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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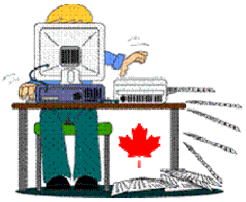

Compiled & Annotated by Barry R. Ashpole

With this issue, Media Watch begins is 13th year of publication.

Canada

What it's really like to die at home in Ontario

ONTARIO | Healthy Debate – Accessed 22 July 2019 – Palliative care (PC) in Ontario is funded through the Ministry of Health & Long-Term Care. The funding is distributed to 14 Local Health Integration Networks (LHINs) which then plan, coordinate, fund, and monitor services in each region. Nursing and personal care in the community is contracted out to many different private agencies. Deciding who is eligible for care is done by a case manager at the LHIN who is a healthcare professional. (With the LHINs set to be dissolved, it is uncertain who will take on responsibility for PC.) Mahoganie Hines is one of 38 nurses who has been hired by the Ministry to consult with and educate non-palliative healthcare clinicians in all settings so they can provide better end-of-life care. The list of what is needed to support someone to die at home is long. "First and foremost, you need a caregiver that is capable," says Hines. "That person has to have a support system. You ideally need a PC outreach team that takes over or supports the family physician's care. As part of that team, you want a physiotherapist and occupational therapist to do a home assessment. You want a psychosocial bereavement clinician to be part of the care. At a minimum, you need personal support workers and nurses for respite and medical care." But in reality, these specialized teams are few and far between. According to the most recent Auditor General of Ontario report on PC in 2014, only 15 such teams exist in Ontario.[1] According to a 2019 study, most teams are located in urban and suburban areas.[2] http://bit.ly/2GnOCKm

Specialist Publications

'Ethical sensitivity and perceptiveness in palliative home care through co-creation' (p.12), in *Nursing Ethics*.

'Understanding what works, why and in what circumstances in Hospice at Home Services for End-of-Life Care: Applying a realist logic of analysis to a systematically searched literature review' (p.11), in *Palliative Medicine*.

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1. '2014 Annual Report,' Auditor General of Ontario, December 2014. (Chapter on PC begins on p.258). [Noted in 15 December 2014 issue of Media Watch (#388, p.2)] **Download/view at:** http://bit.ly/2StffSS

Cont.

2. 'Community-based specialist palliative care teams and health system costs at end of life: A retrospective matched cohort study,' *CMAJ Open*, published online 12 February 2019. [Noted in 18 February 2019 issue of Media Watch (#602, p.10)] **Full text:** http://bit.ly/2N5P5Tq

Noted in Media Watch 14 January 2019 (#597, p.7):

- *BMC PALLIATIVE CARE* | Online – 9 January 2019 – **'Potential quality indicators for seriously ill home care clients: A cross-sectional analysis using Resident Assessment for Home Care data in Ontario.'** In Ontario, several initiatives are underway to improve the quality of palliative care services across the province. For example, Health Quality Ontario and the Ontario Palliative Care Network are developing quality standards and indicators for palliative services.[1,2] The preliminary list of quality indicators proposed here can make a significant contribution to this process as these organizations work collaboratively with home care providers and researchers to establish a set of standardized measures. **Full text:** http://bit.ly/2JLsziR

    1. 'Care for Adults With a Progressive, Life-Limiting Illness,' (Quality Statements in Brief), Health Quality Ontario. **Download/view at:** http://bit.ly/2YkQ8gM

    2. Ontario Palliative Care Network (Action Plan): **Download/view at:** http://bit.ly/2Y4BgZD

    N.B. See 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. [Noted in 4 July 2016 issue of Media Watch (#469, p.2)] **Download/view at:** http://bit.ly/2tCCkHe

Noted in Media Watch 6 June 2016 (#465, p.1):

- ONTARIO | *The Globe & Mail* – 2 June 2016 – **'Ontario unveils proposal for community and home care overhaul.'** The Ontario government unveiled legislation that would overhaul how community and home care is delivered in the province. Under the new legislation the existing Community Care Access Centre (CCAC) model would be dismantled and the role of Local Health Integrated Networks would be greatly expanded to include oversight of home and community care. Under the current system, CCACs oversee home and community care. Many health experts have criticized the CCAC model for years, saying they deliver varying levels of care across the province and add an unnecessary layer of bureaucracy. https://tgam.ca/2LB6S7h

U.S.A.

Court orders consultation with patients or rep in end-of-life and psychiatric drug decisions

CALIFORNIA | *San Francisco Chronicle* – 23 July 2019 – Doctors and staff at nursing homes can administer psychiatric drugs and make end-of-life decisions for patients who have been found mentally incompetent, as long as the patients or their representatives have a say in the decision. That was the verdict from a state appeals court … about a 1992 California law that allowed nursing home physicians to make decisions affecting the health and lives of incapacitated residents with no close friends or relatives to make decisions for them. An Alameda County Superior Court judge ruled in 2016 that the law violated patients' rights to decide their own course of treatment and to seek judicial review of a nursing home's decisions affecting their well-being. The law has remained in effect during the state's appeal, and the First District Court of Appeal said it can be enforced as long as it is interpreted "in a way that respects the constitutionally protected rights of nursing home residents." That means a nursing home must notify the patient and someone representing the patient, that he or she has been found incapable of making health care decisions... He said the nursing home must then appoint an independent representative, not affiliated with its staff, to the team that reviews a physician's treatment plans. http://bit.ly/2Ykje9H

Specialist Publications

'The National Palliative Care Registry: A decade of supporting growth and sustainability of palliative care programs' (p.9), in *Journal of Palliative Medicine*.

Working too hard for a good death: Has competitive dying become a thing?

