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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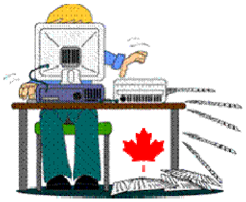

Compiled & Annotated by Barry R. Ashpole

Issues in end-of-life care: Scroll down to Specialist Publications and '"They shouldn't be coming to the ED, should they?" A qualitative study of why patients with palliative care needs present to the emergency department' (p.10), in *BMJ Supportive & Palliative Care*.

Canada

More funding devoted to treating cancers with PR campaigns than those with higher death rates: Study

THE NATIONAL POST | Online – 12 May 2016 – Researchers from Queen's University uncovered jarring gaps between how much research is devoted to individual cancers and the actual toll each disease takes — suggesting a clear edge for those backstopped by powerful marketing, and a handicap for cancers with a stigma of personal blame.[1] Lung malignancies, for instance, account for four out of every 10 Canadians who die from cancer – yet just 15 % of North American clinical trials focus on the disease, they found. And the amount of research carried out in each area seems closely aligned to how much money is poured into that cancer, concluded the Queen's study. Charities and government funders stress that the fundraising and scientific triumphs of cancers like breast and prostate are something to celebrate, but say they do want to address the apparent disparities. Not everyone, though, accepts that resources are in some way misaligned. As a whole, oncology research receives about $500 million yearly in Canada from a combination of government and private-sector sources. To determine how resources are distributed, the Queen's team looked at the number of North American research papers and clinical-trial results published in 2013 for the 10 most lethal cancers, and how much funding each cancer received. The extent of the disparities "was quite striking," says Dr. Chris Booth, a medical oncologist and Canada research chair in cancer population care, who led the study. "There were huge differences." http://goo.gl/xwuZkN

Research funding and cancer death tolls

- Lung: 40.5% of cancer deaths; 16% of clinical trials; 12% of funding
- Colorectal: 13.5% deaths; 5.7% trials; 11.4% funding
- Breast: 10% deaths; 30% trials; 41% funding
- Pancreas: 10% deaths; 5.0% trials; 6.0% funding
- Prostate: 7.6% deaths; 17% trials; 20.5% funding
- Gastroesophageal: 6.7% deaths; 3.3% trials; 2.0% funding
- Bladder: 4.0% deaths; 3.8% trials; 0.7% funding
- Kidney: 3.5% deaths; 6.8% trials; 2.2% funding
- Melanoma: 2.4% deaths; 8.4% trials; 3% funding
- Uterine: 2.0% deaths; 3.3% trials; 1.0% funding

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1. 'Research output and the public health burden of cancer: Is there any relationship?' *Current Oncology*, 2016;23(2):75-80. http://goo.gl/QwDRTv

Open visitation policy will help patients and families, advisor says

SASKATCHEWAN | *The Saskatoon Star Phoenix* – 11 October 2016 – Saskatchewan will now be the first province to take a provincial approach to an open family presence policy in health care facilities, Health Minister Dustin Duncan announced... He hopes all health regions will have the policy in place by the end of the year... Allowing patients to designate one or more family members as partners in care who have unrestricted access to their loved one during hospitalization can improve patient outcomes, according to the Canadian Foundation for Healthcare Improvement.[1] Such policies lead to better coordination of care, fewer medication errors, fewer falls, fewer 30-day readmissions and a better patient and family experience, the foundation says. Open visitation has already been established in pediatrics, critical care, long term care and palliative care units in the Saskatoon Health Region... http://goo.gl/dLgoHe

1. 'Better together: Partnering with families e-collaborative prospectus,' Canadian Foundation for Healthcare Improvement. http://goo.gl/IS0nrU

Palliative care is not about dying, but quality of living

THE TORONTO STAR | Online – 9 May 2016 – At a time when assisted dying dominates discussion about end-of-life care, it's important to address public fears around palliative care (PC) so that people can use the information to improve their quality of life. PC is not what happens when all treatments have failed. It does not mean "giving up" or "stopping the fight." If you are fighting cancer or Lou Gehrig's disease, PC means a team of people – doctors, nurses, social workers and others – will help make sure you have what you need to continue fighting. There is now very clear evidence that people who receive specialized PC actually live longer than those who do not. This is why it's so important to understand that PC is not about giving up – far from it. It's about living the very best you can for as long as you do. PC should be provided by family doctors, specialists and many other health care professionals who are already treating people for disease. This includes basic symptom management, emotional and mental health support and the ability to discuss advance care planning and goals of care. For a person who has complex PC needs, specialized PC clinicians are needed. If you or your family member is living with a serious life-limiting illness, don't fear speaking up and requesting a referral to PC. https://goo.gl/Z6GHmZ

Specialist Publications

'Exploring barriers to and enablers of adequate healthcare for indigenous Australian prisoners with cancer: A scoping review drawing on evidence from Australia, Canada and the U.S.' (p.10), in *Health & Justice.*

'Palliating inside the lines: The effects of borders and boundaries on palliative care in rural Canada' (p.18), in *Social Science & Medicine.*

Assisted (or facilitated) death

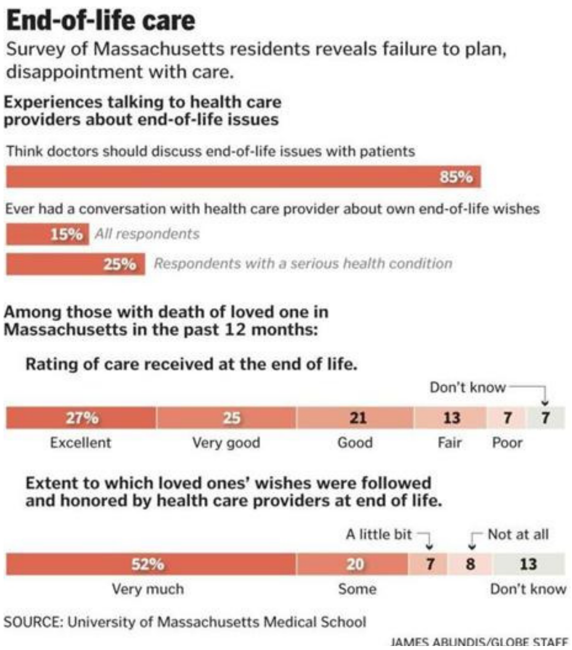
Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 12 May 2016 – **'Liberals to face Senate on assisted-dying bill.'** The Liberals are facing their first showdown with a more independent Red Chamber, with senators preparing to recommend their own batch of changes to the government's doctor-assisted dying bill as the Supreme Court of Canada's 6 June deadline looms. The government hopes to pass Bill C-14 in the House of Commons next week, after a parliamentary committee made a handful of minor amendments to the legislation without significantly altering who will be eligible for doctor-assisted dying in Canada. The Senate's legal and constitutional affairs committee, which heard from 66 witnesses during its week-long pre-study of the bill, will also present recommendations for the House to consider next week. If it passes in the House, as expected, the bill will then make its way to the Senate to continue the legislative process. http://goo.gl/uIMr8p

U.S.A.

