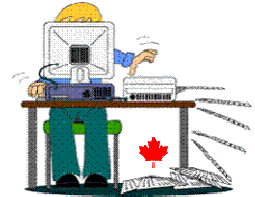


Media Watch...

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

23 September 2013 Edition | Issue #324



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Best practice: Scroll down to [Specialist Publications](#) and 'Development and initial validation of a new outcome measure for hospice and palliative care: The St. Christopher's Index of Patient Priorities (SKIPP)' (p.9), in *BMJ Supportive & Palliative Care*.

Canada

Better health, better care, better value for all: Refocusing health care reform in Canada

HEALTH COUNCIL OF CANADA | Online – Accessed 20 September 2013 – The Council's latest report shows that a decade of health care reform in Canada has produced disappointing results for taxpayers and patients alike. The report finds that with some exceptions, changes to health care have not kept pace with the evolving needs of Canadians: progress on wait times for key procedures cited in the Health Accords [between the federal and provincial governments] has stalled; primary health care services lag behind other countries; home care services do not address long-term needs; and prescription drug costs remain beyond the means of many Canadians. http://healthcouncilcanada.ca/content_bh.php?mnu=2&mnu1=48&mnu2=30&mnu3=53

N.B. There is no mention in the Health Council of Canada's report of hospice or palliative care. The only reference to end-of-life care: "The health accords focused on providing short-term (two-week) home care services for people discharged from hospital and those with mental health issues, and on providing end-of-life care at home" (p.31).

Extract from Health Council of Canada's report

The health system has not kept pace with evolving needs of Canadians. Expenditures on hospital care, drugs, and physicians continue to dominate Canada's health care spending despite the growing need for better prevention and management of chronic disease, improved primary care, and expanded home care services to meet the needs of our aging society.

Updated 23 September 2013

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. Complete listing on p.11.

Decisions in end-of-life care

Québec's values charter: A doctor's perspective

QUÉBEC | *The Toronto Star* (Ontario) – 19 September 2013 – One might argue a doctor's role is to deliver objective information about diagnosis, treatment and prognosis without imparting opinions about existential questions that might be influenced by personal religious beliefs. However, it is often not that simple. For example, doctors advise families about withdrawal of life-sustaining therapy when their loved one is in a vegetative state. They also routinely propose whether and under what circumstances cardiopulmonary resuscitation should be offered to a patient with a grave and terminal illness. Such decisions involve judgments on the value and meaning of life that are clearly outside of the realm of medical science. Similarly, when faced with a grim prognosis or a difficult choice, patients and their loved ones often ask their doctors: "What would you do?" Clearly, the answer to such a question would be heavily influenced by one's beliefs. On face value, one might worry about the influence of a doctor's physical display of personal religious affinity in such morally charged situations. However, I would argue that the opposite is true. http://www.thestar.com/opinion/commentary/2013/09/18/quebecs_values_charter_a_doctors_perspective.html

N.B. English language informational brochure on Québec's proposed Charter of Values: <http://www.nosvaleurs.gouv.qc.ca/medias/pdf/Values.pdf>.

U.S.A.

Immigrants rely on God, family, home in making end-of-life care decisions

THE PHILIPPINE DAILY INQUIRER (U.S. BUREAU) | Online – 21 September 2013 – When it comes to making end-of-life health care decisions, religion, family and home are powerful influences on many terminally ill Filipino immigrants in America. This can pose a challenge to providers of palliative care who must deliver comfort care with sensitivity to seriously ill or dying Filipino patients. "Only God can decide when life ends" is why many seriously ill Filipino immigrant patients and their family members tend to balk at approving advance care directives to physicians, for example. Advance directives completion rates among patients were a low ten percent, according to one study, most probably due to their religious belief that illness is pre-destined, thus making the directives pointless. <http://globalnation.inquirer.net/86151/immigrants-rely-on-god-family-home-in-making-end-of-life-care-decisions>

Noted in Media Watch, 16 September 2013, #323 (p.2):

- *THE PHILIPPINE DAILY INQUIRER* (U.S. BUREAU) | Online – 14 September 2013 – **'More Filipino Americans will need palliative care.'** Greater awareness of palliative care by Filipino Americans will be sorely needed in the coming years, judging from the rising number of elderly as well as high incidences of serious illnesses among them. But Filipino older adults over 65, like most Asians, are less likely to enroll in hospice care, an end-of-life component of palliative care. <http://globalnation.inquirer.net/85601/more-filipino-americans-will-need-palliative-care>

Specialist Publications

'End-of-life care beliefs among Hindu physicians in the U.S.' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'Development and piloting of a school-based intervention on bereavement and severe illness' (p.7), in *American Journal of Hospice & Palliative Medicine*.



