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

The illness experience: Scroll down to <u>Specialist Publications</u> and 'Protecting patients from their bad decisions: Rebalancing rights, relationships, and risk' (p.9), in *Medical Law Review*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) 10 January 2017 'Medically assisted dying team in Manitoba doubles in size.' The Winnipeg Regional Health Authority (WRHA) has more than doubled the number of physicians involved in medically assisted deaths in Manitoba after more patients requested the help than the province initially expected. More than 100 patients have contacted the Medical Assistance in Dying (MAID) team with 24 receiving medically assisted deaths as of 6 January, according to statistics provided to CBC Manitoba by the WRHA: 102 patients or family members have contacted the MAID team as of 6 January; 24 have received medically assisted deaths; 28 died before completing the process; 14 are actively going through assessment; 18 were declined; and, 18 made inquiries. https://goo.gl/fKEWHd
- ONTARIO | The Ottawa Sun 10 January 2017 'Most of the assisted deaths in Ottawa so far have taken place in hospitals.' Eighteen people have had medically assisted deaths in Ottawa since it became legal in Canada last year and the vast majority of those deaths were in a hospital. The percentage of assisted deaths in hospitals in Ottawa is higher than the provincial percentage, but reflects a national trend that is surprising some people. Some anticipated that, as in The Netherlands, the majority of assisted deaths in Canada would take place in patients' homes. https://goo.gl/oZqw5Z

<u>U.S.A.</u>

Mobile team offers comfort care to homeless at life's end

WASHINGTON STATE | *Kaiser Health News* – 12 January 2017 – Since January 2014, the pilot project run by Seattle/King County Health Care for Homeless Network and the University of Washington Medicine's Harborview Medical Center has served more than 100 seriously ill men and women in the Seattle area, tracking them down at shelters and drop-in clinics, in tents under bridges, and parked cars. "It's really necessary that people be taken care of where they are," said Dr. Daniel Lam, director of inpatient

Cont.

and outpatient palliative care services. The team connects clients with medical care, paid for through Medicaid or hospital charity, and then makes sure they follow up. They help patients evaluate complicated treatment options, and, when the time comes, they may be with them when they die. The effort, funded through 2017 by a federal grant of \$170,000 a year, aims to reduce unnecessary or unwanted end-of-life care and to give homeless people a say in the process. Too often, Lam said, such patients are treated in emergency rooms during crises and wind up receiving feeding tubes, mechanical ventilation and long intensive care stays. "These therapies have their place," Lam said. "But we noticed people were getting care they might not have wanted." So far, for patients enrolled in the program for six months, the Seattle project has reduced hospital stays by 25% and emergency room visits by half, according to a June report.¹ https://goo.gl/s2fTKp

 'Palliative Care for Homeless Individuals: Emerging Views,' School of Public Health, University of Washington, June 2016. <u>https://goo.gl/6htl5B</u>

Noted in Media Watch 2 January 2017, #493 (p.18):

- JOURNAL OF URBAN HEALTH | Online 27 December 2016 'The effect of advance directive completion on hospital care among chronically homeless persons: A prospective cohort study.' During the 1-year follow-up period, 38 participants who completed an AD and 37 participants who did not complete an AD had at least one hospitalization. Homeless men who complete an AD through a shelter-based intervention are more likely to have their detailed care preferences documented or used during subsequent hospitalizations. https://goo.gl/NzLvHN
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 30 December 2016 'Homeless individuals approaching the end of life: Symptoms and attitudes.' Homeless individuals often have unique experiences at the end of life (EOL). Eligibility [to participate in this study] required a serious medical condition and for the patient's medical provider to answer "no" to the question "Would you be surprised if this patient were not alive in one year?" https://goo.gl/szzW4u

N.B. Additional articles on end-of-life care for the homeless are noted in Media Watch 5 December 2016, #490 (p.6); 8 August 2016, #474 (p.12); and, 14 March 2016, #453 (pp.14-15).