When you die, will your wishes be known?

MASSACHUSETTS | *The Boston Globe* – 12 May 2016 – When hundreds of Massachusetts residents were asked about end-of-life medical care, the results of a survey [by the Massachusetts Coalition for Serious Illness Care] revealed widespread failure by doctors and patients to prepare for illness and death. Consider: One-third of people with a relative who had died recently said that medical professionals did not fully carry out the dying person's wishes, according to the survey. The telephone survey, of a representative group of 1,851 Massachusetts residents between 8 March and 13 April found that one in five rated their loved one's end-of-life care as fair or poor. The findings also suggest why the final days can be marked by turmoil and misunderstanding: a lack of planning and communication, by doctors as well as patients. Eighty-five percent of the respondents said doctors should discuss end-of-life wishes with patients, but only 15% had ever had such a discussion with a medical provider. Even among those with a serious illness, only 25% had talked about their wishes. Fifty-five percent had failed to name a representative who would make health care decisions if they were incapacitated. https://goo.gl/JXzWiQ



End-of-life care

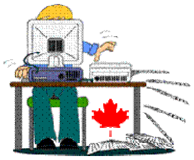
Survey of Massachusetts residents reveals failure to plan, disappointment with care.

SOURCE: University of Massachusetts Medical School

JAMES ABUNDIS/GLOBE STAFF

Related

- MASSACHUSETTS | *The Boston Globe* – 13 May 2016 – **'New coalition confronts fear, distrust in end-of-life care.'** The first question from the audience cast a spotlight on a big challenge facing a new group trying to improve end-of-life care. Were financial incentives "driving the train," asked Susan Fendell, senior attorney with the Mental Health Legal Advisors Committee. Her question to the Massachusetts Coalition for Serious Illness Care, midway through its inaugural meeting ... went to the heart of the fear and distrust that has often made it so hard for people to talk about their goals and preferences. https://goo.gl/eqjDa2



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

Americans' estimates of long-term care costs are wildly off

FORBES | Online – 10 May 2016 – Here's a stunner: The average American underestimates the cost of in-home long-term care by almost 50%. That's just one of the surprising, if frightening, findings in the Genworth 2016 Cost of Care Study...[1] What's more, Genworth found, four out of five adults underestimate the costs of home health care in general. Home health care happens to be the most popular long-term care option – compared to institutional nursing homes and assisted living facilities. Nearly a third of Americans (30%) believe home health care expenses are under $417 a month, but according to Genworth's number-crunching, the national median rate is about nine times that: $3,861 per month for an in-home aide or $3,813 per month for homemaker care (that's hiring someone to handle household tasks such as cooking, cleaning and running errands). Genworth assumes 44 hours a week of home care in its calculations. http://goo.gl/3aJ4Y8

Specialist Publications

'A national study of live hospice discharges between 2000 and 2012' (p.12), in *Journal of Palliative Medicine.*

'Starting and sustaining palliative care in public hospitals: Lessons learned from a state-wide initiative' (p.12), in *Journal of Palliative Medicine.*

'Hospice use, hospitalization, and Medicare spending at the end of life' (p.12), in *The Journals of Gerontology: Series B.*

'Where cancer care falls short, according to patients' (p.13), in *Medscape Medical News.*

1. 'Compare Long Term Care Costs Across the U.S.,' Genworth 2016 Cost of Care Study, May 2016. https://goo.gl/Mok18M

Related

- *FORTUNE* | Online – 9 May 2016- **'These are the best (and worst) states to grow old.'** A new study ... finds that South Dakota is actually the best state in which to grow old, thanks to its quality care for aging citizens – and the below-average cost of that care.[1] Northern states, in fact, had a remarkably strong showing, with three Upper Midwest states sweeping the top three spots. http://goo.gl/ht3sI6

    1. 'The 10 best states to grow old in,' Caring.com, May 2016. https://goo.gl/2yKLY9

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Los Angeles Times* – 9 May 2016 – **'Will hospitals reject California's assisted suicide law?'** Medical leaders at Huntington Hospital in Pasadena voted behind closed doors this week for the facility's hundreds of doctors and affiliated personnel to opt out of California's assisted suicide law, which goes into effect 9 June. If the proposed amendment to the hospital's medical rules is approved by the board of directors this month, Huntington will become one of the largest non-religious medical institutions state-wide to turn its back on a law... The End of Life Option Act allows doctors, medical groups and hospitals to opt out of the law's guidelines for assisting the terminally ill achieve a dignified end. Most, if not all, religious hospitals are expected to reject the law. http://goo.gl/3GidAT

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.17.

International

Transitions in care settings in England

Ombudsman: Patients sent home afraid and with little support

U.K. (England) | BBC News – 11 May 2016 – National Health Service (NHS) patients in England are being sent home from hospital afraid and with little support, an ombudsman report reveals.[1] The independent arbitrator investigated 211 such complaints in a year. The NHS says the findings will be taken seriously and improvement is under way. The report shows some of the most vulnerable patients, including frail and elderly people, are enduring harrowing ordeals when they leave hospital. And poor planning, co-ordination and communication between hospital staff and between health and social care services are failing patients, compromising their safety and dignity. http://goo.gl/4HQRZ6

1. 'A report of investigations into unsafe discharge from hospital,' Parliamentary & Health Service Ombudsman, May 2016. http://goo.gl/eZ3a1q

Specialist Publications

'Comparing palliative care in care homes across Europe (PACE): Protocol of a cross-sectional study of deceased residents in 6 European Union countries' (p.11), in *Journal of American Medical Directors Association.*

'Possible directions for palliative care research in Africa' (p.15), in *Palliative Medicine.*

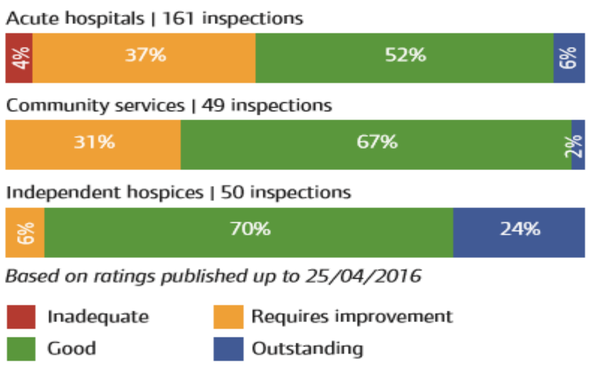
'Institution of the health care agent in Polish legislation: Position of the Polish Working Group on End-of-Life Ethics' (p.16), in *Polish Archives of Internal Medicine.*

End-of-life care in England

Action is needed to address inequalities in end-of-life care

NATIONAL INSTITUTE FOR HEALTH & CARE EXCELLENCE (NICE) | Online – 9 March 2016 – Failure to recognise individuals' needs means patients are receiving poor quality end-of-life care (EOLC), a highly critical report by the Care Quality Commission (CQC) has found.[1] Elderly patients are being kept in hospital for their final days despite many preferring to die at home or in a hospice, and patients diagnosed with a mental health problem or dementia are not receiving the individualised care they need, the CQC found. NICE guidance on EOLC highlights the need for healthcare professionals to recognise when a person is entering their final days of life.[2] The recommendations aim to support medical and social care staff so that they can provide their patients with care that is tailored to their needs and desires. https://goo.gl/mZI0iu

FIGURE 1: OVERALL END OF LIFE CARE INSPECTION RATINGS, BY SECTOR



Note: Figures may not add up to 100% due to rounding
Source: CQC. Data is up to 25 April 2016

1. 'A different ending: Addressing inequalities in end of life care,' Care Quality Commission, May 2016. http://goo.gl/qbOL09
2. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. [Noted in Media Watch, 21 December 2015, #441 (p.7)] https://goo.gl/W7cMmj

Cont.

