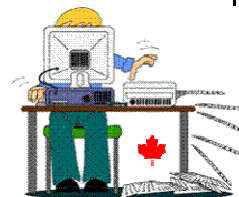


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Informed decision-making: Scroll down to [Specialist Publications](#) and 'Decisions relating to cardiopulmonary resuscitation' (p.11), posted online by the British Medical Association, the (U.K.) Resuscitation Council, and the Royal College of Nursing.

Canada

Toronto General Hospital wants to know: How do you want to die?

ONTARIO | *The Toronto Star* – 10 October 2014 – "How do you want to die?" isn't a question on most hospital admissions forms. But like most choices in life, wait too long and it will be made for you. The palliative care team at Toronto General Hospital wants to change that, by making the most difficult end-of-life decisions part of the normal admissions process, just like showing a health card. The thinking is that the sooner a patient can iron out death's lingering what-ifs, the better their life will be. More than end-of-life experts bent on doing death right, the palliative team is dedicated to making the rest of a patient's life – be it a month, a day or an hour – in all ways better, rather than always longer. The job isn't for most people... but with an aging population, its services increasingly are. "We are a death-denying society," says Dr. James Downar, a doctor on the end-of-life team. "The truth is there are very few illnesses that we actually cure. Most illnesses we manage, and the burden of illness and the burden of treatment can be quite severe." Severe not just for patients and their families, but also for the doctors and nurses caught in the middle. http://www.thestar.com/life/health_wellness/2014/10/11/toronto_general_hospital_wants_to_know_how_do_you_want_to_die.html

Shortage of palliative care beds

Drummondville hospital investigates death of Marcel Roy, man put in supply room

QUEBEC | CBC News (Montreal) – 7 October 2014 – An investigation has been launched into the death of Marcel Roy, an 82-year-old who died in August after he was placed in a supply room inside Ste-Croix de Drummondville Hospital because of a shortage of palliative care beds. Roy spent the last 24 hours of his life confined to a highly trafficked room filled with hospital supplies and equipment. The hospital is conducting an internal investigation, but a seniors' rights group is demanding a public coroner's inquiry. <http://www.cbc.ca/news/canada/montreal/drummondville-hospital-investigates-death-of-marcel-roy-man-put-in-supply-room-1.2790095>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 9 October 2014 – '**How judges view consensus in society.**' The late Supreme Court justice John Sopinka, rejecting a right to assisted suicide in the 1993 Sue Rodriguez case, anchored his majority ruling in the public consensus: "No consensus can be found in favour of the decriminalization of assisted suicide. To the extent that there is a consensus, it is that human life must be respected." A new poll that finds widespread support for assisted suicide may not alter the Supreme Court's views of that consensus, when it hears the Lee Carter case next week. British Columbia Supreme Court Justice Lynn Smith, ruling on that case in 2012, cited polls in which 63% of Canadians supported doctor-assisted suicide. But polls are just one indicator of public opinion; the views of medical organizations, portrayals of the subject in film and the news media, and provincial government responses (in June, Quebec passed a law to allow assisted suicide) form a larger picture of how the public feels. <http://www.theglobeandmail.com/news/national/how-judges-view-consensus-in-society/article20999655/>
- *THE GLOBE & MAIL* | Online – 8 October 2014 – '**Our laws have not kept pace with Canadian views on assisted death.**' In Canada, the "who owns my life?" debate is long overdue. It's a discussion that needs to happen in the courts, in Parliament and, above all, around all our kitchen tables. <http://www.theglobeandmail.com/life/health-and-fitness/health/our-laws-have-not-kept-pace-with-canadian-views-on-assisted-death/article20999775/>
- *THE GLOBE & MAIL* | Online – 8 October 2014 – '**Vast majority of Canadians in favour of assisted dying: poll.**' Billed as "the most comprehensive Canadian survey ever undertaken on the public's perception of dying with dignity," the poll found 91% of people agree a person should not be compelled to endure drawn-out suffering. As well, a large majority – 84% – agreed with the statement that a "doctor should be able to help someone end their life if the person is a competent adult who is terminally ill, suffering unbearably and repeatedly asks for assistance to die." <http://www.theglobeandmail.com/news/national/vast-majority-of-canadians-in-favour-of-assisted-dying-poll/article20981301/>

1. 'Dying with Dignity: Public Perception Survey,' Ipsos Reid, October 2014. http://www.dyingwithdignity.ca/database/files/library/DWD_IpsosReid2014.pdf

U.S.A.

