

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'Palliative care gaps in providing psychological treatment: A review of the current state of research in multidisciplinary palliative care' (p.5), in *American Journal of Hospice & Palliative Medicine*.

Canada

Doctors highlight chronic health-care shortages in Ontario's northern communities

ONTARIO | CTV News – 8 August 2017 – Doctors are sounding the alarm about the chronic shortage of physicians and health-care services in northern Ontario. After a Health Quality Ontario report found people in Ontario's north have a shorter life expectancy and are more likely to die prematurely,¹ the president-elect of the Ontario Medical Association wrote a searing op-ed about the health care crisis.² The Health Quality Ontario report found most of the health-care "inequities" in Ontario's northern communities, such as higher rates of chronic conditions, premature deaths and lack of access to family doctors, can be attributed to the fact that the population is spread over a vast area with many remote communities. <https://goo.gl/H2xNfA>

Extract from Health Quality Ontario report

In the North East Local Health Integration Network (LHIN) region, 25.3% of people aged 12 and older report having two or more chronic conditions, similar to the 24.5% of people in the North West LHIN region, which is significantly higher than the Ontario rate of 19.7%. First Nations and Métis people in Ontario are disproportionately likely to have a host of chronic diseases and conditions, and are at significantly greater risk of disease and illness. Métis people do not have the same level of access to primary and specialist care in Ontario compared to non-Indigenous Ontarians, which affects their broader health and wellbeing, particularly those living in the north

1. 'Health Equity in Northern Ontario,' Health Quality Ontario, August 2017. <https://goo.gl/biSH5G>
2. 'Health care in Northwestern Ontario beyond becoming a crisis,' *The Toronto Star*, 14 July 2017. <https://goo.gl/hXh1Rx>

N.B. Mention of end-of-life care (EoLC) in the Health Quality Ontario report is limited to mention of one family who received home palliative care services. Postings on the Rural Ontario Institute website offer a perspective on EoLC in remote and rural communities: 1) 'End-of-life Care in Rural Communities' <https://goo.gl/P4e4rn>; and, 2) 'Survey: Urban vs. Rural Palliative Medicine' <https://goo.gl/i5KcPZ>. The latter was conducted in 2015 by the Canadian Medical Association. Additional articles on EoLC in rural and remote regions noted in the 5 June 2017 issue of Media Watch (pp.15-16), and on EoLC for Canada's indigenous peoples in the 17 July 2017 issue of the weekly report (#521, p.13). **BRA**

U.S.A.

Nearly 1 in 5 hospice patients discharged while still alive

NATIONAL PUBLIC RADIO | Online – 11 August 2017 – Hospice care is for the dying. It helps patients manage pain so they can focus on spending their remaining time with loved ones. But in recent years, nearly one in five patients have been discharged from hospice before they die, according to government reports. A study published last month in the journal *Health Affairs* finds that hospices with the highest rate of so-called “live discharges” also have the highest profits.¹ The lead author is Rachel Dolin, a David A. Winston fellow researching health policy. Her paper found an association between high live discharge rates and high profit margins, but it didn’t determine the cause. “It’s important to continue to study this area to get a better sense as to whether profits are driving the decision to discharge patients from hospice, rather than patient preferences and needs,” says Dolin. Government reports show that the

median rate of hospice patients discharged before death has climbed steadily since at least 2000, peaking in 2012 and 2013 at almost one patient in five, though more recently the percentage has declined somewhat. But the rate actually varies widely from one care organization to another. Some hospices discharge less than 2% of their patients prior to death, while others discharge more than 80%. Non-profits have lower rates of live discharge than for-profit hospices. <https://goo.gl/xw3Wjr>

Specialist Publications

‘Better together: Co-existence of for-profit and non-profit firms with an application to the U.S. hospice industry’ (p.12), in *Journal of Economic Literature*.

1. ‘A positive association between hospice profit margin and the rate at which patients are discharged before death,’ *Health Affairs*, 2017;36(7):1291-1298. <https://goo.gl/dgkbCg>

N.B. The focus of this issue of *Health Affairs* is on advance illness and end-of-life care. [Noted in Media Watch 10 July 2017, #520 (p.10)] Journal contents page: <https://goo.gl/febK3j>

Noted in Media Watch 27 March 2017, #505 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 March 2017 – ‘**Factors driving live discharge from hospice: Provider perspectives.**’ Study participants emphasized challenges underlying each decision to discharge patients alive, stressing there often exists a grey line between “appropriate” and “inappropriate” discharges. Discussions also focused on scenarios in which financial motivations drive enrollment and disenrollment practices. <https://goo.gl/x3Fa8J>

Noted in Media Watch 5 December 2016, #490 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 November 2016 – ‘**Events leading to hospital-related disenrollment of home hospice patients: A study of primary caregivers’ perspectives.**’ Four major themes contributing to hospitalization emerged: 1) Distressing/difficult-to-witness signs and symptoms; 2) Needing palliative interventions not deliverable in the home setting; 3) Preference to be cared for by non-hospice physicians or at a local hospital; and, 4) Caregivers not comfortable with the death of their care recipient at home. <https://goo.gl/4qWXhA>

Report says Michigan needs better palliative care for cancer patients

MICHIGAN | Michigan Public Radio Network (Lansing) – 7 August 2017 – A new report says Michigan’s healthcare system does not do as well as other states in providing complete care for people with cancer.¹ The American Cancer Society .. says Michigan doesn’t have the tools in place to meet the demand for palliative care (PC). Andrew Schepers with the American Cancer Society says the organization wants the governor to create a commission to send recommendations to the legislature. <https://goo.gl/Qv9MfG>

1. ‘How Do You Measure Up? A Progress Report on State Legislative Activity to Reduce Cancer Incidence & Mortality.’ The American Cancer Society Cancer Action Network’s annual report illustrates where each state stands on key cancer issues: <https://goo.gl/qiPvVw>

International

End-of-life care in New Zealand

Hospices combine as budgets tighten and life expectancy picks up in Auckland's north

NEW ZEALAND | *The North Shore Times* (Auckland) – 9 August 2017 – Three North Auckland hospices have combined as funding shortfalls put pressure on palliative care services. The Hospices of North Shore, Hibiscus Coast and Warkworth/Wellsford will now work under the umbrella of the newly formed Northern Hospice Alliance, combining resources and services to combat rising costs and tighter budgets. The three hospices together employ more than 200 staff, seeing about 340 patients on a daily basis. The services, which give free specialist care and support to people who are dying and their whanau [i.e., extended family], are funded partially by government but also rely on community donations and endowments to function. <https://goo.gl/afrB92>

