Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution — to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general — to help keep them abreast of current, emerging and related issues — and, to inform discussion and encourage further inquiry.

16 March 2015 Edition | Issue #401



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Grief and bereavement: Scroll down to <u>Specialist Publications</u> and 'A systematic review of the peer-reviewed literature on self-blame, guilt, and shame' (p.9), in *Omega – Journal of Dying & Death*.

Canada

Ontario's home care system should be overhauled now: Editorial

ONTARIO | The Toronto Star - 12 March 2015 - A woman goes without eating or drinking for two to three days, even though she was under the supervision of Ontario's home care system. Patients receiving palliative home care get cut off because they don't die fast enough. A patient with diabetes gets sent home after a heart attack. The expectation is that a friend will take care of her. She returns to hospital in a diabetic coma. Those are just three tales from the trenches from personal support workers. patients, nurses, community service provider agencies and other groups involved with home care in this province. Their testimony is contained in a two-year study 1 ... by the Ontario Health Coalition, an advocacy group that is rightly calling for a complete overhaul of the home care system. If that message isn't strong enough to be heard by the Ontario government, many of the group's findings are reinforced by a second report on home care² ... by a group of experts commissioned by the Ontario government. That report ... contains sixteen recommendations to streamline and integrate services to make

it easier for patients and caregivers to navigate a system that is now overly complex and unresponsive. As the experts say, the current home care system simply "fails to meet the needs of clients and families." http://www.thestar.com/opinion/editorials/2015/03/12/ontarios-home-care-system-should-be-overhauled-now-editorial.html

Extract from 'Bringing Home Care' report

Ontario has a number of creative programs in end-of-life care; the Local Health Integrated Networks (LHINs) should examine those programs that work and plan system wide end-of-life home and community care. The LHINs should also consider the findings on palliative care reported in [the] Ontario Auditor General 2014 annual report.¹

 '2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288).'[Noted in Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports 2014 en.htm

Cont.

- 'The Care We Need: Ontarians Speak Out on the State of Home Care A Proposal for Reforming Home Care in the Public Interest,' Ontario Health Coalition, March 2015. http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf
- 2. 'Bringing Care Home,' Report of the Expert Group on Home & Community Care,' March 2015. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

Noted in Media Watch, 29 December 2014, #390 (pp.1-2):

- ONTARIO | The Toronto Star 21 December 2014 'Too few people dying in Ontario get proper palliative care: Editorial.' Thousands of dying Ontarians are not receiving the end-of-life care they want due to an appalling lack of high quality palliative care. Change is obviously needed. Welcome steps forward are outlined in a report calling for dramatic improvements...' http://www.thestar.com/opinion/editorials/2014/12/21/too few people dying in ontario get proper palliative care editorial.html
 - 'Health Care for People Approaching the End of Life: An Evidentiary Framework,' Health Quality Ontario (Ontario Health Technology Advisory Committee). Published in *Ontario Health Technology Assessment Series*, 2014;14(14):1-45. [Noted in Media Watch, 22 December 2014, #389 (p.3)] http://www.hqontario.ca/Portals/0/Documents/eds/synthesis-report-eol-1412-en.pdf

<u>U.S.A.</u>

The trouble with advance directives

THE NEW YORK TIMES | Online – 13 March 2015 – Ever since Congress passed the Patient Self-Determination Act in 1990, health professionals and consumer advocates have urged Americans, especially older adults, to draw up advance directives and distribute them to families and doctors. The campaign does seem to have paid off in one sense: Among Americans over age 60, the proportion who had advance directives when they died rose to 72% in 2010 from 47% in 2000, according to data from the national Health & Retirement Study. Too often, though, an advance directive hardly seems to matter. Stories abound of documents misplaced, stashed in safe deposit boxes, filed in lawyers' offices. Frequently, "the directive never gets to the right place, or isn't referred to when a decision needs to be made," said David M. English, of the American Bar Association's Commission on Law & Aging. http://www.nytimes.com/2015/03/17/health/the-trouble-with-advance-directives.html? r=0

Traditional American funerals are dead - but not buried

AL JAZEERA AMERICA | Online – 12 March 2015 – U.S. cemeteries are banking on the country's growing cremation rate – projected to overtake that of casketed burials for this first time this year – to keep them open and accepting remains for as long as possible. In their remaining acreage and patches of grass, cemeteries are finding places that might not fit a coffin but could fit several urns. In urban areas, like Manhattan and Washington DC, cemetery expansion isn't just expensive; it's often impossible. But cremation's increasing popularity is delaying these cemeteries' inevitable closure. http://america.aljazeera.com/articles/2015/3/12/traditional-us-funerals-are-dead-but-not-buried.html