University of Southern California researchers aim to boost quality of life for seriously ill patients

CALIFORNIA | USC News (Los Angeles) - 10 January 2017 - Which model is more effective when providing relief from the symptoms and stress of a serious illness - primary care or home-based care? A research team led by Susan Enguidanos at the Leonard Davis School of Gerontology will compare outcomes from two groups - patients who receive primary care in hospitals versus those who get home-based palliative care (PC). The university team has received a \$5 million award for a study approved by the Patient-Centered Outcomes Research Institute. About 1,155 seriously ill patients with cancer, heart failure and chronic obstructive pulmonary disease, along with 884 of their caregivers, will be randomly assigned to either group, making this one of the largest trials of PC to date. People who receive PC may live longer and have a better quality of life than people with similar illnesses who don't receive such care.

according to an Institute of Medicine report.¹ However, most PC programs are hospital-based. Few offer care in the community despite findings that most Americans spend the vast majority of their last years of life living at home receiving care that can prevent unnecessary hospitalizations and emergency department visits. https://goo.gl/IDurPC

Specialist Publications

'Regional variation in primary care involvement at the end of life' (p.3), in *Annals of Family Medicine*.

'After the DNR: Surrogates who persist in requesting cardiopulmonary resuscitation' (p.6), in *The Hastings Report.*

 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch 22 September 2014, #376 (p.4)] <u>http://goo.gl/6Q5VNY</u>

International

Assisted (or facilitated) death

Representative sample of recent news media coverage:

U.K. (England, Northern Ireland, Wales) | The Economist - 17 January 2017 - 'Police in Britain increasingly turn a blind eye to assisted suicide.' Although aiding a suicide remains illegal, updated guidance from the Crown Prosecution Service (CPS), which decides when it is in the public interest to proceed with charges, has narrowed the circumstances in which a prosecution will go ahead. Its guidelines, issued in 2010 and updated in 2014, state a prosecution is less likely to be in the public interest if, for example, "the victim had reached a voluntary, clear, settled and informed decision" and the suspect's actions "were of only minor encouragement or assistance." To gauge the impact of these rules. The Economist asked all police forces and the CPS for the number of recorded offences of aiding and abetting suicide they held from the start of 2010 to the end of September 2016. It also asked how many people had been arrested and charged. The results suggest that institutional attitudes, as well as public ones, are changing. The data, which cover England, Wales and Northern Ireland (Scotland lacks a statutory offence of assisting suicide; individuals can be prosecuted under other crimes, such as murder), show a small but rising number of people coming to the authorities' attention for trying to help friends or relatives to end their lives. In all, 83 separate offences were recorded across 43 police forces (six did not reply) during the period. From single digits between 2010 and 2013, the number of offences rose to 17 in 2014 and 23 in 2015. In the first nine months of last year 12 offences were recorded. https://goo.gl/vcl8sH

Specialist Publications

'Achieving prudent dementia care (Palliare): An international policy and practice imperative' (p.8), in International Journal of Integrated Care.

'Poverty reduction in India through palliative care: A pilot project' (p.7), in Indian Journal of Palliative Care.

'Home-based palliative services under two local selfgovernment institutions of Kerala, India: An assessment of compliance with policy and guidelines to local selfgovernment institutions' (p.8), in Indian Journal of Palliative Care.

NEW ZEALAND | Stuff.com.nz – 12 January 2017 – 'Most Kiwis support euthanasia for those with painful, incurable diseases.' Just 12% of Kiwis are completely opposed to the legalisation of assisted dying, according to a University of Auckland study. In a survey of 15,822 people, 66% supported euthanasia as a legal means of ending the lives of people with painful, incurable diseases. The results were taken from the 2014-2015 New Zealand Attitudes & Values Study survey, which ... provided "reliable demographic and personality differences in support for euthanasia." People who were religious, on lower incomes, parents, and those of Pacific or Asian ethnicity tended to be less supportive. https://goo.gl/kbfaZu

