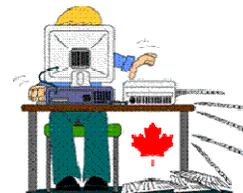


Media Watch...

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.

11 July 2016 Edition | Issue #470



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Compiled & Annotated by Barry R. Ashpole

Knowing death and being there: Scroll down to [U.S.A.](#) and 'A tender hand in the presence of death' (p.3), in *The New Yorker*.

[Canada](#)

Richmond County palliative care doctor pulls services, blames slow provincial action

NOVA SCOTIA | *The Cape Breton Post* (Sydney) – 7 July 2016 – Dr. Bob Martel ... will no longer provide acute palliative care (PC) services for the Strait-Richmond area as of 15 July. He will continue on caring for the six patients he currently has – two in hospital and four being cared for by family at home. Martel said there are too many gaps in service when it comes to end-of-life care in the rural, rapidly aging municipality. He said Richmond is one of three counties in the province without PC nursing services on weekday evenings and on weekends. Other than Martel working as a full-time PC doctor, he said medical PC consultations are only available from out-of-town physicians every three to four weeks. The level of service is not where it should be compared to other regions of the province, he said. There are other resources lacking such as a full-time social worker, dedicated field-based PC nurses, physicians and nurse practitioners, Martel said. It has resulted in Richmond

County having fewer home-based PC deaths “than virtually every other jurisdiction in Nova Scotia,” according to Martel. The province is in its second year of implementing the Nova Scotia PC strategy.¹ Responsibility for the strategy has been turned over to the Nova Scotia Health Authority from the Department of Health % Wellness. Provincial PC co-ordinator Cheryl Tschupruk admitted there are gaps in PC service, but the strategy is working to “build capacity” in a primary health-care setting. <http://goo.gl/hFjuic>

[Specialist Publications](#)

'Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care' (p.14), in *International Journal of Indigenous Health*.

1. 'Integrated Palliative Care: Planning for Action in Nova Scotia,' Nova Scotia Government, May 2014. [Noted in Media Watch, 12 May 2014, #357 (p.1)] <http://goo.gl/73p2x0>

[Media Watch: Online](#)

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

Canada needs to renegotiate health accord with provinces: Report

THE GLOBE & MAIL | Online – 6 July 2016 – A new report says the federal government should learn from past experience as it renegotiates the health accord with the provinces.^{1,2} The study from the C.D. Howe Institute says attempts to achieve health care reform by attaching strings to the money it gives to the provinces have been met with limited success. That's in part because the federal government has little influence over the way provincial and territorial governments respond to policy recommendations on matters inside their jurisdiction. The study was published as the Liberal government is negotiating a new accord after the previous Conservative government let the last one expire. The agreement between Ottawa and the provinces and territories will set shared goals for how billions in federal funds are spent on health care. Federal Health Minister Jane Philpott has said the government hopes to have an agreement in place by year's end. <http://goo.gl/YvQw43>

1. 'The Naylor Report & Health Policy: Canada Needs a New Model,' e-Brief, C.D. Howe Institute, 6 July 2016. <https://goo.gl/EEMt7W>
2. 'Unleashing Innovation: Report of the Advisory Panel on Healthcare Innovation' (widely referred to as the Naylor report after the Advisory Panel's Chair, David Naylor), Ministry of Health, Government of Canada, July 2015. [Noted in Media Watch, 27 July 2015, #420 (p.1)] <http://goo.gl/fSfMIG>

N.B. There is brief reference to home and long-term care in the Institute's e-Brief, but no mention of end-of-life care. The Naylor report, however, does acknowledge the need to strengthen palliative care (PC) resources and services across Canada; end-of-life care is mentioned on p.54 and referenced in Figure 6.2 (p.63). The federal government has indicated that home care and PC are priorities (see 'How much should Ottawa spend on health? It's complicated,' *The Globe & Mail*, 28 June 2016, noted in Media Watch, 4 July 2016, #469 (p.1). **BRA**

Program aims to standardize hospice programs

ONTARIO | Sudbury.com – 5 July 2016 – Northeastern Ontario's seven hospice volunteer visiting programs are leading an effort to develop performance indicators that would help improve the care they provide for patients and their families. The programs enlist volunteers who visit palliative patients in their homes and help provide them with end-of-life care. But they do not currently have identical measures in place to determine how well they are delivering that care. <https://goo.gl/ge6Mnb>

Noted in Media Watch, 28 March 2016, #455 (p.2):

- ONTARIO | *The Timmins Daily Press* – 20 March 2016 – '**Palliative care in Northeastern Ontario a patchwork of service levels.**' While there are a number of qualified health care providers in the area who specialize in palliative care treatments, there are limited outlets for patients to access these services. <http://goo.gl/VeUKZQ>

N.B. Noted in this issue of Media Watch are articles on access to hospice and palliative care unique to Northeastern Ontario.

Noted in Media Watch, 14 March 2016, #453 (p.2):

- ONTARIO | *The Ottawa Citizen* – 11 March 2016 – '**Numerous gaps in Ontario's system for palliative care, report finds.**' The way Ontario's health system cares for the dying is full of holes that need patching, Ottawa South Member of the Provincial Parliament John Fraser says in an official report the provincial government is to use as a guide to those fixes.¹ <http://goo.gl/GEFYP1>

1. 'Palliative & End-Of-Life Care Provincial Roundtable Report,' Ontario Minister of Health & Long-Term Care, March 2016. <http://goo.gl/eRyw8K>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News – 7 July 2016 – **‘More than 160 doctor-assisted deaths in Quebec since 2015.’** Since Quebec’s law allowing doctor-assisted death came into effect in December 2015, 253 Quebec patients have requested the procedure, and 166 have received it. Eighty-seven people who requested doctor-assisted death since December 2015 did not receive it... Of those 87, 16 changed their minds. <http://goo.gl/J8O7S1>
- *THE GLOBE & MAIL* | Online – 5 July 2016 – **‘Assisted-dying laws are only the beginning of the debate.’** On an emotion-laden issue such as this, passing a law does not end the debate – if anything, the arguments of opponents and proponents are amplified once there is legislation to pick apart. Perhaps most important, lesson is that a law has to be interpreted and implemented and that rarely happens in a seamless fashion. Some of the decisions that will impact patients most are made quietly in the backrooms. <http://goo.gl/MGEvxx>
- QUEBEC | *The Montreal Gazette* – 4 July 2016 – **‘McGill University Health Centre to allow medically assisted dying in palliative care unit.’** The Centre said ... it will change its policy and allow medically assisted dying in its palliative care (PC) unit after coming under fire from Health Minister Gaétan Barrette last week. <http://goo.gl/mTZ7Uq>
- THE CANADIAN PRESS | Online – 3 July 2016 – **‘Indigenous parliamentarians brought unique perspective to assisted dying debate.’** Despite the clamour from doctors, lawyers, religious groups and advocates for the disabled, the softer voices of indigenous parliamentarians were instrumental in shaping the government’s cautious approach to medical assistance in dying. <http://goo.gl/vliIFy>

U.S.A.

