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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Towards a "good" death: Scroll down to Specialist Publications and 'Advance care planning: Whose agenda is it anyway?' (p.14), in Palliative Medicine.

Canada
Province mum on funding for Alliston hospice

ONTARIO | The Alliston Herald – 11 August 2014 – The funding future for Matthews House Hospice in Alliston remains uncertain. Recently ... Minister of Health & Long-Term Care Eric Hoskins was questioned by Simcoe-Grey Member of the Provincial Parliament and interim Progressive Conservatives leader Jim Wilson on whether the organization would be one of several hospices getting new funding as part of this year's provincial budget. Hoskins noted that the government has committed to funding twenty additional hospices this year, but didn't say what the future holds for Matthews House. He said the province continues working on its palliative and end-of-life care strategy, and as part of that, will make future decisions based on the recommendations of the residential hospice working group established last year. http://www.simcoe.com/news-story/4753583-province-mum-on-funding-for-alliston-hospice/

Noted in Media Watch, 19 May 2014, #358 (p.1):

- ONTARIO | The Alliston Herald – 16 May 2014 – 'Matthews House Hospice caught in endless funding battle.' After conducting a needs assessment that showed four to five palliative care beds were needed for the community, the hospice, without a funding commitment from the province, opened its temporary residential hospice this past summer in Alliston. The organization receives $38,000 in operation funding for the visiting hospice through a transfer payment from Stevenson Memorial Hospital. After Matthews House separated from Hospice Simcoe in 2008, the province gave it an annual operating budget of $36,000 based on the forty clients it had at the time. Today, Matthews House has about 370 clients... While there is no funding in place for the residential hospice, it does receive about $200,000 worth of care services through the Community Care Access Centre... http://www.simcoe.com/news-story/4520774-matthews-house-hospice-caught-in-endless-funding-battle/

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.15.
Talking about hard truths and end-of-life care

FORBES | Online – 12 August 2014 – The cost of end-of-life care jeopardizes the long term viability of Medicare. The Centers for Medicare & Medicaid services estimates that more than 25% of Medicare spending is directed to the 5% of beneficiaries who die each year, with a third of that cost in the last month of life. The health reform debate in America has been hampered by a lack of progress about end-of-life care and medical futility. Perhaps the time has arrived for America to honestly and intelligently discuss health care rationing and end-of-life care to save Medicare? http://www.forbes.com/sites/realspin/2014/08/12/talking-about-hard-truths-and-end-of-life-care/

Noted in Media Watch, 16 December 2013, #336 (p.2):


Noted in Media Watch, 3 May 2010, #147 (p.3):


N.B. Additional articles on the cost of end-of-life care in the U.S. in the context of rationing health care are noted in Media Watch, 21 October 2013, #328 (p.10).

Clearing the path home

THE NEW YORK TIMES | Online – 11 August 2014 – Health researchers know that transitions – the hand-offs from one setting to another, as in hospital to home – often go awry. “It’s so abrupt,” said Dr. Eric Coleman, a geriatrician at the University of Colorado, Denver. “For three days people do everything for you, and then, 11 minutes before you leave, they turn the tables. ‘Now you take over.’” Your parent is often sleep deprived and medicated at the time; little wonder that nationally about one Medicare patient in five returns to the hospital within a month. To lower that figure, Dr. Coleman began developing the Care Transitions Intervention program 15 years ago. If patients agree, a coach comes to their homes two to four days after discharge. She’s not there to change dressings or help them bathe; home health nurses or aides do that. Instead, over 45 minutes to an hour, the coach – generally a nurse, sometimes a social worker or other health care professional – asks about patients’ goals as they recover. She will discuss the medications your mother takes and symptoms that might indicate a problem requiring medical attention. She’ll help your father strategize about whom to call if he needs help and rehearses what he’ll say. She phones twice over the next few weeks to see if your parent has gotten his questions answered and needs met. Dr. Coleman’s brainchild has spread to over 900 hospitals, care organizations, Medicare Advantage plans and area agencies on aging around the country. The pace of adoption has picked up sharply since Medicare started imposing financial penalties on hospitals with high readmission rates in 2012. http://newoldage.blogs.nytimes.com/2014/08/11/clearing-the-path-home/?_php=true&_type=blogs&_r=0

N.B. Care Transitions Intervention program website: http://www.caretransitions.org/
Evaluation of hospice and palliative care in Veterans Health Administration facilities

The purposes of the evaluation were to determine whether Veterans Health Administration [VHA] facilities performed active hospice and palliative care ... provided end-of-life care training to staff and met selected documentation standards, and also to assess selected Palliative Care Consult Team processes, documentation, and staffing. Inspectors evaluated hospice and palliative care at 54 facilities... Although they observed many positive practices, they identified two opportunities for VHA facilities to improve: the inspectors recommended the Under Secretary for Health, in conjunction with Veterans Integrated Service Network and facility leaders, ensures: 1) facilities provide at least the minimum required Palliative Care Consult Team staffing; and, 2) facilities provide end-of-life care training to staff who work in areas where they are likely to encounter patients at the end of their lives. http://www.va.gov/oig/pubs/VAOIG-14-00727-239.pdf

Noted in Media Watch, 21 March 2014, #351 (p.8):


Illinois prison hospice offers care, redemption

ILLINOIS | The Chicago Tribune – 10 August 2014 – [Ralph] Pollock, 55, is a volunteer in the hospice program for prisoners at Dixon Correctional Center, one of only about 20 prison hospices nationwide where the caregivers are inmates. Both patients and caregivers have been convicted of grievous crimes. But the hospice program is based on the belief that everyone deserves compassion as they are dying. http://www.chicagotribune.com/news/ct-prison-hospice-20140810-story.html#page=1

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report in recent years is available online at the Palliative Care Community Network website: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons.

