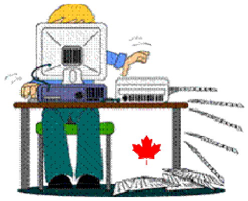
Media Watch...

is intended as an advocacy and research 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.*

4 February 2013 Edition | Issue #291



Compiled & Annotated by Barry R. Ashpole

Withholding or withdrawing life-sustaining treatment: Scroll down to Specialist Publications and 'A nationwide survey of end-of-life decisions and practices in critically ill patients in the cardiac intensive care unit' (p.12), in *The Thoracic & Cardiovascular Surgeon.*

U.S.A.

Grieving parent bill to be revived

WASHINGTON DC | Gannett Washington Bureau – 2 February 2013 – The landmark law, signed by then-President Bill Clinton on 5 February 1993, gives people up to 12 weeks of unpaid leave to care for a newborn or a sick parent, child or spouse. It also gives workers the right to take unpaid leave when they are seriously ill themselves. However, the law, which applies to companies with 50 employees or more, contains no provision for parents to take extended time off when a child dies. Many working parents are offered only a standard three days off to plan and attend a funeral. The Parental Bereavement Act of 2013 would expand the law to allow grieving parents to take unpaid leave for up to 12 weeks. The law defines children as minors under the age of 18. http://www.greatfallstribune.com/article/20130202/NEWS01/302020030/Grieving-parent-bill-revived

Specialist Publications

'Breaking down barriers: Hospice palliative care as a human right in Canada' (p.7), in *Educational Gerontology.*

'Cost-Effectiveness of Palliative Care: A review of the literature' (p.6), published by the Quality of End-of-Life Care Coalition of Canada.

'Integrating a Palliative Approach into the Management of Chronic, Life-Threatening Diseases: Who, How and When?' (p.8), published by the Quality of End-of-Life Care Coalition of Canada.

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

Advance directives

Bill would change end-of-life decisions

TEXAS | *The Austin-American Statesman* – 31 January 2013 – A bill to revise the Texas Advanced Directives Act of 1999, which regulates how and when doctors may allow patients to die by withholding life-sustaining treatment ... would improve notification and appeals processes for a patient's family and extend the time to find a provider willing to continue care from ten to fourteen days. http://www.statesman.com/news/news/state-regional-govt-politics/capitol-digest-bill-would-change-end-of-life-decis/nWCWH/

For some caregivers, the trauma lingers

THE NEW YORK TIMES | Online – 30 January 2013 – Recently, I spoke at length to a physician who seems to have suffered a form of post-traumatic stress after her mother's final illness. There is little research on this topic, which suggests that it is overlooked or discounted. But several experts acknowledge that psychological trauma of this sort does exist. Barry Jacobs, a clinical psychologist ... often sees caregivers who struggle with intrusive thoughts and memories months and even years after a loved one has died. "Many people find themselves unable to stop thinking about the suffering they witnessed, which is so powerfully seared into their brains that they cannot push it away," Dr. Jacobs said. Flashbacks are a symptom of post-traumatic stress disorder, along with feelings of numbness, anxiety, guilt, dread, depression, irritability, apathy, tension and more. Though one symptom or several do not prove that such a condition exists ... these issues are a "very common problem for caregivers," Dr. Jacobs said.http://newoldage.blogs.nytimes.com/2013/01/30/for-some-caregivers-the-trauma-lingers/?ref=health

Dying and death – and the news media

What it feels like to be photographed in a moment of grief

CONNECTICUT | National Public Radio – 28 January 2013 – On the night of the shootings in Newtown, Connecticut, a woman named Aline Marie attended a prayer vigil at St. Rose of Lima Roman Catholic Church, which was packed with local residents and the media. After about 45 minutes, Marie saw the statue of Mary and knelt down to pray. "I sat there in a moment of devastation with my hands in prayer pose asking for peace and healing in the hearts of men," she recalls. "I was having such a strong moment and my heart was open, and I started to cry." Her mood changed abruptly, she says, when "all of a sudden I hear 'click click click click click' all over the place. And there are people in the bushes, all around me, and they are photographing me, and now I'm pissed. I felt like a zoo animal." What particularly troubles her, she says, is "no one came up to me and said 'Hi, I'm from this paper and I took your photograph.' No one introduced themselves. I felt violated." http://www.npr.org/blogs/pictureshow/2013/01/28/169536213/what-it-feels-like-to-be-photographed-in-a-moment-of-grief