A tender hand in the presence of death

STATE OF NEW YORK | *The New Yorker* – 11 July 2016 – Heather [Meyerend, a hospice nurse] is not brisk or efficient, as nurses in hospitals are. She is purposely inefficient, in fact. Most of the time when she visits patients, she doesn’t have much to do: she takes vital signs, she checks that there are enough supplies and medications in the house, she asks if old symptoms have gone away or new ones developed. If she were rushing, she could do all that in about five minutes, but her visits usually last an hour or more. Sometimes there is a complicated medical situation to take care of. Sometimes she does something non-medical that needs to be done, which is the hospice way – she might sweep a floor, she might heat up dinner. But, even when there’s nothing else to do, the idea is to be around longer, to chat, to sit close by, to put her hands on the patient’s skin as she goes about her check-up. Her visit may be the high point of the day for the patient, who may not be able to get out of bed, or for whoever is taking care of the patient, who may not have left the house or seen anybody else for a day or two; either or

both of them may be going a little crazy and may badly need interruption or variety of any kind, ideally someone different to talk to. So Heather moves slowly; she sits down; she delays; she lingers. Dying can be long and bewildering, lonely and painful, frequently undignified, and consumed by pressing and unpredictable and constantly changing and multiplying needs. It’s a relief to have someone around who understands what’s going on and what may happen next. <http://goo.gl/Q9OjQx>

Specialist Publications

‘Hospice face-to-face recertification: Embracing the benefits and challenges’ (p.15), in *Journal of Hospice & Palliative Nursing*.

‘Live and let die: The consequences of Oklahoma’s Non-discrimination in Treatment Act’ (p.16), in *Oklahoma Law Review*.

Cont.

Related

- *THE NEW YORK TIMES* | Online – 2 July 2016 – ‘**Home care workers can finally claim victory.**’ The Supreme Court ensured that millions of working people would get fairer treatment when it decided last week not to consider *Home Care Association of America v. Weil*. That case was the last attempt by home care employers (mostly for-profit agencies) to avoid paying home care workers (mainly women of color) the minimum wage and overtime pay. By declining to hear the case, the court has confirmed that there is no legal rationale for denying basic labor protections to home care workers, who care for the elderly and disabled in the clients’ homes. <http://goo.gl/T6WKdS>

Advance planning for your end-of-life care

CALIFORNIA | Kaiser Health News – 7 July 2016 – Millions of Californians are newly eligible for a health care benefit that could determine the treatment they receive in their final days – and most don’t know it. Medi-Cal, which covers more than 13 million Californians, and Medicare, with more than 5 million California enrollees, now pay for “advance care planning” (ACP) discussions with doctors. ACP isn’t about long-term care options, such as nursing homes or assisted living. It’s about “your wishes for your care if you are not able to speak for yourself,” said Helen McNeal, executive director of the California State University Institute for Palliative Care. “If you’re incapacitated, if you need someone to speak for you, who do you want to speak for you? And what would be your medical wishes?”

she said. But many doctors and patients don’t yet realize that talking about these decisions – and possibly putting them into writing – is a covered benefit. <http://goo.gl/xjDapW>

Specialist Publications

‘**Failure of the current advance care planning paradigm: Advocating for a communications-based approach**’ (p.13), in *HEC Forum*.

‘**Strategies to support surrogate decision makers of patients with chronic critical illness: The search continues**’ (p.15), in *Journal of the American Medical Association*.

ER death rate in U.S. drops by nearly half

UNITED PRESS INTERNATIONAL | Online – 6 July 2016 – Hospital emergency room deaths in the U.S. plummeted by nearly half over a 15-year period, with several factors likely accounting for the drop, a new study indicates. ¹ The upshot: It’s unlikely you’ll die in the ER, say researchers who analyzed almost 368,000 emergency department visits by adults between 1997 and 2011. They found a 48% reduction in deaths over that period. Increasing use of home hospice care and improvements in emergency medicine and public health are among the factors that might help explain the results, study author Dr. Hemal Kan-zaria said. <http://goo.gl/x35rAc>

1. ‘Emergency department death rates dropped by nearly 50%, 1997–2011,’ *Health Affairs*, 2016;35(7): 1303-1308. <http://goo.gl/9G9MIB>

Few young doctors are training to care for U.S. elderly

WEST VIRGINIA | National Public Radio – 3 July 2016 – West Virginia has the third oldest population in the nation, right behind Maine and Florida [but only 36 geriatricians in the state]. That includes ... physicians who specialize in the treatment of adults age 65 and older – as well as nurses, physical therapists and psychologists who know how to care for this population. The deficit of properly trained physicians is expected to get worse. By 2030, one in five Americans will be eligible for Medicare, the government health insurance for those 65 and older. For the past three years, no physicians have entered the fellowship program at West Virginia University-Charleston. In fact, no students have enrolled in any of the four geriatric fellowship programs in West Virginia in the past three years. The U.S. has 130 geriatric fellowship programs, with 383 positions. In 2016, only 192 of them were filled. <http://goo.gl/Cuu4hD>

Cont.

Noted in Media Watch, 16 May 2016, #462 (p.8):

- *BMC PALLIATIVE CARE* | Online – 11 May 2016 – ‘**A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective.**’ 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. <http://goo.gl/8cyuQg>

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>

N.B. Selected articles on meeting the health care needs of an aging population and the potential interface between geriatrics and palliative care are noted in Media Watch, 1 February 2016, #447 (p.3).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE ATLANTIC* | Online – 6 July 2016 – ‘**The volunteers who help people end their own lives.**’ Exit guides, who tend to travel in pairs, educate their clients about all aspects of their eventual suicides and sit with them as they die. Final Exit Network is the only right-to-die group in the country, the group says, that offers this kind of service. Formed in 2004, the non-profit was originally dismissed as fringe by its critics. Now, it has swelled to more than 3,000 members across the country, though it doesn’t have offices and is run entirely by volunteers. With affiliates in Arizona, Idaho, Illinois, Maine, Missouri, New York, and Oregon, the group boasts about 30 guides ... who are determined to help anyone who qualifies. They advise clients to author a discovery plan for someone to find their bodies. They help them talk with family and friends and sometimes pen a note to authorities detailing their motives and methods. <http://goo.gl/QEr95c>
- PENNSYLVANIA | *The Inquirer* (Philadelphia) – 5 July 2016 – ‘**More people can ask for help in dying, but very few do.**’ Anyone who feared that making physician-assisted suicide legal would lead to an onslaught of assisted deaths can relax. A new study led by University of Pennsylvania bioethicist Ezekiel Emanuel finds that only a tiny fraction of the dying want help speeding up the process.¹ However, Emanuel is concerned about the reasons people are choosing to die – horrible pain is sixth on the list - and says doctors remain less supportive of assisted suicide than the general public. He said the topic requires more study and that states that have legalized it should be keeping much better records of problems that patients encounter. Oregon, he said, does not consider it a complication if a patient regains consciousness after taking medication meant to kill him. While people die, on average, within 25 minutes after taking a lethal dose, the range extends to more than four days. Emanuel has a long interest in physician-assisted suicide, and he opposes it. He said he purposely included researchers on his team from The Netherlands and Belgium who support it. <http://goo.gl/OrYH7i>

