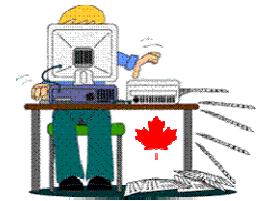


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

The Illness experience: Scroll down to [Specialist Publications](#) and ‘Knowledge of dementia: Do family members understand dementia as a terminal condition?’ (p.11), in *Dementia*.

Canada

Palliative care poor in First Nations communities, researcher says

CBC NEWS | Online – 24 September 2015 – It’s something many Canadians take for granted, but choosing to live out their last days at home is not an option for many First Nations people... Mary Lou Kelley, a professor at Lakehead University, in Thunder Bay, says federal health care dollars that would help First Nations people receive end-of-life care at home have not kept up with the increasing demand. “All health services in the rest of the country have been increased since 1999, but not home and community care in First Nations.” Health care for First Nations is the responsibility of the federal government, and they do provide some home care services, Kelley said. The problem is the system was never designed to provide complex health care to people with chronic or advanced terminal diseases. There have been some improvements when it comes to delivering these services. However, the biggest hurdles are jurisdictional... <http://www.cbc.ca/news/canada/british-columbia/palliative-care-poor-in-first-nations-communities-researcher-says-1.3242924>



Noted in Media Watch, 2 December 2013, #334 (p.1):

- CTV NEWS | Online – 28 November 2013 – ‘**Aboriginal seniors face more health challenges, report...**’ First Nations, Metis and Inuit of advancing years have poorer health than their non-aboriginal counterparts, but don’t receive the same level of health-care services as other Canadian seniors.¹ <http://www.ctvnews.ca/health/aboriginal-seniors-face-more-health-challenges-report-suggests-1.1564234>

1. *Canada’s Most Vulnerable: Improving Health Care for First Nations, Metis and Inuit Seniors*, The Health Council of Canada, November 2013. http://healthcouncilcanada.ca/rpt_det_gen.php?id=801&rf=2

[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.16.

Community Care Access Centres accused of overstating spending on direct patient care

ONTARIO | *The London Free Press* – 23 September 2015 – Ontario’s auditor general has slammed the massive bureaucracy that looks after home care and access to nursing homes in the province. In a report ... Auditor General Bonnie Lysyk wrote Community Care Access Centres (CCACs) failed to correct serious problems revealed in four previous audits since 1998, leaving vulnerable Ontarians exposed to a bureaucracy that treats its clients inequitably, with the level of care dependent upon where you live, not what you need.¹ “In the two decades since the inception of the CCACs, there has never been a thorough review to determine whether the current delivery model is providing consistent, equitable and cost effective care,” Lysyk wrote. While CCACs claim they spend 92% of their funds on direct patient care, the actual amount spent on face-to-face treatment of patients is just 61%... Lysyk plans to include two related audit reports – one on the CCACs’ home-care program that focuses on personal-support services, and the other on the performance of Ontario’s 14 Local Health Integration Networks that fund CCACs, hospitals, and other community health services – in her 2015 Annual Report to be tabled at the end of the year. Critics have pushed to abolish the agencies and have

home care managed instead out of the office of family doctors. The criticism came after *The London Free Press* showed the CEOs of the province’s 14 CCACs had been given massive raises while some of the vulnerable people they served had to fight for basic needs like a support worker to take more than one bath a week. <http://www.lfpress.com/2015/09/23/community-care-access-centres-accused-of-overstating-spending-on-direct-patient-care>

Extract on palliative care from the report of the Office of the Auditor General of Ontario

None of the nine service providers visited ... have nurse practitioners who provide palliative care to patients at home.

N.B. In her 2014 annual report, the Auditor General of Ontario stated that “... although efforts have been made to create an integrated, coordinated system to deliver palliative care, no such system exists. The Ministry [of Health & Long Term Care] lacks information on the palliative care services that are available, their costs, the patient need for these services or what mix of services best meet patient needs.” [Noted in Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

1. ‘Community Care Access Centres – Financial Operations & Service Delivery,’ Office of the Auditor General of Ontario, September 2015. http://www.auditor.on.ca/en/reports_en/CCACs_en.pdf

Selected articles, reports, etc., on Ontario’s home care system

Noted in Media Watch, 21 September 2015, #428 (p.2):

- ONTARIO | *The Globe & Mail* – 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 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.¹ <http://www.theglobeandmail.com/news/national/ontarios-home-care-providers-want-more-say-in-reform-discussions/article26410967/>

1. ‘Bringing Care Home,’ Expert Group on Home & Community Care, March 2015. The Group reviewed over 200 published and unpublished articles, reports and briefing documents related to home and community care; conducted a stakeholders survey (1,147 responses), asked Local Health Integration Networks to conduct a survey of their communities on the Expert Group’s behalf (2,344 responses), and held two sessions with service providers (77 participants). The Expert Group received 27 submissions from interested parties. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

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.**’ If the Ontario Health Coalition message isn’t strong enough to be heard by the Ontario government,¹ 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 (see *The Globe & Mail* article above). <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. Results of consultations with 95 seniors, advocates, community service agencies, home care providers, home care workers and professionals, and primary health care professionals. <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>

Noted in Media Watch, 15 December 2014, #388 (p.11):

- *HEALTH POLICY* | Online – 3 December 2014 – ‘**Factors associated with not receiving homecare, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study.**’ Despite the known benefits of homecare, many end-of-life (EOL) cancer patients never receive these services. The authors used administrative data on all cancer decedents in Ontario in 2006 to determine predictive factors of not receiving homecare, not receiving EOL homecare, and late initiation of EOL homecare. 22,262 decedents met the eligibility criteria, 25% of whom never received homecare in the last six months of life. [http://www.healthpolicyjrn.com/article/S0168-8510\(14\)00334-0/abstract](http://www.healthpolicyjrn.com/article/S0168-8510(14)00334-0/abstract)

