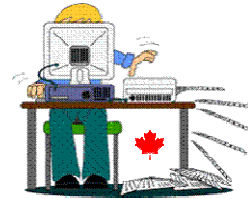


## Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Nursing practice, policy, and research: Scroll down to [Specialist Publications](#) and 'Relational experiences of family caregivers providing home-based end-of-life care' (p.8), in *Journal of Family Nursing*.

## Canada

### Dying woman allowed to keep medical equipment, but care will be cut

ONTARIO | *Toronto Star* – 3 October 2012 – Doris Landry, the 84-year-old who outlived funding for the 'Home First' program, will keep the medical equipment, but will not receive the same amount of care from personal support workers. *The Star* highlighted the story of Landry,<sup>1</sup> a woman who was given a life expectancy of one or two months when she was discharged from hospital into the 'Home First' programming offered by the Central CCAC [Community Care Access Centre] and Central LHIN [Local Health Integration Network]. Landry had been given medical equipment and eight hours of daily care from a personal support worker in her niece's home. <http://www.thestar.com/news/gta/article/1266338--dying-woman-allowed-to-keep-medical-equipment-but-care-will-be-cut>

1. 'Dying woman outlives her 90 days of home care so Community Care Access Centre cuts her services,' *Toronto Star*, 29 September 2012 (noted in Media Watch, 1 October 2012). <http://www.thestar.com/news/gta/article/1264425--dying-woman-outlives-her-90-days-of-home-care-so-ccac-cuts-her-services>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Globe & Mail* – 5 October 2012 – '**Assisted suicide activist Gloria Taylor dies from infection.**' Ms. Taylor, the British Columbia woman who was the lead plaintiff in a lawsuit that challenged laws against physician-assisted deaths, died unexpectedly of an infection resulting from a perforated colon. In June, the B.C. Supreme Court ruled that physician-assisted deaths are protected by the Charter of Rights & Freedoms, and granted Ms. Taylor a personal exemption that would have allowed her the right to seek a physician-assisted death. The federal government appealed that decision, as well as the exemption that applied to Ms. Taylor. The B.C. Court of Appeal in August upheld that exemption. The lawsuit is now headed for the B.C. Court of Appeal and a hearing is scheduled for March 2013. <http://www.theglobeandmail.com/news/british-columbia/assisted-suicide-activist-gloria-taylor-dies-from-infection/article4593512/>

Cont.

- QUÉBEC | CJAD Radio (Montreal) – 5 October 2012 – '**Quebec to legalize doctor-assisted suicide.**' Quebec's new government plans to table legislation legalizing doctor-assisted suicide by this spring. "We really feel that it is necessary to put forward such a possibility for people who, at the end of their life, are suffering in an unbearable manner," says social services junior minister Véronique Hivon. She says the idea was part of the Parti Québécois' election platform, and was also recommended by an all-party National Assembly committee last spring.<sup>1,2</sup> She says her bill will be based on that committee's report. It's guidelines said patients should only have access to the service if they are adult Quebec residents with a serious and incurable illness, and have given their express written consent. <http://www.cjad.com/CJADLocalNews/entry.aspx?BlogEntryID=10446337>
1. 'La Commission spéciale sur la question de mourir dans la dignité dépose son rapport,' Commission spéciale, Assemblée nationale du Québec (French language edition, noted in Media Watch, 26 March 2012):[http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller\\_120323\\_soins-palliatifs/?lang=en](http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en)
  2. 'Dying with Dignity,' Select Committee, National Assembly of Quebec (English language edition, noted in Media Watch, 27 August 2012):  
[http://www.worldtrd.net/sites/default/files/newsfiles/Quebec\\_Report%20in%20English.pdf](http://www.worldtrd.net/sites/default/files/newsfiles/Quebec_Report%20in%20English.pdf)