FORBES | Online – 22 July 2019 – Now it seems, there is a growing need to compete over who will have the best death. You know, the one where we are at home, pain-free but alert, surrounded by our loving families, singing our favorite songs, fully at ease with our last moments of mortal life. For many of us, the reality will be quite different. Despite everyone's best efforts, we may die in a hospital. The kids may not make it in time from their homes in Los Angeles or Chicago. The medications that relieve our pain may also slow our thinking. And we may not have resolved all those family issues that lingered inexplicably for decades. What's troubling about this drive for a good death (or, perhaps in our competitive world, the best death) is that many of us never will achieve it – often for reasons out of our control. And that may leave our surviving loved ones with an even bigger sense of guilt than they already have. And paradoxically, those who cared the most may end up feeling the most guilty and depressed. Failing at some ideal of death may even make dying more difficult. Dr. Andreas Laupacis, a palliative care physician and professor of medicine at the University of Toronto, shared this concern in a wise 2018 essay about the idea of good death: "I worry that the term makes people who die with pain or psychological distress think that it is partially their fault… They haven't tried hard enough or aren't tough enough."[1] http://bit.ly/2Ogem1y

1. 'We like to talk about "a good death." But how often does this really happen?' Healthy Debate, published online 12 September 2018. **Download/view at:** http://bit.ly/2OcGUJz

Palliative care or surgery? New guidelines offer helpful benchmarks

MCKNIGHT'S LONG-TERM CARE NEWS | Online – 22 July 2019 – A new program has been launched that sets quality standards for surgical decision-making for the oldest old. The results may shift the need from step-down post-surgical care to palliative care for some residents over the age of 75. A growing number of seniors are seeking surgical care. Those over age 75 have unique surgical needs and are often at higher risk of post-surgical complications. With that in mind, the new Geriatric Surgery Verification Program, proposed and recently pilot-tested by the American College of Surgeons, has introduced 30 new standards designed to improve surgical care and outcomes for aging adults. http://bit.ly/2M5FGwL

N.B. American College of Surgeons' Geriatric Surgery Verification Program: http://bit.ly/2XZLEXo

Noted in Media Watch 22 July 2019 (#623, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 July 2019 – **'Palliative care consultation is underutilized in critically ill general surgery patients.'** The American College of Surgeons recommends palliative care (PC) and surgeons collaborate on the care of patients with poor prognoses.[1] However, contemporary practice patterns of PC consultation for surgical patients are poorly defined. The authors' data showed patients who received consultation were generally older, white, and insured. Median number of days between palliative consult and death was 3 days. **Abstract:** http://bit.ly/2Lsrr5D

    1. 'Statement of Principles of Palliative Care,' American College of Surgeons, August 2005. **Download/view at:** http://bit.ly/2NXJ1jZ

Noted in Media Watch 11 December 2017 (#542, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 December 2017 – **'Characterizing the role of U.S. surgeons in the provision of palliative care: A systematic review and mixed-methods meta-synthesis.'** Four major themes affected receipt of palliative care (PC) for surgical patients: 1) Surgeon experience and knowledge; 2) Surgeons' attitudes; 3) Surgeons' preferences and decision-making for treatment; and, 4) Perceived barriers. Surgeons overall demonstrated insight into the benefits of PC, but reported limited knowledge and comfort as well as a multitude of challenges to introducing PC to their patients. **Full text:** http://bit.ly/2Y9K5FC

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Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | Associated Press – 24 July 2019 – **'Oregon removes assisted suicide wait.'** Legislation allowing certain terminally ill patients to have quicker access to life-ending medications under the state's first-in-the-nation assisted suicide law has been signed into law, Governor Kate Brown's office... The law allows those with 15 days left to live to bypass a 15-day waiting period required under the Death with Dignity Act... Under the new amendment, doctors can make exceptions to the waiting periods if the patient is likely to die before completing them. The number of people who have taken advantage of Oregon's law has been relatively small. Since it enacted the nation's first physician-assisted suicide law in 1997, nearly 1,500 people died from taking life-ending medications prescribed to them by a physician. In 2018, about 46 per every 10,000 deaths could be attributed to the state's death with dignity law, according to state data. http://bit.ly/2YmtfmN

International

Betsi Cadwaladr University Health Board and Ty Gobaith Children's Hospice join forces to give families and parents choice and support

U.K. (Wales) | *Rhyl, Prestatyn & Abergele Journal* – 24 July 2019 – A new out-of-hours end of life (EoL) nursing service will give families across North Wales choice of where their seriously ill child dies. This has been launched via a partnership between Ty Gobaith Children's Hospice and Betsi Cadwaladr University Health Board. Until now, most EoL care for children in the region takes place at the hospice or in hospital, but research indicates that most families would choose for their child to die at home. The new out-of-hours EoL nursing service will allow families to make a choice and create a network of nurses to support them in their own home. Some families had received this support in the past, but that was through the goodwill of nursing staff and dependent on factors such as where the family lived. The initiative has been funded for two years by the All Wales End of Life Board and Betsi Cadwaladr. It will be led by an EoL coordinator based at Ty Gobaith and staffed by an EoL team of hospice nurses, hospital nurses, community nurses and Cancer & Leukemia in Childhood nurses. http://bit.ly/2MhQ2tP

Specialist Publications

'Role of palliative medicine in pediatric intensive care units' (p.10), in *Monatsschrift Kinderheilkunde*.

'Hospice and palliative care research in mainland China: Current status and future direction' (p.11), in *Palliative Medicine*.

'End-of-life palliative care in patients with terminal dementia' (p.13), in *Revista Costarricense de Salud Pública*.

Time to stop taking hospices for granted

U.K. (England) | *Express & Star* (Wolverhampton) – 22 July 2019 – While hospitals and GPs get all the headlines, the work done by our hospices is often taken for granted. Yet it is clear that without the vital services offered by hospices, the strain on the National Health Service (NHS) would become even greater. With that in mind, it is great to see that ministers are finally taking a close look at the whole system of funding. Hopefully in the very near future a proper solution will be found that ends the reliance that hospices currently have on donations. For Acorns, the start of a long battle to keep its Walsall hospice operational has just begun. The future of the site looked bleak a few weeks ago, but now hope is on the horizon after the Government announced NHS funding for children's hospices will double to £25 million over the next five years. It means Acorns has a reprieve. This is a positive step, particularly for the site's hard working staff and the 230 families that rely on its services. But on its own it does not solve the problem. It is a national tragedy that funding for hospices has reached crisis point, with many sites around the country on the brink of closure. http://bit.ly/32FYVDf

Cont.

