“It’s made a difference”: How word clouds offer solace to family members as a loved one dies

ONTARIO | CBC News – 23 April 2017 – After Daryl Terry was admitted to hospital last October for a kidney infection, the 80-year-old’s condition deteriorated quickly. She was soon moved to the intensive care unit at St. Joseph’s Hospital in Hamilton, Ontario. With a poor prognosis, it seemed she would most likely die in the ICU. It all came as a shock to family and friends, says her daughter, Barbara Terry, and became particularly difficult when the once-vivacious Daryl lost consciousness and was unable to respond. But what came next was a surprise of a different kind for the family. Medical staff gave the family the opportunity to participate in a project created by a McMaster University doctor that aims to humanize the grieving process for families and their health-care providers. The Word Cloud Project helps families create collages of words and memories describing their dying family member. The project emphasizes storytelling and engagement between the health-care provider and the patient. It was outlined in a recent paper in the British Medical Journal.1 In that paper, families who took part in the project describe how creating a word cloud improved connections with the loved one – even after death – by helping the family reflect on the unique characteristics of the dying relative. https://goo.gl/vLBjPZ


Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | CBC News (Vancouver) – 20 April 2017 – ‘Medically assisted death has been legal for almost a year, but another battle is brewing.’ But because the timing of her death might not be “reasonably foreseeable” – a requirement that’s written into the federal law – Julia Lamb says she wouldn’t qualify for medical help to die. As her condition [i.e., spinal muscular atrophy] worsens, Lamb worries her disease could force her to suffer for years – without killing her. Lamb is not asking to give consent for her potential assisted death in advance. But she does want to change the law so that her death doesn’t have to be “reasonably foreseeable” if she decides it’s no longer bearable to live. https://goo.gl/fD0NGZ
ONTARIO | *The Ottawa Citizen* – 19 April 2017 – ‘Nurse practitioners can now provide assisted death in Ontario.’ Long-requested changes will allow Ontario nurse practitioners (NPs) to be primary providers of medically-assisted death, putting them on par with their counterparts in other provinces. The changes took effect after the provincial government amended the College of Nurses of Ontario regulations. [https://goo.gl/H4eOxc](https://goo.gl/H4eOxc)

NOVA SCOTIA | CBC News (Halifax) – 20 April 2017 – ‘Fewer than half of assisted-death requests in Nova Scotia have been granted.’ Sixty-seven Nova Scotians have requested medical assistance to die since Canada’s assisted dying legislation was passed last June. But of those 67 applicants, only 31 actually received medical help to die. The Nova Scotia Health Authority, which oversees assisted dying in the province, said there are several reasons why the remaining applicants may have not received the help they requested. Those 36 applicants may have died while waiting for approval, may not have met the criteria, may have withdrawn their application or may still have an application in progress. [https://goo.gl/JVd5I3](https://goo.gl/JVd5I3)

BRITISH COLUMBIA | *The Times Colonist* (Victoria) – 18 April 2017 – ‘Expansion brings assisted-dying issue to fore.’ The planned expansion of the Comox Valley’s hospice beds has sparked a heated debate about medical assistance in dying (MAiD), which isn’t allowed at the Catholic hospital that runs the facility. MAiD is not provided at Hospice at The Views, which is co-owned and operated by St. Joseph’s General Hospital. The Comox Valley is one of the only hospices on the Island where you can’t access MAiD, said Terri Odeneal, executive director for the Comox Valley Hospice Society. “We believe that hospice palliative care in the Comox Valley should not be different than other communities on Vancouver Island, now that MAiD is legal throughout the country,” Odeneal said. Federal legislation came into effect in June 2016 giving individuals the right to assisted deaths, but like several Catholic organizations across the country, St. Joseph’s has declined to provide the procedure, claiming freedom of conscience and religion. According to [Vancouver Island Health](https://goo.gl/MhsZHo), about 3% of deaths on the Island are medically assisted.

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Specialist Publications

‘Assisted dying and disability’ (p.15), in *Bioethics*.

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**U.S.A.**

Pennsylvania House OKs “right-to-try” drugs not approved by Food & Drug Administration

 PENNSYLVANIA | ABC 27 News (Harrisburg) – 18 April 2017 – The state House of Representatives has passed legislation that would allow the terminally ill to use drugs not yet approved by the U.S. Food & Drug Administration. House Bill 45 would allow manufacturers to make experimental drugs and medical devices available to terminally ill patients after the product successfully complete the first phase of a clinical trial. Republican representative Robert Godshall ... said under his proposal, physicians could not be held liable for recommending the products to eligible patients. The bill does not require insurers to cover the products. [https://goo.gl/4PQRld](https://goo.gl/4PQRld)

N.B. Noted in the 17 April 2017 issue of Media Watch (#508, p.2) are selected articles on “right-to-try” laws.

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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.
When doctors should ignore end-of-life directives

FORBES | Online – 17 April 2017 – Sheila was very clear about her wishes for the end of life. She was 88-years-old and a former hospice volunteer. When her time came, she wanted no ventilator, no feeding tube, no CPR. She even wrote down her wishes – NO LIFE SUPPORT! – in an advance directive (AD), in case she wasn’t able to say what she wanted. ADs such as the one Sheila wrote are common; many hospitals even use their completion rates as a quality metric.) But when sudden difficulty breathing brought Sheila to the emergency room, doctors didn’t follow the orders on her AD. She was intubated and admitted to the ICU on a ventilator. And it turns out, that was exactly the right thing to do. Why? As a physician, I know that ADs are most helpful in situations where it is clear that death is inevitable. They are intended to protect people from receiving “life-sustaining treatments” such as ventilators and CPR, in situations where those treatments only prolong the dying process.

