

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.

14 September 2015 Edition | Issue #427



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

When death is imminent: Scroll down to [Specialist Publications](#) and 'Intimations of dying: A visible and invisible process' (p.12), in *Journal of Palliative Care*.

U.S.A.

Hospice care to be provided to inmates by Delaware Hospice

DELAWARE | *The Cape Gazette* (Lewes) – 10 September 2015 – Delaware Hospice has partnered with Connections Community Support Programs to provide hospice care to inmates at ... Smyrna & Sussex Correctional Institution... Delaware Hospice will provide hospice care that focuses on meeting the physical, emotional and spiritual needs of inmates. Care of the inmates with life-limiting illnesses and their families will come from a multidisciplinary team of professionals. Delaware Hospice has been working with Connections over the past few months to ensure there is no gap with inmate hospice care as the transition between providers takes place. Under the Eighth Amendment, all inmates receive their constitutional right to healthcare including compassionate end-of-life care, as it is considered cruel and unusual punishment for the state not to provide this service. <http://capegazette.villagesoup.com/p/hospice-care-to-be-provided-to-inmates-by-delaware-hospice/1407006>

Prison Hospice Backgrounder

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report is available at the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/pages/view/3389845/additional-offerings>

How much does Medicare spend on end-of-life care for California residents with cancer?

CALIFORNIA | *California Healthline* – 9 September 2015 – Medicare spending on hospice care in the last year of life for cancer patients from 2007 to 2011 was two to four times lower than Medicare spending on inpatient care during such patients' last month of life, depending on the type of cancer, according to a study by the California HealthCare Foundation. The findings indicate that replacing intensive hospital care with hospice care or other outpatient, home-

centered care could be more cost-effective. <http://www.californiahealthline.org/picture-of-health/2015/how-much-does-medicare-spend-on-endoflife-care-for-californians-with-cancer>

Specialist Publications

'What is the difference between palliative care and hospice care?' (p.7), in *Cleveland Clinic Journal of Medicine*.

The real costs of unpaid family caregiving

MASSACHUSETTS | *The Boston Globe* – 7 September 2015 – The value of care provided, unpaid, by family caregivers in 2013 rivalled Walmart's sales that year... The total value of these contributions – \$470 billion – reflects approximately 37 billion hours of care, and was more than total Medicaid spending that year.¹ Some 40 million caregivers provided an average of 18 hours of support a week to parents, spouses, partners, and other loved ones with limitations in daily activities. A rate of \$12.51 – the average estimated value of an hour of family care in the U.S. – was used to calculate the total cost. While these unpaid contributions are vital to reducing strain on state-funded and paid long-term services and supports, providing this care can come at a considerable cost to caregivers... Along with struggling to balance caregiving with full- or part-time work and other family obligations, many take on demanding and complex tasks they may be unprepared for, such as managing medications ... and operating medical equipment. <https://www.bostonglobe.com/lifestyle/2015/09/06/real-costs-unpaid-family-caregiving/SEQxo9ekteyL2eU7b2HIWK/story.html>

1. 'Valuing the Invaluable 2015: Update,' Public Policy Institute, American Association of Retired Persons, July 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

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

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – '**Managing end-of-life medications at home – accounts of bereaved family carers.**' Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. They report anxiety about giving correct and timely dosages and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. They reported that certain analgesic medications, especially opioids, were considered to have a symbolic significance increasing analgesia requirements, and the use of a syringe driver was associated with deterioration and approaching death. Key barriers to managing end-of-life medications at home included: 1) Complex regimes; 2) Unwanted responsibility in deciding when to use "as needed" medication; 3) Disagreements with professional staff; and, 4) Anxiety about medication errors, especially if perceived to have implications for survival. <http://spcare.bmj.com/content/early/2014/09/25/bmjspcare-2014-000658.short?rss=1>

Related:

- NATIONAL PUBLIC RADIO | Online – 10 September 2015 – '**Medicare provides few respite coverage options for caregivers.**' In general, traditional Medicare only pays for respite care if a patient has entered hospice. To be eligible, the doctor has to certify that the patient is terminally ill and expected to live for six months or less. The program pays for the Medicare beneficiary to be moved to a hospital or nursing home for up to five days at a time so the caregiver can get some rest. <http://www.npr.org/sections/health-shots/2015/09/10/437305197/medicare-provides-few-respite-coverage-options-for-caregivers>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The New York Times* – 11 September 2015 – '**California legislature approves assisted suicide.**' In a landmark victory for supporters of assisted suicide, the California State Legislature gave its final approval to a bill that would allow doctors to help terminally ill people end their lives. The bill, which passed in the State Senate by a vote of 23 to 14, will now go to Governor Jerry Brown, who will roughly triple access to doctor-assisted suicide across the country if he signs it. Mr. Brown has given little indication of his intentions. The California bill is modeled on the law in Oregon, with several notable changes. The California law would expire after 10 years and have to be reapproved, and doctors would have to consult in private with the patient desiring to die, as part of an effort to ensure that no one would be coerced to end his or her life – a primary concern for opponents of the law. http://www.nytimes.com/2015/09/12/us/california-legislature-approves-assisted-suicide.html?_r=0

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- *THE NEW YORK TIMES* | Online – 10 September 2015 – ‘**Helping a suicide when the end isn’t near.**’ Several states have passed laws allowing terminally ill people to commit suicide with help from a physician and more states are considering it. Some nations, though, have gone further, permitting such assistance to people with serious, non-fatal, health problems, even severe depression. Is that a dangerous step on a slippery slope toward euthanasia, or an appropriate way to help people who suffer unbearably? Should some people who are not dying be permitted assistance in killing themselves? <http://www.nytimes.com/roomfordebate/2015/09/10/helping-a-suicide-when-the-end-isnt-near>

International

Irish Hospice Foundation conference

“What would you tweet from your deathbed?”