Noted in Media Watch 8 July 2019 (#621, p.2):

- U.K. (England) | Third Sector (Twickenham) – 2 July 2019 – **'Charity succeeds in battle to ring-fence National Health Service funding for children's hospices.'** National Health Service (NHS) England promised last year funding for children's hospices would more than double from £12 million to £25 million by 2023-2024, dependent on clinical commissioning groups providing additional match funding to the government's £7 million investment. But Together for Short Lives last month accused NHS England of reneging on its promise to properly fund children's hospices by making the money available to non-palliative care, too. Following the charity's intervention, NHS England said it would provide the full £25 million itself without input from Clinical Commissioning Groups. http://bit.ly/2NtiZoM

N.B. Recent news media coverage on funding childrens' hospices in England noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England, Northern Ireland & Scotland) | *The Mail on Sunday* (London) – 21 July 2019 – **'Justice Minister David Gauke gives the green light for controversial move to make assisted dying legal...'** A controversial move that could pave the way to decriminalising assisted dying has been given the green light in one of the last acts of Theresa May's Government. Justice Secretary David Gauke has authorised a "call for evidence" on changing the law... Mr. Gauke has privately written to Government colleagues asking for the "positive and negative impacts" of allowing euthanasia in certain clearly defined circumstances. MPs have so far rejected calls to change the law... https://dailym.ai/2YkX1bu

Specialist Publications

Exploring end-of-life care team communication: An interprofessional simulation study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 July 2019 – Effective team communication is necessary for the provision of high-quality health care. Yet, recent graduates from diverse healthcare disciplines report inadequate training in communication skills and end-of-life (EoL) care. This study explored the impact of a withdrawal of life-sustaining measures interprofessional simulation on team communication skills of students representing medicine, nursing, and social work. The 3-phase simulation required teams to communicate with the patient, family, and one another in the care of a seriously ill patient at the EoL. Results revealed fair to good communication across nine communication domains. Overall team communication was strongest in "shares information" and lowest in "understands the patient's and family's perspective" domains. Field notes revealed 5 primary themes: 1)Team dynamics; 2) Awkwardness 3) Empathy is everything; 4) Build a relationship; and, 5) Communicating knowledge when you have it... Logistical challenges encountered in simulation development and implementation are presented, along with proposed solutions that were effective for this study. **Abstract:** http://bit.ly/32T2cim

Publishing Matters

'Distinguishing opinion from evidence in guidelines' (p.14), in *British Medical Journal*.

'Evidence vs consensus in clinical practice guidelines' (p.14), in *Journal of the American Medical Association*.

'Readers beware! Predatory journals are infiltrating citation databases' (p.15), in *International Journal of Public Health*.

'Predatory journals: Can we stem the rot?' (p.15), in *Journal of Postgraduate Medicine*.

Cont.

Related

- *INTERNATIONAL JOURNAL ENVIRONMENTAL RESEARCH & PUBLIC HEALTH* | Online – 11 July 2019 – **'Communicating health information at the end of life: The caregivers' perspectives.'** Adequate information facilitates the decision-making process and reduces suffering by reducing uncertainty and enabling compliance with the wishes of the person at the end of life. In the initial phases of adaptation and coping, the patient and caregiver may develop an attitude called a "conspiracy or pact of silence," avoiding talking or inquiring about the condition; this attitude seems to be very normal and repetitive. Caregivers feel the need to protect the patient's emotions and might not talk about related issues or the real concerns of patients, strengthening the conspiracy of silence. Moreover, professionals tend to adjust to this process. **Full text:** http://bit.ly/2JXBBrOl

"How often have you felt secure (during the palliative care period)?"

Can a single question about family members' sense of security during palliative care predict their well-being during bereavement? A longitudinal study during ongoing care and one year after the patient's death

BMC PALLIATIVE CARE | Online – 25 July 2019 – It has been recognised that more evidence about important aspects of family members' sense of security during palliative care (PC) is needed. The objectives of the study was: 1) To discover what variables are associated with family members feeling secure during PC; 2) To develop a model of family members' sense of security during PC; and, 3) To evaluate if family members' sense of security during ongoing PC predicts well-being during bereavement. Sixteen variables were positively related to family members' sense of security during ongoing PC. The five variables with the highest importance were selected into the model (listed in decreasing importance): 1) Family members' mastery; 2) Nervousness and stress; 3) Self-efficacy; 4) Patient having gynaecological cancer; and 5) Family members' perceived quality of life. Moreover, the family members' sense of security during ongoing PC predicted ten variables indicating their well-being one year after the patient's death, e.g., psychological well-being, complicated grief symptoms, health related quality of life. The findings reveal possibilities to identify family members at risk of negative adjustment to bereavement in clinical practice and may help to develop interventions to support family members during ongoing palliative care. **Full text:** http://bit.ly/2GsnRnV

An instrument to assess the education needs of nursing assistants within a palliative approach in residential aged care facilities

BMC PALLIATIVE CARE | Online – 23 July 2019 – Providing quality palliative care (PC) in residential aged care facilities (i.e., aged care homes) is a high priority for ageing populations worldwide. Older people admitted to these facilities have PC needs. Nursing assistants (however termed) are the least qualified staff and provide most of the direct care. They have an important role at the frontline of care spending more time with residents than any other care provider but have been found to lack the necessary knowledge and skills to provide PC. The level of competence of this workforce to provide PC requires evaluation using a valid and reliable instrument designed for nursing assistants' level of education and the responsibilities and practices of their role. This study provides preliminary evidence for the validity and reliability of three new questionnaires that demonstrate sensitivity for nursing assistants' level of education and required knowledge, skills and attitudes for providing a palliative approach. Implications for practice include the development of PC competencies through structured education and training across this workforce, and ongoing professional development opportunities for nursing assistants, especially for those with the longest tenure. **Full text:** http://bit.ly/2LF6cOe