Related

- U.K. | The Guardian – 13 May 2016 – **'Palliative care for children should not be a bewildering lottery.'** Across the U.K., babies, children and young adults with life-shortening conditions and their families not only face enormous physical, emotional and social difficulties, but also the bewildering inconsistency and complexity of palliative and specialist care provision and its commissioning. The often discussed postcode lottery affecting healthcare provision doesn't stop with location; there is also a lottery around age and complexity of condition. http://goo.gl/k1tZQZ

- U.K. (England) | Community Care – 9 May 2016 – **'CQC to start assessing adult social care's contribution to equal end-of-life care.'** The Care Quality Commission plans to start assessing the quality and equality of end-of-life care provided by adult social care services. The move follows a review that found some groups of people get poorer quality care at the end of their lives because health and care services do not understand or fully consider their needs. These groups include ethnic minorities, the homeless, the frail, prisoners, and people with mental health conditions, dementia or learning disabilities. http://goo.gl/xfvG3I

- U.K. (England) | *The Northern Echo* (High Wycombe, Buckinghamshire) – 8 May 2016 – **'Hospice forced to stop end-of-life care provision due to funding cuts.'** A respected hospice charity is to stop its at-home end-of -life care provision after National Health Service funding cuts made the service too expensive. The trustees of the charity said they had carried out a review of its service and aim to offer a wider range of palliative care and bereavement services to more patients in Richmondshire and Hambleton – but that regretfully it would mean the end to some services. http://goo.gl/huLJDd

- U.K. (England) | Community Care – 7 May 2016 – **'Care Act "failing to deliver" as carers face long waits for assessments.'** An "alarming" number of carers of people with end-of-life conditions are facing long delays in getting assessed for support under the Care Act 2014, a report has warned.[1] A survey of more than 6,000 carers carried out by Carers UK revealed nearly a third (29%) of all carers who'd been offered a carer's assessment, or requested one, waited at least six months to be seen. The percentage was higher (39%) for those supporting people who had a palliative or end-of-life condition, a finding the charity described as "alarming."

    1. 'State of Caring 2016,' Carers UK, May 2016. http://goo.gl/yx1e4V

- U.K. (England) | *The Daily Telegraph* – 7 May 2016 – **'"Unacceptable failures" in end-of-life care at nights and weekends, report finds.'** Hospitals are abandoning dying patients at nights and weekends, with "unacceptable" failures by the National Health Service (NHS) to provide proper end-of-life care around the clock, experts say.[1] The warning was issued by a coalition of doctors and charities as figures showed just one in ten NHS hospitals offers expert care to the dying on a 24/7 basis. Heads of the Royal College of Physicians, Marie Curie and the Association of Palliative Medicine said far more needed to be done to ensure that those facing death were given the comfort, support and pain relief they needed. http://goo.gl/8ocqjn

    1. 'End of Life Care Audit – Dying in Hospital National report for England 2016,' Royal College of Physicians, May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.6)] https://goo.gl/x2qSih

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Anticipatory grief: A mere concept?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2016;33(5):417-420. Anticipatory grief (AG) has been studied, debated, and written about for several decades. This type of grief is also recognized in hospice and palliative care (HPC). The question, however, is whether the reality of AG is sufficiently upheld by professionals at the point of concrete service delivery. In other words, is AG a mere concept or is everyday practice of HPC duly informed of AG as evidenced by the resulting care delivery? http://goo.gl/fsKCnN

Cont.

Selected articles on anticipatory grief

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 May 2016 – **'Family anticipatory grief: An integrative literature review.'** Ten themes emerged: 1) Anticipation of death; 2) Emotional distress; 3) Intrapsychic and interpersonal protection; 4) Exclusive focus on the patient care; 5) Hope; 6) Ambivalence; 7) Personal losses; 8) Relational losses; 9) End-of-life relational tasks; and, 10) Transition. [Noted in Media Watch, 9 May 2016, #461 (p.8)] http://goo.gl/70JqZA

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(1):15-19. **'Anticipatory grief: An evidence-based approach.'** This article reviews the concept of anticipatory grief, explores various assessment tools, and offers communication-based management strategies. Key nursing implications are also discussed. [Noted in Media Watch, 11 January 2016, #444 (p.10)] http://goo.gl/fECilt

- *CLINICAL PSYCHOLOGY REVIEW* | Online – 8 January 2016 – **'Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement.'** Anticipatory grief has been suggested to be grief work before the loss, which would improve bereavement outcome, but recent studies indicate a negative impact. [Noted in Media Watch, 18 January 2016, #445 (p.8)] http://goo.gl/kyj7hz

Palliative care and surgical training: Are we being trained to be unprepared?

ANNALS OF SURGERY | Online – 9 May 2016 – The current system for educating surgical trainees enjoys well-deserved acclaim for producing thoughtful and technically skilled individuals, but continues to inadequately prepare and train young surgeons to care for seriously ill and dying patients. Accordingly, a dramatic change to structure palliative and end-of-life care into surgical training and the willingness of practicing surgeons to actively participate in this care are essential. A focus on trainees will yield a generation of surgeons empowered to shift the culture of surgery away from a cure-focused model towards a more patient-centered stance. http://goo.gl/YjIC36

N.B. Click on 'Article as PDF' to access full text.

