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.

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Effecting change in the illness experience: Scroll down to <u>Specialist Publications</u> and 'Difficult conversations: Teaching medical oncology trainees communication skills one hour at a time' (p.7), in *Academic Medicine*.

Canada

End-of-life debate in everyone's interest

ALBERTA | Sundre Roundup - 25 February 2014 - The Canadian Medical Association (CMA), which represents physicians in every province and territory, has launched an undertaking regarding the highly controversial issue of physician-assisted death. Using a town-hall format over the next three months. the end-of-life (EOL) public input gathering initiative will see stakeholders given a chance to weigh in on whether they believe individuals should have the legal right to end their lives at the time of their choosing. As quite literally a matter of life and death, the outcome of the ongoing EOL debate could end up impacting Canadians for years and decades to come. As one of the most contentious health-care issues facing Canada in 2014, the end-of-life discussion has in fact been going on for many years, with passions always running very high on both sides. http://www.sundreroundup.ca/article/201402 25/SUN0902/302259976/-1/sun09/end-of-life-debate-in-everyone-s-interest

Specialist Publications

'Opportune timing for palliative care specialty designation' (p.8), in Canadian Medical Association Journal.

Noted in Media Watch, 24 February 2014, #346 (p.10):

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 20 February 2014 – 'Canada needs a "dialogue about death" says CMA president.' Canada is facing a severe crisis surrounding end-of-life care due to the stigma surrounding it and funding concerns, Dr. Louis Hugo Francescutti, president of the Canadian Medical Association told the Economic Club of Canada. Unfortunately, palliative care is currently only available to 15-30% of Canadians. http://www.cmaj.ca/site/earlyreleases/20feb14 Canada-needs-a-dialogue-about-death-says-CMA-president.xhtml

N.B. Landmark reports on end-of-life care in Canada:

2012: La Commission spéciale sur la question de mourir dans la dignité dépose son rapport,' Quebec Select Committee on Dying with Dignity.

http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en

2011: 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf

2011: 'The Royal Society of Canada Expert Panel: End of Life Decision Making.' http://rsc-src.ca/sites/default/files/pdf/RSCEndofLifeReport2011 EN Formatted FINAL.pdf

2011: 'Palliative Care: An Enforceable Canadian Human Right?' *McGill Journal of Law & Health*. http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V.,%20No.%201%20-%20Shariff.pdf

2010: 'Raising the Bar: A Roadmap for the Future of Palliative Care in Canada,' Senator Sharon Carstairs, Senate of Canada. http://www.sharoncarstairs.ca/RaisingtheBarJune2010.pdf

2005: 'Still Not There: Quality End-of-Life Care,' Senator Sharon Carstairs, Ottawa. http://www.sharoncarstairs.ca/StillNotThereJune2005.pdf

2000: 'Quality End-of-Life Care: The Right of Every Canadian,' Subcommittee to update 'Of Life and Death' of the Standing Senate Committee on Social Affairs, Science & Technology. http://www.parl.gc.ca/Content/SEN/Committee/362/upda/rep/repfinjun00-e.htm

1995: 'Of Life & Death,' Report of the Special Senate Committee on Euthanasia & Assisted Suicide. http://www.parl.gc.ca/Content/SEN/Committee/351/euth/rep/lad-tc-e.htm

Doctor who treats dying asks for legal "clarity" in end-of-life decisions

ONTARIO | *The Ottawa Citizen* – 23 February 2014 – A lot of patients tell Dr. Angela Genge they would rather commit suicide than live with amyotrophic lateral sclerosis (ALS). But then they start changing their minds. Genge is a neurologist at the Montreal Neurological Institute. ALS patients know they are dying [she told members of the Canadian Bar Association (CBA)]. "People die two to five years after they develop the disease" because eventually they can't breathe or swallow, Genge told the lawyers. "They are very fearful of what that end will be like," she said. "Most who start off wishing to die immediately rather than suffer – once they understand the disease and once they live with the disease for two to three months – will change their minds about the time course in which they want this death to happen." Usually they wish to delay their death. "What changes is how quickly they want to die," and because treatment can keep them alive for years, this difference is "huge." In some cases "they change from wanting to die to wanting to live." http://www.ottawacitizen.com/health/Doctor+treats+dying+asks+legal+clarity+life+decisions/9541415/story.html

N.B. Canadian Bar Association's *National Magazine*'s live webcast of the panel discussion: http://www.nationalmagazine.ca/endoflife.aspx