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IPCRC.NET International Palliative Care Resource Center

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http://bit.ly/2ThijkC

Noted in Media Watch 9 July 2018 (#571, p.14):

- *PALLIATIVE MEDICINE* | Online – 4 July 2018 – **'The palliative care knowledge of nursing home staff: The European Union FP7 PACE cross-sectional survey in 322 nursing homes in six European countries.'** Although the authors found that many problematic issues are the same across countries, huge heterogeneity persists even after adjusting for confounders. Knowledge about basic palliative care (PC) issues is generally poor among nurses and care assistants in all countries, but particularly so in Poland and in Italy. A White Paper of the European Association for Palliative Care on PC education identifies nursing homes as a setting in which the staff, irrespective of their discipline, need to know the basic principles of PC.[1] **Full text:** http://bit.ly/2NjCKif

    1. 'Core Competencies in Palliative Care: White Paper on Palliative Care Education...' *European Journal of Palliative Care*, 2013;20(2):86-91. [Noted in 4 March 2013 issue of Media Watch (#295, p.7)] **Download/ view at:** http://bit.ly/2Ns7RIA

Table in the corner

A qualitative study of life situation and perspectives of the everyday lives of oesophageal cancer patients in palliative care

BMC PALLIATIVE CARE | Online – 22 July 2019 – This study is one of the first studies investigating, from the patients' perspective, how oesophageal cancer has an impact and grip on their lives and day-to-day activities. Symptoms of the illness and side effects from the treatment control the patients' lives and bodies, hindering them from carrying out ordinary, everyday tasks. The four identified sub-themes – "Sense of isolation," "Being in a zombie-like state," "One day at a time," and "At sea" – are discussed in relation to other research with the purpose of reaching a new understanding of the possible dimensions of the patients' experiences with their illness. It is an understanding process, in which theoretical or empirical perspectives are drawn on to help clarify and understand phenomena in the patients' lives. This study illuminates the lives of patients living with incurable oesophageal... The patients' lives are turned upside down, and they experience loss of health, function and familiar, everyday habits. The patients isolate themselves from their social network as the illness progresses and the symptoms and side effects increase. Furthermore, the patients experience loneliness and a lack of continuity during their treatment, which they find challenging and a psychological strain. Thus, as far as normal everyday life, social networks and the health care system are concerned, the patients metaphorically end up at a "table in the corner." **Full text:** http://bit.ly/2K6YGsd

Clinician barriers and facilitators to heart failure advance care plans: A systematic literature review and qualitative evidence synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 July 2019 – Clinicians hesitate to engage with advance care planning (ACP) in heart failure. We aimed to identify the disease-specific barriers and facilitators for clinicians to engage with ACP. Of 2,308 articles screened, the authors reviewed the full text of 42 studies. Seventeen studies were included. The main barriers were lack of disease-specific knowledge about palliative care in heart failure, high emotional impact on clinicians when undertaking ACP, and lack of multidisciplinary collaboration between healthcare professionals to reach consensus on when ACP is indicated. The main facilitators were being competent to provide holistic care when using ACP in heart failure, a patient taking the initiative of having an ACP conversation, and having the resources to deliver ACP at a time and place appropriate for the patient. Training healthcare professionals in the delivery of ACP in heart failure might be as important as enabling patients to start an ACP conversation. This twofold approach may mitigate against the high emotional impact of ACP. Complex interventions are needed to support clinicians as well as patients to engage with ACP. **Abstract:** http://bit.ly/30UYOSz

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Noted in Media Watch 22 July 2019 (#623, p.13):

- *CANADIAN FAMILY PHYSICIAN*, 2019;65(7):479. **'End-of-life discussions in advanced heart failure.'** Guidelines recommend discussing goals of care (GoC) and end-of-life (EoL) issues with patients with advanced heart failure; and, as specialists do not consistently do this, primary care providers are often left with this critical role. Using criteria for advanced HF, mortality can be as high as 75% at 1 year. There is a clear need for advance care planning and GoC and EoL discussions, as well as a palliative care approach. **Full text:** http://bit.ly/2LmohjR

A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy

ITALIAN JOURNAL OF PEDIATRICS | Online – 22 July 2019 – The definition of the eligibility criteria of newborn, infant, child, or adolescent patients for palliative care (PC) is complicated by the fact that these patients generally present with very specific case histories that make it inadvisable to directly adopt existing PC protocols devised for adult patients. The authors define a standard set of criteria for establishing pediatric palliative care (PPC) eligibility. According to the guidelines issued by the Higher Institute of Health, the Board of the Italian Society for Palliative Care appointed a multidisciplinary group of eight health care professionals ... to reach a consensus over PPC eligibility. This panel of relevant experts redacted a report summarizing all available scientific information concerning PPC, which was then submitted to the attention of a multidisciplinary jury composed of specialists and non-specialists of the field. The document thus produced was subsequently reviewed by an extended team of experts. A consensus conference drafted a final document determining the guidelines for PPC eligibility of newborns, infants, children, and adolescents suffering from either oncological or non-oncological diseases. This report provides health care providers with practical guidelines on how to define the eligibility of pediatric patients for PPC. Given the current situation in Italy, these guidelines will be instrumental in assisting the implementation of adequate generalist and specialist PPC services as well as in helping policymakers draft and implement national legislation pertaining to PPC. **Full text:** http://bit.ly/2OkqdMe

Current thinking in paediatric palliative care and transition to adult care

A selection of articles that focus on the "current thinking" in paediatric palliative care, including a selection of articles specific to end-of-life care for adolescents and their transition to adult care, posted 8 July 2019 on the European Association for Palliative Care blog at: http://bit.ly/2XC24jA

N.B. English language article.

