

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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Improving the lives of persons with dementia and their families: Scroll down to [Specialist Publications](#) and 'Assessing palliative care content in dementia care guidelines: A systematic review' (p.8), in *Journal of Pain & Symptom Management*.

U.S.A.

Cancer death rate drops 25% from 1991 peak, still higher for men than women

THE WASHINGTON POST | Online – 5 January 2017 – The cancer death rate in the U.S. has dropped by 25 percent since its 1991 peak, resulting in 2 million fewer cancer deaths than if the rate had stayed the same, the American Cancer Society said ... in a new report.¹ The group attributed the decrease largely to reductions in smoking and improvements in the early detection and treatment of cancer. But a significant gender gap remains. The cancer death rate is 40% higher for men than women, and the incidence of cancer is 20% higher in men. That gender disparity reflects differences in the kind of cancers that men and women develop. <https://goo.gl/VumnzK>

1. 'Cancer Statistics, 2017,' American Cancer Society's, December 2017. <https://goo.gl/2BzrCA>

New nursing home rules offer residents more control of their care

KAISER HEALTH NEWS | Online – 4 January 2017 – About 1.4 million residents of nursing homes across the country now can be more involved in their care under the most wide-ranging revision of federal rules for such facilities in 25 years. The changes reflect a shift toward more "person-centered care," including requirements for speedy care plans... The federal Medicare and Medicaid programs pay for most of the nation's nursing home care – roughly \$75 billion in 2014 – and, in return, facilities must comply with government rules. <https://goo.gl/t2Vm1F>

Related

- *THE NEW YORK POST* | Online – 3 January 2017 – 'Why Medicare isn't actually going bankrupt.' As the new Congress convenes, budget cutters are eyeing Medicare, citing forecasts the program for seniors is running out of money. But federal bean counters have erroneously predicted Medicare's bankruptcy for decades. The facts prove otherwise. New medical findings give plenty of reason for optimism about the cost of caring for the elderly. Medicare spending on end-of-life care is dropping rapidly, down from 19% to 13% of the Medicare budget since 2000. <https://goo.gl/RKj8yx>

Hospice care linked to higher family satisfaction

REUTERS | Online – 4 January 2017 – Families of terminally ill cancer patients may be more satisfied with the end-of-life treatment their loved ones receive when it involves hospice care, a recent study suggests.¹ Researchers examined interview data from 1,970 family members of deceased cancer patients. The patients all had advanced lung or colorectal cancer, and roughly half had received hospice care. Hospice was associated with better symptom relief, attainment of pain-management goals, and quality of end-of-life care, the study found. Families of patients who received at least 30 days of hospice care reported the highest quality of life outcomes. Many people think of hospice as something that should be saved for the very end of life, said study co-author Dr. Alexi Wright of Harvard Medical School and Dana-Farber Cancer

Institute in Boston. “However, our findings suggest that earlier hospice enrollment is associated with better symptom management, less pain, better quality of care, and a higher likelihood that patients will receive the care that they want in their own environment,” Wright added. <https://goo.gl/il9BTT>

Specialist Publications

‘Increasing competition: Measuring the impact of policy prescription in hospice provision’ (p.4), in *American Review of Public Administration*.

‘A trial of concurrent care: Shedding light on the gray zone’ (p.5), in *Journal of Palliative Medicine*.

1. ‘Family Perspectives on Hospice Care Experiences of Patients with Cancer,’ *Journal of Clinical Oncology*, published online 19 December 2016. <https://goo.gl/sGVjeG>

Zen Hospice Project

One man’s quest to change the way we die

THE NEW YORK TIMES MAGAZINE | Online – 3 January 2017 – B.J. Miller, a doctor and triple amputee, used his own experience to pioneer a new model of palliative care at a small, quirky hospice in San Francisco. Miller, now 45, with deep brown eyes and a scruffy, silver-threaded beard, saw patients one day a week at the hospital. He was also entering his fifth year as executive director of a small, pioneering hospice in San Francisco called the Zen Hospice Project, which originated as a kind of compassionate improvisation at the height of the AIDS crisis in San Francisco, when members of the San Francisco Zen Center began taking in sick, often stigmatized young men and doing what they could to help them die comfortably. It is now an independent non-profit group that trains volunteers for San Francisco’s Laguna Honda public hospital as well as for its own revered, small-scale residential operation. Once an outlier, Zen Hospice has come to embody a growing nationwide effort to reclaim the end of life as a human experience instead of primarily a medical one. The goal, as Miller likes to put it, is to “de-pathologize death.” <https://goo.gl/sl47IV>