## U.S.A.

### **Do seniors turn to the right places at end of life?**

REUTERS | Online report – 1 October 2012 – A new study says almost one third of Medicare's beneficiaries use the program to pay for end-of-life care at nursing homes, which may not be equipped to treat or prevent pain and suffering.<sup>1</sup> Those palliative care services are usually associated with hospice care, while nursing homes are typically for rehabilitation and long-term care. The study's researchers ... say the findings suggest that palliative or hospice care should be incorporated into Medicare's nursing home benefits. "Often our focus on these patients is trying to keep them functional or independent for as long as we can. What we may be overlooking is that they are on an end-of-life trajectory," said Dr. Katherine Aragon, the study's lead author from Lawrence General Hospital in Massachusetts. Medicare, the federal health insurance program for the elderly and disabled, pays for 100 days of skilled nursing facility care after a person is hospitalized for at least three days. Under those benefits, the program pays 100% of the bill for the first 20 days of care, and all but a \$144.50 per day copayment after that. That may be less expensive for patients and their families than using Medicare's hospice benefits, which does not pay for room and board. Patients need to pay for that out of pocket, through additional insurance or Medicaid - for which many may not qualify. <http://www.reuters.com/article/2012/10/01/us-do-seniors-turn-to-the-right-places-a-idUSBRE8901B520121001>

1. 'Use of the Medicare post-hospitalization skilled nursing benefit in the last 6 months of life,' *Archives of Internal Medicine*, published online 1 October 2012.  
<http://archinte.jamanetwork.com/article.aspx?articleid=1368358>

Comment on *Archives of Internal Medicine* article:

- 'Aligning prognosis, patient goals, policy, and care models for palliative care in nursing homes,' published online 1 October 2012. <http://archinte.jamanetwork.com/article.aspx?articleid=1368352>

### **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>

## Family caregivers providing more complex senior care to avoid nursing homes

*SENIOR HOUSING NEWS* | Online report – 1 October 2012 – The market for potential assisted living or skilled nursing facility residents is being depleted by family caregivers who are taking on more and more senior care responsibilities, including medical and nursing tasks once only provided in hospitals, according to a new American Association for Retired Person [AARP] report.<sup>1</sup> The level of care that non-professional caregivers are providing has grown increasingly complex to include services that are commonly found not just in assisted living communities but also in nursing homes. Almost half of family caregivers (46%) performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions, the AARP Public Policy Institute and United Hospital Fund survey revealed. <http://seniorhousingnews.com/2012/10/01/family-caregivers-providing-more-complex-senior-care-to-avoid-nursing-homes/>

1. 'Home Alone: Family Caregivers Providing Complex Chronic Care,' AARP, October 2012. [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.pdf)

Of related interest

- *AARP MAGAZINE* | Online report – 1 October 2012 – 'I'm a caregiver, but feel like a nurse!' Ask yourself: Are you suited for the medical jobs of family caregiving? <http://www.aarp.org/home-family/caregiving/info-09-2012/im-a-caregiver-but-feel-like-a-nurse.html>

### Doctor-patient communication

#### Access to doctors' notes aids patients' treatment

*WALL STREET JOURNAL* | Online report – 1 October 2012 – Patients who have access to doctor's notes in their medical records are more likely to understand their health issues, recall what the doctor told them and take their medications as prescribed, according to a study<sup>1</sup> ... the culmination of an experiment ... to improve doctor-patient communication by letting patients know everything their doctor has to say about them, including after a visit. While patients legally have the right to see their entire medical record, including doctor's notes, notes aren't automatically included in requests for records and doctors don't make it easy for patients to see them, says Tom Delbanco, primary-care doctor at Beth Israel Deaconess Medical Center, co-lead author of the study. [http://online.wsj.com/article/SB10000872396390443862604578030382214331320.html?mod=googlenews\\_wsj](http://online.wsj.com/article/SB10000872396390443862604578030382214331320.html?mod=googlenews_wsj)

1. 'Inviting patients to read their doctors' notes...' *Annals of Internal Medicine*, published online 1 October 2012. <http://annals.org/article.aspx?articleid=1363511>

### National Public Radio series

#### Death and dignity in the 21st Century

*WISCONSIN* | 89.7 Radio (Milwaukee) – 1 October 2012 – Stephanie Lecci looks at ethical and legal issues surrounding end-of-life care, caregiver stress, the importance of advanced directives, the growth of the palliative care movement and the difficulty in discussing death with children. [http://www.wuwm.com/news/series.php?page=le\\_deathandddying&series\\_tag=deathandddying](http://www.wuwm.com/news/series.php?page=le_deathandddying&series_tag=deathandddying)