1. ‘Attitudes and practices of euthanasia and physician-assisted suicide in the U.S., Canada, and Europe,’ *Journal of the American Medical Association*, 2016;316(1):79-90. <http://goo.gl/QvxAll>

[Media Watch: Palliative Care Network-e Website](http://goo.gl/8JyLmE)

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>

International

End-of-life care in Australia

More Victorians to be able to die at home under government plan

AUSTRALIA (Victoria) | *The Age* – 7 July 2016 – More Victorians would be able to die at home under an ambitious government plan to overhaul the state's strained and fragmented palliative care (PC) system within two years. The state government will ... release a new framework for end-of-life and PC, and commit \$7.2 million to immediately begin integrating, training and expanding the sector to give Victorians more options towards the end of their lives. About 800 people and 40 organisations were consulted for the plan, many of whom stressed that people want access to PC in their homes and local areas. A recent parliamentary end-of-life choices review found that although most people want to die at home – studies suggest up to 80% – only 14% do, with most dying in hospitals. It also rec-

ommended a doctor-assisted dying scheme. The government plans to introduce laws to protect patient's end-of-life wishes, ensure their preferences are discussed, develop and test new models of home-based care and create a state-wide standard. <http://goo.gl/rO6kRy>

Specialist Publications

'Are rural and remote patients, families and care-givers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence' (p.9), in *Australian Journal of Rural Health*.

Noted in Media Watch, 13 June 2016, #466 (p.7):

- AUSTRALIA (Victoria) | Palliative Care Victoria – 9 June 2016 – **'Parliament of Victoria inquiry into end-of-life choices.'** The 440-page report of the Legal & Social Issues Committee of the Victorian Legislative Council conveys the complexity of the issues under consideration and outlines 12 core values for end-of-life care (EOLC). The report makes 28 specific recommendations to strengthen palliative care and EOLC across Victoria. <http://goo.gl/XDOvF5>

University report explores efficacy of palliative care in England

U.K. | Healthcanal.com – 5 July 2016 – A new report by Sheffield Hallam University has revealed that, despite an abundance of government recommendations on end-of-life care (EOLC) in England, there is uncertainty as to whether they have led to improvements in patient care.^{1,2} On the day the Government will respond to the [2015] 'Review into Choice at the End of Life,'^{3,4} the report by Sheffield Hallam's Centre for Health & Social Care Research says the reason behind the uncertainty is not enough attention has been given to how policies are implemented. The University's ... report reveals that since 2004 there have been 76 government publications impacting on terminal illness. It argues that this excess of information has diluted focus among commissioners and providers and this has made it difficult to ensure the consistency and quality of local EOLC services. The report's authors say that, while there has been progress in some areas, national policy needs to

be clearer and there should be a greater emphasis on evidence-based practice. They also note that there is a lack of clarity over the resources and budgets that should be provided to terminal illness care. The report recommends that those commissioning services should be responsible for ensuring that services are delivered as intended and that there are appropriate frameworks in place to monitor and evaluate efficacy and quality. <http://goo.gl/vEE1lh>

Extract from Sheffield Hallam University report

Since the devolution of powers to Scotland, Wales and Northern Ireland in 1999, four divergent health systems have developed in each nation across the U.K. While this has not resulted in one nation consistently outperforming the others, it does mean that there are distinct policies, strategies and delivery mechanisms in place.

Cont.

1. 'State of the Nations Report: Terminal Illness Care in England, Northern Ireland, Scotland and Wales,' Centre for Health and Social Care Research, Sheffield Hallam University, July 2016. <https://goo.gl/jWPUUh>
2. 'An Updated Assessment on Need, Policy & Strategy: Implications for England,' Marie Curie, July 2016. <https://goo.gl/tj8yOz>
3. 'What's Important to Me: A Review of Choice in End-of-Life Care,' Choice in End-of-Life Care Programme, February 2015. [Noted in Media Watch, 2 March 2015, #399 (p.4)] <https://goo.gl/Cs9ku2>
4. 'Our Commitment to you for End-of-Life Care: The Government Response to the Review of Choice in End of Life Care,' Department of Health, July 2016. <https://goo.gl/HO3GX>

Related

- U.K. (England) | BT.com – 5 July 2016 – '**Plan for round-the-clock access to palliative care experts for dying patients.**' People nearing the end of their life are to have round-the-clock access to palliative care experts under plans to help tackle variations in care. They will be given a key contact so they know who to reach at any time of day, health minister Ben Gummer announced. The move comes as the government introduces a raft of measures to improve care across England in its response to an independent review which said many patients do not receive good quality care which meets their individual needs and wishes. <http://goo.gl/j8eYb1>

“We need more realistic end-of-life expectations”

U.K. | *The Daily Telegraph* – 4 July 2016 – The end of life has become a pointlessly costly affair, a fact emphasised yet again last week by the largest investigation into what is euphemistically known as Potentially Ineffective Care (PIC). This is scarcely a novel issue, but serves a useful purpose in drawing attention to the sheer scale of PIC that almost defies belief: a third of those in “irreversible decline” being admitted to intensive care to be treated with antibiotics and heart medicines; a quarter of those with Do Not Resuscitate orders in their notes none the less being resuscitated; a third of patients with terminal cancer receiving chemotherapy... and so on. It would seem obvious that scarce resources could be put to better use – and much unnecessary suffering avoided – were the public to have a more realistic appreciation of what such heroic interventions might reasonably be expected to achieve. But those unrealistic expectations are driven ... on doctors' reluctance to honestly examine the experience of ageing and dying (thus) increasing the harm we inflict and denying people the basic comforts they need. Significantly, surveys consistently reveal that doctors are also reluctant to choose for themselves those heroic

end-of-life interventions they inflict upon others. It would be a major corrective to those unrealistic expectations if they were to say so openly and emphatically. <http://goo.gl/Tse3h0>

JAMA Patient Page

End-of-life care

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2016;316(1):115. Because of advances in medicine, the dying process can be significantly extended. As a result, patients and their families and friends may face decisions about end-of-life care (EOLC). As difficult as it might be to talk about one's own death, expressing thoughts, values, and desires regarding a “good death” can help a person's loved ones understand the EOLC that person desires. This includes discussions about using life-prolonging measures like life support with a breathing machine or ongoing aggressive medical treatments in the end phase of life. Also, the desired location of care ... can be discussed. A conversation with your physician can provide guidance when deciding on EOLC preferences. <http://goo.gl/a9PYX3>