But many decisions about life-sustaining treatments must be made in situations like Sheila’s, where there is uncertainty about outcomes. https://goo.gl/F4ONQQ

Specialist Publications

‘Nurses’ interest in independently initiating end-of-life conversations and palliative care consultations in a suburban, community hospital’ (p.8), in American Journal of Hospice & Palliative Medicine.

‘Upstreaming and normalizing advance care planning conversations: A public health approach’ (p.8), in Behavioral Sciences.

‘Advance care planning and advance care directives: Ideas whose time has passed?’ (p.9), in Internal Medicine Journal.

Rethinking dialysis: Giving patients choices

MASSACHUSETTS | The Boston Globe – 17 April 2017 – As more elderly people suffer kidney failure, new data reveal a troubling pattern for dialysis patients: A high percentage die anyway, and even those who live longer often don’t live well. That has led some patients and doctors to consider what once might have been unthinkable: disconnecting the dialysis machine. “We used to think, ‘Dialysis, it’s great. You get more life. You get more days. Let’s do it,’” said Jody Comart, director of palliative care for Hebrew SeniorLife, a Greater Boston non-profit... “But now we understand. ‘Well, you get more days. But three days [a week] are taken up by dialysis and exhaustion and feeling crummy and you are likely to have several hospitalizations each year due to complications.’” Dr. Ernest Mandel, medical director of nephrology and dialysis at Hebrew SeniorLife, said that too often dialysis is the default response to kidney failure, occurring without discussion. Patients have no idea what they’re getting into – or that they could choose another route. In 2014, some 420,000 Americans were on dialysis at any given time... Those older than 75 are the fastest-growing group of dialysis patients. https://goo.gl/E9KOMy

Specialist Publications

‘Clinician views of patient decisional conflict when deciding between dialysis and conservative management: Qualitative findings from the PAlliative Care in chronic Kidney diSease study’ (p.15), in Palliative Medicine.

Noted in Media Watch 14 April 2014, #353 (p.9):

- THE NEW YORK TIMES | Online – 24 June 2014 – ‘When advance directives are ignored.’ A large national study, tracking more than 6,000 people over age 60 who died between 2000 and 2010, found that the proportion with advance directives (AD) climbed to 72% from 47%. But how much does it matter? How often are people’s AD ignored or overridden? Do they really ensure that the elderly get the care they want or ward off procedures they don’t? https://goo.gl/PYOhT1

Note in Media Watch 13 March 2017, #503 (p.10):

- **THE GERONTOLOGIST** Online – 10 March 2017 – “End-of-life care? I’m not going to worry about that yet.” Health literacy gaps and end-of-life planning among elderly dialysis patients.

Between 2000 and 2012, the incident dialysis population in the U.S. increased by nearly 60%, most sharply among adults 75 years and older. Despite high mortality risk in this population, only 13% of patients [i.e., study participants] had discussed end-of-life (EoL) preferences with physicians, half had discussed EoL with their social network, and 25% of participants explicitly stated that they had never considered EoL preferences. Less than 30% of participants could correctly define terminology commonly used in EoL conversations. [https://goo.gl/fbLYLc](https://goo.gl/fbLYLc)

An increased death rate means changing care landscape in South Carolina

SOUTH CAROLINA | The Post & Courier (Charleston) – 16 April 2017 – As the baby boomer generation continues to age, geriatric care managers and hospice providers have flooded the health care market in South Carolina (SC) to accommodate an ever-growing population of older patients. In the past five years, annual deaths in SC increased from roughly 42,000 to 47,500. A corresponding demand for providers who deal with end-of-life care has been made clear by an increasing number of people in hospice and receiving in-home services. According to data from the Centers for Medicare & Medicaid Services, billing to Medicare by hospice providers spiked by about $11.8 million in SC between 2007 and 2015. The Hospice & Palliative Care Foundation, which gives aid to those at the end of their life in SC, has seen an increase in its requests for help, especially in the past three years. Hospice enrollment has particularly increased in Horry County, where numbers have doubled since 2007; about 21% of the population was older than 65 in 2015, compared with a national rate of about 15%. [https://goo.gl/L5RlDI](https://goo.gl/L5RlDI)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **MAINE** | The Portland Press Herald – 19 April 2017 – ‘Assisted-death bill fails to earn support of Maine legislative committee.’ A bill that would allow doctors to help terminally ill patients end their lives failed to earn majority support ... from lawmakers on the Health & Human Services Committee and now faces an uphill battle in the full Legislature. Governor Paul LePage said this week that he would veto the bill, which means it would need support from two-thirds of lawmakers, rather than a simple majority, to become law. [https://goo.gl/osTGEZ](https://goo.gl/osTGEZ)

**International**

End-of-life care in England

Terminally ill patients decide how money is spent on their care in pilot scheme

U.K. (England) | The Warrington Guardian – 21 April 2017 – Terminally ill residents have been invited to choose how National Health Service money is spent on their care. Warrington is one of four areas in the country piloting the scheme, which lets patients choose how to use their personal health budget. The [local] clinical commissioning group has teamed up with St. Rocco’s Hospice to help sick people and their families get the most out of the final months, weeks and days together. A personal health budget is not new money, but means residents can decide what treatments, equipment or care they want. [https://goo.gl/OTi4SW](https://goo.gl/OTi4SW)
End-of-life care in Jordan