Related

- NEW ZEALAND | *Bay of Plenty Times* (Tauranga) – 9 August 2017 – **‘Waipuna Hospice stretched thin by Tauranga's ageing population.’** Chief executive Richard Thurlow said the palliative care service had a government funding contract for 558 referrals last financial year. “We hit that on 21 April with May and June still to go.” The service accepted 720 new referrals that year, on top of the 250-300 it was already caring for when the year began – totalling about 1,000 patients. <https://goo.gl/AJPYVZ>

Noted in Media Watch 3 April 2017, #506 (p.6):

- NEW ZEALAND | News Talk ZB (Auckland) – 30 March 2017 – **‘New Zealand government looks to prioritise palliative care.’** The Government's making assurances palliative care (PC) is one of its health priorities. It comes as a review of the sector recommends major changes and improvements because of a rising demand for PC from the country's aging population.¹ <https://goo.gl/Q11Vr1>

1. ‘The Adult Palliative Care Services in New Zealand: Review and Action Plan,’ Ministry of Health, Government of New Zealand, March 2017. <https://goo.gl/PT64BW>



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>

Specialist Publications

‘Ethical controversies in the process of formulating new national guidelines on cardiopulmonary resuscitation in Sweden’ (p.9), in *Clinical Ethics*.

‘The extent of South African authored articles in predatory journals’ (p.16), in *South African Journal of Science*.

‘Beyond death and dying: How Chinese spouses navigate the final days with their loved ones suffering from terminal cancer’ (p.16), in *Supportive Care in Cancer*.

‘End-of-life care in under resourced countries’ (p.14), in the *Journal of Pain & Symptom Management*.

Results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective

U.K. (England) | Public Health England – 8 August 2017 – Although there were some limitations to the quantitative data, providers written accounts helped to identify weaknesses in data capture relating to care home residents. The richness of their free text contributions have in particular, enhanced our understanding of the challenges and potential enablers to the delivery of support from an specialist palliative care (SPC) provider perspective. Some of the identified challenges are not new and others, including the major issue of staff retention, are endemic of a much wider problem in the health and social care sector. Providers written accounts described some of the ways they responded to locally identified challenges. Yet questions linger about what part commissioners [i.e., Clinical Commission Groups] can play in

targeting support at care homes and encouraging them to engage with SPC education and training. Despite all else, the constant thread running through the accounts is the willingness and professional imperative to enable and provide compassionate care. <https://goo.gl/eiCwQA>

Specialist Publications

'The Liverpool Care Pathway: A systematic review discarded in cancer patients, but good enough for dying nursing home patients?' (p.7), in *BMC Medical Ethics*.

'Talking about end-of-life care: Perspectives of nursing home residents' (p.8), in *Geriatric Nursing*.

End-of-life care services in Wales to get £1 million boost

U.K. (Wales) | *South Wales Argus* (Newport) – 7 August 2017 – The money will be used for a number of initiatives to support people who are approaching the end of their lives, and their families. Extra training will be provided for health professionals to help them initiate difficult conversations about end-of-life care (EoLC) with patients and their families. The funding will also support the development of an all-Wales advanced care planning electronic record system, to take forward priorities for research, and to support GPs. It will also be used to encourage a compassionate community approach to EoLC through projects such as the 'Byw Nawr – Live Now' initiative, which aims to get people in Wales talking more openly about dying, death and bereavement.¹ The money will support the delivery of the Welsh Government's three-year 'End-of-Life Care Delivery Plan, 2017-2020,' published earlier this year.² <https://goo.gl/K9GBsG>



1. 'Byw Nawr – Live Now,' Dying Matters in Wales, 2014. <https://goo.gl/vdkHDF>
2. 'End-of-Life Care Delivery Plan, 2017-2020,' National Health Service Wales, March 2017. [The document is available in both English and Welsh.] <https://goo.gl/r7rGZk>

Noted in Media Watch 6 March 2017, #502 (p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2009;38(1):81-86. **'Developing a template to plan palliative care services: The Welsh experience.'** A formula has been developed to meet the specialist palliative care needs across Wales, appropriate to both urban and rural settings, for populations of all ages and to take into account the requirements for hospital support teams and those working in cancer centers. <https://goo.gl/ilwHk9>



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.18.

Specialist Publications

Paediatric palliative care in Canada

Survey highlights the need for specific interventions to reduce frequent conflicts between healthcare professionals providing paediatric end-of-life care

ACTA PAEDIATRICA | Online – 9 August 2017 – Of the 946 professionals (41%) who responded [to a questionnaire], 466 had witnessed or participated in paediatric end-of-life discussions: 73% said these had led to conflict, more frequently between professionals (58%) than between professionals and parents (33%). Frequent factors included professionals' rotations, unprepared parents, emotional load, unrealistic parental expectations, differences in values and beliefs, parents' fear of hastening death, precipitated situations and uncertain prognosis. Discussions with patients and parents and between professionals were the most frequently used coping strategies. Conflicts were frequently resolved by the time of death. Professionals mainly supported designating one principal physician and nurse for each patient, two-step interdisciplinary meetings – between professionals then with parents – post-death ethics meetings, bereavement follow-up protocols, and early consultations with paediatric palliative care and clinical ethics services. <https://goo.gl/QGKvvy>

Palliative care gaps in providing psychological treatment: A review of the current state of research in multidisciplinary palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 August 2017 – The majority of analyzed studies failed to describe how psychological symptoms were identified and treated, which discipline on the team provided the treatment, and whether psychological symptoms improved as a result of the intervention. The authors reviewed 59 multi-component palliative care (PC) intervention articles and analyzed the mental health components of PC interventions and their outcomes in order to better understand the current state of psychological care in PC. The majority of articles (69.5%) did not provide any details regarding the psychological component delivered as part of the PC intervention. Most (54.2%) studies did not specify which provider on the team was responsible for providing the psychological intervention. Studies varied regarding the type of outcome measure utilized; multi-symptom assessment scales were used in 54.2% of studies, mental health scales were employed in 25.4%, quality of life and distress scales were used in 16.9%, and no psychological scales were re-

ported in 28.8%. Fewer than half the studies (42.4%) documented a change in a psychological outcome. <https://goo.gl/MVXij3>

Silence as an element of care: A meta-ethnographic review of professional caregivers' experience in clinical and pastoral settings