World hospice &
palliative care day
Voices for hospices 2013

12 October 2013

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

What does a hospice patient look like?

TEXAS | *The Daily News* (Galveston) – 20 September 2013 – One of the first reactions to discussing hospice care with someone is "I'm not ready for hospice." Their expression seems to say, "Look at me, do I look like I'm dying today?" There is much misinformation about hospice in our culture. Not only does the general public not understand, but doctors and medical professionals are unsure of what a hospice patient looks like. Truly, someone who is unresponsive and laboring to breathe will probably die soon. But that is long past the time that hospice should have been introduced. The goal of hospice is to help someone feel better. Comfort care is providing for relief of pain and symptoms that prevent a person from doing the things that they are used to doing. It is not intended to cure disease; the focus is on relief of symptoms and helping someone feel better. Hospice is about helping someone live until they die. So what does a hospice patient look like? http://www.galvestondailynews.com/ad_features/non_profit_organizations/article_00a0de10-1fb2-11e3-a31b-0019bb30f31a.html

Recognizing caregivers as members of "care teams"

No easy answers on financing long-term care

THE NEW YORK TIMES | Online – 19 September 2013 – The federal Long-Term Care Commission published its full report, but it did little to change the perception that substantial relief for caregivers will be a long time coming.¹ The commission had endorsed a package of 28 recommendations ... prior to the release of the full report.² Among other measures, the recommendations call for recognizing caregivers as members of "care teams," including information about caregivers in patient records, assessing caregiver's need for support, and making services like respite care more widely available. But this group of 15 experts couldn't agree on how to pay for long-term care services need by frail older adults or people with disabilities. The full report doesn't change this. http://newoldage.blogs.nytimes.com/2013/09/19/no-easy-answers-on-financing-long-term-care/?ref=health&_r=0

1. 'Commission on Long-Term Care: Report to Congress,' 18 September 2013. <http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care%20-%20Final%20Report%20-%2009-18-13.pdf>
2. 'Ideas of Federal Panel on Long-Term Care don't include costs,' *The New York Times*, 13 September 2013. <http://newoldage.blogs.nytimes.com/2013/09/13/ideas-of-federal-panel-on-long-term-care-dont-cover-costs/>

Most want to discuss end-of-life care with family but few do, survey finds

MASSACHUSETTS | *The Boston Globe* – 18 September 2013 – There's a yawning gap between what people say is important to discuss about death and dying, and what actually happens, a new survey finds. Ninety-four percent of those queried said it was important to have a conversation with their loved ones about their wishes for end-of-life care, yet fewer than a third have actually held such discussions, according to the survey commissioned by The Conversation Project, a national campaign aimed at helping spur discussions among families and friends about how they want to live life at the end, so that their wishes will be followed. "That's pretty remarkable because 90% of Americans don't agree on anything," said Ellen Goodman, project co-founder. "I think there has been a huge sea change in the number of people who have been thinking about this subject," Goodman said. "I think if you had done this survey even five years ago there would have been a large number who would have tossed off the subject as not important." Women were more likely to have broached the subject, as were people 55 and over, according to the national online survey of 1,067 Americans conducted in July. <http://www.boston.com/lifestyle/health/blogs/white-coat-notes/2013/09/18/most-want-discuss-end-life-care-with-family-but-few-survey-finds/WQab0MZwwZ0pBmtX0bbn3M/blog.html>

