands, Austria and the U.K., respectively, patients most often died at home (60%), in a hospital (41%) or hospice (41%). Advance directives were present in 46% of Dutch, 36% of British and 6% of Austrian patients. Fifty-three percent of patients experienced good quality of care (QoC), irrespective of country. There are various cross-national differences in organization and experiences with end-of-life care for high-grade glioma (HGG), but patient’s perceived QoC as similar in the three countries. <https://goo.gl/nkNTGk>

Pediatric palliative care in Canada

Does the pediatric emergency department have a role in pediatric palliative care?

PAEDIATRICS & CHILD HEALTH | Online – 26 May 2017 – Little is known regarding the role of the pediatric emergency department (ED) in pediatric palliative care (PPC). ED providers seek to maintain continuity of care and uphold pre-established wishes throughout PPC patients ED visits by listening and supporting the patient and family, evaluating the clinical situation, communicating with primary care teams and organising rapid admissions to wards. Each interdisciplinary team interviewed demonstrated particular values and cultures, influencing their understandings of the EDs role in PPC; continuity of care is complicated by these distinct philosophies. Limitations to providing PPC in the ED are related to unsuitable physical environments, lack of uninterrupted time, efficiency expectations, unknown patients, provider lack of knowledge and moral distress. <https://goo.gl/vbmNEb>

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Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 June 2017 – ‘**The validity of using health administrative data to identify the involvement of specialized pediatric palliative care teams in children with cancer in Ontario, Canada.**’ Population-based research to identify underserved populations and the impact of palliative care (PC) is limited as the validity of such data to identify palliative care (PC) services is largely unknown. In this study, health administrative data identified involvement of specialized pediatric PC teams with good sensitivity, but low specificity. Studies using such data alone to compare patients receiving and not receiving specialized pediatric PC are at significant risk of misclassification and potential bias. <https://goo.gl/TDXZfu>

Which patients die in their preferred place? A secondary analysis of questionnaire data from bereaved relatives

PALLIATIVE MEDICINE | Online – 7 June 2017 – Previous studies on factors influencing the place of death have focused on cancer patients dying at home. However, home is not always the preferred place. A total of 797 bereaved relatives filled in the Consumer Quality Index Palliative Care, a validated and reliable questionnaire. Two-thirds of the patients died in the preferred place. A preference for dying at home and having had a stroke decreased the likelihood of dying in the preferred place, while having a partner, dementia, contact with the general practitioner in the last week before death, and continuity of care between professionals increased the likelihood of dying in the preferred place. Furthermore, people who wanted to die at home and also had dementia were more likely to die elsewhere than people without dementia who wanted to die at home. Positive associations were found between continuity of care between healthcare professionals and contact with the general practitioner and the chance of people dying in their preferred place. <https://goo.gl/OEFqCw>

Related

- *PALLIATIVE MEDICINE* | Online – 7 June 2017 – ‘**The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey.**’ In this cross-sectional community household population survey, one-third of 1,265 bereaved respondents [to the Household Survey for England] had provided personal end-of-life care. Just over half accessed palliative care (PC) services and 15% died in a hospice. Place of death and access to PC were strongly related. PC services reduced the proportion of deaths in hospital, and decedents accessing PC were more likely to die at home than those who did not. Respondents’ income was not associated with PC access. Overall, respondents’ income and home death were not related, but decedents with caregivers in the highest income group were least likely to die at home. <https://goo.gl/Wc9w1r>

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

Impact of home-based, patient-centered support for people with advanced illness in an open health system: A retrospective claims analysis of health expenditures, utilization, and quality of care at end of life

PALLIATIVE MEDICINE | Online – 7 June 2017 – Home-based care coordination and support programs for people with advanced illness work alongside usual care to promote personal care goals, which usually include a preference for home-based end-of-life care. More research is needed to confirm the efficacy of these programs, especially when disseminated on a large scale. Advanced Illness Management (AIM) is one such program, implemented within a large open health system in northern California. In this retrospective-matched observational study analyzing medical claims in the final 3 months of life, final month total expenditures for Advanced Illness Management enrollees were reduced by US\$4,824 and inpatient payments by US\$6,127. Enrollees also experienced 150 fewer hospitalizations/1,000 and 1,361 fewer hospital days/1000. The percentage of hospice enrollees increased by 17.9 percentage points, hospital deaths decreased by 8.2 percentage points, and intensive care unit deaths decreased by 7.1 percentage