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | *Burlington Free Press* – 1 February 2013 – **'Doctor-assisted suicide measure backed by Vermont Senate committee.'** A Senate committee voted 5-0 for a bill that would allow doctors to prescribe a lethal dose of medication to terminally ill patients who request it, though the bill's future is far from certain. The vote in the Health & Welfare Committee was expected and will send the bill to the Senate Judiciary Committee, where it will have a less hearty reception. http://www.burlingtonfreepress.com/article/20130201/NEWS03/302010027/Doctor-assisted-suicide-measure-backed-by-Vermont-Senate-committee?odyssey=mod%7Cnewswell%7Ctext%7CFRONTPAGE%7Cp

Cont.

- OREGON PUBLIC HEALTH DIVISION | Online – 16 January 2013 – **'Oregon's Death with Dignity (DWDA) Act: 2012 Report.'** Prescriptions for lethal medications were written for 115 people during 2012 under the provisions of the Act, compared to 114 during 2011. There were 77 known DWDA deaths during 2012. Since the law was passed in 1997, 1,050 people have had DWDA prescriptions written and 673 patients have died from ingesting medications prescribed under the act. http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf

International

DNR orders

Legal clarity sought after Mulross report

IRELAND | *Leitrim Observer* (Carrick-on-Shannon) – 31 January 2013 – The shocking findings of the HIQA [Health Information & Quality Authority] report on Mulross Nursing Home, Kilclare, has prompted national calls for "legal clarity" on the issue of 'Do not Resuscitate' orders. Standing out among the large list of failings at the nursing home ... were the orders of 'Do not Resuscitate,' which had not been discussed with residents, their relatives or members of the multi-disciplinary team. The HIQA inspectors found no evidence of an assessment of the selected residents or communication of the order with the relevant parties. There was also no care plan in place for the residents under the 'Do not Resuscitate' order. http://www.leitrimobserver.ie/news/legal-clarity-sought-after-mulross-report-1-4735529

Specialist Publications

'Where 'DNR' spells danger' (p.10), in *Irish Medical Times*.

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.

Hospice perspective

Why the Liverpool Care Pathway can help if used in the right way

U.K. (ENGLAND | *This is Gloucestershire* (Leicester) – 28 January 2013 – A national audit of the Liverpool Care Pathway [LCP], suggests there are 57,000 patients a year dying in National Health Service [NHS] hospitals without being told that treatment has switched from curative to supportive and palliative care. Many of those negative experiences of the pathway are because decisions regarding care and treatment are not clearly communicated. Many staff feel ill-equipped to deliver bad news. They are concerned if they start these conversations they will be faced with questions to which they may not have the time, skills or expertise to answer. Just as a clinical skill can be learnt, so can the skills of good communication. The LCP evolved from the models of good care provided by hospices. It is a tool for NHS hospitals and care providers to help deliver care for those who are reaching the end of life. It is designed to be attentive to the needs of and relieve suffering in dying patients, to help provide a "good death." It should prompt health care professionals to have open discussions with relatives and, if possible, the patients, to allow them to talk about how they wish to be cared for and where they would like to die. It is about stopping unnecessary medication, to discontinue futile medical interventions, and to shift our focus of care to symptom control, comfort and dignity. The real issue is that those discussions with the patient and/or their relations appear not to be happening. Is it any wonder that the families are distraught? http://www.thisisgloucestershire.co.uk/Big-Issue-Liverpool-Care-Pathway-help-used-right/story-17984824-detail/story.html

Plan for end of life care branded "underhand"

U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) – 31 January 2013 – Lothian health bosses have been branded "sneaky" and "underhand" after it emerged that they had discussed "rebranding" controversial guidance for providing end of life care. http://www.scotsman.com/news/health/plan-for-end-of-life-care-branded-underhand-1-2768608

Specialist Publications

'The realities of the Liverpool Care Pathway' (p.10), in *Nature Reviews Clinical Oncology.*

