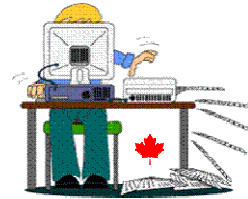


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Barriers to "the conversation": Scroll down to [Specialist Publications](#) and 'After you: Conversations between patients and healthcare professionals in planning for end-of-life care' (p.6), in *BMC Palliative Care*.

Canada

Starved girl taken off life-support dies

ALBERTA | CBC News (Edmonton) – 21 September 2012 – A two-year-old Alberta girl allegedly abused by her parents died in an Edmonton hospital after being taken off life support. The child, who can only be identified as "M," died Thursday night after her ventilator was removed. She had been in a coma since being brought to hospital in May. Her parents, who cannot be named, have been charged with beating and starving the girl and are currently being held in custody. The Alberta Court of Appeal upheld a lower court ruling that ordered the girl be taken off life-support as soon as "reasonably possible." The court also refused to grant a stay of the order pending an appeal to the Supreme Court, stating there were no grounds to take the case to Canada's top court. <http://www.cbc.ca/news/canada/edmonton/story/2012/09/21/edmonton-m-child-dies.html>

Noted in Media Watch, 17 September 2012:

- ALBERTA | *Edmonton Journal* – 14 September 2012 – '**Judicial stay granted on order to halt to life-sustaining treatments for comatose girl.**' Alberta Court of Appeal judge has temporarily stayed a lower-court ruling that life-saving measures be stopped for a comatose child... <http://www.edmontonjournal.com/news/edmonton/Judge+orders+halt+life+sustaining+treatments+comatose/7244807/story.html>

Manitoba takes 'step forward' with spiritual health-care strategic plan

MANITOBA | *Metro Winnipeg* – 20 September 2012 – The Manitoba government has released a strategic plan that brings in more "spiritual" elements to our health-care system. Called Health and the Human Spirit, the plan is the first of its kind in Canada, said Jim Rondeau, Minister of Healthy Living, Seniors & Consumer Affairs. "(It) enhances awareness and gives direction for spiritual health care in Manitoba," said Rondeau. The new four-year plan is based on the work of a wide range of community and professional stakeholders, spiritual care providers, volunteers, counsellors, physicians, psychiatrists, policy analysts and people who have experienced spiritual care in a health-care context. <http://metronews.ca/news/winnipeg/376929/manitoba-takes-step-forward-with-spiritual-health-care-strategic-plan/>

U.S.A.

Cost of end-of-life care

The high cost of out-of-pocket expenses

NEW YORK TIMES | Published online – 21 September 2012 – It comes as a shock: how much people have to spend on medical care for a frail older relative in the last several years of life. A common assumption is that Medicare will pay for almost everything. But that's mistaken. As a study by researchers at the Mount Sinai School of Medicine in Manhattan documents, out-of-pocket costs for older adults at the close of life often place a significant financial burden on individuals and families. The report¹ ... analyzed data about 3,209 people who participated in the national Health & Retirement Study and

who died between 2002 and 2008. The survey, sponsored by the National Institute on Aging, collects information about medical out-of-pocket spending every two years. <http://newoldage.blogs.nytimes.com/2012/09/21/the-high-cost-of-out-of-pocket-expenses/>

Finding of the Health & Retirement Study

On average, people with Medicare coverage paid \$38,688 for medical care in the last five years of life.

1. 'Out-of-pocket spending in the last five years of life,' *Journal of General Internal Medicine*, published online, 5 September 2012 (noted in Media Watch, 10 September 2012) <http://www.springerlink.com/content/427m88565153p76k/>

Of related interest:

- IRELAND | *The Independent* (Dublin) – 24 September 2012 – **'Homes bill elderly for 'hidden extras' of up to €600 per month.'** <http://www.independent.ie/national-news/homes-bill-elderly-for-hidden-extras-of-up-to-600-per-month-3239598.html>

Physicians Orders for Life Sustaining Treatment (POLST)

