

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.

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The illness experience: Scroll down to [Specialist Publications](#) and 'Desire for hastened death: How do professionals in specialized palliative care react?' (p.15), in *Psycho-Oncology*.

Canada

Ombudsman blasts Quebec for erosion of health care

QUEBEC | *The Montreal Gazette* – 17 September 2015 – The combination of years of government budget slashing, layer upon layer, has resulted in a steady decline in the quality of health care in Quebec, the province's ombudsman said... In a blistering report tabled in the National Assembly, Raymonde Saint-Germain said she has witnessed "ever-growing wait times and shrinkage of certain services," directly related to budget cuts, which are having a direct impact on users.¹ Worse, she says, emerging social problems, such as mental health, "are not on the government's radar," even if it's clear the needs are glaring and growing. The same goes for home care for Quebec's increasing aging population. "While I am not questioning the need for and appropriateness of many of the economic measures taken, I have noticed that we cannot always rely on consideration and commitment to counterbalance their adverse effects on individuals and businesses," Saint-Germain writes in her annual report. Specifically, she says long-term-care facilities are reducing their basic services when they should be increasing them. <http://montrealgazette.com/news/quebec/ombudsman-blasts-government-for-continued-budget-cuts>

Extract on end-of-life care from the Quebec Ombudsman report (pp.83-84)

The Quebec Ombudsman noticed that in several regions and numerous institutions, access to and the quality of palliative care is wanting. In 2013, the Quebec Ombudsman presented a brief to the Committee on Health & Social Services as part of the public hearings on Bill 52, the Act respecting end-of-life care.¹ On this occasion it recommended that the end-of-life care policy be updated and that a Department action plan be drawn up in the short term to improve the service offering in every region that requires it. These recommendations stemmed from the Quebec Ombudsman's findings to the effect that some professionals do not have the required skills for providing end-of-life care and services. In the past year, the Quebec Ombudsman has had to remind institutions about their responsibilities in this regard.

1. Ombudsman's speech at the Quebec commission regarding Bill 52, 2013: <https://protecteurducitoyen.qc.ca/en/about-us/speeches/speech-at-the-commission-regarding-bill-52-an-act-respecting-end-of-life-care>

1. 'Quebec Ombudsman: 2014-2015 Report, September 2015.' The ombudsman is independent and reports to the National Assembly. <http://www.myvirtualpaper.com/doc/protecteur-du-citoyen/2015-annual-report/2015090301/#0>

Why health care is a lose-lose issue for politicians

THE GLOBE & MAIL | Online – 16 September 2015 – While health care is consistently identified as the No. 1 concern of Canadians in opinion polls, the issue rarely arises on the campaign trail. Debates among the leaders – and questions from reporters on the campaign trail – will be dominated by talk of the economy, foreign policy, defence and the environment, but health care will barely merit more than a few jingoistic platitudes. This seeming paradox, which has been the norm for decades, is easy enough to explain. “I never had a conversation about health care that didn’t lose me votes,” Joey Smallwood, the legendary premier of Newfoundland and wily politician, is purported to have said. In other words, talking about health care tends to be a lose-lose for politicians. Why is that? First, Canadians love medicare. Despite the fact that it is a public insurance program – and not a particularly well-designed or well-managed one – the public romanticizes and mythologizes medicare to the point where ridiculous statements such as “medicare is what defines us as Canadians” get bandied about, and Tommy Douglas [recognized as the father of socialized medicine in Canada] is elevated to deity. Any politician worth her or his salt knows better than to challenge idolatry. What that means, practically speaking, is that there is no political incentive to challenge the status quo – on the contrary, it’s best to perpetuate it. So, when politicians do talk about health care, they don’t promise change, they promise more money. Another key reason that there is little debate about health care is that there are few fundamental differences in the policies of the major parties, especially on paper. <http://www.theglobeandmail.com/globe-debate/why-no-one-talks-about-health-care-on-the-hustings/article26374042/>

Related:

- *THE GLOBE & MAIL* | Online – 17 September 2015 – ‘**Ontario’s home-care providers want more say in reform discussions.**’ Ontario is about to begin a three-year effort to reform its troubled home-care system, but even before the first meetings begin, there is disagreement about who should have a hand in making changes. Discussions are starting this month against the backdrop of the first of two reports on home care from Ontario’s Auditor-General that will be released ... [next week]. A scathing report to the government from a blue-ribbon panel this spring called on the province to make home-care services easier to navigate and more accountable. An investigation by *The Globe & Mail* found a system plagued by inconsistent standards of care, byzantine processes, and a lack of transparency for patients and family caregivers. <http://www.theglobeandmail.com/news/national/ontarios-home-care-providers-want-more-say-in-reform-discussions/article26410967/>

Noted in Media Watch, 16 March 2015, #401 (p.1):

- ONTARIO | *The Toronto Star* – 12 March 2015 – ‘**Ontario’s home care system should be overhauled now: Editorial.**’ Ontario Health Coalition is calling for a complete overhaul of the home care system.¹ If their 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 care by a group of experts commissioned by the provincial government.² <http://www.thestar.com/opinion/editorials/2015/03/12/ontarios-home-care-system-should-be-overhauled-now-editorial.html>
 1. ‘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

N.B. Of related interest: ‘2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288),’ 9 December 2014. [Noted In Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

[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.18.

Caregivers in B.C. have high levels of anger and worry: Report

BRITISH COLUMBIA | *The Vancouver Sun* – 14 September 2015 – One-third of family caregivers in B.C. are stressed out and may give up on keeping a loved one at home unless they get relief, the province's Seniors Advocate [has] warned...¹ The stress rate is one of the highest in the country, matched only in Ontario, Isobel Mackenzie said in advance of releasing the report. Her office examined assessments of B.C.'s 31,084 home-support clients, which were filed in 2012-2013. They found 29% of unpaid caregivers – usually family members – described themselves as angry, depressed or conflicted because of competing demands from children, work, and their own health problems. Most were spouses trying to keep their ailing husband or wife with them. But about 45% were adult children, many of them also seniors. <http://www.vancouver.sun.com/health/caregivers+have+high+levels+anger+worry+research+finds/11362625/story.html>

1. 'Caregivers in Distress: More Respite Needed,' Seniors Advocate, British Columbia, September 2015. <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2015/09/Caregivers-in-Distress-Report.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE STAR-PHOENIX* (Saskatoon, Saskatchewan) | Online – 14 September 2015 – '**Psychiatrists fear role as "suicide enablers."**' The ... [Supreme Court of Canada] ... ruling is creating deep discomfort in a field of medicine where "cures" are rare, and where many worry there is every possibility severe depression and other mental illnesses could meet the test for assisted suicide ... as set out by the court, as long as the person is competent and can provide free and informed consent. "I have been approached by many psychiatrists who have serious concerns about physician assisted death being applied to mental illnesses," said Dr. Padraic Carr, president of the Canadian Psychiatric Association and professor of psychiatry at the University of Alberta. <http://www.thestarphoenix.com/health/psychiatrists+fear+role+suicide+enablers/11361752/story.html>

Quote from *The Star-Phoenix* article

The big fear for psychiatrists is that they may be participating in physician-assisted death when there is a chance for treatment.