Related

- *CURRENT OPINION IN PEDIATRICS* | Online – 17 July 2019 – **'Palliative care in pediatric heart failure and transplantation.'** This review examines the current role of palliative care (PC) to support this unique population. Pediatric heart failure patients commonly die in ICUs with high burden of invasive therapies together with end-of-life care (EoLC) needs. In addition, several studies advocate for integration of PC early in disease trajectory, not only focused on EoLC. Many advocate for the core tenets of PC – symptom management, communication of prognosis, and advanced care planning – to be provided by the primary cardiology team, with consultation by pediatric PC specialists. There is also a consensus that PC training should be incorporated into pediatric advanced heart disease training programs. **Abstract:** http://bit.ly/2Mi4xxl

Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences

JOURNAL OF CLINICAL NURSING | Online – 20 July 2019 – Transition of adolescents and young adults within healthcare services has become increasingly important as more children are surviving into adulthood with long-term conditions. Yet limited empirical evidence exists regarding transition experiences. In this qualitative study [involving participants from two children's hospitals and four general hospitals in Ireland], transfer occurred between the ages of 16 to early 20s years depending on the service. None of the hospitals had a transition policy and transition practices varied considerably. Adolescents worried about facing the unknown, communicating and trusting new staff and self-management. The transition process was smooth for some young adults, whilst others experienced a very abrupt transfer. Parents desired greater involvement in the transition process with some perceiving a lack of recognition of the importance of their role. In paediatric services, nurses reported following-up adolescents who struggled with treatment adherence and clinic attendance. Whereas after transfer, little effort was made to engage young adults if there were lapses in care, as this was generally considered the young adults' prerogative. The amount of preparation and the degree to which the shift in responsibility had occurred prior to transition appeared to influence successful transition for adolescents and young adults and their parents. **Abstract:** http://bit.ly/2XZgwaj

> **N.B.** Additional articles specific to palliative and end-of-life care for adolescents and their transition to adult care noted in 15 July 2019 issue of Media Watch (#622, p.3).

Staffing a specialist palliative care service, a team-based approach: Expert consensus white paper

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 June 2019 – The Canadian Society of Palliative Care Physicians (CSPCP) is often asked to recommend how many palliative care (PC) specialists are needed to implement and support an integrated PC program. This information would allow health service decision makers and educational institutions to plan resources accordingly to manage the needs of their communities. In 2017, the CSPCP commissioned a working group to develop a staffing model for specialist PC teams based on the interdependence of three key professional roles, an extensive literature search, key stakeholder interviews, and expert opinions. This article is the Society's recommended starting point that will be further evaluated as it is utilized across Canada. **Abstract:** http://bit.ly/2Ou2lWG

The National Palliative Care Registry: A decade of supporting growth and sustainability of palliative care programs

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 July 2019 – Established in 2008, the National Palliative Care Registry™ data elements align with National Consensus Project (NCP) guidelines related to palliative care (PC) program structures and operations [in the U.S.]. The Registry provides longitudinal and comparative data that PC programs can use to support programmatic growth. As of 2018, 1,000 hospitals and 120 community sites have submitted data to the Registry. Over the past decade, the percentage of hospital admissions seen by PC teams (penetration) has increased from 2.5% to 5.3%. Higher penetration is correlated with teaching hospital status, having a PC trigger, and hospital size. Although overall staffing has expanded, only 42% of Registry programs include the recommended four key disciplines: physician, advanced practice or other registered nurse, social worker, and chaplain. Compliance with NCP guidelines on key structures and processes vary across adult and pediatric programs. The Registry allows PC programs to optimize core structures and processes and understand their performance relative to their peers. **Abstract:** http://bit.ly/2SvACTN

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 beginning on p.16.

Does more health literacy really change behavior?

Docs no less likely than others to get aggressive end-of-life care

MEDPAGE TODAY | Online – 24 July 2019 – Despite their high health literacy, Canadian physicians were just as likely as others in the general population to receive aggressive care as they neared death, researchers found. Home was no more likely to be the location of death for doctors than the non-physician population, according to Robert Fowler, MDCM, MS, of Sunnybrook Health Sciences Centre in Toronto, Ontario, and colleagues writing in *JAMA Network Open*.[1] They had examined deaths in Ontario, where coverage under Canada's universal healthcare system allowed the investigators to minimize confounding due to individual financial concerns and access to acute care. Among some 2,500 physicians who died in the province from April 2004 to March 2015, 52.9% made use of palliative care (PC) services in their last 6 months of life compared with 47.4% among about 7,500 non-doctors, along with lower odds of visiting an emergency department. Yet physicians also were more likely to be admitted to the ICU and to die there. "In a system with universal health coverage, informed healthcare decision makers such as physicians do not consistently opt for less-aggressive care across the board, but instead vary in their choices regarding end-of-life care, with increased use of both intensive and PC," Fowler's group concluded. **Full text:** http://bit.ly/2Gv0rOT

1. 'End-of-life care received by physicians compared with non-physicians,' *JAMA Open Network*, published online 24 July 2019. **Full text:** http://bit.ly/2MdUuJV

Noted in Media Watch, 23 May 2016 (#463, p.12):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 16 May 2016 – **'How U.S. doctors die: A cohort study of healthcare use at the end of life.'** Many believe that doctors in the U.S. die differently from the rest of society. The current findings suggest a more-mixed and nuanced picture. Doctors may be more likely to die using hospice, but they are no less likely to use high-intensity hospital care. If anything, they have higher rates of ICU use in the last 6 months of life. Society as a whole and policy-makers focused on containing healthcare costs in particular may be surprised to learn that even physicians, with knowledge of and experience with death and dying, have use of hospitals nearly identical to that of non-physicians. **Full text:** http://bit.ly/30QI3aQ

Role of palliative medicine in pediatric intensive care units

MONATSSCHRIFT KINDERHEILKUNDE | Online – 11 July 2019 – Implementing palliative care (PC) into pediatric intensive care may at first glance sound contradictory; however, advances in intensive and medical care in general increasingly more often lead to difficult decisions about strategies of care in children with life-limiting diseases, so that the topic becomes more and more relevant. Decisions on when to shift the focus of therapeutic interventions from curative to PC are necessary but difficult for doctors in the intensive care unit. The whole multi-professional team will be confronted with many medical and ethical questions. The reasons for insufficient implementation of PC into intensive care medicine are often a lack of facilities and standard procedures and insufficient qualification of the staff in PC. The implementation of PC medicine into intensive care can improve the treatment of children with life-limiting diseases by a standardized approach, such as obtaining a recommendation on the approach in emergencies, joint discussions with parents and relatives and ethics counseling and increase the contentment of the staff. Intensive care and PC medicine are not contradictory but mutually complement each other. The implementation of standard PC procedures into medical care is necessary in order to optimize the treatment of critically ill children. **Abstract (w. list of references):** http://bit.ly/2OciEac

N.B. German language article.