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

October 13 2012

## International

### **Patients being treated 'like medical conditions, not people'**

U.K. | *The Telegraph* – 4 October 2012 – National Health Service patients are suffering poor care in hospitals because they are wrongly viewed by doctors and nurses as simply "medical conditions" to be dealt with rather than individual people, a Royal College warns.<sup>1</sup> Medical staff frequently have such little time to deal with them, that patients' full medical and emotional needs are not met, they say. The lack of time and attention paid to patients means that serious mistakes are being made, warn the Royal College of Physicians. Medication errors can result and sometimes very ill patients or their families are not being asked if the person wishes to be resuscitated, meaning in some cases that the terminally ill can end up receiving futile treatment. Patients are also being left in a high state of anxiety because

staff do not talk to them enough. The institution has joined forces with the Royal College of Nursing to publish new guidance today, urging hospitals to give the morning ward round the priority it deserves.

<http://www.telegraph.co.uk/health/healthnews/9585114/Patients-being-treated-like-medical-conditions-not-people.html>

#### **Extract from *Telegraph* report**

Medication errors can result and sometimes very ill patients or their families are not being asked if the person wishes to be resuscitated, meaning in some cases that the terminally ill can end up receiving futile treatment.

1. 'Ward rounds in medicine: Principles for best practice,' Royal College of Physicians & Royal College of Nursing, October 2012. <http://www.rcplondon.ac.uk/resources/ward-rounds-medicine-principles-best-practice>

### **Now, palliative care at your doorstep**

INDIA | *Times of India* (Thiruvananthapuram) – 2 October 2012 – Bed-ridden patients, who require medical care, can now avail it right at their homes. The city corporation launched its palliative care units in the capital as part of the World Elders' Day observance. The project, titled 'Santhwanam,' envisages cost-free, high-quality treatment for economically backward people suffering from severe ailments. <http://timesofindia.indiatimes.com/city/thiruvananthapuram/Now-palliative-care-at-your-doorstep/articleshow/16634551.cms>

## Population trends

### **UN warns over impact of rapidly ageing populations**

U.K. | BBC News – 1 October 2012 – The world needs to do more to prepare for the impact of a rapidly ageing population, the UN has warned - particularly in developing countries. Within 10 years the number of people aged over 60 will pass one billion, a report by the UN Population Fund said.<sup>1</sup> The demographic shift will present huge challenges to countries' welfare, pension and healthcare systems. The number of older people worldwide is growing faster than any other age group. The report ...estimates that one in nine people around the world are older than 60. The elderly population is expected to swell by 200 million in the next decade to surpass one billion, and reach two billion by 2050. This rising proportion of older people is a consequence of success - improved nutrition, sanitation, healthcare, education and economic well-being are contributing factors, the report says. <http://www.bbc.co.uk/news/world-19784509>

1. 'Ageing in the 21st Century: A Celebration and a Challenge,' UN Population Fund, October 2012. <http://unfpa.org/ageingreport/>

## Two doctors must agree to use of controversial 'death pathway' for patients in their final days

U.K. (ENGLAND & WALES) | *Daily Mail* – 1 October 2012 – No patient should be consigned to the controversial National Health Service process to help the dying in their final days without the involvement of at least two doctors, experts urged. They said the most senior staff available must be involved because 'it is not always easy to tell whether someone is very close to death.' The demand for the highest possible level of supervision of patients on the Liverpool Care Pathway follows allegations that the system is being used to kill off sick people before their time – effectively officially sanctioned euthanasia. Under the pathway, patients judged to be days or hours from death can be denied water or nutrition through a tube, may be heavily sedated, denied treatment that could prolong life and not given any unnecessary tests or treatment.

<http://www.dailymail.co.uk/news/article-2211484/Two-doctors-agree-use-controversial-death-pathway-patients-final-days.html>

Noted in Media Watch, 1 October 2012:

- *BMC RESEARCH NOTES* | Published online – 26 September 2012 – '**Why is the Liverpool Care Pathway used for some dying cancer patients and not others? Healthcare professionals' perspectives.**' <http://www.biomedcentral.com/content/pdf/1756-0500-5-524.pdf>
- U.K. | National Council for Palliative Care – 25 September 2012 – '**Consensus Statement: Liverpool Care Pathway for the Dying Patient.**' <http://www.ncpc.org.uk/sites/default/files/user/LCP%20Consensus%20Statement.pdf>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *Hindu Times* (Delhi) – 5 October 2012 – '**Passive euthanasia gets law panel push.**' The Law Commission has made a recommendation to the government to initiate measures to enact a comprehensive law on passive euthanasia, subject to certain safeguards. "It's not objectionable from a legal and constitutional point of view," the commission, which advises the government on legal issues, said. <http://www.hindustantimes.com/India-news/NewDelhi/Passive-euthanasia-gets-law-panel-push/Article1-940002.aspx>
- SWITZERLAND | Worldwide Radio Switzerland – 4 October 2012 – '**Study: Assisted suicide helpers distressed.**' One in four people who accompany someone to commit assisted suicide suffer massive psychological distress, according to a new study by the University of Zurich.<sup>1</sup> Researchers at the university spoke to 85 people who went with a family member or close friend to an EXIT euthanasia clinic. A quarter suffered from post traumatic stress disorder while 16% had depression. Five percent were found to have long-term grief. The interviews were carried out one to two years after the assisted death of loved ones. The results state that problems can surface 14 to 24 months later and that a death not from natural causes was a heavy burden for those who supported the deceased. <http://worldradio.ch/wrs/news/wrsnews/study-assisted-suicide-helpers-distressed.shtml?32735>
  1. 'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide,' *European Psychiatry*, 2012;27(7):542-546. <http://www.sciencedirect.com/science/article/pii/S0924933810002683>
- U.K. | BBC News – 1 October 2012 – '**Tony Nicklinson right-to-die refused Court of Appeal hearing.**' High Court judges have refused permission for the case of a man who fought for the right to die to go to the Court of Appeal. <http://www.bbc.co.uk/news/uk-england-wiltshire-19797634>

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

### Systemic change

#### **A mirror in which to practice – using action learning to change end-of-life care**

*ACTION LEARNING: RESEARCH & PRACTICE* | Published online – 26 September 2012 – While action learning is a familiar tenet of much management and leadership development activity within the NHS [National Health Service] it is not commonly utilised within the education and development of doctors where didactic methods remain the preferred mechanism to impart factual knowledge necessary to fulfil the autonomous practitioner role. Within the specialism of palliative medicine, the implementation of a national end-of-life (EoL) care strategy will challenge this prediction. The new strategy seeks to enable more people to die in the place of their choosing as such it requires clinicians outside the speciality of palliative care to make it a routine part of their practice. Since doctors are trained to cure or extend life, the strategy requires specialists to change their practice, behaviour and communication to engage the patient and family in decision-making and planning for the EoL. An intensive development programme utilising action learning methods is currently being piloted in two acute hospital settings to equip a small group of specialist senior clinicians to deliver the required changes. This paper describes the use of action learning within this context to explore its utility with an uninitiated and sceptical audience.

<http://www.tandfonline.com/doi/abs/10.1080/14767333.2012.722361>

#### **How to design and implement palliative care public health programmes: Foundation measures. An operational paper by the WHO Collaborating Centre for Public Health Palliative Care Programmes at the Catalan Institute of Oncology**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Published online – 4 October 2012 – The authors describe the elements of a programme (leadership and aims; needs and context assessment; definition of the target patients; general measures in conventional services; specialist services in different settings; sectorised networks; education and training; availability and accessibility of opioids and essential drugs; legislation; standards; budget; valuation and improvement of quality; and evaluation of results and indicators) and the specific recommendations to implement the first steps of each component. Palliative care planning needs to be systematic, inserted in all levels of the healthcare system and adapted to the cultural and organisational status of the system.  
<http://spcare.bmj.com/content/early/2012/10/04/bmjspcare-2012-000215.abstract>

#### **Psychosocial care in cancer: An overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies**

*PSYCHO-ONCOLOGY*, 2012;21(10):1027-1033. The value of the current survey ... lies with the fact it is the first to report on the current status of psychosocial care for cancer patients and their families from a global perspective. Results indicate that while psychosocial oncology has grown over the last decade, it is either not established or not completely established, or not an integral part of care in some countries, especially developing countries, where basic care is sometimes not provided to cancer patients.

<http://onlinelibrary.wiley.com/doi/10.1002/pon.3154/abstract>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Published online – 5 October 2012 – '**Specialists' experiences and perspectives on the timing of referral to palliative care: A qualitative study.**' Significant barriers exist to the timely referral to palliative care, and, in order to improve patient and care quality of life and lessen clinical difficulties, further work is needed to develop streamlined practices that are sensitive to specialty needs and patient desires.  
<http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0264>

Cont.