American children deserve a better death

SLATE MAGAZINE | Online – 3 January 2017 – In the U.S., about 41,000 children and young adults die each year from a variety of illnesses... Many qualified for palliative care (PC) ... and for hospice care, which is provided in the last six months of life. But the number of dying children is dwarfed by the more than 2.5 million adults who die each year, many of whom also qualified for these end-of-life services. And that’s precisely the problem: The low demand has made it very tricky to set up effective PC programs for children. Specialized services for dying children remain relatively scarce. One reason for the problems facing end-of-life care in general is that PC often demands physical closeness between a patient and their provider. Long stays in the hospital could solve this, but often cause other problems, because most Americans want to die in their homes. In response, adult hospice care has grown to the point that many adults, even in rural areas, have access to in-home hospice care. Services for children, however, tend to still be limited to big cities with well-established children’s hospitals, where the few doctors who have done pediatric PC fellowships are concentrated. <https://goo.gl/DDnWwq>

Cont.

Selected articles on pediatric palliative care in the U.S.

- NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 30 July 2015 – ‘**New pediatric resource helps focus attention on children’s unmet needs.**’ Pediatric Palliative & Hospice Care in America’ provides insight into the care needs of young people who might benefit from pediatric palliative/hospice care. The Department of Health & Human Services reports the number of children with special health care needs is increasing; 15.1% of children ages 0-17 (11.2 million) are in this category. [Noted in Media Watch 10 August 2015, #422 (p.5)] <https://goo.gl/NHMsWD>
- CLINICAL PEDIATRICS | Online – 26 June 2015 – ‘**Where children die: Obstacles to quality end-of-life care.**’ Fifty thousand children die annually in the U.S., and 500,000 more live with chronic diseases. After accidental/unanticipated mortalities, 5% of childhood deaths are secondary to cancer and 16% more to other chronic conditions ages 0-24 years. The authors discuss how and where pediatric patients die in America and identify deficiencies in their end-of-life care. [Noted in Media Watch 6 July 2015, #417 (p.10)] <https://goo.gl/Wil068>
- PEDIATRICS | Online – 4 November 2013 – ‘**Pediatric palliative care programs in children’s hospitals: A cross-sectional national survey.**’ Of the 162 hospitals that provided data, 69% reported having a pediatric palliative care program. The rate of new program creation peaked in 2008, with 12 new programs created that year, and 10 new programs in 2011. Most offer only inpatient services, and most only during the work week. The number of consults per year varied substantially across programs, and was positively associated with hospital bed size and number of funded staff members. [Noted in Media Watch 11 November 2013, #331 (p.14)] <https://goo.gl/R2QbtM>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *The Boston Globe* – 3 January 2017 – ‘**Massachusetts physicians open debate on end-of-life options.**’ The vote before the Massachusetts Medical Society was whether to approve a survey – just a survey – of members’ attitudes toward “medical aid in dying.” But the discussion last month launched dozens of doctors into a broader emotional debate over end-of-life decisions for their patients. One doctor invoked the “death with dignity” message of South African Nobel Peace Prize laureate Desmond Tutu, while another cited the “do no harm” mantra of the Greek physician Hippocrates. In the end, the policy-making body decisively endorsed the survey and approved \$25,000 to fund it — a sign that the Massachusetts Medical Society may be reconsidering its historic rejection of what it has called “physician-assisted suicide.” <https://goo.gl/pR0kui>

International

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *NL Times* – 6 January 2016 – ‘**Euthanasia rarely approved for advanced dementia patients, despite lucid requests.**’ Euthanasia is hardly ever approved for advanced dementia patients, despite the fact that the Ministries of Public Health and Security and Justice gave the go ahead that it can be given to dementia patients who requested it in a written declaration while they were still lucid. Since the euthanasia request declaration system was implemented end 2015, there’s only been three known cases of it being used, the *Volkscrant* [newspaper] reports based on information from the euthanasia review committees RTE. Many doctors are unclear about what is allowed and what isn’t, due to conflicting rules in law and doctors’ guidelines. <https://goo.gl/lluLWS>



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.11.