Specialist Publications

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

Regional variation in primary care involvement at the end of life

ANNALS OF FAMILY MEDICINE, 2017;15(1):63-67. Variation in end-of-life care (EOLC) in the U.S. is frequently driven by the health care system. The authors assessed the association of primary care physician involvement at the end of life with EOLC patterns. They assessed 306 hospital referral regions (HRRs), capturing 1,107,702 Medicare Part B beneficiaries with chronic disease who died. HRRs with high vs low primary care physician involvement at the end of life had significantly different patient, population, and health system characteristics. Adjusting for these differences, HRRs with the greatest primary care physician involvement had lower Medicare spending in the last 2 years of life (\$65,160 vs \$69,030) and fewer intensive care unit days in the last 6 months of life (2.90 vs 4.29), but also less hospice enrollment (44.5% of decedents vs 50.4%). Regions with greater primary care physician involvement in EOLC have overall less intensive EOLC. https://goo.gl/Pqdkoj

Patient versus health care provider perspectives on spirituality and spiritual care: The potential to miss the moment

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 12 January 2017 – Most notably [in this study involving patients and physicians, nurses or social workers who routinely cared for patients with advanced life-limiting illnesses], health care professionals (HCPs) struggled to articulate definitions of spirituality whereas patients generally spoke with much more ease, giving rich examples. Equally, HCPs had difficulty relating to stories of patients who had experienced spiritual distress, while patients gave ready responses. Key areas where HCPs and patients differed were identified and set up the strong possibility for an HCP to "miss the moment" in providing spiritual care. These key misses include the perception that spiritual care is simply not something they can provide, the challenge in defining/recognizing spirituality (as HCP and patient definitions were often very different), and the focus on spiritual care, even for those interested in providing, as "task oriented" often with emphasis on meaning making or finding purpose, whereas patients much more commonly described spiritual care as listening deeply, being present and helping them live in the moment. https://goo.gl/CNpp7d

Related

MAYO CLINIC PROCEEDINGS, 2017;92(1):147-152. 'Providing appropriate end-of-life care to religious and ethnic minorities.' Recognizing and addressing cultural and religious/spiritual (RS) values is a critical aspect of providing goal-concordant care for patients facing a serious illness, especially at the end of life. Failure to address a patient's cultural and RS needs can lead to diminished quality of care and worse health outcomes. Given the multitude of cultural and RS values, the authors believe that a framework of cultural and RS curiosity, along with a willingness to engage patients in discussions about these elements of their care within an interdisciplinary team, should be the goal of all providers who are discussing goals, preferences, and values with patients facing advanced terminal illness. <u>https://goo.gl/G60YJV</u>

N.B. Additional articles on "spiritual care" in the context of end-of-life care noted in Media Watch 7 November 2016, #486 (p.12); 24 October 2016, #484 (p.12); and, 12 September 2016, #479 (p.12).

Managing "shades of grey": A focus group study exploring community-dwellers' views on advance care planning in older people

BMC PALLIATIVE CARE | Online – 13 January 2017 – Debates about best advance care planning (ACP) approaches seldom include evidence about how people consider the meaning of ACP, or their preferences about approaching it. This is especially evident for proxies potentially actualising individuals' ACPs. Community-dwellers depict ACP as a relational process for older people (OP), reflecting a matrix of individual, family, social-cultural, and systemic factors affecting motivations to discuss and complete related documents. Typical ACP programs which "step" consumers through documents usually assume that consumers are "ready" to plan all components, when this is in fact seldom the case. Plausibly, many current ACP programs undermine the true issues faced by OP and their offspring/caregivers as they face the uncertainty of the in-between space of living and dying [20]. https://goo.gl/J0hI3U

Cont. next page



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/SCHoAG

Related

- CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY | Online 5 January 2017 'Advance directives and end-of-life care among nursing home residents receiving maintenance dialysis.' Using national data from 2006 to 2007, the authors compared the content of advance direc- tives (AD) among 30,716 nursing home residents receiving dialysis to 30,825 nursing home residents with other serious illnesses during the year before death. In the last year of life, 36% of nursing home residents receiving dialysis had a treatment-limiting directive, 22% had a surrogate decision-maker, and 13% had both in adjusted analyses. Among nursing home residents receiving dialysis, treatment- limiting directives and surrogates were associated with fewer intensive interventions and inpatient deaths, but were in place much less often than for nursing home residents with other serious illnesses. https://goo.gl/ab4lbu
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 6 January 2017 'Integrating supportive care principles into dialysis decision-making: A primer for palliative medicine pro-viders.' Despite advances in pre-dialysis care and dialysis technology, patients with advanced chronic kidney disease and end-stage renal disease continue to experience multiple co-morbidities, a high symptom burden, a shortened life expectancy and substantial physical, emotional, and spiritual suffering. Patients with acute kidney injury and end-stage renal disease, especially if they are older, often undergo prolonged hospitalizations, greater use of intensive medical treatment, and limited survival. Unfortunately, most nephrologists are not trained to conduct shared decision-making conversations to elicit patients' values, preferences, and goals for treatment and address their patients' multifactorial suffering. <u>https://goo.gl/kVtq0S</u>