IRELAND | *The Journal* (Dublin) – 12 September 2015 – More than 300 people gathered at Dublin Castle on to discuss death as part of a [recent] conference organised by the Irish Hospice Foundation (IHF). It was a diverse group – healthcare professionals, people who are ill, people who are bereaved or soon will be, and the bald woman who had to repeatedly explain to well-meaning strangers she has alopecia, not cancer. At a workshop on grief, Dr. Susan Delaney of the IHF told participants they will never become comfortable with death, but can become more comfortable with their discomfort. Delaney noted that many people avoid going to see a friend who has been bereaved because they don’t know the “right thing” to say, but noted: “There’s often nothing nice to be said” when it comes to terminal illness or death. She said people should not stay away from a bereaved person for this reason – rather sit with them, offer to do the shopping, let them shout, or watch TV – whatever they need at that moment. Something people should definitely NOT do is tell the person what they should do or let them know “things could be worse.” <http://www.thejournal.ie/death-cafe-irish-hospice-foundation-2324192-Sep2015/>

U.K. Prisons & Probation: Ombudsman

Prisons “must adjust to older inmates” says ombudsman

U.K. (England & Wales) | BBC News – 10 September 2015 – Prisons will have to adjust to a rapidly ageing prison population, the Prisons & Probation ombudsman says in his annual report.¹ The number of prisoners whose deaths were caused by natural causes increased by 15% to 155 in the year 2014-2015. Ombudsman Nigel Newcomen says prisons will have to take on “care home and even hospice” roles in future. Mr. Newcomen attributes some of the increase in the ageing population to longer sentences and more “late life” prosecutions for historical sex offences. “It is remarkable that the fastest growing segment of the prison population is prisoners over 60 and the second fastest is prisoners over 50” ... “end of” care in prisons is improving but is variable and in some cases “unacceptable.” <http://www.bbc.com/news/uk-34211681>

Extract from Ombudsman report:

[Investigations] have identified some lessons which have not previously been of such widespread importance. For example ... the demand for more dedicated palliative care suites for those reaching the end of their lives (these are now available in at least 10 prisons); and the call for better training and support for staff who must now routinely manage death itself.

Prison Hospice Backgrounder

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report is available at the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/pages/view/3389845/additional-offerings>

1. ‘Prisons & Probation: Ombudsman Independent Investigations,’ 2014-2015 Report, September 2015. http://www.ppo.gov.uk/wp-content/uploads/2015/09/PPO_Annual-Report-2014-15_Web-Final.pdf#view=FitH

End-of-life care in Australia

Change cultural taboo around dying

AUSTRALIA | DPN News – 8 September 2015 – Palliative Care Australia chief executive officer Liz Callaghan ... says dying in Australia is a hard business, made harder by families and loved ones difficulty in talking about end-of-life wishes. “We know that the health system, with its focus on interventions and saving lives, can work against a peaceful death. So it is up to us, up to you, to change it,” Ms. Callaghan says. “You can talk about death, dying and bereavement. You do know how to raise the issues of end-of-life care, how to discuss choosing or turning down medical interventions, how to speak to someone about putting an advance care plan in place. We need your skill set. We need you to start those

conversations. In schools, in community centres, at death cafes.” According to Ms. Callaghan, Australians avoid talking about dying, resulting in difficult deaths and significant impacts on those left behind. She has challenged the palliative care sector to step up and change that culture. <https://news.agedcareguide.com.au/2015/09/08/change-cultural-taboo-around-dying/>

Specialist Publications

‘Advance care planning in Australia: What does the law say?’ (p.6), in *Australian Health Review*.

Noted in Media Watch, 26 January 2015, #394 (p.6):

- AUSTRALIA | *Business Insider* (Sydney, New South Wales) – 19 January 2015 – **‘Most Australians want a good death at home, but only 14% get it.’** Most Australians would prefer to die at home but only about 14% get the opportunity to do so...¹ Dying in Australia is highly institutionalised with 54% ending their days in hospitals, 32% in residential care. However, most (60-70%) prefer to die at home. <http://www.businessinsider.com.au/doctors-when-the-end-comes-most-australians-want-a-good-death-at-home-2015-1>

1. ‘What can we do to help Australians die the way they want to?’ *The Medical Journal of Australia*, 2015;202(1):10-11. A different service mix could better meet end-of-life care needs for little additional cost. <https://www.mja.com.au/journal/2015/202/1/what-can-we-do-help-australians-die-way-they-want>

End-of-life care in Scotland

Lack of data for Scotland’s black, Asian or minority ethnic community

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 8 September 2015 – Everyone who needs palliative care must have the option to receive it at the right time and in a way that is meaningful to them. Sadly we know there are nearly 11,000 people in Scotland every year who don’t get that chance. However, 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 (BAME) communities. Healthcare providers do not routinely monitor who receives specialist palliative care services. Hospital standardised mortality ratios do not include data by ethnicity, nor does the end-of-life indicator in Scotland. Marie Curie has explored this topic in a new report...¹ Much of the existing research literature on the subject is from the U.S., and is based on small qualitative samples which make it difficult to complete a picture that reflects Scotland. But the limited evidence we do have shows that there are a range of barriers for BAME communities accessing palliative care. These include lack of cultural and religious sensitivity in how services are delivered, lack of translation resources, lack of advocates, problems with using family and friends as translators, low numbers of minority doctors and low availability of professional training in cultural awareness. Also, few research studies have explored how people at the end of life, and their carers, define their own cultural needs. <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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England, Northern Ireland & Wales) | *The Daily Mail* – 11 September 2015 – ‘**Shock as “right to die” for the terminally ill law is overwhelmingly defeated by MPs after highly-charged four-hour debate.**’ A law which would give the terminally ill the right to die has been overwhelmingly rejected by MPs. In a highly-charged debate in Parliament, opponents warned it would amount to making “killing people being legal.” After four hours of clashes, the Assisted Dying Bill was thrown out by 330 voters to 118, a majority 212. <http://www.dailymail.co.uk/news/article-3230837/Shock-right-die-terminally-ill-law-overwhelmingly-defeated-MPs-highly-charged-four-hour-debate.html>