Ethical priority setting for universal health coverage: Challenges in deciding upon fair distribution of health services

BMC MEDICINE | Online – 11 May 2016 – Priority setting is inevitable on the path towards universal health coverage. All countries experience a gap between their population's health needs and what is economically feasible for governments to provide. Can priority setting ever be fair and ethically acceptable? Fairness requires that unmet health needs be addressed, but in a fair order. Three criteria for priority setting are widely accepted among ethicists: cost-effectiveness, priority to the worse-off, and financial risk protection. Thus, a fair health system will expand coverage for cost-effective services and give extra priority to those benefiting the worse-off, whilst at the same time providing high financial risk protection. It is considered unacceptable to treat people differently according to their gender, race, ethnicity, religion, sexual orientation, social status, or place of residence. Inequalities in health outcomes associated with such personal characteristics are therefore unfair and should be minimized. This commentary also discusses a third group of contested criteria, including rare diseases, small health benefits, age, and personal responsibility for health, subsequently rejecting them. http://goo.gl/ZTQvkm

Why population health and palliative care need each other

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 12 May 2016 – Two evolving disciplines in medicine have brought new ways of thinking about health and disease. One is palliative care (PC), which focuses on improving the quality of life of patients with serious illnesses and their families. A second is population health, which focuses on improving the health of populations, with a special emphasis on reducing disparities in health outcomes and improving the value of health care. Although PC and population health are related, there has been limited discussion about how these two disciplines can support and complement each other. This synergy is key to improving the quality of care of frail older persons with chronic, life-limiting illnesses. The authors describe the potential synergies between these two disciplines and propose next steps to foster collaboration. http://goo.gl/aMEuXO

How integrated are neurology and palliative care services? Results of a multicentre mapping exercise

BMC NEUROLOGY | Online – 10 May 2016 – The mapping exercise was conducted in eight centres with neurology and palliative care (PC) services in the U.K. The data were provided by the respective neurology and specialist PC teams. Questions focused on: 1) Catchment and population served; 2) Service provision and staffing; and, 3) Integration and relationships. Centres varied in size of catchment areas (39-5,840 square miles) and population served (142,000-3,500,000). Neurology and specialist PC were often not co-terminus. Service provisions for neurology and specialist PC were also varied. This mapping exercise showed heterogeneity in service provision and integration between neurology and specialist PC services, which varied not only between sites but also between diseases. This highlights the need and opportunities for improved models of integration, which should be rigorously tested for effectiveness. https://goo.gl/qaAeO0

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 13 May 2016 – **'Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool (CSNAT).'** Twenty-four caregivers completed the study ... and identified the highest support priorities as "knowing what to expect in the future," "knowing who to contact if concerned," and "equipment to help care." The majority found that this assessment process adequately addressed their needs and gave them a sense of validation, reassurance, and empowerment. http://goo.gl/FUhMSl

Selected articles on palliative care for people living with progressive neurologic disease:

- *NEUROLOGY: CLINICAL PRACTICE* | Online – Accessed 8 February 2016 – **'Neurologists as primary palliative care providers.'** The authors present current knowledge and recommendations regarding communication tasks and practice approaches for neurologists as they practice primary palliative care, including discussing serious news, managing symptoms, aligning treatment with patient preferences, introducing end-of-life care, and using the multi-professional approach. [Noted in Media Watch, 15 February 2016, #449 (p.14)] http://goo.gl/PELgMq

- *PROGRESS IN PALLIATIVE CARE* | Online – 6 June 2015 – **'The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study.'** A qualitative approach was used, interviewing people with advanced amyotrophic lateral sclerosis/motor neurone disease, multiple sclerosis, Parkinson's disease, and multiple systems atrophy and their family carers to ascertain their particular needs. People with progressive disease have many, difficult and distressing symptoms: physical, including pain, movement issues, swallowing and speech problems, psychological, feelings of being abandoned and of anxiety and depression, social, of isolation, of being a burden and of financial issues, and spiritual, of loss of hope and the meaning of life as they approach death. [Noted in Media Watch, 15 June 2015, #414 (p.15)] http://goo.gl/FNyMiT

- *MEDSCAPE MEDICAL NEWS* | Online – 3 June 2014 – **'New European consensus on palliative care in neuro disease.'** A consensus paper for palliative care (PC) for patients with progressive neurologic disease emphasizes the special needs of these patients and how neurologists and PC specialists can work together to fulfil them. The paper is the product of a joint effort of the European Federation of Neurological Societies and the European Association for Palliative Care. [Noted in Media Watch, 9 June 2014, #361 (p.15)] http://goo.gl/1TAwqH

Sedation at the end of life: A nation-wide study in palliative care units in Austria

BMC PALLIATIVE CARE | Online – 14 May 2016 – To date this is the largest study on sedation at the end of life and provides preliminary insights into the prevalence of, and indications for, palliative sedation in Austria. It supports previous data which suggest that palliative sedation, when properly administered, is an appropriate therapeutic procedure that does not shorten the period of time from admission to a palliative care ward/mobile care team until death. In order to minimize variation and enhance safety in clinical practice, implementation of a nation-wide guideline for the use of palliative sedation will be developed in Austria. http://goo.gl/KwUo0v

A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective

BMC PALLIATIVE CARE | Online – 11 May 2016 – Considering the growing need of palliative care (PC) for older people, improving knowledge about PC principles and acquainting general PC skills of geriatricians and other health care professionals is of crucial importance. However, whilst there are good examples of close clinical working between the disciplines, e.g., multidisciplinary team working, there is very limited collaboration in education and policy. Limited understanding about what the other discipline offers, a lack of common practice and limited communication between disciplines and settings were considered as barriers for collaboration between PC and geriatric medicine. To this end, establishing more academic chairs is seen as a priority and would be an important facilitator for further education and development at the intersection of the two disciplines. This could also result in a better collaboration between and integration of PC and geriatric medicine. http://goo.gl/8cyuQq

Noted in Media Watch, 8 June 2015, #413 (p.11):

- *THE GERONTOLOGIST*, 2015;55(3):503-505. **'Guidance at the juncture of palliation and old age.'** Notwithstanding their expertise in caring for persons in the final decades of life, some gerontologists remain unfamiliar with the effective palliation of symptoms for older adults with life-limiting or chronic, debilitating conditions.)] http://goo.gl/7fJYeF

Noted in Media Watch, 3 Mar 2014, #347 (p.10):

- *JOURNAL OF GERIATRIC ONCOLOGY* | Online – 24 February 2014 – **'Cancer in the elderly: Is it time for palliative care in geriatric oncology?'** Elderly who need palliative care (PC) are frequently disregarded as individuals and may experience discrimination because of their age. PC for older patients relates particularly to multiple treatments for various conditions. http://goo.gl/bo4i2i

End-of-life care in Western Australia

A retrospective population based cohort study of access to specialist palliative care in the last year of life: Who is still missing out a decade on?

BMC PALLIATIVE CARE | Online – 10 May 2016 – Encouraging findings are reported for improving palliative care (PC) access in rural and remote areas. Importantly, we have also shown a small but significant increase in access to specialist PC services in Western Australia, specifically in patients dying with non-cancer conditions. However, while PC peak bodies continue to espouse that PC should be available to all who need it regardless of diagnosis, further work is needed. In particular, methods to evaluate improvements such as the authors present here are essential to document progress and are a first step in providing much needed evidence to support changes in funding and clinical practice to support PC for all. http://goo.gl/cUZr5M

Noted in Media Watch, 23 November 2015, #437 (p.13):

- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 16 November 2015 – **'Routine integration of palliative care: What will it take?'** A whole-of-system approach has been advocated, involving quality-improvement strategies that identify and respond to specific gaps in care, coupled with measures of achievement and accountability. Yet, even in systems without barriers to PC, there remain two clinical tasks that appear critical to its successful integration: 1) Recognition of the possibility (and need) for PC; and, 2) Sensitive communication. https://goo.gl/tazUHv