Specialist Publications

Barriers to employment of African American professionals in hospice: A qualitative study with African American social work students’ (p.7), in American Journal of Hospice & Palliative Medicine.

Talking about health care: News framing of who is responsible for rising health care costs in the U.S.,’ (p.11), in Journal of Health Communication.

Organization of nursing and quality of care for veterans at the end of life’ (p.11), in Journal of Pain & Symptom Management

Hospice experience of care survey’ (p.15), published by the Rand Corporation report.

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch

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International

End-of-life care in New Zealand

Government announces $20m hospice boost

NEW ZEALAND | MSN NZ News (Auckland) – 12 August 2014 – The government has announced a $20 million boost for hospices - if it wins the election. Health Minister Tony Ryall says 15,000 people received care and support from hospice services last year. Staff made more than 145,000 visits to people in their homes. Just over 20% of people using hospice services were aged under 60 and three-quarters had a cancer-related disease. The funding includes $13 million to help the country's 29 hospices expand their services. It will also pay for 60 new palliative care specialist nurses. [http://news.msn.co.nz/article.aspx?id=8890186]

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

Two dozen accounts of life, love and dying: The Dignity Project

U.K. (England) | The Daily Hampshire Gazette (Northampton) – 12 August 2014 – Since April, two dozen area residents stepped forward to wrestle in public, in our pages, with these intensely personal questions through the Dignity Project. The Gazette offers five final essays, plus a roundup of shorter commentaries.¹ For some, the issue may have felt remote, or not yet relevant. But reader response suggests many have been eagerly awaiting the weekly installments. For the past four months, these essays provided a great deal of practical advice. Dying is a detail-oriented business and one's wishes must be understood and expressed. But perhaps most of all, contributions offered guidance from people who have traveled this emotionally rough terrain. [http://www.gazettenet.com/home/13116347-95/editorial-two-dozen-accounts-of-life-love-and-dying-the-dignity-project]


Of related interest:

- U.K. (England) | The Guardian – 15 August 2014 – ‘Cancer patients dying early because of postcode lottery.’ Thousands of people are dying early of cancer every year because of an "inexcusable postcode lottery" in how quickly the National Health Service diagnoses and treats the disease.¹ Delays mean cancer patients in some areas of England have up to a 61% higher risk of dying within a year of their diagnosis than those in other places, simply because of where they live. [http://www.theguardian.com/society/2014/aug/15/cancer-patients-dying-early-postcode-lottery]


- U.K. (Wales) | BBC News – 11 August 2014 – 'Minority groups missing out on palliative care, charity says.' Ethnic minority communities in Wales may not be getting the end-of-life care they need, a cancer charity says. Marie Curie Cancer Care said language barriers and concerns over worship and dietary needs could be a barrier to services for patients in Cardiff. The report also found GPs were often reluctant to suggest hospices to members of ethnic minority groups. [http://www.bbc.com/news/uk-wales-south-east-wales-28733081]

Elder care in the U.K.

More than 100 home-care services for elderly given low ratings

U.K. (Scotland) | The Herald (Edinburgh) – 12 August 2014 – More than 100 home-care services for the elderly have been given low ratings for how they are run, according to latest figures from the Care Inspectorate. Another 80 care-at-home providers – as many as one in 10 – have been rated adequate or below for care and support following inspections this year, and 70 have been given low ratings for the quality of staffing. In a separate report, five per cent of private companies were graded "unsatisfactory or weak for every theme." The report says: "There was a notable increase in the number of poorly performing services during 2012-13," adding: "Services achieving these very concerning grades generally improve, but these improvements are not always sustained." More than 62,000 people receive some form of care in their own home in Scotland and there are 814 different registered providers of services, including private firms, councils, the National Health Service and not-for-profit organisations. http://www.heraldscotland.com/news/home-news/more-than-100-care-homes-for-elderly-given-low-ratings.25024732

Of related interest:

- U.K. (England & Wales) | The Daily Telegraph – 14 August 2014 – '900,000 elderly needing care left to fend for themselves.' One in three elderly people who struggle with tasks as basic as washing and dressing are being left to fend for themselves, a stark new study shows.¹ Analysis by Age UK estimates that almost 900,000 older people in England & Wales with care needs receive no support at all, either from their local council or even informally through friends and family. http://www.telegraph.co.uk/health/elderhealth/11030930/900000-elderly-needing-care-left-to-fend-for-themselves.html


