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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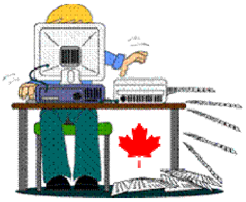


Compiled & Annotated by Barry R. Ashpole

> ***Collusion is a largely unconscious, dynamic bond, which may occur between patients and clinicians, between patients and family members, or between different health professionals.***
>
> **'Collusion in palliative care: An exploratory study with the Collusion Classification Grid' (p.9), in *Palliative & Supportive Care*.**

Canada

With a looming aging crisis, who is helping the caregivers?

THE GLOBE & MAIL | Online – 13 April 2019 – As health advances allow those with chronic illnesses to live longer, respite care remains costly and inconsistent and more patients prefer aging at home, the burden placed on family caregivers (FCGs) will only grow in this country. "Despite little to no training, they are expected to provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers," geriatrician Nathan Stall wrote in an editorial published last month in the *Canadian Medical Association Journal* that called for more robust health, workplace and financial aid for family carers.[1] As the country faces a looming aging crisis, governments have begun to signal that family carers are a priority. In Quebec, Marguerite Blais is the first cabinet minister with the core mandate to lighten the load placed on caregivers, with a provincial strategy now in the works to offer carers more recognition, support and respite care. Momentum is also building in healthcare: a growing movement toward caregiver-friendly approaches is seeing new training rolled out nationally for hospital staff, doctors, nurses and pharmacists on how to more compassionately engage with and help caregivers whose family members are sick. Coast to coast, new organizations and online communities are springing up to teach Canadians how to navigate the daily responsibilities involved in eldercare, while peer-to-peer helplines, social-media platforms and support groups are providing comfort to caregivers dealing with stress and burnout. While experts say a national strategy is needed, these fledgling programs offer a blueprint for the way forward, bringing FCGs to the foreground in medicine, while keeping them healthy themselves. https://tgam.ca/2DdLjnt

Specialist Publications

'Few family caregivers get formal training' (p.2), in Reuters Health News.

1. 'We should care more about caregivers,' *Canadian Medical Association Journal*, 2019;191(9):E245-E246. **Full text:** http://bit.ly/2Ts6E6Z

U.S.A.

Non-profit hospices fight to compete with for-profit chains

HOSPICE NEWS (Chicago, Illinois) | Online – 10 April 2019 – Non-profit hospices have been bleeding market share for several years – but are not going gentle into that good night. Rather, many non-profits are adapting to compete with large for-profit providers that are entering the space in greater numbers. In the 1980s and 1990s non-profits provided virtually all hospice care in the U.S., but the balance has shifted. In 2016, 67% of Medicare-certified hospices were for-profit, and only 20% were non-profits, according to the National Hospice & Palliative Care Organization. For-profit hospices accounted for 100% of new providers established during 2017, the Medicare Payment Advisory Commission reported in March. "This is a real challenge. Many non-profits have very slim margins – sometimes 1 or 2% – and are just trying to make ends meet," Barbara Hansen, of the Oregon Hospice & Palliative Care Association. "Non-profit hospices need to be creative and look at how they can stay in business and compete with for-profits that may be better funded or better supported, especially in the back office." Non-profits are addressing these challenges by adapting strategies often seen in the for-profit space, such as mergers and acquisitions, partnerships, participation in accountable care organizations, quality-focused marketing, and service diversification. http://bit.ly/2FZXG72

Specialist Publications

'Have hospice costs increased following implementation of the hospice quality reporting program?' (p.8), in *Journal of Pain & Symptom Management*.

'What do family caregivers know about palliative care? Results from a national survey' (p.9), in *Palliative & Supportive Care*.

Few family caregivers get formal training

REUTERS HEALTH NEWS | Online – 10 April 2019 – Less than one in 10 family caregivers (FCGs) receive training for assisting older adults with disabilities, a U.S. study suggests.[1] Nearly 18 million FCGs provide help with daily tasks and manage medical needs for older Americans with disabilities... An emerging body of research suggests that education and training can benefit these caregivers and their care recipients, but little is known about what factors might influence whether caregivers receive any training. For the current study, researchers examined survey data from 1,861 family caregivers of 1,230 adults aged 65 and older who had insurance through Medicare, the U.S. health insurance program for the elderly and disabled. Overall, just 7.3% of the caregivers received any training. The study wasn't designed to prove whether education or training might directly improve outcomes for caregivers or for their adult charges. It also wasn't designed to assess what type of education might be most beneficial, or which caregivers might need the most training to assist loved ones at home. Still, the results highlight a missed opportunity to improve patient care...[2] https://reut.rs/2UyjcKv

