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.

27 June 2016 Edition | Issue #468



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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to <u>Specialist Publications</u> and "Close to" a palliative approach: Nurses, and care aides, descriptions of caring for people with advancing chronic life-limiting conditions' (p.8), in *Journal of Clinical Nursing*.

Canada

Ontario has "long way to go" to improve end-of-life care, says researcher

ONTARIO | The Windsor Star - 23 June 2016 -Ontario "has a long way to go" to improve endof-life care, says the lead author of a newly released study that reveals a large proportion of dying people don't get any, get too little or get it only in the hospital when they'd prefer to die at home. 1 Just 52% of people dying in Ontario between 2010 and 2012 had at least one instance of palliative care (PC) in their last year of life, says the study from the Institute of Clinical & Evaluative Sciences. Despite the fact that 80% of people say they'd prefer to spend their final days at home and die in their own bed, only 20% of dying patients receive PC at home and just 10% receive a single palliative house call from their doctor. "That's just one visit," said lead author Dr. Peter Tanuseputro, whose study also found: patients with cancer get two-and-a-half times more PC than people dying of things like congestive heart failure and dementia; half of all PC is delivered pretty late, in the last two months; and one-quarter of dying patients who

get PC only receive one or two visits. More than 50% of Ontarians die in acute care hospitals, 24% die in long-term care and 25% die at home. Those numbers are a "stark contrast" to what people want, said Tanuseputro, who noted that when people receive in-home PC it more than doubles their chances of remaining at home to die. http://goo.gl/lyfJ1K

Extract from The Windsor Star article

Data provided to the *Star*, but not included in the [Institute of Clinical & Evaluative Sciences] study, shows that the Erie St. Clair Local Health Integration Network ... is one of the leaders when it comes to the percentage of dying people getting care (54.5%). The percentage of people getting a doctor house call is almost exactly the Ontario rate and the percentage of dying people receiving palliative care at home is slightly better at 21.9%.

1. 'Palliative care delivery across health sectors: A population-level observational study,' *Palliative Medicine*, 16 June 2016. [Noted in Media Watch, 20 June 2016, #467 (p.15)] http://goo.gl/KSrQ3x

Assisted (or facilitated) death

Representative sample of recent news media coverage:

ONTARIO | The Ottawa Citizen - 22 June 2016 - 'Chief coroner will take reports of Ontario's assisted deaths.' The office of the Chief Coroner for Ontario will collect data on medically-assisted deaths in the province - at least until Queen's Park decides whether it will create an independent body to perform the task. Drug toxicity technically the cause of assisted death - is considered a reportable death under the Ontario Coroners Act, said chief coroner Dr. Dirk Huyer. "This is a new area in medical work - and in society. Until there is provincial legislation, we will receive the reports," said Huver, whose offices across the province investigate about 16,000 deaths a year. http://goo.gl/avLNpl



Specialist Publications

'Doctors left to define foreseeable death ion new law' (p.15), in Canadian Medical Association Journal.

U.S.A.

Narrating medicine: When doctors forget to feel

MASSACHUSETTS | WBUR (Boston) - 23 June 2016 - So much has been written in recent years about shifting patient attitudes toward death and dying and how physicians can support these decisions through palliative care. But often ignored is the other half of the emotional coin: How do these conversations, and ultimately their outcomes, make the physician feel? A physician's duty to speak honestly and empathetically with a dying patient is not one all of us carry evenly or even train for, yet it's a duty many of us must perform. And amidst this duty is an emotional burden that frequently goes unrecognized, with little guidance on managing it. Unfortunately, under a culture of medical stoicism. we subdue or ignore our emotions. But learning to embrace them goes beyond the individual and has profound effects on the patient-physician relationship. As one senior physician told me, "If you don't talk about these feelings they come out in weird ways." What he was referring to was the concept of counter transference, originally used by Sigmund Freud to describe how a therapist responds to the patient's influence on his unconscious feelings. Today, its definition has been broadened to include all of the emotional response of the health care provider toward the patient. The physician is inevitably affected by the patient and the patient's reaction to a diagnosis, treatment or entire medical experience. Especially in the emotionally charged setting of end-of-life care, one can see how counter transference is pervasive. http://goo.gl/238UZg

Specialist Publications

'Bereavement services offered in adult intensive care units in the U.S.' (p.9), in American Journal of Critical Care.

'Enhancing the prospects for palliative care at the end of life: A state-wide educational demonstration project to improve advance care planning' (p.14), in *Palliative & Supportive Care*.

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.16.

Federal legislation update

Doctors, patients urge legislation to improve hospice, palliative care

MODERN HEALTHCARE | Online – 23 June 2016 – Doctors and lawmakers ... touted legislation to train more providers who specialize in hospice and palliative care (PC) and improve options for patients with serious chronic illnesses. At a hearing of the Senate Special Committee on Aging, Senator Sheldon Whitehouse (Democrat, Rhode Island) said he is introducing a bill that would allow for more pilot programs and Medicare waivers regarding hospice care. It would also allow hospice and curative care to be provided to a patient at the same time and would provide for home services before a patient is home-bound. Part of the problem with American hospice and palliative care is the cultural resistance to discussing end-of-life issues, but part of it is also Medicare's payment structure, he said. Research has shown that in the last month of life, more than half of people experience moderate to severe pain and many also have depression. Those who receive PC suffer less, are more physically capable and can interact with others for longer. But they do not die sooner, and their costs are typically lower... Another bill that has been introduced, the Palliative Care and Hospice Education and Training Act, would establish grants for more provider training and would expand PC research. Last session's Care Planning Act is also being eyed as a possible legislative vehicle. It would have created a Medicare benefit called planning services for people with advanced illnesses. http://goo.gl/RHnCEG