Children's Hospice Association Scotland funding boost

U.K. (SCOTLAND) | *Dumbarton & Vale of Leven Reporter* (Clydebank) – 28 January 2013 – Scotland's council leaders agreed an historic deal with the Children's Hospice Association Scotland (CHAS) that will set up a National Funding Agreement between the Convention of Scottish Local Authorities (COSLA) and CHAS for the next two years. Maria McGill, CHAS chief executive, said: "Ever since CHAS first began providing care to children and young people 21 years ago, we have never been guaranteed funding from Scottish councils, until today. The agreement between CHAS and COSLA means that by working together with our local authority colleagues, we now have secured funding from every council across Scotland to help us provide our vital hospice care.http://www.dumbartonreporter.co.uk/news/roundup/articles/2013/01/28/444872-chas-funding-boost/

N.B. CHAS website: http://www.chas.org.uk/

Specialist Publications

'The case for home based telehealth in pediatric palliative care: A systematic review' (p.5), in *BMC Palliative Care.*

'Least said, soonest mended? Responses of primary school teachers to the perceived support needs of bereaved children' (p.9), in *Journal of Early Childhood Research.*

Cont.

Noted in Media Watch, 22 October 2012:

- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – **'The child's voice in pediatric palliative and end-of-life care.'** http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Telegraph* – 1 February 2013 – **'Assisted suicide: General Medical Council signals doctors safe to provide medical records to Dignitas patients.'** Doctors will be able to provide medical records to patients who want them to travel abroad for an assisted suicide without being struck off, new guidelines make clear for the first time. The Council said handing over records to patients who then use them to take their own life is "too distant" from encouraging a suicide to risk their fitness to practise being called into question. http://www.telegraph.co.uk/news/uknews/law-and-order/9840901/Assisted-suicide-GMC-signals-doctors-safe-to-provide-medical-records-to-Dignitas-patients.html

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

The case for home based telehealth in pediatric palliative care: A systematic review

BMC PALLIATIVE CARE | Online – 1 February 2013 – There were 33 studies that met the inclusion criteria of which only six were pediatric focussed. Outcome measures included effects on quality of life and anxiety, substitution of home visits, economic factors, barriers, feasibility, acceptability, satisfaction and readiness for telehealth. While studies generally identified benefits of using home telehealth in palliative care, the utilisation of home telehealth programs was limited by numerous challenges. Research in this area is challenging; ethical issues and logistical factors such as recruitment and attrition because of patient death make determining effectiveness of telehealth interventions difficult. Future research in home telehealth for the pediatric palliative care population should focus on the factors that influence acceptance of telehealth applications, including goals of care, access to alternative modes of care, perceived need for care, and comfort with using technology. http://www.biomedcentral.com/content/pdf/1472-684X-12-4.pdf

Palliative Care in Spain

Impact of a home-based social welfare program on care for palliative patients in the Basque Country

BMC PALLIATIVE CARE | Online – 31 January 2013 – SAIATU is a program of specially trained in-home social assistance and companionship which ... has provided support to end-of-life patients, enabling the delivery of better clinical care by healthcare professionals in Osakidetza, in the Autonomous Community of the Basque Country. This project represents a dramatic advance with respect to other studies conducted to date, and demonstrates how, through the provision of personnel trained to provide social care for patients in the advanced stages of illness, and through strengthening the co-ordination of such social services with existing healthcare system resources, the resulting holistic structure obtains cost savings within the health system and improves the efficiency of the system as a whole. http://www.biomedcentral.com/content/pdf/1472-684X-12-3.pdf

Can palliative care reduce futile treatment? A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 28 January 2013 – Palliative care interventions have the potential to lower health service costs by reducing the intensity of treatments intended to have curative effect while concentrating on quality of life and, in due course, quality of death. A patient receiving treatment inspired by curative intent during the end stage of their life is potentially exposed to medical futility. Of 1964 sources identified, only 12 measured both cost and an appropriate quality outcome. Evidence supported existing research that palliative care interventions generally reduce health service costs. Evidence of concurrent improvement in quality-of-life outcomes was limited; little available evidence derives from randomised trial designs. Small sample sizes and disparate outcome measures hamper statistical assessments.http://spcare.bmj.com/content/early/2013/01/28/bmjspcare-2012-000343.abstract

Extract from *BMJ Supportive & Palliative Care* article

Evidence that palliative interventions cut costs, without reducing quality of life, by minimising futile medical acts is limited. Further research, including both observational studies and controlled trials, should be conducted to collect empirical data in this field.