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. http://goo.gl/8JyLmE

“They shouldn’t be coming to the ED, should they?” A qualitative study of why patients with palliative care needs present to the emergency department

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 May 2016 – Across the developed world, there are concerns about “inappropriate” use of the emergency department (ED). Patients with palliative care needs frequently attend the ED. Previous studies define the “reason” for presentation as the “presenting symptom,” which ignores the perspectives of service users. This paper addresses an acknowledged gap in the literature, which fails to examine the decision-making process that brings patients to the ED. Five themes were identified about how and why emergency services were accessed: 1) Capacity for action; 2) Making sense of local services; 3) Making decisions to access emergency services; 4) Experience of emergency care; and, 5) Coping with change. All narratives captured concerns surrounding the complexity of services. Participants struggled to piece together the jigsaw of services, and were subsequently more likely to attend the ED. Differences between the ways that patients with chronic obstructive pulmonary disease and cancer accessed the ED were prominent. http://goo.gl/nTEq85

Noted in Media Watch, 29 February 2016, #451 (p.12):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 February 2016 – ‘**Why do adults with palliative care needs present to the emergency department? A narrative review of the literature.**’ Given the increasing emphasis on community-based provision of palliative care (PC) and the view that good dying should occur at home, it is unsurprising that policy in many countries has started focusing on preventing hospital admissions at the end of life. However, little attention has been paid to the role of the emergency department (ED) in this regard, despite the fact that a high proportion of hospital admissions among patients with PC needs originate in the ED. http://goo.gl/H2ko6X

Commence, continue, withhold or terminate? A systematic review of decision-making in out-of-hospital cardiac arrest

EUROPEAN JOURNAL OF EMERGENCY MEDICINE | Online – 4 May 2016 – This ... review identifies all research papers examining resuscitation providers’ perspectives on resuscitation decision-making for out-of-hospital cardiac arrest patients. Five themes were identified, describing factors informing resuscitation provider decision-making: 1) The arrest event; 2) Patient characteristics; 3) The resuscitation scene; 4) Resuscitation provider perspectives; and, 5) Medico-legal concerns. Established prognostic factors are generally considered important, but there is a lack of resuscitation provider consensus on other factors, indicating that decision-making is influenced by the perspective of resuscitation providers themselves. Resuscitation decision-making research typically draws conclusions from evaluation of cardiac arrest registry data or clinical notes, but these may not capture all salient factors. http://goo.gl/6kI6HV

Exploring barriers to and enablers of adequate healthcare for indigenous Australian prisoners with cancer: A scoping review drawing on evidence from Australia, Canada and the U.S.

HEALTH & JUSTICE | Online – 3 May 2016 – Prisoners are a group with complex needs and high levels of social disadvantage and exclusion. Indigenous Australians are overrepresented in the prison system and experience higher rates of cancer mortality. This review found a very small evidence base and no studies from Australia. Therefore a strong conclusion to be drawn from the limited data is that further rigorous, empirical research is needed to better elucidate how the barriers to adequate cancer care for prisoners may be identified and overcome, in Australia and internationally. In particular, the experiences of Indigenous prisoners with cancer are largely invisible in the research literature. The main themes identified here offer potential starting points for future research and policy development to better align access and service use with best practice for cancer care in Australia. http://goo.gl/UNX2O5

N.B. End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report can be downloaded at the Palliative Care Community Network website: http://goo.gl/qgd4hp ***BRA***

Attitudes toward palliative care and end of life issues: A prospective survey in patients with metastatic cancer

IRISH MEDICAL JOURNAL, 2016;109(4). Palliative care (PC) positively impacts patient outcomes, decreases hospital admissions and improves quality of life. Despite evidence, PC resources are reported as underutilised. This study evaluated patient attitudes towards PC. Sixty percent [of study participants] believed PC can make people "feel better." 63.4% believed PC is offered when nothing more can be done. Most were unsure or disagreed that opioids are addictive. Eighty percent reported symptom control is more important than prolonging life. Sixty-one percent strongly agreed or agreed that "losing hope makes people die sooner." Although PC was deemed beneficial, a significant relationship exists between familiarity with PC and thinking it's offered when "nothing more can be done." Lack of knowledge about opioids, preference for symptom control over life prolonging measures and the importance of hope were also emphasised. http://goo.gl/3t5I2K

Noted in Media Watch, 25 April 2016, #459 (p.):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 18 April 2016 – '**Perceptions of palliative care among patients with advanced cancer and their caregivers,**' There is a strong stigma attached to palliative care (PC), which may persist even after positive experiences with an early PC intervention. Education of the public, patients and health care providers is paramount if early integration of PC is to be successful. http://goo.gl/3V0xPd

Comparing palliative care in care homes across Europe (PACE): Protocol of a cross-sectional study of deceased residents in 6 European Union countries

JOURNAL OF AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 6 May 2016 – More and more people will live to a very old age in Europe and many of them will develop severe functional and cognitive deficiencies in the last years of life. The number of people dying in care homes after being admitted for a relatively short period is predicted to increase substantially. Hence, this study is timely and aims to optimally inform policy- and decision-makers at international but also at national and regional levels on the current state of affairs of dying in care homes and the possible benefits of different systems of care provision. Using the results of the six-country study,[1] the authors hope to provide important recommendations that can also apply to other countries with similar health and long-term care systems as those of the countries involved in PACE. The PACE methodology can also serve as a reference for other countries that wish to initiate large-scale representative end-of-life care research in these settings. http://goo.gl/NssNai

1. Belgium, Finland, Italy, the Netherlands, Poland, and the U.K.

Related

- *JOURNAL OF RESEARCH IN NURSING*, 2016;21(2):96-107. '**Electronic palliative care coordinating systems (EPaCCS) may not facilitate home deaths: A mixed methods evaluation of end of life care in two English counties.**' Results [of this study] challenge assumptions that EPaCCS facilitates increased home deaths... The implementation of an electronic tool is not enough on its own to ensure that advanced care wishes are available, as long-standing organisational and cultural issues, such as professionals working in silos and professional reluctance to have "end of life" discussions, also need to be addressed. http://goo.gl/WMwEv8

Media Watch: Back Issues – http://goo.gl/frPgZ5

IPCRC.NET International Palliative Care Resource Center

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

Starting and sustaining palliative care in public hospitals: Lessons learned from a state-wide initiative

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 May 2016 – Compared with private, not-for-profit hospitals, significantly fewer public hospitals report that they provide palliative care (PC) services for their patients. Because uninsured and underinsured patients largely depend on public hospitals for acute medical care, they therefore experience disparities in access to inpatient PC services. To address this disparity, the state-wide Spreading Palliative Care in Public Hospitals Initiative (SPCPHI) was established to help implement or expand inpatient PC services in all 17 of California's public acute care hospitals. PC programs in public hospitals must develop the necessary skills and staffing to meet the complex needs of vulnerable patients and their families. These programs face a variety of unique organizational and operational challenges such as limited and uncertain funding, limited access to hospital data and analytic support, and complex regulatory structures, which may hinder growth of PC in these systems. Experiences from the SPCPHI suggest that networking, technical assistance, and start-up funding are helpful to overcome these barriers and to develop high-quality, sustainable PC programs in public hospitals. http://goo.gl/wFZHiJ