1. 'Factors associated with receipt of training among caregivers of older adults,' *JAMA Internal Medicine*, published online 8 April 2019. **Abstract:** http://bit.ly/2Z6feY4

2. 'Family caregivers needed – no training provided,' *JAMA Internal Medicine*, published online 8 April 2019. **Abstract:** http://bit.ly/2IeAo13

Noted in Media Watch 27 August 2018 (#578, p.5):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – Accessed 20 August 2018 – **'Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness.'** An Ispos Reid survey results provide a starting point from which caregiver preferences are revealed. The rapid review of literature … sets forth a set of findings and results specific to the resources required to ensure adequate education, training, and mentorship for caregivers of Canadians experiencing a life-limiting illness. After first introducing the burden of care, the preferences for caregiver education, and the importance of the patient-caregiver dyad, the palliative navigator approach is presented as a key role in the education, training, and mentorship of caregivers. **Full text:** http://bit.ly/2IvS7jM

International

End-of-life care in Australia

Paracetamol, but no morphine: The state of Pacific palliative care

NEW ZEALAND | Radio New Zealand (Wellington) – 10 April 2019 – People in the last stages of terminal illness in the region need better access to morphine to relieve their suffering. Dr. Jo Spratt says families and communities in Pacific countries could also do with more support as they care for those who are dying. The former nurse turned independent researcher has completed a study of palliative care (PC) in the region, where she said governments have a lot on their plate dealing with rising instances of cancer, kidney failure, stroke, lung and cardiovascular disease. She said those caring for the dying may only have access to panadol to relieve people's suffering instead of morphine. The researcher did do the contextual analysis in Solomon Islands and just at a glance it was extremely difficult to understand the system, who could get it, who couldn't, and definitely in rural areas people do not have access to morphine and that's just the mainstay of good PC," Dr Spratt said. "People need that really strong pain relief." Strong traditions in Pacific islands around community care for the dying also needed to be nurtured, she said. http://bit.ly/2U9gLc9

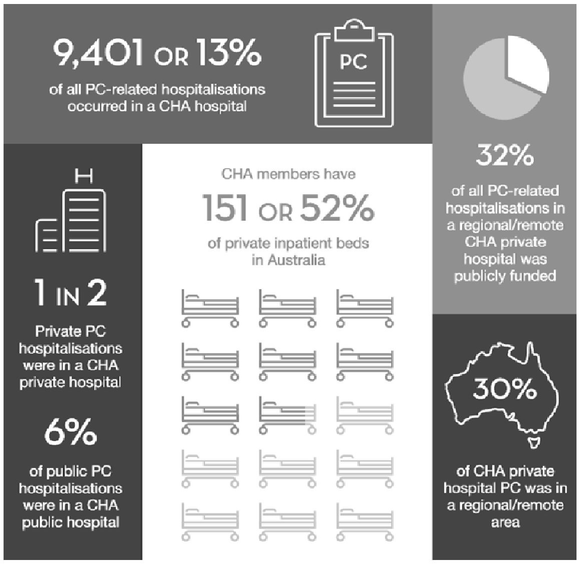
Specialist Publications

'Spiritual care provided by nursing home physicians: A nationwide survey [in The Netherlands]' (p.5), in *BMJ: Supportive & Palliative Care*.

'The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: A systematic mixed studies review' (p.11), in *BMC Medical Ethics*.

Palliative Care in the Catholic Sector

AUSTRALIA (Australian Capital Region) | Catholic Health Australia – Accessed 8 April 2019 – The aim of this [March 2019] report is to contribute to the quality and quantity of information that palliative care (PC) organisations including Catholic Health Australia (CHA), policy makers and decision makers have available. This report uses internally collected and nationally available data and semi-structured interviews from over 30 PC clinicians, PC nursing staff, managers, administrators and researchers from CHA member organisations. CHA members form a national network of over 80 hospitals, more than 25,000 aged care residential beds and numerous community care organisations. No previous work has been carried out to systematically map and categorise the wide variety of PC activities and programmes in the Catholic sector, to understand the potentially wide-ranging impact of these activities or to explore ways in which further collaboration between CHA members might benefit. In undertaking this report it is important to recognise the limitations of our ability to capture the scope of PC in the Australian healthcare system. There is no comprehensive national PC data collection. Also, PC is delivered in many settings, with different funding sources, different reporting requirements and is delivered by a number of different professionals. Capturing the scope of services is difficult to say the least. **Download/view at:** http://bit.ly/2UlvTbe