From the archives:

THE HASTINGS REPORT, 1998;28(4):24-31. '**Should psychiatrists serve as gatekeepers for physician-assisted suicide?**' Mandating psychiatric evaluation for patients who request physician-assisted suicide may not offer the clear cut protection from possible coercion or other abuse that proponents assert. Competence itself is a complex concept and determinations of decision making capacity are not straightforward, nor is the relationship between mental illness and decision making capacity in dying patients clearly understood. And casting psychiatrists as gatekeepers in end-of-life decisions poses risks to the profession itself. <http://onlinelibrary.wiley.com/doi/10.2307/3528610/abstract>

- QUEBEC | CTV News (Montreal) – 11 September 2015 – '**Quebec doctors get guidelines on medically-assisted death.**' Quebec's College of Physicians has released a guide on how health professionals should handle Quebec's law on medically-assisted death. The guide will be available in English in October and is meant to be a reference manual. "It's a tool and as any tool if you want to build something you need something else, and the something else is the training sessions that we give on request," said Dr. Yves Robert, the college's secretary. There will also be a public awareness campaign to eliminate what Robert says are misconceptions about medically assisted death in Quebec. He says it's not euthanasia on demand, but rather the law frames the request to die and the physician's consent within a continuum of care. <http://montreal.ctvnews.ca/quebec-doctors-get-guidelines-on-medically-assisted-death-1.2559541>

Cont.

- ALBERTA | CBC News (Calgary) – 10 September 2015 – **‘Doctor-assisted death feedback being collected by Alberta regulator.’** The organization that regulates Alberta doctors says it is taking a “conservative” approach to the issue of doctor-assisted death. The College of Physicians & Surgeons has released what it calls a “draft advice document” that focuses on issues such as consent and on the right of doctors who for religious or moral reasons don’t want to help a patient to end their life.¹ The document follows a Supreme Court ruling last February that struck down the federal law against physician-assisted dying for competent adult patients enduring intolerable suffering. “Physicians should err on the side of caution during this time of legislative uncertainty,” reads one of the guiding principles in the college’s advice document. “Physicians’ right to freedom of conscience should be respected,” reads another. Other guidelines include that doctors have an obligation not to abandon their patients or obstruct access to legally permissible health services. <http://www.cbc.ca/news/canada/calgary/doctor-assisted-suicide-alberta-1.3223081>

1. ‘Physician Assisted Death: A chance to reflect and provide feedback,’ College of Physicians & Surgeons of Alberta, September 2015. Feedback survey open until 30 October 2015. <http://www.cpsa.ca/standardspractice/advice-to-the-profession/lets-talkpad/>

[U.S.A.](#)

Association of Community Cancer Centers survey highlights challenges and recent trends in U.S. cancer

ASSOCIATION OF COMMUNITY CANCER CENTERS | Online – 18 September 2015 – The association recently released results of its annual Trends in Cancer Programs survey, highlighting the challenges and recent trends seen in U.S. cancer programs. Lack of reimbursement for supportive care services topped the list of challenges facing cancer programs today, with 65% of programs naming this as their biggest challenge, despite the increase in communication with payers on the value of these services. As seen in last year’s survey, the number of patient-centered services provided has continued to grow, but the reimbursement necessary to provide these services is lagging. The majority of cancer programs now offer nurse navigation (89%), psychological counseling (88%) survivorship care (87%), and palliative care (87%). This expansion of services may have contributed to the 61% of survey respondents who cited budget restrictions as their second biggest challenge. <https://acc-cancer.org/surveys/CancerProgramTrends-2015-Overview.asp>

[Specialist Publications](#)

‘Climbing back up the mountain: Reflections from an exploration of end-of-life needs of persons living with HIV/AIDS in Appalachian Tennessee’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

‘Public attitudes on the future sustainability of Medicare’ (p.13), in *Journal of Health Care Finance*.

The rituals of modern death

THE NEW YORK TIMES | Online Commentary – 16 September 2015 – These days only about one in five people dies at home. Most die in hospitals or nursing homes. A unique and telling set of rituals has grown to be associated with death and dying in the hospital. In hospitals, death has many faces depending on how aggressively the patient is being treated. For patients who desire a full-court press to the very end, their last moments usually include a physician like me performing cardiopulmonary resuscitation (CPR) with the base of his palms, elbows locked. This can be a gruesome sight: once I performed CPR on a patient who was getting dialysis through a tube in his abdomen. Every time I compressed his chest, a jet of fluid from his belly would spray out. Very soon, my entire shirt was covered with the patient’s abdominal fluid, and the floor was so slippery I feared losing my balance and falling face first. This macabre theater is usually continued until the supervising physician decides to call it off. Everyone then goes back to their respective jobs, waiting for the overhead announcement of the code blue to sound again. Increasingly though, when death is imminent and more treatment futile, many patients and their family members seek a different end. One of my patients with incurable liver cancer put it best, despite speaking minimal English: “No pain, no cry, just peace.” http://opinionator.blogs.nytimes.com/2015/09/16/the-rituals-of-modern-death/?_r=0

International

End-of-life care in England

How doctors and nurses are “walking on by” as patients are dying because they don’t know how to ease their suffering

U.K. (England) | *The Daily Mail* – 15 September 2015 – Doctors and nurses are “walking past” dying patients because they don’t know how to ease their suffering, experts admitted yesterday. They are inclined to “ignore” the terminally ill and “lose compassion” if they are too busy, MPs were told. Senior National Health Service professionals also pointed out how most doctors have had just 20 hours’ training in end-of-life care during five years at medical school. And in 80% of hospitals there is no out-of-hours coverage by staff specialising in palliative care, they said. Health service experts gave MPs a withering account of end-of-term care in Britain after a report earlier this year revealed how many patients were dying in agony, without dignity and alone.¹ Professor Irene Higginson, a specialist in palliative care at King’s College, London, told MPs that staff “shouldn’t walk past the bed.” “But one of the problems is that a lot of people don’t know what to do or can’t recognise that people are dying,” she said. The academic warned of a “chronic under-investment” in palliative care training and services, calling the 20 hours tuition that undergraduates receive in five years at medical school “far too little.” Professor Mike Richards, chief inspector of hospitals at the Care

Quality Commission, said four fifths of hospitals – 80% – had no specialist staff “on hand” at evenings and weekends. Giving evidence to MPs on the public administration and constitutional affairs committee, he said: “The number of people dying in a hospital across different days of the week is exactly the same. I don’t think this has been given sufficiently high priority by the health service as a whole.” He added that some staff tended to “lose compassion” if they were very busy and wards were understaffed. <http://www.dailymail.co.uk/news/article-3236036/How-doctors-nurses-walking-patients-dying-don-t-know-ease-suffering.html>

Specialist Publications

“It doesn’t do the care for you”: A qualitative study of health care professionals’ perceptions of the benefits and harms of integrated care pathways for end-of-life care’ (p.9), in *BMJ Open*

‘Chronic underfunding in palliative care is key cause of poor care of dying people’ (p.9), in *British Medical Journal*.