Of related interest:

- *ANNALS OF INTERNAL MEDICINE*, 2013;173(2):93. **'Undertreatment improves, but overtreatment does not.'** http://archinte.jamanetwork.com/article.aspx?articleid=1485993
- QUALITY OF END-OF-LIFE CARE COALITION OF CANADA | Online – Accessed 30 January 2013 – **'Cost-Effectiveness of Palliative care: A review of the literature.'** The cost of caring for people during the last months of life consumes a disproportionate share of health care resources. Much of this cost is due to medical needs; however, for people with chronic life-limiting conditions, a substantive amount may be associated with inappropriate or unnecessary curative interventions. http://www.hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf

Open communication with terminally ill cancer patients about illness and death: A comparison between spouses of Ashkenazi and Sephardi ethnic origins

CANCER NURSING | Online – 23 January 2013 – This study compares the level of open communication between caregivers from two ethnic groups and examines the contribution of different caregiver characteristics and situational variables to the explanation of open communication. Spouses of Ashkenazi origin communicated more with their loved ones about illness and death compared with their Sephardi counterparts. These findings demonstrate the importance of ethnic origin to caregivers' open communication with terminal cancer patients about illness and death. Moreover, communication level with patients is mostly explained by the caregiver characteristics. http://journals.lww.com/cancernursingonline/Abstract/publishahead/Open_Communication_With_Terminally_Ill_Cancer.99650.aspx

Extract from *Cancer Nursing* article

Studies document that caregivers face severe difficulties in communicating with their loved ones about both illness and death. To date, a paucity of studies has examined caregiver-patient communication at the end of life within the context of ethnic origin.

Noted In Media Watch, 29 October 2012:

- *JOURNAL OF SUPPORTIVE ONCOLOGY* | Online – 22 October 2012 – **'Initiating palliative care conversations: Lessons from Jewish bioethics.'** The authors suggest a general ethical duty to inform patients of the different care options, especially in a manner that preserves hope. http://www.sciencedirect.com/science/article/pii/S154467941200170X

Cont.

Noted in Media Watch, 23 April 2012:

- *NEW JERSEY JEWISH STANDARD* | Online – 20 April 2012 – **'How Judaism differs in life-death issues.'** http://www.jstandard.com/content/item/how_judaism_differs_in_life-death_issues/22840

The building bridges initiative: Learning with, from and about to create an inter-professional end-of-life program

DYNAMICS, 2012;23(4):37-41. The authors outline the rationale, planning, delivery, results, evaluation and knowledge transfer strategies employed in offering an eight-hour education day offered 12 times in 2010, to 200 staff in three Toronto General Hospital ICU at the University Health Network. The integration of members from the point-of-care staff teams into the planning, development, presentation and attendance was a critical success factor for this initiative. Organizers and participants had the opportunity to build bridges with each other and across teams and programs by engaging in inter-professional learning, sharing narratives and consolidating increasing awareness of resources with facilitation from staff from nursing, medicine, palliative care, bioethics, social work, physiotherapy, respiratory therapy, wellness and spiritual care. http://www.caccn.ca/en/members/login.html?first_exit

Update in hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 January 2013 – This update summarizes and critiques articles published in 2011 that have the highest potential for impact on clinical practice. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0481

Breaking down barriers: Hospice palliative care as a human right in Canada

EDUCATIONAL GERONTOLOGY, 2013;39(4):241-249.The need to attend to terminally ill persons and provide improved quality of living and dying should be a national priority in Canada. Hospice palliative care (HPC), a person-centered approach that addresses the needs of the whole person, improves the quality of living and dying of persons facing a life-threatening illness. To ensure Canadians are able to benefit from HPC, the authors propose that it should be enshrined as a human right in Canada with access guaranteed to all terminally ill persons under the Canada Health Act (CHA). This paper describes numerous barriers that currently exist including, but not limited to, barriers from geographic location, prognosis, ageism, and constraints from the Canadian medical system that have resulted in unequal access to of a patchwork of services. This paper proposes if HPC is formally recognized as a human right, then financial allocation specifically for HPC will require provincial governments to address the substantial inequalities in access to HPC. http://www.tandfonline.com/doi/abs/10.1080/03601277.2013.750930

Noted in Media Watch, 26 September 2011:

- *MCGILL JOURNAL OF LAW & HEALTH*, 2011;5(1):106-160. **'Palliative care: An enforceable Canadian human right?'** This article lays out a series of approaches for establishing an enforceable human right to palliative care in Canada. http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V.,%20No.%201%20-%20Shariff.pdf

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 January 2013 – **'Acknowledging palliative care as a human right.'** Access to palliative care has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0394

Cont.