How to care for your aging parents from a distance

NATIONAL PUBLIC RADIO | Online – 9 October 2014 – Concern about mom or dad's health and well-being is top of mind for many baby boomers today. Worrisome signs of your parent's frailty, progressive memory loss or the decline in health require more and more of your help and attention. But what if you live a good distance away? Whether you live an hour away, in a different state, or maybe even in another country, caregiving at a distance presents very real challenges. <http://www.pbs.org/newshour/updates/long-distance-caregiving-parents/>



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>

More Chinese American elders stating their end-of-life wishes

NEW AMERICA MEDIA | Online – 9 October 2014 – According to the California Healthcare Foundation (CHCF), a majority of people in a 2010 multi-ethnic survey CHCF said they have planned for their care at the end of their lives. But many factors often make their wishes not come true. In fact, although 70% of Californians hope to die at home only 32% do so, while 60% died in a hospital or nursing home. CHCF showed that when patients consider dying, the idea of prolonging their lives at any cost is surprisingly not one of their main concerns. Most people worry more about becoming an economic burden for their families, relieving physical pain, and becoming mentally prepared for death. <http://newamericamedia.org/2014/10/more-chinese-american-elders-stating-their-end-of-life-wishes.php>

1. 'Final Chapter: Californians' Attitudes and Experiences with Death and Dying,' California Healthcare Foundation, February 2012. [Noted in Media Watch, 20 February 2012, #241 (p.3)] <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf>

Of related interest:

- *THE ATLANTIC* | Online – 7 October 2014 – '**Doctors who don't know how to talk about death.**' I learned about a lot of things in medical school, but mortality wasn't one of them. Textbooks had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives, and how it affects those around them seemed beside the point. <http://www.theatlantic.com/health/archive/2014/10/when-doctors-dont-know-how-to-talk-about-death/381123/>

Right-to-life

Poll: Measure 1 likely to pass

NORTH DAKOTA | WDAY News (Fargo) – 9 October 2014 – A ballot measure amending the North Dakota Constitution to recognize "the inalienable right to life of every human being at any stage of development" is likely to pass, according to a new poll. The poll ... conducted by the University of North Dakota College of Business & Public Administration, found 50% of respondents planned to vote in favor of Measure 1. One-third ... said they would vote "no," and 17% were undecided. <http://www.wday.com/content/poll%E2%80%88measure-1-likely-pass-0>

Extract from WDAY News report

Opponents have raised concerns about the measure's impact on end-of-life decisions that could weigh more heavily on the minds of older respondents.

U.S. life expectancy continues to tick upward

NATIONAL PUBLIC RADIO | Online – 8 October 2014 – In the U.S., life expectancy has gone up once more and death rates have fallen. The latest numbers from the Centers for Disease Control & Prevention come from information found in death certificates from the year 2012. And, the study finds that for a child born that year, life expectancy is 78 years and 9.5 months – that's a record. <http://www.npr.org/2014/10/08/354639707/u-s-life-expectancy-continues-to-tick-upward>

1. 'Mortality in the U.S., 2012,' Centers for Disease Control & Prevention, National Center for Health Statistics, October 2014. <http://www.cdc.gov/nchs/data/databriefs/db168.pdf>