The Conference Board of Canada

Feds should invest \$3.3 billion into health care for seniors: Report

CTV NEWS | Online – 21 September 2015 – A new report has put a price tag on aging in Canada.¹ The Conference Board of Canada study, commissioned by the Canadian Medical Association (CMA), says that it would cost the federal government \$3.3 billion in the next year to implement three strategies to cope with the wave of aging baby boomers. In the next five years, the price would jump to \$17.5 billion as boomers put an ever-increasing strain on the Canadian health-care system. “The reality (is) that it costs more to look after people who are aging,” said Dr. Cindy Forbes, president of the CMA. “There are at least three items that are doable and will make a difference to Canadians in the next budget cycle.” The first strategy recommends giving provinces and territories additional money for health care based on the age of their populations. That would require the federal government to boost funding to the Canada Health Transfer (CHT), the country’s largest handover of cash from the federal government to provinces and

territories. Money sent through the CHT must be used for publicly provided health care. The money is currently provided solely based on population, which the report calls uncommon and impractical, because an elderly population has higher health-care costs. According to a recent study in *PLOS One*, the average cost for care in a patient’s last year of life is \$54,000.² <http://www.ctvnews.ca/health/feds-should-invest-3-3b-into-health-care-for-seniors-report-1.2572894>

Extract on palliative care from The Conference Board of Canada report

Palliative care services are ... insufficient. Only a minority of the seniors requiring these services can access them, and those who do typically experience a patchwork of services that are uncoordinated and confusing.

1. ‘Federal Policy Action to Support the Health Care Needs of Canada’s Aging Population,’ The Conference Board of Canada, Ottawa, 21 September 2015. <https://www.cma.ca/Assets/assets-library/document/en/advocacy/conference-board-rep-sept-2015-embargo-en.pdf>

Cont.

2. 'The health care cost of dying: A population-based retrospective cohort study of the last year of life in Ontario, Canada,' *PLOS One*, 26 March 2015. Among 264,755 decedents, the average health care cost in the last year of life was \$53,661. The total captured annual cost of \$4.7 billion represents approximately 10% of all government-funded health care. [Noted in Media Watch, 13 April 2015, #405 (p.12)] <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0121759>

Selected articles, reports, etc., on the economics of end-of-life care and resource utilization at end of life in Canada

Noted in Media Watch, 8 June 2015, #413 (p.15):

- *JOURNAL OF PALLIATIVE CARE*, 2015;31(2):69-75. '**Impact of palliative care consultations on resource utilization in the final 48 to 72 hours of life at an acute care hospital in Ontario, Canada.**' Patients who receive palliative care consultations are associated with significantly lower costs in the final 48 to 72 hours of life than non-palliative patients. The degree of cost reduction at the very end of life appears to be relative to how soon after the patient's admission the palliative care consultation was initiated. <http://www.ingentaconnect.com/content/iug/jpc/2015/00000031/00000002/art00002>
- *PALLIATIVE MEDICINE* | Online – 3 June 2015 – '**Palliative care costs in Canada: A descriptive comparison of studies of urban and rural patients near end of life.**' The total cost per patient was \$26,652 in urban areas, while it was \$31,018 in rural areas. Family assumed 20.8% and 21.9% of costs in the rural and urban areas, respectively. Rural families faced more costs related to prescription medication, out-of-pocket costs and transportation; urban families faced more costs related to formal home care. <http://pmj.sagepub.com/content/early/2015/06/03/0269216315583620.abstract>

Noted in Media Watch, 1 June 2015, #412 (p.9):

- *CANCER* | Online – 29 May 2015 – '**Impact of aggressive management and palliative care on cancer costs in the final month of life.**' Cancer patients who receive aggressive end-of-life care incur 43% higher costs than those managed non-aggressively. Palliative consultation may offset these costs and offer resultant savings. This study used population data to identify a cohort of patients who died of cancer in Ontario, Canada (2005-2009). <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29485/pdf>

Noted in Media Watch, 8 December 2014, #387 (p.11):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 2 December 2014 – '**Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada.**' The estimated total societal cost of end-of-life care was \$34,197.73 per patient over the entire palliative trajectory (4 months on average). Alternative sites of death, while not associated with a significant change in total societal cost of end-of-life care, resulted in changes in the distribution of costs borne by different stakeholders. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12170/abstract>

Truce called in hospice issue

ONTARIO | *Bay Today* (North Bay) – 21 September 2015 – Two competing hospice care committees in North Bay have agreed to a new process that will see a final solution agreed upon by both parties. To determine community interest for a hospice within the Nipissing District, the North East LHIN [Local Health Integrated Network] issued an expression of interest in May this year. Two proposals were received. In 2015, the province announced that it would develop 20 new residential hospices across Ontario. The Ministry of Health & Long-Term Care (MOHLTC) hasn't announced funding to develop a residential hospice in North Bay; however, should funding be announced, the agreed-to process will enable a project to proceed expediently. The MOHLTC does not provide capital funding to build residential hospices. Communities must fundraise 100% of the capital planning and construction costs, as well as 45% of the ongoing operational costs. A 10-bed stand-alone hospice can range between \$5 million and \$7 million in capital and construction costs. The average cost to operate a 10-bed hospice in the province of Ontario is about \$1.6 million. <https://www.baytoday.ca/local-news/truce-called-in-hospice-issue-65441>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 23 September 2015 – **‘Physician-assisted death law will need clarity, CMA says.’** The Canadian Medical Association (CMA) is seeking consistency with provincial laws surrounding physician-assisted dying across Canada before next February. “This is going to be confusing enough and challenging enough without inconsistency across provincial jurisdictions ... we really would like to see a unified approach,” said Dr. Jeff Blackmer the vice-president of medical professionalism at the CMA. Blackmer doesn’t want to see is “patchwork legislation” that would leave some provinces with varying qualifications for the right to die. “We want to avoid a situation where one province has legislation that allows for assisted dying for someone with depression and another province does not ... people with depression will flock to that province,” he said. <http://www.cbc.ca/news/canada/new-brunswick/physician-assisted-death-new-brunswick-1.3240012>

Noted in Media Watch, 17 August 2015, #423 (p.3):