PALLIATIVE MEDICINE | Online – 8 August 2017 – In interactions between professional caregivers, patients and family members at the end of life, silence often becomes more prevalent. Silence is acknowledged as integral to interpersonal communication and compassionate care, but is also noted as a complex and ambiguous phenomenon. International, interdisciplinary research and opinion endorses the value of silence in clinical care. As a multi-functional element of interpersonal relationships, silence operates in partnership with speech to support therapeutic communication. As a caregiving practice, silence is perceived as particularly relevant in spiritual and existential dimensions of care when words may fail. <https://goo.gl/aXHib8>

Related

- *INTERNATIONAL REVIEW OF PSYCHIATRY* | Online – 7 August 2017 – **'A person-centred approach in medicine to reduce the psychosocial and existential burden of chronic and life-threatening medical illness.'** The authors discuss the main psychosocial and existential burden related to chronic and advanced illnesses, and the diagnostic and therapeutic implications for a dignity preserving care within a person-centred approach, examined in terms of care of the person's whole health, for the fulfilment of the person's health aspirations... <https://goo.gl/jUCDq4>

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- *PALLIATIVE MEDICINE* | Online – 8 August 2017 – ‘**Death anxiety interventions in patients with advanced cancer: A systematic review.**’ Nine unique quantitative studies were identified, including five randomised controlled trials, involving a total overall of 1,179 advanced cancer patients. All studies were psychotherapeutic in nature and centred on existential themes such as meaning, dignity, relationships and spiritual well-being. The therapies investigated shared overlapping themes, but varied in duration, therapist experience, training required, and burden on patient. <https://goo.gl/vd5bjq>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 9 August 2017 – ‘**Meaning of life, representation of death, and their association with psychological distress.**’ The authors’ findings support the hypothesis that participants who represent death as a passage and have a strong perception of the meaning of life tend to report lower levels of distress, anxiety, and depression. They recommend that perceived meaning of life and representation of death be more specifically examined in the cancer and palliative care settings. <https://goo.gl/k21RUP>

Noted in Media Watch 17 July 2017, #521 (p.11):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):114-118. ‘**Psychological ideas in palliative care: Diagnosis and formulation.**’ There is growing recognition in the palliative care community of the emotional and psychological needs of patients – and their carers – as they reach the end of life. But not every patient needs, wants or has access to formal contact with a psychologist. What’s more, all members of a multidisciplinary team are likely to experience the impact of psychological matters in their daily practice with patients and colleagues, whether or not their role is to explicitly address those.

N.B. Earlier articles in this series: ‘**Attachment theory**’ in the 27 February 2017 issue of Media Watch (#501, p.7) and ‘**Emotional regulation**’ in the 3 April 2017 issue of the weekly report (#506, p.11). Access to articles in the *European Journal of Palliative Care* requires a subscription. Journal website: <https://goo.gl/bmg5E5>.

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

Addressing the challenges of palliative care for homeless veterans

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 August 2017 – Multidisciplinary focus groups, interviews with community and Veterans Affairs (VA) leaders and with 29 homeless veterans were conducted in five cities. A forum of national palliative and homelessness care leaders and representatives from each focus group then convened. The forum developed 12 recommendations to address the following barriers: 1) Declining health often makes independent living or plans to abstain impossible, but housing programs usually require functional independence and sobriety; 2) Managing symptoms within the homelessness context is challenging; 3) Discontinuities within and between systems restrict care; 4) VA regulations challenge collaboration with community providers; 5) Veterans with unstable housing who are at EoL and those who care for them must compete nationally for prioritization of their care. Care of veterans at EoL without homes may be substantially improved through policy changes to facilitate access to appropriate housing and care, better dissemination of existing policy, cross-discipline and cross-system education, facilitated communication among VA, community, homeless and EOL providers, and pilot testing of VA group homes or palliative care facilities that employ harm reduction strategies. <https://goo.gl/sXwLf7>

N.B. Additional articles on end-of-life care for the homeless noted in the 24 July 2017 issue of Media Watch (#522, p.4).

Primary palliative care education: A pilot survey

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 August 2017 – The demand for palliative services is outpacing the availability of specialist palliative care (PC) clinicians. One strategy to fill this gap is to improve “primary palliative care” skills and knowledge of all clinicians who care for seriously ill patients. Previous educational efforts have shown mixed results and one possible explanation is unrecognized discordance of educational goals between those offering education and potential primary PC learners. The results suggest substantial areas of both concordant and discordant opinions with respect to educational topics and learning settings. <https://goo.gl/tDpuop>

Noted in Media Watch 3 October 2016, #482 (p.6):

- *AMERICAN JOURNAL OF MEDICINE* | Online – 29 September 2016 – ‘**Future of the palliative care workforce: Preview to an impending crisis.**’ The authors project no more than a 1% absolute growth in palliative care (PC) physicians in 20 years. During the same two decade period, the number of persons eligible for PC will grow by over 20%, resulting in a ratio of only one physician for every 26,000 patients by 2030. <https://goo.gl/0TkS6L>

Advance directives in hospice healthcare providers: A clinical challenge

AMERICAN JOURNAL OF MEDICINE | Online – 7 August 2017 – On a daily basis, healthcare providers, especially those dealing with terminally ill patients, such as hospice workers, witness how advance directives (ADs) help ensure the wishes of patients. They also witness the deleterious consequences when patients fail to document the care they desire at their end of life. To the best of the authors’ knowledge there are no data concerning the prevalence of ADs among hospice healthcare providers. They, therefore, explored the prevalence and factors influencing completion rates in a survey of hospice healthcare providers. The majority of hospice healthcare providers [i.e., 56% of 890 survey respondents] had not completed an advance directive (AD). These results are very similar to those for other healthcare providers treating patients with terminal diseases, specifically oncologists. Since, at completion, 43% said that they would now complete an AD, such a survey of healthcare providers may help increase completion rates. <https://goo.gl/BWoQvQ>

Palliative care in the top end: The continuing cancer bias

AUSTRALIAN JOURNAL OF RURAL HEALTH | Online – 11 August 2017 – No abstract is available. For access options: <https://goo.gl/jromDu>

The Liverpool Care Pathway: A systematic review discarded in cancer patients, but good enough for dying nursing home patients?