Noted in Media Watch, 14 February 2011, #188 (p.8):

JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY | Online – 5 February 2011 – 'Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.' Despite an international consensus that ALS management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. Late referral to palliative services in ALS is not uncommon and may impact negatively on the quality of life of ALS patients and their caregivers. http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3

Assisted (or facilitated) death

Representative sample of recent news media coverage:

* THE GLOBE & MAIL | Online – 23 February 2014 – 'Liberals vote to decriminalize medically assisted suicide.' The Liberal Party of Canada is in favour of decriminalizing medically assisted suicide, adopting a resolution on the controversial matter at the end of its four-day policy convention. The issue was decided in a tight vote at a plenary session at the convention ... signaling a clear position by the party in relation to assisted suicide for some critically ill patients. The resolution showcases a willingness of the party to take a stance on issues of freedom and choice, offering a contrast with the positions of the Conservative government. http://www.theglobeandmail.com/news/politics/liberals-vote-to-legalize-assisted-suicide/article17055601/

Specialist Publications

'A study of Canadian hospice palliative care volunteers' attitudes toward physician-assisted suicide' (p.13), in American Journal of Hospice & Palliative Medicine.

N.B. The policy resolution was a joint proposal from the Young Liberals of Canada and the National Women's Liberal Commission. In October 1986, the Liberal Party of Canada passed a similar resolution; no action, however, was taken on the issue

U.S.A.

At the end of life, hospices try to bridge the racial and ethnic divide

CALIFORNIA ENDOWMENT HEALTH JOURNALISM FELLOWSHIPS | Reporting on Health - 27 February 2014 - An inability to attract communities of color has been the greatest failing of the 40-year-old hospice movement in the U.S. In its neglect, hospice has marched in step with the health care system overall. Still, the movement that was so far-sighted in its compassionate, holistic approach to the care of the dying has had a blind spot regarding race and ethnicity. People of color are the fastest growing populations in America, and by mid-century, they will represent the majority. Yet more than 80% of hospice patients are white. Age accounts for some of the disparity - populations of color skew younger. But they have higher death rates from many cancers and other diseases, and many more patients can benefit from hospices services. Terminally ill white patients are much more likely to hear about hospice through a relative or friend, somebody they trust who had a good experience with a program. People of color typically learn about hospice in the hospital, from a stranger. A study summed up a common reaction among Latinos: "I didn't know what hospice was. I thought it was a place worse than a hospital." Hospice pioneers in the 1970s battled such misconceptions but most did not venture beyond their white middleclass worlds. http://www.reportingonhealth.org/2014/02/26/end-life-hospices-try-bridge-racial-andethnic-divide

- National Hospice & Palliative Care Organization, Facts & Figures, 2013.
 [Noted in Media Watch, 4 November 2013, #330 (p.3)]
 http://www.nhpco.org/sites/default/files/public/Statistics
 Research/2013 Facts Figures.pdf
- "The worst thing about hospice is that they talk about death": Contrasting hospice decisions
 and experience among immigrant Central and South American Latinos with U.S.-born White,
 non-Latino cancer caregivers,' *Palliative Medicine*, 2010;24(4):427-434. [Noted in Media
 Watch, 10 September 2012, #270 (p.11, under 'Worth Repeating.').
 http://pmj.sagepub.com/content/24/4/427.short

Study finds few benefits in "medical home" care model

MAINE PUBLIC BROADCASTING NETWORK | Online – 27 February 2014 – A study found one of the first, longest-running "medical home" health reform pilots in the U.S. has yielded few improvements in quality and no reduction in costs. The study has created a bit of a stir among health reform advocates. The takeaway from the study, says [co-author] Mark Friedberg, is not that medical homes are a failed idea. It's how you implement the model and evolve that matters. http://www.mpbn.net/News/MaineNewsArchive/tabid/181/ctl/ViewItem/mid/3475/ItemId/32475/Default.aspx

 'Association between participation in a multi-payer medical home intervention and changes in quality, utilization, and costs of care,' *Journal of the American Medical Association*, 2014;311(8):815-825. http://jama.jamanetwork.com/article.aspx?articleid=1832540

How a palliative-care team changes everything

THE WALL STREET JOURNAL | Online – 26 February 2014 – Many patients and families are understandably confused and conflicted when it comes to end-of-life care. In America, we have a "more is better" philosophy, coupled with a (literal) "never say die" attitude. In some cases, this bias toward aggressive care is appropriate, but I have been struck over the years by the many, many times in which we end up providing care to patients that turns their final days into a medicalized version of torture. Not only is this inhumane, it is wildly expensive for families and the health-care system. http://blogs.wsj.com/experts/2014/02/26/how-a-palliative-care-team-changes-everything/