N.B. The Conversation Project website: <http://theconversationproject.org/news/>

International

World Alzheimer Report 2013

Journey of Caring: An analysis of long-term care for dementia

ALZHEIMER DISEASE INTERNATIONAL | Online – 19 September 2013 – This report reveals, as the world population ages, the traditional system of "informal" care by family, friends and community will require much greater support. Globally, 13% of people 60 or over require long-term care. Between 2010 and 2050, the total number of older people with care needs will nearly treble from 101 to 277 million. Long-term care is mainly about care for people with dementia; around half of all older people who need personal care have dementia, and 80% of older people in nursing homes are living with dementia. Worldwide cost of dementia care is currently over US\$600billion, or around 1% of global Gross Domestic Product. <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>

Extract from World Alzheimer Report

Only 9% of people with dementia at the end of life on acute medical wards were referred to palliative care specialists, compared to 25% of people without cognitive problems. Dementia is not often thought of as a terminal illness that requires specialist care. The lack of specific dementia training for staff working in end-of-life facilities could play a role in this.

N.B. Discussion of end-of-life care begins on p.37 of the report.

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia ... [and] ... a framework to provide guidance for clinical practice, policy and research. 64 experts from 23 countries evaluated a set of 11 domains and 57 recommendations. <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

N.B. Noted in Media Watch, 14 January 2013, #288 (pp.8-9), are several articles from past issues of the weekly report on end-of-life care for people living with dementia.

Patient involvement in end of life care

Getting it right: End of life care and user involvement in palliative care social work

U.K. | Association of Palliative Care Social Workers – 19 September 2013 – Findings from this report indicate palliative care social workers have a commitment to user involvement in policy and practice... Without such support ... [and] ... with the continuing prospect of cuts in funding for public services ... these are particularly difficult times for ensuring that the momentum for user involvement is not undermined in palliative or end-of-life care. There are signs that this is happening. http://www.apcsw.org.uk/uploads/3/0/8/4/3084378/getting_it_right.pdf

Selected articles on social work in palliative care noted in past issues of Media Watch:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE* | Online – Accessed 19 May 2013 – **'Considering the role of social work in palliative care: Reflections from the literature.'** Social workers are well placed to provide skilled psychosocial support of all kinds to those struggling to come to terms with terminal illness. [Noted in Media Watch, 20 May 2013, #306 (p.12)] <http://oro.open.ac.uk/37581/1/Considering%20the%20role%20of%20social%20work%20in%20EJPC%20PDF.pdf>

Cont.

- **COMMUNITY CARE** | Online – 19 July 2012 – **'Social work "too often missing from end-of-life care."** Social workers have a vital role to play in end-of-life care, but they often struggle to perform it because of cuts, workloads and a lack of confidence, says a report from the National End of Life Care Programme.¹ [Noted in Media Watch, 23 July 2012, #263 (p.7)] <http://www.communitycare.co.uk/Articles/19/07/2012/118394/Social-work-39too-often-missing-from-end-of-life.htm>

1. 'The route to success in end of life care – achieving quality for social work,' National End of Life Care Programme, The College of Social Work & National Health Service, July 2012. http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Social_Work_Route_to_Success_web.pdf

Home care fees rise by up to 160% as rationing takes hold

U.K. (ENGLAND & WALES) | *The Daily Telegraph* – 19 September 2013 – Elderly and disabled people who need care in their own homes have been hit with rises of up to 160% in their bills in just five years, new research shows. The number of areas in which the state support for care is available to anyone other than the most frail has also halved in the same period, it discloses. A study by Which?, the consumer rights group, exposes the full extent to which councils are rationing care as they attempt to absorb major cuts to their budgets. Based on information obtained under the Freedom of Information Act, it discloses that there are now only 12 local authorities in England and Wales still offering care to people who needs are officially assessed as "moderate." <http://www.telegraph.co.uk/health/elderhealth/10318136/Home-care-fees-rise-by-up-to-160pc-as-rationing-takes-hold.html>

Social attitudes in the U.K.

Discussing death and planning for end of life

BRITISH SOCIAL ATTITUDES SURVEY | Online – 18 September 2013 – There is an intricate triangle of what people think and feel, what they are prepared to discuss openly, and what they have put into action. When asked to look ahead to their own deaths, a majority of people surveyed – more than two-thirds – expressed a wish to die at home. Such a desire is understandable and is tempered for some by the need to be clear that support services would be available. Irrespective of age, a majority of the people surveyed felt comfortable talking about death (although not necessarily their own), with older respondents slightly more likely to feel this. http://www.bsa-30.natcen.ac.uk/media/36320/bsa_30_dying.pdf

Health and social care integration: How do we make it work?