- *MEDICAL NEWS TODAY* | Online report – 2 October 2012 – '**Landmark survey reveals governments failing to address pandemic of global untreated cancer pain.**' Governments around the world are leaving hundreds of millions of cancer patients to suffer needlessly because of their failure to ensure adequate access to pain-relieving drugs, an unprecedented new international survey reveals. <http://www.medicalnewstoday.com/releases/250892.php>

### **Advance care planning and interpersonal relationships: A two-way street**

*FAMILY PRACTICE* | Published online – 1 October 2012 – [In this study] ACP was seen as having both positive and negative impacts on interpersonal relationships. It was thought to enhance family relationships, help resolve conflicts between families and health professionals and improve trust and understanding between patients and health professionals. Negatively, it could take the family's attention away from patient care. The link between ACP and interpersonal relationships was perceived to be bidirectional – the nature of interpersonal relationship that patients have with their families and health professionals has a profound impact on what form of ACP is likely to be useful. <http://fampra.oxfordjournals.org/content/early/2012/09/28/fampra.cms063.abstract>

### **End-of-life care and interprofessional communication: Not simply a matter of "more"**

*HEALTH & INTERPROFESSIONAL PRACTICE* | Published online – 24 September 2012 – Given the way in which ideologies and normative practices shape and contribute to ineffective communicative patterns, the findings [of this study] suggest that the issue is not only how much communication is happening, but the nature of that communication. Thus, addressing the conflicting and/or competing messages, goals, or processes shaping the flow and processes of communication within the interprofessional team is necessary. In particular, explicitly addressing the complex interplay between autonomous professional practice and interprofessional team collaboration is a crucial step in supporting more effective communication and team cohesion. <http://commons.pacificu.edu/hip/vol1/iss3/5/>

Of related interest:

- *ANNALS OF ONCOLOGY* | Published online – 1 October 2012 – '**Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians' and patients' estimates of survival.**' Multidisciplinary teams were better at predicting survival than doctors' or nurses' alone. Patients were substantially worse. Among nurses, recency of review was related to improved prognostic accuracy. <http://annonc.oxfordjournals.org/content/early/2012/09/29/annonc.mds341.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Published online – 2 October 2012 – '**An educational intervention to improve resident comfort with communication at the end of life.**' The curriculum impacted resident reports of comfort with specific topics in end-of-life care, including discussions of code status and comfort care. Furthermore, the authors found that this curriculum, although brief, demonstrated a small impact on resident reports of self-efficacy for communication. Their findings demonstrate the feasibility of incorporating end-of-life communication skills training into an existing internal medicine resident curriculum. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0173>
- *QUALITY HEALTH RESEARCH* | Published online – 3 October 2012 – '**Dancing around death: Hospitalist-patient communication about serious illness.**' Acknowledging or not acknowledging the possibility of dying emerged as a key process. Acknowledgment was rare, and depended on synergistic communication behaviors between patient and physician. Facilitators included patients cuing for information and disclosing emotional distress, and physicians exploring the patient's understanding of his or her illness and emotional distress. When hospitalists focused on acute issues, stated that they were awaiting test results, and deferred to other physicians, discussion moved away from acknowledgment. Meaningful discussion of end-of-life issues, including goals and values, fears about death and dying, prognosis, and options for palliative care followed open acknowledgment. <http://qhr.sagepub.com/content/early/2012/10/02/1049732312461728.abstract>

## **Understanding bereaved family members' dissatisfaction with end-of-life care in nursing homes**

*JOURNAL OF GERONTOLOGICAL NURSING* | Published online – 17 September 2012 – With increasing numbers of older adults identifying a nursing home as their final place of care, it is important to assess the quality of dying in this setting and understand factors that impact family members' dissatisfaction with end-of-life care. Bereaved family members [study participants] who were dissatisfied with care identified significantly more concerns in all domains assessed and were more likely to have problems with: a) receiving confusing information from nursing staff about the resident's care, including medical treatments; b) receiving inadequate information from nursing staff; and, c) feeling that end-of-life care was different than they had expected.