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

No program for inmates at life's end

MASSACHUSETTS | *The Boston Globe* – 6 October 2014 – More than 30 other inmates diagnosed as terminally ill or permanently incapacitated present what has become an increasingly common predicament for the corrections system: As health care costs skyrocket, what do you do with an inmate who is so ill he is no longer a danger, but is instead a burden? Massachusetts is one of just five states without a medical placement program, often called a compassionate release program, a mechanism to transfer a terminally ill inmate out of state prison custody. The state has considered the idea of an emergency medical placement program since at least 2011. A state consultant's report that year warned of skyrocketing health care costs, and an aging inmate population. From 2002 to 2011, the state saw a 63% jump in the number of inmates aged 50 or older. The number of inmates older than 60 grew by 80%. State health care spending per inmate increased by 12% from 2007 to 2011, according to a separate report ... released earlier this summer.¹ <http://www.bostonglobe.com/metro/2014/10/05/commutation-sought-for-terminally-ill-convicted-murder/rRAZd0sO0tPH4qVOEAlzBK/story.html>

1. 'State Prison Health Care Spending,' The Pew Charitable Trusts (Philadelphia) and the MacArthur Foundation (Chicago), July 2014. [Noted in Media Watch, 14 July 2014, #366 (p.2)] <http://www.pewtrusts.org/~media/Assets/2014/07/StatePrisonHealthCareSpendingReport.pdf>

Of related interest:

- FLORIDA | *The Miami Herald* – 8 October 2014 – '**Old, sick and behind bars.**' Florida Tax-Watch is making a bold recommendation to the governor, the Legislature and the Department of Corrections – and it's worthy of serious consideration. The non-profit, non-partisan watchdog of our tax dollars this week issued a 20-page report urging the powers-that-be to consider letting old, sick inmates in Florida's prisons out early to reduce their numbers and cost.¹ <http://www.miamiherald.com/opinion/editorials/article2628443.html>

1. 'Florida's Aging Prisoner Problem,' Florida TaxWatch, September 2014. <http://www.floridataxwatch.org/resources/pdf/ElderlyParoleFINAL.pdf>

Improving Medicare Post-Acute Care Transformation (IMPACT) Act

Extra scrutiny for hospices

THE NEW YORK TIMES | Online – 6 October 2014 – Bipartisan legislation ... will soon bring greater federal oversight to hospice programs across the country. The IMPACT Act ... is chiefly concerned with how nursing homes, rehab centers and home health agencies assess and report data on quality and other measures. But tucked into the legislation are provisions increasing the frequency of hospice inspections and allowing Medicare to review programs in which a large proportion of patients receive care for six months or more, considered a long hospice stay. Like nursing homes and home health agencies, which also rely heavily on Medicare and Medicaid, hospices undergo periodic state surveys in order to be recertified for reimbursement. Until now no federal law specified how often those surveys must take place. Medicare aimed to conduct surveys every 6 years, but after budget cuts

extended that to every 8 years – compared with every 3 years for home health agencies, and every 15 months for nursing homes. http://newoldage.blogs.nytimes.com/2014/10/06/extra-scrutiny-for-hospices/?_php=true&_type=blogs&ref=health&_r=0

Specialist Publications

'Evaluation of hospital-based palliative care programs' (p.10), in *American Journal of Hospice & Palliative Medicine*.

'The effect of hospice on hospitalizations of nursing home residents' (p.12), in *Journal of the American Medical Directors Association*.

Cont.

Noted in Media Watch, 22 September 2014, #376 (p.5):

- *THE WASHINGTON POST* | Online – 19 September 2014 – '**Congress approves tighter scrutiny of hospices.**' Hospice agencies must subject themselves to government inspections at least once every three years under new legislation approved by Congress, part of a measure that addresses concerns about substandard operators in the booming industry. http://www.washingtonpost.com/business/economy/congress-approves-tighter-scrutiny-of-hospices/2014/09/19/94f8e218-4010-11e4-b03f-de718edeb92f_story.html

"Green burials" are on the rise as baby boomers plan for their future, and funerals