Palliative care gains favor as it lowers costs

THE WALL STREET JOURNAL | Online -23 February 2014 - Insurers are establishing programs that give the sickest patients the chance to receive extra care for their pain, suffering and emotional needs, in a move that turns out to cut spending substantially. The programs have their critics, who say the insurers' real goal is to bolster profits by pushing patients to forgo costly treatments that could prolong their lives. But supporters counter that the lowered costs are simply a fortunate side effect, and that fulfilling patients' wishes and needs is the main goal. "By improving quality of care for that group, it can also reduce the number of repeat hospitalizations and other emergency interventions, which is extremely expensive for payers," says Emily Warner, a senior

policy analyst at the Center to Advance Palliative Care at the Icahn School of Medicine at Mount Sinai. In recent years insurers ... have created such programs – a trend likely to continue as the population ages and efforts are made to both cut costs and improve care for patients at the end of their lives. http://www.marketwatch.com/story/palliative-care-gains-favor-as-it-lowers-costs-2014-02-23-17449323?pagenumber=1

Specialist Publications

'National hospice survey results: For-profit status, community engagement, and service' (p.9), in *JAMA Internal Medicine*.

Noted in Media Watch, 13 January 2014, #340 (p.3):

■ NEBRASKA | *The Journal Star* (Lincoln) – 4 January 2014 – **'Protect true hospice care.'** The danger is that the for-profit companies that are gaming the system will damage the image of hospice, and worse, make some people reluctant to enter hospice care. http://journalstar.com/news/opinion/editorial/editorial-protect-true-hospice-care/article-b207e9cf-1dd5-5baa-aaca-958fdaa61de2.html?comment_form=true

N.B. Noted in this issue of Media Watch is a representative sample of articles on for-profit hospice in the U.S. noted in past issues of the weekly report.

Prison hospice

Roses and thistles: These graduates earned a degree in compassion

IOWA | *The Des Moines Register* – 22 February 2014 – A rose to inmates at the Iowa State Penitentiary who are volunteering to provide hospice care to fellow inmates. Eleven inmates recently graduated from a training program by Lee County Hospice to work in the prison's hospice unit. The penitentiary pays outside care providers in addition to relying on volunteers, which is unique among the state's prison system. This is becoming an increasingly important service within the penitentiary, which houses some inmates who will never leave the prison alive. For many of them, their last days will be spent in hospice care with support provided by fellow convicts. For some, this display of human kindness inside the walls of prison will be their last. The Iowa State Penitentiary's hospice is the subject of a documentary film, 'Prison Terminal: The Last Days of Private Jack Hall,' which tells the story of the final months of Hall's life and the hospice volunteers who cared for him. The documentary, nominated for an Oscar, is scheduled to premiere on HBO 31 March 2014. The documentary ... may be the last documentary of life inside the prison that will close later this year. http://www.desmoinesregister.com/article/20140223/OPINION/302230055/-1/becker_trial/Roses-Thistles-These-graduates-earned-degree-compassion?nclick_check=1

N.B. 'Prison Terminal: The Last Days of Private Jack Hall' website: http://www.prisonterminal.com/index.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

• ARIZONA | The Daily Reporter (Greenfield, Indiana) – 25 February 2014 – 'Arizona legislator says bill narrows definition of assisted suicide, makes prosecution easier.' The Arizona House has approved a bill that aims to make it easier to prosecute people who help someone commit suicide. House Bill 2565 defines assisting in suicide as offering and providing the physical means used to commit suicide, such as a gun. Current state statute does not clearly define what it means to "assist." House approved the bill 41-18. It will now move to the Senate. http://www.greenfieldreporter.com/view/story/b94f9197040d4fc4b35de673964467e4/AZ-XGR-Assisted-Suicide

International

End-of-life care in Scotland

Neonatal hospice care is a new, and vital, focus

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 25 February 2014 – Palliative care for newborn babies can help families make precious memories that last a lifetime, says Pat Carragher. For any new parents, getting the right care for their new baby is hugely important. But nowhere is this more crucial than in neonatal wards and children's hospices, when a very young baby needs palliative care. As the only children's hospice charity in Scotland, Children's Hospice Association Scotland has seen a steady rise in the number of babies referred to us who are very young and require palliative care. Up until now the children's hospice movement has not concentrated on this area. Each year in Scotland, some 400 to 450 children and young people die before the age of 18. Of these, more than 100 are babies less than one year old, and most die in a hospital neonatal ward. So we are working with baby units across Scotland and asking ourselves if this is the very best outcome for those babies and their families, or whether we can provide more support to those whose baby needs end of life care. http://www.scotsman.com/news/neonatal-hospice-care-is-a-new-and-vital-focus-1-3318421