- *NATURE REVIEWS CLINICAL ONCOLOGY*, 2013;10(2);80-89. **'Palliative care reduces morbidity and mortality in cancer.'** A growing body of evidence supports the integration of palliative care into routine cancer care, owing to the benefits in symptom control, quality of life, patient satisfaction, and resource utilization. Palliative care can be delivered in inpatient, outpatient, and home-based settings. http://www.nature.com/nrclinonc/journal/v10/n2/abs/nrclinonc.2012.211.html

- QUALITY OF END-OF-LIFE CARE COALITION OF CANADA | Online – Accessed 30 January 2013 – **'Integrating a Palliative Approach into the Management of Chronic, Life-Threatening Diseases: Who, How and When?'** Medical advances mean that many people will live many years with chronic, life-threatening illnesses. Most will eventually die of these diseases and should have the right and support to make informed decisions about their care at the end-of-life. Rather than dimming people's hope, frank discussions about the prognosis and trajectory of these illnesses can help people enhance their quality of both living and dying... http://www.hpcintegration.ca/media/24374/Integrating%20a%20palliative%20approach%20-%20Who,%20How%20and%20When%20EN%20Final.pdf

End-of-life care in Europe

Palliative Care for People with Learning Disabilities Network

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(1):48-50. The way palliative care services are integrated within intellectual disability services, and the readiness of palliative services to provide good care for patients who have intellectual disabilities, will be different in every country. How people with intellectual disabilities are supported at the end of life is dependent on the place people with intellectual disabilities have in society and their level of integration; on the training and attitudes of those who provide care for people with intellectual disabilities; and on the availability of palliative care services for the general population In the U.K., there is a strong emphasis on involving people with intellectual disabilities in all aspects of their lives, and that includes end-of-life care. The Palliative Care for People with Learning Disabilities [PCPLD] Network has undoubtedly played a part in bringing professionals from diverse backgrounds together, and in helping those working with people with intellectual disabilities at the end of life to feel less isolated. http://www.eapcnet.eu/LinkClick.aspx?fileticket=8PIz1FAom1k%3d&tabid=1622

N.B. PCPLD Network website: http://www.pcpld.org/

Noted in Media Watch, 26 November 2012:

- *AMERICAN JOURNAL ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2012; 117(6):509-532. **'Unique and universal barriers: Hospice care for aging adults with intellectual disability.'** http://www.aaiddjournals.org/doi/abs/10.1352/1944-7558-117.6.509

Early palliative care in advanced lung cancer: A qualitative study

JAMA INTERNAL MEDICINE | Online – 28 January 2013 – Early ambulatory palliative care (PC) is an emerging practice, and its key elements have not been defined. The authors conducted a qualitative analysis of data from a randomized controlled trial that demonstrated improved quality of life, mood, and survival in patients with newly diagnosed metastatic non-small cell lung cancer who received early PC integrated with standard oncologic care versus standard oncologic care alone. Addressing symptoms and coping were the most prevalent components of the PC clinic visits. Initial visits focused on building relationships and rapport with patients and their families and on illness understanding, including prognostic awareness. Discussions about resuscitation preferences and hospice predominantly occurred during later visits. Comparing PC and oncologic care visits around critical time points, both included discussions about symptoms and illness status; however, PC visits emphasized psychosocial elements, such as coping, whereas oncologic care visits focused on cancer treatment and management of medical complications. http://archinte.jamanetwork.com/article.aspx?articleid=1566605

Cont.