Specialist Publications

Palliative care exposure in internal medicine residency education : A survey of [the U.S.] Accreditation Council for Graduate Medical Education internal medicine program directors

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 January 2017 – As the baby boomer generation ages, the need for palliative care (PC) services will be paramount and yet training for PC physicians is currently inadequate to meet the current PC needs. Nonspecialty-trained physicians will need to supplement the gap between supply and demand. Yet, no uniform guidelines exist for the training of internal medicine residents in PC. To the authors' knowledge, no systematic study has been performed to evaluate how internal medicine residencies currently integrate PC into their training. In this study, they surveyed 338 Accreditation Council for Graduate Medical Education-accredited internal medicine program directors. The authors queried how PC was integrated into their training programs. The vast majority of respondents felt that PC training was "very important" (87.5%) and 75.9% of respondents offered some kind of PC rotation, often with a multidisciplinary approach. Moving forward, they are hopeful that the data provided from their survey will act as a launching point for more formal investigations into PC education for internal medicine residents. <https://goo.gl/tlStlG>

Related

- *ACTA CLINICA BELGICA* | Online – 4 January 2017 – '**Are future medical oncologists sufficiently trained to communicate about palliative care? The medical oncology curriculum in Flanders, Belgium.**' The authors investigated to what extent communication skills for communicating PC with patients are trained in the formal academic training program in medical oncology in Flanders, Belgium. The programme is based on the recommendations for a Global Core Curriculum in Medical Oncology, developed by The American Society of Clinical Oncology (ASCO) together with the European Society for Medical Oncology (ESMO). Few recommendations for training communication skills to communicate about PC were found in the ASCO/ESMO recommendations and even less in the Flanders' programme documents. <https://goo.gl/AmOR3j>
- *HEALTHCARE* | Online – 30 December 2016 – '**On the ground floor looking up: Managing trainees' uncertainty at the end of life.**' Recent U.S. healthcare policy changes set the stage for integrating palliative and end-of-life care (EOLC) into routine medicine. However, these changes may not affect the daily practice of medical trainees – fellows, residents, and medical students – who, as front-line care providers, are not always equipped with the skills needed to treat terminally ill patients. The authors review evidence on trainees' discomfort with EOLC and highlight limitations of recent policy changes. <https://goo.gl/KwoQQg>

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

Increasing competition: Measuring the impact of policy prescription in hospice provision

AMERICAN REVIEW OF PUBLIC ADMINISTRATION | Online – Accessed 7 January 2017 – As in general health care services, little is known about the potential relationship between supply and demand for hospice services. In 1982, there were 25,000 hospice patients, or about five individuals considered terminally ill, as defined in hospice care, for every 1,000,000 in the population. In the most recent figures, provided by the National Hospice & Palliative Care Organization (NHPCO) report in 2014, there were about 1.54 million hospice patients in 2013, or about five individuals considered terminally ill for every 1,000 in the population (NHPCO, 2014). The number of hospice providers also grew from 44 providers in 1984 (NHPCO, 2010) to more than 5,800 providers in 2013 (NHPCO, 2014). This hospice growth is from a "grass roots movement" to a projected US\$18.2 billion federal program in fiscal year 2014. NHPCO (2014) statistics show the use of hospice care for the dying is increasing in the United States, but the increase does not appear to be reducing the cost of treatment in the final months of life, an outcome that was promoted as the focal support for hospice care in Medicare at the inception of the program. With costs rising, the diagnosis of the terminally ill increasing, and changes occurring in market share, what are the implications to both provision and quality? <https://goo.gl/gjbFEh>

Cont.

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 January 2017 – ‘**A trial of concurrent care: Shedding light on the gray zone.**’ Patients are hospice eligible when they have an estimated prognosis of 6 months and the readiness to forgo attempts at disease-modifying treatments related to their terminal illness. The decision to enroll in hospice is relatively clear when the prognosis is based on an incurable illness for which there are no further life-prolonging therapies. However, when the prognosis is based on a serious chronic illness for which possible interventions remain but must be forgone to access hospice support, the decision process is more complex. Such patients may benefit from a trial of concurrent care, receiving both disease-modifying and comfort-focused hospice care, while determining whether or not to pursue further treatment. This article illuminates the need for concurrent care for hospice patients with serious illness. <https://goo.gl/E8WEc3>