Oregon end-of-life care program spreads, report finds

OREGON | *The Oregonian* (Portland) – 20 September 2012 – An Oregon effort to ensure people near the end of life receive the care they want continues to spread across the country, according to a new report. The Oregon Physicians Orders for Life Sustaining Treatment (POLST) program, created two decades ago and put into state law by the Legislature in 2009, has been adopted by 15 states and is under consideration in 28 others, according to the report, prepared by the Retirement Research Foundation and the Archstone Foundation. That's an increase just over last year. Then, the program, which includes an electronic registry of detailed end-of-life care instructions, had been adopted in only 12 states. The report, which advises other states on lessons learned, will formally be released 1 October 2012, but a draft copy has already been released.¹ http://www.oregonlive.com/health/index.ssf/2012/09/oregon_end-of-life_care_progra.html

1. 'New report highlights success of Oregon's groundbreaking POLST program,' Oregon Health & Science University, September 2012. http://www.ohsu.edu/xd/about/news_events/news/2012/09-19-report-highlights-polst.cfm?WT_featured=news&WT_rank=news

Of related interest:

- WISCONSIN | *Daily Citizen* (Beaver Dam) – 21 September 2012 – **'Madison health care to emphasize end of life care discussions.'** Madison's health care systems will encourage patients and families to talk more about end-of-life care decisions, in an effort organized by the Wisconsin Medical Society... http://www.wiscnews.com/bdc/news/local/article_673f4a54-045f-11e2-946c-0019bb2963f4.html

Prison hospice

Hospice program provides care, comfort for Maine's aging prison population

MAINE | *Bangor Daily News* – 19 September 2012 – Santanu Basu has been a resident of Maine State Prison for a long time already, and has a lot more time to go before he's released. If he's ever released, that is. So Basu, a convicted murderer, has resolved to do good during the remaining decades of his 62-year sentence by acting as a hospice volunteer. He will provide end-of-life care to some of the prison's oldest, sickest and most vulnerable inmates. "I'm probably going to die in here," the 45-year-old said... "I want to give back to the program, because I'm probably going to need it myself." Elderly prisoners are a fast-growing segment of the incarcerated population both in Maine and nationally. Basu said that before taking the intensive hospice training, he saw death as a difficult obstacle. But now, he said, that has changed, and his sense of compassion and care for others has increased significantly. "I feel that whatever I can do to help others makes me feel better about myself," Basu said. "Maybe that's a selfish way to look at it — but the hospice program has brought out that part of me that was always there." With more and more aging and chronically ill inmates, prisons in Maine and other states have looked to hospice programs and prisoner volunteers such as Basu to help ease the last days of those living and dying behind bars. <http://bangordailynews.com/2012/09/19/health/hospice-program-provides-care-comfort-for-maines-aging-prison-population/>

Of related interest:

- *HUFFINGTON POST* | Published online – 22 September 2012 – '**Do elderly inmates belong in Illinois' Prisons?**' http://www.huffingtonpost.com/rev-amy-zietlow/compassionate-release-b_1901527.html

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.12.

Letting children share in grief

NEW YORK TIMES | Published online – 19 September 2012 – A few decades ago, children often didn't attend funerals. The thinking was that they should be sheltered from the pain of losing a loved one. And, as Americans started living longer, the need to even broach the subject of death was delayed because many grandparents survived deep into their golden years. But recently, the opposite view – that children should be as involved in the grieving process as adults are – has been taking hold, reflecting an increasingly common belief that children are better off when their grief is acknowledged and they are allowed to mourn in the company of relatives and peers. In contrast, a century or more ago, when illness, death and grief all took place at home, children learned to regard them as a natural part of life, said Alan Wolfelt, a psychologist who runs the Center for Loss and Life Transition in Fort Collins, Colorado, which has trained a generation of grief counselors. But Amer-

ica has since become a "mourning avoidant" culture, he added, in part because many 40- and 50-year-olds still have living parents. And that longevity, he wrote in an e-mail, has "resulted in a tendency to overprotect children from the realities of grief and loss." Indeed, death is such a foreign concept to some families, he said, that he has been told, "We just don't do death."

http://www.nytimes.com/2012/09/20/garden/letting-children-share-in-grief.html?pagewanted=all&_moc.semityn.www

Specialist Publications

Of related interest:

'A call to the field: Complicated grief in the DSM-5' (p.10), in *OMEGA – Journal of Death & Dying*.