BMC MEDICAL ETHICS | Online – 10 August 2017 – The Liverpool Care Pathway (LCP) is an interdisciplinary protocol, aiming to ensure that dying patients receive dignified and individualized treatment and care at the end-of-life. LCP was originally developed in 1997 in the U.K. from a model of cancer care successfully established in hospices. It has since been introduced in many countries, including Norway. The method was withdrawn in the U.K. in 2013. This review investigates whether LCP has been adapted and validated for use in nursing homes and for dying people with dementia. The search identified 12 studies, but none describing an evidence-based adaption of LCP to nursing home patients and people with dementia. No studies described the LCP implementation procedure, including strategies for discontinuation of medications, procedures for nutrition and hydration, or the testing of such procedures in nursing homes. No effect studies addressing the assessment and treatment of pain and symptoms that include dying nursing home patients and people with dementia are available. If LCP is not the optimal intervention in NHs, what should replace it, and how would this be better? In a comprehensive white paper on behalf of the European Association for Palliative Care ... a Delphi expert rating evaluated 11 domains and 57 recommendations on palliative care and organized the domains as important for end of life care in people with dementia...¹ <https://goo.gl/xY9Eb6>

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1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 2014;28(3):197-209. [Noted in Media Watch 8 July 2013, #313 (p.10)] <https://goo.gl/LoFDWE>

Related

- *GERIATRIC NURSING* | Online – 1 August 2017 – '**Talking about end-of-life care: Perspectives of nursing home residents.**' Three key domains emerged: 1) Preferences for today; 2) Anticipating the end of my life; and, 3) Preferences for final days. Residents linked their everyday living and end-of-life preferences by using "if and then" logic to convey anticipation and readiness related to end-of-life. These findings suggest new strategies to start discussions of end-of-life care preferences with nursing home residents. <https://goo.gl/WFvdYq>

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

- *JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE*, 2017;18(6):465-469. '**International survey of end-of-life care in nursing homes.**' This article reports the findings of a survey on end-of-life care in nursing homes of 18 long-term care (LTC) experts across 15 countries. They strongly agreed hospice and palliative care should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. <https://goo.gl/U3c3Xy>

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

When a parent dies: A systematic review of the effects of support programs for parentally bereaved children and their caregivers

BMC PALLIATIVE CARE | Online – 10 August 2017 – The included studies were published between 1985 and 2015, with the majority published 2000 onwards. They were published within several disciplines, such as psychology, social work, medicine and psychiatry, which illustrates that support for bereaved children is relevant for different professions. The interventions were based on various forms of support: group interventions for the children, family interventions, guidance for parents and camp activities for children. In fourteen studies, the interventions were directed at both children and their remaining parents. These studies revealed that when parents are supported, they can demonstrate an enhanced capacity to support their children. In three studies, the interventions were primarily directed at the bereaved children. The results showed positive between group effects both for children and caregivers in several areas, namely large effects for children's traumatic

grief and parent's feelings of being supported; medium effects for parental warmth, positive parenting, parent's mental health, grief discussions in the family, and children's health. <https://goo.gl/Vp1HdX>

Complicated grief in Canada: Exploring the client and professional landscape

JOURNAL OF LOSS & TRAUMA | Online – 10 August 2017 – The authors wanted to learn: a) What tools Canadian practitioners used to identify or diagnose complicated grief (CG), and; 2) What interventions or strategies they used to address CG. Sixty three professionals responded to a survey. There were no straightforward answers to these questions... Practitioners used a wide assortment of tools and strategies with no consensus on any one approach or tool. <https://goo.gl/4S5jfU>

Related

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 8 August 2017 – '**Distrust in the end-of-life care provided to a parent and long-term negative outcomes among bereaved adolescents: A population-based survey study.**' The authors investigated the negative, long-term outcomes of cancer-bereaved sons' and daughters' distrust in the care that was provided to a dying parent. In those who reported no or little trust (i.e., distrust), they found statistically significantly higher risks of various negative outcomes at the time of survey: bitterness toward health care professionals for not having done everything that was possible ... and, for having stopped treatment..., self-destructiveness (e.g., self-injury) and psychological problems (e.g., moderate to severe depression...). <https://goo.gl/zNxmK3>

Heroin in the hospice: Opioids and end-of-life discussions in the 1980s

CANADIAN MEDICAL ASSOCIATION JOURNAL | In press – Accessed 8 August 2017 – At the end of the 1970s, a Toronto-based celebrity doctor and syndicated columnist, Kenneth Walker, who wrote under the pseudonym W. Gifford Jones, launched a campaign to legalize heroin... In his view, it was one answer to the problem of treating end-of-life (EoL) pain in Canadian society. This ignited debates about patient-consumer choice in the medical marketplace and heroin as a valid analgesic. While this remains a largely untold story, heroin use in the hospice was thoroughly infused with politics, social values and cultural norms of the time. His story embodies how the politics of pain, opioid addiction, and proper EoL therapies present enduring challenges in a modern democratic society. <https://goo.gl/jg8Qdp>

N.B. Kenneth Walker's campaign prompted the federal government to establish in 1995 the Special Senate Committee on Euthanasia & Assisted Suicide. The committee recommended against legalizing heroin and tabled a range of recommendations to improve pain management in cancer, at the time the main focus of hospice and palliative care. View/download the committee's report at: <https://goo.gl/V1tL23> **BRA**

Ethical controversies in the process of formulating new national guidelines on cardiopulmonary resuscitation in Sweden

CLINICAL ETHICS | Online – 9 August 2017 – The Delegation for Medical Ethics within the Swedish Society of Medicine has taken the initiative to create national ethical guidelines on cardiopulmonary resuscitation (CPR). The reasons were indications of differences in the way decisions about CPR were made and documented and requests expressed by health-care professionals for new national ethical guidelines. The purpose of this article is to present ethical issues on which it was difficult to reach consensus due to divergent opinions expressed by the people and organisations involved. The arguments for and against a particular point of view or wording in the text are presented. The main controversies were related to the following six issues; 1) Determining whether or not CPR is beneficial for the patient; 2) The presence of close loved ones during CPR; 3) Performing CPR for the benefit of people other than the patient” 4) Ambulance personnel's mandate to decide not to initiate and to terminate CPR outside hospital; 5) Limiting the length and content of CPR; and, 6) Whether or not to specify a week of gestation before which CPR should not be started. <https://goo.gl/tJjcvD>

Noted in Media Watch 21 March 2016, #454 (p.13):