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points. End-of-life chemotherapy use and non-inpatient expenditures in months 2 and 3 prior to death did not differ significantly from the control group. AIM has a positive impact on inpatient utilization, cost of care, hospice enrollment, and site of death. This suggests that home-based support programs for people with advanced illness can be successful on a large scale in supporting personal end-of-life care choices. <https://goo.gl/ZKKWem>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 May 2017 – ‘**Delivery of community-based palliative care: Findings from a time and motion study.**’ A process map of palliative care (PC) delivery was created and descriptive statistics were used to calculate the proportion of time spent on discrete activities and within each activity category. Over 50 hours of activities were recorded during which the clinicians interacted with 25 patients and engaged in 20 distinct tasks. Physicians spent 94% of their time on tasks related to patient care and 1% on administrative tasks. Nurse practitioners and registered nurses spent 82% and 53% of their time on patient-related tasks and 2% and 37% on administrative tasks, respectively. <https://goo.gl/PXH3cW>

“If I had stayed back home, I would not be alive any more...”

Exploring end-of-life preferences in patients with migration background

PLOS ONE | Online – Accessed 5 June 2017 – In patients with life-limiting conditions and a history of migration, a higher risk of not dying at home and limited access to palliative care (PC) services has been reported. Participants in this study included migrant and non-migrant adult patients with far advanced, life-limiting disease receiving PC in different specialist level settings (e.g., specialist home PC, PC inpatient unit, inpatient hospice). The 37 interviewees (19 native Germans and 18 patients from Europe and the U.S., Israel, Turkey and Indonesia) expressed eleven themes covering health care- and patient-related issues, of which four emerged to be specific for migrants: 1) Worse survival in home country; 2) The perception of an altered identity and “not belonging”; 3) Language skills as prerequisite to survive; and, 4) Longing for “home” while being attached to Germany. From these categories, three overarching themes were derived: 1) A limited understanding of the concept of PC; 2) The suppression of end-of-life discussions for its association with suffering and loss of autonomy; and, 3) The significance of complex individual migration histories. Based on these findings, the concept of a “double home” experience is proposed. Barriers to access to PC should be minimized for all patients while cultural stereotyping has to be avoided. <https://goo.gl/D2ZHiB>

Noted in Media Watch 18 April 2016, #458 (p.11):

- *JOURNAL OF INTERCULTURAL STUDIES*, 2016;37(2):103-117. ‘**The “other” in end-of-life care: Providers’ understandings of patients with migrant backgrounds.**’ The analysis brings to the fore three themes: 1) The expectation that the existence of difference and uncertainty is a given when caring for patients with migrant backgrounds; 2) The expectation that the extension of responsibility that difference entails creates a variety of dilemmas; and, 3) The expectation that difference will bring about misunderstandings and that patients’ needs can go unmet as a result of this. <http://goo.gl/35YcU>

N.B. Selected articles on repatriation to their homeland of patients living with a terminal illness are noted in the 28 November 2016 issue of Media Watch (#489, pp.15-16).

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Supporting the support system: How assessment and communication can help patients and their support systems

PROFESSIONAL CASE MANAGEMENT, 2017;22(4):174-180. As part of the assessment phase of the case management process, case managers (CMs) determine the extent of the patient's support system or social support network such as family and close friends. Although their advocacy is primarily for the patient receiving case management services, CMs also become aware of the needs of the support system members as they face their loved one's serious illness, severe injury, geriatric care demands, or end of life. CMs can use their communication skills, especially motivational interviewing, with patients and their support systems to identify stresses and issues that can impact the pursuit of health goals. In addition, CMs ensure that individuals and their support systems are kept informed such as about the health condition, stage of disease, plan of care, treatment options, and care transition plan. Professional CMs expand their role as advocates, serving primarily the patients ("clients") who receive case management services and also members of the support system. By becoming more aware and sensitive to the needs of the support system, CMs help reduce stress on the support system, which can contribute to positive outcomes for patients ("clients"). <https://goo.gl/vNS27m>

Noted in Media Watch 6 February 2017, #498 (p.5):

- *BRITISH MEDICAL JOURNAL* | Online – 2 February 2017 – **'Supporting relatives and carers at the end of a patient's life.'** This article discusses how to best support relatives and carers at the end of a patient's life. While the focus is on the hospital setting, the principles are applicable to community and care home settings. In this article, "relative" encompasses family members, care givers, and those close to the patient. The article presumes throughout that the patient has given consent for information to be shared with relatives. <https://goo.gl/68QwIF>