International

End-of-life care and the economy

Extreme debt and an ageing population could cause recession to last over twenty years

U.K. (SCOTLAND) | *Daily Record* (Glasgow) – 19 September 2012 – The recession could last over 20 years as the economy struggles to cope with an ageing population and extraordinary levels of debt, experts have warned. Even if the economy does start to grow, it will plunge one-fifth of homeowners into "real trouble" as rising interest rates stretch household budgets to breaking point. The Scottish Government may have to abandon universal services for elderly people or tax the working population more to pay for it, experts said. This could lead to "inter-generational breakdown" as young families with student loans and high mortgages resent being taxed to pay for free services for a "seriously lucky" elderly generation which grew up in an era of student grants and generous pensions, it was also claimed. Health professionals may also have

to consider "how protracted we wish to make people's deaths". One expert suggested asking older people if they want "do-not-resuscitate" notices in their homes if they are found by ambulance crews.

<http://www.dailyrecord.co.uk/news/business-consumer/extreme-levels-of-debt-and-ageing-population-1332084>

Extract from the *Daily Record* report

Members of the Scottish Parliament and experts suggested that too much focus is placed on carrying out operations designed to prolong life for a short time, which can unintentionally shorten life, and that this distracts from providing a decent quality of life for elderly people.

More hospices needed 'to care for people dying gradually'

U.K. | *Daily Telegraph* – 18 September 2012 – More hospices and care homes are needed to cope with increasing numbers of people dying "gradual" deaths. The country faces a growing crisis in its ability to care for people suffering cancer, dementia and other long-term ailments, according to specialists who say that supply is not keeping pace with demand.¹ Better health care, and to some extent a fitter older population, means fewer people are experiencing "sudden" deaths. While increased longevity is to be welcomed doctors say not enough resources are being devoted to making the last days of the elderly as comfortable as possible. Gradual deaths from cancer and other chronic dis-

eases are already "a considerable burden" for European countries. Health planners need to look at improving end-of-life care, particularly for those not suffering from cancer. <http://www.telegraph.co.uk/health/healthnews/9549432/More-hospices-needed-to-care-for-people-dying-gradually.html>

Specialist Publications

Of related interest:

'Rapid death after admission to palliative care' (p.8), in *Internal Medicine Journal*.

1. 'The burden of non-acute dying on society: Dying of cancer and chronic disease in the European Union,' *BMJ Supportive & Palliative Care*, published online 28 August 2012.

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>

Palliative care in Northern Ireland

Northern Ireland Children's Hospice in cash plea to ease burden on patients' parents

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 18 September 2012 – A shocking gap in services for some of the most vulnerable children in Northern Ireland means lives are being put at risk, it has been claimed. Parents of children with life-limiting conditions are so stretched they are missing important medical appointments themselves – with devastating consequences for some. The Northern Ireland Children's Hospice has called for the Government to improve funding to support parents in such a position. <http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/northern-ireland-childrens-hospice-in-cash-plea-to-ease-burden-on-patients-parents-16212007.html>

Of related interest:

- U.K. (NORTHERN IRELAND) | BBC News (Belfast) – 17 September 2012 – **'New 'one call' bereavement service launched.'** A new bereavement service to help relatives check if they are eligible for funeral costs has been launched by the Social Security Agency. It is believed that 60% of benefit customers who die are in receipt of more than one benefit or service from the agency. The new 'one-call' service allows relatives to report a death or make a claim. A surviving partner will now be able to find out in one call if they are entitled to state pension credit, income support, bereavement or social fund funeral payment benefits. <http://www.bbc.co.uk/news/uk-northern-ireland-19599354>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | Associated Press – 19 September 2012 – **'Assisted suicide bill prepared.'** A fresh attempt to legalise assisted suicide is under way after Members of the Scottish parliament backed the preparation of a new Bill. Margo MacDonald has lodged a second proposal after receiving the required 18 signatures of support following a consultation earlier this year. A previous attempt to give people the right to choose when to die was defeated at Holyrood (the Scottish parliament). <http://www.google.com/hostednews/ukpress/article/ALeqM5j6AOXpOV8m5ZNaVbL1hrf5-GXd5Q?docId=N0251691348023545977A>
- IRELAND | *The Independent* (Dublin) – 17 September 2012 – **'Couple in right-to-die case want to stay anonymous.'** A couple on the brink of a landmark High Court battle over the controversial issue of assisted suicide will seek to protect their identities. The matter is expected to be brought before a judge as a severely disabled and wheelchair-bound woman suffering from multiple sclerosis requests her partner be allowed to help her end her life without fear of prosecution. Suicide is not illegal in Ireland but assisting suicide can be punishable by up to 14 years' imprisonment. The couple's legal team are expected to argue the legislation is unconstitutional as an able-bodied person can end their own life without penalty, yet someone with a disability or terminal illness can't do so as anyone who helps them faces prosecution. <http://www.independent.ie/national-news/couple-in-righttodie-case-want-to-stay-anonymous-3232441.html>