Government snags 301 people in nationwide health-care fraud sweep

WASHINGTON DC | Bloomberg - 23 June 2016 - The government charged 301 individuals with allegedly participating in various health-care fraud schemes that led to roughly \$900 million in fraudulent Medicare claims. The nationwide operation was led by Medicare Fraud Strike Force teams, which combine representatives from local and federal enforcement agencies, and covered 36 federal judicial districts. The Department of Justice began announcing the so-called fraud takedowns in 2010, and the annual announcements compile unrelated healthcare fraud cases. The latest takedown ... sets records for the number of individuals charged, the amount of fraudulent claims, and the number of districts covered by the investigations. Last year's takedown charged 243 defendants for their alleged participation in fraud schemes that led to \$712 million in fraudulent claims. The use of real-time data played a key role in the takedowns, Tom O'Donnell, assistant inspector general for investigations at the Health & Human Services Office of Inspector General... O'Donnell said that in 2007 it took months to get claims data, while now it's available in real time, almost as soon as a claim is submitted, http://goo.gl/ig76zV

Extract from Bloomberg article

Tom O'Donnell, assistant inspector general for investigations at Health & Human Services identified home health and hospice fraud as areas the Office of Inspector General will watch more closely.

Related

CALIFORNIA | My News LA (Los Angeles) – 20 June 2016 – 'Medicare millionaire fraud: 8 years in prison as "dying" patients were just fine.' Prosecutors said that between March 2009 and June 2013, California Hospice submitted nearly \$9 million in fraudulent bills to Medicare and Medi-Cal for purportedly providing end-of-life care to patients who were, in fact, doing well. The public health programs paid nearly \$7.5 million on those bogus bills. http://goo.gl/3CQtUA

Noted in Media Watch, 14 March 2016, #453 (p.5):

■ PENNSYLVANIA | The Pittsburgh Post-Gazette – 6 March 2016 – 'Hospice fraud becoming a costly problem for Medicare.' No one knows how big the problem of hospice fraud is – all types of improper Medicare payments are estimated at \$65 billion for 2010 – but federal investigators prosecuted more than 60 cases in the last year alone, involving hundred of millions of dollars nationwide. The system that was built to help dying patients live out their remaining days with dignity and comfort has few quality metrics to meet, no minimum requirements for how often care is provided, and low barriers to getting into the business. http://goo.gl/qKlLre

Getting serious about home care for aging Americans

THE FISCAL TIMES | Online – 21 June 2016 – [A new] legislative effort comes alongside a new report ... which addresses the nations' elder caregiving crisis. ¹ As documented in the report, working family caregivers are 50% more likely than their non-caregiver colleagues to experience daily physical pain. They also suffer from subtle, but equally intrusive bouts of mental and emotional anguish. The report highlights the growing importance of formal elder caregiving, needed even more as demographic and cultural changes increase the burdens on family caregivers. As the report states, "The ratio of potential family caregivers to those over 80 will steeply decline from 7:1 today to 4:1 by 2030, and seniors live an average of more than 280 miles from their nearest (adult) child." Mobility is a feature of modern American life; it's time to incorporate that fact into a more reality-based elder caregiving model. http://goo.gl/KQA5lg

1. 'Caring for America's Seniors; The Value of Home Care,' Home Care Association of America & Global Coalition on Aging, 2016. https://goo.gl/Ma4ymo

Related

■ HAWAII | The Garden Island (Lihue) – 18 June 2016 – 'New law supports family caregivers.' Governor David Ige signed into law ... a bill requiring hospitals to establish procedures giving family caregivers the opportunity to receive instruction in the medical tasks required when their loved ones are discharged. The CARE Act ... paves the way for greater consideration of caregivers in hospital discharge processes. The law takes effect July 2017. There are more than 154,000 unpaid family caregivers in Hawaii... Collectively, Hawaii's caregivers provided unpaid care valued at \$2.1 billion in 2013 alone. http://goo.gl/0DCaXf

N.B. No mention is made of home care for people living with a terminal illness. BRA

The devastating process of dying in America without insurance

THE NATION | Online – 20 June 2016 – Some 28 million people in the U.S. do not have health insurance... Though the care needs that arise with terminal illness are simple, they are often prohibitively difficult to meet without insurance. The uninsured and their families are left to navigate public and charity end-of-life care options that vary widely across the country, if they are available at all. There are no data on how or where the uninsured access this care, and the scope of unmet need is virtually unknown. What is known is that, at the end of their lives, many uninsured people quite literally cannot afford to die with dignity. The country's 11 million undocumented immigrants face particularly high barriers to accessing health care, including hospice, as they are legally barred from enrolling in any federally funded insurance program. Some 63% of the undocumented population goes without insurance coverage, and studies show that they tend to seek health care less in general, partly due to fears that interacting with any authority could lead to deportation. http://goo.gl/GDR2Qm

N.B. Selected articles on undocumented immigrants in the U.S. are noted in Media Watch of 14 December 2015, #440 (p.9).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEWSMAX | Online 24 June 2016 'Gallup: Most Americans still find euthanasia acceptable.' Most Americans believe euthanasia should be made legal, and that a doctor should be allowed to end his patient's life by painless means should that person request it, a new Gallup poll finds. ¹ The numbers of people in favor of the practice has climbed steadily from the 1940s and 1950s, when most people thought it should be illegal. http://goo.gl/snbfxw
 - 1. 'Euthanasia Still Acceptable to Solid Majority in U.S.,' Gallup, 24 June 2016. http://goo.gl/FhJKCE