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

Conclusiveness of the Cochrane Reviews in palliative and supportive care for cancer: A systematic analysis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 September 2015 – The authors concluded that a large number of clinical trials were not carried out well in palliative care and supportive oncology. Each Cochrane Review (CR) was analyzed for conclusiveness, number of randomized controlled trials (RCTs), number of participants enrolled, the need for further studies, and the reasons. Only 45% (30 of 66) of the CRs reached definitive clinical recommendations. The number of RCTs and participants enrolled in conclusive CRs were significantly higher than those in inconclusive CRs. <http://ajh.sagepub.com/content/early/2015/09/08/1049909115605058.abstract>

Noted in Media Watch, 7 September 2015, #426 (p.12):

- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):133-140. ‘**Evidence-based palliative care 13 years on: Has anything changed?**’ There is a paucity of data on whether interventions in individual palliative care units are evidence based. Results show the evidence base for interventions in palliative care continues to evolve, but that there are still areas for which further high-quality studies are needed. <http://search.proquest.com/openview/4d455887ccea4b6127fde6e347f82e/1?pg-origsite=gscholar>

Noted in Media Watch, 31 August 2015, #425 (p.13):

- *HEALTH INFORMATION & LIBRARIES JOURNAL* | Online – 21 August 2015 – ‘**How effective are palliative care clinicians in finding the evidence in their field?**’ Many palliative care clinicians search PubMed ineffectively. Targeted skills training and Palliative CareSearch Filter promotion may improve evidence retrieval. <http://onlinelibrary.wiley.com/doi/10.1111/hir.12120/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>

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.

Advance care planning in Australia: What does the law say?

AUSTRALIAN HEALTH REVIEW | Online – 28 August 2015 – Formal documentation increases the chances a person's wishes will be known and followed. One of the biggest impediments for doctors, however, is uncertainty surrounding the law, which is complicated and varies between the states and territories. Substitute decision maker (SDM) legislation varies regarding who can be appointed, how they are appointed, the powers that a SDM can be given, and the decision making principles that the SDM needs to follow. In circumstances where a SDM hasn't been appointed, the hierarchy for determining the default SDM for a person also varies between states. Whilst many have legislated advance care directives (ACD) forms, these allow for different things to be documented, and have different requirements to be valid. The Australian population is mobile, with patients frequently moving between states. The status of ACP documentation created in a state other than the state in which a patient requires treatment also varies, with some states recognising interstate ACDs whilst others do not. This article outlines the legal status of ACDs within Australian jurisdictions in Australia, including the legal validity of interstate ACDs, and argues uniform laws and documents would assist awareness and understanding of, and compliance with, ACDs. http://www.publish.csiro.au/view/journals/dsp_journals_pip_abstract_Scholar1.cfm?nid=270&pip=AH15120

Noted in Media Watch, 20 January 2014, #341 (p.5):

- *AUSTRALIAN AGEING AGENDA* | Online – 17 January 2014 – **'Doctors unclear on advance care planning laws.'** Many doctors are confused about the legality of advance care directives and the authority of substitute decision-makers, leaving them open to possible legal action, research has found.¹ According to the study led by Professor Colleen Cartwright from Southern Cross University only half of surveyed doctors in New South Wales (NSW) correctly understood that an enduring power of attorney does not allow the person appointed to make healthcare decisions. Doctors were also unclear about the order of authority if no enduring guardian had been appointed, which in NSW is not the next-of-kin. <http://www.australianageingagenda.com.au/2014/01/17/doctors-unclear-advance-care-planning-laws/>

1. 'Medical practitioners' knowledge and self-reported practices of substitute decision-making and implementation of advance care plans,' *Internal Medicine Journal*, 24 December 2013. Survey of 650 general practitioners and 350 medical specialists from specialties most often involved in end-of-life decisions. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12354/abstract>

Related:

- *BMJ OPEN* | Online – 28 August 2015 – **'Feasibility and acceptability of advance care planning in elderly Italian and Greek speaking patients as compared to English-speaking patients: An Australian cross-sectional study.'** Of 112 patients, 109 (97%) had at least one discussion, 63 (54%) completed advance care directives, either nominating a substitute decision-maker, documenting their wishes or both, and 76 (68%) included family in discussions. There were no differences between the Greek-speaking and the Italian-speaking patients, or between the non-English speaking and the English-speaking patients in any of these measures. Only 14 non-English speaking patients, (30%) utilised interpreters, but when utilised, patients were much more likely to complete advance care directives. <http://bmjopen.bmj.com/content/5/8/e008800.abstract>

Overcoming language barriers in healthcare: A protocol for investigating safe and effective communication when patients or clinicians use a second language

BMC HEALTH SERVICES RESEARCH | Online – 10 September 2015 –The rising number of migrant patients and foreign-trained staff means that communication errors between a healthcare practitioner and patient when one or both are speaking a second language are increasingly likely. However, there is limited research that addresses this issue systematically. This protocol outlines a hospital-based study examining interactions between healthcare practitioners and their patients who either share or do not share a first language. Of particular interest are the nature and efficacy of communication in language-discordant conversations, and the degree to which risk is communicated. Our aim is to understand lan-

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guage barriers and miscommunication that may occur in healthcare settings between patients and healthcare practitioners, especially where at least one of the speakers is using a second (weaker) language. <http://www.biomedcentral.com/content/pdf/s12913-015-1024-8.pdf>

Noted in Media Watch, 1 June 2015, #412 (p.14, under 'Worth Repeating'):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2005;8(5):1016-1024. '**Communication about end-of-life care between language-discordant patients and clinicians: Insights from medical interpreters.**' Communication about health care and especially end-of-life care is difficult for clinicians and patients when they do not speak the same language. The authors developed three frameworks for understanding high-quality language-discordant communication about end-of-life care. The first addresses physician and interpreter professionalism, including humanistic qualities and emotional support capabilities important for high quality care. The second is physician-centered and highlights communication skills, as well as coordination with other providers and cultural sensitivity. The third is interpreter-centered, focusing on role conflicts, including struggles concerning expectations to provide strict interpretation versus being a cultural broker. Interpreters' recommendations for improving quality of this care include pre-meetings with interpreters before encounters involving delivery of bad news and explicit discussions with interpreters about whether the clinician expects strict interpretation or cultural brokering.. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2005.8.1016>

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

What is the difference between palliative care and hospice care?