- ONTARIO | CBC News – 14 August 2015 – **‘Ontario forms expert panel on assisted dying.’** The Ontario government is setting up an advisory group to study physician-assisted dying, leading 11 provinces and territories in examining the controversial subject. The panel is similar to the one established by the federal government to inform its end-of-life legislation. The federal, provincial and territorial governments will need to craft laws around the court ruling by February 2016, when the ruling takes effect. Ontario and the participating provinces and territories say the primary responsibility to provide health care resides with them, and the panel will craft their response to the court ruling. <http://www.cbc.ca/news/canada/toronto/ontario-forms-expert-panel-on-assisted-dying-1.3191186>
- *THE NATIONAL POST* | Online – 22 September 2015 – **‘Canadian panel looking at assisted dying learns much from European experience.’** The head of a panel looking into legislative options to govern doctor-assisted death says a fact-finding tour in Europe has opened members’ eyes to the many complexities surrounding a practice that’s soon to become legal in Canada. Dr. Harvey Max Chochinov said he and the other members of the External Panel recently returned from an intensive 11-day study of how physician-aided dying has been implemented in The Netherlands, Belgium and Switzerland, where patients can legally have their deaths hastened. “We learned a tremendous amount from experts who have a great deal of experience with end-of-life regimes in their countries,” said Chochinov, Canada Research Chair in Palliative Care at the University of Manitoba. “We saw people from such diverse perspectives – people who still continue to struggle with the issue of physician-hastened dying and are very much opposed to it ... And we saw others who were, of course, much more comfortable and described this as something that has become part of their cultural experience around death and dying.” The panel was appointed to consult experts and the Canadian public before providing the government with potential options for crafting new legislation, but their work, for the most part, is on hold until the federal election is decided 19 October. <http://news.nationalpost.com/health/canadian-panel-looking-at-assisted-dying-learns-much-from-european-experience>

U.S.A.

Near the end, it’s best to be “friended”

THE NEW YORK TIMES | Online – 25 September 2015 – The unconscious man in his 90s was brought to an emergency room where Dr. Douglas White was a critical care physician. The staff couldn’t find any relatives to make medical decisions on his behalf. “He had outlived all his family,” recalled Dr. White, who now directs an ethics program at the University of Pittsburgh Medical Center. “We were unable to locate any friends. We even sent the police to knock on his neighbors’ doors.” Nobody could find an advance directive, either. In the end, the hospital’s ethics committee had to help guide the medical team to decisions about continuing life support. Experts describe patients like this one as “unbefriended.” But you can also be unbefriended, even if you do have friends and family, if you are incapacitated and haven’t appointed someone you trust as a health care proxy. <http://www.nytimes.com/2015/09/29/health/near-the-end-its-best-to-be-friended.html?ref=health& r=0>

An aging population, without the doctors to match

THE NEW YORK TIMES | Online – 22 September 2015 – Most health care professionals have had little to no training in the care of older adults. Currently, 97% of all medical students in the U.S. do not take a single course in geriatrics. Recent studies show that good geriatric care can make an enormous difference. Older adults whose health is monitored by a geriatrician enjoy more years of independent living, greater social and physical functioning and lower presence of disease. In addition, these patients show increased satisfaction, spend less time in the hospital, exhibit markedly decreased rates of depression and spend less time in nursing homes. Currently there are fewer than 8,000 geriatricians in practice nationwide – and that number is shrinking. At the same time, the nation's fastest-growing age group is over 65. Government projections hold that in 2050 there will be 90 million Americans 65 and older, and 19 million people over age 85. The American Geriatrics Society argues that, ideally, the U.S. should have one geriatrician for every 300 aging people. But with the looming shortage of geriatricians, the society projects that by 2030 there will be only one geriatrician for every 3,798 older adults. Why such a growing gap between an increasing number of patients and a decreasing number of doctors required to treat them? Geriatrics is a low-paying field of medicine, even though it requires years of intensive specialization. <http://www.nytimes.com/2015/09/23/opinion/an-aging-population-without-the-doctors-to-match.html?action=click&pgtype=Homepage&module=opinion-c-col-left-region®ion=opinion-c-col-left-region&WT.nav=opinion-c-col-left-region&r=0>

Specialist Publications

'Education, implementation, and policy barriers to greater integration of palliative care: A literature review' (p.17), in *Palliative Medicine*.

Selected articles, reports, etc., on physician “supply and demand” in the U.S.

Noted in Media Watch, 9 March 2015, #400 (p.3):

- *THE WASHINGTON POST* | Online – 3 March 2015 – **'U.S. faces 90,000 doctor shortage by 2025, medical school association warns.'** The U.S. faces a shortage of as many as 90,000 physicians by 2025, including a critical need for specialists to treat an aging population that will increasingly live with chronic disease, the association that represents medical schools and teaching hospitals reported...¹ <http://www.washingtonpost.com/news/to-your-health/wp/2015/03/03/u-s-faces-90000-doctor-shortage-by-2025-medical-school-association-warns/>

1. 'The Complexities of Physician Supply and Demand: Projections from 2013-2025,' Association of American Medical Colleges, March 2015. The first comprehensive national analysis that takes into account both demographics and recent changes to care delivery and payment methods. <https://www.aamc.org/download/426242/data/ihsreportdownload.pdf>

Noted in Media Watch, 24 November 2014, #385 (p.11):

- *ONCOLOGY TIMES* | Online – 14 November 2014 – **'Nearly half of palliative care clinicians plan to exit the field within a decade.'** 1 in 4 of palliative care clinicians surveyed say there is a good chance that they will leave by 2018. While retirement is the most common reason palliative care specialists are planning to leave, many respondents also cited burnout as another reason they are considering their exit. <http://journals.lww.com/oncology-times/blog/asco11spotlightnews/pages/post.aspx?PostID=167>

Cont.