- U.K. (Northern Ireland) | BBC News – 13 August 2014 – 'Northern Ireland care homes: Commissioner begins review into regulation.' The Commissioner for Older People ... is launching a review into the regulation of care homes in Northern Ireland. She said: "Clearly the current system does not adequately protect those who rely on it for their care." The commissioner is to recommend changes about the regulation, inspection and delivery of nursing, residential and domiciliary care. http://www.bbc.com/news/uk-northern-ireland-28761817

- U.K. (England) | The Daily Telegraph – 9 August 2014 – 'We failed elderly because we were too scared care home owners would sue us, watchdog admits.' The elderly and vulnerable were failed by a watchdog set up to protect them because it feared legal threats from owners of care homes, it has admitted. The head of the Care Quality Commission said it has too often "backed off" from making attempts to close unsafe homes and "tended not to fight back" when it was legally challenged. David Prior, chairman of CQC, made the disclosures as the regulator vowed to change its approach, to be "much more robust" in taking on poor providers of care. He said its own data suggests at least 750 care homes providing care to elderly and disabled people have been failing to hit at least one basic standard for more than a year. http://www.telegraph.co.uk/health/healthnews/11021374/We-failed-elderly-because-we-were-too-scared-care-home-owners-would-sue-us-watchdog-admits.html

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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://www.ipcrc.net/barry-r-ashpole.php

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Doctors need to swot up on end-of-life laws: Research

AUSTRALIA (New South Wales) | The Sydney Morning Herald – 11 August 2014 – Australian patients are at risk of being killed or saved when they do not want to [sic] by doctors who do not understand laws regarding the withholding and withdrawing of life-sustaining medical treatment, research suggests.¹ A survey completed by 867 doctors in Victoria, New South Wales and Queensland in 2012 and 2013 found "critical gaps" in their legal knowledge that could expose them to criminal charges including murder, manslaughter or assault if they act against a patient's wishes. On average doctors correctly responded to three out of seven questions about laws regarding end-of-life care ... [that] ... covered the validity of advance directives and consent from and the authority of substitute decision makers. Participants included doctors who specialise in geriatrics, intensive care, oncology, palliative care, kidney, respiratory and emergency medicine.


Specialist Publications


1. 'Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment,' Medical Journal of Australia, 2014;201(4):1-4. Among doctors who practise in the end-of-life field there are some significant knowledge gaps about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity. Significant consequences for both patients and doctors can flow from a failure to comply with the law.


Of related interest:

- AUSTRALIA (New South Wales) | The Sydney Morning Herald – 17 August 2014 – 'Doctors fear turning off a patient's pacemaker risks murder charge.' Doctors are calling for Australians with pacemakers to write clear instructions about the circumstances in which they would like them switched off in case they want doctors to help them die at some point in the future.


Assisted (or facilitated) death

Representative sample of recent news media coverage:

- LITHUANIA | The Baltic Times (Vilnius) – 13 August 2014 – 'Lithuana official proposes to legalize euthanasia.' The draft law ... proposes to establish general guidelines for euthanasia and its conditions and procedures. [Marija Ausrine] Povilioniene calls to "regulate rights and obligations of those patients who have expressed wish for euthanasia as well as to regulate the licensing of the provision of euthanasia services." The draft law establishes the right of a person who is terminally ill, experiencing unbearable physical and (or) spiritual pain that cannot be relieved, to voluntarily choose to end his life; the right to order to conduct euthanasia for him in advance, if he would not be able to express his will himself due to unconscious condition determined by a disease or injury.

http://www.baltictimes.com/news/articles/35356/#.UywMuNdX8k

Cont.
SWITZERLAND | Reuters – 11 August 2014 – ‘Growing numbers sign up to Swiss right-to-die society.’ A Swiss organization that helps people take their own lives and defends their right to refuse medical treatment says it has seen a higher number of applications than usual this summer. Exit said it was receiving 60 to 100 new membership requests daily from people who wanted to make living wills – documents specifying how they want to be medically treated if they are gravely ill and unable to communicate. Unlike in previous years, the number of applications has not slowed during the months of July and August when people tend to be away on holiday, said Bernhard Sutter, vice president of Exit, which was founded in 1982. http://uk.reuters.com/article/2014/08/11/us-health-assistedsuicide-idUKKBN0GB1EM20140811

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Barriers to employment of African American professionals in hospice: A qualitative study with African American social work students

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 August 2014 – A major barrier to African American hospice utilization is the lack of African American hospice professionals. This qualitative study with 10 female African American social work students in a Midwestern university explored whether the participants were interested in hospice employment. Results provided information about reasons for the overall lack of diversity in hospice, reasons for the lack of African American staff in hospice, reasons for the lack of African American patients in hospice, and avenues toward knowledge about hospice by African American professionals. Barriers to African American employment included a lack of hospice content in social work education, differences between African American cultural and religious beliefs and hospice philosophy, and that the lack of African American hospice patients resulted in a lack of desire for employment in hospice. Strategies for recruiting and retaining African American hospice social workers are proposed. http://ajh.sagepub.com/content/early/2014/08/11/1049909114546543.abstract