1. ‘Dying Without Dignity: Investigations by the Parliamentary & Health Service Ombudsman into complaints about end of life care,’ 25 May 2015. [Noted in Media Watch, May 2015, #411 (p.6)] http://www.ombudsman.org.uk/_data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf

Related:

- U.K. (England) | London Cancer Alliance, PallE8 & Marie Curie – 18 September 2015 – ‘**A review of specialist palliative care provision and access across London.**’ This first report on specialist palliative care services across London found there are significant variations in provision across the capital. <https://www.mariecurie.org.uk/globalassets/media/documents/research/london-spc-provision-report.pdf>
- U.K. (England) | Public Health England – 14 September 2015 – ‘**Consultation on proposed individual-level data collection from specialist palliative care.**’ The National End-of-Life Care Intelligence Network has published a report on the findings from an online consultation about the proposed new data collection... <http://www.hscic.gov.uk/isce/publication/scci2036>

Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

End-of-life care in Scotland

Report says 10,000 people miss out on palliative care before dying



U.K. (Scotland) | *The Courier* (Dundee) – 15 September 2015 – More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it, a new report has suggested.¹ Professor David Clark, of [the End-of-Life Studies Group at] Glasgow University, said an estimated 40,000 people in Scotland could benefit from the specialist form of care. However, a new report, produced for Holyrood's Health Committee, said about a quarter of the group might not receive it. Projections based on data from England suggest an estimated 10,600 people in Scotland die each year without receiving any palliative care. It said that "reliable studies" looking at the need for palliative care estimated that "in rich countries around 82% of all people who die would benefit from palliative care" – with this equating to about 40,000 people a year in Scotland. <http://www.thecourier.co.uk/news/scotland/report-says-10-000-people-miss-out-on-palliative-care-before-dying-1.900108>

1. 'A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: What can the indicators tell us?' Health & Sport Committee, September 2015. <http://endoflifestudies.academicblogs.co.uk/wp-content/uploads/sites/22/2015/09/Scottish-Parliament-Palliative-Care-Report-20150915.compressed.pdf>

End-of-life care in Wales

Children's end-of-life care "needs attention," a report says

U.K. (Wales) | BBC News – 15 September 2015 – Children's palliative care in Wales needs more "strategic attention" by ministers and the National Health Service, a new report says.¹ The Welsh Institute for Health & Social Care said lessons of previous reports remained "largely unheard." It said clinicians and service providers were working "against the odds" to address needs. Health Minister Mark Drakeford is attending an event in the Senedd [National Assembly for Wales] ... to launch the report. About 1,054 children and young people required palliative care services in Wales in 2014. Of these, it is estimated 10% died during the year. One difficulty identified in the report was that children's palliative care services sometimes came under adult palliative care when decisions were made. The report said much of children's palliative care is not about the final period of life but about helping children and families cope better with a series of conditions which may last many years. <http://www.bbc.com/news/uk-wales-34248968>

Extract from the Welsh Institute for Health & Social Care report

Where previous reports and plans recognised the crucial differences between children's and adult services, this has now become blurred. The problem is that those working in children's services have become somewhat distanced and disenfranchised from this process and conclude, understandably if not correctly, that the needs of children are not recognised, understood or prioritised.

Specialist Publications

'Children's palliative care in low- and middle-income countries' (p.8), in *Archives of Disease in Childhood*.

'Children's palliative care is "challenge" for Welsh nurses' (p.14), in *Nursing Times*.

1. 'Palliative Care for Children & Young People in Wales,' Welsh Institute for Health & Social Care, September 2015 http://www.tyhafan.org/uploads/Documents/USW_WIHSC_Report_insides_Layout_1.pdf

N.B. The authors reference 'Palliative Care Planning Group Wales: Report to the Minister for Health & Social Services,' published in June 2008. (See pp.26-36, 'Children & Young People's Palliative Care.')

<http://wales.pallcare.info/files/Sugar%20report%20july%202008.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | *The Brussels Times* – 17 September 2015 – ‘**Where does Belgium’s legalisation of euthanasia leave Belgian prison inmates?**’ Not so long ago, Farid Bamouhammad considered assisted suicide because of the desperation he felt at the prospect of a life behind bars. It is understood that any application he may have made for euthanasia had little chance of success because it would not meet the conditions required by the euthanasia law in Belgium. Even so, it is known that 15 other Belgian prisoners have demanded euthanasia on similar grounds. Belgium legalised euthanasia in 2002, one of three countries to allow the practice, the others being the Netherlands and Luxembourg. <http://brusselstimes.com/opinion/4101/where-does-belgium-s-legalisation-of-euthanasia-leave-belgian-prison-inmates>
- U.K. (England & Wales) | *The Daily Telegraph* – 11 September 2015 – ‘**Assisted dying campaign sets sights on courts after Commons defeat.**’ The long-running campaign to relax Britain’s anti-euthanasia laws is set to switch to the courts after Parliament emphatically rejected moves to legalise assisted dying. MPs voted by a margin of almost three to one against a bill ... which would have allowed terminally ill patients in England & Wales to be given help to end their lives. It was the first time in almost twenty years that the Commons has voted on the issue and the first time ever that it has been given a full second reading debate in the elected chamber. But despite high profile support from the former Director of Public Prosecutions Sir Keir Starmer, who drafted the current prosecution guidelines on assisted suicide, and former Archbishop of Canterbury Lord Carey, it was voted down by 330 votes to 118. The scale of the defeat makes it unlikely that it would be considered by MPs again before the next election [in 2020] and will be seen as marking the end of a concerted parliamentary assault... <http://www.telegraph.co.uk/news/uknews/assisted-dying/11859504/Assisted-dying-campaign-sets-sights-on-courts-after-Commons-defeat.html>

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

Climbing back up the mountain: Reflections from an exploration of end-of-life needs of persons living with HIV/AIDS in Appalachian Tennessee