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

Medical technology makes "time of death" harder to pinpoint

THE ATLANTIC | Online – 11 March 2015 – As medical technology becomes more advanced, it also becomes more difficult for doctors to discern the line between life and death. PET scans, which have been widely used since the 1990s, are a good example. Rather than solely showing body anatomy like an MRI or CT scan would, a PET scan can actually detect cellular activity in tissues. In a study published last year¹ ... 13 out of 41 patients in a persistent vegetative state showed detectable brain activity on PET scans, results that the investigators thought were consistent with "minimal consciousness" ... an optimistic term; the PET scans may have been detecting only the play of random signals across neural wires that had long since failed to relay coherent thought. One year later, four of those 13 patients with detectable brain activity had died, and the remaining nine had either stayed "minimally conscious" or recovered "a higher level of consciousness," though the authors did not elaborate on what that meant. This is an interesting finding, but it also complicates how doctors might approach the end of life. http://www.theatlantic.com/health/archive/2015/03/medical-technology-makes-time-of-death-harder-to-pinpoint/386968/

 'Diagnostic precision of PET imaging and functional MRI in disorders of consciousness...' The Lancet, 2014;384(9942):514-522. (This clinical validation study was undertaken at the University Hospital of Liège, Belgium.) http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2814%2960042-8/abstract

The death with dignity debate misses the point

FORBES | Online – 11 March 2015 – For most of us, the critical question is how we will live with chronic conditions, not just how we will die. We make a terrible mistake if we focus only on the last days of life when so many of us will live for years with chronic – perhaps even terminal – but manageable diseases. For instance, men will need personal supports and services in frail old age for an average of 18 months. Women typically will need such support for three years before they die. And younger people with disabilities may need some level of personal assistance for decades. None of these people are dying (at least no more than the rest of us). They are living. http://www.forbes.com/sites/howardgleckman/2015/03/11/the-death-with-dignity-debate-misses-the-point/

Teaching doctors how to engage more and lecture less

THE WASHINGTON POST | Online – 9 March 2015 – Oncotalk is part of a burgeoning effort to teach doctors an essential but often overlooked skill: clinical empathy. Unlike sympathy, which is defined as feeling sorry for another person, clinical empathy is the ability to stand in a patient's shoes and to convey an understanding of the patient's situation as well as the desire to help. Clinical empathy was once dismissively known as "good bedside manner" and traditionally regarded as far less important than technical acumen. But a spate of studies in the past decade has found that it is no mere frill. Increasingly, empathy is considered essential to establishing trust, the foundation of a good doctor-patient relationship. Studies have linked empathy to greater patient satisfaction, better outcomes, decreased physician burnout and a lower risk of malpractice suits and errors. http://www.washingtonpost.com/national/health-science/teaching-doctors-how-to-engage-more-and-lecture-less/2015/03/09/95a98508-ae30-11e4-9c91-e9d2f9fde644 story.html

Of related interest:

THE WASHINGTON POST | Online – 9 March 2015 – 'How I discovered an important question a doctor should ask a patient.' I remember a visiting palliative-care physician's words about caring for the fragile elderly: "We forget to ask patients what they want from their care." <a href="http://www.washingtonpost.com/national/health-science/how-i-discovered-an-important-question-a-doctor-should-ask-a-patient/2015/03/09/ca350634-bb9c-11e4-bdfa-b8e8f594e6ee_story.html?tid=hpModule_9d3add6c-8a79-11e2-98d9-3012c1cd8d1e

Assisted (or facilitated) death

Representative sample of recent news media coverage:

MONTANA | The News & Observer (Raleigh, North Carolina) – 12 March 2015 – 'House endorses right-to-die bill allowing doctor prosecution.' The Montana House of Representatives endorsed a bill by one vote that would make it illegal for doctors to prescribe life-ending medication to terminally ill patients who ask for it. The House endorsed the bill 51-49 on second reading. If it passes third reading, the measure will head to the Senate for consideration. http://www.newsobserver.com/living/health-fitness/article13939169.html

International

End-of-life care in England

Patients are "dying in hospital because they fear leaving bills to pay"

U.K. (England | *The Telegraph* – 15 March 2015 - Too many people are dying in hospital because they fear leaving loved ones with bills to pay if they receive their care at home, MPs have warned. An influential parliamentary committee is calling for free "social care" for all terminally-ill patients. Currently, personal care provided at home via social services, is "means-tested""and is only free for those with assets of less than £23,500. In a report published today on endof-life care, the Commons Health Select Committee calls for an overhaul of the system. MPs said too many patients who wanted to die in their own homes surrounded by loved ones, felt compelled to spend their dying days in hospital where care is free, so that bereaved families were not left facing large bills. Dr. Sarah Wollaston, Conservative chairman of the committee, said that the current system was "wrong" and there was a "strong humanitarian case" to make radical changes to it. http://www.telegraph.co.uk/news/health/elde r/11471570/Patients-are-dying-in-hospitalbecause-they-fear-leaving-bills-to-pay.html