International

End-of-life care in Thailand

Terminally ill need home-based care

THAILAND | The Bangkok Post - 22 June 2016 In Thailand, we mostly take care of terminally ill patients with what is called "sustaining" care in hospitals. In fact, most of these patients would prefer to stay at home where things are familiar rather than in a hospital. But Thailand does not have the necessary conditions in place, apart from some informal arrangements, to make this possible. Seeing how our neighbours Singapore and Malaysia approach this issue might help us understand it better and acknowledge the importance of home-based care for terminally ill patients. While home-based care doesn't mean patients will live longer, their passing is likely to be more peaceful than it would in the institutional surroundings of a hospital. Singapore and Malaysia have long recognised the importance of home-based care for terminally ill patients, providing "home hospice" services for more than 25 years. Services are provided by charities in those two countries free of charge or for very little, reducing the financial burden on patients

and their families. While the services provided in the two countries are quite similar, the financial and human resource support they receive varies. http://goo.gl/NIHmYk

Specialist Publications

'Reason-giving and medical futility: Contrasting legal and social discourse in the U.S. with the U.K. and Ontario, Canada' (p.6), in *Chest*.

'Cardiac implantable electronic devices and endof-life care: An Australian perspective' (p.7), in Heart, Lung & Circulation.

'U.K. audit on end-of-life care results in widespread negative media coverage' (p.10), in *Medical Ethics Advisory*.

'Palliative care and the Portuguese health system' (p.13), in *Porto Biomedical Journal*.

N.B. Thailand, Singapore and Malaysia were ranked 44th, 12th and 38th, respectively, of the 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/JsSbW3

Last wish: Hong Kong survey reveals most elderly would rather die in hospital than at home

CHINA (Hong Kong) | *The South China Morning Post* (Hong Kong) – 21 June 2016 – 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 (PC) unit found that only about 14% of patients receptive to the idea. Instead of pushing the trend of dying at home, an expert in PC suggested that the government could first try the concept in elderly care homes, which have better manpower and facilities. http://goo.gl/AJoJ48

Related

CHINA (Hong Kong) | The South China Morning Post (Hong Kong) – 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. Hong Kong has only 19 palliative care specialists ... and university training has been criticised by experts. http://goo.gl/3GVYIT

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

CHINA (Hong Kong) | The South China Morning Post (Hong Kong) – 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

Elder and home care in the U.K.

Privatisation is hurting the social care workforce

U.K. | *The Guardian* – 21 June 2016 – Privatisation has been a major trend in social care since the 1990s, but practices such as zero hour contracts, 15 minute care slots and sub-minimum wage pay are increasing public concern. Once the domiciliary care workforce was made up of local authority home helps who had valued, secure jobs. Now it is typified by low paid, part-time care assistants, with minimal job security and career prospects. The workforce is increasingly attracted to other sectors, such as supermarkets, for better terms and conditions. A recent review painted a dismal picture of working conditions in the care sector. ¹ http://goo.gl/QsMkjW

1. 'The Kingsmill Review: Taking Care An Independent Report into Working Conditions in the Care Sector,' 2016. http://goo.gl/OgdPi6

Specialist Publications

Moral hazard in pediatrics

THE AMERICAN JOURNAL OF BIOETHICS, 2016;16(7):29-38. "Moral hazard" is a term familiar in economics and business ethics that illuminates why rational parties sometimes choose decisions with bad moral outcomes without necessarily intending to behave selfishly or immorally. The term is not generally used in medical ethics. Decision makers such as parents and physicians generally do not use the concept or the word in evaluating ethical dilemmas. They may not even be aware of the precise nature of the moral hazard problem they are experiencing, beyond a general concern for the patient's seemingly excessive burden. This article brings the language and logic of moral hazard to pediatrics. The concept reminds us that decision makers in this context are often not the primary party affected by their decisions. It appraises the full scope of risk at issue when decision makers decide on behalf of others and leads us to separate, respect, and prioritize the interests of affected parties. https://goo.gl/jV1hyC

Reason-giving and medical futility: Contrasting legal and social discourse in the U.S. with the U.K. and Ontario, Canada

CHEST (American College of Chest Physicians) | Online - 11 June 2016 - Disputes regarding life-prolonging treatments are stressful for all parties involved. These disagreements are appropriately almost always resolved with intensive communication and negotiation. Those rare cases that are not require a resolution process that ensures fairness and due process. The authors describe recent cases from different countries (the U.S., U.K., and Canada) to qualitatively contrast the legal responses to intractable, policy-level disputes regarding end-of-life care in each of these countries. In so doing, they define the continuum of clinical and social utility among different types of dispute resolution processes, and emphasize the importance of public reasongiving in the societal discussion regarding policylevel solutions to end-of-life treatment disputes. The authors argue precedential, publicly available, written rulings for these decisions most effectively help to move the social debate forward in a way that is beneficial to clinicians, patients, and citizens. http://goo.gl/D2xCso

Palliative care ethics: A case commentary on discontinuing interventions at the end of life

THE AMERICAN JOURNAL OF BIOETHICS, 2016; 16(7):58-60. Some hospitals never permit health care providers to override patient/surrogate requests for such interventions. Many other hospitals have futility policies that only permit overriding patient/surrogate requests for physiologically futile interventions. Some hospitals permit health care teams to withhold interventions that a health care team (or review body) deems to be futile because they: 1) Offer little chance of prolonging a patient's life; 2) Are unseemly, only offer disproportionate harms; and/or 3) Are insufficient to enable the patient to live outside of an acute care hospital. http://goo.gl/4MzH0Y

Noted in Media Watch, 21 December 2015, #441 (p.14):

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 17 December 2015 – 'Medically inappropriate
or futile treatment: Deliberation and justification.' This paper reframes the futility debate, moving
away from the question "Who decides when to end what is considered to be a medically inappropriate
or futile treatment?" and toward the question "How can society make policy that will best account for
the multitude of values and conflicts involved in such decision-making?" http://goo.gl/0Ucl2W

N.B. Selected articles on medical futility are noted in Media Watch of 23 May 2016, #463 (p.13).