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Related

- AUSTRALIA (New South Wales) | New South Wales Ministry of Health – Accessed 8 April 2019 – ***End of Life and Palliative Care Framework 2019-2024.*** The Framework integrates key principles from multiple strategies, guidelines and standards related to end of life (EoL) and palliative care (PC) as an overarching "umbrella." It will also guide the future direction of state-wide policy and strategy relating to EoL and PC. The Framework has also been informed by international, national and state policies, as well as relevant strategies. The Framework builds on the extensive suite of existing tools and documents. **Download/view at:** http://bit.ly/2uP9gNo

End-of-life care in England

Severn Hospice to reduce beds at Telford site as National Health Service funding is cut

U.K. (England) | *The Shropshire Star* (Ketley, Telford) – 8 April 2019 – The charity is to close two beds from its in-patient centre in Telford following the decision by Telford & Wrekin Clinical Commissioning Group to cut funding by 25%. The cut will leave a £250,000 hole in the charity's budget, and bosses have accused the organisation of letting down the people it is supposed to serve. Severn Hospice chief executive Heather Palin said the cuts would not save the taxpayer a single penny, as the patients would instead have to be cared for in hospital. She said: "In stark terms someone who is dying might now face their death somewhere in a hospital rather than in a hospice. It will cost the Clinical Commissioning Group considerably more than its grant to us to care for that same patient in Princess Royal Hospital. By saving 25% of the grant they pay to us, they will have to bear 100% of the impact on their budget and resources elsewhere. And the best care the hospital could possibly provide among all its other priorities will not be anything like the dedicated support we can give patients and their families." Palin said the hospice could no longer absorb continued cuts to its funding after a decade of year-on-year real-term reductions. http://bit.ly/2Kjb9MV

Related

- U.K. (England) | *The Henley Standard* – 8 April 2019 – **'Hospice beds cut by half.'** Sue Ryder hospice has closed six of its 12 beds at Joyce Grove, saying they were no longer needed because of a drop in demand for inpatient care. At the same time, the number of patients being cared for at home has soared. Sue Ryder says the move doesn't represent a cut in services because the beds have been out of use for some time and have only now been removed because it wanted to ensure the trend was not temporary. Over the past six months the bed occupancy rate has been between 50-60% at most and on several weeks it dropped to 40% or less... http://bit.ly/2FWKuA6

Specialist Publications

Feeling like a burden to others and the wish to hasten death in patients with advanced illness: A systematic review

BIOETHICS | Online – 8 April 2019 – Studies that have explored the wish to hasten death (WTHD) in patients with advanced illness have found that the feeling of being a burden may trigger WTHD. Research suggests that both the feeling and the wish are indicators of multidimensional suffering whose meaning may depend on the patient's biographical background. The authors carried out a systematic review and meta-ethnography. 14 qualitative studies, reported in 16 articles, met the inclusion criteria. The analysis identified two themes: the personal and social dimensions that could help to explain the feeling of being a burden in these patients. These dimensions reveal how this feeling is linked to physical, psychological/ emotional, existential and social factors. The feeling of being a burden cannot be understood without considering patients' personal interpretation of their dependency or care needs, and hence it is also necessary to understand their biographical background. Such an understanding is crucial to inform clinical policies based on the moral duty to provide all patients with humane care. **Abstract:** http://bit.ly/2Il7ewg

N.B. Additional articles on the wish to hasten death noted in 4 February 2019 issue of Media Watch (#600, p.15).

End-of-life care in The Netherlands

Spiritual care provided by nursing home physicians: A nationwide survey

BMJ: SUPPORTIVE & PALLIATIVE CARE | Online – 4 April 2019 – Over half (55.2%) of the physicians [i.e., survey respondents] stated that there were indications that the resident had spiritual needs... Some indications concerned the way conversations were initiated and by whom (the residents, relatives or the physician). Other indications concerned reasons to provide spiritual care (SC). Issues concerning spiritual well-being were discussed, such as meaning, purpose, acceptance of death and completion of life. Religious needs were also a reason to provide SC. Of the physicians who reported that they did not provide SC (51.6%), 26.4% stated that they did not do so because of lack of training, 22.9% because of lack of time, and 11.8% because they had known the patient only for a short time. In response to "other reasons," 69.4% mentioned SC was already provided by another discipline or organised by family, difficulty in communication with the resident, dementia, the patient had no spiritual need, there was a rapid decline in health, did not consider to do provide SC/did not know how to do so, and not the physician's responsibility. Additional training in reflecting upon the physician's own perception of spirituality and training in multidisciplinary spiritual caregiving may contribute to the quality of end-of-life care for nursing home residents. **Full text:** http://bit.ly/2G4Fbj4

Publishing Matters

'Predatory journals on trial: Allegations, responses, and lessons for scholarly publishing from *FTC v. OMICS*' (p.11), in *Journal of Scholarly Publishing*.