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – Accessed 21 September 2015 – Little is known about the ... end-of-life (EOL) concerns of persons living with HIV/AIDS (PLWHA) in Appalachia, where religious and cultural values are largely traditional. The focus of this study was to examine data regarding EOL needs assessment related to advanced care planning. A common metaphor tied content to both struggle and triumph as well as the beauty and ruggedness of the Appalachian region: “Climbing back up the mountain.” Rich descriptions of the significance of the metaphor match with stigma as the greatest hurdle to overcome in planning and interacting with others, including health care providers and significant others, about EOL care needs and advanced planning preferences. Further, the metaphor was derived directly from quotes offered by participants. Sources of stigma were often intersecting: the disease itself, associations with “promiscuity,” sexual minority status, illicit drug use, and so on. Strong spiritual images were contrasted with a common avoidance and disdain of organized religion. <http://ajh.sagepub.com/content/early/2015/08/17/1049909115600857.abstract>



Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 September 2015 – ‘**Use and predictors of end-of-life care among HIV patients in a safety net health system.**’ Though highly active anti-retroviral therapy has improved survival among many HIV patients, there are still those with advanced illness and limited access to care who may benefit from palliative care and hospice. This was a retrospective cohort study of HIV patients in a large, urban safety net hospital in 2010. Physicians abstracted data from the electronic medical record on patient and clinical factors and end-of-life care use. Though 28% died, only 6% of the sample received palliative care consultation, and 6% of the sample enrolled in hospice. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00457-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00457-1/abstract)

Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care

AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE | Online – 17 September 2015 – The authors conducted a trial at two hospitals. Patients had a predicted mortality >30% and a surrogate decision-maker. Facilitators supported communication between clinicians and families, adapted communication to family needs, and mediated conflict. The intervention was associated with decreased depressive symptoms at 6-months... It was not associated with ICU mortality (25% control vs. 21% intervention), but decreased ICU costs among all patients (per-patient: \$75,850 control, \$51,060 intervention) and particularly among decedents (\$98,220 control, \$22,690 intervention). Among decedents, the intervention reduced ICU and hospital length of stay (28.5 vs. 7.7 days and 31.8 vs. 8.0 days respectively). This is the first study to find a reduction in intensity of end-of-life care with similar or improved family distress. <http://www.atsjournals.org/doi/abs/10.1164/rccm.201505-0900OC#.VfwSsc9RGos>

Noted in Media Watch, 8 September 2014, #374 (p.5):

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2014;23(5):380-386. ‘Clinicians’ perceptions of the usefulness of a communication facilitator in the intensive care unit.’ Clinicians (i.e., study participants) perceived facilitators as 1) Facilitating communication between patients’ families and clinicians; 2) Providing practical and emotional support for patients’ families; and, 3) Providing practical and emotional support for clinicians. Clinicians were enthusiastic about the communication facilitator, but concerned about overlapping or conflicting roles. <http://ajcc.aacnjournals.org/content/23/5/380.short>

Children’s palliative care in low- and middle-income countries



ARCHIVES OF DISEASE IN CHILDHOOD | Online – 14 September 2015 – One-third of the global population is aged under 20 years. For children with life-limiting conditions, palliative care services are required.

However, despite 80% of global need occurring in low- and middle-income countries (LMICs), the majority of children’s palliative care (CPC) is provided in high-income countries. This paper reviews the status of CPC services in LMICs – highlighting examples of best practice among service models in Malawi, Indonesia and Belarus – before reviewing the status of the extant research in this field. It concludes while much has been achieved in palliative care for adults, less attention has been devoted to the education, clinical practice, funding and research needed to ensure children and young people receive the palliative care they need. <http://adc.bmj.com/content/early/2015/09/13/archdischild-2015-308307.abstract>

Noted in Media Watch, 15 June 2015, #414 (p.9):

- *BRITISH JOURNAL OF CANCER* | Online – 4 June 2015 – ‘The prioritisation of paediatrics and palliative care in cancer control plans in Africa.’ The authors conducted an analysis of accessible national cancer control plans in Africa... Eighteen national plans and one Africa-wide plan (10 English, 9 French) were accessible, representing 9 low-, 4 lower-middle-, and 5 upper-middle-income settings. Palliative care needs were recognised in 11 national plans, representing 157,490 children, or 24% of the estimated Africa-wide burden for children aged 0-14 years; four plans specified paediatric palliative needs. <http://www.nature.com/bjc/journal/vaop/ncurrent/abs/bjc2015158a.html>

N.B. Scroll down to ‘Children’s palliative care is “challenge” for Welsh nurses’ (p.14), in *Nursing Times*.

Related:

- *PEDIATRICS* | Online – 16 September 2015 – ‘Family experience and PICU death: A meta-synthesis.’ One main theme and three sub-themes emerged. “Reclaiming parenthood” encompasses the ways in which the parental role is threatened when a child is dying in the PICU, with the subthemes “Being a parent in the PICU,” “Being supported,” and “Parenting after death” elucidating the ways parents work to reclaim this role. When a child dies in a PICU, many aspects of the technology, environment, and staff actions present a threat to the parental role both during and after the child’s death. Reclaiming this role requires support from health care providers and the wider community. <http://pediatrics.aappublications.org/content/early/2015/09/08/peds.2015-1068.abstract>

End-of-life care in England

“It doesn’t do the care for you”: A qualitative study of health care professionals’ perceptions of the benefits and harms of integrated care pathways for end-of-life care

BMJ OPEN | Online – 14 September 2015 – Four main themes emerged, each including two sub-themes. Participants were divided between those who described mainly the benefits of integrated care pathways, and those who talked about potential harms. Benefits focused on processes of care, for example, clearer, consistent and comprehensive actions. The recipients of these benefits were staff members themselves, particularly juniors. For others, this perceived clarity was interpreted as of potential harm to patients, where over-reliance on paperwork lead to prescriptive, less thoughtful care, and an absolution from decision-making. Independent of their effects on patient care, integrated care pathways for dying had a symbolic value: they legitimised death as a potential outcome and were used as a signal that the focus of care had changed. However, a weak infrastructure, including scanty education and training in end-of-life care and a poor evidence base, that appeared to undermine the foundations on which The Liverpool Care Pathway was built. The potential harms of integrated care pathways for the dying identified in this study were reminiscent of criticisms subsequently published by the Neuberger review.¹ These data highlight: 1) The importance of collecting, reporting and using qualitative data when developing and evaluating complex interventions; 2) That comprehensive education and training in palliative care is critical for the success of any new intervention; and, 3) The need for future interventions to be grounded in patient-centred outcomes, not just processes of care. <http://bmjopen.bmj.com/content/5/9/e008242.abstract>