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 28 January 2013 – **'Living with advanced cancer and an uncertain disease trajectory: An emerging patient population in palliative care?'** http://spcare.bmj.com/content/early/2013/01/28/bmjspcare-2012-000381.abstract

Least said, soonest mended? Responses of primary school teachers to the perceived support needs of bereaved children

JOURNAL OF EARLY CHILDHOOD RESEARCH | Online – 28 January 2013 – Every 22 minutes in the U.K., a child is bereaved of a parent, making up some 24,000 a year. An even greater number experience the loss of a grandparent. There is a limited, but growing, body of research into the impact of grief and bereavement on young children and how their support needs might be met. This article expands upon research with primary school teachers articulating something of their knowledge and experience in encountering bereaved children. The mixed methodology research includes quantitative and qualitative data that incorporate teachers' responses to the fictionalised narrative of a bereaved 6-year-old. The discussion elucidates teachers' confidence – or reluctance – in broaching the topic, highlighting the lack of specific training within teacher education for understanding and supporting bereaved children. Compassionate understanding is offered to some children, but many others detect a wall of silence, which, when encountered in early childhood, can have detrimental consequences for their personal, social and academic development. The article calls for policy and practice that will ameliorate this situation. http://ecr.sagepub.com/content/early/2013/01/25/1476718X12466201.abstract

Supporting and promoting palliative care for older people

JOURNAL OF HEALTH VISITING, 2013;1(1):27-30. Most health visiting roles prioritise the health and wellbeing of families and children, the care of older people is no longer a policy focus. However, when an older person faces a life limiting condition, the whole family should be the focus of care and support. Health visitors can have a key role here as part of a multidisciplinary team, by providing family care and support, providing information, using their communication skills, and in preventive care. Health visitors can contribute to enabling care for older people who are dying through this family-focused lens of care. http://www.journalofhealthvisiting.com/cgi-bin/go.pl/library/abstract.html?uid=96336

Honouring the donor: In death and in life

JOURNAL OF MEDICAL ETHICS | Online – 26 January 2013 – Elective ventilation (EV) is ventilation – not to save a patient's life, but with the expectation that s/he will die – in the hope that organs can be retrieved in the best possible state. The arguments for doing such a thing rest on the value of the lives being saved by the donated organs, maximally honouring the donor's wishes where the patient can be reasonably thought to wish to donate, and a general principle in favour of organ donation where possible as an expression of human solidarity. Arguments against include difficulties surrounding the patient's consent to donation, the possibility of changing our perception of organ donation and care in dying, and the moral distress potentially caused to intensive care unit (ICU) staff involved in EV. EV can occur before or after the patient is declared dead and it is EV before the declaration of death (EVb) that occasions the ethical worries. http://jme.bmj.com/content/early/2013/01/25/medethics-2012-101159.abstract

Noted in Media Watch, 9 July 2012:

- *END OF LIFE JOURNAL*, 2012;2(2). **'The barriers to organ and tissue donation in palliative care.'** http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care

Do not resuscitate: The court's policy role in life and death

LEXOLOGY | Online – 31 January 2013 – Shortly before Christmas the [U.K.] High Court stopped the high profile judicial review proceedings in the case of *R(Tracey) v Cambridge University Hospitals NHS Trust & Secretary of State for Health*. The Claimant, Mr. Tracey, had brought a judicial review challenge to the use of 'Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR) orders in the medical records of patients at Addenbrookes Hospital. It was said by the Claimant and his family that two DNACPRs had been imposed on his late wife's medical records without consultation with the deceased or her family and, without their consent... The Hospital ... contended that the Claimant was wrong both on the facts surrounding the placement of the DNACPRs and on the law. The Claimant had also claimed against the Secretary of State for Health on the basis that the failure to have in place adequate national guidelines for the use of DNACPR notices was unlawful in public law and HRA terms. In the event of a dispute as to the appropriate course of treatment of a person without mental capacity the court's declaration can be sought to determine what is in the "best interests" of the patient. This judicio-clinical role relates though to a closely defined set of circumstances. However in number of high profile cases over the past decade enterprising Claimants have sought ... to expand the role of the court into a broader category of clinical and even moral decision making. http://www.lexology.com/library/detail.aspx?g=78fd7451-b7ed-463c-b1f8-4773a161b6d1

Where 'DNR' spells danger

IRISH MEDICAL TIMES | OpEd – 1 February 2013 – More often to do with social care rather than health care ... [Health Information & Quality Authority (HIQA)] ... reports are, however, of greater interest ... when medical practice is at issue, as seems to have been the case at Mullross Nursing Home in Carrick on Shannon... HIQA found that 'Do Not Resuscitate' orders were included in the files, but that there was no evidence available that the provider had ensured that this had been discussed with the resident or their relatives or members of the multidisciplinary team. http://www.imt.ie/opinion/2013/02/where-dnr-spells-danger.html