U.K. | *The Guardian* (Commentary) – 18 September 2013 – In health and social care, "integration" is the latest mantra for improving care. While our health and social care system often divides and separates us ... we are all in this to improve care for patients. We are at our best when we focus on that, and at our worst when we forget it. Integration is a perfect example of this truism. When some people talk about integration they actually mean organisational and provider integration – creating single accountable care organisations or lead providers. Others mean integrating commissioning – bringing local authority and health commissioning together into a single place. Some mean improving collaboration and co-ordination with the voluntary and other sectors. Yet others mean integrating governance – for example, creating health and wellbeing boards. And there are yet more who mean integrating finance – for example by pooling budgets or creating integrated health and social care funds. They're all integration, they're all important steps, but none of them, by and of themselves, directly improves patient outcomes. Let's please ensure that the move to integration improves patient outcomes and doesn't just end up making organisational, governance, budgetary or structural changes that do little to change patient pathways. <http://www.theguardian.com/healthcare-network/2013/sep/18/health-social-care-integration-success>

Cont.

Selected articles on health and social services integration noted in past issues of Media Watch:

- *BRITISH MEDICAL JOURNAL* | Online – 19 June 2013 – '**Independent commission will look at split between health and social care in England.**' An independent commission to consider the future of health and social care in England has been set up by the health think tank the King's Fund, which aims to publish the findings in time for the 2015 general election. [Noted in Media Watch, 24 June 2013, #311 (p.8)] <http://www.bmj.com/content/346/bmj.f3973>
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 11 June 2013 – '**Factors that promote and hinder joint and integrated working between health and social care services: A review of research literature.**' The findings suggest there is some indication that recent developments, in particular the drive to greater integration of services, may have positive benefits for organisations as well as for users and carers of services. [Noted in Media Watch, 17 June 2013, #310 (p.13)] <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12057/abstract>

Shining a spotlight on children's hospice volunteers

U.K. | Together for Short Lives – Accessed 16 September 2013 – This recently published report focuses on the impact of volunteering, the role it plays in hospice care for children, and the future of volunteering in this sector. More than 17,000 volunteers give 38,000 hours of their time each week, which equates to an annual value of £23 million. The average hospice was found to have 353 volunteers, providing a massive boost to their capacity to support children with life-limiting and life-threatening conditions and their families. Many demonstrated that they are working with volunteers in innovative ways to help improve the services offered to children and their families. [http://www.togetherforshortlives.org.uk/assets/0000/4766/Shining a spotlight on children s hospice volunteers report.pdf](http://www.togetherforshortlives.org.uk/assets/0000/4766/Shining_a_spotlight_on_children_s_hospice_volunteers_report.pdf)

Noted in Media Watch, 3 June 2013, #308 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 May 2013 – '**Volunteer activity in specialist paediatric palliative care: A national survey.**' This is the most detailed national survey of volunteer activity in palliative care services [in the U.K.] for children and young people to date and highlights the range and depth of volunteers' contribution to specialist paediatric palliative care services... <http://spcare.bmj.com/content/early/2013/05/31/bmjspcare-2012-000355.abstract>

N.B. Noted in Media Watch, 22 April 2013, #302 (pp.7-8) is several articles on hospice volunteers.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (QUEENSLAND) | *The Brisbane Times* – 21 September 2013 – '**Euthanasia to remain a criminal offence.**' Successive petitions asking for assisted suicide or euthanasia have been rejected by the Attorney-General, who acknowledges it as an issue which "polarises" the community. "At the essence of this debate, is how best to balance the competing values of the desire of individuals to choose to die with dignity when suffering and the need to uphold the inherent right to life of every person," Attorney-General Jarrod Bleijie responded. <http://www.brisbanetimes.com.au/queensland/euthanasia-to-remain-a-criminal-offence-20130920-2u57b.html>
- U.K. | 2012 British Social Attitudes Survey – 18 September 2013 – '**Life & death.**' The view that life is a sacred gift means that religious institutions often oppose euthanasia as well as abortion. This is a topic where the traditional religious view has long lacked widespread public support. Even 30 years ago (in 1983) only 23% of the public agreed that if a patient has "a painful incurable disease" a doctor should not be allowed "by law to end the patient's life, if the patient requests it." The proportion now stands even lower, at just 16%. But, in contrast to both abortion and same-sex relationships, this is one topic on which the country's legislators have so far proved reluctant to align the law with majority public opinion. <http://www.bsa-30.natcen.ac.uk/read-the-report/key-findings/personal-relationships.aspx>

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

End-of-life care beliefs among Hindu physicians in the U.S.