“90% in need of palliative care in Kingdom do not receive it”

JORDAN | The Jordan Times (Amman) – 18 April 2017 – Around 90% of people in Jordan in need of palliative care (PC) ... do not receive it... Additionally, around 80% of Jordanians in need of opioid analgesics ... do not have access to them, said Omar Shamieh, chairman of the National Palliative Care Committee. Improving access to palliative medical and home care services helps reduce hospital bills and emergency room visits, and helps lessen the pain felt by patients of chronic diseases and cancer, while reducing the suffering of their families, added Shamieh, who also chairs the King Hussein Cancer Centre’s Hospice & Palliative Care Department. Meanwhile, strengthening PC policies, improving the capacities of workers in the field, providing support to families and community volunteers, as well as coordinating with private and public health insurance programmes to cover PC costs, could help Jordan realise its international commitments to enhance its provision of PC, he said. The Palliative & Home Care Education Programme ... offers a wide range of educational and training opportunities designed for healthcare professionals, as well as for family caregivers and volunteers, at different skill levels, according to organisers, who added that the programme has so far trained around 500 healthcare professionals. Shamieh noted that some challenges still need to be addressed, such as the lack of public awareness of the advantages of PC, social misconceptions about pain relief, overly restrictive regulations for opioid pain relief and the insufficient skills and capacities of some health workers. https://goo.gl/GMuWwk

Specialist Publications


For old folks left to die at Myanmar’s roadsides and cemeteries, these homes are their last hope

MYANMAR | Channel NewsAsia – 16 April 2017 – Daw Khin is the vice-president of Twilight Villa, a nursing home in Myanmar which takes in abandoned sick elderly citizens whom other homes turn away. Cases of seniors being left abandoned by families near markets, railway stations and even cemeteries are on the rise. “These grandpas and grandmas at our nursing home have been cast aside at hospitals and under bridges like rubbish,” she said with heat. Daw Khin is among a small but growing number of individuals and local non-profit organisations that have stepped forward to help the sick elderly who are in the last years or even months of life. They have no training in nursing nor geriatrics, driven only by their passion to provide this group with dignified end-of-life care. Daw Khin, a criminal lawyer by profession, co-founded Twilight Villa along with local philanthropist and award-winning writer Daw Than Myint Aung in 2010, after they found that nursing homes were unwilling to accept the sick elderly. She said some of these seniors are referred to them by the police, and they have little memory of their identities. https://goo.gl/HyNO0K

N.B. In recent years, progress on improving the quality of end-of-life care in Myanmar has been steady. In August 2015, for example, the first palliative care (PC) clinic in the country was opened at the Yangon General Hospital. Support to advance PC in Myanmar has been forthcoming through the Lien Collaborative for Palliative Care ‘Training-of-Trainer in Palliative Care’ program. The Collaborative is an initiative co-developed by the Singapore-based Asia Pacific Hospice Palliative Care Network and the Lien Foundation.
Paupers’ funerals rise by 50% in four years

U.K. (England, Scotland & Wales) | iNews TV – 16 April 2017 – The number of people who have paupers’ funerals because they die penniless and without relatives to meet the cost is soaring across the U.K. Councils have reported a 50% rise in just four years in the amount of burials and cremations for which they have to pick up the bill. Most people who receive a “public health funeral” are cremated or buried in an unmarked grave. The leap in numbers was attributed to the soaring cost of funerals and people’s savings dwindling as they live longer. Since 2011, cash-strapped authorities have faced an £8.8 million bill for “public health funerals” – an average of more than £60,000 for each town hall. The sharp rise was uncovered in freedom of information requests to councils in England, Scotland and Wales by the Liberal Democrats. https://goo.gl/vAxA6u2

N.B. Additional articles on the rise of paupers’ funerals in the U.K. are noted in the 6 March 2017 issue of Media Watch (#502, p.5).

“Crippling” shortages of care workers in Scotland

U.K. (Scotland) | The Herald (Glasgow) – 16 April 2017 – New figures show independent care homes and services which care for elderly people in their own homes are facing an increasing struggle to attract workers.† The data compiled by Scottish Care, which represents the independent care sector, found more than three-quarters of care homes have current staff vacancies and 90% of care-at-home services said they have difficulty in filling job positions. The private sector provides the majority of care home places in Scotland and just over half of home care hours for older people. A separate survey among care workers in the private sector by the GMB Scotland union also paints a picture of a workforce under increasing stress, with more than two-thirds considering leaving for another job. And almost one-in-five workers said they felt under pressure every day to cut corners in their work, with many pointing to increased staffing levels as one thing which would improve care for residents. With predictions that the number of elderly people requiring some form of care will increase by two-thirds over the next 25 years, experts are warning there is an urgent need to examine how it can be sustained in the future. https://goo.gl/4nd9RB

1. ‘Survey of care staff in care home, care at home and housing support services for older people,’ Scottish Care, April 2017. https://goo.gl/fGu4kY

Noted in Media Watch 13 February 2017, #499 (p.4):