N.B. It is not clear which investigation into potentially ineffective care the author is referring to. The most recent study on medical futility (i.e., an international literature review) is 'Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem,' published in the *International Journal for Quality in Healthcare*, 27 June 2016, and noted in Media Watch, 4 July 2016, #469 (p.7). <http://goo.gl/4mwpLS> **BRA**

Specialist Publications

Lack of agreement with what we think is right does not necessarily equal an ethical problem: Respecting patients' goals of care

AMERICAN JOURNAL OF BIOETHICS, 2016;16(8):13-15. Survival is only one consideration regarding patient care – quality of life and costs and burdens of an intervention may supersede survival for some patients. Furthermore, decisions about implantable cardioverter defibrillators implantation must be grounded in patients' beliefs and wishes around end-of-life care. <http://goo.gl/9192di>

Noted in Media Watch, 27 June 2016, #468 (p.7):

- *HEART, LUNG & CIRCULATION*, 2016;25(8):814-819. '**Cardiac implantable electronic devices and end-of-life care: An Australian perspective.**' This article focuses on the subset of patients who may request, or be appropriate for, device deactivation and discuss the issues surrounding end-of-life decisions, along with the ethical and legal implications of device deactivation. <http://goo.gl/yyFHHE>

N.B. Selected articles on implantable cardioverter-defibrillators in the context of end-of-life care are noted in Media Watch, 1 February 2016, #447 (p.11).

Living with dying in the pediatric intensive care unit: A nursing perspective

AMERICAN JOURNAL OF CRITICAL CARE (American Association of Critical Care Nurses), 2016;25(4): 350-356. Despite reported challenges encountered by nurses who provide palliative care (PC) to children, few researchers have examined this phenomenon from the perspective of nurses who care for children with life-threatening illnesses in pediatric intensive care units. Five major themes were detected [in this study conducted with 12 pediatric intensive care units in the northeastern U.S.]: 1) Journey to death; 2) A life-long burden; and, 3) Challenges delivering care; 4) Maintaining self; and, 5) Crossing boundaries. These themes were illuminated by 12 sub-themes: 1) The emotional impact of the dying child; 2) The emotional impact of the child's death; 3) Concurrent grieving; 4) Creating a peaceful ending; 5) Parental burden of care; 6) Maintaining hope for the family; 7) Pain; 8) Unclear communication by physicians; 9) Need to hear the voice of the child; 10) Remaining respectful of parental wishes; 11) Collegial camaraderie and support; and, 12) Personal support. Findings revealed sometimes challenging intricacies involved in caring for dying children and the children's families. However, the nurses voiced professional satisfaction in providing PC and in support from colleagues. Future research is needed to identify additional supportive resources that may help staff process and cope with death and dying. <http://goo.gl/auOHty>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 July 2016 – '**Shifting focus in pediatric advance care planning from advance directives to family engagement.**' The foundational principle of palliative care is to provide comfort, ameliorate symptoms, and offer emotional support when death is inevitable. Advance care planning (ACP) elicits patients' goals for the future. One important result of an ACP discussion may be an advance directive, a written order delineating explicit wishes regarding medical interventions. <http://goo.gl/31vnbV>
- *PEDIATRIC CRITICAL CARE MEDICINE* (Society of Critical Care Medicine and the World Federation of Pediatric Intensive & Critical Care Societies) | Online – 30 June 2016 – '**Screening criteria improve access to palliative care in the PICU.**' Patients were divided into three groups based on palliative care (PC) status: 1) Patients new to the PC team; 2) Patients with an existing PC relationship; and, 3) Patients who did not have a PC referral. By the end of study, patients who had an existing relationship with the PC team were more likely to still be alive and to have limitations of medical interventions in place, whereas patients who did not have a PC referral were more likely to be deceased and to have died in the PICU. Patients who were new to the PC team experienced greater delay in PC referral and had significantly longer PICU and hospital length of stay than those who were already known to the PC team. <http://goo.gl/lo77lj>

Integrated palliative care in Europe: A qualitative systematic literature review of empirically-tested models in cancer and chronic disease

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 July 2016 – This is the first qualitative systematic literature review of models on integrated palliative care (PC) in patients with malignant and non-malignant disease in Europe. It represents the combined effort of an international consortium of six partners in six different European countries (Belgium, Germany, Hungary, Spain, The Netherlands and United Kingdom). Based on the results, the authors have proposed a generic framework for integrated PC in patients with cancer and chronic disease. The proposed generic identifies the importance of employing a PC-trained multidisciplinary team and of having a threefold focus: 1) On treatment; 2) Consulting; and, 3) Training. Each component of the framework has been already empirically assessed, however, the overall framework has not. Such a study not only will provide empirical evidence on the framework's efficacy but will also shed light on possible weaknesses that can be only traced post-implementation. Additionally, it would be interesting to conduct the same systematic review in non-European countries and performed a comparative analysis in a worldwide scale. <http://goo.gl/M33pHC>

Related

- *JOURNAL PAIN & SYMPTOM MANAGEMENT* | Online – 8 July 2016 – '**Palliative care declarations: Mapping a new form of intervention.**' It is 21 years since the journal published the 'Declaration of Florianapolis,' drawing attention to the need for improved access to pain and palliative care (PC) services in Latin America. In the intervening years, there has been a growing tendency for PC associations and organizations to issue formal public statements of this type. Declarations have become part of the international PC landscape. They appear to require significant orchestration and planning and yet they have not been examined from a research perspective. <http://goo.gl/E0MAKd>
- 1. 'Opioid availability in Latin America: The Declaration of Florianapolis,' *Journal of Pain & Symptom Management*, 1995;10(3):233-236. <http://goo.gl/K0Qxl0>

Are rural and remote patients, families and caregivers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence

AUSTRALIAN JOURNAL OF RURAL HEALTH (National Rural Health Alliance) | Online – 5 July 2016 – Peer-reviewed studies from 1996 to the present dealing with the experience of rural and remote patients and caregivers at the end-of-life compared with that of urban people were extracted for narrative synthesis. The eight studies included showed that palliative needs of rural and remote residents are related to context. Diagnosis and treatment are less well managed in rural areas. Rural differences include: 1) People are more accepting of death and less likely to intervene to delay death; and, 2) Caregivers tend to be younger and include friends as well as family and local support networks are important. Rural and remote end-of-life needs are shaped by reduced access and availability of services, which has a negative influence on outcomes. This is counterbalanced by an acceptance of death and local support networks. Well-designed longitudinal studies with samples comprised of rural and urban residents for comparison are required to monitor how end-of-life need might change with the approach of death. Clinicians, health services and policy makers need a better understanding of rural attitudes and of how rural community networks mobilise to support end-of-life care in their rural and remote communities. <http://goo.gl/QS1e7w>

Related

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 6 July 2016 – '**Reducing avoidable admissions in rural community palliative care: A pilot study of care coordination by General Practice registrars.**' This is a small proof of concept pilot study limited by lack of randomisation. The results demonstrate the feasibility of using a General Practice registrar to manage continuity of care for rural community palliative care patients. Given the potential confounding factors, further investigation via a larger randomised trial is required. <http://goo.gl/6gqk25>

Cont.