Treatment targeted at underlying disease versus palliative care in terminally ill patients: A systematic review

BMJ OPEN | Online – 6 January 2017 – The findings of this review have several important implications for physicians, patients and policymakers. Physicians are obligated legally and ethically to provide patients with evidence on alternative management options in the end-of-life setting. Some states [in the U.S.], such as New York and California make the failure to discuss the management alternatives in terminal setting punishable by law... However, repeated assessments of the quality of decision-making in the end-of-life setting over the last two decades continue to show that is inadequate. In 2014, 55 million people died worldwide, the vast majority of whom did not receive adequate end-of-life care. The fundamental reason for this state of affairs is the lack of reliable estimates about the efficacy and safety of active treatment (AT) versus PC in patients in terminal phase of their lives. Even though it is known that PC does improve survival when it is added to AT, it is not known if AT is superior to PC alone. To the best of the authors' knowledge, this is the first systematic review assessing the role of AT compared with PC in patients with terminal illness with expected survival of <6 months. The findings showed that overall AT compared with PC does not improve survival and is associated with significantly higher incidence of fatigue, nausea/ vomiting, mucositis, grade III/IV neuropathy, anaemia, leukopenia, neutropaenia, and myalgia leading to poor QOL. https://goo.gl/OmKdPx



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.12.



Back Issues of Media Watch http://goo.gl/frPgZ5

After the DNR: Surrogates who persist in requesting cardiopulmonary resuscitation

THE HASTINGS REPORT | Online - 11 January 2017 - Some health care organizations allow physicians to withhold cardiopulmonary resuscitation (CPR) from a patient, despite patient or surrogate requests that it be provided, when they believe it will be more harmful than beneficial. Such cases usually involve patients with terminal diagnoses whose medical teams argue that aggressive treatments are medically inappropriate or likely to be harmful. Although there is state-to-state variability[in the U.S.] and a considerable judicial gray area about the conditions and mechanisms for refusals to perform CPR, medical teams typically follow a set of clearly defined procedures for these decisions. The procedures are based on the principle of nonmaleficence and typically include consultation with hospital ethics committees, reflecting the guidelines of relevant professional associations. Ethical debates about when CPR can and should be limited tend to rely more on discussions of theory, principles, and case studies than systematic empirical study of the situations in which such limitations are applied. Sociologists of bioethics call for empirical study, arguing that what ethicists and health professionals believe they are doing when they draft policies or invoke principles does not always mirror what is happening on the ground. In this article, the authors begin the task of modeling the empirical analyses sociologists call for, focusing on a cohort at Massachusetts General Hospital. They inductively analyzed ethics committee notes and

medical records of nineteen patients whose surrogates did not accept the decision to withhold CPR. <u>https://goo.gl/4CyvmX</u>



Additional perspectives on the subject matter of the three articles from *The Hastings Report* noted in this issue of Media Watch are included in the current issue of the journal (under 'Other Voices'). Contents page: https://goo.gl/yUVg7m

N.B. The illustration on the cover of the current issue of *The Hastings Report* is a painting, 'Family Waiting' (1989), by Canadian artist Robert Pope (1956-1992). Robert captured on canvas his personal journey with Hodgkin's disease. I had the good fortune to work with The Robert Pope Foundation in organizing a national tour of Canada of a selection of the artist's works, visiting 50+ cities during the spring and fall of the years 1997-2001. With a parallel education program, Robert's work helped to expose health care professionals (and also the general public) to a unique perspective on the illness experience. **BRA**

The limits of surrogates' moral authority and physician professionalism: Can the paradigm of palliative sedation be instructive?