Cardiac implantable electronic devices and end-of-life care: An Australian perspective

HEART, LUNG & CIRCULATION, 2016;25(8):814-819. Cardiac implantable electronic devices (pace-makers and defibrillators) are increasingly common in modern cardiology practice, and health professionals from a variety of specialties will encounter patients with such devices on a frequent basis. This article will focus on the subset of patients who may request, or be appropriate for, device deactivation and discuss the issues surrounding end-of-life decisions, along with the ethical and legal implications of device deactivation. http://goo.gl/yyFHHE

N.B. Selected articles on implantable cardioverter-defibrillators in the context of end of life are noted in Media Watch of 1 February 2016, #447 (p.11).

Human-computer interaction

A framework for negotiating ethics in sensitive settings: Hospice as a case study

INTERACTING WITH COMPUTERS | Online – 15 June 2016 – Recognizing a lack of clear ethical direction from any one code of ethics (COE), the authors analyze across COEs offered by the professional associations related to their team's research backgrounds to develop a framework for exploring ethical dilemmas in human-computer interaction (HCI) research. While the individual COE tended to be overly specific and prescriptive, the authors' framework highlights common concerns, applicable to a broad range of contexts. They then apply this framework to reflect on two ethical dilemmas, they faced during their work with hospice patients and their families. Through this exercise, the authors demonstrate how the framework can be applied to ethical dilemmas in HCI research. http://goo.gl/uEtAVp

Cont. next page



Back issues of the weekly report can be downloaded at http://goo.gl/frPgZ5. Enter keyword/s in the search box. Links to back issues of Media Watch that include mention of the subject or topic of interest (among other links to information/resources on the IPCRC website) will be displayed.

Related

COMPUTERS, INFORMATICS, NURSING | Online – 16 June 2016 – 'Communication needs of critical care patients who are voiceless.' A computer communication application was offered to patients in intensive care/critical care units in three hospitals in South Florida. Four qualitative themes were revealed, which directly relate to ... the 'End of Life Care and Decision Making Evidence-Based Care Guidelines' and the 'Pain Assessment in Special Populations Guidelines.' This knowledge is important for developing effective patient-healthcare provider communication. https://goo.gl/HpEOHz

N.B. Unable to trace the two guidelines the authors mention. BRA

Noted in Media Watch, 30 November 2015, #438 (p.14):

SOCIAL SCIENCES | Online – 20 November 2015 – 'Who wants to live forever? Living, dying and grieving in our digital society.' Through a review of the current literature exploring how social media are being used as a new space to grieve and mourn, this paper contributes to the literature by arguing for the need for clarity in the lexicon being used by thanatologists and other disciplines. The paper concludes by joining the call for further research into the nascent phenomena being generated by human-computer interaction. http://goo.gl/ACqKD3

"If you don't know, all of a sudden, they're gone": Caregiver perspectives about prognostic communication for disabled elderly adults

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2016;64(6):1299-1306. Semistructured telephone interviews were conducted with caregivers who were asked about experiences and preferences related to clinician communication about life expectancy, including preferences for and attitudes toward being included in discussions about life expectancy, how such information should be delivered, and how clinicians should address concerns about uncertainty and hope. According to participants, clinician concerns about taking away hope or the uncertainty of prognostic information should not deter them from bringing up the topic of life expectancy. Thematic analysis suggested several approaches that may facilitate prognosis communication: establishing a relationship with the caregiver and care recipient; delivering the prognosis in clear, plain language; and responding to emotion with empathy. http://goo.gl/snYlma

"Close to" a palliative approach: Nurses, and care aides, descriptions of caring for people with advancing chronic life-limiting conditions

JOURNAL OF CLINICAL NURSING | Online – 17 June 2016 – Ageing populations worldwide are drawing increasing attention to palliative care (PC). In particular, people with advancing chronic life-limiting conditions often have unmet needs and may die in acute medical, residential care and home health settings without access to PC. A palliative approach (PA) offers an upstream orientation to adopt PC principles to meet the needs of people with life-limiting chronic conditions, adapt PC knowledge to other chronic illness conditions, and integrate and contextualise this knowledge within the healthcare system... The overarching theme was that of participants close to a PA in that they cared for people who would benefit from a PA, they were committed to providing better end-of-life care, and they understood PA as an extension of specialised PC services. Participants varied in their self-reported capacity to integrate a PA, as they were influenced by role clarity, interprofessional collaboration and knowledge. http://goo.gl/WE7NKk