THE WASHINGTON POST | Online – 6 October 2014 – As baby boomers head toward retirement and the great hereafter, they're thinking more about what will become of their remains. And what they're thinking is what they've thought during every phase of life: Status quo? Buck that. For some, that means planning elaborate send-off parties and purchasing tricked-out mausoleums. But for an increasing number, it entails a return to simplicity, a desire that has given rise to the green burial movement and, naturally, a burgeoning industry to support it. http://www.washingtonpost.com/lifestyle/style/green-burials-are-on-the-rise-as-baby-boomers-plan-for-their-future-and-funerals/2014/10/06/d269cfbc-3eae-11e4-b03f-de718edeb92f_story.html

End-of-life care

CALIFORNIA | KPBS TV (San Diego) – 3 October 2014 – More than 4,000 nursing home patients are on life support in California, costing Medi-Cal \$636 million annually [double the cost of a decade ago]. <http://video.kpbs.org/video/2365338380/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NEW YORK TIMES* | Online – 7 October 2014 – '**Expanding the right to die.**' Since Oregon became the first state to legalize physician-assisted suicide for terminally ill patients, Montana, New Mexico, Vermont and Washington have permitted it. Should the right to die be expanded further, and if so, what should the standards be? Perspectives presented in *The New York Times* online discussion include: 'Oregon shows that it can work sensibly and fairly,' 'Doctor-assisted suicide is unethical and dangerous,' 'Everyone deserves to die with dignity,' 'Too many questions remain about assisted suicide,' 'Limit aggressive treatments for the sickest and oldest citizens,' and 'Denying someone a peaceful death can be unethical.' <http://www.nytimes.com/roomfordebate/2014/10/06/expanding-the-right-to-die>

International

End-of-life care in Thailand

Palliative care to be extended

THAILAND | *The Bangkok Post* – 11 October 2014 – The Public Health Ministry will extend palliative care for terminally ill people to cover all of its 16 hospitals from seven at present. Minister Rajata Rajatanavin said the Medical Services Department would develop a system and standards of care for terminally ill patients to suit each disease and each type of medical facility... Standardised services including pain management and palliative care, as well as mental and spiritual advice, will be provided to help both patients and their relatives. Suphan Srithamma, director-general of the department, said seven of its facilities had offered palliative care in their quality-of-life wards for the past 10 years. <http://www.bangkokpost.com/news/social/437060/palliative-care-to-be-extended>

Cont.

Of related interest:

- INDIA (Uttar Pradesh) | *The Times of India* – 11 October 2014 – '**End-of-life care facility in Uttar Pradesh soon, but no policy yet.**' Uttar Pradesh government has proposed a project for palliative care that ensures health facilities for those living terminal illnesses... However, the state is yet to formulate a policy on this. "We have proposed palliative care facility in 10 districts as a pilot project, said principal secretary, health and family welfare, Arvind Kumar. <http://timesofindia.indiatimes.com/city/lucknow/End-of-life-care-facility-in-UP-soon-but-no-policy-yet/articleshow/44779846.cms>

Too few parents make plans in case they die early

U.K. | Childhood Bereavement Network – 7 October 2014 – Parents are failing to make adequate plans for their children should they die early, a new survey by the Childhood Bereavement Network has revealed. <http://www.dyingmatters.org/news/too-few-parents-make-plans-case-they-die-early>

Of related interest:

- IRELAND | *The Irish Times* (Dublin) – 6 October 2014 – '**Dealing with childhood bereavement is vital, says Minister.**' [Minister for Children James] Reilly said 28% of children [living in Ireland] had lost a grandparent by the age of nine, while over 2% had lost a parent. "Counselling and support services are key to helping these children cope with their grief," Dr. Reilly said ... as he unveiled a new guide to help adults support a child who has been bereaved.¹ <http://www.irishtimes.com/news/health/dealing-with-childhood-bereavement-is-vital-says-minister-1.1953434>

1. 'The Irish Childhood Bereavement Care Pyramid,' The Irish Childhood Bereavement Network. <http://www.childhoodbereavement.ie/pyramid/>