THE HASTINGS REPORT | Online – 11 January 2017 – With narrow exception, physicians' treatment of incapacitated patients requires the consent of health surrogates. Although the decision-making authority of surrogates is appropriately broad, their moral authority is not without limits. Discerning these bounds is particularly germane to ethically complex treatments and has important implications for the welfare of patients, for the professional integrity of clinicians, and, in fact, for the welfare of surrogates. Palliative sedation is one such complex treatment; as such, it provides a valuable model for analyzing the scope of surrogates' moral authority. Guidelines for palliative sedation that present it as a "last-resort" treatment for severe and intractable suffering yet require surrogate consent in order to offer it are ethically untenable, precisely because the moral limits of surrogate authority have not been considered. https://goo.gl/OwJ4Ci

Conflating capacity and authority: Why we're asking the wrong question in the adolescent decision-making debate

THE HASTINGS REPORT | Online – 11 January 2017 – Are adolescents sufficiently capacitated to make their own medical decisions? Is the mature-minor doctrine, an uncommon legal exception to the rule of parental decision-making authority, something we should expand or eliminate? Bioethicists have dealt with the curious liminality of adolescents – their being neither children nor adults – in a variety of ways. However, recently there has been a trend to rely heavily, and often exclusively, on emerging neuroscientific and psychological data to answer these questions. Using data from magnetic resonance imaging and functional MRI studies on the adolescent brain, authors have argued both that the adolescent brain isn't sufficiently mature to broadly confer capacity on this population and that the adolescent brain is sufficiently mature to assume adolescent capacity. Scholars then accept these data as sufficient for concluding that adolescents should or should not have decision-making authority. Two critical mistakes are being made here. The first is the expectation that neuroscience or psychology is or will be able to answer all our questions about capacity. The second, and more concerning, mistake is the conflation of decision-making capacity with decision-making authority. https://goo.gl/ciyAEi

Related

JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY | Online – 11 January 2017 – 'Experiences and preferences for end-of-life care for young adults with cancer and their informal carers: A narrative synthesis.' The studies [reviewed] were heterogeneous in their aims, focus, and sample, but described different aspects of end-of-life care for people with cancer. Positive experiences included facilitating adaptive coping and receiving palliative home care, while negative experiences were loss of "self" and non-facilitative services and environment. Preferences included a family-centered approach to care, honest conversations about end of life, and facilitating normality. There is little evidence focused on the end-of-life needs of young adults. Analysis of reports including some young adults does not explore experience or preferences by age; therefore, it is difficult to identify age-specific issues clearly. https://goo.gl/Q3lLxU

Noted in Media Watch 24 October 2016, #484 (p.9):

 JAMA PEDIATRICS | Online – 17 October 2016 – 'Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review.' In most cases, clinicians should gently, but persistently engage adolescents directly in conversations about their disease prognosis and corresponding hopes, worries, and goals. These conversations need to occur multiple times, allowing significant time in each discussion for exploration of patient and family values. While truth-telling does not cause the types of harm that parents and clinicians may fear, discussing this kind of difficult news is almost always emotionally distressing. https://goo.gl/v91oh0

End-of-life care in India

Poverty reduction in India through palliative care: A pilot project

INDIAN JOURNAL OF PALLIATIVE CARE, 2017;23(1):41-45. In India, where 1% of the population suffers from chronic or terminal illness, patients stop working, families prioritise care over income, and households increase expenditure on treatments and cures. As households fall into greater poverty, they sell assets, take out unsustainable debt, and the situation spirals out of their control. The poorest households are particularly affected, as their illiteracy and lack of influence make it most difficult for them to gain access to government benefits. Palliative care (PC) in India has an inherent potential to reduce household poverty, including through reducing households' expenditure on medical care, assisting patients and their family members to receive government benefits, and enabling some family members and patients to work again. Emanuel Health Association's PC services are achieving these poverty reduction impacts even before the Association has developed them for poverty reduction. With the development and refinement of these services, more patients and family members could enrol in PC, and earlier. More households would spend less money on inappropriate treatments and hospital visits and medicines, would make these savings earlier, would enrol for all government benefits, would earn more again, would save more money over the course of the illness, and would organise inheritance to benefit women and girls. Severe illness devastates poor households' income and expenditure, driving them into hopeless poverty. Holistic PC has vast potential to limit all these effects. https://goo.gl/HFAUtd