CLEVELAND CLINIC JOURNAL OF MEDICINE, 2015;82(9):569-571. The two often appear together in titles of reports in the literature. As a result, patients and physicians may be confused and, thus, reluctant to utilize palliative care services. To avoid the confusion, certain programs have included the term "supportive" oncology care in their title. This appears to facilitate palliative care referral, but may be misleading. Hospice care is a service funded ... under Medicare ... and is largely provided as outpatient home care for those deemed terminally ill. An illness must be certified as terminal by two physicians. Medicare defines terminal illness as a life expectancy of 6 months or less if the illness runs its normal course. Unlike hospice care, home-based palliative care does not include 24-hour on-call service. Comprehensive services (e.g., home health aide, durable equipment, medications) are not provided as they are under hospice care: patients must qualify under Medicare stipulations for such services outside of hospice care. For example, home oxygen can only be supplied if the patient's oxygen saturation is less than 90%, while under the hospice benefit it is provided without regard to oxygen saturation and is based on symptom need. For home-based palliative care, patients must be largely homebound or unable to be seen regularly in the outpatient clinic. This type of care can be a bridge to hospice care for patients who feel they are not ready for hospice care at the time of discharge from acute care. Those who receive palliative care at home are less likely to be hospitalized at the end of life, are more likely to be transitioned to hospice at an appropriate time, and are more likely to have relief of symptoms. http://www.ccjm.org/current-issue/issue-single-view/what-is-the-difference-between-palliative-care-and-hospice-care/dbd0b810d7f84620f832105dec72e47c.html?email=INSERT_EMAIL&ocid=INSERT_CUSTOM01

Noted in Media Watch, 27 July 2015, #420 (pp.4-5):

- *THE NEW YORK TIMES* | Online – 22 July 2015 – '**Medicare to try a blend of hospice care and treatment.**' Most older Americans close to death have to make a difficult choice: to continue with traditional medical treatment or switch to hospice care, which focuses not on a cure but on easing their remaining days. Medicare is testing a third alternative: both. A pilot program, designed to affect the care of about 150,000 Medicare patients over the next four years, will allow patients with terminal diseases to receive hospice care to manage suffering and counseling to plan for the end of life – but still see doctors and get treatments, like chemotherapy or hospitalization, intended to fight their illnesses. <http://www.nytimes.com/2015/07/22/upshot/medicare-to-try-a-blend-of-hospice-care-and-treatment.html? r=0&abt=0002&abg=1>

Constitutional and legal protection for life support limitation in India

INDIAN JOURNAL OF PALLIATIVE CARE, 2015;21(3):258-261. The perceived lack of legal guidance is the greatest barrier to taking a treatment limiting decision in India. The physician approach in India seems to be hampered by misperceptions of legal liability linked to treatment limitation, in major part due to the unclear signals from the legal community. The Supreme Court has upheld suicide laws that may potentially be mis-applied to limitation decisions; the Law Commission of India has clarified many concepts, but appears to have insufficient information regarding the needs of the dying patient and his or her family; the Aruna Shanbaug judgment pronounced ambiguously on passive euthanasia; the ethical code of the Medical Council of India barely devotes a few lines on the question, focusing mainly on procedure for limitations at brain death and declaring euthanasia to be illegal. In essence, legal opinions appear to be ill-informed of the day-to-day ethical dilemmas surrounding foregoing of futile treatments toward the end of life. Faced with the risks of lawsuits and societal unawareness of legitimate treatment foregoing options, the Indian physician is often compelled to take the path of least resistance: to continue expensive, burdensome and heroic efforts till the very end or resort to an ethically problematic “left against medical treatment” decision. The result is that India has one of the poorest end-of-life care in the world...¹

<http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2015;volume=21;issue=3;spage=258;epage=261;aulast=Mani>

1. India was rated 40th, of the 40 countries surveyed, in *The Quality of Death: Ranking End-of-Life Care Across the World*, which was commissioned by The Lien Foundation, of Singapore, and published in the U.K. by the Economist Intelligence Unit, 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Representative sample of articles on ethics and the law in the context of the provision and delivery of end-of-life care in India noted in past issues of Media Watch:

- *THE TIMES OF INDIA* | Online – 19 May 2015 – ‘**India needs a complete law on “end-of-life” care.**’ India does not have a comprehensive legal framework that lets patients and families take control of their last days and do the right things. As a default option, doctors tend to follow the safest option, which is to do nothing. As a society we avoid discussing an issue that affects all of us and leads to unnecessary trauma, prolonged grief, and a wastage of scarce resources. Remember most individuals, especially in cities die in hospital, not at home. [Noted in Media Watch, 25 May 2015, #411 (p.8)] <http://timesofindia.indiatimes.com/india/India-needs-a-complete-law-on-end-of-life-care/articleshow/47336216.cms>
- *MEDICAL JOURNAL ARMED FORCES INDIA*, 2013;69(1):2-3. ‘**End-of-life care: Should we struggle on, or let go?**’ Numerous studies have found that the medical care of the dying to be unnecessarily prolonged, painful, expensive and emotionally burdensome to both patients and their families. [Noted in Media Watch, 29 April 2013, #303 (p.14)] <http://medind.nic.in/maa/t13/i1/maat13i1p2.pdf>

End-of-life care in Norway

“Picking up the pieces” – Meanings of receiving home nursing care when being old and living with advanced cancer in a rural area



INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 10 September 2015 – This study aimed to illuminate the lived experience and to interpret the meaning of receiving home nursing care when being old and living with advanced cancer in a rural area in Norway. The analysis revealed three themes, each with sub-themes: 1) Being content with what one gets; 2) Falling into place; and, 3) Losing one’s place. The phrase “picking up the pieces” was found useful to sum up the meaning of this lived experience. The three respective themes refer to how the pieces symbolize the remaining parts of life or available services in their environment, and how the older persons may see themselves as pieces or bricks in a puzzle. A strong place attachment (physical insideness, social insideness, and autobiographical insideness) is demonstrated by the informants in this