National Health Service still using Death Pathway despite "ban"

U.K. (England) | The Daily Mail - 14 March 2015 - The discredited Liverpool Care Pathway is still being used in some hospitals despite having been scrapped, a Commons report will reveal. A cancer charity warns that despite a National Health Service ban, the controversial end-of-life programme is still in use under "a different name." Nurses told MPs some hospitals have merely "tweaked" the end-of-life protocol and given it another title... The Royal College of Nursing said its members had "not seen a significant difference" in the way care is delivered in England since the pathway was withdrawn last year. http://www.dailymail.co.uk/news/article-2994291/NHS-using-Death-Pathway-despiteban-charity-warning-controversial-end-lifeprogramme-merely-operating-different-name.html

 'End-of-life Care,' House of Commons Health Committee, 15 March 2015. http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf

Of related interest:

U.K. (England) | The Telegraph – 12 March 2015 – 'Elderly given power to decide where to die.' A consultation document ... has set out plans to give patients more powers to plan and make decisions about their "end of life care." Jeremy Hunt, the Health Secretary ... wants to "strengthen" the right for patients to be involved in more decisions about their own care. http://www.telegraph.co.uk/news/health/elder/11468862/Elderly-given-power-to-decide-where-to-die.html

Cont.

- U.K. (England) | The Telegraph 11 March 2015 'Elderly "stranded" in hospitals after home care spending slashed by a quarter.' A hoped-for drive to prevent elderly people ending up in hospitals or nursing homes unnecessarily has been cast into doubt by new figures showing spending on care for people at home has been cut by a quarter since the [Conservative-Liberal] Coalition came to power. Analysis by Age UK shows that, although local councils have sought to shield social care spending from the full force of budget cuts, spending on community care services in England has been slashed by almost £560m since 2010.¹ http://www.telegraph.co.uk/news/politics/11462017/Elderly-stranded-in-hospitals-after-home-care-spending-slashed-by-a-quarter.html
 - 'As spend on social care tumbles Age UK reveals "double whammy" for older people of cuts to both health & social care services in the community, http://www.ageuk.org.uk/latest-press/spend-on-social-care-tumbles/

Elderly "have internalised" message they're a burden on society...

AUSTRALIA | ABC News – 12 March 2015 – By 2050, about five per cent of Australia's population will be over the age of 85, with many of us expected to live to our mid-90s. The challenges of the ageing population are something we've been hearing a lot about in the past couple of weeks, since the Federal Government released its Intergenerational Report. The message is that more old people and falling budget revenues are going to put a huge strain on our health and welfare systems. But now one doctor is raising concerns about the way we're discussing the ageing population. She believes we're sending older Australians a message that they're an intolerable burden. http://www.abc.net.au/7.30/content/2015/s4196703.htm

 '2015 Intergenerational report: Australia in 2055,' Department of the Treasury, Government of Australia, March 2015. http://apo.org.au/research/2015-intergenerational-report-australia-2055

Of related interest:

AUSTRALIA | The Age – 14 March 2015 – 'Our future selves: Why the elderly deserve respect.' Let's stop seeing the elderly as "cute" or a financial drain when they become sick – and instead regard them as our future selves. http://www.theage.com.au/good-weekend/our-future-selves-why-the-elderly-deserve-respect-20150313-1308f9.html

Corrections & Clarifications

Noted in the issue of Media Watch of...

9 March 2015, #400 (p.5) – *The Daily Mail* reported on draft guidelines issued in the U.K. by the National Institute for Health & Care Excellence regarding home care services ('Elderly must get 30-minute home care visits carers told: New rules introduced to end scandal of drive by appointments'). Access the Institute's 'Home care: Delivering personal care and practical support to older people living in their own homes' at: http://www.nice.org.uk/guidance/gid-scwave0713/documents/home-care-draft-full-guideline2

16 February 2015, **#397 (p.14)** – The journal of the Norwegian Medical Association published a commentary on 'Guidelines for palliative sedation at the end of life...' ('Palliative sedation at the end of life – revised guidelines,' *Tidsskrift for Den norske legeforening*, 2015;135:220-221). An English language version is now available at: http://legeforeningen.no/Emner/Andre-emner/Publikasjoner/Retningslinjer (scroll down to second bullet point).