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipccr.net/barry-r-ashpole.php>

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

After you: Conversations between patients and healthcare professionals in planning for end-of-life care

BMC PALLIATIVE CARE | Published online – 17 September 2012 – Patients [study participants] demonstrated varying degrees of reticence, evasion or reluctance to initiate any conversations about end of life care preferences. Most assumed that staff would initiate such conversations, while staff were often hesitant to do so. Staff-identified barriers included the perceived risks of taking away hope and issues of timing. Staff were often guided by cues from the patient or by intuition about when to initiate these discussions. This study provides insights into the complexities surrounding the initiation of Advance Care Planning involving conversations about end of life care preferences with patients who are identified as having palliative care needs, in particular in relation to the risks inherent in the process of having conversations where mortality must be acknowledged. <http://www.biomedcentral.com/content/pdf/1472-684X-11-15.pdf>

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 tool or change document.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. 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.
5. 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.

Living to the end - palliative care for an ageing population



<http://www.worldday.org/>

October 13 2012

Consumer Quality Index Palliative Care

Measuring patients' experiences with palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 20 September 2012 – The Consumer Quality Index Palliative Care (CQ-index PC) is a structured questionnaire for measuring the quality of palliative care from the perspective of care users. CQ-indices assess which care aspects need quality improvement by relating answers about actual care experiences to answers about the importance of certain aspects of care. 15 care organisations participated [in this study]. Patients [study participants] considered the following aspects the most important: 'offering help in good time in acute situations,' 'caregivers having the necessary expertise' and 'caregivers taking the patient seriously.' The three care aspects with the highest 'need for improvement' scores were: 'support when the patient feels depressed,' 'support when the patient is anxious' and 'support when the patient has shortness of breath.' The CQ-index PC provides opportunities for care organisations to assess which care aspects have the highest priority for quality improvement within their organisation. <http://spcare.bmj.com/content/early/2012/09/20/bmjspcare-2011-000055.abstract>

Of related interest:

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2012;15(3):141-146. **'A review on palliative care research outcomes: Focus on the quality of life.'** The authors examine the current status of and challenges in quality of life studies and discuss possible solutions. <http://www.koreamed.org/SearchBasic.php?RID=0155KJHPC/2012.15.3.141&DT=1>
- *ONCOLOGY NURSING* | Published online – 13 September 2012 – **'Small acts targeted to patients' preferences enhance palliative care efforts.'** <http://www.oncologynurseadvisor.com/small-acts-targeted-to-patients-preferences-enhance-palliative-care-efforts/article/258079/>

- *CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Published online – Accessed 23 September 2012 – **'The ethics of end-of-life care for patients with ESRD.'** <http://cjasn.asnjournals.org/content/early/2012/09/19/CJN.03900412.abstract>

Defining end-of-life care from perspectives of nursing ethics

NURSING ETHICS, 2012;19(5):608-618. This article reports on the authors' examination of terms related to end-of-life care and define end-of-life care from nursing ethics perspectives. Current terms ... such as terminal care, hospice care, and palliative care, are based on a medical model ... restrictive in terms of diagnosis and prognosis. <http://nej.sagepub.com/content/19/5/608.abstract>

N.B. This issue of *Nursing Ethics* includes several articles on end-of-life care: Contents page: <http://nej.sagepub.com/content/19/5.toc>

Noted in Media Watch, 3 September 2012:

SUPPORTIVE CARE IN CANCER | Published online – 31 August 2012 – **'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" ...'** <http://www.ncbi.nlm.nih.gov/pubmed/22936493>

Noted in Media Watch, 6 August 2012:

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 2 August 2012 – **'Development of a generic working definition of 'supportive care'** <http://spcare.bmj.com/content/early/2012/08/02/bmjspcare-2012-000222.abstract>

Noted in Media Watch, 16 April 2012:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 10 April 2012 – **'Comfort measures only: Agreeing on a common definition...'** <http://ajh.sagepub.com/content/early/2012/03/05/1049909112440740.abstract>

Cont. next column.