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 September 2013 – Studies from the U.S. and Europe show physicians' religiosity is associated with their approach to end-of-life care. No such studies have focused on Hindu physicians practicing in the U.S. Most [survey] participants believed their religious beliefs do not influence their practice of medicine and do not interfere with withdrawal of life support. The practice of discussing end-of-life issues with the patient, rather than primarily with the family, seems to have been adopted by Hindu physicians in the U.S. <http://ajh.sagepub.com/content/early/2013/09/16/1049909113505138.abstract>

N.B. Several articles on Hindu perspectives on dying and death are noted in Media Watch, 2 September 2013, #321 (p.9).

[High-school educational project on palliative care](#)

Development and piloting of a school-based intervention on bereavement and severe illness

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 September 2013 – This study was aimed at developing and piloting a school-based intervention on severe illness-induced bereavement through a project focused on spreading knowledge of palliative care among high school students... The intervention entailed screening of a topic-related movie and a classroom meeting. Eight classes from two high schools participated, and a before-after evaluation was used to assess intervention feasibility and impact. In the after evaluation, content analysis on the "strategies" question showed that answers concerning closeness and sharing were reported more frequently. <http://ajh.sagepub.com/content/early/2013/09/04/1049909113503394.abstract>

Noted in Media Watch, 4 February 2013, #291 (p.9):

- *JOURNAL OF EARLY CHILDHOOD RESEARCH* | Online – 28 January 2013 – '**Least said, soonest mended? Responses of primary school teachers to the perceived support needs of bereaved children.**' There is a limited, but growing, body of research into the impact of grief and bereavement on young children and how their support needs might be met. <http://ecr.sagepub.com/content/early/2013/01/25/1476718X12466201.abstract>

Spiritual background and its association with the medical decision of DNR at terminal life stages

ARCHIVES OF GERONTOLOGY & GERIATRICS | Online – 12 September 2013 – Although understanding the patient's medical, nursing and social background is important, a comprehensive appraisal essential for treating the "whole patient" is incomplete without a spirituality assessment. Religious beliefs and practices affect medical and health, care decisions and require recognition as a dynamic in coping with suffering, loss, life and death. Taking a spiritual background obtains information that is meaningful to the patient's life and may influence the medical decision-making relating to health. A study was undertaken to determine whether assessing the spiritual background influences medical decisions-making regarding the use of, DNR. People who are perceived as being religious or as being greatly influenced by faith/spirituality opposed the recommendation implementing DNR. Obtaining a spiritual background assists the physician to understand the patient or family spirituality, facilitates sensitivity to value frameworks and preferences in making medical and health-related, decisions. [http://www.agjournal.com/article/S0167-4943\(13\)00138-6/abstract](http://www.agjournal.com/article/S0167-4943(13)00138-6/abstract)

Cont.

Of related interest:

- *THE GERONTOLOGIST*, 2013;53(5):801-816. **'Pathways from religion to advance care planning: Beliefs about control over length of life and end-of-life values.'** Of the [survey] sample, 68.9% had an informal discussion and 46.2% both discussed their preferences and did formal ACP [advance care planning]. Conservative Protestants and those placing great importance on religion/spirituality had a lower likelihood of ACP. These associations were largely accounted for by beliefs about God's controlling life length and values for using all available treatments. Beliefs and values about control account for relationships between religiosity and ACP. <http://gerontologist.oxfordjournals.org/content/53/5/801.abstract>
- *JOURNAL OF ADVANCED NURSING* | Online – 16 September 2013 – **'Spiritual care of the child with cancer at the end of life: A concept analysis.'** Analysis identified six attributes: assessing spiritual needs; assisting the child to express feelings; guiding the child in strengthening relationships; helping the child to be remembered; assisting the child to find meaning; and, aiding the child to find hope. Antecedents include existential questions and spiritual distress. Consequences include a peaceful death, spiritual growth, a relationship of trust and enhanced end-of-life care. Spiritual care is a vital aspect of holistic nursing care; however, gaps in knowledge and practice prevent children from receiving adequate spiritual care at the end of life. Nurses would benefit from increased awareness, skills and knowledge about spiritual care. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12257/abstract;jsessionid=6EAF0E628D93F80DDEA568CD9EF6D8DD.d01t04?systemMessage=Wiley+Online+Library+will+be+unavailable+for+approximately+4+hours+between+09%3A00+EDT+and+14%3A00+EDT+on+Saturday%2C+28+September+2013+as+we+make+upgrades+to+improve+our+services+to+you.+There+will+also+be+some+delays+to+online+publishing+between+25+to+28+September+2013.+We+apologize+for+the+inconvenience+and+appreciate+your+patience.+Thank+you+for+using+Wiley+Online+Library%21&userIsAuthenticated=false&deniedAccessCustomisedMessage=>
- *NURSING STANDARD*, 2013;28(2):41-45. **'Spiritual care at the end of life.'** Healthcare professionals and those involved in policy development are questioning how to make a "good" death the expectation, rather than the exception. However, there is a lack of awareness of the importance of spirituality to patients' lives and how good spiritual care can enhance quality of life and improve patient outcomes. This article examines the role of spirituality in palliative care, focusing on spiritual assessment, communication and compassion in nursing. The article attempts to provide a working definition of spirituality, focusing on who should provide spiritual care and the difficulties in meeting spiritual needs of individuals at the end of life. <http://rcnpublishing.com/doi/abs/10.7748/ns2013.09.28.2.41.e7977>

Selected articles on spirituality and end-of-life care noted in past issues of Media Watch:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3):111. **'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.'** This issue of the *Journal of Social Work in End-of-Life & Palliative Care* gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care. [Noted in Media Watch, 24 June 2013, #311 (p.12)] <http://www.tandfonline.com/doi/full/10.1080/15524256.2013.793988>

N.B. Journal contents page: <http://www.tandfonline.com/toc/wswe20/current>

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>

- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. **'Six understandings of the word 'spirituality' in a secular country.'** Spirituality ... is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>

Public awareness and attitudes toward palliative care in Northern Ireland

BMC PALLIATIVE CARE | Online – 17 September 2013 – Public awareness of the concept of palliative care and of service availability remains insufficient for widespread effective and appropriate palliative care to be accepted as the norm. In particular, those without previous family-related experiences lack awareness. This has implications for palliative care service provision and policy. An increased awareness of palliative care is needed, in order to improve knowledge of and access to services when required, empower individuals, involve communities and ultimately to realise the objectives contained within international strategies for palliative and end-of-life care. <http://www.biomedcentral.com/content/pdf/1472-684X-12-34.pdf>

Noted in Media Watch, 20 May 2013, #306 (p.5):

- U.K. (NORTHERN IRELAND) | University of Ulster – 16 May 2013 – **'Dying matters taught at school: New research.'** Secondary schoolchildren should be educated about death and dying, one of the recommendations in a new palliative care report. 'Exploring Public Awareness of Palliative Care' is the first study of its kind in Northern Ireland to explore public perceptions towards palliative care. <http://news.ulster.ac.uk/releases/2013/6965.html>

Development and initial validation of a new outcome measure for hospice and palliative care: The St. Christopher's Index of Patient Priorities (SKIPP)

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 16 September 2013 – SKIPP can detect patients' [i.e., hospice inpatients and homecare patients] perception of change in quality of life and main concerns, and the difference patients think the service has made to them. Its design with current and retrospective components addresses response shift and means it can be used for quality improvement or clinical purposes with only one administration, an advantage in frail populations. <http://spcare.bmj.com/content/early/2013/09/16/bmjspcare-2012-000352.abstract>

Death acceptance: Facilitated communication with low-English proficiency patients at end of life