Noted in Media Watch, 16 July 2012, #262 (p.10):

- **HEALTH LEADERS** | Online – 13 July 2012 – ‘**Palliative care challenged by physician shortage.**’ There is about one cardiologist in the U.S. for every 71 people experiencing a heart attack; one oncologist for every 141 newly diagnosed cancer patients; and only one palliative care physician for every 1,200 people living with a life-threatening illness.¹ <http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage>
- 1. ‘Estimate of current hospice and palliative medicine physician workforce shortage,’ *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] [http://www.jpmsjournal.com/article/S0885-3924\(10\)00602-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00602-0/abstract)

International

End-of-life care in Australia

Growing aging population puts pressure on palliative care

AUSTRALIA | *The Observer* (Gladstone, Queensland) – 23 September 2015 – A report from the Australian Institute of Health & Welfare shows palliative care-related hospitalisations have risen more than 50% over the past decade ... almost 62,000 palliative care hospitalisations in the 2012-2013 financial year – an increase of 52% since 2003-2004. Spokesman Geoff Neideck said the report showed older people accessed palliative care services more frequently. <http://www.gladstoneobserver.com.au/news/palliative-care-hospitalisations-rise-50-percent/2782861/>

1. ‘Palliative Care Services in Australia 2015,’ Australian Institute of Health & Welfare, September 2015. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129552885>

Noted in Media Watch, 27 October 2014, #381 (p.8):

- **AUSTRALIAN HEALTH REVIEW** | Online – 19 October 2014 – ‘**Dying in Australian hospitals: Will a separate national clinical standard improve the delivery of quality care?**’ More than 50% of Australian deaths occur in hospital. Despite this, hospitals often view themselves as poorly equipped to provide quality care to people dying expected deaths... While home deaths are one outcome, changing demographics of Australian society, coupled with the fact for many people hospital is the preferred place of death, dictate a need for hospitals to consider how the care of dying people can be better provided. http://www.publish.csiro.au/view/journals/dsp_journals_pip_abstract_scholar1.cfm?nid=270&pip=AH14175

Noted in Media Watch, 7 September 2015, #426 (p.16):

- **PALLIATIVE MEDICINE** | Online – 1 September 2015 – ‘**Palliative care in hospital: Why is it so difficult?**’ Care of the dying used to be the bread and butter of family doctors – why and where has that confidence gone? At the same time, families are not available or confident to care, community services are fragmented, we do not talk about dying, and we do not prepare or plan ahead. The end result of ... is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. Studies have suggested that many who are in hospital could be supported elsewhere – however, this depends on citizens, health services and social care working much more cohesively together. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315600996.full>

Specialist Publications

‘**End-of-life decisions in the Intensive Care Unit (ICU): Exploring the experiences of ICU nurses and doctors – A critical literature review**’ (p.10), in *Australian Critical Care*.

Elder care in England

Home care visits must last longer, watchdog says

U.K. (England) | *The Independent* – 23 September 2015 – Home care workers must be given enough time to spend with elderly and disabled people and must have enough travelling time between appointments, a health watchdog has said.¹ The National Institute for Health & Care Excellence (NICE) said home help visits of less than 30 minutes were not acceptable unless part of a wider package of support. It has published new guidance for councils that commission care as well as firms providing services. Eight councils provided more than 593,000 care visits lasting five minutes or less in the three years from 2010-2011 to 2012-2013. The new NICE guidance says contracts should “allow home care workers enough time to provide a good quality service, including having enough time to talk to the person and their carer, and to have sufficient travel time between appointments. <http://www.independent.co.uk/life-style/health-and-families/health-news/home-care-visits-must-last-longer-watchdog-says-10513611.html>

1. ‘Delivering Personal Care and Practical Support to Older People Living in Their Own Homes,’ National Institute for Health & Care Excellence, September 2015. <https://www.nice.org.uk/guidance/ng21>

Noted in Media Watch, 2 February 2015, #395 (p.7):

- U.K. (England) | *The Daily Mail* – 31 January 2015 – ‘**Indignity, a dearth of compassion, terrible suffering and utter chaos...**’ A *Daily Mail* investigation has revealed a catalogue of failings – inadequate training, call times of 15 minutes or even less in which carers must meet their clients’ most basic needs; carers asked to be literally in two places at once because they are allocated insufficient travelling time. It all adds up to a grim picture, according to the former care minister Paul Burstow.¹ <http://www.dailymail.co.uk/news/article-2933902/Indignity-dearth-compassion-terrible-suffering-utter-chaos-investigation-ll-terrify-family-lay-bare-agonising-death-Britain-s-home-care-system.html>

1. ‘Key to Care: Report of the Burstow Commission on the Future of the Home Care Workforce,’ Local Government Information Unit, December 2014. Paul Burstow was Minister of Care Services 2010-2012. <http://www.lgiu.org.uk/wp-content/uploads/2014/12/KeyToCare.pdf>

Scottish Parliament Health & Sport Committee inquiry

Call for Scottish Government to improve children’s palliative care

U.K. (Scotland) | Children’s Hospice Association Scotland (CHAS) – 23 September 2015 – CHAS has challenged a key Scottish Parliament committee to back its call for better access to care for children with life-limiting conditions. CHAS chief executive Maria McGill [recently] pressed for round-the-clock care for children with life-limiting conditions when she gave oral evidence to the Scottish Parliament’s Health & Sport Committee... Members of the Scottish Parliament are hearing evidence as part of the committee’s inquiry into the standard of palliative and end-of-life care in Scotland. Ms. McGill also told committee members how vital it is to make more people aware of the lifeline children’s palliative care services which support children across Scotland. While recognising the progress that has been made, Ms McGill recommended that action is needed if the Scottish Government is to realise its aim of providing high quality palliative care for every child in Scotland with a life-shortening condition. CHAS provides the only hospice service in Scotland to babies, children and young people with life-shortening conditions and their families. <http://www.togetherforshortlives.org.uk/news/8579-call-for-scottish-government-to-improve-childrens-palliative-care>



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[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>

Selected articles, reports, etc., on end-of-life care in Scotland

Noted in Media Watch, 21 September 2015, #428 (p.6):

- U.K. (Scotland) | *The Courier* (Dundee) – 15 September 2015 – **‘Report says 10,000 people miss out on palliative care before dying.’** More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it.¹ An estimated 40,000 people in Scotland could benefit from the specialist form of care. <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>

Noted in Media Watch, 14 September 2015, #427 (p.4):

- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 8 September 2015 – **‘Lack of data for Scotland’s black, Asian or minority ethnic community.’** We don’t have a complete picture of palliative care across the country. Nor do we have robust data on access to, and quality and consistency of, care across black, Asian or minority ethnic communities.¹ <http://www.scotsman.com/news/comment-lack-of-data-for-scotland-s-bame-community-1-3881360>
 1. ‘Palliative and End-of-Life Care for Black, Asian and Minority Ethnic Groups in Scotland – Exploring the Barriers,’ Policy & Public Affairs, Marie Curie (Scotland), 7 September 2015. http://www2.mariecurie.org.uk/ImageVaultFiles/id_2357/cf_100/Palliative_and_end_of_life_care_for_Black_Asian_an.PDF

Noted in Media Watch, 31 August 2015, #425 (p.7):

- U.K. (Scotland) | *The National* (Glasgow) – 27 August 2015 – **‘Families’ struggle over future young patients didn’t expect.’** Extra support is needed to help the families of young people with life-limiting conditions adapt to a future they were not expected to have, a new report has found. <http://www.thenational.scot/news/families-struggle-over-future-young-patients-didnt-expect.6846>
 1. ‘Multiple and Multi-Dimensional Understanding the Life Transitions of Young Adults Cared for by CHAS and the Impact on their Parents, Siblings and Professionals,’ Educational & Life Transitions Research Centre, University of Dundee, Sue Ryder Care Centre for the Study of Supportive, Palliative & End-of-Life Care, University of Nottingham, for the Children’s Hospice Association Scotland,’ 2015. http://www.chas.org.uk/assets/0001/5083/Multiple_and_Multi-Dimensional_Transitions-Executive_Summary.pdf

Noted in Media Watch, 20 July 2015, #419 (p.8):

- U.K. (Scotland) | *The Herald* (Glasgow) – 14 July 2015 – **‘We have a duty of care to patients with life threatening illnesses and their families.’** Research suggests nearly 11,000 people are not accessing palliative care.¹ The Palliative Care Register last year listed only 12,000 people receiving it. http://www.heraldscotland.com/opinion/13420753.Agenda_We_have_a_duty_of_care_to_patients_with_life_threatening_illnesses_and_their_families/
 1. ‘Triggers for Palliative Care: Implications for Scotland,’ Marie Curie Scotland, June 2015. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-scotland-summary.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>

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

End-of-life care in Australia

End-of-life decisions in the Intensive Care Unit (ICU): Exploring the experiences of ICU nurses and doctors – A critical literature review

AUSTRALIAN CRITICAL CARE | Online – 18 September 2015 – This review considered both qualitative and quantitative research conducted from January 2006 to March 2014 that report on the experiences of ICU doctors and nurses in end-of-life decision making. Studies with a focus on paediatrics, family/relatives perspectives, advance care directives, and euthanasia were excluded. There were differences reported in the decision making process and collaboration between doctors and nurses (which depended on physician preference or seniority of nurses), with overall accountability assigned to the physician. Role ambiguity, communication issues, indecision on futility of treatment, and the initiation of end-of-life discussions were some of the greatest challenges. The impact of these decisions included decreased job satisfaction, emotional and psychological “burnout.” Further research is warranted to address the need for a more comprehensive, standardised approach to support clinicians in end-of-life decision making in the ICU. [http://www.australiancriticalcare.com/article/S1036-7314\(15\)00079-X/abstract](http://www.australiancriticalcare.com/article/S1036-7314(15)00079-X/abstract)

Noted in Media Watch, 10 August 2015, #422 (p.10):

- *AUSTRALIAN CRITICAL CARE* | Online – 28 July 2015 – ‘**End-of-life care practices of critical care nurses: A national cross-sectional survey.**’ Analysis identified six domains of end-of-life care practice: 1) Information sharing; 2) Environmental modification; 3) Emotional support; 4) Patient and family centred decision-making; 5) Symptom management; and, 6) Spiritual support. Statistics identified a high level of engagement in information sharing and environmental modification practices and less frequent engagement in items from the emotional support and symptom management practice areas. [http://www.australiancriticalcare.com/article/S1036-7314\(15\)00076-4/abstract](http://www.australiancriticalcare.com/article/S1036-7314(15)00076-4/abstract)
- *AUSTRALIAN CRITICAL CARE*, 2015;28(2):64-70. ‘**The nature of death, coping response and intensity of bereavement following death in the critical care environment.**’ The results from this evaluation provide insight into the impact of bereavement after death in the critical care environment and inform potential preventative approaches at the time of death to reduce bereavement intensity. [http://www.australiancriticalcare.com/article/S1036-7314\(15\)00036-3/abstract](http://www.australiancriticalcare.com/article/S1036-7314(15)00036-3/abstract)

How parents and practitioners experience research without prior consent (deferred consent) for emergency research involving children with life threatening conditions: A mixed method study

BMJ OPEN | Online – 18 September 2015 – This [multi-centre] study provides evidence to support the use of deferred consent in paediatric emergency medicine; it also indicates the crucial importance of practitioner communication and appropriate timing of deferred consent discussions. Alternatives to prospective informed consent to enable children with life-threatening conditions to be entered into trials of emergency treatments are needed. Across Europe, a process called deferred consent has been developed as an alternative. Little is known about the views and experiences of those with first-hand experience of this controversial consent process. To inform how consent is sought for future paediatric critical care trials, we explored the views and experiences of parents and practitioners involved in the CATHeter infections in CHildren (CATCH) trial, which allowed for deferred consent in certain circumstances. Some parents [i.e., study participants] were momentarily shocked or angered to discover that their child had or could have been entered into CATCH without their prior consent. Although these feelings resolved after the reasons why consent needed to be deferred were explained and that the CATCH interventions were already used in clinical care. Prior to seeking deferred consent for the first few times, CATCH practitioners were apprehensive, although their feelings abated with experience of talking to parents about CATCH. Parents reported that their decisions about their child’s participation in the trial had been voluntary. However, mistiming the deferred consent discussion had caused distress for some. Practitioners and parents supported the use of deferred consent in CATCH and in future trials of interventions already used in clinical care. <http://bmjopen.bmj.com/content/5/9/e008522.full>

Cont.