Experiences with palliative care in rural regions in Germany

AUSTIN JOURNAL OF NURSING & HEALTH CARE | Online – Accessed 5 January 2017 – Outpatient palliative care (PC) in rural regions is a challenge for all carers. In contrast to urban settings there are many factors that influence providing PC. The authors report about their experiences with a multi-professional and interdisciplinary four-level network to provide PC. Using the PC network including medical staff and health care providers most of the patients can die at home as they wanted. This model is a possible way for realizing outpatient PC in rural regions. Most important implication for practice is the need to build up networks through integrating local carers. Community nurses and general practitioners must be qualified following a special structured schedule. Short-term changing informations about the patients performance status and needs between all involved carers is necessary. <https://goo.gl/ABT7IW>

Noted in Media Watch 26 September 2016, #481 (p.8):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 19 September 2016 – ‘**Rural residents’ perspectives on the rural “good death”: A scoping review.**’ Twenty articles (for 17 studies and one systematic review) were identified. These papers revealed data collected from rural patients with a life-limiting illness and family caregivers, rural healthcare providers, the wider rural community, rural community leaders and rural health administrators and policy makers. Currently, there is insufficient data to generalise rural residents’ perspectives and what it means for them to die well. <https://goo.gl/37rXhq>

N.B. Additional articles on end-of-life care in rural communities and remote regions noted in Media Watch 22 August 2016, #476 (p.11), 16 May 2016, #462 (p.18), and 18 April 2016, #459 (p.4).

Distance learning for updating health professionals in palliative care: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 6 January 2017 – The UK, the U.S., Canada and Australia stood out within the palliative care research papers. Among the 590 articles chosen, only 14 papers were included in this review due to the inclusion criteria. Nine used a mixed approach and 5 used online methods. The length of the courses, however, varied extensively and several methods were found to have been employed for teaching purposes, including videos, audio, images, poetry and simulation cases. Although the literature is abundant in this area, there is limited research exploring the construction process of courses and how they can be applied to countries with limited resources. It is important to highlight, however, that the mixed teaching strategy, which allows for theoretical and practical activities at a low cost, is imperative for countries with limited resources in healthcare. <https://goo.gl/LbIKkW>



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8l>

Stakeholder meeting: Integrated knowledge translation approach to address the caregiver support gap

CANADIAN JOURNAL ON AGING | Online – 5 January 2017 – Family caregivers (FCG) are an integral and increasingly overburdened part of the health care system. There is a gap between what research evidence shows is beneficial to caregivers and what is actually provided. Using an integrated knowledge translation approach, a stakeholder meeting was held among researchers, FCGs, caregiver associations, clinicians, health care administrators, and policy makers. The objectives of the meeting were to review current research evidence and conduct multi-stakeholder dialogue on the potential gaps, facilitators, and barriers to the provision of caregiver supports. A two-day meeting was attended by 123 individuals. Three target populations of FCGs were identified for discussion: 1) Caregivers of seniors with dementia; 2) Caregivers in end-of-life care; and, 3) Caregivers of frail seniors with complex health needs. The results of this meeting can and are being used to inform the development of implementation research endeavours and policies targeted at providing evidence-informed caregiver supports. <https://goo.gl/1DJ16g>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2017 – **‘Family caregiver participation in palliative care research: Challenging the myth.’** Despite international guidelines emphasizing consumer directed care and autonomous decisions in research participation, there is a common myth that research can be an additional and unwanted burden on patients and their family members. This study provides quantitative and qualitative evidence challenging the myth. In contrast to health professional concerns, family caregivers appreciated the opportunity to participate and benefited from their involvement in research. <https://goo.gl/ghZQ0b>

Too hot, too cold or can we get it just right? What emotional distance should oncologists keep from their patients?

CLINICAL ONCOLOGY | Online – 30 December 2016 – Cancer clinicians frequently deal with emotionally challenging situations such as discussing the diagnosis or prognosis and transitions to palliative care with patients and their families. The doctor/patient relationship may be short and intensive or one lasting for many years. Until fairly recently, a formal paternalistic relationship was the norm in medicine; this has now been replaced by a more patient-centred approach. An unintended consequence of the move towards less formal relationships may be the loss of the emotional protection to the doctor. <https://goo.gl/qT09i5>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2017 – **‘Barriers to medical compassion as a function of experience and specialization: Psychiatry, pediatrics, internal medicine, surgery and general practice.’** Compassion is an expectation of patients, regulatory bodies, and physicians themselves. Most research has, however, studied compassion fatigue rather than compassion itself and has concentrated on the role of the physician. <https://goo.gl/jDTqrR>