Rapid death after admission to palliative care

INTERNAL MEDICINE JOURNAL, 2012;42(9):984-989. Brief end-of-life admissions are disruptive for patients and their families, and increase staff stress. Extremely rapid deaths ... are particularly challenging for all involved. From 1 January 2010 to 23 August 2011, 256 patients died on the Palliative Care Unit (Caritas Christi) at St Vincent's Hospital Melbourne. Forty-two died within 24 hour (16%), while 214 survived beyond 24 hour (84%). This study is designed to help clinicians identify patients likely to deteriorate rapidly. Alternative options could include earlier transfer to the palliative care unit or palliation on their home ward with palliative care consultation. <http://onlinelibrary.wiley.com/doi/10.1111/j.1445-5994.2012.02790.x/abstract>

Psychological responses of terminally ill patients who are experiencing suffering

INTERNATIONAL JOURNAL OF NURSING STUDIES | Published online – 19 September 2012 – Analysis of the [study] participants' answers to the different questions of the semi-structured interview has allowed us to identify a main category – "To realize that life is short." There are three categories where the different ways of facing up to the end of life concentrate: "re-evaluation of life," "opportunity for growth," "resignation/acceptance." Nurses have to try to alleviate the impact the terminal illness has on the subject, not only by controlling the symptoms but also encouraging the patient's responses, by promoting the feeling of satisfaction in life, providing honest and sensitive information, establishing with the patient realistic goals, and facilitating a quality communication between patients and their family. [http://www.journalofnursingstudies.com/article/S0020-7489\(12\)00289-1/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(12)00289-1/abstract)

Communication skills

If I paint a rosy picture, will you promise not to cry?

JOURNAL OF CLINICAL ONCOLOGY, 2012;30(27):3421-3423. It can be a tough question. Many of our patients are not going to be OK, and most physicians have not received the kind of communication skills training that would make them feel as competent having difficult conversations as they do performing difficult medical procedures. Although patients want guidance and hope, they also want candor. The fear that candor is incompatible with hope is unfounded, but telling a patient the truth in a way that is caring and not brutal requires skill. Our gut instinct and our medical training often instruct us to fix whatever problems we encounter, and this gets us into trouble when the problem cannot be fixed. Sometimes we actively mislead the patient, and sometimes we mislead ourselves, giving third-, fourth-, and fifth-line chemotherapy rather than facing reality. Perhaps, if we had more candid conversations, we would not have so many patients receiving chemotherapy when they have only days or a few weeks to live, and we would not have so many hospice referrals delayed until a few days before death. <http://jco.ascopubs.org/content/30/27/3421.full>

Performance and palliative care: A drama module for medical students

MEDICAL HUMANITIES | Published online – 12 September 2012 – This paper describes an innovative ... module for medical students facilitated by drama educators and a palliative medicine doctor. The module incorporates drama, end-of-life care, teamwork and reflective practice. The module contents, practical aspects of drama teaching and learning outcomes are discussed. Various themes emerged from a study of Harold Pinter's play, *The Caretaker*, which were relevant to clinical practice: silence, power, communication, uncertainty and unanswered questions. <http://mh.bmj.com/content/early/2012/09/11/medhum-2012-010203.short>

Noted in Media Watch, 2 April 2012:

JOURNAL OF MEDICAL HUMANITIES | Published online – 18 March 2012 – 'I could never quite get it together: Lessons for end-of-life care in Harold Pinter's *The Caretaker*.' <http://www.springerlink.com/content/c6637225291246p8/>