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FRANCE | TelesurTV 11 March 2015 'French legislators reject euthanasia bill.' The French Parliament [has] rejected legislation that would allow "deep and terminal sedation" for patients "whose lives are threatened." With 89-70 votes against, the legislation ... was rejected due to stiff opposition from radical-left lawmakers, including the left-wing of the socialists as well as the environmentalist party. Initially, the new law would have allowed doctors to prescribe "deep and continuous sedation on the demand of the patient, until his/her death" for terminally ill, conscious people whose treatment was not working. It would also have applied to those who stop taking medication, and stipulated that doctors must respect a patient's prior refusal to life prolonging treatment. http://www.telesurtv.net/english/news/French-Legislators-Reject-Euthanasia-Bill-20150311-0024.html
- SWITZERLAND | Expatica (Amsterdam, The Netherlands) 11 March 2015 'Record numbers join Swiss right-to-die organisation.' The Swiss right-to-die organisation Exit that helps with assisted suicide said its membership reached a record high in 2014 with the number of applicants increasing by 20%. The trend has continued into 2015 with 5,000 new applicants joining Exit in the first two months of the year. The group also said it carried out 583 assisted suicides in 2014, up by 124 from the previous year; 56% involved women and the average age was 77.5 years. http://www.expatica.com/ch/news/country-news/Record-numbers-join-Swiss-right-to-die-organisation 452214.html

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

Metaphor in End-of-Life Care Project

The online use of violence and journey metaphors by patients with cancer, as compared with health professionals: A mixed methods study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 March 2015 – Patients with cancer [i.e., study participants] use both violence metaphors and journey metaphors approximately 1.5 times per 1,000 words to describe their illness experience. Health professionals [i.e., study participants] use each type of metaphor significantly less frequently. Patients' violence metaphors can express and reinforce negative feelings, but they can also be used in empowering ways. Journey metaphors can express and reinforce positive feelings, but can also be used in disempowering ways. Violence metaphors are not by default negative and journey metaphors are not by default a positive means of conceptualising cancer. A blanket rejection of violence metaphors and an uncritical promotion of journey metaphors would deprive patients of the positive functions of the former and ignore the potential pitfalls of the latter. Instead, greater awareness of the function ... of patients' metaphor use can lead to more effective communication about the experience of cancer.

http://spcare.bmj.com/content/early/2015/03/05/bmjspcare-2014-000785.abstract

Inside patients' homes: A metaphorical analysis of home hospice nurses' experiences working with dying patients

OMEGA – JOURNAL OF DEATH & DYING | Online – 4 March 2015 – Interviews revealed four main metaphors emphasizing how home hospice nurses conceive and communicate their experiences working with patients: a calling, hallowed ground, going with the flow, and life lessons. These metaphors highlight how home hospice nurses transcend organizational role descriptions, feel empowered to make a difference, appreciate the inevitable unpredictability of their work, and draw upon patient interactions for self-reflection. http://ome.sagepub.com/content/early/2015/03/04/0030222815575282.abstract

Cont.

Noted in Media Watch, 10 November 2014, #383 (p.8):

■ U.K. | The Independent — 3 November 2014 — 'Mind your language: "Battling" cancer metaphors can make terminally ill patients worse.' Media portrayals of cancer as a "battle to be fought" are leading to feelings or failure and guilt among terminally ill patients, experts in language and end-of-life care have said. While talking about "fighting" cancer could be useful for some, it should be for the patient themselves to introduce the metaphor, said Elena Semino, professor of linguistics and verbal art at Lancaster. Her study, carried out alongside palliative care specialists, analysed 1.5 million words of discussion, representing the views of around 200 people closely involved with cancer care. Semino, who carried out the study at Lancaster's Economic & Social Research Council Centre for Corpus Approaches to Social Science, is now working with the National Health Service to produce a "metaphor manual." http://www.independent.co.uk/life-style/health-and-families/health-news/mind-your-language-battling-cancer-metaphors-can-make-terminally-ill-patients-worse-9836322.html

N.B. Metaphor in End-of-Life Care Project, Lancaster University: http://ucrel.lancs.ac.uk/melc/

Threading the cloak: Palliative care education for care providers of adolescents and young adults with cancer

CLINICAL ONCOLOGY IN ADOLESCENTS & YOUNG ADULTS | Online - 9 March 2015 - Medical providers are trained to investigate, diagnose, and treat cancer. Their primary goal is to maximize the chances of curing the patient, with less training provided on palliative care [PC] ... and the unique developmental needs inherent in this population. Early, systematic integration of PC into oncology practice represents a valuable, imperative approach to improving the overall cancer experience for adolescents and young adults (AYAs). The importance of competent, confident, and compassionate providers for AYAs warrants the development of effective educational strategies for teaching AYA PC. Just as PC should be integrated early in the disease trajectory of ... PC training should be integrated early in professional development of trainees. http://www.dovepress.com/front_end/threadi ng-the-cloak-palliative-care-education-forcare-providers-of-ad-peer-reviewed-fulltextarticle-COAYA