'Fining one "predatory" publisher won't fix the problem of bad science in journals' (p.11), in *Stat*.

Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 10 April 2019 – **'The physician's role in responding to existential suffering: What does it mean to comfort always?'** Existential suffering (ES) is commonly experienced by patients with serious medical illnesses despite the advances in the treatment of physical and psychological symptoms that often accompany incurable diseases. Palliative care clinicians wishing to help these patients are faced with many barriers including the inability to identify ES, lack of training in how to address it, and time constraints. They are uniquely positioned to coordinate the necessary resources for addressing ES in their patients. **Abstract:** http://bit.ly/2Ihw6Wr

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 April 2019 – **'Spiritual care at the end of life: Does educational intervention focused on a broad definition of spirituality increase utilization of chaplain spiritual support in hospice?'** Patients who receive good spiritual care (SC) report greater quality of life and better coping, and such support is strongly associated with greater well-being, hope, optimism, and reduction of despair at end of life. Despite these benefits, evidence shows that many patients and caregivers refuse SC when a hospice team offers it, possibly resulting in unnecessary suffering. **Abstract:** http://bit.ly/2Uwh2uU

- *JOURNAL OF RELIGION & HEALTH* | Online – 6 April 2019 – **'Ritualization as alternative approach to the spiritual dimension of palliative care: A concept analysis.'** The authors propose not to approach spiritual care as a separate activity but as a part of care practice as a whole. Care practices can gain special significance through a process of ritualization. As a result, rituals and ritual-like acts create space for the spiritual dimension of care. In the context of palliative care, the spiritual dimension of care becomes especially important. When illness cannot be cured, the focus should be on what is of meaning and value in the time that is left. **Full text:** http://bit.ly/2UDMkPE

Cont.

Noted in Media Watch 11 February 2019 (#601, p.12):

- *MEDICAL SCIENCES* | Online – 7 February 2019 – **'Spiritual care in palliative care: A systematic review of the recent European literature.'** Spiritual care (SC) was seen as attention for spirituality, presence, empowerment and bringing peace. It implied creative, narrative and ritual work. Though several studies reported positive effects of SC, like the easing of discomfort, the evidence for SC is low. Requirements for implementation of SC in palliative care were developing spiritual competency, including self-reflection, and visibility of spirituality and SC, which are required from spiritual counselors that they participated in existing organizational structures. **Full text:** http://bit.ly/2I4b25O

Noted in Media Watch 22 October 2018 (#586, p.5):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2018 – **'Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients…'** The Psychosocial & Spiritual Needs Evaluation scale was developed through a 7-stage process: 1) Literature review; 2) Expert panel establishment; 3) Discussion and agreement on the most relevant dimensions of psychosocial care; 4) Description of key indicators and consensus-based questions to evaluate such dimensions; 5) Assessment of the scale by palliative care professionals; 6) Evaluation by patients; and, 7) Analysis of scale's psychometrics properties. **Abstract (w. list of references):** http://bit.ly/2Ckr8DM

Are district nurses well placed to provide equitable end-of-life care to individuals who are homeless?

BRITISH JOURNAL OF COMMUNITY NURSING | Online – 10 April 2019 – This literature review aimed to answer the focus question: Are district nurses well placed to provide equitable end of life care (EoLC) for homeless individuals? It focused on 10 primary research studies, from which two themes emerged and subsequently formed the basis of the discussion: 1) The difficulty in predicting disease trajectory in people who are homeless; and, 2) The gaps in existing systems. The main findings from these themes were a lack of education on the recognition of the dying and a general lack of knowledge of the complex challenges faced by and health needs of homeless people, which cause stigma from both the general public and health professionals towards these marginalised individuals. Further, there is certainly a lack of suitable places to deliver palliative and EoLC for people who are homeless. Available services are inflexible and have no tolerance for substance misuse, which creates an access barrier for homeless people in need of EoLC. **Abstract:** http://bit.ly/2P5WCme

N.B. Additional articles on EoLC for the homeless in the U.K. noted in 25 February 2019 issue of Media Watch (#603, p.4).