- *RESUSCITATION* | Online – 11 March 2016 – ‘**Themes and variations: An exploratory international investigation into resuscitation decision-making.**’ 88% of survey respondents reported a method for implementing do not attempt cardiopulmonary resuscitation decisions, 90% of which discussed resuscitation wishes with patients at least half the time. 94% thought national guidance should exist, with 53% of countries surveyed reporting existence of such guidance. <http://goo.gl/sNCM0G>

Noted in Media Watch 25 January 2016, #446 (p.16):

- *RESUSCITATION* | Online – 14 January 2016 – ‘**A survey of key opinion leaders on ethical resuscitation practices in 31 European Countries.**’ The authors report the responses to a survey covering four domains of resuscitation: 1) Approaches to end-of-life care and family presence during CPR; 2) Determinants of access to best resuscitation and post-resuscitation care; 3) Diagnosis of death and organ donation; and, 4) Emergency care organisation. <http://goo.gl/me0mUy>

Family satisfaction with end-of-life care in the intensive care unit: A systematic review of the literature

DIMENSIONS OF CRITICAL CARE NURSING, 2017;36(5):278-283. The authors' search yielded 466 articles. Review of the titles and abstracts resulted in 122 articles that underwent full review; 30 articles met study inclusion and were included in the final analysis. Major themes identified from the literature included communication, decision making, nursing care, intensive care unit (ICU) environment, and spiritual care. Families can provide valuable insight and information on the quality of care provided in the ICU

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at end of life. Their perceptions of communication, decision making, nursing care, the ICU environment, and spiritual support strongly influence their satisfaction or dissatisfaction with end-of-life care (EoLC) in the ICU. Personalized and frequent communication, assistance in the decision-making process, compassionate nursing care, a warm, family-friendly environment, and spiritual support can help alleviate the sequelae and enhance family satisfaction with EoLC in the ICU. <https://goo.gl/o9uimn>

Noted in Media Watch 5 September 2016, #478 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 31 August 2016 – ‘**Palliative care in critical care settings: A systematic review of communication-based competencies essential for patient and family satisfaction.**’ There is an emerging literature on the physician competencies most meaningful to patients and their families. However, there has been no systematic review on physician competency domains outside direct clinical care most important for patient- and family-centered outcomes in critical care settings at the end of life. <http://goo.gl/Z8zQuV>

Noted in Media Watch 3 August 2015, #421 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 July 2015 – ‘**A systematic review of family meeting tools in palliative and intensive care settings.**’ The authors sought to identify tools available to aid the conduct of family meetings in palliative, hospice, and intensive care unit settings. They identified 16 articles containing 23 tools in seven categories: 1) Meeting guide; 2) Meeting planner; 3) Documentation template; 4) Meeting strategies; 5) Decision aid/screener; 6) Family checklist; and, 7) Training module. <https://goo.gl/C56HuV>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 August 2017 – ‘**Legal support for palliative care patients.**’ The authors trace the origins of legal support for palliative care (PC) patients, detail models of legal support, and describe achievements and challenges. There is robust and growing acceptance of legal support as a key component of holistic PC, and many PC professionals are identifying and addressing the legal needs they encounter through mediation, guidance on basic rights or referrals to a lawyer. <https://goo.gl/9wXDWg>

“To die with dignity”: An update on palliative care

INTERNAL MEDICINE JOURNAL, 2017;47(8): 865-871. Significant developments have occurred in the discipline of palliative care (PC) in the modern era. This article explores those developments, challenges some widely held misconceptions about the role and daily practice of the discipline, highlights the growing recognition of the role of PC in non-malignant diseases, briefly discusses innovations in symptom management and reflects on the underlying principles, maturation and challenges faced by the discipline. The practice of PC is broad. There is an expansive nature to all clinical interactions. There are certainly no artificial barriers. In other words, the discipline is more than symptomatology. This is vital. Symptoms may be the beginning, but never the end of the exploration. In the same way that the physical may be the beginning, but is never the end of the person. Sadness, grief, fear of the future, feelings of being a burden, worries about how their family will cope, depression, regrets, humour, and love in all its

expression. A clear command of the physical aspect of our patient's illness, an open and creative mind in all aspects of our work – both are expected. PC, this most counter-intuitive of disciplines, sits within internal medicine as a permanent reminder of the mortality of our patients and our collective responsibility to help them achieve a dignified death. <https://goo.gl/v2rxB5>

Extract from *Internal Medicine Journal* article

Arguably, of all the disciplines of internal medicine, palliative care (PC) is the least understood and most shrouded in myth and misconception. Sadly, that misunderstanding has been perpetuated by inadequate education in and exposure to PC at undergraduate and postgraduate levels. Unfortunately, it has resulted in many physicians holding erroneous views and attitudes to PC. Primary amongst those views is that this is a discipline only relevant in the final weeks of life.

Cont.

Related

- *PALLIATIVE MEDICINE & HOSPICE CARE*, 2017;3(2):22-25. **‘Emerging quality improvement concepts to enhance the patient and family experience in hospice and palliative care.’** The author describes three quality improvement models to improve the patient and family experience of care: 1) Involvement of the primary care providers throughout the patient’s disease course; 2) Modeling of decision-making behavior for surrogates using narratives; and, 3) Increasing engagement with end-of-life care among the public-at-large. <https://goo.gl/16iJ8k>

End of life and people with intellectual disability

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 31 July 2017 – It has only been four years since the last special issue on death and dying...¹ End-of-life (EoL) research is relatively new in the field, but with “a small but growing international interest.” That characterization is partly challenged by the size (15 papers and one consensus statement) of the the current special issue. Recognition of international interest is evident from the geographic spread of papers, from five countries – Australia, Ireland, New Zealand, the U.K., and the U.S. – ably illustrating that dying and death know no international boundaries, are ageless, timeless and span all cultures and faiths. Even so, as an emerging field, there are inevitable gaps in the research base. This special issue addresses some of those gaps in that, to our knowledge, several papers represent the first research on important, but previously unexamined topics and/or participant groups. <https://goo.gl/8F4NzD>

Patients with disabilities: Avoiding unconscious bias when discussing goals of care

AMERICAN FAMILY PHYSICIAN. 2017;96(3):192-195. False assumptions about patients’ quality of life can affect prognosis, the treatment options that we present, and the types of referrals that we offer. In this case [study], the physician equated complex disability with terminal illness. This common confusion can result in premature withdrawal of life-preserving care. Disability is not a disease. Persons with physical, mental, and cognitive disabilities can and do live rich, full lives. They are often healthy, even if they need support for basic activities of daily living. Despite a high prevalence of chronic medical conditions, the life expectancy of persons with developmental disabilities approaches that of the general population. <https://goo.gl/RwHNht>