Noted in Media Watch, 24 December 2012:

- U.K. | *The Guardian* – 21 December 2012 – **'Court blocks judicial review over 'do not resuscitate' orders.'** http://www.guardian.co.uk/society/2012/dec/21/court-blocks-judicial-review-dnr

The realities of The Liverpool Care Pathway

NATURE REVIEWS CLINICAL ONCOLOGY, 2013;10(2);61-62. The Liverpool Care Pathway ... was constructed because it was recognized at the time that there were centres of excellence in end-of-life care, but that not all people treating patients at this critical stage had the training to provide optimal care. The aim of the pathway is to enable patients to spend their last days as dignified and pain-free as possible. To that end, the pathway has gone through various updates by the Marie Curie Palliative Care Institute since it was first drawn up, and emphasizes training: "a robust continuous learning and teaching programme must underpin the implementation and dissemination of the Liverpool care pathway generic document." The pathway requires a thorough clinical assessment by a trained multidisciplinary team to determine whether a patient is in the last days or hours of life. Once this conclusion has been reached, the pathway requires a clear communication of the finding to the patient (if possible) and to the family and/or carers. To assist this discussion, leaflets and documentation have been produced that are intended to convey this important information in as clear and concise a way as possible. However, a report that was picked up by the U.K. press in late 2012, has highlighted that half of patients on the pathway were not aware that they had been placed on it, indicating that communication is a primary issue. http://www.nature.com/nrclinonc/journal/v10/n2/full/nrclinonc.2013.3.html

How death anxiety impacts nurses' caring for patients at the end of life: A review of literature

OPEN NURSING JOURNAL | Online – 24 January 2013 – This paper explores the literature on death anxiety and nurses' attitudes to determine whether fear of death impacts on nurses' caring for dying patients. Three key themes identified were: 1) nurses' level of death anxiety; 2) death anxiety and attitudes towards caring for the dying; and, 3) death education was necessary for such emotional work. Results suggested that the level of death anxiety of nurses working in hospitals in general, oncology, renal, hospice care or in community services was not high. Some studies showed an inverse association between nurses' attitude towards death and their attitude towards caring for dying patients. Younger nurses consistently reported stronger fear of death and more negative attitudes towards end-of-life patient care. Nurses need to be aware of their own beliefs. Studies from several countries showed that a worksite death education program could reduce death anxiety. http://www.benthamscience.com/open/tonursj/openaccess2.htm

Of related interest:

- *CANCER NURSING* | Online – 25 January 2013 – **'The Swedish version of the Frommelt Attitude Toward Care of the Dying Scale: Aspects of validity and factors influencing nurses' and nursing students' attitudes.'** Care culture might influence nurses' attitudes toward caring for dying patients; the benefits of education need to be explored. http://journals.lww.com/cancernursingonline/Abstract/publishahead/The_Swedish_Version_of_the_Frommelt_Attitude.99639.aspx

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'Palliative Care Network: Media Watch'')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: http://www1.petermac.org/apli/links.htm (Scroll down to 'Links,' then to 'Media Watch')

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.hpcconnection.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

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

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

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

Withholding or withdrawing life-sustaining treatment

A nationwide survey of end-of-life decisions and practices in critically ill patients in the cardiac intensive care unit

THE THORACIC & CARDIOVASCULAR SURGEON, 2012;61(1). Concerning medical reasons cranial computed tomography with poor prognosis, multi-organ failure, and failure of assist device therapy were the three most frequently cited medical reasons [by participating health professionals] to WH/WD [withholding/withdrawing] life-sustaining treatment. Overall, 32.6% answered that ethical aspects influence their decision-making process. Poor expected quality of life, the patient's willingness to limit medical care, and the families' choice were the top three reported ethical reasons. Information on the medical and ethical parameters determining the decision of withholding and/or withdrawal of life support in cardiac surgery patients is lacking. Therefore, this survey contributes in creating standards of end-of-life care in heart surgery ICUs. This supports to build consensus and avoid conflicts among caregivers, patients and families at each step of the decision-making process. https://www.thieme-connect.com/ejournals/abstract/10.1055/s-0032-1332304

"It hurts to know…and it helps": Exploring how surrogates in the ICU cope with prognostic information