Time for change? A national audit on bereavement care in intensive care units

JOURNAL OF THE INTENSIVE CARE SOCIETY | Online – 17 June 2016 – The aim of the present national audit was to compare bereavement services in England against the nine recommendations set out by the Intensive Care Society guidelines. Although most ICUs [i.e., survey respondents] provided administrative information (96% had an information booklet), training (53%), auditing (19%) and adequate facilities (27%) ...bereavement care is underdeveloped in English ICUs. This important but underreported topic should be prioritised in the critical care research agenda. https://goo.gl/VIU5tU

Related

• AMERICAN JOURNAL OF CRITICAL CARE, 2016;25(2):110-117. 'Bereavement services offered in adult intensive care units in the U.S.' Most [survey] respondents reported that their ICUs did not offer bereavement follow-up services, and many barriers were noted. When bereavement follow-up care was offered, it was mainly informal (e.g., condolence cards, brochures). ICUs in hospitals with palliative care (PC) were almost eight times more likely to provide bereavement support than were ICUs in hospitals without PC. http://goo.gl/48KIL7

Personally meaningful rituals: A way to increase compassion and decrease burnout among hospice staff and volunteers

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 June 2016 – Rituals can increase a sense of connectedness, meaning, and support, especially after the death of those for whom we care. Hospice staff may benefit from the use of personal rituals as they cope with the frequent deaths of their patients, ultimately aiming to provide compassionate care while minimizing burnout. Three hundred ninety hospice staff and volunteers from across 38 [U.S.] states completed an online survey. The majority of hospice staff and volunteers used personally meaningful rituals after the death of their patients to help them cope (71%). http://goo.gl/AoElto

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

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2016;51(4):690-696. 'Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.' Overall, the authors observed a burnout rate of 62% [among survey respondents], with higher rates reported by non-physician clinicians. Most burnout stemmed from emotional exhaustion, with depersonalization comprising a minor portion. Factors associated with higher rates of burnout include working in smaller organizations, working longer hours, being younger than 50 years, and working weekends. http://goo.gl/amM8OB

N.B. Select articles on burnout among hospice and palliative care professionals are noted in the issue of Media Watch of 9 November 2015, #435 (pp.13-14).

A look into spirituality in social work practice within the hospice setting

JOURNAL OF RELIGION & SPIRITUALITY IN SOCIAL WORK: SOCIAL THOUGHT | Online – 17 June 2016 – Social workers are part of the multidisciplinary team providing holistic care to people within the hospice setting; however, concerns exist about the preparation of social workers to address spiritual issues. An exploratory qualitative study with 16 experienced hospice social workers was conducted to examine the impact of hospice work on social worker spirituality and vice versa. Results indicated that matters involving spirituality arose frequently in the work and 15 participants had offered spiritual care to a patient in need, despite many of them not feeling prepared by their education to do so. Implications for social work hospice practice and for social work education are discussed. http://goo.gl/CDWTDK

Related

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 20 June 2016 – 'The soul's legacy: A program designed to help prepare senior adults cope with end-of-life existential distress.' The project described in this article provides tools for chaplains to address the real issues that terrify us all, but particularly the elderly: death, isolation, and meaninglessness. http://goo.gl/UbSXMi

Noted in Media Watch, 16 May 2016, #462 (p.18):

RELIGIONS | Online – 9 May 2016 – 'History, culture and traditions: The silent spaces in the study of spirituality at the end of life.' An exploration of the concept of spirituality, an overview of the trajectory of the study of spirituality, and a review of existing methodological stances reveal the silent space in current approaches to understanding spirituality at the end of life. http://goo.gl/IVoFJS

N.B. Selected articles on spirituality in the context of end-of-life care are noted in the issues of Media Watch of 4 April 2016, #456 (p.7) and 8 June 2015, #413 (pp.10-11).

The impact of personal budgets on unpaid carers of older people

JOURNAL OF SOCIAL WORK | Online – 17 June 2016 – Unpaid carers [i.e., study participants] played a central role in supporting older budget holders irrespective of the type of budget received. The allocation of a personal budget may have decreased the amount of "hands-on" care they provided, enabling them to do different things for and with the person cared for, but most did not relinquish direct involvement in care provision. Both kinds of personal budget provided greater flexibility to juggle caring tasks with other roles, such as childcare or paid employment. However, carers supporting direct payment users did experience higher levels of stress. This seemed linked to the additional responsibilities involved in administering the direct payment. Carers seemed relatively unsupported by their local Adult Social Care Department: the survey found that only one in five said they had ever received a carer assessment. The findings offer a detailed exploration of the impact of personal budgets on carers, suggesting that even in countries with relatively well-developed systems of support for carers such as England their impact remains overlooked. http://goo.gl/eQjVhY

Noted in Media Watch, 2 May 2016, #460 (p.10):

PALLIATIVE MEDICINE | Online – 29 April 2016 – 'Differences in out-of-pocket costs of healthcare in the last year of life of older people in 13 European countries.' In this study, the proportion of people with out-of-pocket costs ranged from 21% to 96%... Out-of-pocket costs ranged from 2% to 25% of median household income. Secondary and institutional care was most often the largest contributor to out-of-pocket costs, with care received in a care home being the most expensive type of care in 11 of 13 countries. http://goo.gl/Fnh2uQ