Cont.

Noted in Media Watch 24 June 2019 (#619, p.11):

- *PEDIATRIC CRITICAL CARE MEDICINE* | Online – 14 June 2019 – **'When a child dies in the PICU: Practice recommendations from a qualitative study of bereaved parents.'** Bereaved parents identified several areas for care delivery and improvement across three time periods: during hospitalization; during the dying phase; and, during bereavement. During hospitalization, parents' recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, demedicalized rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services, as well as improved information delivery. **Abstract:** http://bit.ly/2Ko5MuV

Noted in Media Watch 3 June 2019 (#616, p.9):

- *JOURNAL OF PALLIATIVE CARE* | Online – 29 May 2019 – **'Stopping the momentum of clinical cascades in the PICU: Intentional responses to the limits of medicine.'** The majority of pediatric deaths occur in intensive care units and, among children who survive their pediatric intensive care unit (PICU) stay, many are left with significant morbidities, profound disability and/or technology dependence. Additionally, more than 50% of children admitted to the PICU have baseline chronic medical conditions and these patients are at increased risk of mortality, prolonged ICU length of stay and aggressive interventions clinicians may assumed to be desired by families because they utilized them in the past. Oftentimes, these outcomes are the consequence of a cascade of interventions that, over time, have diminishing potential to improve patient survival. **First page view:** http://bit.ly/2wuDA0E

Hospice and palliative care research in mainland China: Current status and future direction

PALLIATIVE MEDICINE | Online – 21 July 2019 – Hospice care emerged in mainland China in 1988, 30 years ago, but its development since that time has been slow. In 1994, the Ministry of Health listed hospice care into the Catalogue of Diagnostic & Therapeutic Subjects of Medical Institutions, but the public's awareness of hospice and palliative care (PC) and the supply of it are still limited. Large numbers of people still die in acute hospitals. In recent years, hospice and PC has witnessed rapid development: in February 2017, the State Health Planning Commission issued a guideline for hospice care, which began to promote the work of hospice care nationwide. In May of 2019, the second batch of national pilot work on hospice care were chosen, 71 regions including whole area of Shanghai are being involved in developing local hospice care service. In parallel to this clinical expansion, PC research in mainland China has also been developing. **Full text:** http://bit.ly/2JWXI7d

Noted in Media Watch 17 June 2019 (#618, p.5):

- CHINA | Xinhua (Beijing) – 10 June 2019 – **'China to promote end-of-life care services.'** China has begun to pilot an end-of-life care (EoLC) program in Shanghai as well as in over 70 other cities and municipal districts. The pilot program was first launched in five cities and municipal districts in 2017. The National Health Commission released a circular on the pilot program in May, calling for more research and investigations, recruitment of more talent as well as improved mechanisms to serve the program. A total of 283,000 patients received EoLC across the country in 2018. China had about 170 million people aged 65 or above as of the end of 2018, which accounted for nearly 12% of its total population. http://bit.ly/2F1GSNz

N.B. Additional articles on hospice and PC in China noted in past issues of Media Watch: 3 June and 18 March 2019 (#616 and #606, respectively, and 22 October 2018 (#586, p.7).

Understanding what works, why and in what circumstances in Hospice at Home Services for End-of-Life Care: Applying a realist logic of analysis to a systematically searched literature review

PALLIATIVE MEDICINE | In Press – Accessed 21 July 2019 – Forty-nine papers were reviewed, of which 34 were included, contributing evidence to at least one of eight theory areas: 1) Marketing and referral; 2) Sustainable funding model; 3) Service responsiveness and availability; 4) Criteria for service admission;

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5) Knowledge and skills of care providers; 6) Integration and co-ordination; 7) Anticipatory care; and, 8) Support directed at carers. The literature review showed how it was possible to develop a coherent framework and test it against 34 published papers and abstracts. Central to this review was theory building, and as further evidence emerges, programme theories can be refined and tested against any new empirical evidence. Key statements: Hospice at home services comprise of a diverse range of services based on local needs and contextual factors but little is known about which models work best, for whom and under what circumstances. Key areas to be taken into account in optimal hospice at home provision include the importance of the sustainability of the hospice at home service, supporting carer needs and having anticipatory care in place. There are gaps in the evidence in understanding how referral categories, training for non-specialist staff and better care co-ordination influences optimal hospice at home service provision. **Abstract:** http://bit.ly/2Z312Ph

N.B. Click on pdf icon to download/view full text.

Related

- *NURSING ETHICS* | Online – 7 July 2019 – **'Ethical sensitivity and perceptiveness in palliative home care through co-creation.'** In research on co-creation in nursing, a caring manner can be used to create opportunities whereby the patient's quality of life (QoL) can be increased in palliative home care (PHC). This can be described as an ethical cornerstone and the goal of palliative care. Co-creation can be defined as the joint creation of vital goals for patients through the process of shared knowledge between nurses, patients and their relatives. This study explored nurses' experiences of caring encounters and co-creation in PHC from an ethical perspective. An overall theme, a main , and four sub-themes emerged. Through ethical sensitivity and perceptivity, nurses can balance their actions in the moment and change their nursing care actions according to the patient's wishes through co-creation in encounters. **Abstract:** http://bit.ly/2Z4YMXs

Methods for overcoming barriers in palliative care for ethnic/racial minorities: A systematic review