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study and suggests that the rural context may provide an advantageous healthcare environment. Its potential to be a source of comfort, security, and identity concurs with cancer patients' strong desire for being seen as unique persons. The study shows that district nurses play an essential role in the provision of palliative care for older rural patients. However, the therapeutic value of being in one's familiar landscape seems to depend on how homecare nurses manage to locate it and use it in a more or less person-centred manner. Communication skills and attentiveness to psychosocial aspects of patient care stand out as important attributes... <http://www.ijghw.net/index.php/ghw/article/view/28382>

A mixed method thematic review: The importance of hope to the dying patient

JOURNAL OF ADVANCED NURSING | Online – 9 September 2015 – Hope is often linked to the future and is a significant factor for patients dealing with adversity, such as a terminal illness. The concept of hope is underreported in the literature. Seven key themes that increased hope were found: 1) Disease status; 2) Positive personal relationships; 3) Positive character traits; 4) Quality of life; 5) Setting and achieving goals; 6) Spirituality/religion; and, 7) Hope after death. Hope is a very complex and personal phenomena requiring hope-enhancing strategies to be individualized. More research is needed with groups whose culture, youth or type of illness may affect their ability to foster and maintain hope. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12765/abstract>

Representative sample of articles on hope in the context of end-of-life care noted in past issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 August 2015 – ‘**Does disclosure of terminal prognosis mean losing hope? Insights from exploring patient perspectives on their experience of palliative care consultations.**’ This study aimed to elicit seriously ill patients’ perspective and experience of an inpatient palliative care consultation, and to explore patient attitudes toward information derived from the consultation. [Noted in Media Watch, 24 August 2015, #424 (p.16)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0038>
- *PROGRESS IN PALLIATIVE CARE* | Online – 9 March 2015 – ‘**Palliative care professionals’ evaluations of the feasibility of a hope communication tool: A pilot study.**’ Palliative care professionals sometimes experience hope as a barrier for end-of-life communication, for instance when patients have unrealistic hope. A hope communication tool may help them to address hope during clinical encounters but has not been developed yet. [Noted in Media Watch, 16 March 2015, #401 (p.12)] <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000003>
- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 6 May 2015 – ‘**Solicitude: Balancing compassion and empowerment in a relational ethics of hope – an empirical-ethical study in palliative care.**’ The ethics of hope has often been understood as a conflict between duties: do not lie versus do not destroy hope. However, such a way of framing the ethics of hope may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. [Noted in Media Watch, 11 May 2015, #409 (p.12)] <http://link.springer.com/article/10.1007/s11019-015-9642-9>
- *PALLIATIVE MEDICINE* | Online – 15 April 2013 – ‘**Should palliative care patients’ hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals’ perspectives on hope of palliative care patients.**’ Of the 37 articles, 31 articles were of sufficient quality. The majority of these articles described perspectives of nurses or physicians. Three perspectives on hope of palliative care patients were found: 1) Realistic perspective – hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth; 2) Functional perspective – hope as coping mechanism should help patients, and professionals focused on fostering hope; and, 3) narrative perspective – hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it. [Noted in Media Watch, 22 April 2013, #302 (p.12)] <http://pmj.sagepub.com/content/early/2013/04/11/0269216313482172.abstract>

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

Cystic fibrosis healthcare workers feel unprepared in providing suitable end-of-life care and desire more education: Results of a nationwide survey

JOURNAL OF CYSTIC FIBROSIS | Online – 8 September 2015 – Little is known about the depth of knowledge and preparedness of cystic fibrosis (CF) caregivers in delivering end of life and palliative care to CF patients and families. The majority of non-physician CF care providers (55%) had more than 15 years of experience in their discipline and 84% of physician had greater than 15 years of experience. The majority reported that they felt “somewhat” or “very” involved in palliative or end-of-life care in their current role. Yet, when asked whether they felt adequately prepared to deliver palliative and end of life care, only 18% reported that they were “fully prepared” and 45% felt that they were only “minimally” or “not” prepared. Further, only one third of respondents received more than 10 hours of education in general palliative or end-of-life care, while only 10% had received more than 10 hours of education specific to CF end of life care. The majority (73%) of CF healthcare providers preferred more education specific to CF end of life care. [http://www.cysticfibrosisjournal.com/article/S1569-1993\(15\)00201-5/abstract](http://www.cysticfibrosisjournal.com/article/S1569-1993(15)00201-5/abstract)

Advance care planning in cystic fibrosis: Current practices, challenges, and opportunities

JOURNAL OF CYSTIC FIBROSIS | Online – 8 September 2015 – Advance Care Planning (ACP) often occurs late in the disease course. Important decisions default to surrogates when opportunities for ACP are missed. [http://www.cysticfibrosisjournal.com/article/S1569-1993\(15\)00178-2/abstract](http://www.cysticfibrosisjournal.com/article/S1569-1993(15)00178-2/abstract)

Representative sample of articles on end-of-life care for people living with cystic fibrosis noted in past issues of Media Watch:

- *PRIMARY HEALTH CARE*, 2015;25(6):18-24. ‘**Understanding and managing cystic fibrosis.**’ Of the 32,248 patients registered in Europe with cystic fibrosis, 49.3% are more than 18-years-old, although the median age of death across Europe is 28 years, based on the latest available figures. Children born with CF today are expected to live into their fifties and sixties. [Noted in Media Watch, 6 July 2015, #417 (p.13)] <http://journals.rcni.com/doi/abs/10.7748/phc.25.6.18.e714>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):277-281. ‘**Palliative care and cystic fibrosis – the benefits of integrated working.**’ Palliative care and CF teams can work together to provide synergistic care and treatment for CF patients and their families, and when this is done well there are huge benefits for patients, and families and carers, as well as for health care professionals. [Noted in Media Watch, 10 November 2014, #383 (p.12)]