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 6 July 2016 – ‘**Factors affecting rural volunteering in palliative care: An integrated review.**’ The invisibility of volunteers in rural palliative care (PC) research is a concern in understanding the issues affecting the sustainability of quality palliative care provision in rural communities. Recommendations for future Australian research includes examination of the suitability of current models of PC practice in addressing the needs of rural communities; the recruitment, training, ongoing education and support of volunteers in rural PC provision to ensure equitable care for all communities in Australia regardless of location. <http://goo.gl/8ogqTu>

N.B. Additional articles on end-of-life care in rural communities and remote regions are noted in the issues of *Media Watch*, 4 April 2016, #456 (pp.2, 12); 8 February 2016, #448 (p.9); 4 January 2016, #443 (p.9); 30 November 2015, #438 (p.12); 14 September 2015, #427 (p.8); 7 September 2015, #426 (p.17); 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).

End-of-life care in England

Out-of-hours primary care use at the end of life: A descriptive study

BRITISH JOURNAL OF GENERAL PRACTICE (Royal College of General Practitioners) | Online – 6 July 2016 – Out of a total of 496,931 contacts, there were 6,045 coded “palliative”; those contacts provided care to 3,760 patients. Patients contacting the out-of-hours (OOH) service with palliative care needs did so predominantly during weekend daytime periods, and over a third had more than one contact. Patients were predictably older than the average population, but contacts coded as “palliative” were relatively less deprived than contacts to the OOH service for all causes, even after adjusting for age and sex. The current “one-size-fits-most” model of OOH primary care may not allow for the specific needs of patients at the end of life (EOL). Wider analysis of palliative patient flow through urgent care services is needed to identify whether healthcare access at the EOL is inequitable, as well as the capacity requirements of a community-based service that can provide high-quality end-of-life care. <http://goo.gl/ZYKGyr>

Noted in *Media Watch*, 9 March 2015, #400 (p.12);

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 March 2015 – ‘**Out-of-hours palliative care: What are the educational needs and preferences of general practitioners?**’ Offering genuine choice to patients over place of care and death requires the provision of high-quality palliative care (PC) 24/7. Confidence in key PC competences is severely lacking. <http://goo.gl/lZ2RyT>

Related

- *BRITISH JOURNAL OF GENERAL PRACTICE* (Royal College of General Practitioners) | Online – 6 July 2016 – ‘**Providing end-of-life care in general practice: Findings of a national GP questionnaire survey.**’ 97% [of respondents] felt that general practice plays a key role in the delivery of care to people approaching the end of life and their families. Four interdependent themes emerged from the data: 1) Continuity of care – which can be difficult to achieve because of resource concerns including time, staff numbers, increasing primary care workload, and lack of funding; 2) Patient and family factors – with challenges including early identification of palliative care needs and recognition of the end of life, opportunity for care planning discussions, and provision of support for families; 3) Medical management – including effective symptom-control and access to specialist palliative care services; and, 4) Expertise and training – the need for training and professional development was recognised to enhance knowledge, skills, and attitudes towards end-of-life care. <http://goo.gl/HOaBWN>



World hospice &
palliative care day

‘Living and dying in pain: It doesn’t have to happen’

8 October 2016

<http://goo.gl/iKZH4k>

Best practices in developing a national palliative care policy in resource limited settings: Lessons from five African countries

eCANCER | Online – 7 July 2016 – Given the high unmet need for palliative care (PC) in Africa and other resource limited settings, it is important that countries embrace the public health approach to increasing access through its integration within existing healthcare systems. To give this approach a strong foundation that would ensure sustainability, the World Health Organisation urges member states to ensure that policy environments are suitable for this intervention. The development, strengthening, and implementation of national PC policies is a priority. Given the lack of a critical mass of PC professionals in the region and deficiency in documenting and sharing best practices as part of information critical for regional development, policy development becomes a complex process. This article shares experiences with regard to best practices when advocating the national PC policies. It also tells about policy development process, the important considerations, and cites examples of policy content outlines in Africa. <http://goo.gl/1GI8rO>

Noted in Media Watch, 16 May 2016, #462 (p.15):

- *PALLIATIVE MEDICINE*, 2016;30(6):517-519. **‘Possible directions for palliative care research in Africa.’** 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 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 discussed. <http://goo.gl/TmSwl2>

Noted in Media Watch, 16 November 2015, #436 (p.8):

- AFRICA | *The Mail & Guardian* (Nairobi, Kenya) – 9 November 2015 – **‘Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails.’** The Index highlights the advances countries are making in taking care of their citizens at the end of life,¹ as well as the remaining challenges and gaps in policy and infrastructure. Although Africa is still overwhelmingly young, the proportion of older people in the population is rising, and non-communicable diseases such as heart disease, diabetes and cancer are on the rise. The need for palliative care, therefore, is set to rise significantly. **Link to article and infographic (right):** <http://goo.gl/o5tllV>

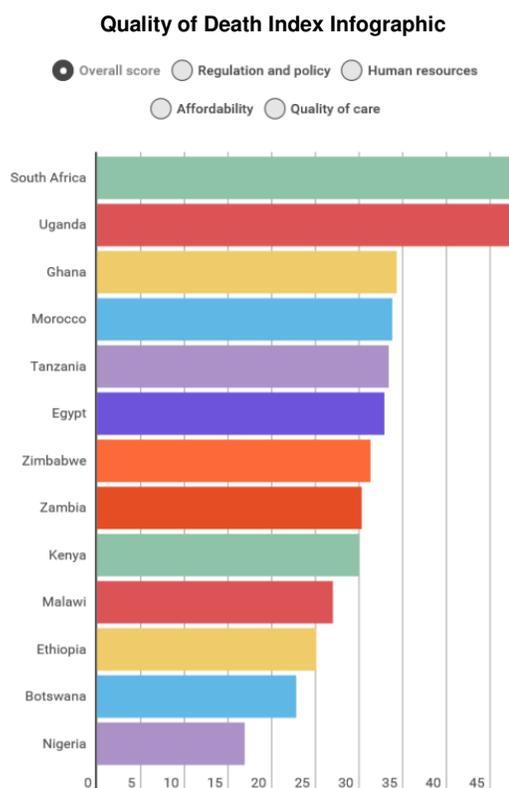
1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/VWQFuk>