PALLIATIVE & SUPPORTIVE CARE | Online – 26 July 2019 – Ethnic/racial minority groups are less likely to discuss issues involving end-of-life (EoL) treatment preferences and utilize palliative care (PC) or hospice services. Some barriers may be differences in language, religion, lower levels of health literacy, or less access to healthcare services and information. The authors conducted a systematic review on interventional studies that investigated methods to overcome the barriers faced by ethnic/racial minorities when accessing EoL services, including completing advanced directives, accepting PC, and enrolling in hospice. Nine articles were included … with target populations including African Americans, Hispanic or Latinos, and Asian or Pacific Islanders. Three main avenues of interventions included methods to enhance patient education, increase access to healthcare, or improve communication to establish better rapport with target populations. Studies indicate that traditional delivery of healthcare services may be insufficient to recruit patients from ethnic/racial minorities, and outcomes can be improved by implementing tailored interventions to overcome barriers. **Abstract (w. list of references):** http://bit.ly/2YrPRCz

Grief: A brief history of research on how body, mind, and brain adapt

PSYCHOSOMATIC MEDICINE | Online – Accessed 22 July 2019 – Morbidity and mortality following the death of a loved one has long been a topic of research. Early researchers characterized somatic and psychological symptoms and studied immune cell changes in bereaved samples. More recent research has repeatedly demonstrated increased rates of morbidity and mortality in bereaved samples, as compared to married controls, in large epidemiological studies. Recent developments also include the development of criteria for prolonged grief disorder (also termed complicated grief). Newer methods, including neuroimaging, have observed that the greatest impact of the death of a loved one is in those who have the most severe psychological grief reactions. Mechanisms tying bereavement to medical outcomes are scarce, but differences in rumination, in inflammation and in cortisol dysregulation between those who adapt well and those who do not, have been offered with some evidence. Recommendations to propel the field forward include longitudinal studies to understand differences between acute reactions and later adaptation, comparing samples with grief disorders from those with more typical responses, and integrating responses in brain, mind and body. **Abstract:** http://bit.ly/2KKRh3C

End-of-life palliative care in patients with terminal dementia

REVISTA COSTARRICENSE DE SALUD PÚBLICA | Online – Accessed 21 July 2019 – Dementia is a condition that typically involves a gradual and progressive deterioration of the cognition, behavior and functioning of an individual, to death. Palliative medicine assists patients who face progressive degenerative processes like this one and provides them with supplies to improve their quality of life, relieve their pain and support those who assist them; in an interdisciplinary and integral way until the end of his life. This work aims to briefly expose, through a review of current literature, knowledge and current theories about dementia as a terminal condition that requires palliative care (PC); from a holistic perspective, focusing on the management and objectives of patient care with this condition, which brings together both the medical and the patient's vision, their support network and their environment. Dementia is described as a terminal condition that requires PC from the moment of diagnosis, the specific needs of the patient with this condition and the implications of their care, requiring a comprehensive approach and a clear, humanized and patient-centered approach to goals of care; that meet their needs, consider and respect their individuality and contemplate aspects such as their advanced wills. **Full text:** http://bit.ly/2JYdCbV

> **N.B.** Spanish language article. Additional articles on PC for people living with dementia noted in 20 May 2019 issue of Media Watch (#614, pp.14-15).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CLINICAL GERONTOLOGIST* | Online – 19 July 2019 – **'ACT now: The intersection of Acceptance & Commitment Therapy with palliative care in a veteran with chronic suicidal ideation.'** Suicide rates are increasing in the U.S. and groups at elevated risk include older adults, veterans, and those with life-limiting illnesses. However, the treatment of suicidality at end-of-life (EoL) has been little studied. There is emerging evidence that palliative care (PC) itself may be protective against suicide and there is some support for the use of Acceptance & Commitment Therapy (ACT) at EoL. The overlapping mechanisms of PC and ACT are especially well-suited for individuals struggling with suicidality in the context of life-limiting illness. A case from a Veterans Affairs Home-Based Primary Care (HBPC) team is used to illustrate the challenges and opportunities when providing EoL care to an older veteran with chronic suicidal ideation. Prior mental health treatment had limited impact on his suicidality. However, with an integrated ACT and PC approach, the HBPC team was better able to focus on the veteran's goals. This approach was helpful in reducing suicidal ideation and engaging him in EoL decision-making discussions. This case highlights the valuable role of PC in suicide prevention and how the addition of ACT can aid in the effective treatment of chronic suicidal ideation at the EoL. **Abstract:** http://bit.ly/2xZ15zB

- *LEGAL MEDICINE* | Online – 22 July 2019 – **'Euthanasia and other end of life in patients suffering from dementia.'** Medicine aims to relieve patient suffering and cure illness. To relieve suffering is the heart of what doctors do. However, respect for individual autonomy and self-determination are fundamental principles in Western medical ethics and decision-making, often expressed as a desire for control over the timing and manner of death. Patients who become demented often formulate advance euthanasia and assisted suicide directives. Dealing with such request is quite complex because of the specific medical and conflicting ethical questions they raise. Some specific medical and ethical issues arise regarding these substantive requirements when evaluating the euthanasia request of a person suffering from dementia. In jurisdictions that allow euthanasia, the most fundamental prerequisite for a person to make autonomous decisions is capacity. Whether anyone with moderate or severe dementia, and even some with mild dementia, could be deemed to be competent by these criteria is debatable, but during the course of their disease people with dementia sooner or later lose their capacity to make self-determined decisions. **Abstract:** http://bit.ly/2YqCnTo