N.B. Access to this article requires a subscription. Journal contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=540

- *PROGRESS IN PALLIATIVE CARE*, 2011;19(5):230-234. ‘**A symptom-based approach to palliative care in cystic fibrosis.**’ Although life expectancy has increased dramatically, children and adults living with cystic fibrosis will still die before their unaffected peers, and careful attention to issues in end-of-life care is still a part of their care... [Noted in Media Watch, 10 October 2011, #222 (p.11)] <http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000005/art00003>

Media Watch: Back Issues



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

Medical decision making for older adults: An international perspective comparing the U.S. and India

JOURNAL OF GERIATRIC CARDIOLOGY, 2015;12(4):329-334. There has been a significant decline in cardiovascular morbidity and mortality amidst pervasive advances in care, including percutaneous revascularization, mechanical circulatory support, and transcatheter valvular therapies. While advancing therapies may add significant longevity, they also bring about new end-of-life decision-making challenges for patients and their families who also must weigh the advantages of reduced mortality to the possibility of longer lives consisting of high morbidity, frailty, pain, and poor quality of living. Advance care entails options of withholding or withdrawing therapies, and has become a familiar part of cardiovascular care for older patients in Western countries. However, as advanced cardiovascular practices extend to developing countries, the interrelated concept of advance care is rarely straight forward as it is affected by local cultural traditions and mores, and can lead to very different inferences and use. This paper

discusses the concepts of advance care planning, surrogate decision-making, orders for resuscitation and futility in patients with cardiac disease with comparisons of West to East, focusing particularly on the U.S. versus India. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4554781/>

Extract from the *Journal of Geriatric Cardiology*

Planning for end-of-life care is particularly challenging as it is typically regarded by many Indians as an inappropriate consideration in a discussion regarding caregiving. Even for the very elderly, the notion of death is rarely “accepted” as part of a rational concept of care. Instead, it is more common that families believe that every caregiving option be utilized for life prolongation. Such presumptions are generally reinforced by the patterns of extended families living together in small domiciles, generating intense interpersonal linkages, and even reverence for older adults.

Patients’ perception of time in palliative care: A metasynthesis of qualitative studies

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2015;17(5):434-441. This study shows the interconnected nature of physical, social and emotional aspects of time perception and the profound social impact of providing and receiving care. “The suspended time of waiting” was a central theme because of its importance in patients’ accounts and because it was susceptible to change by health professionals. Other themes: “time of the diseased body,” “perspectives change with time,” “from the end to the aim of time.” http://journals.lww.com/jhpn/Abstract/2015/10000/Patients_Perception_of_Time_in_Palliative_Care_A.10.aspx

Weaving palliative care into the tapestry of pediatrics

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2015;17(5):434-441. Since the ... report ‘When Children Die’¹ proclaimed early integration of palliative care would benefit children through the trajectory of an illness, disease, or condition, children’s hospitals have strived to create pediatric palliative care programs. An innovative model will describe a highly successful pediatric palliative care program established initially with nursing staff at relatively low cost. Recognizing many of the principles of palliative care are inherent in established health care roles, the goal was to formally incorporate these concepts into direct caregivers’ practice. It will be shown this “role enhancement” can be beneficial, especially for beginning programs. Through education and practice opportunities, palliative care principles can be infiltrated to the bedside with improved acceptance. Begun with philanthropic funds and completely operationally funded after 5 years, the number of patients and families soared, overutilization of invasive interventions plummeted, visits to the emergency department and hospital admissions decreased, and ... satisfaction rose. http://journals.lww.com/jhpn/Abstract/2015/10000/Weaving_Palliative_Care_Into_the_Tapestry_of.12.aspx

1. ‘When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families,’ Institute of Medicine, July 2002. <https://iom.nationalacademies.org/Reports/2002/When-Children-Die-Improving-Palliative-and-End-of-Life-Care-for-Children-and-Their-Families.aspx>

An introduction and overview of Social Model Hospice Care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2015;17(5):456-462. The Social Model Hospice is an option for families facing the harsh realities of caring for a loved one at the end of life as well as addressing the gap that exists between desired and actual place of death for hospice patients. Honoring the individual's values, goals, and informed preferences, the model complements and enhances traditional medical hospice care. It is provided in a community home, utilizing a network of volunteers and paid staff, in combination with traditional medical hospices, addressing the lack of resources and the burden often accompanying care of the dying. Cantor introduced the idea of social care with the elderly,^{1,2} but recently, this concept has been expanded to include end-of-life care. Early research has shown caregiver well-being and bereavement are improved with utilization of a social model hospice. Grassroots, geographic expansion of this community-based model offers one solution to mitigating the growing caregiver crisis. http://journals.lww.com/jhpn/Abstract/2015/10000/An_Introduction_and_Overview_of_Social_Model.15.aspx

1. 'Social care: Family and community support systems,' *Annals of the American Academy of Political & Social Science*, 1989;503:99-112. <http://www.ncbi.nlm.nih.gov/pubmed/10293092>
2. 'Family and community: Changing roles in an aging society,' *The Gerontologist*, 1991;31(3):337-346. <http://gerontologist.oxfordjournals.org/content/31/3/337.abstract>

Related:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2015;17(5):404-412. '**Experiences of family caregivers making the transition from home to the palliative care unit: Weighing the two sides.**' Findings [of this study] reflected family caregivers' experiences in the home, during the transition, and on the palliative care unit. Both positive and negative experiences were revealed. In the home, participants felt honored to provide care but also encountered difficulties, such as accessing resources. Being on the palliative care unit, the provision of care from knowledgeable health care professionals was a relief. However, participants felt like a "guest" because there was little control over the environment. http://journals.lww.com/jhpn/Abstract/2015/10000/Experiences_of_Family_Caregivers_Making_the.9.aspx