Life transitions of adolescents and young adults with life-limiting conditions

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2016;22(12):608-617. A systematic review was conducted to appraise and classify evidence related to the life transitions of adolescents and young adults with life-limiting conditions. Eighteen studies were included in the final review, with two major life transitions identified as pertinent: “illness transition” and “developmental transition.” These concurrent transitions were found to be relevant to adolescents and young adults with life-limiting conditions, generating complex needs. Sub-themes within the transitions were also identified. Furthermore, the illness transition was found to also impact significant others, namely family members, having physical, mental and emotional health implications and requiring them to make adaptations. <https://goo.gl/alVrcT>

Organizational capacities for “residential care homes for the elderly” to provide culturally appropriate end-of-life care for Chinese elders and their families

JOURNAL OF AGING STUDIES, 2017;40(1):1-7. Developing culturally appropriate end-of-life care (EOLC) for Chinese elderly and families is not an endemic challenge for Hong Kong, but that of the Western countries with a noticeable trend of rising Chinese population. The particular development of Hong Kong healthcare system, which is currently the major provider of EOLC, makes Hong Kong a fruitful case for understanding the confluence of the West and the East cultures in EOLC practices. This study therefore aims at building best practice to enhance the capacity of residential care homes in providing culturally appropriate EOLC. Findings of this study shed light on how to empower residential care homes with necessary environmental, structural and cultural-resource-related capacity for providing quality EOLC for Chinese elders and their families. <https://goo.gl/t9wIWj>

Noted in Media Watch 27 June 2016, #468 (pp.5-6):

- CHINA (Hong Kong) | *The South China Morning* – 21 June 2016 – ‘**Last wish: Hong Kong survey reveals most elderly would rather die in hospital than at home.**’ Dying at home might be a solution to ease overcrowding in public wards, but the idea might spark a debate in the community as a survey undertaken by a local hospital’s palliative care unit found that only about 14% of patients receptive to the idea <http://goo.gl/AJoJ48>
- CHINA (Hong Kong) | *The South China Morning Post* – 21 June 2016 – ‘**Severe lack of end-of-life care in Hong Kong, warn doctors.**’ Understaffed and undertrained, Hong Kong’s end-of-life care services struggle to meet needs of an ageing population, despite government plans to expand the stretched provisions to cover support for those who wish to die at home. <http://goo.gl/3GVYIT>

Noted in Media Watch 9 May 2016, #461 (p.5):

- CHINA (Hong Kong) | *The South China Morning Post* – 3 May 2016 – ‘**Hong Kong’s ageing population must have a bigger say in their end-of-life care.**’ Hong Kong enjoys a very low mortality rate and the highest life expectancy rate in the world: in 2014, life expectancy was 81.2 years for men and 86.9 years for women. The city’s evolving demographic and social landscapes continue to have profound effects on how we deliver public health care services with limited resources while managing community expectations. <http://goo.gl/nTKmBP>

The ethics of predatory journals

JOURNAL OF BUSINESS ETHICS | Online – 30 December 2016 – Predatory journals operate as vanity presses, typically charging large submission or publication fees and requiring little peer review. The consequences of such journals are wide reaching, affecting the integrity of the legitimate journals they attempt to imitate, the reputations of the departments, colleges, and universities of their contributors, the actions of accreditation bodies, the reputations of their authors, and perhaps even the generosity of academic benefactors. Using a stakeholder analysis, this study of predatory journals suggests that most stakeholders gain little in the short run from such publishing and only the editors or owners of these journals benefit in the long run. The authors also discuss counter-measures that academic and administrative faculty can employ to thwart predatory publishing. <https://goo.gl/NIKCnh>

N.B. Additional articles on predatory journals are noted in Media Watch, e.g., 19 December 2016, #492 (p.6); 5 December 2016, #490 (p.2); 5 September 2016, #478 (p.14); 30 May 2016, #464 (p.11); and, 11 April 2016, #457 (p.7).