Improving physician well-being: Lessons from palliative care

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2019;191(14):E380-E381. The well-being of doctors has become a primary concern of medical associations globally, and for good reason: physicians, on the whole, are not doing well. One relatively unexamined factor related to physician burnout is coping with patient death. Treating patients at the end of their lives, and coping with patient death, can undoubtedly cause stress, including burnout, but little research has documented this relationship empirically. One medical discipline deals with death more often, and much better, than most others: palliative care (PC). There are aspects of PC – not seeing death as failure, working on interdisciplinary teams, practising compassionate leadership, developing competencies to address suffering – that can help physicians in other disciplines cope with these stresses and help reduce burnout. **Full text:** http://bit.ly/2IlKblc

Key points

PC principles include practising compassionate leadership, addressing suffering, working on interdisciplinary teams and not seeing patient death as a failure.

This ethos of PC teams may help other physicians deal with the emotional stresses of their work.

Cont.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 April 2019 – **'Moral distress and attitudes about timing related to comfort care for hospitalized patients: A survey of inpatient providers and nurses.'** Providing non-beneficial care at the end of life and delays in initiating comfort care have been associated with provider and nurse moral distress. The majority of providers and nurses reported that comfort care was started too late in a patient's course. Nurses experienced higher levels of moral distress than providers when caring for patients using a comfort care order set. **Abstract:** http://bit.ly/2KsM3LE

Noted in Media Watch 11 March 2019 (#605, p.14):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 7 March 2019 – **'Meaning of work and personal protective factors among palliative care professionals.'** Healthcare professionals who work in palliative care units face stressful life events on a daily basis, most notably death. For this reason, these professionals must be equipped with the necessary protective resources to help them cope with professional and personal burnout. Despite the well-recognized importance of the construct "meaning of work," the role of this construct and its relationship with other variables is not well-understood. **Abstract (w. references):** http://bit.ly/2HiTjGG

N.B. Additional articles on burnout (i.e., compassion fatigue) noted in 25 February 2019 issue of Media Watch (#603, p.6).

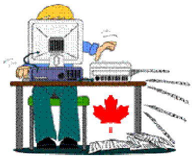
Medical-legal partnerships to enhance residency training in advance care planning

FAMILY MEDICINE, 2019;51(4):353-357. The results of this study suggest that medical-legal partnerships have potential to improve residents' competence and comfort with advance care planning (ACP) discussions. Ratings of resident performance increased from beginner/novice levels to novice/developing levels after at least two directly observed sessions, representing an increase in competence from that of a beginning first-year resident to that expected of a second- or early third-year resident. Residents also reported increased comfort leading ACP discussions. A key next step, therefore, would be to repeat the intervention with a larger sample, using more objective outcome measures … and with comparison to a control group. **Full text:** http://bit.ly/2VunU8u

Awareness as a dimension of healthcare access: Exploring the case of rural palliative care provision in Canada

JOURNAL OF HEALTH SERVICES RESEARCH & POLICY | Online – 10 April 2019 – This analysis aims to identify awareness-associated barriers to delivering rural palliative care (PC) services, along with suggestions for improving service delivery from the perspective of local healthcare providers. Identified barriers to PC awareness and suggestions on how to enhance this awareness, and ultimately PC delivery, corresponded with three key themes arising from the data: 1) Limited PC knowledge/education; 2) Communication; and, 3) Coordination. A thorough understanding of these … as well as the connections between them, may help enhance how rural PC is delivered in the future. **Abstract:** http://bit.ly/2Z7ubcj

N.B. Additional articles on PC in rural and remote regions of Canada noted in 25 February 2019 issue of Media Watch (#603, p.7).



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

Have hospice costs increased following implementation of the hospice quality reporting program?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 April 2019 – The [U.S.] Centers for Medicare & Medicaid Services (CMS) Hospice Quality Reporting Program (HQRP) introduced the requirement that hospices nationwide begin collecting and submitting standardized patient-level quality data on 1 July 2014. The authors conducted a cross-sectional study using data from the 2012 and 2014 Medicare hospice cost reports linked to hospice claims. They measured total costs per patient day (PPD), general costs PPD, and visiting services costs PPD for freestanding hospices. The authors estimated the incremental costs of operating in 2014 vs. 2012 using hierarchical random effects models and adjusting for year, wage-index, care volume, case-mix and hospice and market characteristics, stratified by hospice ownership type. Hospice costs increased following the CMS HQRP quality data collection/submission requirement. Complementary studies need to understand whether increased costs brought additional benefits. **Abstract:** http://bit.ly/2uV71bj

Elisabeth Kübler-Ross and the "five stages" model in a sampling of recent textbooks published in 10 countries outside the U.S.