Related

INDIAN JOURNAL OF PALLIATIVE CARE, 2017;23(1):65-70. 'Home-based palliative services under two local self-government institutions of Kerala, India: An assessment of compliance with policy and guidelines to local self-government institutions.' Despite having made much progress, the program in two local self-government institutions is still short of a public health approach, and major guidelines of the palliative policy seem to have been given a miss. It also lacks the flavor of a community-owned program with a committed organizational structure, dedicated staff and delivery mechanism, seamless care through continuous monitoring, high frequency of visits, and adequate referrals. Finally, it appears too fragmented and restricted in its scope to meet the needs of the poor, the homeless, and those without caregivers unless it is located within an inclusive long-term care strategy involving a mix of health and social security measures. Evidently, this would require a huge structural reconfiguration of the delivery system – a task whose magnitude and profundity necessitate greater state responsibility and political will in including palliation within a broader social organization of care. https://goo.gl/kuxH98

N.B. India was ranked 67th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch 12 October 2015, #431 (p.6)] <u>http://goo.gl/bT3PV5</u>

Achieving prudent dementia care (Palliare): An international policy and practice imperative

INTERNATIONAL JOURNAL OF INTEGRATED CARE, 2016;16(4). This paper examines the provision of integrated advanced dementia care within seven European countries and critically reviews the potential contribution of the Prudent Healthcare perspective as a starting point for reform. Progressive efforts to innovate, promote quality and integrate care are tempered with the reality of resource constraints. Some policy makers in Europe and North America have turned their attention to the principles of Prudent Healthcare as a potential mechanism to maximise benefits for patients within available resources. As dementia progresses, living well requires increasing levels of support and care, people living with advanced dementia have complex health and social care needs, are highly dependent on others but are not yet at the terminal end stage of the condition. People with advanced dementia can benefit from a dementia specific palliative approach to care (Palliare), that helps them to live the best life possible for the months and often years they live with advanced dementia. It is also highly desirable to align policy innovations with integrated palliative care (PC) practice models and the education of the dementia workforce to accelerate informed improvements in advanced dementia care. There may be some coherence, at least superficially between Prudent Healthcare and integrated PC models such as Palliare. It is argued that for successful implementation, both require practitioners to be equipped with knowledge and skills and be empowered to deliver high quality care often within impoverished care environments. Adoption of the prudent perspective will however require development of a repertoire of approaches to hear the voice or proxy voice of people living with advanced dementia and to commit to the development and implementation of new evidence for advanced dementia practice. https://goo.gl/YhWi3s

Related

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Inprint – Accessed 14 January 2017 – 'Consensus Statement of the International Summit on Intellectual Disability & Dementia Related to End-of-life Care in Advanced Dementia.' The International Summit on Intellectual Disability & Dementia's report on end-of-life care in advanced dementia provides a synthesis statement which encompasses defining the state of advanced dementia, proposing use of palliative care services (including hospice), and recommending special efforts for enabling advanced directives and advance care planning prior to the extensive progression of dementia. https://goo.gl/8tyLrQ

Hospice staff perceptions of information needs among patients and families during hospice admissions visits

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(1):82-88. Interviews [in this qualitative study were] conducted with 16 admissions staff members from four hospice agencies... Patients and families often lacked knowledge of patient condition and illness progression and awareness of changes in bodily needs for nutrition/hydration and medication near death. Misconceptions about pain medicine in hospice are another area identified. Patients and families did not always realize risks of life-sustaining treatments. The availability of interdisciplinary service was not often known. Insufficient patient-health care provider communication contributes to lack of information in these areas. Although admissions staff can fill information gaps, patient-health care provider conversations on end-of-life issues should occur earlier than waiting until the patient is referred to hospice. Future studies should examine strategies to address informational needs and assess patient/family satisfaction with provided information. https://goo.gl/NciIA8

A provider-based survey to assess bereavement care knowledge, attitudes, and practices in pediatric oncologists