<http://www.healio.com/nursing/journals/JGN/%7B6B265CDE-23EE-4945-B5B5-120B27EC4603%7D/Understanding-Bereaved-Family-Members-Dissatisfaction-with-End-of-Life-Care-in-Nursing-Homes>

## **Continuous sedation until death: Mapping the literature by bibliometric analysis**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 1 October 2012 – Sedation at the end of life, regardless of the nomenclature, is an increasingly debated practice at both clinical and bioethical levels. However, little is known about the characteristics and trends in scientific publications in this field of study. This is the first bibliometric analysis on continuous sedation until death that can be used to inform future studies. Further research is needed to refine controversies on terminology and ethical acceptability of the practice, as well as conditions and modalities of its use. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00341-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00341-7/abstract)

## **Soins palliatifs à domicile: Évolutions et perspectives**

('Palliative care at home: Developments and perspectives')

*MÉDECINE PALLIATIVE: SOINS DE SUPPORT - ACCOMPAGNEMENT - ÉTHIQUE*, | Published online – 4 October 2012 – Home palliative care data remain little supported and/or disparate and constitute a brake analysis in perspective. A probative data however: to make access to palliative care at home a reality throughout the territory, a number of issues remain for years to come. For liberal professionals, the need to develop teamwork, training, support and closer ties with the hospital continues. The supply of graduates care (liberals, SSIAD, HAD) still presents differentiations according to the territories, requiring adapt supply to the needs of patients and reducing the Manager logic between these devices, with each mission of coordination. The refocusing of palliative care on the coordination and support networks should not obscure the clinical dimension that corresponds to one of the expectations of liberal professionals. The continuous training of these professionals must evolve to form together with the palliative approach. It unfolds slowly in social medical institutions, for which the support and companionship to the bed of the patient must continue and intensify. A company issues lies in the choices that will be made to support relatives accompanying the sick at home. Finally the development of palliative care to a significant medicalization in institutions could, if we take custody, modify the end of life even at home. <http://www.sciencedirect.com/science/article/pii/S1636652212001225>

Of related interest:

- *JOURNAL OF FAMILY NURSING* | Published online – 27 September 2012 – '**Relational experiences of family caregivers providing home-based end-of-life care.**' This article describes the provision of end-of-life care to older adults with advanced cancer from the perspective of family caregivers. Family caregiving in home-based end-of-life care was portrayed in this study as three dialectical relational care experiences: 1) prioritizing care recipient needs-ignoring own needs; 2) feeling connected-feeling isolated; and, 3) juggling to manage-struggling to survive. Study findings suggest that the socio-cultural context of end-of-life care is not conducive to quality care and provide several insights for future directions in nursing practice, policy, and research.

<http://jfn.sagepub.com/content/early/2012/09/27/1074840712462134.abstract>



## Préoccupations éthiques en médecine palliative pédiatrique

('Ethical challenges in pediatric palliative care medicine')

*MÉDECINE PALLIATIVE: SOINS DE SUPPORT - ACCOMPAGNEMENT - ÉTHIQUE*, | Published online – 26 September 2012 – This article examines the principal ethical concerns that have been identified in pediatric palliative care medicine. The recognized standard for determining treatment decisions for children, including palliative care, is the child's best interests. That is, the treatment option that offers the greatest proportion of benefits in relation to burdens should be regarded as the ethically optimal treatment choice for the child. Disagreements sometimes arise, because the benefits and burdens associated with treatment decisions are frequently valued differently by patients, parents, and health care professionals. Collaborative discussions can help resolve such disagreements. In North America and many Western European settings, the parents are considered the formal decision-makers for treatment decisions for children. In France, physicians are the recognized decision-makers for life-sustaining treatment decisions. Other issues discussed include: the interests of others; permissible palliative care measures for children; as well as tragedy and moral distress. Strategies are outlined for reconciling ethical concerns in pediatric palliative care. <http://www.sciencedirect.com/science/article/pii/S1636652212000839>

Of related interest:

- *NURSING OUTLOOK* | Published online – 1 October 2012 – '**Perinatal and pediatric issues in palliative and end-of-life care from the 2011 summit on compassionate care.**' <http://www.sciencedirect.com/science/article/pii/S0029655412002369>
- *VULNERABLE CHILDREN & YOUTH STUDIES* | Published online – 25 September 2012 – '**Primary caregivers' experiences living with children involved in pediatric palliative care in New Zealand.**' <http://www.tandfonline.com/doi/abs/10.1080/17450128.2012.720396>