1. ‘Review of Liverpool Care Pathway for Dying Patients,’ Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Noted in Media Watch, 12 January 2015, #392 (p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 January 2015 – ‘**Views and experiences of using integrated care pathways (ICPs) for caring for people in the last days to hours of life: Results from a cross-sectional survey of U.K. professionals.**’ Ninety-three per cent (1,138/1,228) of respondents used The Liverpool Care Pathway (LCP) or a local variant. Eighty-eight per cent (1,089/1,234) felt ICPs enabled professionals to provide better care for individuals and their families/carers. ICPs were viewed as promoting patient-centred holistic care, improving pain and symptom control, providing guidance and standards and improving communication with patients/families. <http://spcare.bmj.com/content/early/2015/01/06/bmjspcare-2014-000768.abstract>

Related:

- *BRITISH MEDICAL JOURNAL* | Online – 15 September 2015 – ‘**Chronic underfunding in palliative care is key cause of poor care of dying people.**’ Longstanding underfunding of palliative care training and services is a major cause in the National Health Service (NHS) in England of failure to provide good care, MPs have been told. Experts in palliative care appearing before the parliamentary select committee on public administration and constitutional affairs said that doctors received only a tiny amount of formal training in this aspect of care. The committee was holding a one-off evidence session on the findings of the Office of the Parliamentary & Health Service Ombudsman’s May 2015 report ‘Dying Without Dignity.’¹ <http://www.bmj.com/content/351/bmj.h4969>

1. ‘Dying Without Dignity: Investigations by the Parliamentary & Health Service Ombudsman into Complaints About End-of-Life Care,’ May 2015. [Noted in Media Watch, 25 May 2015, #411 (p.6)] http://www.ombudsman.org.uk/data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf

[Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com/community/pg/file/owner/MediaWatch)

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Provider perspectives on the influence of family on nursing home resident transfers to the emergency department: Crises at the end of life

CURRENT GERONTOLOGY & GERIATRICS RESEARCH | Online – 16 August 2015 – A growing body of evidence suggests that nursing home (NH) residents experience many detrimental and costly care transitions, particularly at the end of life (EOL). These findings underscore the strong need for greater upstream anticipatory guidance and preparation for “in-the-moment” decision-making to reduce family conflict, crisis, and panic when there is a change in condition. Moreover, study findings further suggest that improved access to timely and appropriate palliative care support and expertise in the NH setting may reduce many of these burdensome and unnecessary transitions at the EOL. With greater national efforts focused on providing person-centered care, improving care transitions, and reducing health care costs for frail older adults in NHs, policymakers and payers should recognize the value of high quality palliative care in the NH setting. <http://www.hindawi.com/journals/cggr/2015/893062/>

N.B. Selected articles on palliative care patients who present to the emergency department noted in past issues of Media Watch are listed in the issue of the weekly report of 7 September 2015, #426 (pp.13-14).

Health care professionals’ perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature

DEMENTIA | Online – 16 September 2015 – This paper provides an overview of the evidence on the perspective of health care professionals (HCPs) in relation to advance care planning (ACP) for people with dementia, residing in long-term care settings. A systematic literature search identified 14 papers for inclusion. Four themes were identified for discussion; 1) Early integration and planning for palliative care in dementia; 2) HCPs ethical and moral concerns regarding ACP; 3) Communication challenges when interacting with the person with dementia and their families; and, 4) HCPs need for education and training. Despite evidence that HCPs recognise the potential benefits of ACP, they struggle with its implementation in this setting. <http://dem.sagepub.com/content/early/2015/09/16/1471301215604997.abstract>

Related:

- *BMC PALLIATIVE CARE* | One line – 17 September 2015 – ‘**End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation.**’ Across three studies, 29 care homes, 528 residents, 205 care home staff, and 44 visiting health care professionals participated. End-of-life interventions for people with dementia were characterised by uncertainty in three key areas; 1) What treatment is the “right” treatment; 2) Who should do what and when; and, 3) In which setting end-of-life (EoL) care should be delivered and by whom? This paper proposes an emergent framework to inform the development and evaluation of EoL care interventions in care homes. <http://www.biomedcentral.com/content/pdf/s12904-015-0040-0.pdf>
- *JOURNAL OF VASCULAR & INTERVENTIONAL RADIOLOGY* | Online – 11 September 2015 – ‘**Informed consent challenges in frail, delirious, demented, and do-not-resuscitate adult patients.**’ Without informed consent, any invasive procedure becomes an assault. The prevailing legal and ethical standard is that the physician has a fiduciary duty to give enough information to the patient so that a reasonable person can make an informed decision to accept or refuse the proposed treatment. The patient’s frailty, delirium and/or dementia, and end-of-life concerns and expectations can make informed consent a difficult task. This review examines informed consent requirements for adults and provides communication tools to enable shared decision making while engendering patient–physician trust. <http://www.sciencedirect.com/science/article/pii/S1051044315007666>
- *THE LANCET PSYCHIATRY*, 2015;2(9):774-775. ‘**Advance care planning in dementia.**’ ACP for people with dementia is an intervention crying out for better implementation. The scale of need is great, with a conservative estimate of 650,000 people with dementia in England... ACP is an opportunity for people with dementia to share wishes, preferences, and refusals of treatment, and transfer decision making while their capacity is retained – to exercise the same autonomy as those with other life-limiting illnesses. [http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(15\)00311-9/abstract](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(15)00311-9/abstract)

Cont.

Noted in Media Watch, 27 July 2015, #420 (p.12):

- *BJPSYCH BULLETIN* | Online – 1 April 2015 – ‘**Advance care planning and palliative medicine in advanced dementia.**’ The disconnect between the willingness of carers and health professionals to discuss these issues, and the low levels of uptake and engagement reported in the studies reviewed, call for more exploration. <http://pb.rcpsych.org/content/39/2/74>

Noted in Media Watch, 26 November 2012, #281 (p.7):

- *PALLIATIVE MEDICINE* | Online – 21 November 2012 – ‘**Professionals’ experiences of advance care planning in dementia and palliative care, “a good idea in theory, but ...”**’ While professionals agreed advance care planning was a good idea in theory, implementation in practice presented significant challenges. <http://pmj.sagepub.com/content/early/2012/11/15/0269216312465651.abstract>

End-of-life care in Belgium

Family physicians’ role in palliative care throughout the care continuum: Stakeholder perspectives

FAMILY PRACTICE | Online – 16 September 2015 – While palliative care is still often viewed as care for the final stage of life provided usually by specialist health care professionals, ideally, a palliative care approach would start at an earlier stage, with an important role being assigned to the family physician (FP). However, the description of what the FP’s tasks would be in the integration of a palliative care approach into the care continuum remains vague. The tasks attributed to the FP could be categorized into four roles: FP as 1) Available medical expert; 2) Communicator; 3) Collaborator; and, 4) Life-long learner committed to improving their palliative care competencies by training. Some perceived tasks varied depending on the different phases of illness (such as around diagnosis), while others were applicable throughout the whole illness course. Participants mostly had the same perception of the FPs’ tasks, but there was disagreement on, for example, the timing of care planning. This study helps to elucidate the tasks and roles required of FPs to make integration of a palliative care approach into the care continuum possible. <http://fampra.oxfordjournals.org/content/early/2015/09/14/fampra.cmv072.short?rss=1>