Related:

- *JOURNAL OF CLINICAL ETHICS*, 2015;26(3). **‘Ethical bargaining and parental exclusion: A clinical case analysis.’** Although there has been significant attention in clinical ethics to when physicians should follow a parent’s wishes, there has been much less discussion of the obligation to solicit viewpoints and decisions from all caregivers who have equal moral and legal standing in relation to a pediatric patient. How should healthcare professionals respond when one caregiver dominates decision making? We present a case that highlights how these problems played out in an ethical bargain. Ethical bargaining occurs when the parties involved choose not to pursue a morally preferable option for the sake of coming to a resolution. <http://www.clinicalethics.com/>

The impact of the environment on patient experiences of hospital admissions in palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 September 2015 – Almost all [study] participants described a range of factors associated with the environment which impacted negatively on their experiences of hospitalisation. This included challenges with the physical surroundings, the impact on social relationships with other patients, families and health professionals, and the influence of the cultural milieu of the hospital setting. Emulating the “ideal” environment for palliative care such as that provided in a hospice setting is an unrealistic goal for acute hospitals. Paying attention to the things that can be changed, such as enabling family to stay and improving the flexibility of the physical environment while improving the social interplay between patients and health professionals, may be a more realistic approach than replicating the hospice environment in order to reduce the burden of hospitalisations for patients with palliative care needs. <http://spcare.bmj.com/content/early/2015/09/25/bmjspcare-2015-000891.abstract>

Knowledge of dementia: Do family members understand dementia as a terminal condition?

DEMENTIA | Online – 21 September 2015 – Current research identifies advanced dementia to be the terminal phase of this progressive and incurable condition. However, there has been relatively little investigation into how family members of people with advanced dementia understand their relative’s condition. Findings revealed that the majority of family members [i.e., study participants] could not recognize the terminal nature of dementia. Relying on predominantly lay understandings, they had little access to formal information and most failed to conceptualize a connection between dementia and death. Moreover, family members engaged in limited dialogue with aged care staff about such issues, despite their relatives being in an advanced stage of the disease. Findings ... suggest that how family members understand their relative’s condition requires greater attention. The development of staff/family partnerships that promote shared communication about dementia and dying may enhance family members’ understandings of the dementia trajectory and the types of decisions they may be faced with during the more advanced stages of the disease. <http://dem.sagepub.com/content/early/2015/09/21/1471301215605630.abstract>

Selected articles, reports, etc., on end-of-life care for people living with advanced dementia

Noted in Media Watch, 14 September 2015, #427 (p.15):

- *PALLIATIVE MEDICINE* | Online – 9 September 2015 – **‘Development of a model for integrated care at the end of life in advanced dementia...’** There are few evidence-based interventions to improve end-of-life care in advanced dementia. Twenty-nine statements [from people with dementia, carers and health and social care professionals in England, from expert opinion and existing literature] were agreed and mapped to individual, group, organisational and economic/political levels of healthcare systems. The resulting main intervention components are: 1) Influencing local service organization through facilitation of integrated multi-disciplinary care; 2) providing training and support for formal and informal carers; and. 3) Influencing local healthcare commissioning and priorities of service providers. <http://pmj.sagepub.com/content/early/2015/09/08/0269216315605447.abstract>

Cont.

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

- **BMC PALLIATIVE CARE** | Online – 25 July 2015 – ‘**Expert views on the factors enabling good end-of-life care for people with dementia: A qualitative study.**’ Four key factors ... were identified from the expert interviews: 1) Leadership and management of care; 2) Integrating clinical expertise; 3) Continuity of care; and, 4) Use of guidelines. The relationships between the four key factors are important. Leadership and management of care have implications for the successful implementation of guidelines, while the appropriate and timely use of clinical expertise could prevent hospitalisation and ensure continuity of care. A lack of integration across health and social care can undermine continuity of care. <http://www.biomedcentral.com/content/pdf/s12904-015-0028-9.pdf>

N.B. Selected articles on end-of-life care for people living with dementia noted in past issues of Media Watch are listed in the issue of the weekly report of 15 June 2015, #414 (pp.13-14).

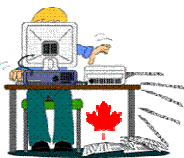
Doing more does not mean doing better: The Federation of Associations of Hospital Doctors in Internal Medicine contribution to the slow medicine program for a sustainable and wise healthcare system

ITALIAN JOURNAL OF MEDICINE, 2015;9(3):281-286. Consistently with its own vision on the necessity to implement a sustainable and frugal medicine, in 2013 the Italian Federation of Associations of Hospital Doctors in Internal Medicine (FADOI) decided to adhere to the slow medicine program, ‘Doing more does not mean doing better,’ launched in Italy in late 2012, following the Choosing Wisely® campaign of the American Board of Internal Medicine Foundation started in the U.S. in 2010. According to the program, FADOI has now produced a list of ten evidence-based recommendations of the “do not type,” regarding different practices whose benefits for the patients are questionable at least, if not harmful at worst. The list was obtained from a questionnaire submitted to 1,175 FADOI members, containing a purposely selected choice of 32 pertinent recommendations already published by Choosing Wisely®, and reflects the qualified opinion of a large number of Italian internists. These recommendations are now endorsed by the FADOI, as a contribution to the discussion among doctors, health professionals, nurses, patients and citizens about what is worth choosing in medicine; they are also meant to promote a shared decision making process in the clinical practice. <http://www.italjmed.org/index.php/ijm/article/view/itjm.2015.580/574>

N.B. English language article.