Factors associated with family satisfaction with end-of-life care in the ICU: A systematic review

CHEST | Online – 7 August 2014 – The search yielded 1,072 articles with 23 articles describing 14 studies meeting inclusion criteria. All studies obtained satisfaction data from family members via surveys and structured interviews. Specific communication strategies increasing satisfaction included: expressions of empathy, non-abandonment, and assurances of comfort and provision of written information. Additionally, support for shared decision-making, family presence at time of death, and specific patient care measures such as extubation before death were associated with increased satisfaction. http://journal.publications.chestnet.org/article.aspx?articleid=1895262

Of related interest:

- JOURNAL OF PALLIATIVE MEDICINE | Online – 12 August 2014 – 'Is physician awareness of impending death in hospital related to better communication and medical care?' Physicians [i.e., study participants] reported that they had been aware of the impending death in 67% of their dying patients. If they had been aware, discussing death with patients and relatives was more likely, as well as changing the treatment goal into comfort care ... in the last three days of life. When physicians had been aware of impending death, they rated the quality of dying higher. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0203

- PATIENT EDUCATION & COUNSELING | Online – 14 August 2014 – 'Interpreted medical interaction: When doctors and patients do not speak the same language.' It is widely recognised that when professionals interact with their clients, there is considerable scope for communication difficulties and breakdowns – misapprehensions, misunderstandings and even complete incomprehension – because they do not "speak the same language." Lawyers have their way of expressing matters – legalese—that can be quite opaque to the layperson: it is acknowledged in legal scholarship that difficulties arise when clients, particularly plaintiffs, do not understand the legal concepts and language of causality and responsibility, for instance. http://www.pec-journal.com/article/S0738-3991(14)00325-5/abstract
A palliative approach to dialysis care: A patient-centered transition to the end of life

CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY | Online – Accessed 12 August 2014 – As the importance of providing patient-centered palliative care for patients with advanced illnesses gains attention, standard dialysis delivery may be inconsistent with the goals of care for many patients with end stage renal disease. Many dialysis patients with life expectancy of <1 year may desire a palliative approach to dialysis care, which focuses on aligning patient treatment with patients’ informed preferences. This commentary elucidates what comprises a palliative approach to dialysis care and describes its potential and appropriate use. http://cjASN.asnjournals.org/content/early/2014/08/06/CJN.00650114.short

Selected articles on end-of-life care for people living with chronic kidney disease noted in past issues of Media Watch:

- AMERICAN JOURNAL OF KIDNEY DISEASES, 2014;63(6):913-927. ‘Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in chronic kidney disease.’ The authors suggest that chronic kidney disease management should encompass palliative care strategies that promote emotional resilience, sense of well-being, and self-value. Also, respectful and attentive communication may empower patients to convey their values and preferences about their own care. [Noted in Media Watch, 9 June 2014, #361 (p.12)] http://www.ajkd.org/article/S0272-6386(13)01536-9/abstract


- CLINICAL JOURNAL OF THE AMERICAN SOCIETY NEPHROLOGY | Online – 14 January 2010 – ‘End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease.’ Survey participants relied on the nephrology staff for extensive end-of-life care needs not currently systematically integrated into their renal care, e.g., pain and symptom management, advance care planning... [Noted in Media Watch, 18 January 2010, #132 (p.5)] http://cjASN.asnjournals.org/content/5/2/195.abstract?sid=ffe4ad3e-bb66-4daa-bc3c-43a7330495b2

Exploring key topics in palliative care: Pain and palliative care for older people

CLINICAL MEDICINE, 2014;14(4):416-418. The palliative care requirements of the older population, and of those with dementia, have been clarified and there are examples of quality-improvement programmes throughout the U.K. that address these needs. The challenge, at a strategic level, is to enable these pockets of excellence to become standard treatment for all. At an individual level, the assessment and treatment of any symptoms must be tailored to the patient. There is good evidence for, and national guidelines on, the use of current analgesics. http://www.clinmed.rcpjournal.org/content/14/4/416.full.pdf+html

Of related interest:

- REVUE MÉDICALE DE LIÈGE, 2014;69(5-6):402-406. ‘End-of-life care in the elderly.’ The increase in life expectancy is associated with a good quality of life until a very old age. However, the unavoidable aging process eventually affects the autonomy of the patient and may force the individual to live in a nursing home. The alteration of sensorial functions and the increased number of degenerative diseases may finally induce a physical and psychological burden that might lead to resort to palliative care, end-of-life sedation, and in some cases, euthanasia. http://www.rmlg.ulg.ac.be/show.php

N.B. French language article.
Building community capacity for end of life: An investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory

CRITICAL PUBLIC HEALTH | Online – 12 August 2014 – This study identified and examined community-based activities around death, dying and end-of-life care which might reflect a health-promoting palliative care (HPPC) philosophy. This approach is argued to restore community ownership of, and agency in, dying and death through the building of community capacity. However, the enactment of the HPPC approach has not been extensively examined in Australia. Current understandings of community capacity-building relating to end of life are orientated toward service provision. A qualitative interpretive approach was used to engage with local community groups in the Australian Capital Territory with an interest in death, dying and end-of-life care. The themes of practical support, respect and responsiveness and connection and empowerment were identified, reflecting community activities initiated in response to the experience of life-limiting illness. Building community capacity offers to restore community agency in end-of-life concerns, while potentially enhancing health service provision through collaborative partnerships. This study indicates an existing community capacity, demonstrated by activities that promote socialisation, peer support and normalisation of death and dying. However, as these activities occur primarily in response to illness, proactive and preparatory interventions in HPPC are a priority.
http://www.tandfonline.com/doi/abs/10.1080/09581596.2014.945396#.U_CFfsVdX8k

Palliative HIV care: Opportunities for biomedical and behavioral change

CURRENT HIV/AIDS REPORTS | Online – 9 August 2014 – Advances in treatment are contributing to substantial increases in life expectancy for individuals living with HIV, prompting a need to develop care models for the effective management of HIV as a chronic illness. With many individuals continuing to experience symptoms and complications that add to the disease burden across the spectrum of HIV disease, the discussion herein explores the complementary role that early palliative care can play in HIV primary care as a strategy for enhancing long-term quality of life. After first defining the concept of early palliative care, its scope in the context of current clinical realities in HIV treatment and implications for HIV care models is described. After reviewing the emerging extant research literature on HIV palliative care outcomes, a program description is offered as an illustration of how palliative care integration with HIV primary care can be achieved.
http://link.springer.com/article/10.1007/s11904-014-0226-8#

Patients’ perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis

EUROPEAN JOURNAL OF CANCER CARE | Online – 6 August 2014 – Key themes [to emerge in this study] included: 1) obtaining diagnosis and referral for advanced cancer treatment; 2) preference for specialist oncology care; 3) a preference for GP to act as an advocate; and, 4) obtaining ongoing routine care from their GP. GP involvement in the patients’ management was dependent on: 1) time since diagnosis; 2) GP’s involvement in diagnosis and referral; 3) doctor/patient relationship; 4) additional chronic conditions requiring management; 5) frequency of seeing oncologist; and, 6) specialist recommendation to involve GP. Patients want GPs to have varying levels of involvement following an advanced cancer diagnosis. Not all communication between GPs and patients was positive suggesting communication skills training may be a priority.

Noted in Media Watch, 11 August 2014, #370 (p.14):

- LA PRESSE MÉDICALE | Online – 24 July 2014 – ‘Inadequate involvement of general practitioners in end of life’s decisions in an intensive care unit.’ Patients’ general practitioners could be relevant consultants for collegial decisions of withholding or withdrawing treatment...
On resilience and acceptance in the transition to palliative care at the end of life

HEALTH | Online – 12 August 2014 – Specialist palliative care is a prominent and expanding site of health service delivery, providing highly specialised care to people at the end of life. Its focus on the delivery of specialised life-enhancing care stands in contrast to biomedicine’s general tendency towards life-prolonging intervention. This philosophical departure from curative or life-prolonging care means that transitioning patients can be problematic, with recent work suggesting a wide range of potential emotional, communication and relational difficulties for patients, families and health professionals. Yet, we know little about terminally ill patients’ lived experiences of this complex transition. [In this article] ... the authors explore their embodied and relational experiences of the transition to inpatient care, including their accounts of an ethic of resilience in pre-palliative care and an ethic of acceptance as they move towards specialist palliative care. Exploring the relationship between resilience and acceptance reveals the opportunities, as well as the limitations, embedded in the normative constructs that inflect individual experience of this transition. This highlights a contradictory dynamic whereby participants’ experiences were characterised by talk of initiating change, while also acquiescing to the terminal progression of their illness

http://hea.sagepub.com/content/early/2014/08/12/1363459314545696.abstract

Needs of people with severe dementia at the end of life: A systematic review

JOURNAL OF ALZHEIMER’S DISEASE | Online – 4 August 2014 – A total of ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned. Other categories were spiritual, supportive, and environmental needs and needs related to individuality. Needs were often named, but what they entailed operationally was not highlighted in detail. This systematic review shows the paucity of empirical findings on the needs of people with severe dementia. The structured presentation of thematic categories points to a clearer delineation of these needs. Thus, this overview emphasizes the topics for future research and can likewise serve as an orientation for care provision.

http://iospress.metapress.com/content/8wk34806v5630580/

N.B. Several articles on end-of-life care for people living with dementia are noted in Media Watch, 23 June 2014, #363 (p.11).