OMEGA – JOURNAL OF DEATH & DYING | Online – 11 April 2019 – A previous article in this journal examined some aspects of the enduring influence of Elisabeth Kübler-Ross's "five stages" model through a sampling of recent American textbooks in selected academic disciplines and professional fields. This article offers a parallel sampling of 47 textbooks published in 10 different countries outside the U.S. The questions to be answered are as follows: 1) Does the "five stages" model appear without significant change in the textbooks described here?; 2) Is the "five stages" model applied in these textbooks to issues involving loss, grief, and bereavement as well as to those involving terminal illness and dying?; 3) Is the "five stages" model criticized in some or all of these textbooks?; 4) If so, is the criticism sufficient to argue that, while the "five stages" model might be presented as an important historical framework, it should no longer be regarded as a sound theory to guide contemporary education and practice? **Abstract:** http://bit.ly/2KwyaMo

> **N.B.** Additional articles on "five stages" model noted in 19 November 2018 issue of Media Watch (#590, p.15).

Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings

PALLIATIVE MEDICINE | Online – 10 April 2019 – Nursing homes often represent the junction between the curative and the palliative phase. In all, 18 studies met inclusion criteria. A "life crisis" often resulted in a changed need of care, and the transition towards palliative care (PC) was sustained by a "patient-centered environment." Family carers described good EoL care as providing resident basic care and spiritual support; recognizing and treating symptoms; assuring continuity in care; respecting resident's EoL wishes; offering environmental, emotional and psychosocial support; keeping family informed; promoting family understanding; and establishing a partnership with family carers by involving and guiding them in a shared decision-making. These elements improved the quality of EoL of both residents and their family, thus suggesting a common ground between good EoL care and PC. The findings provide a family-driven framework to guide a sensitive and compassionate transition towards PC in nursing home. **Abstract:** http://bit.ly/2Icxzxj

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Related

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 8 April 2019 – **'Do-not-resuscitate and do-not-hospitalize orders in nursing homes: Who gets them and do they make a difference?'** This study outlines identifiable factors influencing whether residents have a do-not-resuscitate (DNR) and/or do-not-hospitalize (DNH) order upon admission. Both orders led to lower rates, but not absolute avoidance, of hospitalizations near and at death. Upon admission, 60.7% of residents [i.e. the patient population studied] were recorded to have a DNR and 14.8% a DNH order. Those who were older, female, widowed, lived in rural facilities, lived in higher income neighborhoods prior to entry, had higher health instability or cognitive impairment, and spoke English or French were more likely to receive a DNR or DNH. **Abstract:** http://bit.ly/2GhsnGc

Collusion in palliative care: An exploratory study with the Collusion Classification Grid

PALLIATIVE & SUPPORTIVE CARE | Online – 10 April 2019 – Collusion is a largely unconscious, dynamic bond, which may occur between patients and clinicians, between patients and family members, or between different health professionals. It is widely prevalent in the palliative care setting and provokes intense emotions, unreflective behavior, and negative impact on care. However, research on collusion is limited due to a lack of conceptual clarity and robust instruments to investigate this complex phenomenon. The authors have therefore developed the Collusion Classification Grid (CCG), which they aimed to evaluate with regard to its potential utility to analyze instances of collusion, be it for the purpose of supervision in the clinical setting or research. This case series of collusions assessed with the CCG is a first step before the investigation of larger samples with the CCG. Such studies could search and identify setting-dependent and recurrent types of collusions, and patterns emerging between the items of the CCG. **Abstract (w. list of references):** http://bit.ly/2Gg4jnp

Noted in Media Watch 9 January 2017 (#494, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2017 – **'Collusions between patients and clinicians in end-of-life care: Why clarity matters.'** Collusion, an unconscious dynamic between patients and clinicians, may provoke strong emotions, un-reflected behaviours and a negative impact on care. Collusions, prevalent in the healthcare setting, are triggered by situations which signify an unresolved psychological issue relevant for both, patient and clinician. After an introductory definition of collusion, two archetypal situations of collusion – based on material from a regular supervision of a palliative care specialist by a liaison psychiatrist – and means of working through collusion are presented. **Full text:** http://bit.ly/2Gg4jnp

What do family caregivers know about palliative care? Results from a national survey [in the U.S.]