- U.K. (Scotland) | The Herald (Glasgow) – 7 February 2017 – ‘Care staff “at breaking point” over end-of-life provision.’ Older people at the end of their lives are being let down by the care system, with too many unable to achieve a “good death” and dying alone, according to a survey from Scottish Care.† The umbrella organisation for independent care providers says staff in care homes or providing care in people’s own homes are stretched to breaking point by the needs of terminally ill residents. More than 100,000 people work in independent care homes and home care services, supporting more than 63,000 people, including around 52,000 aged over 65. https://goo.gl/4jflq62

1. ‘Trees that bend in the wind: Exploring the experiences of front line support workers delivering palliative and end-of-life care,’ Scottish Care, February 2017. https://goo.gl/PkXh6D

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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
Expanding the palliative care domains to meet the needs of a community-based supportive care model

The current framework of palliative care (PC) domains in the U.S. National Consensus Project (NCP) Guidelines for Quality Palliative Care offers an opportunity to reassess the domains of care delivered at home, earlier in the course of illness. The results of this study were used to inform a home-based, upstream model of supportive care for serious illness. Quotes relating to the experience of late-life serious illness were derived from transcripts of 12 semi-structured group interviews conducted with patients, family, and professionals. Quotes originally coded to the NCP domains of PC were then coded to the proposed domain set, which included new categories of family/caregiver, legal/financial, and legacy/bereavement domains. A total of 489 quotes were assigned to the proposed expanded set of domains. One hundred one (19%) coded to the family/caregiver domain, 28 (5%) to the legacy/bereavement domain, and 27 (5%) to the legal/financial domain. Ninety-seven (87%) of the 111 quotes coded to family/caregiver had been initially coded to the NCP social aspects of care. Family/caregiver themes included challenges, rewards, insights, and family growth. The preponderance of family-related issues suggests that including the family domain may promote recognition and support of family caregivers and the services they provide. Although this study provides some support for including the legacy/bereavement and legal/financial domains, additional research is needed to determine whether there is a basis for including them in the domain structure. https://goo.gl/0zk9A3

Related

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 April 2017 – ‘Common care practices among effective community-based specialist palliative care teams: A qualitative study.’ Despite wide variation in models of care among community-based specialist palliative care (PC) teams, this large qualitative study identified several common themes in care practices that can guide the development of other teams. First, the distinct models of care were generally summarised into three models: 1) Primary care and specialist providers either collaborated by transferring, sharing or consulting in care; 2) Teams explicitly or implicitly followed 7 common care practices related to: specialised expertise 24/7, intra-team communication, timeliness, physical symptom and psychosocial–spiritual management, education, peace and fulfilment, and advocacy for patient preferences; 3) All teams emphasised the importance of team building, even more than using clinical tools and processes. https://goo.gl/T020Jt

Noted in Media Watch 10 April 2017, #507 (p.15):

- PALLIATIVE MEDICINE | Online – 5 April 2017 – ‘What do we know about different models of providing palliative care? Findings from a systematic review of reviews.’ A wide range of organisational models of palliative care (PC) exist. However, decision makers need more information about which models are likely to be most effective in different settings and for different patient groups. Much of the evidence relates to home-based PC, although some models are delivered across care settings. Reviews report several potential advantages and few disadvantages of models of PC delivery. However, under-reporting of the components of intervention and comparator models are major barriers to the evaluation and implementation of models of PC. https://goo.gl/thpFmR

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8l
Nurses’ interest in independently initiating end-of-life conversations and palliative care consultations in a suburban, community hospital

Patients who receive early palliative care (PC) consults have clinical courses and outcomes more consistent with their goals. Nurses have been shown to be advocates for early PC involvement and are able to lead advanced care planning discussions. The purpose of this study was to assess whether, after a brief educational session, nurses at a suburban, community hospital could demonstrate knowledge of PC principles, would want to independently initiate end-of-life (EoL) conversations with patients and families, and would want to place specialty PC consults. Most participants would want to be able to directly consult PC and would feel comfortable initiating EoL conversations after the educational session. [https://goo.gl/af6Jel](https://goo.gl/af6Jel)

**Quotable Quotes**

*There is a direct correlation between the quality of care and the quality of communication.*

**Related**

- **BEHAVIORAL SCIENCES** | Online – 17 April 2017 – ‘How older adults and their families perceive family talk about aging-related end-of-life issues: A dialectical analysis.’ For older adults, approaching end-of-life (EoL) brings unique transitions related to family relationships. Unfortunately, most families greatly underestimate the need to discuss difficult issues. For example, parents approaching EoL issues often struggle with receiving assistance from others, avoiding family conflict, and maintaining their sense of personhood. In addition, discussions of EoL issues force family members to face their parents’ mortality, which can be particularly difficult for adult children to process emotionally. [https://goo.gl/qDgPGo](https://goo.gl/qDgPGo)

- **DIMENSIONS OF CRITICAL CARE NURSING**, 2017;36(3):218-221. ‘The Conversation Project: A reminder for critical care nurses.’ There has been much talk and published about ‘The Conversation Project,’ an effort to inform people about their options and wishes toward end of life. A brief review of this project is presented, as well as tips to get started and the author’s experience in caring for four aging parents and determining their desires for end-of-life care. [https://goo.gl/5DWkWH](https://goo.gl/5DWkWH)