The intersection of palliative care and interventional radiology: Enhancing understanding and collaboration

SEMINARS IN INTERVENTIONAL RADIOLOGY, 2017;34(2):140-144. In the treatment of cancer patients, many interventional radiologic procedures are palliative in nature. The goal for these therapies is often something other than cure, such as prolonged survival or improved quality of life. The goals of therapy should be matched with the patient's wishes, and must include open communication between the health care provider and the patient. Hospice and palliative medicine is its own specialty, and a multidisciplinary approach to the care of cancer patients should include discussions with these health care specialists. This article briefly defines (PC) care in general, describes the specialty of hospice and palliative medicine, and discusses how hospice differs from PC. Finally, it highlights opportunities for interventional radiology specialists to incorporate more deliberately PC skills and competencies into their own practice and to collaborate with PC specialists. <https://goo.gl/Wdo6mt>

Noted in Media Watch 21 September 2015, #428 (p.10):

- *JOURNAL OF VASCULAR & INTERVENTIONAL RADIOLOGY* | Online – 11 September 2015 – **'Informed consent challenges in frail, delirious, demented, and do-not-resuscitate adult patients.'** Without informed consent, any invasive procedure becomes an assault. The prevailing legal and ethical standard is that the physician has a fiduciary duty to give enough information to the patient so that a reasonable person can make an informed decision to accept or refuse the proposed treatment. The patient's frailty, delirium and/or dementia, and end-of-life concerns and expectations can make informed consent a difficult task. <https://goo.gl/VJQOD8>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MCGILL JOURNAL OF LAW & HEALTH* | Inprint – 31 May 2017 – ‘**Organ donation and medical assistance in dying (MAiD): Ethical and legal issues facing Canada.**’ One issue that has not been addressed in depth in the Canada ... is whether those accessing MAiD would be eligible to donate organs and tissues, and the ethico-legal issues this may pose. This is a challenging question that brings together the controversial introduction of MAiD with the ethically sensitive practice of organ donation. This paper analyzes the ethico-legal issues raised in four possible scenarios for donation to occur in the context of MAiD: living donation of non-vital organs before MAiD, extended living donation of vital organs in anticipation of MAiD, deceased donation following MAiD, and MAiD by removal of organs. Extended living donation of vital organs and MAiD by removal of organs are unlikely to be accepted, and indeed the authors recommend against them. However, these possibilities have been raised in the medical ethics literature and they address them as part of a full review of this topic. In conclusion, the authors provide recommendations to address the combination of organ donation and MAiD within what we believe to be acceptable ethical parameters. <https://goo.gl/4f39sG>

Worth Repeating

On Goldilocks, care coordination, and palliative care: Making it “just right”

PRIMARY CARE RESPIRATORY JOURNAL | Online – 19 February 2014 – Hospice/palliative care is not just end-of-life care (EoLC), it is specialised medical care for patients with serious illness. Although definitions of “serious illness” may vary, it is clear that far more patients could benefit from hospice/palliative care than we can actually serve, given the existing workforce challenges and the lack of clarity in how to pay for specialist palliative care (PC) throughout the world. The needs of patients and caregivers are similar regardless of the underlying life-limiting illness. Appropriate timing of referrals is key, but this timing must be clearly defined for each disease group, with differences to be expected between cancer and chronic obstructive pulmonary disease. Not every patient needs to see a PC specialist, and the timing matters greatly when resources are limited. Thus, as PC continues to move further upstream in a patient’s journey, these limitations necessitate that we be better able to match the right type of care with the right patient at the right time. Models of “care coordination” offer one potentially promising strategy for addressing this problem. In this issue of the *Primary Care Respiratory Journal*, Epiphaniou and colleagues report the results of a longitudinal qualitative study of patients’ experiences with EoLC coordination in the U.K.¹ These results highlight several important truths about the current state of care coordination. [Noted in Media Watch 24 February 2014, #346 (p.15)] <https://goo.gl/2oC94y>

1. ‘Coordination of end-of-life care for patients with lung cancer and those with advanced COPD: Are there transferable lessons? A longitudinal qualitative study,’ *Primary Care Respiratory Journal*, published online 29 January 2014. <https://goo.gl/DfXwek>

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.

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Something Missed or Overlooked?

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

Media Watch: Online

International

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

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: <https://goo.gl/IXO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

Canada

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>

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>

Barry R. Ashpole
Guelph, Ontario CANADA

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