PALLIATIVE & SUPPORTIVE CARE | Online – 8 April 2019 – Despite their key role in caring for individuals with serious, chronic illness, there have been no national studies examining family caregiver (FCGs) awareness and perceptions of palliative care (PC). The authors' objectives were to ascertain level of knowledge of PC among U.S. FCGs and describe demographic variation in awareness and perceptions of PC. Using the 2018 National Cancer Institute Health Information National Trends Survey, they identified unpaid FCG caring or making healthcare decisions for someone with a medical, behavioral, disability, or other condition. Respondents were asked about their awareness of the term "palliative care" and, if aware, how much they agreed with statements representing common (mis)perceptions about PC (e.g., "palliative care is the same as hospice"). One-half of FCGs of adults with serious chronic illness have never heard of PC. Even among those who had heard of PC, the majority do not distinguish it from hospice care and death. Given the role FCGs may play in decisions to access PC, public messaging efforts are needed to clarify PC services in a way that is patient- and family-centered. **Abstract (w. list of references):** http://bit.ly/2I5qWNf

Cont.

Noted in Media Watch 1 April 2019 (#608, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 March 2019 – **'Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey.'** About 71% (2,097) of all respondents had no knowledge of palliative care (PC). Multivariable analyses indicated the middle-aged and elder population have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract (inc. link to references):** http://bit.ly/2JCTteG

Noted in Media Watch 1 January 2018 (#544, p.19):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018;21(S1):S30-S36. **'The impact of public health awareness campaigns on the awareness and quality of palliative care.'** A comprehensive public awareness campaign about palliative care should be based on clear and shared terminology, use well piloted materials, and the full range of mass media to suit different ages, cultures and religious/spiritual perspectives. There is evidence about key factors for success: targeting, networking, and use of specific, measurable, achievable, realistic time-bound objectives; continuous evaluation; and complementary to national and international policy. **Full text:** http://bit.ly/2VxtBlZ

Pediatric palliative care

Disparities in inpatient intensity of end-of-life care for complex chronic conditions

PEDIATRICS | Online – 10 April 2019 – Children with complex chronic conditions (CCCs) require a disproportionate share of healthcare services and have high mortality rates, but little is known about their end-of-life (EoL) care. The authors performed a retrospective population-based analysis using a California State administrative database of children aged 1 to 21 years with a CCC who died of disease-related causes between 2000 and 2013. Rates of and socio-demographic and clinical factors associated with previously defined inpatient EoL intensity indicators were determined. These included: 1) Hospital death (HD); 2) Receipt of a medically intense intervention within 30 days of death (ICU admission, cardiopulmonary resuscitation, hemodialysis, and/or intubation); and, 3) Having ≥2 intensity markers (including HD). There were 8,654 children in the study population with a mean death age of 11.8 years. The most common CCC categories were neuromuscular (47%), malignancy (43%), and cardiovascular (42%). Sixty-six percent of the children died in the hospital, 36% had a medically intense intervention in the last 30 days of life, and 35% had ≥2 intensity markers. Living in a low-income neighborhood was associated with increased odds of HD, a medically intense intervention, and ≥2 intensity markers. Hispanic and "other" race and/or ethnicity were associated with HD and ≥2 intensity markers. Age 15 to 21 years was associated with HD, a medically intense intervention, and ≥2 intensity markers. **Abstract:** http://bit.ly/2VHsoc2

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 April 2019 – **'Simulation-based palliative bare communication for pediatric critical care fellows.'** Pediatric palliative care (PPC) education is lacking in pediatric critical care medicine (PCCM) fellowships, despite the desire of many program directors and fellows to expand difficult conversation training. This experiential simulation-based PPC communication curriculum taught PCCM fellows valuable palliative communication techniques although revealed growth opportunities within more complex communication tasks. The preparation, methods, and lessons learned for an effective palliative simulation curriculum can be expanded upon by other pediatric training programs, and a more rigorous research program should be added to educational series. **Abstract:** http://bit.ly/2v1W8EI

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- *PEDIATRICS* | Online – Accessed 11 April 2019 – '**Ethics rounds: A casebook in pediatric bioethics.'** The ethical issues that arise in pediatrics are very different from those that arise in other clinical settings. The differences arise partly because young children cannot make decisions for themselves. Thus, the principle of autonomy, a principle that is so important in resolving the dilemmas that arise in the care of adults, is irrelevant in ethical dilemmas involving young children. Furthermore, autonomy is, essentially, a procedural principle. It doesn't claim to determine what choice is right. It only specifies who should be empowered to make the decision about what is right. This collection presents a series of cases that highlight some ethical dilemmas that arise in pediatrics. The use of cases to teach bioethics is controversial. **Access the collection of cases at:** http://bit.ly/2Udmvlh