**Upstreaming and normalizing advanced care planning conversations: A public health approach**

*BEHAVIORAL SCIENCES* | Online – 12 April – As a society, we simply don’t talk about this universal experience called dying and death; in fact, we ignore it until we have to face it. Thus, it is often in a crisis experience when we have to make decisions while we are laden with uncertainty and intense emotions. Sixty percent of people say making sure their family is not burdened by tough decisions is extremely important, yet 56% of them have not held a conversation about its context. Instead of waiting to make end-of-life decisions, let us begin to think about what matters most while we are living, what we value most, and how we translate these values into conversations about what is important. As a public health concern, if we can upstream the advance care planning discussion into usual health promotion activities, perhaps, as a society, we can begin to normalize and reshape how we make decisions about the last chapters of our lives. [https://goo.gl/VA6YFa](https://goo.gl/VA6YFa)

**Related**

- **BEHAVIORAL SCIENCES** | Online – 18 April 2017 – ‘Designing effective interactions for concordance around end-of-life care decisions: Lessons from hospice admission nurses.’ This analysis reveals diverse points of struggle within hospice decision-making processes around hospice care and the need for communication techniques that promote trust and acceptance of end-of-life care (EoLC). Lessons learned from talking about hospice care can inform other quality initiatives around communication and informed decision-making in the context of advance care planning, palliative care, and EoLC. [https://goo.gl/8liXKZ](https://goo.gl/8liXKZ)
International variations in clinical practice guidelines for palliative sedation: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 20 April 2017 – In this review, the authors identify and compare national/regional clinical practice guidelines on palliative sedation (PS) against the European Association for Palliative Care (EAPC) PS framework and assess the developmental quality of these guidelines using the Appraisal Guideline Research & Evaluation (AGREE II) instrument. Thirteen guidelines – Belgium, Canada (3), Ireland, Italy, Japan, the Netherlands, Norway, Spain, Europe, and U.S. (2) – were selected. Eight contained at least 9/10 recommendations published in the EAPC framework; nine recommended “pre-emptive discussion of the potential role of sedation in EoLC”; nine recommended “nutrition/hydration while performing sedation,” and eight acknowledged the need to “care for the medical team.” There were striking differences in terminologies used and in life expectancy preceding the practice. Selected guidelines were conceptually similar, comparing closely to the EAPC framework recommendations, albeit with notable variations. Based on AGREE II, three guidelines achieved top scores and could therefore be recommended for use in this context. Also, domains “scope and purpose” and “editorial independence” ranked highest and lowest, respectively – underscoring the importance of good reportage at the developmental stage. https://goo.gl/c8Nhbr

Cont. next page

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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Links to Sources

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

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.
CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 1 July 2016 – ‘A systematic literature review on the ethics of palliative sedation: An update (2016).’ In a 2010 review of palliative sedation (PS), the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of PS may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. http://goo.gl/qWxPgk

Conflicts of interest and expertise of independent commenters in news stories about medical research

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(15):E553-E559. Despite recommendations that news stories about health research include comments from independent sources, only about 1 in 6 stories generated in response to clinical research published in major medical journals included such comments. The authors findings suggest that independent commenters in health news stories often appear to lack expertise or have academic and financial conflicts of interest that are not disclosed, or both. The disposition of comments by independent commenters was strongly associated with the congruence or discordance of commenters’ conflicts of interest with the findings of the source research. These observations may be important because media coverage of medical research affects the views and behaviour of the general public, and academic and clinical communities. Readers of news stories would reasonably expect independent commenters to be knowledgeable, and any financial or academic conflicts that might affect interpretation of the work to be explicitly reported. If commenters’ conflicts of interest are not reported, it might affect the ability of readers to evaluate the comments, and influence their overall response. https://goo.gl/EFMqlN

N.B. Selected articles on how the news media reports on medical research, in particular related to cancer, are noted in the 12 September 2016 issue of Media Watch (#479, pp.7-8).

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

Association between aggressive care and bereaved families’ evaluation of end-of-life care for veterans with non-small cell lung cancer who died in Veterans Affairs facilities

CANCER | Online – 17 April 2017 – To the authors’ knowledge, little is known regarding the relationship between patients’ and families’ satisfaction with aggressive end-of-life care (EoLC). They examined the associations between episodes of aggressive care (i.e., chemotherapy, mechanical ventilation, acute hospitalizations, and intensive care unit admissions) within the last 30 days of life and families’ evaluations of EoLC among patients with non-small cell lung cancer (NSCLC). Greater than 72% of veterans with advanced lung cancer [i.e., the patient population studied] who died in an inpatient setting had at least one episode of aggressive care and 31% received chemotherapy within the last 30 days of life. For all units except for hospice/palliative care (HPC), when patients experienced at least one episode of aggressive care, bereaved families rated care lower compared with when patients did not receive any aggressive care. For patients dying in an HPC unit, the associations between overall ratings of care and ≥2 inpatient admissions or any episode of aggressive care were not found to be statistically significant. Rates of aggressive care were not associated with age, and family ratings of care were similar for younger and older patients. https://goo.gl/WnbEV6

Noted in Media Watch 28 November 2016, #489 (p.12):

MILITARY MEDICINE, 2016;181(11):E1575-E1580. ‘An ethic of heroism shapes next of kin’s perceptions of veterans’ end-of-life care in Veterans Affairs Medical Centers.’ Appreciation of next of kin’s assumptions regarding veterans’ care can inform the culture of end-of-life services in Veterans Affairs Medical Centers, contributing to the development of supportive practices aligned with next of kin’s perspectives. This study explores next of kin’s accounts of Veterans’ hospital care during the last days of life to identify salient issues shaping perceptions of Veterans’ care. https://goo.gl/1IRZ5q