End-of-life care in Ireland

Focus more on emotional care of terminally ill: Study

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 6 October 2014 – Terminally ill patients receiving palliative treatment have called for a greater focus on their emotional care and better planning for their future. These are among the findings of a study of the experiences of palliative care among patients, their families and carers undertaken by the All Ireland Institute of Hospice & Palliative Care ... 64% of respondents said "planning for the future" was the biggest practical worry in their experience. And half of those surveyed said their "emotional and psychological needs" were least well met. When asked what could have been better in their experience of palliative care, 39% said coordination of care or treatment, 21% said better emotional support, and 9% said better information. <http://www.irishexaminer.com/ireland/focus-more-on-emotional-care-of-terminally-ill-study-290029.html>

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

£4.5 billion spent annually on end-of-life care, but delivery could be improved

U.K. (England) | Deloitte Centre for Health Solutions – 6 October 2014 – At least £4.5 billion is spent each year in England caring for those at the end of their lives, according ... an independent research arm of the business advisory firm.¹ Yet the report finds that while some individuals, particularly those accessing hospice or specialist community and hospital palliative services, receive high standards of care, many others do not. The report's analysis of national reviews and audits over the past 18 months, highlights shortcomings and concerns about the large degree of variation in services across the country. Transforming care at the end-of-life argues that while there has been a great deal of positive activity following the Department of Health's End-of-life Care

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Strategy [2008] significant inequalities remain. This was highlighted by Public Health England's 2013 National Survey of Bereaved Relatives, which found that while 43% of respondents thought care was excellent or outstanding, 24% said it was only fair or poor.² Likewise the 2013 review of The Liverpool Care Pathway; the 2013-2014 National Care of the Dying Audit for Hospitals; and the recent House of Lords debate on assisted suicide all identified examples of good practice but also serious shortcomings and concerns.^{3,4} http://www.deloitte.com/view/en_GB/uk/news/news-releases/b58460c1695d8410VgnVCM1000003256f70aRCRD.htm

1. 'Transforming Care at the End-of-life: Dying Well Matters,' Deloitte Centre for Health Solutions, October 2014. http://www.deloitte.com/view/en_GB/uk/industries/life-sciences/transforming-care-at-the-end-of-life/index.htm
2. 'National Survey of Bereaved People (VOICES),' Office for National Statistics, July 2014. [Noted in Media Watch, 14 July 2014, #366 (p.5)] <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html>
3. 'Independent Report: Review of Liverpool Care Pathway for Dying Patients [in England],' Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>
4. 'National Care of the Dying Audit of Hospitals,' The Royal College of Physicians of London (in collaboration with Marie Curie Palliative Care Institute Liverpool), 14 May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)] <http://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

Of related interest:

- U.K. (England) | *Hemel Today* – 9 October 2014 – '**Know your hospices! Survey reveals low awareness of palliative care in county.**' A Hertfordshire survey has shown little awareness of the end-of-life care services offered in the county. Six in ten of the survey respondents knew that hospices provided palliative or end-of-life care, although they were not aware of the detail of the full range of care services offered. <http://www.hemeltoday.co.uk/news/more-news/know-your-hospices-survey-reveals-low-awareness-of-palliative-care-in-county-1-6346272>
- U.K. (England) | National Council for Palliative Care – 9 October 2014 – '**The Specialist Palliative Care Workforce Survey.**' Key finding is the proportion of nurses working in palliative care aged over 50 continues to increase, potentially paving the way for a gap in palliative care nursing provision unless further work is undertaken to understand the reasons for the gaining workforce. http://www.ncpc.org.uk/sites/default/files/NCPC_SPC_Workforce_Survey_2013.pdf

Elder care in the U.K.