Expressions of loss and separation

Writing grief: A writing workshop within a hospice bereavement program

CHRYSALIS: THE JOURNAL OF TRANSFORMATIVE LANGUAGE ARTS, 2016;1(3):52-61. Just as Elisabeth Kübler-Ross’s famous ‘Five Stages of Grief’ is not a cookie cutter description of the grieving process for every person, no writing workshop is a one-size-fits-all method for writing about loss. As the workshop leader, I’ve come to recognize that I’m there to help people use the act of writing to make sense of this most difficult time of their lives. While the goal in most writing workshops is to develop skill and refine writing, the primary goal in the grief writing workshop is to aid the grieving process by providing

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a tool for examining and reflecting on the experience. Author Jessica Handler writes, “Loss transforms the stories that we expected of our lives.” My job is to help participants honor and chronicle the old stories while finding the words to begin telling the new ones. It’s long been acknowledged by psychologists and social workers that human beings are hard-wired to use stories to interpret events and make sense of life. The grief writing workshop reflects this. By constructing a narrative about loss and the people we’ve lost, growth, understanding and healing is possible. <http://goo.gl/y9rS0J>

N.B. Search Google by the title of the article will provide a link to the full text of the journal article. BRA

Related

- *JOURNAL OF ADVANCED NURSING* | Online – Accessed 9 July 2016 – ‘**Grief and loss in older people residing in nursing homes: (Un)detected by nurses and care assistants?**’ Findings suggest an established personal sensitivity for grief care considered from the nursing staff points of view. Nevertheless, a common denominator was the necessity to further develop a supportive and multidisciplinary grief care policy ingrained in the existing care culture. Suggested components of this grief care policy are: 1) Centring attention on non-death-related loss and the cumulative nature of loss in residents; 2) Building capacity by means of reflective practices; and, 3) The importance of self-care strategies for nursing staff. Further, the findings from this study point towards a need for education and training. <http://goo.gl/GR7zRR>

Health issues of incarcerated women in the U.S.

CIÊNCIA & SAÚDE COLETIVA (Brazilian Association of Collective Health) | Online – Accessed 5 July 2016 – The health care needs of women in jails and prisons are complex; it is certainly a challenge to provide quality services within a system that emphasizes custody and control over treatment. Currently, the medical and psychological needs of women in jails and prisons are not being met in the U.S. National, state, and local policy and practice undervalues women and especially fosters stigma of incarcerated women. Lack of gender equity in society and insensitivity to the needs of incarcerated women must be addressed in the U.S., and in every country, if social justice is an important goal. Federal and state courts will continue to be a very important source of advocacy for quality health care for incarcerated women. Public health policies and standards to improve overall health in a society must also include improvements in prison health services. This requires a strong integrated health care network of competent professionals to provide quality medical care. Improved health care holds the potential to reduce trauma to incarcerated women, improve

physical and psychological health, and benefit the women whether they are released back to the community or not. For the majority of women who are released, quality health care holds the potential to reduce recidivism and create healthier family systems. <http://goo.gl/wcc6B4>

Extract from *Ciência & Saúde Coletiva* article

Develop programs for terminally ill female inmates that can include placement in a community hospice program to ensure that the woman’s medical and emotional needs are met.

[Prison Hospice Backgrounder](#)

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: <http://goo.gl/ggd4hp>

N.B. English language article.

[Media Watch: Back Issues](#)

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://goo.gl/frPgZ5>

A systematic literature review on the ethics of palliative sedation: An update (2016)

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 1 July 2016 – Palliative sedation has been the subject of intensive debate since its first appearance in 1990. In a 2010 review of palliative sedation, 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 palliative sedation may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. Good clinical guidelines and policies are still required to address issues of emotional distress and waylay concerns that palliative sedation hastens death. The empirical evidence suggests some movement toward consensus on the practice of palliative sedation. However, a continued need exists for evidence-informed practice guidelines, education, and research to support the ethical practice of palliative sedation at the end of life. Until that time, clinicians are advised to adopt a framework or guideline that has been expert driven to ensure consistent and ethical use of palliative sedation at the end of life. <http://goo.gl/qWxPgk>

Noted in Media Watch, 12 May 2014, #357 (p.6)

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: Analysis of international guidelines and position statements.**’ Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://goo.gl/IUy00q>

Clinician prediction of survival versus the Palliative Prognostic Score: Which approach is more accurate?

EUROPEAN JOURNAL OF CANCER (European Organisation for Research & Treatment of Cancer, the European Cancer Organisation, the European Association for Cancer Research, and the European Society of Breast Cancer Specialists) | Online – 30 June 2016 – Clinician prediction of survival (CPS) has low accuracy in the advanced cancer setting, raising the need for prediction models such as the palliative prognostic (PaP) score that includes a transformed CPS (PaP-CPS) and five clinical/laboratory variables (PaP-without CPS). However, it is unclear if the PaP score is more accurate than PaP-CPS, and whether PaP-CPS helps to improve the accuracy of PaP score. The authors compared the accuracy among PaP-CPS, PaP-without CPS and PaP-total score in patients with advanced cancer. They found that PaP score was more accurate than CPS, and the addition of CPS to the prognostic model reduced its accuracy. This study highlights the limitations of clinical gestalt and the need to use objective prognostic factors and models for survival prediction. <http://goo.gl/z0B0eu>

Failure of the current advance care planning paradigm: Advocating for a communications-based approach

HEC FORUM | Online – 8 July 2016 – The purpose of advance care planning (ACP) is to allow an individual to maintain autonomy in end-of-life (EOL) medical decision-making even when incapacitated by disease or terminal illness. The intersection of EOL medical technology, ethics of EOL care, and state and federal law has driven the development of the legal framework for advance directives (ADs). However, from an ethical perspective the current legal framework is inadequate to make ADs an effective EOL planning tool. One response to this flawed AD process has been the development of Physician Orders for Life Sustaining Treatment (POLST). POLST has been described as a paradigm shift to address the inadequacies of ADs. However, POLST has failed to bridge the gap between patients and their autonomous, preferred EOL care decisions. Analysis of ADs and POLST reveals that future policy should focus on a communications-based approach to ACP that emphasizes ongoing interactions between healthcare providers and patients to optimize EOL medical care to the individual patient. <http://goo.gl/QvZLSo>

Cont.