Cont.
Potential palliative care quality indicators in heart disease patients: A review of the literature

JOURNAL OF CARDIOLOGY | Online – 17 April 2017 – In spite of the increasing interest in palliative care (PC) for heart disease, data on the detailed methods of PC and its efficacy specifically in heart disease are still lacking. The authors summarize seven potential categories of quality indicators in heart disease: 1) Presence and availability of a PC unit, PC team, and outpatient PC; 2) Human resources such as number of skilled staff; 3) Infrastructure; 4) Presence and frequency of documentation or family survey; 5) Patient-reported outcome measure data and disease-specific patient quality of life; 6) Questionnaires and interviews about the quality of PC after death, including bereaved family surveys; and, 7) Admission-related outcomes such as place of death and intensive care unit length of stay. Although detailed measurements of PC quality have not been validated in heart disease, many indicators developed in cancer patients might also be applicable to heart disease. https://goo.gl/1yFiCF

Prognosticating with the hospitalized-patient one-year mortality risk score using information abstracted from the medical record

JOURNAL OF HOSPITAL MEDICINE, 2017;12(4):224-230. Predicting death risk in patients with diverse conditions is difficult. The Hospitalized-patient One-year Mortality Risk (HOMR) score accurately determines death risk in adults admitted to hospital using health administrative data unavailable to clinicians and most researchers. Patients [i.e., 4,996 adults admitted in 2011 to a non-psychiatric service at a tertiary hospital] had a mean age of 55.6 ... with 563 (11.3%) dying. The mean chart HOMR score was 22 ... and significantly predicted death risk; a 1-point increase in HOMR increased death odds by 19%... Chart HOMR was strongly discriminative ... and well calibrated... https://goo.gl/1Pahte

Cont.
Related

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 20 April 2017 – ‘How are non-numerical prognostic statements interpreted and are they subject to positive bias?’ Frank, clear communication with family members of terminally ill or incapacitated patients has important implications for well-being, satisfaction with care and sound decision-making. However, numerical prognostic statements, particularly more negative ones, have been found to be interpreted in a positively biased manner. Less precise, non-numerical statements, preferred by physicians, and particularly statements using threatening terms (dying vs surviving) may be even more subject to such biases. https://goo.gl/eFTexK

Palliative care development in European care homes and nursing homes: Application of a typology of implementation

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 13 April 2017 – The authors undertook a mapping exercise in 29 European countries... Through a descriptive and thematic analysis of survey data, they identified factors that contribute to the development and implementation of palliative care (PC) into care homes at different structural levels. A typology of PC implementation for the care home sector was developed and applied to the countries surveyed. The authors identified three levels of PC implementation: 1) Macro (national/regional policy, legislation, financial and regulatory drivers); 2) Meso (implementation activities, such as education, tools/frameworks, service models, and research); and, 3) Micro (PC service delivery). This typology was applied to data collected from 29 European countries and demonstrates the diversity of PC implementation activity across Europe with respect to the scope, type of development, and means of provision. The authors found that macro and meso factors at two levels shape PC implementation and provision in care homes at the micro organizational level. At a time of great demographic change and increased financial pressures, care homes are an important component of the health and social care economy, especially for a significant proportion of frail older people. They are also the place where these people will experience their dying and deaths. https://goo.gl/h35EXR

1. Albania, Austria, Belgium, Croatia Hrvatska, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, The Netherlands, Norway, Poland, Portugal, Romania, Spain, Sweden, Switzerland, Turkey, and the U.K.

Selected articles on end-of-life care in care and nursing homes:

- NURSING OLDER PEOPLE, 2017;29(3):23-27. ‘Practice improvement as a result of an end-of-life care programme for care homes.’ Case studies show participating in the Six Steps+ programme increases care home staff’s knowledge, skills and confidence, and enhances the quality of end-of-life care for residents. [Noted in Media Watch 10 April 2017, #507 (p.14)] https://goo.gl/Vjji1X

- NURSING OLDER PEOPLE | Online – 31 January 2017 – ‘Developing, implementing and evaluating an end-of-life care intervention.’ Care home staff confidence in receiving emotional and clinical support and managing end-of-life care symptoms increased, but confidence in discussing death and dying with residents and relatives decreased. [Noted in Media Watch 6 February 2017, #498 (p.13)] https://goo.gl/ELtQVD

- HEALTH SERVICES MANAGEMENT RESEARCH | Online – 27 October 2015 – ‘The cost of providing end-of-life care for nursing care home residents: A retrospective cohort study.’ Death in hospital vs. in nursing care home was associated with an average increase in costs of £4,223. Interventions are needed which help nursing care home staff to identify when an individual is dying, and have the skill and confidence to make difficult decisions regarding care provision at the end of life. [Noted in Media Watch 2 November 2015, #434 (p.11)] https://goo.gl/HHu29b
Seeking certainty? Judicial approaches to the (non-)treatment of minimally conscious patients