Teaching about life and living in courses on death and dying

OMEGA - JOURNAL ON DEATH & DYING - 11 March 2015 - Many who teach or are enrolled in classes on death and dying regularly hear critical remarks about these courses - mostly from individuals who have never attended such courses. This article suggests the value of a brief reflection on some examples of such remarks in order to put them into a more realistic context. More importantly, this article offers a depiction of what actually is taught in these types of courses. In short, this article offers a rebuttal to misrepresentations of courses on death and dying, while giving primary attention to what death and dying courses really have to teach about life and living. http://ome.sagepub.com/content/early/2015/03/06 /0030222815575902.full.pdf+html

Cont. next page



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

Of related interest:

■ JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2015;17(2):113-118. 'Determinants of access to pediatric hospice care: A conceptual model.' Although determinants that influence families' decisions to access pediatric hospice care have been identified, the relationship between these determinants and access to pediatric hospice care has not been explicated or grounded in accepted health care theories or models. This article presents a conceptual model describing the determinants of hospice access. Predisposing (demographic; social support; and knowledge, beliefs, and values), enabling (family and community resources), and need (perceived and evaluated needs) factors were identified through the use of hospice literature. http://journals.lww.com/jhpn/Abstract/2015/04000/Determinants of Access to Pediatric Hospice Care .8.aspx

Carers providing end-of-life care at home have limited formal support in managing medications

EVIDENCE-BASED NURSING | Online – 5 March 2015 – Families caring for patients at endof-life are often expected to provide numerous and complex care tasks while simultaneously coping with their grief and the hospice patient's suffering. Managing hospice patient medications is a critical and complex task and one in which caregivers have been shown to feel illprepared. http://ebn.bmj.com/content/early/2015/03/05/eb-2014-102028.extract

Noted in Media Watch, 9 February 2015, #396 (p.14):

PRIMARY HEALTH CARE | Online – 30 January 2015 – 'Caring for dying family member raises concerns about medication.' Supporting those who wish to die at home is a stated government policy goal, but it is mainly family carers who provide the care in the home. http://rcnpublishing.com/doi/abs/10.7748/phc.25.1.15.s22?journalCode=phc

Noted in Media Watch, 29 September 2014, #377 (p.9):

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 September 2014 – 'Managing end of life medications at home – accounts of bereaved family carers...' Barriers to managing ... medications at home include: 1) complex regimes; 2) unwanted responsibility in deciding when to use "as needed" medication; 3) disagreements with professional staff; and, 4) anxiety about medication errors (if perceived to have implications for survival). http://spcare.bmj.com/content/early/2014/09/25/bmjspcare-2014-000658.short?rss=1

End-of-life care in Denmark

The ten barriers to appropriate management of patients at the end of their life

INTENSIVE CARE MEDICINE | Online – 7 March 2015 – It has been more than 60 years since the concept of intensive care was applied in Copenhagen, Denmark, and it was not until the 1970s that the concept became a recognised specialty with its own conferences, textbooks, journals, qualifications and societies. Intensivists have made great advances in how to effectively sustain life and are probably now at the stage where the effective implementation of these lessons is as important as the underlying knowledge. However, while intensivists have been concentrating on these advances, a major challenge has emerged, almost imperceptibly. The majority of patients we are now treating do not have a single diagnosis; rather, they have multiple agerelated co-morbidities that add up to a clinical condition which, as yet, has no universally accepted name or score. Yet, we are still using the same technology to treat these patients that we used previously to treat younger patients who had a single diagnosis and potentially reversible conditions. http://link.springer.com/article/10.1007/s00134-015-3712-6

Of related interest:

■ SUPPORTIVE CARE IN CANCER | Online – 3 March 2015 – 'Involvement of supportive care professionals in patient care in the last month of life.' A palliative care team or consultant had been involved in the last month of life in 12% of all patients [who were studied] for whom death was expected; this percentage was 3% for pain specialists, 6% for psychologists or psychiatrists and 13% for spiritual caregivers. Involvement of palliative care or pain specialists was most common in younger patients, in patients with cancer, and in patients who died at home. Involvement of psychological or spiritual caregivers was most common in older patients, in females, in patients with dementia, and in patients who died in a nursing home. http://link.springer.com/article/10.1007/s00520-015-2655-3#