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(7):390-395. There is a paucity of research that describes communication patterns among nurses, patients and caregivers during palliative discussions. A successful outcome of communication strategies ... is an enhanced understanding of patient's lived experiences ... to bridge the theory-to-practice gap in palliative care. http://journals.lww.com/jhpn/Abstract/2013/10000/Human_Becoming_Death_Acceptance_Facilitated.7.aspx

Religious leaders' perspectives of ethical concerns at the end of life

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(7):396-402. The aims of this study were to describe the perspectives and experiences of religious leaders who have assisted individuals facing end-of-life ethical concerns and to evaluate the feasibility of conducting a larger study. Interviews were conducted ... with religious leaders from 4 different religions: Catholicism, Judaism, Islam, and Hinduism. Analysis revealed common themes among [their] experiences ... including respect and dignity of life and the body, challenges at end of life, and beliefs about the afterlife, which all have far-reaching effects on the practices at end of life. Understanding these ... can further the ability of health care professionals to help those facing end-of-life situations. http://journals.lww.com/jhpn/Abstract/2013/10000/Religious_Leaders_Perspectives_of_Ethical.8.aspx

Contending with advanced illness: Patient and caregiver perspectives

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 September 2013 – [Study] participants engaged in a process of contending with advanced illness. The major phases comprising this process were suffering, struggling, and settling. Struggling included enduring the experience and fighting the illness. During the phase of settling, the focus shifted away from curative efforts and toward supportive care. Conditions that facilitated the movement into this phase included receiving clear and consistent information about the patient's health status, trusting health care providers, having attended to advance care planning in some form, and being aware of and able to acknowledge the terminal nature of the illness. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00394-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00394-1/abstract)

Of related interest:

- *EVIDENCED-BASED NURSING* | Online – 19 September 2013 – '**Home palliative care services increase the chance of adults with advanced illness dying at home and reduce symptom burden without impact on caregiver grief.**' This review found evidence of the benefits of providing home-based palliative care, supporting people to die at home, particularly those with advanced cancer. It is possible for service planners to calculate the levels of service required and project future need; however, planning is complex and multi-factorial. <http://ebn.bmj.com/content/early/2013/09/19/eb-2013-101505.extract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 September 2013 – '**Perspectives of family members on planning end-of-life care for terminally ill and frail older people.**' Family members [i.e., study participants] took different positions in the ACP [advance care planning] process depending on how much responsibility the family member wanted to take on and to what extent the family member felt the patient expected him/her to play a part. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00392-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00392-8/abstract)

[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.

Developing relationships with in-memoriam charitable donors: Insights from the bereavement literature

SOCIAL BUSINESS, 2013;3(2):143-161. This study ... focuses on two particularly challenging aspects of bereavement: namely, the urge to search and the shattering of assumptive worlds. It considers areas generally associated with recovery from grief: finding meaning in the death, the continuation of bonds with the deceased, social support and, finally, symbolic immortality. This paper suggests ways in which non-profit organisations can add value to the experience of their bereaved supporters and, potentially, develop long-lasting, mutually beneficial relationships with them. <http://www.ingentaconnect.com/content/westburn/sb/2013/00000003/00000002/art00005>

Media Watch Online

Asia

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

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

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

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

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>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

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

International

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

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

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)

Worth Repeating

How far are people with learning disabilities involved in funeral rites?

BRITISH JOURNAL OF LEARNING DISABILITIES, 2003;31(1):42-45. Research and clinical experience both suggest that people who have not been fully involved in funeral rituals have delayed and/or prolonged grief reactions. This study in a multicultural inner London [England] borough examined local religious and cultural practices following bereavement of people with learning disabilities. Interviews were sought with funeral directors and representatives from six religious groups to build up a picture of local practice, resources and knowledge, particularly with regard to how people with learning disabilities are involved in the process. It was found that most of the local funeral directors had little direct experience of people with learning disabilities. The religious group representatives who were interviewed also spoke of a lack of involvement of people with learning disabilities. A pamphlet has been designed for funeral directors and religious groups to give to families or friends of people with learning disabilities who have been bereaved. <http://onlinelibrary.wiley.com/doi/10.1046/j.1468-3156.2003.00216.x/abstract;jsessionid=BD2176D299B3A366F221B75C5768A12D.d04t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net