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

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System’s Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. <http://goo.gl/9gFs4X>

End-of-life care in Canada

Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care

INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH, 2016;11(1):50-74. This paper describes the development and implementation of a community-based palliative care (PC) program in Six Nations of the Grand River Territory, Ontario, Canada. Six Nations’ innovative program is grounded in a vision to provide access to quality PC at home and incorporate Haudenosaunee traditional teachings. A community-based Project Advisory Committee led the development process, and a Leadership Team of local and regional PC partners led implementation. Outcomes included: 1) Creation of a Palliative Shared Care Outreach Team, including a First Nations physician, nurse, and social worker; 2) Development of a detailed care pathway for clients who need PC; 3) Increased home deaths (55) as compared to hospital (22) or hospice (6) deaths; 4) Access to PC education and mentorship for local healthcare providers; 5) Incorporation of traditional teachings to support clients and staff dealing with death, dying, grief, and loss; and, 6) Creation of a PC program booklet for Six Nations Health Services. This unique initiative reduces disparities in access to quality palliative home care and demonstrates that First Nations communities can successfully undertake a process of community capacity development to create unique and culturally responsive PC programs. Challenges included overcoming federal and provincial jurisdictional issues in provision of health services through collaborative partnerships at the local and regional level. <https://goo.gl/im094P>



Selected articles on end-of-life care for First Nations (i.e., indigenous) peoples in Canada

- ONTARIO | CBC News – 24 September 2015 – ‘**Palliative care poor in First Nations communities, researcher says.**’ Choosing to live out their last days at home is not an option for many First Nations people. Mary Lou Kelley, a professor at Lakehead University, says federal health care dollars that would help First Nations people receive end-of-life care at home have not kept up with the increasing demand. [Noted in Media Watch, 28 September 2015, #429 (p.1)] <http://goo.gl/2DJKB5>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 June 2015 – ‘**Indigenous people’s experiences at the end of life.**’ The findings of this study provide a beginning to an understanding of the end-of-life experiences of indigenous peoples. More research is critical if palliative care services, the healthcare system, and healthcare providers are to reduce barriers to “preparing the spirit” for the journey at the end of life. [Noted in Media Watch, 22 June 2015, #415 (p.14)] <http://goo.gl/i2DeQU>
- CTV NEWS | Online – 28 April 2015 – ‘**Auditor General takes aim at First Nations health...**’ The quality of health care in remote First Nations communities is sorely lacking¹ ... a conclusion that aboriginal leaders call a further indictment of how they are being treated by Ottawa. [Noted in Media Watch, 4 May 2015, #408 (p.2)] <http://goo.gl/QjnsS5>

1. ‘Access to Health Services for Remote First Nations Communities,’ Auditor General of Canada, Spring 2015. <http://goo.gl/UTAMBv>

N.B. There is no mention in the Auditor General’s report of end-of-life care. **BRA**

Strategies to support surrogate decision makers of patients with chronic critical illness: The search continues

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2016;316(1):35-37. Patients with chronic critical illness (defined as a critical illness that requires prolonged mechanical ventilation) are at high risk for death or severe functional impairment. The surrogate decision makers for these patients face challenging decisions about whether to continue life-prolonging treatments given uncertain outcomes. A growing body of research indicates that surrogates often experience symptoms of depression, anxiety, and posttraumatic stress in the months following the intensive care unit (ICU) admission of a family member. <http://goo.gl/NuAyQh>

Related

- *BMC PALLIATIVE CARE* | Online – 7 July 2016 – ‘**An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes.**’ This study highlights end-of-life discussions should be ongoing rather than a one-off task driven conversation. Four major themes described strategies for improving practice: 1) Educating families and staff about dementia progression and end-of-life care; 2) Appreciating the greater value of in-depth end-of-life discussions compared with simple documentation of care preferences; 3) Providing time and space for sensitive discussions; and, 4) Having an independent healthcare professional or team with responsibility for end-of-life discussions. <http://goo.gl/JnA6lx>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(1):51-62. ‘**Effect of palliative care-led meetings for families of patients with chronic critical illness: A randomized clinical trial.**’ Among families of patients with chronic critical illness, the use of palliative care-led informational and emotional support meetings compared with usual care did not reduce anxiety or depression symptoms and may have increased posttraumatic stress disorder symptoms. These findings do not support routine or mandatory palliative care-led discussion of goals of care for all families of patients with chronic critical illness. <http://goo.gl/YnECmQ>
- *PATIENT EDUCATION & COUNSELING* | Online – 6 July 2016 – ‘**Shared decision-making as an existential journey: Aiming for restored autonomous capacity.**’ The fundamental uncertainty, state of vulnerability, and lack of power of the ill patient, imbue shared decision-making with a deeper existential significance and call for greater attention to the emotional and relational dimensions of care. Hence, the authors propose that the aim of shared decision-making should be restoration of the patient’s autonomous capacity. <http://goo.gl/qxQU0c>

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

Hospice face-to-face recertification: Embracing the benefits and challenges

JOURNAL OF HOSPICE & PALLIATIVE NURSING (Hospice & Palliative Care Nurses Association), 2016;18(4):317-323. The Medicare hospice benefit provides quality end-of-life care for those with a prognosis of 6 months or less to live and their families. The utilization of the benefit has increased since its implementation in 1982. Eligibility requirements and conditions of participation guide the admission and recertification of patients enrolled in hospice care. The face-to-face (FTF) requirement for hospice recertification is a major revision of the conditions of participation as of 2011.¹ The FTF recertification process was established to deter unsubstantiated benefits for those who do not qualify for hospice care and prevent Medicare fraud. Ultimately, this process is designed to enhance the quality and delivery of hospice care to those who need it most. Hospices, practitioners, patients, and caregivers are collaborating to comply with these requirements. This article describes the benefits and challenges of the FTF requirement and the role nursing plays in this relatively new provision. Regulation recommendations are presented for ease of compliance. <http://goo.gl/W0y7SZ>

1. ‘Patients surviving six months in hospice care: Who are they?’ *Journal of Palliative Medicine*, 16 June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.12)] <http://goo.gl/zDOYzQ>

What are the components of interventions focused on quality-of-life assessment in palliative care practice? A systematic review

JOURNAL OF HOSPICE & PALLIATIVE NURSING (Hospice & Palliative Care Nurses Association), 2016;18(4):310-316. Current research is insufficient to determine how to implement interventions focused on quality-of-life assessment in palliative care (PC). Interventions and their components were identified and discussed. Identifying problems and monitoring change or response to treatment, screening for hidden problems and facilitating communication were the three different types of intervention identified. None of the interventions fulfilled all the 11 Quality of Life Assessment Principles in Palliative Care.¹ Overall, six characteristics of the components were identified: 1) The quality-of-life measure; 2) Educational training; 3) Completing the measure (patients or proxy); 4) Collecting quality-of-life data (baseline and further assessment); 5) Identifying a coordinator; and, 6) Presenting quality-of-life data. Because of heterogeneity of interventions, it is not possible to recommend one preferred intervention. <http://goo.gl/Tm4Tru>

1. 'Does quality of life assessment in palliative care look like a complex screening program?' *Health & Quality of Life Outcomes*, 14 January 2013. [Noted in Media Watch, 21 January 2013, #289 (p.7)] <http://goo.gl/R8gLAf>

Live and let die: The consequences of Oklahoma's Non-discrimination in Treatment Act