Related:

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 21 September 2015 – ‘**Moral distress amongst American physician trainees regarding futile treatments at the end of life: A qualitative study.**’ Physician trainees [i.e., study participants] experienced significant moral distress when they felt obligated to provide treatments at or near the end of life that they believed to be futile. Some trainees developed detached and dehumanizing attitudes towards patients as a coping mechanism, which may contribute to a loss of empathy. Successful coping strategies included formal and informal conversations with colleagues and superiors about the emotional and ethical challenges of providing care at the end of life. <http://link.springer.com/article/10.1007/s11606-015-3505-1>



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>

Oncologist experience implementing goals of care discussions in everyday ambulatory oncology practice: Implications for education

JOURNAL OF CANCER EDUCATION | Online – 19 September 2015 – Despite evidence that Goals of Care (GOC) discussions should occur early in the disease trajectory, the majority occur close to end of life. In a pilot, oncologists routinely initiated GOC discussions with all patients in their everyday ambulatory practice. Following the pilot, 9 of 12 eligible oncologists participated in semi-structured interviews about their experiences. Analysis resulted in the identification of seven principles of good GOC discussions embedded in the oncologists' interviews, four barriers to engaging in GOC discussions and foundational education needs. Participants believed that the appropriate trigger for a GOC discussion is a diagnosis of advanced cancer, not simply a diagnosis of cancer, and supported the importance of selective and strategic targeting of GOC discussions. <http://link.springer.com/article/10.1007/s13187-015-0915-z>

Related:

- *ILLNESS, CRISIS & LOSS* | Online – 22 September 2015 – ‘**Agency and communion in end-of-life decision-making.**’ The balancing of agency and communion within small communities of support may provide the opportunity to inform end-of-life decision-making and acceptance of the dying process. <http://icl.sagepub.com/content/early/2015/09/21/1054137315606819.abstract>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE*, 2015;11(2):132-146. ‘**Practicing end-of-life conversations: Physician Communication Training Program in Palliative Care.**’ Scripts [based on actual family conferences with patients, families, and the health care team] focus on improving physicians' basic skills in conducting family meetings, discussing advance directives, prognosis, brain death, and withdrawal of life support. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074140>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE*, 2015;11(2):147-166. ‘**Educating aging service agency staff about discussing end-of-life wishes.**’ A training program was developed with the goal of increasing agency serving older adults understanding of the process and benefits of health care proxies and advance directives through hands-on experience, increasing relevant skills and willingness to discuss with consumers, and to implement an agency protocol increasing documentation for consumers. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074144>
- *PALLIATIVE MEDICINE* | Online – 22 September 2015 – ‘**They know! – Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes.**’ The main findings were the differing views about decision-making and advance care planning of residents and relatives. Residents do trust relatives and staff to make important decisions for them. The relatives are in contrast insecure about the residents' wishes and experience decision-making as a burden. The majority of the residents had not participated in advance care planning. None of the residents stated challenges connected to end-of-life care or mentioned the wish for euthanasia. <http://pmj.sagepub.com/content/early/2015/09/22/0269216315605753.abstract>

Assessing advance care planning: Examining autonomous selections in an advance directive

JOURNAL OF CLINICAL ETHICS, 2015;26(3). The authors examined the management of completed advance directives including why participants completed a document, what procedures and values they chose, with whom they held end-of-life conversations, and where they stored their document. Advance directives are most often completed to allow patients [i.e., survey respondents] to prepare and control the healthcare they wish to receive when dying. One-half to two-thirds of individuals refuse common end-of-life medical procedures, and the rest request the procedures. There was a correlation between the choice to refuse or request a procedure and the age of the participant. Participants reported that their end-of-life conversations most often occurred with their spouse. Respondents often reported that their advance directive was stored with their physician and power of attorney for healthcare, conversations with those individuals rarely happened. Advance directives document patients' requests for and refusals of end-of-life care. Physicians and surrogates need to be better educated so that the documents are part of a meaningful conversation with the patient. Because patients' choices change over their lifespan, these documents need to be revisited regularly and not completed as a onetime event. <http://www.clinicalethics.com/>

A systematic content analysis of policy barriers impeding access to opioid medication in Central and Eastern Europe: Results of the Access to Opioid Medication in Europe project



JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 September 2015 – Reliable access to opioid medication is critical to delivering effective pain management, adequate treatment of opioid dependence and quality palliative care. However, over 80% of the world population is estimated to be inadequately treated for pain because of difficulties in accessing opioids. While barriers to opioid access are primarily associated with restrictive laws, regulations and licensing requirements, a key problem that significantly limits opioid access relates to policy constraints. Twenty-five policy barriers were identified (e.g., economic crisis, bureaucratic issues, lack of training initiatives, stigma and discrimination), classified under four pre-determined categories (financial/economic aspects and governmental support, formularies, education and training, and societal attitudes). Key barriers related to issues of funding allocation, affordability, knowledge and fears associated with opioids. Reducing barriers and improving access to opioids requires policy reform at the governmental level with a set of action plans being formulated and concurrently implemented aimed at different levels of social, education and economic policy change. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00460-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00460-1/abstract)

N.B. Access to Opioid Medication in Europe project, University of Glasgow (End of Life Studies) website: <http://endoflifestudies.academicblogs.co.uk/access-to-opioid-medication-in-europe-atome-project-results-and-achievements-by-eugenia-larjow/>

Noted in Media Watch, 3 August 2015, #421 (p.12):

- *PALLIATIVE MEDICINE* | Online – 31 July 2015 – ‘**Coverage and development of specialist palliative care services across the World Health Organization European Region (2005-2012): Results from a European Association for Palliative Care Task Force survey of 53 countries.**’ Improvement was statistically significant for Western European countries, but not for Central and Eastern countries. Estimations of 2012 coverage for inpatient palliative care service, home care team and hospital support team are 62%, 52% & 31% for Western European and 20%, 14% & 3% for Central and Eastern, respectively. <http://pmj.sagepub.com/content/early/2015/07/31/0269216315598671.full.pdf+html>

Cultivating a culture of mentorship in palliative social work

JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE, 2015;11(2):101-106. It is no longer news that we’re facing a major shortage of social workers in the fields of oncology, geriatrics and palliative care. People are living longer with multiple chronic and advanced illnesses, and psychosocial supportive care needs of patients and family members are widely documented. The need to train and retain qualified clinicians in palliative social work is significant, as is our duty to pass the collected wisdom of an aging generation of leaders who have pioneered the field over the last 35 years. Formal mentorship programs have shown promise in promoting professional and personal development in related professions (i.e., medicine, nursing...), but the literature on mentorship lacks methodological and conceptual consistency, and has yet to fully unpack mentorship, identify what works and what doesn’t, and measure the utility of various models. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074138?journalCode=wswe20>

Related:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE*, 2015;11(2):107-131. ‘**Mentoring the next generation of social workers in palliative and end-of-life care: The Zelda Foster Studies Program.**’ Findings from the first six years of two components of the program are examined to illustrate the feasibility, benefits, and challenges of formal mentorship programs. The authors describe the background, structure, and evaluation of the initiative’s mentorship programs, and discuss the implications of mentorship in palliative and end-of-life care for social work education, practice, and research. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074142>

Cont.