Grief & bereavement

A systematic review of the peer-reviewed literature on self-blame, guilt, and shame

OMEGA – JOURNAL OF DYING & DEATH / Online – 11 March 2015 – Self-blame, guilt, and shame are common in bereaved parents, albeit to varying degrees, with differential relationships to sex, and diminishing over time. There is some evidence that guilt and shame predict more intense grief reactions and that self-blame predicts post-traumatic symptomology, anxiety, and depression in bereaved parents. Awareness of these affective states may assist clinicians in the identification of bereaved parents who are at a higher risk of developing adverse psychological outcomes. Implications for practice and recommendations for future research are discussed. http://ome.sagepub.com/content/early/2015/03/09/0030222815572604.full.pdf+html

Of related interest:

- OMEGA JOURNAL OF DEATH & DYING | Online 10 March 2015 'Growing from grief: Qualitative experiences of parental loss.' Grieving children are more likely to experience symptoms of depression and anxiety compared with their non-grieving peers. Five theoretical constructs were found [among study participants]: adjustment to catastrophe, support, therapy, continuing a connection with the deceased parent, and reinvestment. The findings have clinical applications for bereaved children, their families, and clinical programs targeting this population. http://ome.sagepub.com/content/early/2015/03/09/0030222815576123.full.pdf+html
- OMEGA JOURNAL OF DEATH & DYING | Online 9 March 2015 "'One size doesn't fit al" Partners in Hospice Care, an individualized approach to bereavement intervention.' The authors concluded in a recent study that a one-size-fits-all approach typical of group interventions often does not adequately accommodate the range of situations, life experiences, and current needs of participants. They describe how this limitation informed the design and implementation of an individually delivered intervention format more specifically tailored to the unique needs of each bereaved person. Although an individually delivered format has its own challenges, these can be effectively addressed through standardized interventionist training, regular communication among staff, and a flexible approach toward participants' preferences... http://ome.sagepub.com/content/early/2015/03/06/0030222815575895.full.pdf+html

Online grief support communities: Therapeutic benefits of membership

OMEGA – JOURNAL OF DEATH & DYING | Online – 6 March 2015 – Online grief support communities have become popular in recent years for those seeking information and empathetic others following the death of someone close to them. Hundreds of Facebook pages and Web sites are now devoted to bereavement – and health-care professionals need to assess what therapeutic benefits virtual communities might offer to help people manage grief and integrate death into their lives. In the current study ... individuals report less psychological distress as a result of joining these groups – and this psychosocial benefit increased over time. Individuals who were members for a year or more characterized their grief as less severe compared with those who had a shorter tenure in the community. Additional findings and implications are discussed. http://ome.sagepub.com/content/early/2015/03/06/0030222815575698.full.pdf+html

Noted in Media Watch, 8 December 2014, #387 (p.13):

■ NEW REVIEW OF HYPERMEDIA & MULTIMEDIA | Online – 27 November 2014 – 'A community for grieving: Affordances of social media for support of bereaved parents.' The purpose of this paper was to study bereaved parents' use of a closed peer grief support community on Facebook and the features of the community important to them. The affordances of social media become vital resources for coping with grief in ways not available previously, comprising aspects of the closed nature of the group, shared experiences, time, and accessibility. http://www.tandfonline.com/doi/abs/10.1080/13614568.2014.983557#.VH3R6tLF YQ

Noted in Media Watch, 3 November 2014, #382 (p.13):

■ JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS | Online – 21 October 2014 – 'Death on Facebook: Examining the roles of social media communication for the bereaved.'

This study examines the ways in which the social networking site Facebook was helpful and unhelpful to participants when someone they knew died. Analysis revealed three themes describing participants' experiences ... during bereavement: news dissemination, preservation, and community. http://spr.sagepub.com/content/early/2014/10/21/0265407514555272.abstract

A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs

PALLIATIVE MEDICINE | Online – 11 March 2015 – Four themes were identified from the data: being cared for and feeling safe, receiving care to manage at home, relief for family and "feeling better and/or getting better." The benefits of being in hospital were reported to extend beyond treatments received. Most participants reported their preference was to come to hospital even if they had been able to access the care they received in hospital at home. This research contributes to a greater understanding of the benefits associated with hospitalisation for patients with palliative care needs. The findings suggest that such benefits extend beyond the treatment patients receive and challenge current assumptions regarding the role of the acute hospital in palliative care. http://pmj.sagepub.com/content/early/2015/03/13/0269216315575841.abstract

Of related interest:

JOURNAL OF PALLIATIVE CARE, 2015;31(1):13-20. 'Dying in the hospital: Perspectives of family members.' Although most patients express a preference to die at home, many (30% in the U.S.) still die in hospital. Families do not interpret clinical cues leading up to death in the same way that healthcare providers do; families need clear and direct explanations from providers. Clinicians should assess patient and family understandings of prognosis and communicate clearly and directly. Family members value being with their loved one at the time of death... http://www.ingentaconnect.com/content/iug/jpc/2015/00000031/00000001/art00003

Chronically homeless persons' participation in an advance directive intervention: A cohort study

PALLIATIVE MEDICINE | Online – 11 March 2015 – Socio-demographic characteristics, health status and health care use were not associated with completion of an advance directive. Participants were more likely to complete an advance directive if they reported thinking about death on a daily basis, believed thinking about their friends and family was important, or reported knowing their wishes for end-of-life care but not having told anyone about these wishes. Among individuals who completed an advance directive, 61.2% named a substitute decision maker, and 94.1% expressed a preference to receive cardiopulmonary resuscitation in the event of a cardio-respiratory arrest if there was a chance of returning to their current state of health. A counselor-guided intervention can achieve a high rate of advance directive completion among chronically homeless persons. http://pmj.sagepub.com/content/early/2015/03/05/0269216315575679.abstract

Noted in Media Watch, 16 February 2015, #397 (p.10):

■ DEATH STUDIES | Online – 12 February 2015 – 'What constitutes a good and bad death?'
Perspectives of homeless older adults.' The themes for a good death were: 1) dying peacefully; 2) not suffering; 3) experiencing spiritual connection; and, 4) making amends with significant others. Themes for a bad death were: 1) experiencing death by accident or violence; 2) prolonging life with life supports; 3) becoming dependent while entering a dying trajectory; and, 4) dying alone. http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629

N.B. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: http://www.sophie-project.eu/pdf/ENHW 2014.pdf. Several articles on end-of-life care for the homeless are noted in Media Watch, 3 February 2014, #343 (p.4).

Perspectives on the role of the speech and language therapist in palliative care: An international survey

PALLIATIVE MEDICINE | Online – 11 March 2015 – Internationally, speech and language therapists believe they have a role in palliative care. Respondents highlighted that this area of practice is under-resourced, under-acknowledged and poorly developed. They highlighted the need for additional research as well as specialist training and education for speech and language therapists... http://pmj.sagepub.com/content/early/2015/03/05/0269216315575678.abstract

How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of GPs, nurses and family carers

PLOS ONE | Online – 10 March 2015 – Five key themes that could help avoid hospitalisation at the end of life emerged from [face-to-face] interviews: 1) marking the approach of death, and shifting the mindset; 2) being able to provide acute treatment and care at home; 3) anticipatory discussions and interventions to deal with expected severe problems; 4) guiding and monitoring the patient and family in a holistic way through the illness trajectory; 5) continuity of treatment and care at home. [These] ... can be seen as strategies that could help in avoiding hospitalisation at the end of life. It is recommended that for all patients residing at home, GPs and community nurses work together as a team from the moment that it is marked that death is approaching up to the end of life. http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0118971

Representative sample of articles on avoidable hospital readmissions of patients with hospice or palliative care needs noted in past issues of Media Watch:

- PALLIATIVE MEDICINE, 2014;28(7):917-918. 'Avoidable for whom? Hospital use at the end of life.' The use of health services by people with palliative care needs has come under particular scrutiny. Indeed, a policy concern in many countries is reducing the number, and length, of acute hospital admissions among people who are at the end of life. This is typically presented as a "win-win" situation as a "good death" is viewed as hard to achieve in a hospital setting. However, papers in this edition add to a growing body of evidence which indicates that, while this argument may appear both appealing and straightforward on paper, the realities of dying are more complex and unpredictable.^{1,2} [Noted in Media Watch, 9 June 2014, #361 (p.11)] http://pmi.sagepub.com/content/28/7/917.extract
 - What justifies a hospital admission at the end of life? A focus group study on perspectives
 of family physicians and nurses,' Palliative Medicine, 2014;28(7):941-948. [Noted in Media
 Watch, 24 February 2014, #346 (p.13)] https://pmj.sagepub.com/content/28/7/941.abstract
 - 'General practitioners' perspectives on the avoidability of hospitalizations at the end of life...'
 Palliative Medicine, 2014;28(7):949-958. [Noted in Media Watch, 7 April 2014, #352 (p.13)]
 http://pmj.sagepub.com/content/early/2014/04/02/0269216314528742.abstract