U.K. audit on end-of-life care results in widespread negative media coverage

MEDICAL ETHICS ADVISORY | Online - 1 July 2016 - "Secret do-not-attempt cardiopulmonary resuscitation (DNACPR) orders," "imposed without family consent," and "unforgivable," These are just a few of the U.K. newspaper headlines that appeared after an audit of 9,302 patients who died in National Health Service (NHS) hospitals conducted by London's Royal College of Physicians revealed that for 19% of cases, there was no evidence that the DNACPR order was discussed with the patient's loved ones. In 16% of cases, there was no documentation of a discussion with the patient. ¹ "The DNACPR question was just one of dozens we asked. But, of course, the press, TV, and radio in U.K. picked up on it. It was widely covered, with a quite negative slant," says Sam H. Ahmedzai ... the lead author on the study and the clinical lead for the Royal College of Physicians end-of-life care (EOLC) audit committee. The audit, which had been commissioned by the Healthcare Quality Improvement Partnership for NHS England, covered two aspects of EOLC in hospitals. One examined the protocols, policies, governance, and training aspects of EOLC at 140 acute NHS hospitals in England. The second was a retrospective case notes audit of the actual clinical care of patients who died in those hospitals in May 2015. Ahmedzai appeared on numerous TV and radio shows explaining that DNACPR related only to CPR, and that for the large majority of people who died in English hospitals, there would have been no valid indication for CPR. http://goo.gl/u9gn79

'End of Life Care Audit – Dying in Hospital National Report for England 2016,' Royal College of Physicians, May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.6)] https://goo.gl/x2qSih

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

Treatment withdrawal, allow a natural death, passive euthanasia: A care-full choice of words

NURSING IN CRITICAL CARE (British Association of Critical Care Nurses), 2016;21(4):193-194. When we talk about concepts and care at the end of life (EOL), it is important to be clear to ourselves and to others about what we mean, what we say and what our motivations are behind the care given. When we talk to patients/families and to our colleagues, there can be no place for ambiguity or euphemisms. Words must be selected carefully and precisely. Language used at the EOL can be emotionally charged with the potential for misunderstanding. For example, think about what is said when talking with families about managing pain and distress at the EOL. Talking about how "pain and sedative drugs will be given until pain and distress is relieved, even though this could ultimately shorten life" or saying that "everything will be given to relieve pain and distress" may appear to be the same. But, which of this is more transparent about the processes of care, the potential impact of that care and of the underlying intentions behind that care? How we have used words when talking with patients and families in critical care has always been important. However, with increasing public and professional debate about choice and care at the EOL, the use of words is now even more important. Words are powerful and can have influence on

many levels; words can affect how we feel and how we think. We need to be care-full of the words we use and be clear about what they mean to patients and families, to our colleagues and to how they speak of our values and ethics as critical care nurses. http://goo.gl/NsQAtS

Ethical dilemmas faced by hospice nurses when administering palliative sedation to patients with terminal cancer

PALLIATIVE & SUPPORTIVE CARE | Online - 21 June 2016 - Facilitating a "peaceful death" was the primary goal of the nurses, where through the administration of palliative sedation they sought to enable and support patients to be "comfortable," "relaxed," and "calm" at the terminal stage of their illness. Ethical dilemmas related to decision making were a factor in achieving this. These were: medication decisions, "juggling the drugs," "causing the death," sedating young people, the family "requesting" sedation, and believing that hospice is a place where death is hastened. Hospice nurses in the U.K. frequently encounter ethical and emotional dilemmas when administering palliative sedation. Making such decisions about using palliative sedation causes general discomfort for them. Undertaking this aspect of care requires confidence and competence on the part of nurses... http://goo.gl/cKbRXp

Palliative and end-of-life care for people living with dementia in care homes: Part 1

NURSING STANDARD | Online - 23 June 2016 - The terms palliative and end-of-life (EOLC) care are often used interchangeably and healthcare practitioners may perceive palliative care (PC) is only appropriate during the terminal stages of an illness. This article ... provides healthcare practitioners with an overview of the concept of PC. It explains how this can be differentiated from EOLC and how it should be commenced in a timely manner, so people who are living with dementia can contribute to the planning of their future care and death. The policies and tools used in the provision of palliative and end-of-life care are discussed, including advance care planning and The Gold Standards Framework. The article is framed in a care home context; there is little research about how to optimise PC for people living with dementia in care homes. The second part will discuss EOLC and the best practices for providing EOLC, including

nutrition and hydration, oral hygiene, pain management and spiritual care, http://goo.gl/hJhYK0

Preparedness for death: How caregivers of elders with dementia define and perceive its value

THE GERONTOLOGIST | Online – 23 June 2016 – Only one third of caregivers interviewed were prepared for the death, and the majority who were prepared were enrolled in hospice. Five primary themes revealed ways that caregivers define various domains of preparedness: 1) Accepting reality; 2) Knowing death is near; 3) Getting your "house in order"; 4) Saying "what you need to say"; and, 5) Giving "permission" to die. The results support further attention to the development and testing of interventions to address the unmet needs of caregivers of family members with dementia to help prepare them for the death in a variety of contexts. http://goo.gl/9wtJZe

Cont.

Related

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 21 June 2016 – 'Education and training to enhance end-of-life care for nursing home staff: A systematic literature review.' Twenty-one studies were reviewed. Methodological quality was poor. Education was not of a standard that could be expected to alter clinical behaviour and was evaluated mainly from the perspectives of staff: self-reported increase in knowledge, skills and confidence delivering care rather than direct evidence of impact on clinical practice and patient outcomes. Follow-up was often short term, and despite sound economic arguments for delivering effective end-of-life care to reduce burden on the health service, no economic analyses were reported. http://goo.gl/bYyKgL

N.B. To access full text click on PDF icon.