Do-not-resuscitate order: A view throughout the world

JOURNAL OF CRITICAL CARE | Published online – 13 September 2012 – This review focuses on several aspects, regarding withholding and/or withdrawing therapies and advance directives in different continents. It is widely known that there is a great diversity of cultural and religious beliefs in society, and therefore, some critical ethical and legal issues have still to be solved. To achieve a consensus, the authors believe in the priority of continuing education and training programs for health care professionals. It is their opinion that a serious reflection on ethical values and principles would be useful to understand the definition of medical professionalism to make it possible to undertake the best way to avoid futile and aggressive care. There is evidence of the lack of DNR order policy worldwide. Therefore, it appears clear that there is a need for standardization. To improve the attitude about the DNR order, it is necessary to achieve several goals such as: increased communication, consensus on law, increased trust among patients and health care systems, and improved standards and quality of care to respect the patient's will and the family's role. <http://www.sciencedirect.com/science/article/pii/S0883944112002249>

'If and when?': The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying

JOURNAL OF INTELLECTUAL DISABILITY RESEARCH | Published online – 14 September 2012 – While in principle, staff [study participants] unanimously supported the belief that people with ID [intellectual disability] should know about dying, there was limited in-practice engagement with clients about the topic. Engagement varied according to staff experience, client capacity to understand and the nature of the 'opportunity' to engage. Four 'opportunities' were identified: 'when family die,' 'incidental opportunities,' 'when clients live with someone who is dying' and 'when a client is dying.' Despite limited engagement by staff, people with ID are regularly exposed to dying and death. People with ID have a fundamental right to know about dying and death. Sophisticated staff skills are required to ensure that people with ID can meaningfully engage with end-of-life issues as opportunities arise. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2012.01593.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 6 August 2012:

- *JOURNAL OF CLINICAL ETHICS*, 2012;23(1):71-78. **'Surrogate medical decision making on behalf of a never-competent, profoundly intellectually disabled patient who is acutely ill.'** http://www.clinicalethics.com/single_article/tiec6ux3a3A.html

Noted in Media Watch, 18 June 2012:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Published online – 8 June 2012 – **'Caring for people with intellectual disabilities and life-limiting illness...'** <http://www.tandfonline.com/doi/abs/10.1080/15524256.2012.685440>

Noted in Media Watch, 27 February 2012:

- *JOURNAL OF PALLIATIVE MEDICINE* | Published online – 21 February 2012 – **'Practical approaches toward improving end-of-life care for people with intellectual disabilities...'** <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0132>

Noted in Media Watch, 23 January 2012:

- *PALLIATIVE MEDICINE* | Published online – 16 January 2012 – **'A new model for breaking bad news to people with intellectual disabilities.'** <http://pmj.sagepub.com/content/early/2012/01/16/0269216311433476.abstract>

A call to the field: Complicated grief in the DSM-5

OMEGA – *JOURNAL OF DEATH & DYING*, 2012;65(4):251-155. While complicated grief has been addressed in part through some recommendations for modifications in the upcoming fifth version of the *Diagnostic & Statistical Manual of Mental Disorders* (DSM-5), there remain reasons for substantial concern about its scope therein and within clinical practice. Continued research is urged, and specific caveats are identified for exploring the complex dimensions of loss and grief. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,8;journal,1,259;linkingpublicationresults,1:300329,1>

Of related interest:

- *DEATH STUDIES*, 2012;36(9):771-794. 'Commentary on the inclusion of persistent complex bereavement-related disorder in DSM-5.' <http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.706982>
- *JOURNAL OF LOSS & TRAUMA: INTERNATIONAL PERSPECTIVES ON STRESS & COPING*, 2012;17(6):508-521. 'Posttraumatic stress disorder after bereavement: Early psychological sequelae of losing a close relative due to terminal cancer.' <http://www.tandfonline.com/doi/abs/10.1080/15325024.2012.665304>

N.B. Proposed changes to DSM-5 have been the focus of many articles, reports, etc. See Media Watch dated 30 July 2012 (p.7); 9 July 2012 (p.8); 13 February 2012 (pp.13,14); 2 January 2012 (p.7); 12 September 2011 (p.8); 22 August 2011 (p.9); 2 May 2011 (1); 4 April 2011 (p.8); 7 March 2011 (p.12); 7 February 2011 (p.8).

Media Watch Online

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

U.S.A.