Related

- *THE JOURNALS OF GERONTOLOGY: SERIES B* | Online – 10 May 2016 – **'Hospice use, hospitalization, and Medicare spending at the end of life.'** The Medicare hospice benefit was passed into law in 1982, with the goal of improving the quality of end-of-life care by providing palliative and support services for terminally ill patients during the final 6 months of life. Initially, hospices primarily served Medicare beneficiaries with cancer, but by 2008, non-cancer diagnoses accounted for 69% of all hospice users. In recent years, more older adults started using the benefit, increasing from 23% of Medicare decedents in 2000 to 44% in 2010. http://goo.gl/xsmgqb

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 May 2016 – **'A national study of live hospice discharges between 2000 and 2012.'** Live hospice discharges represent a potential vulnerability in the Medicare hospice benefit. Little is known about how live discharges have varied over time. The unadjusted overall rate of live discharges increased from 13.7% in 2000 to 18.1% in 2012. For-profit hospice programs had an adjusted live discharge rate of 17.7% in 2000 and 22.7% in 2012. During the same period, the adjusted live discharge rate for non-profit hospice programs increased from 15.2% to 16.3%. The overall rate of burdensome transitions increased from 2.9% in 2000 to 5.3% in 2012. Similar to the overall rate of live discharge, for-profit hospices had a higher rate of burdensome transitions (6.4%) than non-profit hospices (4.0%) in 2012. http://goo.gl/XvkzEU

Screening for intimacy concerns in a palliative care population: Findings from a pilot study

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 May 2016 – Pilot data from this quality improvement project suggest a clear need for intimacy assessment in palliative care (PC) consultation. Intimacy is impacted by serious illness and patients/partners want to discuss issues with clinicians. PC clinicians can incorporate intimacy discussions as part of a routine assessment without adding significant amount of time. Although the vast majority (96%) of patients [i.e., study participants] reported that they had not been asked about intimacy concerns before the PC consult, a slight majority (56.2%) reported that illness had either significantly or moderately impacted intimacy. http://goo.gl/2rTFZH

Selected articles on sexuality and intimacy in terminal illness

- *CURRENT ONCOLOGY REPORTS* | Online – 15 January 2016 – **'Communication about sexuality in advanced illness aligns with a palliative care approach to patient-centered care.'** Palliative care (PC) providers, while not expected to be sexual health experts, can provide comprehensive patient-centered care by including sexual health as part of their evaluation. Principles on addressing sexuality in the palliative setting and practical ways of incorporating sexual history into the PC assessment are provided. [Noted in Media Watch, 25 January 2016, #446 (p.11)] http://goo.gl/SshIrL

Cont.

- *PALLIATIVE MEDICINE* | Online – 21 January 2014 – **'Experiences of sexuality and intimacy in terminal illness: A phenomenological study.'** When someone is living with a life-limiting illness, their coupled relationship is also dying. In their being-towards-death-of-the-couple, patients and partners of patients experienced connecting and disconnecting within their coupled relationship. [Noted in Media Watch, 27 January 2014, #342 (p.16)] http://goo.gl/yUWWA6

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 March 2013 – **'An integrative review of sexual health issues in advanced incurable disease.'** The loss of sexual health can impact a person's overall quality of life and well-being. Studies regarding the sexual health of patients with life-limiting illnesses are generally narrative reviews, expert opinions, or exploratory in nature. [Noted in Media Watch, 1 April 2013, #299 (p.14)] http://goo.gl/fZyigf

The burnout syndrome in palliative home care workers: The role of coping strategies and meta-cognitive beliefs

MEDITERRANEAN JOURNAL OF CLINICAL PSYCHOLOGY, 2016;4(1):1-12. Healthcare professionals are daily confronted with events involving the suffering of others, which are likely to generate highly negative and stressful emotions. In palliative care (PC) the emotional commitment is exacerbated by the constant confrontation with the theme of suffering and death. The failure to successfully down-regulate negative emotions is a key risk factor for a severe form of discomfort, known as burnout syndrome. Burnout is a psychological state of exhaustion, related to stress at work. Recent studies have shown that healthcare worker coping strategies may function either as a risk or a protective factor for the development of distress and emotional problems. Furthermore, other studies highlighted the role of the dimensions of meta-cognition as vulnerability factors in predicting the development of psychological symptoms. The aim of this study is to examine and assess the relationships between burnout, coping strategies and meta-cognitive beliefs in workers involved in home PC. The hypothesis of the present work is that the appropriate use of positive and flexible coping strategies and functional meta-cognitive beliefs may relate to the management of distress and emotional problems. The results show the presence of a statistically significant correlation between the variables investigated. http://goo.gl/SKF4Pd

Where cancer care falls short, according to patients

MEDSCAPE MEDICAL NEWS | Online – 12 May 2016 – U.S. cancer patients want more information about their illness, treatment (options, benefits, and risks), clinical trials, insurance coverage, and where to get emotional, financial, and practical support, according to a new report from ... CancerCare.[1] The report reflects the perspectives of a diverse group of more than 3,000 cancer patients who completed surveys about their experience. "One very clear finding from several of our surveys is that while patients feel their clinical teams do an excellent job of caring for them medically, they aren't getting the information they need to make informed decisions about treatment," Ellen Sonet ... chief strategy and alliance officer for CancerCare ... told *Medscape Medical News*. About one third of respondents reported having inadequate information about the benefits, potential side effects, and the goals of their treatment plan. More than 80% said they did not have enough information about clinical trials. http://goo.gl/4kI5a9

Extract from CancerCare report

Familiarity with both palliative care (PC) and hospice correlated to respondent education levels. However, the survey revealed widespread misconceptions about each. Nearly half of the respondents believed paying for PC would be very expensive. About one fifth thought getting PC would mean they were giving up hope. Among respondents 25 to 54, nearly 40% feared becoming addicted to pain medicine, 28% said PC would delay their death, and 18% thought it would hasten death. With regard to hospice, 40% of respondents believed it would be very expensive, and only 40% of these respondents believed that PC would relieve a burden on their caregivers. Patients under 65 were significantly more likely to engage in conversations about hospice care with a clinical care team member than were those 65 and older.