More than 2,000 care homes have no manager

U.K. (England) | *The Daily Telegraph* – 5 October 2014 – More than 2,000 care homes looking after elderly or disabled adults have no registered manager, according to figures to be published this week. The results mean 12% of all care homes in England lack the leadership required to ensure vulnerable people, including frail pensioners with dementia, are cared for properly... The figures, from the Care Quality Commission, showed by 1 October this year, some 2,053 of England's 17,222 registered care homes were without managers. Almost 1,400 of these were providing nursing or personal care for older people, while 900 were looking after dementia patients. <http://www.telegraph.co.uk/health/healthnews/11141427/More-than-2000-care-homes-have-no-manager.html>

End-of-life care in Wales

When a patient says, "I want to die"

U.K. (Wales) | *The Star* (Kuala Lumpur, Malaysia) – 5 October 2014 – While not many of us would ever contemplate the possibility of ending our own lives, there are certain circumstances that might make death seem more desirable than continuing on. One of these situations includes suffering from a terminal disease, especially one that involves continuous pain, discomfort or disability. But according to Cardiff University ... professor of palliative medicine Baroness Dr. Ilora Finlay pain is often not the main motivating emotion behind a patient's desire to die; it is fear. "Fear of the future, fear of what lies ahead – often based on bad experiences of what they have witnessed of death. Fear of being a burden – not wanting their family to remember them badly, and having to be dependent on others," she explained. Those talking about assisted suicide ... are often searching for a sort of insurance policy, a way out in case things get too bad, she said. The request also often arises due to a lack of confidence in the healthcare system, where patients do not fully believe in

the ability of healthcare professionals to see them through the course of their disease. <http://www.thestar.com.my/Lifestyle/Health/2014/10/05/When-a-patient-says-I-want-to-die/>

Extract from *The Star* article

In Wales, where Prof. Finlay chairs the government's Palliative Care Strategy Implementation Board, data on patients who were deemed to be on their last 48 hours of life has been collected for the past 12 years. With over 26,000 cases to date, Prof. Finlay stressed the margin of error in predicting when someone will die. She noted that 3% of those thought to be in their final 48 hours actually improve sometimes living for almost three months. And amongst those given a prognosis of weeks or months, some live well for many years. The point, she makes, is that medicine is, in the end, still a probabilities game, and patients need to remember that while making their final decision on whether or not to check out of life.

Noted in Media Watch, 17 March 2014, #349 (p.16, under 'Worth Repeating'):

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. **'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.'** Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication... <http://pmj.sagepub.com/content/20/7/703.abstract>

Demographic and population trends

Medical cards and GP visit cards cover 43% of population

IRELAND | *The Irish Times* (Dublin) – 4 October 2014 – Despite its name, a "medical card" is generally allocated on financial grounds rather than on grounds of illness. This was outlined in the Health Act 1970, which says the assessment for a card is determined by reference to the means, including income and expenditure, of a person and their partner or dependants. The threshold for a single person under 65 living alone is €184 a week, but ... other factors are taken into account – savings, mortgage payments, childcare costs, travel-to-work expenses, etc. The thresholds for people over 65 are higher, and far higher for over-70s, though the latter have been reduced in recent budgets. The threshold for a GP visit card, which provides for free doctor visits but no other benefits, is 50% higher than for full medical cards. Almost two million people, or 43% of the population, are covered by either a medical card or a GP visit card. The number of cards has increased by 74% since 2005, as a result of increasing unemployment and an ageing population. <http://www.irishtimes.com/news/health/medical-cards-and-gp-visit-cards-cover-43-of-population-1.1951700>

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

A prospective analysis on fatigue and experienced burden in informal caregivers of cancer patients during cancer treatment in the palliative phase

ACTA ONCOLOGICA | Online – 7 October 2014 – Although fatigue is the most frequently occurring symptom in patients with cancer, hardly anything is known about fatigue of their informal caregivers and the impact fatigue might have on perceived burden with providing care. The authors investigated the presence of fatigue in caregivers, its course and the relation of fatigue severity between caregivers and patients. Furthermore, they explored in caregivers whether fatigue severity was correlated to experienced burden. Almost a quarter of caregivers of patients on active palliative treatment were severely fatigued... Fatigue in both patients and caregivers was related to caregivers' burden. This observation should be taken into account with the growing demand on caregivers and the increase in cancer treatment options in the palliative setting. <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.953254>