End-of-life care in Pakistan

St. Joseph's Hospice in Islamabad faces closure

PAKISTAN | *The News International* (Karachi) – 24 February 2014 – Since 1964, St. Joseph's Hospice has treated hundreds of maimed and sick patients, overwhelmingly Muslims, who had nowhere else to go even as Pakistan experienced two military coups, wars in neighboring Afghanistan and a dangerous rise in militancy. But as wealthy donors and foreign benefactors fled the violence and unrest, so too did the endowments the hospice relies on to treat some 100 patients who visit daily. Pakistan's abysmal health care sector is starved for money, the latest technology and drugs – and those who can't afford care have turned to St. Joseph's. The hospice has a monthly budget of about 1.5 million rupees – \$15,000 – but officials there say they have been facing a shortfall of half a million rupees (about \$5,000) a month. They've borrowed money and cut costs as low as they can, but there's not much more they can do. "Initially, we managed to handle the situation, but now the situation is alarming," said Margaret Walsh, an Irish nun who has run the facility as the chief administrator since 2009. http://www.thenews.com.pk/article-138966-St.-Josephs-Hospice-in-Islamabad-faces-closure

Noted in Media Watch, 16 December 2013, #336 (p.7):

PAKISTAN | The Express Tribune (Islamabad) – 8 December 2013 – 'Humanity in need: As funds dry, historic hospice needs help.' For six decades, the destitute and needy in ... Rawalpindi have had a place where they knew they would be looked after, regardless of caste or creed. However, in a few months, that could all be a thing of the past. Saint Joseph's Hospice in Rawalpindi has been in dire financial straits ever since foreign donors started packing up and leaving the country after 9/11. http://tribune.com.pk/story/642663/humanity-in-need-as-funds-dry-historic-hospice-needs-help/

N.B. St. Joseph's Hospice website: http://www.stjosephshospice.com.pk/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Channel 5 News 27 February 2014 'Two in three people want assisted dying option for dementia patients.' Nearly two in three people would support assisted dying for dementia patients who can no longer recognise their family, if they had expressed the wish to die when they were still mentally capable, according to a Channel 5 News / YouGovpoll. http://www.channel5.com/shows/5-news/features-archived/channel-5-news-two-in-three-people-want-assisted-dying-option-for-dementia-patients
- INDIA | NDTV (New Delhi) 25 February 2014 'Supreme Court refers plea to allow euthanasia to Constitution bench.' A five-judge Constitution bench will decide whether a "living will" or voluntary euthanasia can be allowed if a person is terminally ill or may go into a vegetative state with no hope of recovery. http://www.ndtv.com/article/india/supreme-court-refers-plea-to-allow-euthanasia-to-constitution-bench-487828?curl=1393336771

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

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

Difficult conversations: Teaching medical oncology trainees communication skills one hour at a time

ACADEMIC MEDICINE | Online – 19 February 2014 – Medical oncologists need outstanding, patient-centered communication skills to build trust and rapport with their patients and help them make well-informed decisions. Key skills include exploring patients' perspectives, responding to emotion with empathy, and maintaining mindfulness during highly charged conversations. These skills can be taught and learned. Most previously described communication skills training curricula for oncology providers involve multiday retreats, which are costly and can disrupt busy clinical schedules. Many curricula involve a variety of oncology providers, such as physicians and nurses, at various stages of their careers. The authors developed a monthly, one-hour communication skills training seminar series for physicians in their first year of medical oncology subspecialty training. Learners had the opportunity to practice skills during sessions and with patients between sessions. They acquired important skills and found the curriculum to be clinically relevant, judging by anonymous surveys and anonymous responses on reflective writing exercises. http://journals.lww.com/academicmedicine/Abstract/publishahead/Difficult Conversations Teaching Medical.99145.aspx

Of related interest:

- JOURNAL OF NURSING EDUCATION & PRACTICE, 2014;4(4):168-171. 'The voice of nurse educators on teaching end of life care in U.S. schools of nursing.' Two hundred and four participants responded to the question of whether they had been able to integrate EOLC [end-of-life care] content into their respective programs and 138 answered in the affirmative, although almost all of the participants, even those who claimed some success in the integration of EOLC content, shared having met with various obstacles. How much EOLC education was integrated and what was actually taught varied considerably. Significant barriers were identified by many respondents and recommendations for improvement were offered. <a href="http://scholar.google.ca/scholar_url?hl=en&q=http://www.sciedu.ca/journal/index.php/jnep/article/download/3751/2462&sa=X&scisig=AAGBfm2IKCynkA2oA0zM_XbKrjgjcWJFqQ&oi=scholar_alrt
- PRIMARY HEALTH CARE, 2014;24(1):18-25. 'End of life care: An educational pathway for community nurses.' This article reports on an innovative educational pathway for district and community nurses aimed at enhancing confidence and competence in dealing with end of life care (EoLC). Nurses were aligned with a mentor from a specialist palliative care team and, after completing a training needs analysis, created their own development plan. Participants undertook a range of formal and informal education, and a rise in confidence was identified, specifically in communication skills and symptom management. Such practice-based education may offer a powerful and convenient approach to EoLC education for community staff. http://rcnpublishing.com/doi/abs/10.7748/phc2014.02.24.1.18.e804

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.13.

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch

End-of-life care in Canada

Opportune timing for palliative care specialty designation

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online - 28 February 2014 - It may be a coincidence that palliative care recently came into its own as a subspecialty, but the timing is fortuitous, given the proposed Quebec legislation on medically assisted death and the pending Supreme Court case on euthanasia. These moves make it imperative to improve education and access to palliative care, says Dr. Doris Barwich, president of Canadian Society of Palliative Care Physicians... The society is concerned that the Quebec legislation is coming forward as an option in the continuum of end-of-life care, but "at the same time, we're not educating physicians in terms of how to communicate with people at the end of life or how to identify options in pain and symptom management, how to really support people and get teams involved," says Barwich. "The requests for hastened death are usually directly linked to the amount of support that people are receiving. That's a really critical first piece." The specialty, which was formally recognized by the Royal College of Physicians & Surgeons on 14 November 2013, will be accessible to physicians from many different specialties, including family medicine. The two-year training programs are projected to begin in 2016 at various institutions across Canada. Practicing palliative care physicians who want specialty designation will need to document their experience and write an exam. The first exam will be held in 2018. With specialty status, the society will ramp up advocacy, education and research in the field. It provides recognition for physicians in the specialty. http://www.cmaj.ca/site/earlyreleases/28feb14 Opportune timing for palliative care specialty d esignation.xhtml

Quality of end-of-life care for those who die at home: Views and experiences of bereaved relatives and carers

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(2):63-67. This paper reports findings from a study that explored bereaved relatives' and carers' experiences of end-of-life care at home using the Care of the Dying Evaluation questionnaire. Data from questionnaires completed by seventy-two carers of patients who had died at home in the North West of England underwent qualitative analysis. In general, good quality care was provided, but there were times when adequate support was not evident in relation to pain control and what to expect when death was imminent. http://www.ijpn.co.uk/cgi-

bin/go.pl/library/article.html?uid=103385;article=IJPN 20 2 63 67

The acute hospital setting as a place of death and final care: A qualitative study on perspectives of family physicians, nurses and family carers

HEALTH & PLACE, 2014;27:77-83. While the focus of end-of-life care research and policy has predominantly been on "death in a homelike environment," little is known about perceptions of the acute hospital setting as a place of final care or death. Study participants generally perceived the acute hospital setting to be inadequate for terminally ill patients, although they indicated that in some circumstances it might be a "safe haven." http://www.sciencedirect.com/science/article/pii/S1353829214000215

Of related interest:

PALLIATIVE & SUPPORTIVE CARE | Online – 13 February 2014 – 'Where to die? That is the question: A study of cancer patients in Israel.' Most patients prefer to die at home, but barely 30% do so. This study examines the variables contributing to dying at home. The findings indicate the chances of dying at home are higher if the patient is non-Ashkenazi, the family got social worker care, the patient lived in a self-owned house, the patient lived with his family, the family members worked, and the patient's stay in Israel since immigration was longer. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9174097&fulltextType=RA&fileId=S1478951513000904

N.B. Ashkenazic Jews are the Jews of France, Germany, and Eastern Europe, and their descendants.