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- *PALLIATIVE & SUPPORTIVE CARE* | Online – 25 July 2019 – "**An indelible mark." The response to participation in euthanasia and physician-assisted suicide among doctors: A review of research findings.**' The debate regarding euthanasia and physician-assisted suicide (E/PAS) raises key issues about the role of the doctor, and the professional, ethical, and clinical dimensions of the doctor-patient relationship. Where studies measured psychological impact, 30-50% of doctors described emotional burden or discomfort about participation, while findings also identified a comfort or satisfaction in believing the request of the patient was met. Significant, ongoing adverse personal impact was reported between 15% to 20%. A minority of doctors sought personal support, generally from family or friends, rather than colleagues. The themes identified from the qualitative studies were summarized as: 1) Coping with a request; 2) Understanding the patient; 3) The doctor's role and agency in the death of a patient; 4) The personal impact on the doctor; and, 5) Professional guidance and support. Participation in E/PAS can have a significant emotional impact on participating clinicians. For some doctors, participation can contrast with perception of professional roles, responsibilities, and personal expectations. Despite the importance of this issue to medical practice, this is a largely neglected area of empirical research. **Abstract (w. list of references):** http://bit.ly/2GvIH5X

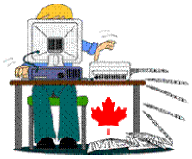
Publishing Matters

Distinguishing opinion from evidence in guidelines

BRITISH MEDICAL JOURNAL | Online – 19 July 2019 – Development of evidence based guidelines requires people with clinical, public health, or other relevant expertise and judgments about the evidence. The evidence underpinning those judgments should be identified, selected, appraised, synthesised, and presented systematically and transparently. But sometimes using evidence systematically and transparently can be challenging: evidence may be unpublished or indirect, diseases rare, contextual information missing, or resources limited. In these situations, obtaining evidence from experts can be efficient, and experts may be the only or main source of evidence. Using experts as a source of evidence has several problems and may seem at odds with evidence based medicine. However, its goal is to use expertise wisely in the context of evidence. The authors contend that there is a difference between evidence that comes from experts (expert evidence) and expert opinion, and argue that the way in which expert evidence is used in a guideline's development has an important bearing on the robustness and trustworthiness of the guideline. **Full text:** http://bit.ly/2LAASQS

Evidence vs consensus in clinical practice guidelines

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 19 July 2019 – All clinical practice guideline recommendations, whether the available evidence is considered as being of high quality or very low quality, require both a judicious consideration of the relevant evidence and consensus from the panel regarding both the interpretation of the evidence and the tradeoff between the benefit vs the harm or burden of the recommended health intervention. As a result, making a distinction between evidence-based and consensus-based guidelines is both misguided and misleading because both require consensus. The crucial difference between evidence-based medicine and non-evidence-based medicine methods is that the former necessitates that judgments are consistent with underlying evidence, whereas the latter do not. **Full text:** http://bit.ly/2GomVB0



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://bit.ly/2RPJy9b

Readers beware! Predatory journals are infiltrating citation databases

INTERNATIONAL JOURNAL OF PUBLIC HEALTH | Online – 24 July 2019 – Publishing in predatory journals has been described as a "waste of people, animals and money." Because predatory journals were assumed not to be indexed in well-known academic search engines and citation databases, it was assumed that their publications would rarely be cited by other scholars or be applied in practice. But publications in these scientifically questionable journals have already infiltrated citation databases such as PubMed (U.S. National Library of Medicine) and Scopus (Elsevier)... Many initiatives aimed at combating predatory journals have focused on reducing submissions by warning researchers not to publish in them. With citation databases already contaminated, researchers, academic institutions, journals, publishers and research funders will need additional strategies to prevent the further spread of predatory publications. **Full text:** http://bit.ly/3109vDq

Noted in Media Watch 20 May 2019 (#614, p.18):

- *THE SCIENTIST* | Online – 9 May 2019 – **'Academics raise concerns about predatory journals on PubMed.'** PubMed, the U.S. National Library of Medicine's repository of millions of abstracts and citations, has long been one of the most highly regarded sources for searching biomedical literature. For some members of the scientific community, the presence of predatory journals – publications that tend to churn out low-quality content and engage in unethical publishing practices – has been a pressing concern. To understand how predatory journals might get into PubMed, it's important to first recognize the database's components. PubMed was originally created in 1996 as a public interface to MEDLINE, the National Library of Medicine's (NLM's) database of citations and abstracts from selected journals in the medical and the life sciences. **Full text:** http://bit.ly/2PZjRz3

Noted in Media Watch 10 September 2018 (#580, p.12):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(35):E1042-E1045. **'How predatory journals leak into PubMed.'** PubMed handles millions of queries daily and represents a key source of knowledge for health researchers worldwide. Much medical research that underpins clinical practice relies on the findings generated by peer-reviewed studies that are retrieved via biomedical databases, in particular, those that are free to search such as MEDLINE and PubMed. Thus, it is imperative that these databases are free of contamination by the outputs of predatory journals with their critically flawed peer review procedures. The authors analyze why this is happening and identify some possible solutions to stop the penetration of predatory journals and publishers into biomedical databases. **Access options:** http://bit.ly/2Jggl2M

N.B. See 'RE: How predatory journals leak into PubMed,' *Canadian Medical Association Journal*, published online 10 December 2018 [Noted in 17 December 2018 issue of Media Watch (#594, p.13)] **Full text:** http://bit.ly/30dEhsU

Predatory journals: Can we stem the rot?

JOURNAL OF POSTGRADUATE MEDICINE, 2019;65(3):129-131. A survey on motivations of authors to publish in presumed predatory journals has shown frustration with time taken by standard journals, repeated rejections, pressure to publish for promotions and lack of mentorship among other reasons for the choosing these journals. While the measures listed will help naïve and unsuspecting scientists steer clear of predatory journals other measures will be needed to discourage scientists those who knowingly submit their research to these journals. These will have to be tackled by supervisory and perhaps punitive measures to be implemented by universities and colleges, sponsors of research projects and ethics committees. Universities and colleges, ethics committees, research funding organizations will also need to rethink their systems and processes for assessment to see if they are actually encouraging submission to these journals. Finally, individual integrity is what will go a long way in stemming the rot and addressing the fraud and deception that has set in. **Full text:** http://bit.ly/2yeA3UP

Would this article be of interest to a colleague?

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Academia Nacional de Cuidados Paliativos (Brazil): http://bit.ly/2G2ISGr

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