MEDICAL LAW REVIEW | Online – 18 April 2017 – A modest, but growing, body of case law is developing around the (non-)treatment of patients in the minimally conscious state. The authors sought to explore the approaches that the courts take to these decisions. They identify five key features of the rulings to date. First, the judges appear keen to frame the cases in such a way that these are rightly matters for judicial determination. Secondly, the judges appraise the types and forms of expertise that enter the courtroom, seeming to prefer the “objective” and “scientific,” and particularly the views of the doctors. Thirdly, the judges appear alert to the reasonableness of the evidence (and, indeed, the parties) and will look favourably on parties who are willing to co-operate. But the judges will not simply endorse any consensus reached by the parties; rather, the judges will reach their own decisions. Those decisions must be taken in the best interests of the patient. Fourthly, the judges approach this assessment in different ways. A balancing exercise is not consistently undertaken and, even in those cases in which it is, the weight accorded to particular factors varies. As the authors discuss, the consistency and predictability of the law in this area is open to question. Finally, however, they cautiously suggest that some consistent messages do begin to emerge: the courts’ apparent preference for certainty in diagnosis and prognosis provide pointers for how cases might be decided. https://goo.gl/5S5GWu

Related

- NEUROPSYCHOLOGICAL REHABILITATION | Online – 11 April 2017 – ‘Understanding the decision-making environment for people in minimally conscious state.’ Patients in minimally conscious state (MCS) show minimal, fluctuating, but definitive signs of awareness of themselves and their environments. They may exhibit behaviours ranging from the ability to track objects or people with their eyes, to the making of simple choices which requires the ability to recognise objects and follow simple commands. While patients with MCS have higher chances of further recovery than people in vegetative states, this is not guaranteed and their prognosis is fundamentally uncertain. https://goo.gl/de5t0M

Noted in Media Watch 2 January 2017, #493 (p.15):

- JOURNAL OF MEDICAL ETHICS | Online – 16 December 2016 – ‘A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness.’ Best interests decision-making and end-of-life care for patients in permanent vegetative or minimally conscious states is a complex area of clinical and legal practice, which is poorly understood by most clinicians, lawyers and members of the public. The Oxford Shrieval lecture by Mr. Justice Baker … has sparked debate on the respective roles of clinicians, and in the U.K. the Court of Protection and the Mental Capacity Act 2005 in decisions to withhold or withdraw life-sustaining treatments from patients with disorders of consciousness. https://goo.gl/UQcVVi


End-of-life care in England

“Our 24-hour palliative care hub offers a single point of access”

NURSING STANDARD, 2017;31(33):22-25. The need for coordinated, seven-day end-of-life care in north Manchester was evident from the statistics. Deaths in hospital were higher than the national and regional average. In 40% of cases, there was no medical need for the patient to be in hospital in the first place, and research showed 73% of patients would prefer to die at home. Furthermore, 70% of patients felt they were not getting enough support, often resulting in a hospital admission. https://goo.gl/SZUkFb

Noted in Media Watch 21 March 2016, #454 (p.6):

- U.K. | The Daily Express – 18 March 2016 – ‘Bill calling for access to 24-hour palliative care support reaches Commons.’ The Access to Palliative Care Bill [awaiting second reading in the House of Lords] to make sure no one should experience “poor or indifferent” care when they are dying has been given the green light by the House of Lords and will be introduced to the MP in the commons. http://goo.gl/tjANzA
Paediatric palliative care in England

GPs urged to improve care for terminally ill children

ONMEDICA | Online – 18 April 2017 – GPs should ensure that specialist care and support is made available to children in England who are terminally ill and their families, according to new draft guidance published today by the National Institute for Health & Excellence (NICE).¹ NICE’s draft quality standard on end-of-life care for infants, children and young adults ... recommends that terminally ill children should have access to around-the-clock homecare and their families should have 24-hour access to specialist medical support and advice. NICE said that estimates suggest there are around 40,000 terminally ill children and young people in England and research has said that 68% of families would prefer to spend their final days together at home. NICE says families caring for a terminally ill child should be supported so that the child can receive the right care in the environment of their choice, so that they can enjoy the highest quality of life possible. It says that service providers (such as GPs, hospitals, hospices and district nursing services) should ensure that systems are in place for infants, children and young people with a life-limiting condition to have a named medical specialist who coordinates their care. GPs and other health providers should also make sure that the care of these children is discussed and coordinated with their named medical specialist while children should have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care. In addition, GPs should ensure that systems are in place for terminally ill children to be involved in developing an advance care plan.

https://goo.gl/sBrZfP


Pediatric end-of-life care barriers and facilitators: Perception of nursing professionals in Jordan

INDDIAN JOURNAL OF PALLiative CARE, 2017;23(2); 199-206. The authors of this study concluded that the greatest barrier ... to providing pediatric end-of-life care (EoLC) ... was dealing with an angry family member. In addition, multiple physicians involved in the care of one patient who differ in opinion about the direction of care was rated as the greatest barrier related to healthcare professionals ... and, no available support person for the family such as a social worker or religious leader was rated as the greatest organizational-related barrier. Furthermore, having family members accept that the pediatric patient is dying was rated as the greatest facilitator related to patient-family... As well, physicians agreement about the direction of pediatric EoLC was rated as the greatest facilitator related to healthcare professionals. The greatest facilitating factor dealing with organization support was allowing family members adequate time to be alone with a pediatric patient after he or she has died. https://goo.gl/K5SH8X

Emergency department staff priorities for improving palliative care provision for older people: A qualitative study