An overview of hospice and palliative care nursing models and theories

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(2):75-81. The aim of this paper is to describe existing palliative care and hospice nursing models and theories and identify their core concepts. Literature published between 2002 and 2012 on such models was reviewed and subjected to analysis. Ten core concepts were identified that fell into three categories: patient, nurse, and therapeutic relationship. In developing a therapeutic relationship with patients, nurses have a "privileged" experience that may lead to existential growth and job satisfaction. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=103387;article=IJPN 20 2 75 81

Role of the psychiatrist in palliative care

A comprehensive review of palliative care in patients with cancer

INTERNATIONAL REVIEW OF PSYCHIATRY, 2014;26(1):87-101. Patients with advanced cancer, and other life-threatening medical illnesses are at increased risk for developing major psychiatric complications and have an enormous burden of both physical as well as psychological symptoms. In fact, surveys suggest that psychological symptoms such as depression, anxiety, and hopelessness are as frequent, if not more so, than pain and other physical symptoms in palliative care settings. In this article the authors provide a comprehensive review of basic concepts and definitions of palliative care and the experience of dying, and the role of the psychiatrist in palliative care including assessment and management of common psychiatric disorders in the terminally ill, with an emphasis on suicide and desire for hastened death. Psychotherapies developed for use in palliative care settings and management of grief and bereavement are reviewed. http://informahealthcare.com/doi/abs/10.3109/09540261.2013.868788

Noted in Media Watch, 14 October 2013, #327 (p.12):

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 October 2013 – 'Current state of psychiatric involvement on palliative care consult services: Results of a [U.S.] national survey.' There are shared objectives between psychiatry and palliative care; however, co-involvement on treatment teams is limited. Research is needed to identify ways to facilitate the interface of palliative care and psychiatry. http://www.jpsmjournal.com/article/S0885-3924(13)00401-6/abstract

End of life care in the U.S.

National hospice survey results: For-profit status, community engagement, and service

JAMA INTERNAL MEDICINE | Online – 24 February 2014 – The impact of the substantial growth in for-profit hospices in the U.S. on quality and hospice access has been intensely debated, yet little is known about how for-profit and non-profit hospices differ in activities beyond service delivery. A total of 591 hospices completed the authors' survey (84% response rate). For-profit hospices were less likely than non-profit hospices to provide community benefits, including serving as training sites, conducting research and providing charity care. For-profit compared with non-profit hospices cared for a larger proportion of patients with longer expected hospice stays including those in nursing homes. For-profit hospices were more likely to exceed Medicare's aggregate annual cap and had a higher patient disenrollment rate. For-profit were more likely than non-profit hospices to engage in outreach to low-income communities and minority communities and less likely to partner with oncology centers. Although Medicare's aggregate annual cap may curb the incentive to focus on long-stay hospice patients, additional regulatory measures ... should be considered as the share of for-profit hospices in the U.S. continues to increase. https://archinte.jamanetwork.com/article.aspx?articleid=1832198

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 27 February 2014 'Hospice agencies' hospital contract status and differing levels of hospice care.' Given that a significant portion of hospices do not have a contract with a hospital, policy makers need to understand barriers to contracts with a hospital/SNF [skilled nursing facility] for GIP [general inpatient care] and consider a hospice's contract status as one of the standards for hospice certification. http://ajh.sagepub.com/content/early/2014/02/26/1049909114524815.abstract
- JAMA INTERNAL MEDICINE | Online 24 February 2014 Commentary on 'National hospice survey results: For-profit status, community engagement, and service.' In recent years, the tremendous growth in the number of for-profit hospices has received increasing scrutiny in both the lay press and medical journals. Academicians, reporters, and government regulators have raised concerns about for-profit hospices' aggressive marketing practices, narrower scope of services offered, and enrollment of a case mix of patients with longer lengths of stay and higher profits. Although there is no direct evidence that the quality of care provided to patients differs by hospice ownership, some believe that for-profit hospices ... are more often motivated by making money rather than by the altruistic goal of providing quality care to dying patients. https://archinte.jamanetwork.com/article.aspx?articleid=1832191

Cancer in the elderly: Is it time for palliative care in geriatric oncology?