Selected articles, reports, etc., on the role of social work in end-of-life care

Noted in Media Watch, 17 March 2014, #349 (p.14):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 14 March 2014 – **'Relationship between pain and chronic illness among seriously ill older adults: Expanding role for palliative social work.'** Study findings suggest positive associations between pain and chronic disease, pain and multi-morbidity, as well as an inverse association between pain and education. Policy implications for workforce development and public health are many. Amplification of palliative social work roles to relieve pain and suffering among seriously ill older adults at all stages of the chronic illness trajectory is needed. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877861>

Noted in Media Watch, 18 February 2013, #293 (p.6):

- *BRITISH JOURNAL OF SOCIAL WORK* | Online – 14 February 2013 – **'Advance care planning in the U.S. and U.K.: Comparative analysis of policy, implementation and the social work role.'** As a member of the ... care team concerned with psychosocial care, social workers can assume vital roles, including patient/family education; promoting meaningful communication among patients, family members and health care providers; and, assisting people facing illness in documenting their preferences... <http://bjsw.oxfordjournals.org/content/early/2013/02/14/bjsw.bct013.abstract>

Noted in Media Watch, 18 June 2012, #258 (p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 13 June 2012 – **'Hospice and palliative social workers' engagement in life review interventions.'** The opportunity for many individuals to bring closure at the end of life may be lost due to limited access to life review interventions. <http://ajh.sagepub.com/content/early/2012/06/12/1049909112449067.abstract>

Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective

JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE, 2015;11(2):178-201. This article focuses on culturally sensitive clinical issues related to best practices with lesbian, gay, bisexual, transgender (LGBT) elder patients at end of life (EOL)... Vital concepts, including practice evaluation and clinical skills, are presented through a cultural and oncology lens. There is a paucity of LGBT research and literature as well as a shortfall of Master of Social graduate school education specific to social work palliative and end-of-life care practice with LGBT elders. The content of this article is designed to be adapted and used as an educational tool for institutions, agencies, graduate programs, medical professions, social work, and students. Learning the unique elements of LGBT cultural history and their implications on EOL care can improve social work practice. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074141>



Selected articles, reports, etc., on end-of-life care for an aging LGBT population

Noted in Media Watch, 20 July 2015, #419 (p.15):

- *PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 29 May 2015 – **'Hospice and palliative care for older lesbian, gay, bisexual and transgender adults: The effect of history, discrimination, health disparities and legal issues on addressing service needs.'** LGBT persons are more likely to experience economic insecurity, lack health insurance, experience invisibility, and be victimized and mistreated. This is especially true of older LGBT adults who grew up in a less tolerant era when sexual minorities were criminalized and stigmatized as pathological, sinful, and immoral. Their minority status has led to health issues and health care disparities, and requires health professionals to consider systems in a way that redefines family, addresses legal concerns, and responds with options of care... http://openventio.org/Volume1_Issue2/Hospice_and_Palliative_Care_for_Older_Lesbian_Gay_Bisexual_and_Transgender_Adults_The_Effect_of_History_Discrimination_Health_Disparities_and_Legal_Issues_on_Addressing_Service_Needs_PMHCOJ_1_107.pdf

Cont.

Noted in Media Watch, 2 March 2015, #399 (p.6):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 26 February 2015 – ‘**American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement.**’ Providing high-quality health care for older LGBT adults will require active steps by organizations, institutions, advocacy groups, and health professionals that create an environment that is free from discrimination. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13297/abstract>

Noted in Media Watch, 30 December 2013, #338 (p.2):

- *ADVOCATE* (U.S.) | Online – 27 December 2013 – ‘**End-of-life care for an aging LGBT population.**’ With the number of self-identified LGBT adults age 65 or older expected to double by 2030 – from 1.5 million to 3 million – the time has never been more urgent to discuss this silent challenge: How do we meet the unique end-of-life care needs for an aging LGBT population? LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care...¹ <http://www.advocate.com/health/2013/12/27/end-life-care-aging-lgbt-population>

1. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*, National Resource Center on LGBT Aging, November 2011. <http://www.lgbtagingcenter.org/resources/resource.cfm?r=419>

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>

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

Education, implementation, and policy barriers to greater integration of palliative care: A literature review

PALLIATIVE MEDICINE | Online – 24 September 2015 – Early integration of palliative care (PC) into the management of patients with serious disease has the potential to both improve quality of life of patients and families and reduce healthcare costs. Despite these benefits, significant barriers exist in the U.S. to the early integration of PC in the disease trajectory of individuals with serious illness. The authors identified key barriers to PC integration across three World Health Organization domains: 1) Education domain: lack of adequate education/training and perception of PC as end-of-life care; 2) Implementation domain: inadequate size of palliative medicine-trained workforce, challenge of identifying patients appropriate for PC referral, and need for culture change across settings; and, 3) Policy domain: fragmented healthcare system, need for greater funding for research, lack of adequate reimbursement for PC, and regulatory barriers. <http://pmj.sagepub.com/content/early/2015/09/23/0269216315606645.abstract>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 September 2015 – ‘**University-community-hospice partnership to address organizational barriers to cultural competence.**’ Models for culturally competent hospice services have been developed, but are not in general use. Organizational barriers include a lack of: 1) Funding/budgeting for additional staff for community outreach; 2) Applications from culturally diverse professionals; 3) Funding/budgeting for additional staff for development of culturally competent services; 4) Knowledge about diverse cultures; and, 5) Awareness of which cultural groups are not being served. A research project addressed these organizational barriers through a multicultural social work student field placement in one rural hospice. <http://ajh.sagepub.com/content/early/2015/09/21/1049909115607295.abstract>

[Media Watch: Editorial Practice](#)

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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.

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