## Quels pères face au refus de soins... en fin de vie ?

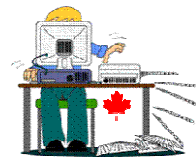
('Refusal of care... at the end of life')

*MÉDECINE PALLIATIVE: SOINS DE SUPPORT - ACCOMPAGNEMENT - ÉTHIQUE*, 2012; 11(4):181-188. Health professionals are willing to respect the refusal of care, particularly at the end of life, without always seeking for a meaning. Their representations, their projections, their feelings lead to some specific attitudes. For nine nurses [study participants], defensive coping strategies were used, with for the majority, some avoidance behavior (not listening, trivialization, avoidance), but also negotiation. Only three nurses adopt an open-mind and questioning attitude. This research should lead us to be more aware about the meaning of the refusal of care, beneficence, respect for autonomy, its limits and underlying conflicts of values. Only a relationship, involving all the multidisciplinary team in a clinical approach focusing on communication, trust, patience, promotes the emergence and respect of patient autonomy. <http://www.sciencedirect.com/science/article/pii/S1636652211001875>

Cont. next page

### [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>



Of related interest:

- *BIOETHICS* | Published online – 1 October 2012 – 'End-of-life decisions and the reinvented rule of double effect...' <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12001/abstract>
- *PALLIATIVE MEDICINE*, 2012;26(7):947-953. 'Issues and needs in end-of-life decision making: An international modified Delphi study.' Ninety palliative care experts from nine countries participated in a modified Delphi study. Experts mentioned 219 issues in end-of-life decision making related to the medical domain, 122 issues related to the patient wishes and 92 related to relatives' wishes, regardless of profession or country. <http://pmj.sagepub.com/content/26/7/947.abstract>

### Corpses, conflict and insignificance? A critical analysis of post-mortem practices

*MORTALITY* | Published online – 4 October 2012 – This paper critically examines personalisation by exploring three groups integrally linked to post-mortem practices: funeral directors, secular celebrants and bereaved people. Drawing on ethnographic research data, this discussion reveals that personalisation is a complex term that frequently obscures the processes, meanings and difficulties encountered in organising post-mortem practices in contemporary New Zealand society. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.731724>

### Palliative care in Romania: Between poor resources and poor management

*PROGRESS IN PALLIATIVE CARE* | Published online – 4 October 2012 – Romania is a European Union (EU) country with poor resources and all underfinanced components of the deconstructed healthcare system are competing for the same limited funds. Palliative care must compete with other serious healthcare issues, including the highest EU incidences for tuberculosis, infant mortality, and uterine cervix cancer mortality. Therefore, the evolution of palliative care in Romania was largely the result of important input from non-governmental organizations, which are now the main providers of palliative care services, including education on the subject. Palliative care has changed in Romania over the past 20 years for a number of reasons, including motivated people, two national associations, annual conferences, a new physician subspecialty, standards of care, online journals, a new opioid law, and a dedicated subcommittee of the Ministry of Health. We consider that the most viable solution for now and in the near future should be the implementation of small autonomous teams that will be able to respond to specific needs of each local area according to available resources. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000030>

### De l'accompagnement des mourants à la médecine palliative en passant par les soins palliatifs

('From the accompaniment of dying patients to palliative medicine, including palliative care')

*MÉDECINE PALLIATIVE: SOINS DE SUPPORT - ACCOMPAGNEMENT - ÉTHIQUE* | Published online – 26 September 2012 – To change from the concept of "accompaniment of dying patients" to the concept of "palliative care," then to that of "palliative medicine" is significant of an evolution in the way of thinking the end of life and death in our society. Confrontation with death brings on in us three representations: the death of the other, the death of me and the death of you. The very existence of palliative care structures is a reminder that "we all will die." This reminder of limits and uncertainty is not easy to recognize for a medicine that would like all powerful and effective. This creates resistances. Palliative care can be considered as "a way of challenging the established order and of proposing alternative actions or new conceptions fulfilling objectives not met. The contribution of palliative medicine would be to reconcile scientific rigor of reasoning, the use of available technical possibilities of modern medicine, and the concern of the human being. The terminology "palliative medicine" is a larger representation, more noble, more academic than "palliative care" that requires a technical training and a specific teaching about the values of medicine for all health professionals. <http://www.sciencedirect.com/science/article/pii/S1636652212001079>

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Of related interest:

- *PUBLIC HEALTH* | Published online – 2 October 2012 – 'Population, mortality and place of death in Germany (1950–2050) – Implications for end-of-life care in the future.' Unlike in other industrialized countries, most people in Germany die outside of hospital. The need to plan for growing end-of-life care needs and ageing is urgent in Germany but also applies to the rest of Europe. <http://www.sciencedirect.com/science/article/pii/S003335061200234X>

### **End-of-life care on the intensive care unit in England & Wales: An overview for hospital medical practitioners**

*SURGERY*, 2012;30(10):563-566. Modern intensive care fulfils advanced supportive roles in the care of patients with actual or threatened multiple organ dysfunction. Such roles prolong patients' lives and whilst intensive care mortality rates have reduced in the last two decades, death following intensive care admission remains relatively common. Dealing with death and caring for dying patients is therefore a day-to-day reality of intensive care medicine and an urgent treatment. Clinicians have a duty to recognize the progression towards death and understand the ethical and legal concepts guiding best practice. This includes understanding the concept of medical futility, the ethical and medico-legal framework of decision-making in such circumstances and what factors constitute a good death on a case by case basis. This approach can enable the provision of effective care for the patient (encompassing both physical and holistic aspects of end-of-life care) and effective guidance for the family.

[http://www.surgeryjournal.co.uk/article/S0263-9319\(12\)00145-7/abstract](http://www.surgeryjournal.co.uk/article/S0263-9319(12)00145-7/abstract)

### **Overtreatment, over here**

*BRITISH MEDICAL JOURNAL* | Published online – 3 October 2012 – How much of what we offer to patients is unnecessary? Worse still, how much harm do we do to individuals and society through overtreatment? In the 30 years since Ivan Illich wrote his seminal and, at the time, shocking book *Medical Nemesis*, the idea that medicine can do clinical and societal harm as well as good has become commonplace. But are we doing enough to bring medicine's harmful hubris under control?

<http://www.bmj.com/content/345/bmj.e6684>

### **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.

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN RESPIRATORY JOURNAL*, 2012;40(4): 949-956. **'Expressed wishes and incidence of euthanasia in advanced lung cancer patients.'** This study explores expressed wishes and requests for euthanasia (i.e. administration of lethal drugs at the explicit request of the patient), and incidence of end-of-life decisions with possible life-shortening effects in advanced lung cancer patients in Flanders, Belgium. <http://www.ersj.org.uk/content/40/4/949.abstract>
- *JOURNAL OF AGING STUDIES*, 2012;26(4):377-385. **'Alzheimer's disease and euthanasia.'** This paper discusses the ethical debate surrounding assisted suicide for persons suffering end-stage Alzheimer's. It first presents a classification of the dissociative situations between "human individual" and "human person". It then moves on to discuss challenges to diagnosed persons and their caregivers in relation to the cardinal virtues of spinozistic ethics – strength of character, firmness and generosity. Finally, a number of ideas attached to the debate – "right of choice," "death with dignity," "quality of life" and "compassion in dying" – are discussed in order to clarify their foundations. <http://www.sciencedirect.com/science/article/pii/S089040651200028X>

### 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.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>

#### **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>

## Worth Repeating

### **Interdisciplinary spiritual care for seriously ill and dying patients: A collaborative model**

*CANCER JOURNAL*, 2006;12(5):398-416. Spirituality is essential to healthcare. It is that part of human beings that seeks meaning and purpose in life. Spirituality in the clinical setting can be manifested as spiritual distress or as resources of strength. Patients' spiritual beliefs can impact diagnosis and treatment. Spiritual care involves an intrinsic aspect of care, which underlies compassionate and altruistic caregiving and is an important element of professionalism amongst the various healthcare professionals. It also involves an extrinsic element, which includes spiritual history, assessment of spiritual issues, as well as resources of strength and incorporation of patients' spiritual beliefs and practices into the treatment or care plan. Spiritual care is interdisciplinary care-each member of the interdisciplinary team has responsibilities to provide spiritual care. [http://journals.lww.com/journalppo/Abstract/2006/09000/Interdisciplinary\\_Spiritual\\_Care\\_for\\_Seriously\\_Ill.9.aspx](http://journals.lww.com/journalppo/Abstract/2006/09000/Interdisciplinary_Spiritual_Care_for_Seriously_Ill.9.aspx)

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