Parents with cancer: Searching for the right balance between telling the truth and protecting children

PALLIATIVE & SUPPORTIVE CARE | Online -21 June 2016 - Recent scientific approaches to cancer patients draw attention to the psychological aspects of the disease and the involvement of their families, who are forced to reorganize themselves in order to manage the patient's illness. Functional responses to a stressful event facilitate open communication between family members and empathy for the patient's children. who need to be involved and informed about the illness in a clear and open fashion. The primary goal of this study was to explore the communication styles used by cancer-stricken parents with their children and to identify a correlation with the patient's levels of anxiety and depression and their ability to cope. The authors also sought to understand whether location, severity, and time from diagnosis influenced communication, coping, anxiety, or depression. Our results showed statistically significant correlations between higher levels of anxiety and depression and more closed communication styles. The "hopelessness/helplessness," styles "cognitive avoidance," and "anxious preoccupation" were associated with a closed communication style that is correlated with higher levels of anxiety and depression. Tumor location, time from diagnosis, and stage of disease did not show statistically significant correlations with anxiety, depression, coping mechanisms, or communication styles. http://goo.gl/OLKJrT



A literature search was undertaken in 2015 for the Children & Youth Grief Network of the Region of Peel, Ontario, Canada. International in scope, it focused on key articles, reports, etc., published between 2010 and 2015, reflecting "current thinking" on the many different aspects of grief and bereavement support for children and young people. **BRA**

Download the reports on the literature search at: http://goo.gl/ydHfq9

Documenting presence: A descriptive study of chaplain notes in the intensive care unit

PALLIATIVE & SUPPORTIVE CARE | Online - 20 June 2016 - Four primary themes emerged from chaplain documentation. First, chaplains frequently used "code language," such as "compassionate presence," to recapitulate interventions already documented elsewhere in a checklist of ministry interventions. Second, chaplains typically described what they observed rather than interpreting its clinical significance. Third, chaplains indicated passive follow-up plans, waiting for patients or family members to request further interaction. Fourth, chaplains sometimes provided insights into particular relationship dynamics. As members of the patient care team, chaplains access the medical record to communicate clinically relevant information. The present study suggests that recent emphasis on evidence-based practice may be leading chaplains, at least in the medical center the authors studied, to use a reduced, mechanical language insufficient for illuminating patients' individual stories. The authors express the hope that their study will promote further consideration of how chaplain documentation can enhance patient care and convey the unique value that chaplains add to the clinical team. https://goo.gl/fkRlxS

Cont.

Noted in Media Watch, 20 July 2015, #419 (p.11):

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 13 July 2015 – 'Recognizing success in the chaplain profession: Connecting perceptions with practice.' The current investigation examines the communicative hallmarks [i.e., non-verbal vs. verbal hallmarks] of successful chaplaincy work as articulated by professional chaplains providing spiritual care at the end of life. http://goo.gl/AyjULC

Standing in another's shoes: How agents make life-and-death decisions for their principals

PERSPECTIVES | Online – 14 June 2016 – This paper examines relationships in which agents [e.g., surrogate decision makers] enjoy considerable discretion and have limited, conflicting, or ambiguous guidance from their principals, characteristic of many governance and organizational settings and professional relationships. It draws on observational research in two intensive care units where principals (patients) lack capacity to specify their objectives and cannot control, monitor, incentivize, converse with, or fire the agent charged with making life-and-death medical decisions on their behalf. Observing agents at the bed-side provides a rare opportunity to understand – in real time – how agents fashion appropriate actions to take on behalf of principals with whom they cannot communicate and who rarely gave them sufficient guidance. Managers not infrequently must act for another without clear or authoritative direction. Insights from the study of medical decision-makers inform diverse literatures that feature extreme delegation to the agent. http://goo.gl/wgMBkM

Noted in Media Watch, 20 June 2016, #467 (p.12):

- JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online 15 June 2016 'Compromised autonomy: When families pressure patients to change their wishes.' When patients are unduly pressured by their families to make medical decisions that are not in line with previously held values, beliefs, or perspectives, autonomy is compromised. http://goo.gl/WguFRf
- CRITICAL CARE MEDICINE | Online 6 January 2015 'How clinicians discuss critically ill patients' preferences and values with surrogates: An empirical analysis.' In a third of ICU family conferences for patients at high risk of death, neither clinicians nor surrogates discussed patients' preferences or values about end-of-life decision making. In less than 12% of family conferences did participants address the values of high importance to most patients... [Noted in Media Watch, 19 January 2015, #393 (p.9)] http://goo.gl/WMMMmK

N.B. Read two opposing perspectives on the question 'Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU?' in the journal *Chest*, noted in Media Watch, 15 June 2015, #414 (p.12).

Palliative care and the Portuguese health system

PORTO BIOMEDICAL JOURNAL | Online – 17 June 2016 – In Portugal, the cumulative effect of the reduction in mortality and birth rates has resulted in an ageing population. The ageing population will create in the medium term a new dynamic of recruitment in various sectors, including health. With increased life expectancy, the care of chronically ill has become an important area in the context of health services, since they need to be increasingly more focused on the need to provide palliative rather than curative care. Rationalization of resources must be a goal so that waste is minimized. The present model of palliative care (PC) ceases to respond to the pressing needs. What to do, to adapt to the changes brought by demographic change and by innovation? What models should be adopted for better resource optimization in PC? A literature review was carried out, including articles that compared the main differences between hospital and home care. Portugal has a multi-sectoral PC model, in light of what happens in reference countries, however, a better rationalization of resources will be required in order to ensure optimization in the distribution of patients. The authors conclude that there is a gap between the patient's will and what is recommended. To respect the individual preferences of the patient, it is necessary to develop quality home-based PC services, focusing on training and the expansion of field teams. http://goo.gl/FF5Fm4

N.B. English language article.