JOURNAL OF GERIATRIC ONCOLOGY | Online – 24 February 2014 – Elderly who need palliative care are frequently disregarded as individuals and may experience discrimination because of their age. Palliative care for older patients relates particularly to multiple treatments for various conditions. This causes extra complexities for the researchers. The aim of the study [to evaluate the needs in elderly patients affected by cancer and the state of the art of the research in palliative care in this setting] was not fully achieved due to the paucity of literature focusing upon these issues. The areas of investigation that need to be addressed comprise: establishing the prevailing symptoms in elderly patients, understanding patients' psychological/spiritual well-being and quality of life and elucidating the sources of caregiver burden, adapting research methodologies specifically for palliative care and comparing the needs and the outcomes of this age group to younger patients. http://www.geriatriconcology.net/article/S1879-4068(14)00036-8/abstract

Noted in Media Watch, 24 February 2014, #346 (p.9):

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 21 February 2014 – 'Regardless of age: Incorporating principles from geriatric medicine to improve care transitions for patients with complex needs.' This article provides a framework for incorporating geriatrics principles into care transition activities by discussing the following elements: 1) identifying factors that make transitions more complex; 2) engaging care "receivers" and tailoring home care to meet patient needs; 3) building "recovery plans" into transitional care; 4) predicting and avoiding preventable readmissions; and, 5) adopting a palliative approach, when appropriate, that optimizes patient and family goals of care. http://link.springer.com/article/10.1007/s11606-013-2729-1

Precedent autonomy should be respected in life-sustaining treatment decisions

JOURNAL OF MEDICAL ETHICS | Online – 24 February 2014 – In the 2011 landmark case of W v M, the English Court of Protection ruled that it was unlawful to withdraw artificial nutrition and hydration from a woman who had been in a minimally conscious state for 8 years. From the perspective of the court, the absence of a written advance directive negated the woman's previous, autonomous interests and, consequently, emphasis was given to her current welfare and well-being. While life itself is a moral good, prolonging life for a person in regular pain with no hope of recovering to a more complete state of awareness simply because that person only verbalized her wishes about her treatment decisions seems to drastically undervalue the principle of autonomy. http://jme.bmj.com/content/early/2014/02/23/medethics-2013-102004.short

Cont.

Noted in Media Watch, 3 October 2011, #221 (p.6):

■ U.K. | The Daily Telegraph – 28 September 2011 – 'Judge rejects family's right to die case.' In the first case of its kind in this country, Mr. Justice Baker said that preservation of life was a fundamental principal of law. The woman's mother and sister had urged him to allow her to die, describing her "pointless existence" and saying she would not have wanted to live in such a state. But the judge found that the woman, identified only as "M," did have "some positive experiences" and crucially there was a "reasonable prospect" that those experiences could be extended. In a landmark 43,000 word judgment, he acknowledged that prior to her illness, "M" had told her family that she would not want to be kept alive in such circumstances. http://www.telegraph.co.uk/health/healthnews/8794013/Judge-rejects-familys-right-to-die-case.html

A palliative care approach for people with advanced heart failure: Recognition of need, transitions in care, and effect on patients, family carers, and clinicians

THE LANCET | Online - 26 February 2014 - Despite international and national consensus guidelines, patients with advanced heart failure have substantial unmet palliative care needs. U.K. policy recommends that identification of those requiring palliative care should be based on prognosis (last year of life). However, heart failure has an unpredictable course, and clinicians might not discuss a palliative approach for fear of causing alarm and destroying hope. We aimed to explore aspects of a palliative care approach for people with advanced heart failure and assessed recognition of need, transitions in care, and effect on patients, family carers, and clinicians. General Practice Research Database (GPRD) data showed gross inequity in documented recognition of the need for a palliative care approach between patients with cancer and patients with heart failure: patients with heart failure were poorly represented on the palliative care register, and those who were represented, were registered close to death. Prognostic markers, identified in both the systematic review and the GPRD, had little clinical usefulness for identifying the last year of life. From interview data, clinicians seemed reluctant to discuss a palliative care approach without clear irreversible deterioration of the patient. However, patients welcomed, and some initiated, conversations about the change in focus of care. After such discussion, patients, carers, and clinicians found this approach beneficial, even with subsequent periods of stability or improvement. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)60313-5/fulltext#article_upsell

Noted in Media Watch, 13 January 2014, #340 (p.11):

■ JOURNAL OF THE AMERICAN HEART ASSOCIATION | Online – 2 January 2014 – "Not the 'grim reaper service": An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure.' Providers [i.e., study participants] had limited knowledge regarding what palliative care is, and how it can complement traditional heart failure therapy to decrease related suffering. Nevertheless, providers expressed interest for integrating palliative care into traditional care, but were unsure of how to initiate same. http://jaha.ahajournals.org/content/3/1/e000544.abstract?sid=0cecc158-d515-d9f-bcbb-a124374c1c70

'Report calls for better palliative and end-of-life care for patients that relapse following transplant.'