"It's not that easy" – Medical students' fears and barriers in end-of-life communication

JOURNAL OF CANCER EDUCATION | Online – 12 August 2014 – Students [i.e., study participants] felt insufficiently prepared and insecure. Discussing end-of-life issues was experienced as challenging and emotionally moving. Within the conversations, although students sometimes showed blocking behaviour in reaction to emotional impact, they valued the consideration of emotional aspects as very important. The results of this study indicate an urgent need for better communication training for medical students. Due to the fact that bedside teaching in palliative care is not feasible for all students, training with standardized simulated patients can be a way to generate an authentic learning situation.

http://link.springer.com/article/10.1007/s13187-014-0712-0

Noted in Media Watch, 2 June 2014, #360 (pp.8-9):


N.B. Several articles on bedside teaching in the context of end-of-life care are noted in this issue of Media Watch.
Talking about health care: News framing of who is responsible for rising health care costs in the U.S.

JOURNAL OF HEALTH COMMUNICATION | Online – 12 August 2014 – This content analysis examines how the American news media have presented the problem of high and rising health care costs, looking particularly at the question of who is responsible. More specifically, the authors examine how often the media have discussed the 5 major causes of the problem: a) patients; b) health care providers; c) insurance companies; d) the government; and, d) pharmaceutical companies. Results revealed that patients were most often mentioned as the cause of increasing health care costs. The authors also found that the media’s attribution of responsibility to patients has increased over the years. Overall, media coverage of rising health care costs peaked in 1993, 2004, and 2009, suggesting that coverage was influenced by newsworthy events (e.g., the president endorsing legislation or signing a bill into law) that draw the public’s attention. http://www.tandfonline.com/doi/full/10.1080/10810730.2014.914604

Organization of nursing and quality of care for [U.S.] veterans at the end of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 August 2014 – The Veterans Health Administration has improved the quality of end-of-life (EOL) care over the past several years. Several structural and process variables are associated with better outcomes. Little is known, however, about the relationship between the organization of nursing care and EOL outcomes. [Survey] respondents were 17% more likely to give an “excellent” overall rating of the quality of EOL care received by the veteran in facilities with better nurse work environments. The nurse work environment also was a significant predictor of providers listening to concerns and providing desired treatments. Nurse staffing was significantly associated with an “excellent” overall rating, alerting of the family prior to death, attention to personal care needs, and the provision of emotional support after the patient's death. http://www.jpsmjournal.com/article/S0885-3924(14)00397-2/abstract

Transnationals' experience of dying in their adopted country: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 August 2014 – Social and emotional challenges of migration and integration include managing memories and perceptions of country of birth, leaving loved relatives behind, and the challenges of maintaining traditions, such as cultural food and practices. For many migrants, the strong connection with their birth country is never completely severed, which may become pertinent at particular events and stages in life with inherent emotional impact. This may be particularly the case for end-of-life experience. The authors undertook a systematic review of published evidence of research to identify the lived experience of migrants dying in a country different from their country of birth. Seven qualitative studies met the criteria. Thematic analysis of these studies identified three main themes: sense of dual identity, importance of traditions from their country of origin, and dying preferences. Findings have implications for the provision of palliative end-of-life care for dying transnationals, particularly in relation to providing support for migrants who are dying to resolve social and emotional issues. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0044

Of related interest:

- SUPPORTIVE CARE IN CANCER | Online – 16 August 2014 – 'I want to fly home: A terminal cancer patient’s right to go home.' As palliative care physicians, we sometimes find ourselves immersed in the dilemma of a patient with terminal cancer requesting to fly back home, often overseas. This particular situation is filled with an array of complex variables: establishing that the medical condition is stable enough for overseas travel, dealing with a significant cost (sometimes in patients with scarce economical resources), securing proper care on the receiving end, symptom management during flight, and dealing with the possibility of in-flight death, among others. http://link.springer.com/article/10.1007/s00520-014-2391-0
Noted in Media Watch, 10 September 2012, #270 (p.4):

- *AIR MEDICAL JOURNAL, 2012;31(5):238-241, 'Air medical repatriation: Compassionate and palliative care consideration during transport.'* The number of elderly and very elderly international travelers continues to increase. Many are afflicted with multiple, often severe, medical conditions; a significant portion of these elderly travelers are considered end stage with respect to their disease state. While traveling, they are exposed to travel hazards and deterioration of their already compromised health. ...compassionate repatriation of these elderly patients is associated with a range of complex challenges. http://www.sciencedirect.com/science/article/pii/S1067991X11002483

**Do palliative care interventions reduce emergency department visits among patients with cancer at the end of life? A systematic review**

*JOURNAL OF PALLIATIVE MEDICINE | Online – 12 August 2014 – Evidence regarding whether palliative care interventions implemented in the hospital, home or outpatient clinic are more effective than usual care at reducing emergency department visits is not strongly substantiated based on the literature reviewed. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0092*

Of related interest:

- *PALLIATIVE MEDICINE | Online – 12 August 2014 – 'What is the incidence of patients with palliative care needs presenting to the emergency department? A critical review.'* There is an absence of evidence regarding the incidence of patients with palliative care needs presenting to the Emergency Department. Further research needs to be undertaken in this area to ensure both clinicians and policymakers have sufficient information for service provision. http://pmj.sagepub.com/content/early/2014/08/07/0269216314543318.abstract
Undocumented and at the end of life