1. 'The 2016 Patient Access and Engagement Report,' CancerCare, May 2016. http://goo.gl/6YXTj4

End-of-life care in Oman

Palliative care: Time for action

OMAN MEDICAL JOURNAL, 2016;31(3):161-163. Similar to other developing countries, Oman is encountering the challenge of a rising incidence of cancer due to an aging population and a higher prevalence of lifestyle-related risk factors. Despite the remarkable progress made in the health care services, palliative care (PC) services are still limited. The time has come now to strengthen the PC movement in Oman. This can only be achieved by exerting more efforts to convince policymakers about the enormous benefits of PC to the health care system as a whole. There should be attempts to integrate PC at every level of care, especially at the primary health care level to include home and community-based care. The community, clinical, and administrative leaders should be engaged to help them to identify the great need for PC. Efforts are also required to overcome known barriers, and to identify and overcome unique challenges in Oman. http://goo.gl/2SDTFF

Carers of people affected by cancer and other long-term conditions at end of life: A qualitative study of providing a bespoke package of support in a rural setting

PALLIATIVE MEDICINE | Online – 9 May 2016 – A U.K. charity, Macmillan Cancer Support funded a local intervention whereby carers of people affected by cancer and other long-term conditions at end-of-life are offered a bespoke package of support. This report describes the qualitative experiences of carers in receipt of the intervention. Five themes ... were identified: 1) Awareness and advertising; 2) Focus of support on the carer; 3) Modes of communication; 4) Personal attributes and skills of the support worker; and, 5) Streamlining and signposting. The intervention was successful within a social care setting. The participants had no overtly negative opinions on the service in its current format and all held it in high regard. Carers felt a sense of reassurance from having background support and maintained that their situation would have been worse had this support not been there. http://goo.gl/qBYBs

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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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.

Related

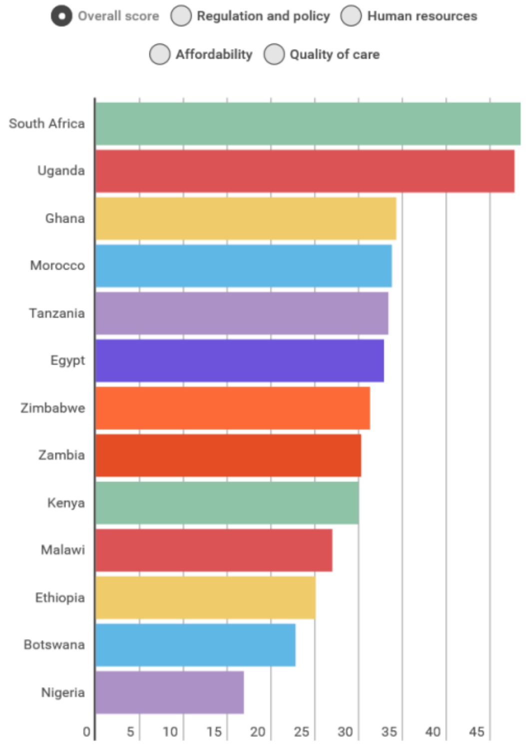
- *CHRONIC ILLNESS* | Online – 10 May 2016 – **'Worry and time: The unseen costs of informal care.'** Worry is a practice that most carers report engaging in and it is one that comes with a temporal cost – it keeps people busy looking after the needs of others during the day and it keeps some people awake when they would rather be sleeping. Worry takes time and effort, it informs people's construction of their own sense of self, motivates acts of care, and informs carers' imaginings of what their future and that of their loved one(s) may entail. http://goo.gl/G2aF70

- SPRINGEROPEN | Online – 14 May 2016 – **'The voices of family caregivers of seniors with chronic conditions: A window into their experience using a qualitative design.'** Caregivers identified barriers to resilience, including demands on their time, changing roles and responsibilities, challenges of learning about medical conditions, their own emotional responses, financial strains, changing family dynamics, and personal health. Caregivers also identified several facilitators to resilience, including motivations for caregiving, sense of purpose and validation, spirituality, emotional experiences, and coping strategies. http://goo.gl/cgvtmC

Possible directions for palliative care research in Africa

PALLIATIVE MEDICINE, 2016;30(6):517-519. The state of evidence for palliative care (PC) in Africa remains poor, but has been steadily increasing over the years, thereby increasing the body of knowledge in the region and the evidence base for better practice. The challenges associated with conducting PC research in Africa include lack of a research culture; lack of research skills and knowledge among health care professionals; professional isolation; lack of agreement on outcome measures, key definitions and concepts; a dearth of research funding; the absence of national strategies for PC research; and, the absence of a strategic research vision. The level of health care coverage remains low in Africa, access to PC limited and research systems poor. WHO recommends four strategies for strengthening research systems in health, also applicable to PC; these are subsequently discussed. http://goo.gl/TmSwI2

Quality of Death Index Infographic[1]



[1] '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, Commissioned by the Lien Foundation, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/VWQFuk

Related

- *PALLIATIVE MEDICINE* | Online – 13 May 2016 – **'A call for increased paediatric palliative care research: Identifying barriers.'** While current guidance emphasises the need to include children and young people (CYP), both those with good health and those with life-limiting conditions (LLCs) or life-threatening illnesses (LTIs) in decisions about health and health research, it is commonly accepted that this is not easily achieved in practice. Challenges faced by researchers aiming to recruit CYP with LLCs or LTIs and their families are numerous, including small sample sizes and limited funding as well as difficulties with research ethics committees, the unpredictable nature of the illnesses and society's perceptions of the potential physical and psychological burden for participants and their families. http://goo.gl/EVPHs5

Tidying rooms and tending hearts: An explorative, mixed-methods study of hospital cleaning staff's experiences with seriously ill and dying patients

PALLIATIVE MEDICINE | Online – 9 May 2016 – Palliative care is based on multi-professional team work. In this study, we investigated how cleaning staff communicate and interact with seriously ill and dying patients as well as how cleaning staff cope with the situation of death and dying. Cleaning staff described interactions with patients as an important and fulfilling aspect of their work. About half of participants indicated that patients talk with them every day, on average for 1-3 min. Conversations often revolved around casual topics such as weather and family, but patients also discussed their illness and, occasionally, thoughts regarding death with cleaning staff. When patients addressed illness and death, cleaning staff often felt uncomfortable and helpless. Cleaning staff perceive that they have an important role in the clinic – not only cleaning but also supporting patients. Likewise, patients appreciate being able to speak openly with cleaning staff. http://goo.gl/nN7IXr

Withholding information to protect a loved one

PEDIATRICS (American Academy of Pediatrics) | Online – Accessed 12 May 2016 – Parents respond to the death of a child in very different ways. Some parents may be violent or angry, some sad and tearful, some quiet and withdrawn, and some frankly delusional. The authors present a case in which a father's reaction to his daughter's death is a desire to protect his wife from the stressful information. The wife is in the second trimester of a high-risk pregnancy and so is particularly fragile. The authors asked pediatricians and bioethicists to discuss the ways in which they might respond to the father's understandable but troubling request. http://goo.gl/pSeS9v

Noted in Media Watch, 9 May 2016, #461 (p.15, under 'Worth Repeating'):

- *CLINICAL ETHICS*, 2008;3(1):42-45. **'The withholding of truth when counselling relatives of the critically ill: A rational defence.'** A strategy for the staged disclosure of information and the confirmation of hopelessness is described, the aim being to find a compromise between providing a true opinion about a patient's prognosis, and regard for the opposing factors described. http://goo.gl/IFMTB4

Institution of the health care agent in Polish legislation: Position of the Polish Working Group on End-of-Life Ethics