Noted in Media Watch, 27 July 2015, #420 (p.12):

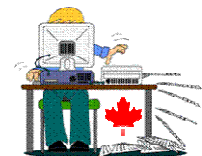
- *BMC MEDICAL EDUCATION* | Online – 24 July 2015 – ‘**Family physicians enhance end-of-life care: Evaluation of a new continuing medical education learning module in British Columbia.**’ The authors present the evaluation findings from the Practice Support Program (PSP) module on enhancing end-of-life care within primary care. <http://www.biomedcentral.com/content/pdf/s12909-015-0392-4.pdf>

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

- *PALLIATIVE MEDICINE* | Online – 17 February 2014 – ‘**Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients.**’ Barriers and facilitators found relate to communication styles, the perceived role of a family physician (FP), and continuity of care. FP do not systematically assess non-acute care needs, and patients do not mention them or try to mask them from the FP. <http://pmj.sagepub.com/content/early/2014/02/14/0269216314522318.abstract>

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>



Communication that heals

Mindful communication practices from palliative care leaders

HEALTH COMMUNICATION | Online – 11 September 2015 – The authors sought mindful communication practices from palliative care leaders in American Hospital Association Circle of Life award-winning units. Four key practices emerged [in this study]: 1) Know your audience; 2) Ask questions; 3) Discard scripts; and, 4) Recognize your role. The discussion articulates how key mindful communication practices may be used as a stage model, where key practices may be used individually or in concert, by sole practitioners or within interdisciplinary teams, and also by new and seasoned clinicians. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2014.953739>

Pets' impact on your patients' health: Leveraging benefits and mitigating risk

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2015;28(4):526-534. Pets enhance emotional well-being and physical health, are sources of social capital, and strongly affect non-medical determinants of health. Family physicians who know of pets in their patients' families have identified a motivator for the patient to make positive and healthier lifestyle choices and have discovered another potent contributor to treatment plans. Application in practice is simple, straightforward, and non-invasive. Asking about pets gives physicians a new approach to exploring a patient's home life with a few simple and innocuous questions when taking an environmental history. Further, the demonstrated interest in a pet strengthens the physician-patient therapeutic alliance. <http://www.jabfm.org/content/28/4/526.full.pdf+html>

N.B. The Circle of Life Awards honor innovative palliative and end-of-life care in hospices, hospitals, health care systems, long-term care facilities, and other direct care providers and are co-sponsored by the American Academy of Hospice & Palliative Medicine, the Hospice & Palliative Nurses Association, the Hospice & Palliative Credentialing Center, the Hospice & Palliative Nurses Foundation, and the National Association of Social Workers. <http://www.aha.org/about/awards/col/awardees.shtml>

Noted in Media Watch, 30 April 2012, #251:

- *ACADEMIC MEDICINE*, 2012;87(6):815-819. 'The impact of a program in mindful communication on primary care physicians.' Themes that emerged in this study: 1) Sharing personal experiences from medical practice with colleagues reduced professional isolation; 2) Mindfulness skills improved participants' perceptions of their ability to be attentive and listen deeply to their patients' concerns and respond to them more effectively; and, 3) Developing greater self-awareness was positive and transformative, yet they struggled to give themselves permission to attend to their own needs and personal growth. http://journals.lww.com/academicmedicine/Abstract/publishahead/The_Impact_of_a_Program_in_Mindful_Communication.99638.aspx

End-of-life care in Singapore

Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment

HEALTH POLICY | Online – 11 September 2015 – Singapore is in the midst of several healthcare reforms in efforts to finance and deliver health services for a rapidly aging population. The primary focus of these reforms is to make healthcare services, including those at the end of life (EOL), affordable. Given the increasingly high health care costs at the EOL, policy makers need to consider how best to allocate resources. One strategy is to allocate resources based on the preferences of sub-populations most likely to be affected. This paper aims to quantify preferences for EOL care both among community dwelling older adults (CDOAs) and among patients with a life-limiting illness. A discrete choice experiment was administered to CDOAs and advanced cancer patients in Singapore and willingness to pay (WTP) for specific EOL improvements was estimated. The authors find that patients have a higher WTP for nearly all EOL attributes compared with CDOAs. They also show that, for both groups, moderate life-extension is not the most important consideration; WTP for one additional life year is lower than common thresholds for cost-effectiveness. [http://www.healthpolicyjrnl.com/article/S0168-8510\(15\)00223-7/abstract](http://www.healthpolicyjrnl.com/article/S0168-8510(15)00223-7/abstract)

Cont.

Noted in Media Watch, 14 April 2014, #353 (p.7):

- SINGAPORE | National News Agency of Malaysia – 8 April 2014 – ‘**Survey: 77% of Singaporeans wish to die at home.**’ Singaporeans want to die at home, die affordably, and not leave financial burdens behind.¹ <http://www.bernama.com.my/bernama/v7/wn/newsworld.php?id=1028961>
- 1. ‘Death Attitudes Survey’ (Highlights/Summary), The Lien Foundation, Singapore, 3 April 2014. http://lienfoundation.org/sites/default/files/Death%20Attitudes%20Findings%20LBD%20Rise%20Final_3April.pdf

End-of-life care in the U.S.

Public attitudes on the future sustainability of Medicare

JOURNAL OF HEALTH CARE FINANCE, 2015;42(1). Most [survey] respondents believed that Medicare will fall into economic crisis within the next 20 years. Few respondents believed that Medicare should ration spending on end-of-life care, but there were differences by age: people age 45-64 were much less likely to endorse rationing than those age 18-29. Most respondents, especially those over 65, reported that they would rather enroll in a private insurance plan that costs more money but would cover expensive treatments. <http://www.healthfinancejournal.com/index.php/johci/article/view/37/39>

Case report

Hope in palliative care: Cultural implications

JOURNAL OF PALLIATIVE CARE, 2015;31(3):189-192. A 72-year-female diagnosed with left breast cancer underwent surgery followed by chemotherapy that she could not tolerate. Subsequently she developed local recurrence and metastases to bone. The local disease ulcerated and fungated; symptoms were managed with radiotherapy and symptom control medications. The patient's hope changed from prolonging life to symptom management with progression of disease. The oncologist witnessed relatives giving false hope to the patient. A major feature of human culture lies in the fostering of hope, but fostering false hope may create an ethical tension in palliative practice. Various aspects of hope are discussed. <http://www.ingentaconnect.com/content/iug/jpc/2015/00000031/00000003/art00009>

Noted in Media Watch, 9 August 2010, #161 (p.6):

- *AMERICAN MEDICAL NEWS* | Online – 2 August 2010 – ‘**Families’ optimism often at odds with physicians’ prognoses.**’ Family members of intensive care patients are likely to be more optimistic about their loved ones’ chances of survival, regardless of how a physician presents a grim prognosis.¹ <http://www.ama-assn.org/amednews/2010/08/02/prsb0802.htm>
- 1. ‘A randomized trial of two methods to disclose prognosis to surrogate decision makers in ICUs,’ *American Journal of Respiratory & Critical Care Medicine*, 2010;182(7):905-909. <http://www.atsjournals.org/doi/pdf/10.1164/rccm.201002-0262OC>

N.B. Representative sample of articles on hope in the context of end-of-life care noted in past issues of Media Watch is listed in the weekly report of 14 September 2015, #427 (p.9).