Intimations of dying: A visible and invisible process

JOURNAL OF PALLIATIVE CARE, 2015;31(3):166-171. Death and dying are not subjects currently taught to medical and nursing students in great depth, yet they are something they will increasingly face in clinical practice over the next 20 years, as the baby boomers reach old age. Worcester seventy-five years ago encouraged every medical student to be present at the deathbed of several patients in order to build clinical experience. I would endorse this for those setting out on a career in nursing. Working in palliative care for many years, more recently with frail older people in care homes, has heightened my interest in the process of dying. This interest was first awakened in me in 1978, when I was working at St. Christopher's Hospice in London. My background was in oncology. I had been at the hospice for two weeks, and I had just completed the 6 p.m. medication round, when the matron, who always checked the wards at the end of the day, sought me out to tell me that one of my patients was dying. I was horrified that I had failed to notice. Matron went to sit with the patient while I prepared an injection. Having given the injection, I was about to leave the room when Matron suggested that I stay. The patient died about 40 minutes later. That the matron had known death was imminent made a profound impression on me, as did the way in which she had served as a role model in the important task of being with the dying. <http://search.proquest.com/openview/4d455887ccea4f7d78a892261bf12/1?pq-origsite=gscholar>

Noted in Media Watch, 19 August 2013, #319 (p.19):

- U.S. | *The Atlantic* – 12 August 2013 – '**Medicine's most important teachers.**' Canadian Sir William Osler [1849-1919] once said that medical education at its best "begins with the patient, continues with the patient, and ends with the patient." <http://www.theatlantic.com/health/archive/2013/08/medicines-most-important-teachers/278573/>

Cont.

Noted in Media Watch, 25 February 2013, #294 (p.13, under 'Worth Repeating'):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2011;1(2):193-197. '**Overcoming the challenges of bedside teaching in the palliative care setting.**' Bedside teaching is the process of active learning in the presence of a patient and is one of the most traditional teaching techniques used in undergraduate medicine. Students and patients both appear to benefit from the experience. However, bedside teaching with medical students and palliative care patients presents a number of challenges for the patient, the learner, and also the educator. <http://spcare.bmj.com/content/1/2/193.abstract?sid=68a10cdd-e64a-4b9a-b17e-947fe2be9bab>

Healthcare needs of patients with amyotrophic lateral sclerosis in Singapore: A patient-centred qualitative study from multiple perspectives

JOURNAL OF PALLIATIVE CARE, 2015;31(3):150-157. One challenge for those who manage amyotrophic lateral sclerosis (ALS) is to understand patients' needs. The aim of this study was to examine the needs of Singapore ALS patients from their perspective as well as that of their caregivers and healthcare professionals in order to develop a template for better services. All 30 [study] participants, key stakeholders in the field of caring for ALS patients, identified these needs categories: 1) Psychological – diagnosis must be staged and comfortably paced, and efforts must be made to encourage patients' resilience; 2) Social – positive relationships, open communication, and spiritual support must be developed; 3) Physical – attention should be paid to alleviating discomfort and disability; and, 4) Environmental – appropriate services should be made available. The identified needs categories do overlap, but there are significant differences. The authors findings provide a template for developing individualized patient services, which should be done within the framework of a comprehensive palliative care program. <http://search.proquest.com/openview/4d455887ccea4b58d23ff0f472b31d/1?pq-origsite=gscholar>

Representative sample of articles on palliative care for patients living with amyotrophic lateral sclerosis noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 September 2014 – '**Palliative care issues in amyotrophic lateral sclerosis (ALS): An evidenced-based review.**' In this article, the authors provides an evidenced-based review of palliative care options not usually addressed in national and international ALS guidelines. [Noted in Media Watch, 15 September 2014, #375 (p.7)] <http://ajh.sagepub.com/content/early/2014/09/08/1049909114548719.abstract>
- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online – 5 February 2011 – '**Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.**' Despite an international consensus that amyotrophic lateral sclerosis (ALS) management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. [Noted in Media Watch, 14 February 2011, #188 (p.8)] <http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3>

End-of-life care in Croatia

The reality of dysthanasia

MEDICINA FLUMINENSIS (of the Croatia Medical Association), 2015;51(3):393-395. Life and death are two inseparable parts of human reality, and along the art of living there is also the art of dying. Contrary to euthanasia, in our institutions daily "dysthanasia" is carried out. Dysthanasia is a term for a slow and painful, unworthy death due to supporting the process of dying with useless treatment that denies human dignity. In Western European countries the term "therapeutic perseverance" is used, while in the U.S. the term "medical futility" is used. http://hrcak.srce.hr/index.php?show=clanak&id_clanak_jezik=212514

N.B. Croatia language article. To access the full article, click on 'Puni tekst.'

Cont.

Noted in Media Watch, 26 January 2015, #394 (p.7):

- WELFARE SOCIETY TERRITORY | Online – 19 January 2015 – ‘**Where the terminally ill die without palliative care.**’ For the terminally ill in Croatia, there is no public healthcare. The situation is so bad that some patients are left without food or water in their homes, dying in excruciating pain. This is the dramatic reality denounced by the Croatian Association for Palliative Medicine, which is calling for a drastic sea change. <http://www.west-info.eu/where-the-terminally-ill-die-without-palliative-care/>



Noted in Media Watch, 16 July 2012, #262 (p.11):

- *MEDICINA FLUMINENSIS*, 2012;48(2):131-141. ‘**Palliative care in Croatia on the threshold of entering the European Union: Medical-legal and medical-ethical review.**’ Recommendations from the European Association for Palliative Care prove the flaw in the Croatian system of palliative care, with special emphasis on the need to prompt establishment of a national health policy of palliative care. http://hrcak.srce.hr/index.php?show=clanak&id_clanak_jezik=125308

Irish community nursing study reveals changing older user profile

NURSING TIMES (U.K.) | Online – 9 September 2015 – Public health nursing services in the Republic of Ireland for people aged over 50 are being used the most by those aged 85 years and above, with this trend set to continue due to an ageing population, according to a new study.¹ <http://www.nursingtimes.net/nursing-practice/specialisms/public-health/irish-community-nursing-study-reveals-changing-older-user-profile/5090212.article>

Extract from Institute of Community Health Nursing report

The high mortality rate in service users points to a service with an important role in end-of-life care for individuals and their families in the community.