NARRATIVE INQUIRY IN BIOETHICS, 2014;4(2):83-85. Three of the most contentious issues in contemporary American society – allocation of medical resources, end-of-life care, and immigration – converge when undocumented immigrant patients are facing the terminal phase of chronic illness. The lack of consistent, pragmatic policy in each of these spheres leaves us with little guidance for how to advocate for undocumented patients at the end of life. Limited resources and growing need compound the problem. Care for patients in this unfortunate situation should be grounded in clinical and economic reality as well as respect for the dignity of the individual to...

http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/narrative_inquiry_in_bioethics/v04/4.2.mendola.html

Noted in Media Watch, 4 June 2012, #256 (p.12):


Cutting the Gordian knot of futility: A case for law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment

NEW ZEALAND UNIVERSITIES LAW REVIEW, 2014;26(1):24-59. In Australia and New Zealand, courts, hospitals, health care professionals, patients, and their families and friends are wrestling with gut-wrenching conflicts that can arise when the health care team believes that treatment should not be provided and the patient's loved ones believe that it should. Occasionally, details of specific cases spill over into the media, engaging the public in the often-heated debate. Talk of "unrealistic expectations," "false hope," and "futility" abounds and tests for defensible withholding or withdrawal of treatment, such as "a reasonable prospect of returning a patient to a meaningful quality of life" and "accepted medical practice," are proposed. In this paper, the authors attempt to take a step back from the drama and vitriol and suggest an approach to law and policy reform grounded in identification of core values, careful conceptual analysis, and a dose of humility and pragmatism. To that end, they reflect on the core values that do (or should) underpin a regulatory framework for deciding on whether potentially life-sustaining treatment should be withheld or withdrawn. http://eprints.qut.edu.au/74688/2/74688.pdf

N.B. The "Gordian knot" is a metaphor for an intractable problem.

Noted in Media Watch, 21 July 2014, #367 (p.10):

- JOURNAL OF LAW & MEDICINE, 2014;12(4):920-941. "'Best interests' and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the parens patriae jurisdiction.' Disputes about withholding and withdrawing life-sustaining treatment are increasingly coming before Australian Supreme Courts. Such cases are generally heard in the parens patriae jurisdiction where the test applied is what is in the patient's "best interests." http://eprints.qut.edu.au/73554/2/73554a.pdf

Of related interest:

- JOURNAL OF CRITICAL CARE | Online – 11 August 2014 – 'Withholding or withdrawing of treatment in elderly patients admitted to the intensive care unit.' Life sustaining treatment (LST) limitation for elderly patients is highly controversial. In that context, it is useful to evaluate the attitudes to LST in the elderly among experienced ICU physicians with different backgrounds and cultures. Most experts disagree or strongly disagree (77%) that age should be used as the sole criterion for withholding or withdrawing LST and almost all disagree (91%) that there should be a specific age for such decision making. However, the vast majority (91%) acknowledge that age should be an important consideration in conjunction with other factors. http://www.jccjournal.org/article/S0883-9441(14)00330-X/abstract
Researching moral distress among New Zealand nurses: A national survey

*NURSING ETHICS* | Online – 7 August 2014 – The results [of this study] imply moral distress in nursing remains a highly significant and pertinent issue that requires greater consideration by health service managers, policymakers and nurse educators. Most frequent situations to cause nursing distress having to provide less than optimal care due to management decisions, seeing patient care suffer due to lack of provider continuity, and working with others who are less than competent. [http://nej.sagepub.com/content/early/2014/08/07/0969733014542679.abstract](http://nej.sagepub.com/content/early/2014/08/07/0969733014542679.abstract)

Advance care planning: Whose agenda is it anyway?

*PALLIATIVE MEDICINE, 2014;28(8):997-999.* One of the challenges we face in end-of-life care today is juggling the multiple agendas within advance care planning [ACP]. Whose agenda is it anyway? Patients, families, health-care professionals, funders or commissioners of care, legislative frameworks or society as a whole? How do we support adults with a life-shortening illness to live with, prepare and plan for dying in an individual way without focussing only on planning for incapacity, treatment decisions or fitting them into a preconceived and possibly inflexible system of how a good death should be. How do we bring together the multiple agendas allowing equal weight to both the process and outcomes? ACP has to be more than a "tick box policy driven formulaic response." [http://pmj.sagepub.com/content/28/8/997.extract](http://pmj.sagepub.com/content/28/8/997.extract)

Noted in Media Watch, 19 May 2014, #358 (p.10):

- *PALLIATIVE MEDICINE | Online – 12 May 2014 – ‘Advance care planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008-2012.’ Factors influencing uptake of ACP in palliative care are complex and multifaceted reflecting diverse and often competing needs of patients, health professionals, legislature and health systems. [http://pmj.sagepub.com/content/early/2014/05/12/0269216314531313.abstract](http://pmj.sagepub.com/content/early/2014/05/12/0269216314531313.abstract)