PALLIATIVE MEDICINE | Online – 21 April 2017 – Emergency department-based palliative care (PC) services are increasing, but research to develop these services rarely includes input from emergency clinicians, jeopardizing the effectiveness of subsequent PC interventions. In-depth interviews with 15 emergency clinicians (nurses and doctors) at a large teaching hospital emergency department in the U.K. exploring experiences of PC delivery for older people. Eight challenges emerged: 1) Patient age; 2) Access to information; 3) Communication with patients, family members, and clinicians; 4) Understanding of PC; 5) Role uncertainty; 6) Complex systems and processes; 7) Time constraints; and, 8) Limited training and education. Clinicians selected four challenges as improvement priorities: 1) Time constraints; 2) Communication and information; 3) Systems and processes; and, 4) Understanding of PC. As resulting improvement plans evolved, “training and education” replaced “time constraints” as a priority. Clinician priorities for improving emergency department-based PC were identified through collaborative, iterative processes. Though generally aware of older palliative patients’ needs, clinicians struggled to provide high-quality care due to a range of complex factors. https://goo.gl/wwPgUR
Clinician views of patient decisional conflict when deciding between dialysis and conservative management: Qualitative findings from the PAlliative Care in chronic Kidney diSease study

PALLIATIVE MEDICINE | Online – 18 April 2017 – As part of the wider National Institute for Health Research, PAlliative Care in chronic Kidney diSease study, interviews were conducted with clinicians across 10 renal centres in the U.K. Three major themes with associated sub-themes were identified. The first, ‘Frequent changing of mind regarding treatment options,’ revealed how patients frequently altered their treatment decisions, some refusing to make a decision until deterioration occurred. The second theme, ‘Obligatory beneficence,’ included clinicians helping patients to make informed decisions where outcomes were uncertain. In weighing up risks and benefits, and the impact on patients, clinicians sometimes withheld information they thought might cause concern. Finally, ‘Intricacy of the decision’ uncovered clinicians’ views on the momentous and brave decision to be made. They also acknowledged the risks associated with this complex decision in giving prognostic information which might be inaccurate. Findings identify decisional conflict in patient decision-making and a tension between the prerequisite for shared decision-making and current clinical practice. Clinicians also face conflict when discussing treatment options due to uncertainty in equipoise between treatments and how much information should be shared. The findings are likely to resonate across countries outside the U.K. https://goo.gl/s9da08

Noted in Media Watch 17 April 2017, #508 (p.8):

- CURRENT OPINION IN NEPHROLOGY & HYPERTENSION | Online – 7 April 2017 – ‘Palliative and end-of-life care in nephrology: Moving from observations to interventions.’ In comparison with patients who have other serious illnesses, patients with advanced kidney disease have a higher rate of intensive care utilization at the end of life (EoL) and receive palliative care (PC) less frequently. Consensus and clinical practice guidelines have therefore recommended the incorporation of PC earlier in the disease trajectory. This review summarizes recent literature on this aspect of care and will highlight future directions for patient-centered care within palliative nephrology. https://goo.gl/QGfH50


Social workers’ experiences as the family support person during cardiopulmonary resuscitation attempts

SOCIAL WORK IN HEALTH CARE | Online – 11 April 2017 – During in-hospital cardiopulmonary resuscitation attempts, a designated family support person (FSP) may provide guidance and support to family members. Research on nurses and chaplains in this role has been published. Social workers also regularly fulfill this service, however, little is known about how they perceive and enact this role. To explore their experiences, qualitative interviews were conducted with FSP social workers. Analysis identified five themes: 1) Walking in cold; 2) Promoting family presence; 3) Responding to the whole spectrum of grief; 4) Going beyond the family support role; and, 5) Repercussions of bearing witness. Social workers perform a variety of tasks to promote family presence during resuscitation attempts and provide psychosocial support over the continuum of care. The FSP role impacts social workers emotionally and professionally. Implications for hospital policy, staffing, and clinical practice are discussed. https://goo.gl/2BcvLK

Assisted (or facilitated) death

BIOETHICS | Online – 17 April 2017 – ‘Assisted dying and disability.’ This article explores at least two dominant critiques of assisted dying from a disability rights perspective. In spite of these critiques, the author concludes that assisted dying ought to be permissible. He arrives at the conclusion that if we respect and value people with disabilities, we ought to permit assisted dying. https://goo.gl/DK5DTc
Worth Repeating

Misunderstandings about prognosis: An approach for palliative care consultants when the patient does not seem to understand what was said

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 December 2012 – Called in after discussions about prognosis between referring clinicians and patients, palliative care (PC) consultants sometimes find that the patient does not seem to understand what the referring clinician believes he or she explained. However, holding a more explicit discussion about prognosis may compromise the PC clinician’s rapport with both the patient and the referring clinician. The authors, therefore, propose a two-part approach to explore apparent prognostic misunderstandings: first, generate a differential diagnosis for why the patient and referring clinician have different reports of what was said, and second, cultivate a partnership with the referring clinician to provide a unified patient care plan. [Noted in Media Watch 17 December 2012, #284 (p.8)]

https://goo.gl/9YeMxE

Media Watch: Online

International
INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/j46LpJ
INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPqZ5
PALLIATIVE CARE NETWORK COMMUNITY: http://goo.gl/8JyLmE
PALLIMED: http://goo.gl/7mrqMQ [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): https://goo.gl/JL3j3C

Canada
ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): https://goo.gl/lOSNC7

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/5d1l9K
U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

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