POLISH ARCHIVES OF INTERNAL MEDICINE | Online – 5 May 2016 – The paper aimed to prepare a draft proposal of legal regulations introducing into Polish legislation the institution of the health care agent. It has been grounded in 6 expertise workshops, in conjunction with several online debates. Statutory appointment of a health care agent allows every citizen to appoint in this capacity a person who, to the best of his or her knowledge, would best represent his or her interests in the event that the principal should ultimately lose the capacity to make medical decisions on his or her own behalf. http://goo.gl/b3SAI7

N.B. English language article

Communication in palliative care: Talking about the end of life, before the end of life

POSTGRADUATE MEDICAL JOURNAL | Online – 6 May 2016 – This review explores some of the many barriers faced by clinicians in relation to end-of-life care discussions, including prognostic uncertainty, fear of causing distress, navigating patient readiness and feeling unprepared for these conversations. The value of core clinical communication skills, potential strategies for improvement and areas for future research are also discussed. It is essential that clinicians offer patients facing life-threatening illness, and those close to them, the opportunity to discuss end-of-life issues in line with their information and decision-making preferences. With a growing and ageing global population, supporting both generalist and specialist providers of palliative care in this task is key. With careful preparation, fears of undertaking these discussions should not be a barrier to initiating them. http://goo.gl/i2WgNW

Cont.

Related

- *HEALTHCARE*, 2016;4(2):24. **'Ethical issues surrounding end-of-life care: A narrative review.'** Healthcare providers should take an initiative and discuss patient's goal for end-of-life care or palliative care, as their preferences can change from person to person. Some patients might target for cure or some for comfort care, hence this trustful communication can avoid the ethical crisis surrounding that topic. The stability of these health preference goals is another issue as it has a potentiality to change with illness. http://goo.gl/udHlVV

- *JOURNAL OF INTERPROFESSIONAL CARE*, 2016;30(3):397-400. **'Priming professionals for a complex communication environment: Findings from a pilot study.'** Factors such as time pressure, distractions, and profession-specific jargon can contribute to poor communication in complex working environments such as healthcare. Technical solutions are often sought to improve patient care when simple improvements in communication would suffice. This article describes an icebreaker activity, an interprofessional game, aimed to prime and engage experienced healthcare professionals on the topic of communication, specifically related to care transitions. http://goo.gl/Ta07mY

- *MEDITERRANEAN JOURNAL OF SOCIAL SCIENCES*, 2016;7(3):70-80. **'Communication as a component of the quality of life in the integrated care for the dying.'** In Slovenia, a half of all people still die at hospital or care institutions. This study shows that, according to community nurses' point of view, communication is a critical component of palliative care. Each component of "good death" depends primarily on the communication of all actors involved in the process. It greatly affects the quality of care and the quality of life of the dying and their family members. Apart from supporting the patient and family, communication helps build trust and is the foundation for overcoming obstacles and distractions, relieving the symptoms of advanced, incurable disease. http://goo.gl/8KjNiE

  N.B. Click on 'Full Text: PDF.'

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/0Q1Mh4

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

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

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

Asia

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

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

Canada

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

Europe

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

HUNGARY | Hungarian Hospice Foundation: http://goo.gl/5d1l9K

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

History, culture and traditions: The silent spaces in the study of spirituality at the end of life

RELIGIONS | Online – 9 May 2016 – This paper aims to demonstrate the absence of contextual factors in studying spirituality at the end of life and to highlight the growing recognition of the importance of history, culture and traditions as resources to enrich our understanding of spirituality. An exploration of the concept of spirituality, an overview of the trajectory of the study of spirituality, and a review of existing methodological stances reveal the silent space in current approaches to understanding spirituality at the end of life. http://goo.gl/IVoFJS

Related

- *JOURNAL OF RELIGION & HEALTH* | Online – 6 May 2016 – **'Prevalence and nature of spiritual distress among palliative care patients in India.'** This study describes the prevalence and nature of spiritual distress among Indian palliative care patients. Spirituality was shaped by the Indian religious and economic context. Analysis resulted in three clusters: 1) Trustful patients (46.4 %); 2) Spiritually distressed patients (17.4 %); and, 3) Patients clinging to divine support (36.2 %). These were found to be associated with pain scores, and educational level. http://goo.gl/GaeMoV

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

Palliating inside the lines: The effects of borders and boundaries on palliative care in rural Canada

SOCIAL SCIENCE & MEDICINE | Online – 7 May 2016 – Borders and boundaries can be used to define a variety of differing spaces such as the familial, social, economic, political, as well as issues of access – including access to health services. Despite the implicit connection between borders, boundaries, and health, little research has investigated this connection from a health geography perspective. This secondary thematic analysis contributes to addressing this notable gap by examining how borders and boundaries are experienced and perceived to impact access to palliative care (PC) in rural Canada from the perspectives of the formal and informal providers of such care. Drawing upon data from qualitative interviews with formal and informal palliative caregivers residing in four different rural Canadian communities, five forms of borders and boundaries were found to directly impact care delivery/receipt: 1) Political; 2) Jurisdictional; 3) Geographical; 4) Professional; and, 5) Cultural. Implicitly and explicitly, participants discussed these borders and boundaries while sharing their experiences of providing PC in rural Canada. http://goo.gl/9vyVH7

ROI RURAL ONTARIO INSTITUTE

'End-of-life care in rural communities.' http://goo.gl/WPJvBI

'National palliative medicine survey looks at urban versus rural.' http://goo.gl/GEJL4u

N.B. Noted in the 18 April 2016 issue of Media Watch, #459 (p.4), are additional articles on end-of-life care in rural communities and remote regions.

The importance of patient dignity in care at the end of life

THE ULSTER MEDICAL JOURNAL, 2016;85(1):45-48. Despite being viewed as an abstract concept, the importance of patient dignity in end-of life care (EOLC) cannot be denied. The author proposes that the concept of dignity may be likened to that of love – important, widely understood, difficult to define, and cannot be taught in a black-or-white manner. As dignity is subjectively experienced and each patient is unique in their requirements, it is important that healthcare professionals use an open approach to assess each patient's needs and aim to meet these accordingly, using discretion as to what is appropriate when providing care for patients of different ages, cultures and religions. Simple measures such as the Patient Dignity Question and life storytelling can help healthcare professionals view the patient receiving EOLC as a person; thereby helping them to promote patient dignity and address needs which would otherwise not be known. http://goo.gl/G5XCKT

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *NURSING ETHICS* | Online – 5 May 2016 – **'Nurses' attitudes towards euthanasia in conflict with professional ethical guidelines.'** Despite the significant role of nurses in end-of-life care, their attitudes towards euthanasia are under-represented both in the current literature and the controversial debate that is ongoing in several countries. The majority (74.3%) of the [survey] participants would accept euthanasia as part of Finnish healthcare, and 61.8% considered that Finland would benefit from a law permitting euthanasia. Most of the nurses (89.9%) thought that a person must have the right to decide on his or her own death; 77.4% of them considered it likely that they would themselves make a request for euthanasia in certain situations. http://goo.gl/yGvoqQ

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