Palliative medicine consultation reduces length of stay, improves symptom management, and clarifies advance directives in the geriatric trauma population

JOURNAL OF TRAUMA NURSING, 2015;22(5):261-265. It was hypothesized that patients with palliative medicine consultation (PMC) would have a shorter length of stay. Patients with a PMC were more likely to have a documented advance directive discussion and a code status update. Length of stay was reduced for patients with a PMC on or before trauma day 2 compared to those with a PMC after trauma day 2. http://journals.lww.com/journaloftraumanursing/Abstract/2015/09000/Palliative_Medicine_Consultation_Reduces_Length_of.7.aspx

End-of-life care in Wales

Children's palliative care is "challenge" for Welsh nurses



NURSING TIMES (U.K.) | Online – 15 September 2015 – Planning and providing end-of-life care for children is a “major challenge” for specialist nurses in Wales, according to a major report that highlights current barriers to staff networking.¹ Just five specialist nurses are currently charged with providing care to over 1,000 young patients with a range of complex needs, warned the report, which was published today. It pulls together findings from a system-wide review of services currently available for children in Wales who need specialist care throughout their lives and are expected to die during childhood. The report suggested that, at any one time, there were 1,050 children in Wales that would benefit from specialist paediatric palliative care, around 10% of which would die in any one year. It said the relatively small numbers in need of care had resulted in their needs becoming swallowed up by wider plans for adult palliative and end-of-life care. The report warned “limited specialist resources” remained a problem for the clinical workforce in providing palliative and end of live care for children across a large geographical area and complex range of conditions. <http://www.nursingtimes.net/nursing-practice/specialisms/end-of-life-and-palliative-care/childrens-palliative-care-is-challenge-for-welsh-nurses/5090375.article>

1. 'Palliative Care for Children & Young People in Wales,' Welsh Institute for Health & Social Care, September 2015 http://www.tyhafan.org/uploads/Documents/USW_WIHSC_Report_insides_Layout_1.pdf

N.B. Scroll back to [International](#) and 'Children's end-of-life care "needs attention," a report says' (p.6).

Spiritual history taking in palliative home care: A cluster randomized controlled trial

PALLIATIVE MEDICINE | Online – 16 September 2015 – Many health-care providers experience barriers to addressing spiritual needs, such as not having the right vocabulary. The *ars moriendi* model might be a feasible tool for spiritual history taking in palliative care. A total of 245 health-care providers participated in the study (204 nurses, 41 physicians), which showed no demonstrable effect of spiritual history taking on patient scores for spiritual well-being, quality of life, health-care relationship trust or pain. Further research is needed to develop instruments that accurately assess the effectiveness of spiritual interventions in palliative care populations. <http://pmj.sagepub.com/content/early/2015/09/15/0269216315601953.abstract>

Related:

- *BMC PALLIATIVE CARE* | Online – 18 September 2015 – '**A mobile hospice nurse teaching team's experience: Training care workers in spiritual and existential care for the dying...**' The mobile teaching team taught care workers to identify spiritual and existential suffering, initiate existential and spiritual conversations and convey consolation through active presencing, and silence. The team members transferred their personal spiritual and existential care knowledge through situated “bedside teaching” and reflective dialogues. The mobile teaching team perceived the care workers benefitted from the situated teaching because they observed care workers became more courageous in addressing dying patients' spiritual and existential suffering. <http://www.biomedcentral.com/content/pdf/s12904-015-0042-y.pdf>

Noted in Media Watch, 17 August 2015, #423 (p.18):

- *PALLIATIVE MEDICINE* | Online – 12 August 2015 – '**Doctors discussing religion and spirituality: A systematic literature review.**' Religion and spirituality are discussed infrequently by physicians although frequency increases with terminal illness. Many prefer chaplain referral to discussing religion and/or spirituality with patients themselves. Discussions are facilitated by prior training and increased physician religiosity and spirituality. Insufficient time and training were the most frequently reported barriers. <http://pmj.sagepub.com/content/early/2015/08/04/0269216315600912.abstract>

N.B. Selected articles on spirituality in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 8 June 2015, #413 (pp.10-11).

End-of-life care in Ireland

Walls, wisdom, worries, and wishes: Engaging communities in discussion about death, dying, loss, and care using Café Conversation

PROGRESS IN PALLIATIVE CARE | Online – 12 September 2015 – This paper reflects on the adaptation of the World Café concept to engage with members of the public in Compassionate Communities Café Conversation, focussing on enabling people to understand the importance of thinking and talking about the end of life. The approach enables people to come together to share their experience and ideas, wisdom, worries, and wishes. The seven design principles of the World Café are central to the process, together with the sharing of resources developed to engage people in discussion as well as practical activity. This paper outlines the preparation, presentation, and pilot evaluation of the Compassionate Communities Café Conversation experience in two towns in the Mid-West of Ireland. This approach offers a potentially very useful framework for use by others as part of a health promoting approach to palliative care. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000011>

Related

- *PROGRESS IN PALLIATIVE CARE* | Online – 15 September 2015 – **‘Hospices in partnership? Public health, end of life, and the responsibility of hospices.’** The true partners in a public health approach towards the end-of-life are ... dying people, their families and friends, and members of the communities within which they are living and dying. However, we ignore important partnerships with nurses, doctors, and other healthcare professionals at our peril. This paper situates hospices within the broader community and uses vignette’s to highlight approaches to community engagement and the challenges of partnership. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000014>
- *PROGRESSING IN PALLIATIVE CARE* | Online – 13 September 2015 – **‘Putting the “public” into public health: Innovative partnerships in palliative and end-of-life care: The Kenya experience.’** The Kenya Hospice & Palliative Care Association works together with its stakeholders such as the Ministry of Health, government hospitals, mission hospitals, hospices, and community-based organizations, and training institutions to ensure that there is greater awareness of and access to palliative care across the country. In the past 7 years, there has been a significant improvement in palliative care in Kenya focusing on availability, accessibility, and affordability of services through scaling up existing services as well as integrating palliative care into the public health care system. This paper briefly outlines this development while highlighting the challenges faced in the geographical context of sub-Saharan Africa. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000013>

Desire for hastened death: How do professionals in specialized palliative care react?