Quality of life in palliative care: An analysis of quality-of-life assessment

*PROGRESS IN PALLIATIVE CARE | Online – Accessed 17 August 2014 –* Through an extensive literature research multiple instruments were found. Of these, four were chosen to be examined further (Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW), European Organisation for Research & Treatment of Cancer Quality of Life Questionnaire – Core 15 – of Palliative Care, Rotterdam Symptom Checklist, and Palliative Care Outcome Scale. The SEIQoL-DW seems to be best suited for use in a clinical situation even though its use can be challenging for both researcher and patient. It is the most flexible assessment instrument of those analysed here and therefore seems to be best suited to investigate such a complex matter as quality of life. [http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000102](http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000102)

**Quotable Quotes**

Care of the dying is a complex art that demands a range of many skills, including ethical skills and competencies so that sight is not lost of the fundamental bond between professional and patient. Where ethics support is part of a standard practice of health care organisations, the international evidence indicates that health care staff are more ethically literate leading to improved patient and family outcomes and less moral stress, desensitisation and burnout for health professionals who are struggling at the coalface due to current budgetary constraints.

[U.S.] Hospice experience of care survey

RAND CORPORATION | Online – August 2014 – The Centers for Medicare & Medicaid Services (CMS) has implemented care experience surveys for a variety of settings but none for hospice care. CMS contracted RAND to design and field-test a future Consumer Assessment of Health-care Providers & Systems survey to measure the experiences patients and their caregivers have with hospice care. It was developed to: 1) provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program; 2) aid hospices with their internal quality improvement efforts and external benchmarking with other facilities; and, 3) provide CMS with information for monitoring the care provided. http://www.rand.org/pubs/research_reports/RR657.html

Media Watch Online

International


PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ [Scroll down to ‘International Websites’ and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/ithenews.html

ONTARIO | Mississauga Halton Palliative Care Network: http://www.mhpcon.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to ‘Additional Resources’]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ [Scroll down to ‘Media Watch’]

U.K. | Omega, the National Association for End-of-Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **JOURNAL OF BIOETHICAL INQUIRY** | Online – 16 August 2014 – ‘Questions and answers on the Belgian model of integral end-of-life care: Experiment? Prototype?’ This article analyses domestic and foreign reactions to a 2008 report in the British Medical Journal on the complementary and, as argued, synergistic relationship between palliative care and euthanasia in Belgium. The earliest initiators of palliative care in Belgium in the late 1970s held the view that access to proper palliative care was a precondition for euthanasia to be acceptable and that euthanasia and palliative care could, and should, develop together. http://link.springer.com/article/10.1007/s11673-014-9554-z

- **JOURNAL OF LAW & MEDICINE**, 2014;21(4):762-773. ‘Minors’ decision-making capacity to refuse life-saving and life-sustaining treatment: Legal and psychiatric perspectives.’ Laws in Belgium and The Netherlands permit euthanasia and assisted suicide for seriously ill children who experience “constant and unbearable suffering” – they have the capacity to request death by lethal injection if they convey a "reasonable understanding of the consequences" of that request. The child's capacity to understand death is therefore a prerequisite to the implementation of the request. However, modern neuro-psychological and fMRI (functional Magnetic Resonance Imaging) studies of the relationship between the neuro-anatomical development of the brain in human beings and their emotional and experiential capacity demonstrate that both are not fully developed until the early 20s for girls and mid-20s for boys. Unlike Belgium and The Netherlands, the clinical and legal implications of the immaturity of the brain on medical decision-making of minors, in particular life and death decisions, have been implicit in the Australian courts’ approach to the refusal of life-saving and life-sustaining treatment by minors. http://europepmc.org/abstract/med/25087358

- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 11 August 2014 – ‘Predictors of pursuit of physician-assisted death.’ The authors found that physician-assisted death (PAD) requesters had higher levels of depression, hopelessness, and dismissive attachment (attachment to others characterized by independence and self-reliance), and lower levels of spirituality. There were moderate correlations among the variables of spirituality, hopelessness, depression, social support, and dismissive attachment. There was a strong correlation between depression and hopelessness. Low spirituality emerged as the strongest predictor of pursuit of PAD in the regression analysis. http://www.jpsmjournal.com/article/S0885-3924(14)00398-4/abstract

- **ORVOSI HETILAP**, 2014;155(32):1259-1264. 'Euthanasia outside Europe.' In Europe, active euthanasia is legalized only in The Netherlands, Belgium, Luxembourg and Switzerland. In Australia, the Act on the Rights of the Terminally Ill of 1995 legalized the institution of assisted suicide, which is not identical to active euthanasia. The difference lies in the fact that legalized active euthanasia means that the author of a murder is not punishable (under certain circumstances), whilst assisted suicide is not about murder, rather about suicide. In the first case, the patient is killed on his or her request by someone else. In the second case, the patient himself or herself executes the act of self-killing (by the assistance of a healthcare worker). In Australia, the institution of assisted suicide was repealed in 1997. Assisted suicide is legal in the U.S. in Vermont, Washington, Montana and Oregon. In Uruguay, the active form of euthanasia has been legal since 1932. http://europepmc.org/abstract/med/25087217

N.B. Hungarian language article.

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