1. ‘Death and Dying,’ *Journal of Applied Research in Intellectual Disabilities*, 2013;26(3):183-256. [Noted in Media Watch 22 April 2013 (#302, p.9)] Contents page: <https://goo.gl/U9qTv3>

N.B. Several articles mentioned in the above editorial had not been posted on the journal’s website at the time this issue of Media Watch was distributed. Among those that can be viewed/downloaded:

- **‘Emergency medical services providers’ perspective of end-of-life decision making for people with intellectual disabilities,** published online 24 May 2017. [Noted in Media Watch 29 May 2017 (#514, p.9)] <https://goo.gl/T5CPSa>
- **‘Intellectual disabilities and decision making at end of life: A literature review,’** published online 5 July 2016. [Noted in Media Watch 1 August 2016, #473 (p.14)] <https://goo.gl/aB3tJy>

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 recently published a White Paper containing thirteen norms and related statements, real-life examples, and available resources.¹

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. Access to the *European Journal of Palliative Care* requires a subscription. Volume 3, No. 1 contents page: <http://goo.gl/qWex7>

Better together: Co-existence of for-profit and non-profit firms with an application to the U.S. hospice industry

JOURNAL OF ECONOMIC LITERATURE | In press – Accessed 7 August 2017 – Although non-profit dominance is commonly studied, some markets maintain a mix of both non-profit and for-profit firms. This is puzzling; if firms serve the same market, why isn't one optimal ownership chosen? The authors show that the co-existence of non-profit and for-profit firms can lead to a greater diversity of consumer types being served, even if both firms merely act as profit-maximizers. Each ownership type specializes and divides the breadth of consumer types between themselves. The authors show this is the case for a market where firms serve consumers for multiple consumption durations, but where charitable donations are part of a non-profit firm objective function and happen after services have been provided. This is especially true if the value of the goods or service may be non-excludable beyond the immediate consumption or direct consumer. The authors show that non-profit and for-profit providers split the patient market according to length of stay and provide evidence that participation of both ownership types leads to a wider range of patients being served. <https://goo.gl/sMD7JX>

N.B. Scroll down to 'Better together...' to access full text of the article.

Noted in Media Watch 2 May 2016, #460 (p.9):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 30 April 2016 – '**Effect of ownership on hospice service use: 2005-2011.**' In addition to for-profit and not-for-profit hospice agencies differing according to important dimensions, there is substantial heterogeneity within these ownership categories, highlighting the need to consider factors such as agency size and chain affiliation in understanding variations in Medicare beneficiaries' hospice care. <http://goo.gl/wwXgBl>

Noted in Media Watch 25 April 2016, #459 (p.11):

- *THE GERONTOLOGIST* | Online – 21 April 2016 – '**Who knew? Hospice is a business. What that means for all of us.**' Although other health care programs are regularly pilloried in the press, hospice programs are often lauded. Indeed, they sometimes appear so mission-driven that one might mistake them for charities. They are not. Whether for-profit or not-for-profit enterprises, they are businesses – and concerned about their bottom line. <http://goo.gl/02DmFt>

Noted in Media Watch 19 January 2015, #393 (p.2):

- *THE WASHINGTON POST* | Online – 14 January 2015 – '**How the drive for profits is shaping end-of-life care.**' A federal watchdog has warned that financial incentives in Medicare may be warping the ways that hospice care works in the U.S. The inspector general for the Department of Health & Human Services has warned – yet again – that financial incentives in Medicare may be warping the ways that hospice care works in the U.S. <http://goo.gl/iU8z2O>

What has philosophy got to do with it? Conflicting views and values in end-of-life care

JOURNAL OF MEDICAL ETHICS | Online – 9 August 2017 – Philosopher Frances Kamm analyses and criticises in detail a set of highly influential U.S. documents/guidelines and research studies relating to end-of-life care (EoLC) and advanced care planning.¹ These documents, written by a diverse group of experts working in and around palliative care, were designed to address widely recognised problems in care of the dying in the U.S. The documents analysed by Kamm are not the sort of thing that usually elicit ethical analysis. They are not endorsing withdrawal of artificial nutrition and hydration at the (EoL) of life. They do not delve into elective ventilation, terminal sedation or assisted suicide, or other controversial choices at the EoL. Instead, the various documents attempt to identify and recommend evidence-based initiatives in EoLC. Several of them focus on ways to encourage and improve patients' conversations about their preferences for medical treatment towards the EoL. We might be tempted to wonder what could be wrong with that? What does philosophy have to contribute to these topics? However, as Kamm makes clear in her paper, documents like these are sometimes ambiguous about the concepts that they invoke and they make assumptions that could be challenged. <https://goo.gl/RFtpRM>

Cont.

1. 'Advanced and end of life care: cautionary suggestions,' *Journal of Medical Ethics*, published online 7 February 2017. <https://goo.gl/NSrLJw>

Practice patterns, attitudes, and barriers to palliative care consultation by gynecologic oncologists

JOURNAL OF ONCOLOGY PRACTICE | Online – 7 August 2017 – The majority of gynecologic oncologists [i.e. survey respondents] perceived palliative care (PC) as a useful collaboration that is underused. Fear of perceived abandonment, however, by the patient and family members was identified as a significant barrier to PC consult. Members of the Society of Gynecologic Oncology were electronically surveyed... Thirty percent of respondents thought that PC services should be incorporated at first recurrence, whereas 42% thought PC should be incorporated when prognosis for life expectancy is ≤ 6 months. Most participants (75%) responded that PC consultation is reasonable for symptom control at any stage of disease. Respondents were most likely to consult PC services for pain control (53%) and other symptoms (63%). Eighty-three percent of respondents thought that communicating prognosis is the primary team's responsibility, whereas the responsibilities for pain and symptom control, resuscitation status, and goals of care discussions were split between the primary team only and both teams. <https://goo.gl/RCKPS5>

Noted in Media Watch 21 November 2016, #488 (p.13):

- *OBSTETRICS & GYNECOLOGY* | Online – 3 November 2016 – '**Palliative care in obstetrics and gynecology.**' Obstetrics and gynecology patients for whom palliative care (PC) is most appropriate include women with gynecologic cancer and women with a fetus or neonate with a potentially life-limiting illness. Integration of PC for these patients offers clinical and health care utilization benefits, including improved symptom management, improved quality of life, and high-value care. <https://goo.gl/pUvhwg>