NEWS MEDICAL | Online – 26 February 2014 – Haematological disorders of the blood and bone marrow, such as leukaemia, are commonly treated with a bone marrow transplant. However relapse is common and often leads to treatment failure and death. Despite this there is little research available to guide nurses through the process of palliative and end-of-life care for patients that relapse following bone marrow transplant. Survey results by Griffith University's National Centre for Research Excellence in Nursing have found senior haematology nurses in Australia and New Zealand believe relapsed transplant patients are often referred to palliative care services too late in their cancer journey, with little consideration given to EOL planning. http://www.news-medical.net/news/20140226/Report-calls-for-better-palliative-and-EOL-care-for-patients-that-relapse-following-transplant.aspx

pg. 11

"It is the 'starting over' part that is so hard": Using an online group to support hospice bereavement

PALLIATIVE & SUPPORTIVE CARE | Online – 24 February 2014 – Although hospice agencies are required to provide informal caregivers ... with bereavement support when their loved one passes, most interventions lack standardization and remain untested. The authors employed the Dual Processing Model of Bereavement as a framework for assessing the potential of a secret Facebook group for bereaved hospice caregivers. The majority of online talk was oriented to restoration, revealing abrupt and anticipated triggers that evoked feelings of loss. Caregivers shared loss orientation through storytelling, sharing and giving advice, and encouraging others to manage the challenges of coping. Caregiver anxiety and depression were lower after the intervention. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9174157&fulltextType=RA&fileId=S1478951513001235

Noted in Media Watch, 5 March 2012, #243 (p.11):

 OMEGA – JOURNAL OF DEATH & DYING, 2012;64(4):275-302. 'Does the Internet change how we die and mourn?' The article outlines issues the Internet presents to death studies. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;journal,1,255;linkingpublicationresults,1:300329,1

Death investigations, objections to autopsy, and the religious and cultural "other"

RELIGIONS, 2014;5(1):165-178. Sudden, violent and otherwise unexplained deaths are investigated in most western jurisdictions through a Coronial or medico-legal process. This paper explores the disjuncture between medico-legal discourses, which position the body as corpse, and the rise of more "therapeutic" discourses which recognise the family's wishes to reposition the body as beloved and lamented. http://www.mdpi.com/2077-1444/5/1/165

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.

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

■ AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE – 21 February 2014 – 'A study of Canadian hospice palliative care volunteers' attitudes toward physician-assisted suicide.' The purpose of this study was to examine the attitudes of hospice palliative care (HPC) volunteers who provide in-home support and members of the community toward ... physician-assisted suicide (PAS). The majority of volunteers and community members (1 support legalizing PAS; 2) would choose HPC over PAS for themselves if they were terminally ill; and, (3 think Canadians should place more priority on developing HPC rather than on legalizing PAS. http://ajh.sagepub.com/content/early/2014/02/20/1049909114523826.abstract

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2014/2/media-watch/

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-qlobal-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

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

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.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://www.hospicehaz.hu/en/training/ [Scroll down to 'Media Watch']

 $\label{lem:care-partial} U.K.\ |\ Omega,\ the\ National\ Association\ for\ End-of-Life\ Care:\ \underline{http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c$

Worth Repeating

Death, mourning, and medical progress

PERSPECTIVES IN BIOLOGY & MEDICINE, 2009;52(1):103-115. A number of changes can be observed in the way people are coming to think about death, mourning, and medical progress. The palliative care movement was initiated some 30 years ago to respond to widespread ignorance or neglect of pain relief for the dying, which was then coming to public attention and becoming a key part of the nascent hospice movement. Yet if an important feature of the latter movement was acceptance of the reality of death, in recent years there has emerged a blending of clinical treatment and hospice care, a kind of compromise with the idea of death as an inevitability. Meanwhile, the combination of real progress in forestalling death and the matching medical and media hype about past and coming victories over mortality mean that death itself is coming to be seen as a biological accident, a contingent event, not a fixed given. People die now because of bad luck, indifference to good living habits, unfortunate genetics, and the like, or because they have the misfortune of dying before a cure for their fatal disease is at hand. Mourning likewise is changing. The old custom of the deceased being laid out in their living rooms, followed by a funeral, has long given way to a movement away from public funerals to private ones followed later by a memorial ceremony. No more dead bodies on display to grieve over, but soothing ceremonies of remembrance, http://muse.ihu.edu/journals/pbm/summary/v052/52.1.callahan.html

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