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

Europe

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>

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

International

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

Changes over a decade in end-of-life care and transfers during the last 3 months of life: A repeated survey among proxies of deceased older people

PALLIATIVE MEDICINE | Published online – 17 September 2012 – Compared to 2000, in 2010 older people had a significantly lower functional ability 3 months before death. Over the 10-year period, people were significantly less likely to receive no care (12% vs. 39%) and more likely to receive formal home care (45% vs. 15%). Older people aged over 80 years, females, and those in the 2010 sample were more likely to receive formal home and institutional care than informal or no care. Regardless of the study year, older people receiving informal home

care were more likely to die in hospital. <http://pmj.sagepub.com/content/early/2012/09/07/0269216312457212.abstract>

Extract from the *Palliative Medicine* article

Two scenarios of care in the last 3 months of life seem to arise: staying at home as long as possible with a higher chance of hospital death or living in a residential or nursing home, reducing the chance of hospital death.

Of related interest:

- *INTERNAL MEDICINE JOURNAL*, 2012;42(9):1040-1042. **'Referral to specialist palliative care.'** Recent literature has suggested that earlier referral to palliative care can improve quality of life and prognosis. The decision to refer to palliative care is a complex process that can involve an interplay of interpersonal, subjective and institutional factors. Negotiating this referral process can be challenging to a medical specialist from a professional and personal viewpoint. What remains unknown is what actually influences the individual clinician to refer a patient to palliative care. <http://onlinelibrary.wiley.com/doi/10.1111/j.1445-5994.2012.02879.x/abstract>

Developing a pediatric pain service

PEDIATRIC ANESTHESIA, 2012;22(10):1016-1024. While many larger pediatric centers now have acute pain services, there remains a need for better pain management in facilities and geographic locations with fewer resources. Institutional acknowledgement and desire to change, appropriate staffing, and funding are major obstacles. Better recognition and assessment as well as safer and more efficacious treatment of pain are the principal objectives when establishing a pain service. It is important to determine whether the proposed service intends to treat acute, chronic, procedural, and/or cancer and palliative pain as each requires different skills and resources. An ideal and comprehensive pediatric pain service should be equipped to diagnose and treat acute, persistent (chronic), procedural, and cancer/palliative pain. It is not feasible or necessary for every hospital to manage all. Establishing the scope of practice (based on case mix and case-load) in any given hospital will determine which resources are desired. Country-specific standards, local staffing, and fiscal constraints will influence which resources are available. <http://onlinelibrary.wiley.com/doi/10.1111/pan.12004/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

End-of-life care with families of addiction

SOCIAL WORK TODAY, 2012;12(5):28. End-of-life care is never easy, but professionals must be aware of some distinct challenges facing families of addiction. No two families are alike when it comes to end-of-life care. And while every situation has its own challenges, end-of-life care can be further complicated by elements of past or current addiction within the family-under-care's unit. Whether it's the patient or a family member who has struggled with addiction, this fact changes the family dynamic and introduces some important considerations for the caregivers providing end-of-life treatment. While there are many variables in these situations, one fact remains constant: A family systems approach to end-of-life care is preferable, not only for families of addiction but for any end-of-life care situation. <http://www.socialworktoday.com/archive/091712p28.shtml>

Worth Repeating

What can people approaching death teach us about how to care?

PATIENT EDUCATION & COUNSELING, 2010;81(2):251-256. This study sought to hear what patients approaching death had to say about doctor-patient interactions and care in order that doctors can learn how to demonstrate care more effectively so that each patient feels cared for as an individual. Participants' recollections of experiences with doctors showed that genuine demonstration of care begins with doctors seeking common ground with the patient as a fellow human being and individual. The psychological and physical suffering that results from allowing stereotypical assumptions and behaviours to shape doctor-patient interaction was clear. The consequences of allowing the stereotypes and power of the primary context in which patients and doctors interact challenge the process of building a caring doctor-patient relationship. Caring doctors overcame this by exploring and carefully attending to the individual characteristics and needs of patients as people first and foremost. To demonstrate genuine care doctors must learn to recognise and question the social expectations and inherent assumptions of medical contexts and roles of patient and doctor and allow unique characteristics of patient and context to guide their interactions. [http://www.pec-journal.com/article/S0738-3991\(10\)00042-X/abstract](http://www.pec-journal.com/article/S0738-3991(10)00042-X/abstract)

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