Noted in Media Watch 25 August 2015, #372 (p.9):

- *GYNECOLOGIC ONCOLOGY*, 2014;135(2):244-248. '**Needs assessment of palliative care education in gynecologic oncology fellowships: We're not teaching what we think is most important.**' There is no correlation between which palliative care (PC) topics are currently being taught and which are considered most important. Interest in new PC curricular materials is high, representing an opportunity for curricular development and dissemination. <https://goo.gl/tKGfkY>

Palliative care for tuberculosis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 August 2017 – In 2014, 1.5 million people died of tuberculosis (TB) worldwide, including 400,000 co-infected with HIV. TB remains a major cause of death and suffering globally in spite of the fact that it is supposed to be a curable disease. Drug resistant forms of TB have developed as a result of poor treatment compliance, including multi-drug and extreme drug resistant forms that take longer to treat and have higher likelihoods of treatment failure. In 2010, at the initiation of the TB community, a partnership was formed between the WHO 'Stop TB Program, the Worldwide Hospice Palliative Care Alliance,' and the Open Society Foundation's 'International Palliative Care Initiative' to explore how to improve the ability of TB professionals to deliver palliative care to their patients. This article describes the progress made in the last six years and the barriers remaining. <https://goo.gl/gyJy1S>

Noted in Media Watch 18 June 2012, #258 (p.15):

- *THE LANCET INFECTIOUS DISEASES* | Online – 11 June 2012 – '**Palliative and end-of-life care in the global response to multidrug-resistant tuberculosis.**' An international expert symposium was convened to articulate an appropriate palliative care response for people with multidrug-resistant tuberculosis. Several policies should be updated to ensure that palliative and end-of-life care is in place alongside treatment should cure be achieved ... and, to the end of life if not. <https://goo.gl/j1BYBB>

End-of-life care in under resourced countries

During the past week, the *Journal of Pain & Symptom Management* posted several articles on the development/status of palliative care (PC) in under resourced countries, for example:

‘The palliative care journey in Kenya and Uganda.’ This update assesses the policy environment, progress in education, access to essential medicines, PC implementation efforts, and legal and human rights work. East African nations have huge disease burdens, both communicable and non-communicable. HIV and cancer are the major causes of mortality in Kenya and Uganda and put huge demands on the healthcare system as well as on the country’s economies. <https://goo.gl/pPcgFx>

N.B. Additional articles on PC in Kenya and Uganda noted in the 10 July 2017 issue of Media Watch (#520, p.12).

‘Development of palliative care in Armenia.’ In the last seven years considerable progress has been made, but many problems remain unresolved. Policies developed include completion of a national needs assessment, a recognized working group on PC formed, national standards approved, a concept paper on PC approved, resolutions on PC as a specialized service approved, PC became a subspecialty in medicine, PC qualifications developed, and a social assistance package approved. <https://goo.gl/Ad5HhL>

N.B. Human Rights Watch reports on PC in Armenia noted in the 20 February 2017 issue of Media Watch (#500, p.5).

‘Palliative care in Kazakhstan.’ A National Palliative Care Strategy provides the legislative framework that mandates the components of PC that must be available at no cost for patients living with cancer. PC courses are provided in several of the medical universities and nursing schools with practical training in local hospices who also offer seminars each year to practicing health care professionals. There is no PC or palliative medicine specialty in the national classifier of specialties. <https://goo.gl/k4G5yy>

N.B. Additional articles on PC in under resourced countries, including Kazakhstan, noted in the 14 October 2013 issue of Media Watch (#327, pp. 13-14).

‘Palliative care development in Mongolia.’ Mongolia began PC development in 2000 with the creation of the Mongolian Palliative Care Society and the Palliative Care Department [at the Mongolian National University of Medical Sciences]. PC is included in the Mongolia’s Health Law, Health Insurance Law, Social Welfare Law, National Cancer Control Program, and the National Program for Non-Communicable Diseases, and has approved ‘Palliative Care Standards & Pain Management Guidelines.’ <https://goo.gl/iRiyAL>

N.B. Additional articles on PC in Mongolia noted in the 10 April 2017 issue of Media Watch (#507, p.4).

Related

‘WHO Public Health Model: A roadmap for palliative care development.’ The Open Society Foundation’s International Palliative Care Initiative began to support PC development in Central and Eastern Europe and the Former Soviet Union in 1999. As a public health concern, progress in PC requires integration into health policy, education and training of health care professionals, availability of essential pain relieving medications and health care services. <https://goo.gl/n6aUDd>

‘Promoting palliative care internationally: Building leaders to promote education, practice, and advocacy.’ The End-of-Life Nursing Education Consortium curriculum was designed to meet the needs of nurses caring for patients with serious and complex illnesses at the end of their lives. This curriculum has been taught in every state across America and in 91 countries around the world and has been translated into 8 languages. Over 21,400 trainers have returned to their institutions and educated over 642,000 colleagues. <https://goo.gl/KtamYj>

‘Pain & Policy Studies Group: Two decades of working to address regulatory barriers to improve opioid availability and accessibility around the world.’ The Pain & Policy Studies Group (PPSG), a global research program at the University of Wisconsin Carbone Cancer Center, has worked passionately to fulfil its mission of improving pain relief by achieving balanced access to opioids worldwide. Its early work highlighted the conceptual framework of balance leading to development of the guidelines and criteria for evaluating opioid policy. <https://goo.gl/5ikptF>

N.B. Additional articles on opioid policy initiatives noted in the 3 February 2014 issue of Media Watch (#343, pp. 10-11).