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 5 April 2019 – **'The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: A systematic mixed studies review.'** This systematic mixed studies review shows how family members seem to be thoroughly involved at different levels of the Dutch practice of euthanasia and physician assisted suicide (EAS). The results reveal how considerations about family members and the social context appear to carry much weight for both patients and physicians when considering a request EAS. The review also shows how the active participation of family members in EAS decision-making can cause ambivalent feelings and experiences. The results provide a new perspective on the Dutch practice of EAS and challenge the underlying ethical-legal framework, which is based on the patient-physician dyad and the related concepts of autonomy and relief of suffering. Further empirical and ethical inquiry, as well as professional and public debate about the interpretation of the Dutch euthanasia law is needed. **Full text:** http://bit.ly/2U2cEys

Publishing Matters

Predatory journals on trial: Allegations, responses, and lessons for scholarly publishing from *FTC v. OMICS*

JOURNAL OF SCHOLARLY PUBLISHING, 2019;50(3):183-200. On 25 August 2016, the U.S. Federal Trade Commission (FTC) sued OMICS Group Inc., iMedPub LLC, Conference Series LLC, and Srinubabu Gedela, all affiliated with open access mega-publisher OMICS International, for deception in their solicitation of journal articles and advertising of conferences. The ongoing lawsuit seeks to stop OMICS's deceptive practices and disgorge U.S. $50.5 million in ill-gotten gains. OMICS has in turn claimed over $2.1 billion for harm caused by the lawsuit to its business and employees. This article describes the main arguments, counter-arguments, and court decisions in the 5,920 pages of pleadings, exhibits, and orders that have been filed through 14 October 2018. The article then evaluates the case to formulate key takeaways for publishers, editors, academics, and universities. Depending on its ultimate outcome, the case against OMICS may be a turning point in the practices of questionable open access online publishers, making this interim case assessment pertinent to all concerned about the future of academic publishing. **Abstract:** http://bit.ly/2Gb44bL

Fining one "predatory" publisher won't fix the problem of bad science in journals

STAT (Boston, Massachusetts) | Online – 5 April 2019 – Science publishers aren't supposed to be in the disinformation business. And that's precisely what a federal judge in Nevada was saying late last month when she slapped OMICS International with a $50 million penalty in a suit brought by the U.S. Federal Trade Commission (FTC). The ruling clearly is a win for honest brokers in scientific publishing. But it's not the solution to the problem of so-called predatory journals – a term used to describe for-profit publications that pretend to offer peer review and editing but in reality do little, if any, of either. Predatory publishers like OMICS, which is far from alone in this space … thrive because the market for scientific papers is insatiable – and growing. Last year, researchers produced somewhere between 2 million and 3 million pa-

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pers. In a sense, then, OMICS is inadvertently right about one thing: Relying on peer reviewers to vet papers prior to publication is less critical than legitimate publishers would like us to believe. Critics of OMICS … have long alleged that the company's promises of conventional peer review are largely empty. According to the decision, the FTC found that "out of 69,000 published articles, only 49% indicate that some form of review was conducted." The judge also noted that although OMICS claims to have more than 50,000 expert editors on its mastheads, the company provided a list with just 14,598 unique names, "and evidence of an agreement to serve as an editor for only 380 individuals." So, while punishing OMICS for its bad-faith practices is warranted, and might deter some would-be predators from similar misbehavior, don't expect the fundamental problems in science publishing to go away without an effort to address their root causes. Predatory publishers such as OMICS are symptoms of those problems, not the problems themselves. There would be no prey – knowing or otherwise – if there weren't a market. http://bit.ly/2U3vyF8

Noted in Media Watch 8 April 2019 (#609, p.14):

- *THE NEW YORK TIMES* | Online – 3 April 2019 – '**"Predatory" scientific publisher is hit with a $50 million judgment.**' In the world of scientific research, they are pernicious impostors. So-called predatory journals, online publications with official-sounding names, publish virtually anything, even gibberish, that an academic researcher submits – for a fee. Critics have long maintained that these journals are eroding scientific credibility and wasting grant money. But academics must publish research to further their careers, and the number of questionable outlets has exploded. Now the Federal Trade Commission has stepped in, announcing that it has won a $50 million court judgment against Omics International. https://nyti.ms/2VsyWex

N.B. OMICS publications include the *Journal of Palliative Care & Medicine*: http://bit.ly/2TVQkXv

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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