Dying in intensive care units of India: Commentaries on policies and position papers on palliative and end-of-life care

JOURNAL OF CRITICAL CARE | Online – 23 December 2016 – Since early 2000 India has joined the global discourse on implementing end-of-life care (EOLC) within ICUs. Policies, position statements and guidelines related to foregoing life-support treatments and introducing palliative and EOLC within ICU are critically reviewed with reference to the contextual realities. The “over-simplistic” EOLC recommendations proposed in these documents overlook the medico-legal and medico-ethical complexities prevailing in the country. Also, voices of nurses and large groups of healthcare professionals are excluded, “culture” is undermined, heterogeneity in the ICU infrastructure is unaddressed, and “risk aversion” aptitude of the physicians is apparent in the documents. These documents need to be recast to suit Indian reality <https://goo.gl/NKXt9v>

Assessing palliative care content in dementia care guidelines: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 January 2017 – This systematic review provides new information regarding the quantity of current palliative care (PC) content within international dementia care guidelines. With dementia prevalence rising and no cure on the horizon it is crucial that clinicians integrate a palliative approach into their care. Guidelines provide a valuable tool for clinician reference and palliative content or recommendations pertaining to each domain of the ‘Square of Care’ can reduce the suffering of patients and families at all stages of illness. Guideline developers and researchers are challenged with the results of this review to develop evidence-based recommendations and clinical practice guidelines content regarding spirituality, end of life and loss or grief in order to increase PC content improving the lives of persons with dementia and their families. <https://goo.gl/kHXXzV>

Related

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 31 December 2016 – ‘**Palliative care in dementia 1986-2016: Progress and remaining challenges.**’ Palliative or hospice care research and practice for people with advanced dementia have made great strides since in 1986, the *Journal of the American Medical Association* published on the development and evaluation of the first dementia-specific hospice program.¹ Research and hospice programs have expanded, and access to palliative care for people with dementia in Western countries has improved. <https://goo.gl/SeH2Jv>
 1. ‘Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type,’ *Journal of the American Medical Association*, 1986;256:2210-2213. <https://goo.gl/sliIEV>
- *MEDIAL LAW REVIEW* | Online – 5 January 2017 – “**This man with dementia**” – “**othering**” the **person with dementia in the court of protection.**’ In recent years, dementia has been subjected to an increasing ethical, legal, and political gaze. This article analyses how the [U.K.] Court of Protection considers the perspective of the person with dementia when making best interests decisions on their behalf under the Mental Capacity Act 2005. The article draws upon feminist and disability literature to highlight how the Court has, on occasions, “othered” the person with dementia during the process of making best interests decisions. <https://goo.gl/Pul80V>
- *MORTALITY* | Online – 4 January 2017 – “**Every time I see him he’s the worst he’s ever been and the best he’ll ever be**”: **Grief and sadness in children and young people who have a parent with dementia.**’ Research suggests the grief experienced by the family members of persons with dementia has a distinctive nature that differentiates it from sorrow attendant on most other ill health causes. Over a variable period of time, the way in which dementia manifests in cognitive and physical changes tends to be experienced as a series of serious losses, each of which can be a source of grief leading to significant stress and emotional, mental, psychosocial and physical ill health. <https://goo.gl/cdDrrJ>

N.B. Additional articles on end-of-life care for people living with dementia are noted in Media Watch, e.g., 12 December 2016, #491 (p.8); 5 December 2016, #490 (p.7); 17 October 2016, #483 (pp.9-10); 1 August 2016, #473 (p.11); and, 4 July 2016, #469 (pp.15-16).

Collusions between patients and clinicians in end-of-life care: Why clarity matters

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 January 2017 – 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 health care 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 (PC) specialist by a liaison psychiatrist – and means of working through collusion are presented. The theoretical framework of collusion is then described and the conceptual shortcomings of the PC literature in this respect discussed, justifying the call for more clarity. Finally, cultural aspects and societal injunctions on the dying, contributing to the development of collusion in end-of-life care, are discussed. <https://goo.gl/uLkTDS>

Noted in Media Watch 27 July 2009, #107 (p.7):

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2009;15(1):2-9. ‘**Communication with relatives and collusion in palliative care: A cross-cultural perspective.**’ Handling collusion among patients and family members is one of the biggest challenges that palliative care professionals face across cultures. Collusion comes in different forms and intensity and is often not absolute. <https://goo.gl/v9tILw>

“End of life could be on any ward really”: A qualitative study of hospital volunteers’ end-of-life care training needs and learning preferences