OKLAHOMA LAW REVIEW, 2016;68(3):585-619. While we do not know how the Act is affecting physicians or patients in Oklahoma, a plain-language interpretation of the Act would restrict the ability of physicians to make medical decisions that correspond to their professional ethics. While there is a right to refuse medical treatment, there is no corresponding right to demand medical treatment from physicians, and therefore physicians should only have the responsibility to provide treatment that corresponds with the standard of care – especially if life-sustaining treatment (LST) would, in a physician's opinion, not reach that standard. Supplying a framework for the ethical dilemma of discontinuing LST, as Texas has done with Texas Advance Directive Act, benefits both the patient, or surrogate decision maker, and the physician by providing expectations for dispute-resolution procedures and by establishing a fair decision-making process for a physician faced with an ethical dilemma. The historic goal of the medical profession to "do no harm" should continue to guide the decisions of physicians rather than the pro-life motto "at all costs." If the legislature allows physicians to do their jobs in an ethical way, public attitudes might change to view physicians not as those condemning patients to death but instead allowing them to exit this world peacefully. <http://goo.gl/820HGGe>

Developing research, policy and practice in palliative care for people with intellectual disabilities will benefit everyone

PALLIATIVE MEDICINE, 2016;30(7):613-615. People with intellectual disabilities are a sizeable minority group, making up approximately 2% of the population [in the U.K.]. They need specific attention when they reach the end of life. While many of the palliative care needs of people with intellectual disabilities may be no different from those of the general population, they often present with unique issues, challenges and disadvantageous circumstances that make it more difficult to meet those needs. It has been shown decisively that people with intellectual disabilities have poorer health outcomes than the general population for reasons unrelated to the causes of their cognitive impairment, but rather, due to failings within healthcare systems. This is compounded by persistent negative attitudes and assumptions about quality of life of people with life-long cognitive impairments <http://goo.gl/gjXixz>

Noted in Media Watch, 28 March 2016, #455 (p.9):

- *BMC PALLIATIVE CARE* | Online – 24 March 2016 – '**Developing research priorities for palliative care of people with intellectual disabilities in Europe: A consultation process using nominal group technique.**' The proposal of four major priority areas and a range of minor themes for future research in intellectual disability, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed and support the building of collaborations. <http://goo.gl/fNxm6x>

Cont.

Noted in Media Watch, 8 February 2016, #448 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):45-47. **'Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell.'** The Taskforce on Palliative Care for People with Intellectual Disabilities of the European Association for Palliative Care (EAPC) recently published a White Paper containing 13 norms and related statements, real-life examples, and available resources. ¹ Journal contents page: <http://goo.gl/qIWex7>

1. 'Defining Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, Using Delphi Methods: A White Paper from the European Association of Palliative Care,' *Palliative Medicine*, 11 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.19)] <http://goo.gl/FQUsti>

N.B. Additional articles on palliative care for people living with intellectual disabilities are listed in this issue of Media Watch.

“Because it’s the wife who has to look after the man”: A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life

PALLIATIVE MEDICINE | Online – 1 July 2016 – Research indicates that women are the primary family caregivers for others at life’s end and, because of ageing populations, will keep fulfilling this role as they age. Yet, little is known about how the gendered nature of caregiving contributes to older women’s understandings of providing care. Six focus groups were conducted with 39 community dwelling older adults (36 women and 3 men) using two vignettes to prompt discussion about experience of end-of-life caring and attitudes towards advance care planning. Three themes regarding gender and caregiving were identified: 1) The expectation women will care; 2) Women’s duty to care; and, 3) Women’s construction of men in relation to caregiving and illness. The women adhered to stereotypical gender norms that regard women as primary caregivers. <http://goo.gl/w2dhTF>

Noted in Media Watch, 1 February 2016, #447 (p.15):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 January 2016 – **‘Gender and family caregiving at the end-of-life in the context of old age: A systematic review.’** Palliative family caregiving for older adults is gendered. Gender affects why people care and the consequences of providing care. <http://goo.gl/Cx9qge>

Noted in Media Watch, 26 October 2015, #433 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 October 2015 – **‘Gender differences in caregiving at end of life: Implications for hospice teams.’** The primary aim of this study was to determine how, if at all, caregiving at end of life varies by gender. Females had significantly lower self-esteem and more negative impact on their schedule, health and family support than males. <http://goo.gl/QflvhC>



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>

What makes a good palliative care physician? A qualitative study about the patient's expectations and needs when being admitted to a palliative care unit

PLOS ONE | Online – 7 July 2016 – The aims of the study were to examine 1) Patients' knowledge of palliative care (PC); 2) Patients' expectations and needs when being admitted to a PC unit; and, 3) Patient's concept of a good PC physician. The results revealed four themes: 1) Information about PC; 2) Supportive care needs; 3) being treated in a PC unit; and, 4) qualities required of PC physicians. The data showed that patients lack information about PC, that help in social concerns plays a central role in PC, and attentiveness as well as symptom management are important to patients. Patients desire a personal patient-physician relationship. The qualities of a good PC physician were honesty, the ability to listen, taking time, being experienced in their field, speaking the patient's language, being human, and being gentle. Patients experienced relief when being treated in a PC unit, perceived their care as an interdisciplinary activity, and felt that their burdensome symptoms were being attended to with emotional care. Negative perceptions included the overly intense treatment. <http://goo.gl/q0pQh3>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 July 2016 – ‘**Communicating with dying patients and their families: Multimedia training in end-of-life care.**’ The majority of students [i.e., study participants] demonstrated positive attitudes toward the care of dying patients and their families. Despite this high pre-test positive attitude, there was a statistically significant overall positive attitude change after the intervention. The lowest pre-test positive attitudes and lowest post-test positive attitude shifts, although all statistically improved, involved addressing the thoughts and feelings of dying patients and in coping with their own emotional response. <http://goo.gl/P7v2VM>

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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.

Palliative care and spirituality: An integrative literature review

REVISTA BRASILEIRA DE ENFERMAGEM (Brazilian Nursing Association), 2016;69(3):554-563. The articles reviewed in this study about palliative care (PC) and spirituality have shown the spiritual dimension as a core component of care to patients with no possibility of recovering health through healing therapy, because it promotes better well-being, relieving pain and other symptoms. Spirituality is a term that has several meanings. As such it can be hard for professionals to meet the spiritual needs of patients and hamper the production of proper instruments for the spiritual evaluation of patients under PC, due to the wide range of instruments that fail to comprise all items of the spiritual dimension (intra-, inter-, and trans-personal). In this sense there is a need for a clear definition of the concept of spirituality to allow health professionals to offer their patients proper and high-quality spiritual support capable of meeting all of their spiritual needs. New surveys should be developed, mainly at the national level, to sustain the spiritual support delivered by professionals assisting patients under PC. There is also an urgent need for studies that investigate the instruments that evaluate spirituality, focusing on patients under PC and their trans-cultural adjustment, since, in this study, some instruments may have been left aside. <http://goo.gl/Rrj4av>

N.B. Portuguese language article. English language version: <http://goo.gl/KWlStB>. Selected articles on spirituality in the context of end-of-life care are noted in the issues of Media Watch, 27 June 2016, #468 (p.9), 4 April 2016, #456 (p.7), and 8 June 2015, #413 (pp.10-11).

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/hhrU3q>

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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