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 January 2017 – An internet-based survey instrument was pilot tested, refined, and distributed to pediatric oncologists in the U.S. Electronic surveys were distributed to 2,061 pediatric oncologists and 522 surveys (25%) were fully completed. Participants were asked how likely they are to engage in particular bereavement activities (phone calls, condolence cards, memorial services, family meetings, or referrals for counseling) following the death of a pediatric cancer patient. Eighty-two percent of participants, at least, sometimes engage in at least one of these activities. Being female, an attending physician, and increased time in clinical practice were predictive of active participation in bereavement care. Nearly all participants (96%) believe that bereavement care is part of good clinical care, while 8% indicate that bereavement support is not their responsibility. Lack of time and resources were the biggest barriers to providing bereavement support. https://goo.gl/7Q0hp4

Related

 DEATH STUDIES | Online – 10 January 2017 – 'Parental bereavement: Looking beyond grief.' While parental grief is well studied, the complexities of challenges bereaved parents face are not understood. This study describes parental bereavement challenges during the first 6 months following the death of their child. Challenges are characterized by the absence of the child, their emotional response, and the changed relationships with family and friends. <u>https://goo.gl/bVMoTg</u>

Protecting patients from their bad decisions: Rebalancing rights, relationships, and risk

MEDICAL LAW REVIEW | Online – 11 January 2017 – Patients have a right to autonomy that encompasses making medical decisions that others consider "bad." The ambits of this right in law and clinical practice are explored in this article, which describes an expansion of welfare protections across different aspects of medical law and explores their justifications and implications. In England and Wales, the Mental Capacity Act 2005 sets out protections for those who fall within its definition of incapacity. Those who retain capacity are ostensibly free to make decisions others consider unwise. But the decisions of those with borderline capacity; those whose decisions conflict with the public interest in protecting the patient from harm; and those considered "vulnerable" are, in circumstances explored in this article, susceptible to override. The article explores the effects of these developments on the relationship between patients' autonomy rights and clinicians' responsibilities. https://goo.gl/y4t9OH



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials. <u>http://goo.gl/OTpc8I</u>

End-of-life care in Singapore

The practice of terminal discharge: Is it euthanasia by stealth?

NURSING ETHICS | Online – 4 January 2017 – "Terminal discharges" are carried out in Singapore for patients who wish to die at home. However, if due diligence is not exercised, parallels may be drawn with euthanasia. The authors present a theoretical discussion beginning with the definition of terminal discharges and the reasons why they are carried out in Singapore. By considering the intention behind terminal discharges and utilising a multidisciplinary team to deliberate on the clinical, social and ethical intricacies with a patient- and context-specific approach, euthanasia is avoided. It is hoped that this will provide a platform for professionals in palliative medicine to negotiate challenging issues when arranging a terminal discharge, so as to avoid the pitfall of committing euthanasia in a country such as Singapore where euthanasia is illegal. It is hoped that a set of guidelines for terminal discharges may someday be realised to assist professionals in Singapore and around the world. https://goo.gl/21A0El

Aligning guidelines and medical practice: Literature review on pediatric palliative care guidelines

PALLIATIVE & SUPPORTIVE CARE | Online – 9 January 2017 – Although concurrent administration of curative and palliative care is recommended, timely referral to pediatric palliative care (PPC) services remains problematic. This literature review aims to identify barriers and recommendations for proper implementation of palliative care for children through the looking glass of PPC guidelines. Concerning barriers, most of the papers [reviewed] focused on gaps within medical practice and the lack of evidence-based research. Common recommendations therefore included: 1) Training and education of healthcare staff; 2) Formation of a multidisciplinary PPC team; 3) Research on the benefits of PPC; and, 4) Raising awareness about PPC. A small number of publications reported on the absence of clear guidance in PPC documents regarding bereavement care, as well as on the difficulties and challenges involved in multidisciplinary care teams. Results indicate that a critical assessment of both the research guidelines and medical practice is required in order to promote timely implementation of PPC for pediatric patients. https://goo.gl/G2Qrey

Noted in Media Watch 12 December 2016, #491 (p.12):