PSYCHO-ONCOLOGY | Online – 16 September 2015 – Desires for hastened death (DHD) are prevalent in terminally ill patients. Studies show that health professionals (HP) are often underprepared when presented with DHD. HPs in specialized palliative care (SPC-HP) often encounter DHD. Narrative interviews were conducted with 19 SPC-HPs at four German University Hospitals. Twelve response categories and six corresponding functions were identified. On the patient level, responses categorized as symptom control, exploring the reasons and generating perspective, reorientation, and hope were particularly used to ease the patient’s burden. On the interaction level, creating a relationship was fundamental. On the SPC-HP level, various methods served the functions self-protection and showed professional expertise. Profound personal and professional development is necessary to respond to the inherent challenges presented by DHD. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3959/abstract>

N.B. Selected articles on the desire to hasten death in the context of end-of-life care noted in past issues of Media Watch:

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – **‘The desire to hasten death: Using grounded theory for a better understanding – “When perception of time tends to be a slippery slope.”** Patients [i.e., study participants] expected health professionals to listen to and respect their experiences.

Cont.

Emerging hypotheses: a) Patients try to balance life time and anticipated agony, and the perception of time is distressing in this balancing act; b) Anticipated images of agony and suffering in the dying process occur frequently and are experienced by patients as intrusive; c) Patients expressing a desire to hasten death are in need of more information about the dying process; and, d) Patients wanted their caregivers to listen to and respect their wish to hasten death, and they did not expect the caregivers to understand this as an order to actually hasten their death. [Noted in Media Watch, 30 March 2015, #403 (p.19)] <http://pmj.sagepub.com/content/early/2015/03/20/0269216315577748.abstract>

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. '**Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.**' Health professionals may struggle to determine whether a "desire to die" statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. Where the relevant literature was lacking, the recommendations were drafted by the authors (clinicians and/or academics from the following disciplines: nursing, medicine, psychiatry, psychology, sociology, aged care and theology), based on their expert opinion. Strategies for advancing the evidence base for the maturation of guidelines in this area are offered. [Noted in Media Watch, 17 March 2014, #349 (p.16, under 'Worth Repeating')] <http://pmj.sagepub.com/content/20/7/703.abstract>

Related:

- *ANNALS OF FAMILY MEDICINE*, 2015;13(5):408-409. '**Voluntary stopping of eating and drinking (VSED), physician-assisted death (PAD), or neither in the last stage of life? Both should be available as a last resort.**' When a suffering patient requests VSED or PAD, the first steps should always be a careful evaluation to understand why, to ensure the adequacy of palliative care, and to assess the patient's decision-making capacity. While a patient's values and preference remain in the center of decision making, evaluating clinicians must also take into account legal limits and their personal values. VSED can be an important option for some suffering patients who wish an earlier death, but the meaning attached to this practice can vary considerably from a welcomed, patient-controlled escape to an absurd end that adds to suffering as much or more than alleviating it. Furthermore, VSED also takes too long to adequately respond to overwhelming, immediate physical suffering. The comparative risks, benefits and burdens of these last resort practices continue to be debated among well-intended, sophisticated, experienced palliative care practitioners as well as the broader society as we try to find better ways to respond to those infrequent but very troubling patients who suffer unacceptably despite receiving state of the science palliative care. <http://www.annfammed.org/content/13/5/408.full>
- *ANNALS OF FAMILY MEDICINE*, 2015;13(5):410-411. '**Voluntary stopping of eating and drinking (VSED), physician-assisted suicide (PAS), or neither in the last stage of life? PAS: No; VSED: It depends.**' An adequate answer to the question is neither clear nor straightforward. The author's position is that if one has reservations about PAS, as she does, then one ought to have some reservations about VSED as well. The ethical permissibility of PAS continues to be an issue of ongoing ethical dispute. This much is obvious. What is much less obvious is the idea that the ethical permissibility of PAS and VSED are linked. The ethical permissibility of the latter depends in part on the ethical permissibility of the former. <http://www.annfammed.org/content/13/5/410.full>

Validation of a new instrument for self-care in Spanish palliative care professionals nationwide

THE SPANISH JOURNAL OF PSYCHOLOGY | Online – 14 September 2015 – Self-care is a cornerstone issue for those who deal with stressful events, as it is the case of palliative care professionals. It has been related to awareness, coping with death, and quality of life, among others, but no measurement instruments have been used in palliative care professionals. This research presents and validates a brief new measure with clinical and psychometric good properties, called Professional Self-Care Scale. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9951598&fulltextType=RA&fileId=S1138741615000712>

Cont.

Noted in Media Watch, 24 August 2015, #424 (p.14):

- *PALLIATIVE MEDICINE* | Online – 17 August 2015 – ‘**The transformation process for palliative care professionals: The metamorphosis, a qualitative research study.**’ During their professional activity, palliative care professionals go through a series of phases, depending on the relationship between the cost of caring and the satisfaction of caring, which can influence both the care provided to patients and families and their own personal circumstances. Being aware of this risk, and implementing self-care strategies, can protect professionals and enable them to conduct their work... <http://pmj.sagepub.com/content/early/2015/08/12/0269216315583434.abstract>

A systematic review of telehealth in palliative care: Caregiver outcomes

TELEMEDICINE & E-HEALTH | Online – 11 September 2015 – Of the nine studies [that met study inclusion criteria], five measured caregiver quality of life, three caregiver anxiety, and two caregiver burden. All the studies measuring caregiver quality of life showed no significant difference after telehealth interventions. The caregiver anxiety score decreased after the intervention in two studies, and one reported significantly reduced caregiver burden. Although feasibility of or caregiver satisfaction with the telehealth intervention was not the focus of this review, most studies reported such findings. Of the nine studies, the majority were rated as having moderate quality using the Cochrane Collaboration’s tool for assessing risk of bias. <http://online.liebertpub.com/doi/abs/10.1089/tmj.2015.0090>

Noted in Media Watch, 24 August 2015, #424 (p.18):

- *PALLIATIVE MEDICINE* | Online – 19 August 2015 – ‘**Implementation of a pilot telehealth programme in community palliative care: A qualitative study of clinicians’ perspectives.**’ The technology challenged the care team to critically explore aspects of current service provision and the potential to alter the dynamic of relationships between patients and families and community palliative care clinicians. <http://pmj.sagepub.com/content/early/2015/08/18/0269216315600113.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.
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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
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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.

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/09/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-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>

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