PALLIATIVE MEDICINE | Online – 6 January 2017 – Over half of all deaths in Europe occur in hospital, a location associated with many complaints. Initiatives to improve inpatient end-of-life care (EOLC) are therefore a priority. In England, over 78,000 volunteers provide a potentially cost-effective resource to hospitals. Many work with people who are dying and their families, yet little is known about their training in EOLC. Five focus groups were conducted with 25 hospital volunteers (aged 19–80 years). Four themes emerged as follows: 1) Preparation for the volunteering role; 2) Training needs; 3) Training preferences; and, 4) Evaluation preferences. Perceived training needs in EOLC included communication skills, grief and bereavement, spiritual diversity, common symptoms, and self-care. Volunteers valued learning from peers and EOLC specialists using interactive teaching methods including real-case examples and role plays. A chance to “refresh” training at a later date was suggested to enhance learning. Evaluation through self-reports or observations were acceptable, but ratings by patients, families and staff were thought to be pragmatically unsuitable owing to sporadic contact with each. <https://goo.gl/tUFUcY>

N.B. Additional articles on hospice and palliative care volunteers are noted in Media Watch 12 December 2016, #491 (p.8); 28 November 2016, #489 (p.8); and, 25 July 2016, #476 (pp.5-6,11).

[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>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ASIAN BIOETHICS REVIEW*, 2016;8(4):290-301. ‘**Terminal discharges and passive euthanasia: Two fundamentally different entities that should not be likened to each other.**’ In Singapore, it is not uncommon for terminal discharges (TDs) to be carried out from hospitals. Such discharges see terminally ill patients being sent home to die, in accordance to their said wishes. In practice, however, concerns may develop over prognostication, potential compromises in care and routine cessation of treatments that cannot be maintained in the home setting. As a result, if due diligence is not exercised, parallels may be drawn with passive euthanasia. The author discusses the circumstances in which TDs are undertaken, and touches on familial determinations of care and circumnavigation of direct patient involvement. <https://goo.gl/xODknJ>
- *JOURNAL OF MEDICAL ETHICS* | Online – 6 January 2017 – ‘**Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care.**’ This article analyses the various essentialistic arguments for the incompatibility of euthanasia and palliative care (PC). The empirical evidence from the euthanasia-permissive Benelux countries shows that since legalisation, carefulness (of decision making) at the end of life has improved and there have been no significant adverse “slippery slope” effects. It is problematic that some critics disregard the empirical evidence as epistemologically irrelevant in a normative ethical debate. Next, rejecting euthanasia because its prevention was a founding principle of PC ignores historical developments. Further, critics’ ethical positions depart from the PC tenet of patient centeredness by prioritising caregivers’ values over patients’ values. Also, many critics’ canonical adherence to the WHO definition of PC, which has intention as the ethical criterion is objectionable. A rejection of the Belgian model on doctrinal grounds also has nefarious practical consequences such as the marginalisation of PC in euthanasia-permissive countries, the continuation of clandestine practices and problematic palliative sedation until death. In conclusion, major flaws of essentialistic arguments against the Belgian model include the disregard of empirical evidence, appeals to canonical and questionable definitions, prioritisation of caregiver perspectives over those of patients and rejection of a plurality of respectable views on decision making at the end of life. <https://goo.gl/d5dU4V>

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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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Worth Repeating

Discovering the truth beyond the truth

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 December 2014 – Truth within the field of medicine has gained relevance because of its fundamental relationship to the principle of patient autonomy. In order to fully participate in their medical care, patients must be told the truth – even in the most difficult of situations. Palliative care emphasizes patient autonomy and a patient-centered approach, and it is precisely among patients with chronic, life-threatening, or terminal illnesses that truth plays a particularly crucial role. For these patients, finding out the truth about their disease forces them to confront existential fears. As physicians, we must understand that truth, similar to the complexity of pain, is multi-dimensional. In this article, the authors discuss the truth from three linguistic perspectives: the Latin *veritas*, the Greek *aletheia*, and the Hebrew *emeth*. *Veritas* conveys an understanding of truth focused on facts and reality. *Aletheia* reveals truth as a process, and *emeth* shows that truth is experienced in truthful encounters with others. In everyday clinical practice, truth is typically equated with the facts. However, this limited understanding of the truth does not account for the uniqueness of each patient. Although two patients may receive the same diagnosis (or facts) each will be affected by this truth in a very individual way. To help patients apprehend the truth, physicians are called to engage in a delicate back-and-forth of multiple difficult conversations in which each patient is accepted as a unique individual. [Noted in Media Watch 29 December 2014, #390 (p.9)] <https://goo.gl/AESoJv>

Media Watch: Online

International

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

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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