JOURNAL OF PALLIATIVE MEDICINE | Online – 31 January 2013 –Surrogates experience a tension between wanting to know what to expect and needing to remain hopeful. This underlies their experience receiving prognostic information and may lead to behaviors that allow continued hope in the face of bad news, including: 1) focusing on small details rather than the big picture; 2) relying on gut instincts or personal beliefs about the patient; 3) seeking more positive prognostic information from other sources, and, for a minority; 4) avoiding or disbelieving prognostic information. Surrogates emphasize the importance of frequent communication and call on physicians to gently help them prepare for the worst and hope for the best.http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0331

Of related interest:

PALLIATIVE MEDICINE | Online – 1 February 2013 – **'Disconnect between emergency contacts and surrogate decision-makers in the absence of advance …'**http://pmj.sagepub.com/content/early/2013/01/29/0269216312474486.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HEC [HEALTHCARE ETHICS COMMITTEE] FORUM* | Online – Accessed 29 January 2013 – **'Voluntary euthanasia, physician-assisted suicide, and the right to do wrong.'** It has been argued that voluntary euthanasia (VE) and physician-assisted suicide (PAS) are morally wrong. Yet, a gravely suffering patient might insist that he has a moral right to the procedures even if they were morally wrong. There are also philosophers who maintain that an agent can have a moral right to do something that is morally wrong. In this article, the author assesses the view that a suffering patient can have a moral right to VE and PAS despite the moral wrongness of the procedures in light of the main argument for a moral right to do wrong found in recent philosophical literature. The author maintains that the argument does not provide adequate support for such a right to VE and PAS. http://link.springer.com/article/10.1007/s10730-013-9208-2

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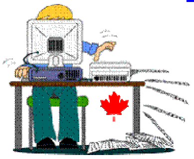

Barry R. Ashpole

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

- *JOURNAL OF MEDICAL ETHICS* | Online – 2 February 2013 – **'Attitudes toward euthanasia and physician-assisted suicide: A study of the multivariate effects of healthcare training, patient characteristics, religion and locus of control.'** Public and healthcare professionals differ in their attitudes towards euthanasia and physician-assisted suicide, the legal status of which is currently in the spotlight in the U.K. In addition to medical training and experience, religiosity, locus of control and patient characteristics (e.g., patient age, pain levels, number of euthanasia requests) are known influencing factors. Previous research tends toward basic designs reporting on attitudes in the context of just one or two potentially influencing factors; The authors aimed to test the comparative importance of a larger range of variables in a sample of nursing trainees and non-nursing controls. http://jme.bmj.com/content/early/2013/02/01/medethics-2012-100729.abstract
- *PROGRESS IN PALLIATIVE CARE* | Online – 29 January 2013 – **'Palliative care ethics: The problems of combining palliation and assisted dying.'** The performing of euthanasia is now offered as an option by certain palliative care service institutions in Belgium. Although it is understandable that some physicians are in favour of it, the model is rejected in this article, for both clinical and ethical reasons. Furthermore, the idea of "palliative futility" associated with the model is shown to be incoherent. In countries where assisted dying is legal, palliative care providers should refrain from participating in such practices if they are to remain true to the basic values of such care. The widespread conception that withholding and withdrawing treatment amounts to a "hastening" of death is also rejected. http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000040

Worth Repeating

Music therapy with imminently dying hospice patients and their families: Facilitating release near the time of death

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2003;20(2):129-134. Hospice care seeks to address the diverse needs of terminally ill patients in a number of physical, psychosocial, and spiritual areas. Family members of the patient often are included in the care and services provided by the hospice team, and hospice clinicians face a special challenge when working with families of patients who are imminently dying. When loved ones are anticipating the patient's impending death, they may find it difficult to express feelings, thoughts, and last wishes. Music therapy is a service modality that can help to facilitate such communication between the family and the patient who is actively dying, while also providing a comforting presence. Music therapy as a way to ease communication and sharing between dying patients and their loved ones is discussed in this article. The ways in which music therapy can facilitate a means of release for both patients and family members in an acute care unit of a large U.S. hospice organization are specifically described. Case descriptions illustrate how music therapy functioned to allow five patients and their families to both come together and let go near the time of death. Elements to consider when providing such services to imminently dying patients and their families are discussed. http://ajh.sagepub.com/content/20/2/129.short

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