- BRITISH MEDICAL JOURNAL | Online 8 December 2016 'End-of-life care for infants, children and young people with life limiting conditions: Summary of National Institute for Health & Care Excellence guidance.' This guideline was commissioned with the aim to standardise end-of-life care for infants, children, and young people living with a life-limiting condition, and thus promote equity and consistency. This article summarises the most recent guidance from the recent National Institute for Health & Care Excellence (NICE) on the planning and management of end of life care in infants, children, and young people.¹ https://goo.gl/nyUO4n
 - 1. 'End-of-life care for infants, children and young people with life-limiting conditions: Planning and management,' National Institute for Health & Care Excellence, December 2016. <u>https://goo.gl/8GLw37</u>

Related

BMC PALLIATIVE CARE | Online – 12 January 2017 – 'A prospective study on the characteristics and subjects of pediatric palliative care case management provided by a hospital based palliative care team.' Four hundred fifty-five contacts took place with parents of 70 patients.... Sixty-two percent of all contacts were with the specialized nurse. The child life specialists, psychologist and social worker were also regularly consulted, [but]the chaplain was not consulted. Ninety-five percent of all contacts took place between 8 a.m. and 6 p.m. during weekdays, a limited number between 6 p.m. and 9 p.m. Twenty-five percent of all contacts were proactively initiated by the PPCT, [and] 25 % were initiated by parents. In these care characteristics, no differences were seen for MD and NMD patients. Psychosocial topics were addressed most frequently. MD patients consulted the PPCT more often about school and NMD patients about socio-economic issues. https://goo.gl/BBfmfB

Oncologists' negative attitudes towards expressing emotion over patient death and burnout

SUPPORTIVE CARE IN CANCER | Online – 13 January 2017 – The participants [in this study] included a sample of 177 oncologists from Israel and Canada. Oncologists completed a questionnaire package that included a socio-demographic survey, a burnout measure, a survey assessing negative attitudes towards expressing emotion, and a survey assessing desired interventions to cope with patient death. Higher burnout scores were related to higher negative attitudes towards perceived expressed emotion ... of those who viewed this affect as a weakness and as a sign of unprofessionalism. Approximately half of the on-cologists found each of the five categories of institutional interventions (pedagogical strategies, emotional support, group/peer support, taking time off, and research and training) helpful in coping with patient death. Institutions should promote interventions that are varied and that focus on the needs of oncologists in order to reduce burnout. Interventions that legitimize expression of emotion about patient death may be useful. Another way to reduce stigma would be to require oncologists to "opt out" rather than "opt in" to accessing a selection of social and/or individual interventions. <u>https://goo.gl/BJ55RS</u>

Noted in Media Watch 9 January 2017, #494 (p.6):

CLINICAL ONCOLOGY | Online – 30 December 2016 – 'Too hot, too cold or can we get it just right? What emotional distance should oncologists keep from their patients?' 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/gT09i5

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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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

Strategic targeting of advance care planning interventions: The Goldilocks phenomenon

JAMA INTERNAL MEDICINE | Online – 3 February 2014 – Strategically selecting patients for discussions and documentation about limiting life-sustaining treatments – choosing the right time along the end-of-life trajectory for such an intervention and identifying patients at high risk of facing end-of-life decisions – can have a profound impact on the value of advance care planning (ACP) efforts. Timing is important because the completion of an advance directive (AD) too far from or too close to the time of death can lead to end-of-life decisions that do not optimally reflect the patient's values, goals, and preferences: a poorly chosen target patient population that is unlikely to need an AD in the near future may lead to patients making unrealistic, hypothetical choices, while assessing preferences in the emergency department or hospital in the face of a calamity is notoriously inadequate. Because much of the currently studied ACP efforts have led to a disappointingly small proportion of patients eventually benefitting from an AD, careful targeting of the intervention should also improve the efficacy of such projects. A key to optimal timing and strategic selection of target patients for an ACP program is prognostication, and we briefly highlight prognostication tools and studies that may point us toward high-value AD interventions. [Noted in Media Watch 10 February 2014, #344 (p.6)] https://goo.gl/OWrLN6

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

Asia

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

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

Canada

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

Europe

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

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

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

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