- BRITISH MEDICAL JOURNAL | Online 6 June 2014 'Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life, and hospital deaths...' A pooled analysis of 11 community based, palliative care teams strongly suggests that ... exposure to the specialist team intervention compared with usual care significantly reduces the risk of being in hospital or having an emergency department visit in the last two weeks of life and of dying in hospital. [Noted in Media Watch, 9 June 2014, #361 (p.11)] https://www.bmj.com/content/348/bmj.g3496
- PALLIATIVE MEDICINE | Online 1 April 2014 'General practitioners' perspectives on the avoidability of hospitalisations at the end of life...' According to 24% of the 319 GPs [surveyed], the last hospitalisation in the final three months of their patient's life could have been avoided: 46% by proactive communication with the patient; 36% by more communication between professionals around hospitalisation; 28% by additional care and treatment at home; and, 10% by patient and family support. [Noted in Media Watch, 7 April 2014, #352 (p.11)] http://pmi.sagepub.com/content/early/2014/04/02/0269216314528742.abstract

Palliative care professionals' evaluations of the feasibility of a hope communication tool: A pilot study

PROGRESS IN PALLIATIVE CARE | Online – 9 March 2015 – Palliative care professionals have recognized the importance of hope for their patients. However, they sometimes experience hope as a barrier for end-of-life communication, for instance when patients have unrealistic hope. Fourteen healthcare professionals ... participated in the study... A hope communication tool helped participants to reach depth and address end-of-life issues. Most participants used it for other reasons than described in the tool. They used it when they faced difficulties that related to patients' hope or hope-related themes, such as unrealistic hope or fear. Participants also gave feedback on the open or abstract character of questions, the assumptions of questions, and the distinctions between categories. http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.00000000003

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ARCHIVES OF SUICIDE RESEARCH | Online 9 March 2015 'Attitudes toward assisted suicide: Does family context Matter?' Respondents [i.e., study participants] were more likely to support physician-assisted suicide if they heard about an older patient or a patient experiencing physical pain than a younger patient or one suffering from depression, respectively. For family-assisted suicide, respondent support was higher when the patient had physical pain than depression, and when the patient's spouse or friend was supportive of the wish to die... http://www.tandfonline.com/doi/abs/10.1080/13811118.2015.1004477#.VQK-edLF YQ
- GACETA MÉDICA DE MÉXICO, 2015;151(1):119-30. 'Palliative care regulation and assisted death.' This article analyzes the Mexican regulation on palliative care and its relationship with the public debate on assisted death or suicide. The article focuses on the rights that people with incurable diseases have, given the current contents of the General Health Statute and other applicable rules. Its main purpose is to activate the public debate on these matters. http://www.ncbi.nlm.nih.gov/pubmed/25739492
 - N.B. Spanish language article.
- NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online Accessed 9 March 2015 'Assessment of euthanasia request by Support & Consultation on Euthanasia in the Netherlands (SCEN) physicians.' Uniformity of assessment is important to avoid legal disparity in this patient group. The authors found no medical or ethical benchmarks for determining the unbearable nature of suffering. A verifying assessment by the SCEN physician can only provide an opinion regarding the presence of hopeless pain that is classified as "unbearable." A negative SCEN assessment undermines a person's sense of justice at a difficult time, while the hopeless suffering may well be accepted as unbearable in comparable cases. http://europepmc.org/abstract/med/25714765

N.B. Dutch language article.

Worth Repeating

What "best practice" could be in palliative care: An analysis of statements on practice and ethics expressed by the main health organizations

BMC PALLIATIVE CARE | Online – 7 January 2010 – The authors carried out an analysis of the statements on practice and ethics of palliative care expressed by the main health organizations to show which dimensions of end-of-life care are taken into consideration. Overall, 34 organizations were identified, 7 international organisations, and 27 organisations operating on the national level in four different countries (Australia, Canada, U.K. and the U.S.). Up to 56 documents were selected and analysed. Most are position statements. Relevant quotations from the documents were presented by "areas" and "sub-areas." In general, the "sub-areas" of symptoms control as well as those referring to relational and social issues are more widely covered by the documents than the "sub-areas" related to "preparation" and to "existential condition." Indeed, the consistency of end-of-life choices with the patient's wishes, as well as completion and meaningfulness at the end of life is given only a minor relevance. An integrated model of the best palliative care practice is generally lacking in the documents. http://www.biomedcentral.com/content/pdf/1472-684x-9-1.pdf

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

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.

Barry R. Ashpole Guelph, Ontario CANADA

'phone: 519.837.8936

e-mail: barryashpole@bell.net

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2015/02/media-watch/#CHINESE

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

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

Australia

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://hpcconnection.ca/general-resources/in-the-news/

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

Europe

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

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

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

Back Issues of Media Watch



http://www.ipcrc.net/archive-global-palliative-care-news.php