1. ‘Demographic and health profile of older adults utilising public health nursing services in Ireland: Findings from The Irish Longitudinal Study on Ageing,’ Institute of Community Health Nursing, July 2015. <http://tilda.tcd.ie/assets/pdf/Demographic%20and%20health%20profile%20of%20older%20adults%20utilising%20public%20health%20nursing%20services%20in%20Ireland.pdf>

End-of-life care in England

New framework for action on end-of-life and palliative care

NURSING TIMES (U.K.) | Online – 8 September 2015 – A new framework on end-of-life care has been drawn up by a group of statutory health bodies which is hoped will spur clinical commissioning groups and health and well-being boards to make this type of care a priority in local areas.¹ The National Palliative & End-of-Life Care Partnership, made up bodies including National Health Service England, the Association of Adult Social Services, charities and groups representing patients and professionals, has compiled six “ambitions” on how care for those nearing death should be delivered... [i.e.,] 1) Each person is seen as an individual; 2) Each person gets fair access to care; 3) Maximising comfort and wellbeing; 4) Care is coordinated; 5) All staff are prepared to care; and, 6) Each community is prepared to help] <http://www.nursingtimes.net/nursing-practice/specialisms/end-of-life-and-palliative-care/-new-framework-for-action-on-end-of-life-and-palliative-care/5090142.article>

1. ‘Ambitions for Palliative and End-of-Life Care: A national framework for local action 2015-2020,’ National Palliative & End-of-Life Care Partnership, September 2015. <http://endoflifecareambitions.org.uk/>

Cont.

Noted in Media Watch, 13 July 2015, #418 (p.8):

- U.K. (England) | National End-of-Life Care Intelligence Network – 6 July 2015 – ‘**End-of-life care profiles for clinical commissioning groups.**’ These profiles ... draw together a wide range of information to give an overview of variations in cause and place of death ... for each clinical commissioning group in England. They will help commissioners and providers ... get a clearer picture of the end-of-life care needs of their local populations. They will help with the planning and delivery of services and will support drives locally towards improving end-of-life care. There are 170 indicators, presented in four separate tools... http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles

N.B. Clinical commissioning groups are National Health Service (NHS) organisations set up by the Health & Social Care Act 2012 to organise the delivery of NHS services in England.

Related:

- U.K. (England) | Together for Short Lives – 10 September 2015 – ‘**Jointly commissioning palliative care for children and young people.**’ A new guide aims to help clinical commissioning groups, local authorities and health and wellbeing boards in England to work together to improve commissioning for palliative care for children and young people. The guide provides a step-by-step guide to bringing about better outcomes for children, young people and their families. Many families struggle to cope with the round-the-clock care needed by their seriously ill child. Without properly funded care and support, these families can reach breaking point, putting extra pressure on GPs and emergency services. http://www.togetherforshortlives.org.uk/professionals/resources/8558_jointly_commissioning_palliative_care_for_children_and_young_people

Development of a model for integrated care at the end of life in advanced dementia: A whole systems U.K.-wide approach

PALLIATIVE MEDICINE | Online – 9 September 2015 – There are few evidence-based interventions to improve end-of-life care in advanced dementia. A total of 29 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>

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).

[Media Watch: Palliative Care Network-e Website](#)

The website promotes education amongst health care providers in places around the world where the know-ledge 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>

Scottish Parliament's Health & Sport Committee inquiry

Full health record access for pharmacists “would reduce palliative care delays”

THE PHARMACEUTICAL JOURNAL | Online – 9 September 2015 – Community pharmacists should be given read and write access to the health records of palliative care patients to reduce delays in receiving medicines, according to the Royal Pharmaceutical Society Scotland. Responding to the Scottish Parliament's Health & Sport Committee inquiry into palliative care,¹ the Society says the lack of pharmacist access to these records also poses a “significant risk” to patient safety. It calls for community pharmacists to be allowed access when a patient expressly consents. <http://www.pharmaceutical-journal.com/your-rps/full-health-record-access-for-pharmacists-would-reduce-palliative-care-delays/20069239.article>

1. Scottish Parliament's Health & Sport Committee inquiry into palliative care website: <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/91055.aspx>

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 Belgium

What are physicians' reasons for not referring people with life-limiting illnesses to specialist palliative care services? A nationwide survey

PLOS ONE | Online – 10 September 2015 – Many people who might benefit from specialist palliative care services are not using them. Palliative care services were not used in 79% of cases of people with organ failure, 64% of dementia, and 44% of cancer. The most frequently indicated reasons: 1) Existing care already sufficiently addressed palliative and supportive needs (56%); 2) Palliative care was not deemed meaningful (26%); and, 3) There was insufficient time to initiate palliative care (24%). The reasons differed according to patient characteristics: in people with dementia the consideration of palliative care as not meaningful was more likely to be a reason for not using it; in older people their care needs already being sufficiently addressed was more likely to be a reason. For those patients who were referred the timing of referral varied from a median of six days before death (organ failure) to 16 days (cancer). Specialist palliative care is not initiated in almost half of the people for whom it could be beneficial, most frequently because physicians deem regular caregivers to be sufficiently skilled in addressing palliative care needs. This would imply that the safeguarding of palliative care skills in this regular “general” care is an essential health policy priority. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0137251>

Noted in Media Watch, 12 December 2011, #231 (p.9):

- *PALLIATIVE MEDICINE* | Online article – 5 December 2011 – ‘**Social-cultural factors in end-of-life care in Belgium: A scoping of the research literature.**’ Belgium provides a unique opportunity to witness how euthanasia is put into practice when legalized, in a context where palliative care is also highly developed and where many health care institutions have Catholic affiliation, providing an important example to others. <http://pmj.sagepub.com/content/early/2011/12/05/0269216311429619.abstract>

Media Watch: Editorial Practice

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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

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