Selected articles on end-of-life care in Portugal

- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 7 June 2016 'Ranking of palliative care development in the countries of the European Union.' The U.K. achieved the highest level of development, followed by Belgium and The Netherlands, and Sweden. The Netherlands, Malta and Portugal showed the biggest improvements... http://goo.gl/B3G4Ya
- PALLIATIVE MEDICINE | Online 10 July 2015 'Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world.'

 There is a long standing trend towards hospitalised dying, more pronounced among the oldest old. To meet people's preferences for dying at home, the development of integrated specialist home palliative care teams is needed. [Noted in Media Watch, 13 July 2015, #418 (p.14)] http://goo.gl/zYE2er
- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 21 December 2012 'A cross-sectional survey of the activity of palliative care teams in Portugal.' Of the 21 teams identified, 10 accepted to participate in the study. A total of 164 patients were included with a median of 15.5 per team: 60 (37%) were identified as inpatients in palliative care units; 59 (36%) by an intra-hospital support team; 26 (16%) as outpatients; and 19 (12%) at home. [Noted in Media Watch, 24 December 2012, #285 (P.5)] http://goo.gl/GlmQmP

N.B. Portugal was rated 31st (of the 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/JsSbW3

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

Overcoming barriers in care for the dying: Theoretical analysis of an innovative program model

SOCIAL WORK IN HEALTH CARE | Online – 22 June 2016 – This article explores barriers to end-of-life (EOL) care (including development of a death denying culture, ongoing perceptions about EOL care, poor communication, delayed access, and benefit restrictions). The Compassionate Care Program is a practice model designed to bridge gaps in care for the dying and is one example of a program offering concurrent care, a recent focus of evaluation through the Affordable Care Act. Concurrent care involves offering curative care alongside palliative or hospice care. Additionally, the program offers comprehensive case management and online resources to enrollees in a national health plan... The article concludes with implications for policy and practice, and discusses the important role of social work in impacting change within EOL care. http://goo.gl/7cR3a9

Related

■ PALLIATIVE & SUPPORTIVE CARE | Online – 20 June 2016 – 'Enhancing the prospects for palliative care at the end of life: A state-wide educational demonstration project to improve advance care planning.' Participant motivation to foster advance care planning, discussions of palliative care, and end-of-life conversations was facilitated by the reframing of these conversations as identifying goals of care and priorities for living well during an important stage of life. Successful strategies included helping providers and patients to adopt a broader meaning for "sustaining hope" (not for cure, but for engaging in highly valued activities), developing provider communication skills and comfort in initiating potentially difficult discussions, engaging a new community health workforce who will develop trusting relationships with patients in home-based services, and fostering self-awareness and self-care among palliative care providers. http://goo.gl/pjUoPC

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. http://goo.gl/8JyLmE

Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ CANADIAN MEDICAL ASSOCIATION JOURNAL | Online - 21 June 2016 - 'Doctors left to define foreseeable death ion new law.' What does "reasonably foreseeable death" mean? A month? Six? Two years? This is the question medical groups, physicians' insurer and regulators are asking following the ... passage of a law allowing physician-assisted dying. There's potentially a lot at stake: if doctors get it wrong, they could face criminal charges. The Canadian Medical Protective Association recommends its physician members call them for advice about all requests for physician-assisted dying. Defining the term is an issue Canada's 13 regulatory colleges must consider as they revamp guidelines in accordance with the new legislation. But it's also a question the federal ministries of health or justice could answer. No one has so far. Canada isn't the first country or jurisdiction to legalize physician-assisted dying, but it is the first to introduce a wide-ranging bill over such a geographically large area. http://goo.gl/oewQy1

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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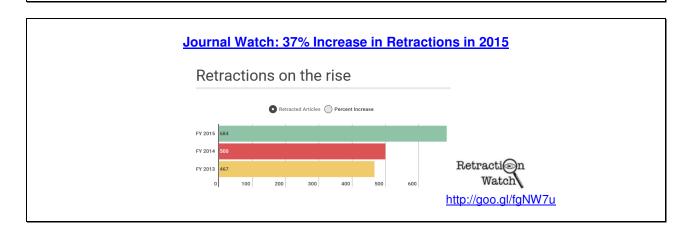
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- 5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
- **6.** Due to its relevance, an article may be listed 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

Death of a parent and the children's experience: Don't ignore the elephant in the room

JOURNAL OF INTERPROFESSIONAL CARE, 2010;24(4):450-459. This paper explores two interlinked components of practitioner's support to children when a parent or carer is at the end of life or has died. The primary issue relates to communication and the competence and confidence of practitioners when working with this community of children. The paper suggests that related to this is the lack of training practitioners receive, both as students and through continual professional development, within the fields of social care and health. The metaphor of the elephant in the room is used to delineate how practitioners avoid such discussions and thereby miss opportunities to support children experiencing potentially the most traumatic life event they

have faced. Drawing on current research and the author's experience and reflections as a researcher and practitioner the paper suggests that children experiencing the death of a parent or carer are not being recognized as children in need but rather requiring interventions from specialist services. [Noted in Media Watch, 21 June 2010, #154 (p.9)] http://goo.gl/QpklOl

Quotable Quotes

When there's an elephant in the room introduce him. Randy Pausch (1960-2008)

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/hhrU3q

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]

Δsia

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

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://goo.gl/XrhYCH

Canada

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

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/5d1l9K

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

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