A review of palliative and hospice care in the context of Islam: Dying with faith and family

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 August 2017 – By starting to understand Muslim culture, we can seek common ground with Islamic culture within the American experience and bridge opportunities for better palliative and hospice care here and in Middle Eastern countries. The U.S., Canada, and Europe are education hubs for Middle Eastern students, creating an opportunity for the palliative and hospice care philosophy to gain access by proxy to populations of terminally ill patients who can benefit from end-of-life care. Within the guide of the key search terms, the authors learned that, at a glance, over 100 articles meet the search criteria, but after a closer inspection, only a portion actually contributed knowledge to the literature. This confirmed the need for research in this vein. More importantly, they posit that once the layers of culture, religion, norms, and nationality are removed, human beings share a kinship based on family, spirituality, death and dying, and fear of pain. This is evident when we compare the Middle Eastern end-of-life experience with the western end-of-life care. <https://goo.gl/pQHfnb>

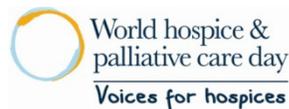
Noted in Media Watch 26 June 2017, #518 *p.13):

- *THE PERMANENTE JOURNAL*, 2017;21(2):16-190. ‘Supporting Muslim patients during advanced illness.’ This article explores areas of importance in the context of advanced illness for practitioners of Islam. These include the conditions needed for prayer, the roles of medical treatment and religious authority, the importance of modesty, the religious concordance of clinicians, the role of family in medical decision making, advance care planning, and pain and symptom management. Initial recommendations to optimize care for Muslim patients and their families, informed by the described tenets of Muslim faith, are provided for clinicians and health systems administrators. <https://goo.gl/CHC3UF>

N.B. Additional articles on the Islamic perspective on death, end-of-life, and end-of-life care are noted in the 14 November 2016 issue of Media Watch (#487, p.11).

Notes from the hospital bedside: Reflections on researcher roles and responsibilities at the end of life in dementia

QUALITY IN AGEING & OLDER ADULTS | Online – Accessed 8 August 2017 – This study explores some of the ethical and practical dilemmas faced by an experienced researcher in undertaking research with a person with dementia... The presented case study ... raises three critical reflection points: 1) Researcher providing care (i.e., the place and positioning of compassion in research observation); 2) What do the stories mean? (i.e., the reframing of the subject’s words, gestures and behaviours as end of life (EoL) review, potentially highlights unresolved personal conflicts and reflections on loss); and, 3) Communication is embodied (i.e., the need to move beyond the recording of words to represent lived experience and into more multi-sensory methods of data capture). Researcher guidance and training about EoL observations in dementia is presently absent in the literature and this case study stimulates debate in a much overlooked area, including the role of ethics committees. <https://goo.gl/XdZTzd>



14 October 2017

Universal health coverage and palliative care – Don’t leave those suffering behind

<https://goo.gl/diYn7i>

The extent of South African authored articles in predatory journals

SOUTH AFRICAN JOURNAL OF SCIENCE, 2017;113(7/8):1-9. The authors present a first estimate of the extent of predatory publishing amongst South African academics. This estimate is based on an analysis of all South African authored papers that qualified for subsidy over the period 2005 to 2014. The analysis shows that 4,246 South African papers were published in 48 journals which the authors reclassified (refining Beall's classification¹) as either being probably or possibly predatory. A breakdown of these papers by year shows that the greatest increase in predatory publishing has occurred since 2011. Results are also presented of the distribution of these papers by individual university and scientific field. The authors conclude with some suggestions about predatory publishing and its pervasive consequence for our trust in science and how this

should be addressed by the major stakeholders in the South African higher education system. <https://goo.gl/pJazoq>

Extract from the *South African Journal of Science* article

In the final analysis, it is clear that predatory publishing poses a serious challenge to science in South Africa. If it continues to increase at the rate of growth seen in the past 5 years, predatory publishing may well become accepted practice in some disciplines and at some universities. Not only will it affect the very fabric of the science system (our confidence in the peer-review system), but it will also undermine the trust and confidence of the general public in science and its products.

1. 'What I learned from predatory publishers,' *Biochemia Medica*, 2017;27(2):273-279. [Noted in Media Watch 19 June 2017, #517 (p.7)] <https://goo.gl/wjNV3K>

N.B. Additional articles on predatory journals noted in the 19 June 2017 issue of Media Watch (#517, p.7).

Beyond death and dying: How Chinese spouses navigate the final days with their loved ones suffering from terminal cancer

SUPPORTIVE CARE IN CANCER | Online – 7 August 2017 – While advances in biomedicine exist for cancer, its diagnosis and treatment still bring the threat of mortality to the forefront of spouses' lives. Family conflict is largely due to unmet expectations that generate a lot of physical and emotional distress for spouses, as the primary surrogates. Moreover, older individuals in Hong Kong tend to lack control of where they die and who is present at the end of their lives. Deeper understanding of Chinese spouses' perspectives is needed to generate new insights, particularly in how spouses cope with caregiving. Spousal caregivers were purposively recruited through a hospice unit of two regional hospitals in Hong Kong, China. The overarching theme was a socially constructed "we" experience of confronting mortality, characterized by five subthemes: 1) Balancing end-of-life tension between cure and comfort; 2) Prioritizing the family goals and concerns; 3) De-medicalizing caregiving; 4) working for mutuality; and, 5) Creating a legacy of love. The study suggests that clinicians might consider harnessing the capacity of spouses to help work through confronting experiences of mortality and transforming events for goals that go beyond death. This places a major emphasis on salutary strategies surrounding transitions from curative to palliative care. <https://goo.gl/TcBMDU>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 11 August 2017 – ‘**Responses to assisted suicide requests: An interview study with Swiss palliative care physicians.**’ Swiss palliative care (PC) physicians [i.e. study participants] regularly receive assisted suicide requests while none reported having received specific training in managing these requests. Participants reported being involved in assisted suicide decision making most were not willing to prescribe the lethal drug. After advising patients of the limits on their involvement in assisted suicide, the majority explored the origins of the patient’s request and offered alternatives. Many participants struggled to reconcile their understanding of PC principles with patients’ wishes to exercise their autonomy. <https://goo.gl/Aan2vh>
- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 11 August 2017 – ‘**Enhancing informed consent for physician aid in dying: Potential role of handout on possible benefits of palliative care.**’ In the U.S., physician aid in dying (PAD) is now legal in several states. However, neither a requirement for a palliative care (PC) consultation nor a defined education in PC exists for physicians participating in PAD or patients requesting assistance. Patients with advanced chronic and serious illness often experience complex physical, psychosocial, and spiritual distress. PC focuses on relieving this distress and improving patient quality of life through early identification and intervention in all domains of suffering, including physical, psychological, social, and spiritual. The authors present a case for providing an educational handout to patients who inquire about PAD. This handout explains the potential benefits of PC as an additional procedural safeguard to existing regulations. Such information would help to ensure the integrity of the informed consent process, enhance shared decision making, and improve patient comprehension of the options. <https://goo.gl/abmBSZ>

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[Something Missed or Overlooked?](#)

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

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

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

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

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>
[Scroll down to 'Are you aware of Media Watch?']

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



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

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

Barry R. Ashpole
Guelph, Ontario CANADA

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