Science for sale: The rise of predatory journals

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 2014;107(10):384-385. A new threat has emerged to the integrity of academic publishing: predatory journals. These unscrupulous publishers are exploiting the open-access model by corrupting the peer-review process, which is often absent or minimal. Their motivation is the procurement of evaluation and publication fees, which in the absence of traditional subscription rates are necessary to cover operating costs. Some claim to assess submissions within seventy-two hours and digitally publish them upon acceptance and receipt of the fee. If the peer-review process were only that simple! While most medical professionals keep abreast of their fields by consulting a collection of established journals in their specialties, the existence of a large body of essentially unevaluated material in dubious open access journals is cause for concern. <http://jrs.sagepub.com/content/107/10/384.full>

Connectedness at the end of life among people admitted to inpatient palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 October 2014 – At the end of life ... illness and body decline may challenge a person's ability of staying and feeling connected. The aim of this phenomenological study was to interpret meanings of connectedness, through narrative interviews with persons admitted to inpatient palliative care in Sweden. Results involving connectedness through the body, connectedness to, and uncanniness toward other patients, and connectedness to significant others and society are discussed. The study underscores the importance of connectedness until death. However, in inpatient palliative care this is complex. Patients can co-create or challenge each other's sense of connectedness through the symbolism of illness and diseased bodies. <http://ajh.sagepub.com/content/early/2014/10/09/1049909114554077.abstract>

What death is. A literary approach between fears and hope

ANNALI DELL'ISTITUTO SUPERIORE DI SANITÀ, 2014;50(3):249-265. According to [the] World Health Organization ... some fifty-six million people die every year. Even if each death affects only five people we may say that in a year 300 million people meet death, which is one twentieth of the world population, five percent. This renders end-of-life care a global problem of public health care just because of the huge number of people. However ... an inquiry over the last 100,000 books (non-fiction essays, including medical books, showed that only two hundred (0.2%) looked at the problem of death. http://www.iss.it/binary/publ/cont/ANN_14_03_08_del_santo.pdf

N.B. English language article.

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 October 2014 – **'A review of the construct of demoralization: History, definitions, and future directions for palliative care.'** Demoralization ... is characterized by hopelessness and helplessness due to a loss of purpose and meaning. The purpose of this review was to consolidate the conceptual understanding of demoralization and argue for its existence as a psychiatric syndrome. <http://ajh.sagepub.com/content/early/2014/10/01/1049909114553461.abstract>

Evaluation of hospital-based palliative care programs

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 October 2014 – This study evaluated current hospital-based palliative care programs using recommendations from the Center to Advance Palliative Care (CAPC) as a framework. Seven hospitals located in Buffalo, New York, were included based on the existence of a hospital-based palliative care program. Data was collected from August through October of 2013 ... from these hospitals using a guide comprised of questions based on CAPC's recommendations. A gap analysis was conducted to analyze the current state of each hospital's program based upon CAPC's definition of a quality palliative care program. The findings identify challenges facing both existing/evolving palliative care programs, and establish a foundation for strategies to attain best practices not yet implemented. <http://ajh.sagepub.com/content/early/2014/10/01/1049909114553460.abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 1 October 2014 – **'Experiences of patients, family caregivers and professional caregivers with integrated palliative care in Europe: Development of a patient study protocol in five countries.'**¹ Integrated palliative care approaches in Europe are largely unknown and under-investigated. Evidence is largely based on evaluation of individual services and proxy views. More research is needed to explore experiences of patients, however national ethical requirements complicate doing prospective patient studies in palliative care. Patient studies at international scale that must fulfil ethical requirements of several countries are even more complicated. <file:///C:/Users/Barry/Downloads/1652-6795-2-PB.pdf>

1. Belgium, Germany, Hungary, The Netherlands, U.K.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 October 2014 – **'A qualitative analysis of patient and family perspectives of palliative care.'** Presence, reassurance, and honoring choices emerged as central themes linked to satisfaction with palliative care services. Themes were defined as including health care professional attributes of respect, approachability, genuineness, empathy, connectedness, compassion, sensitivity, an ability to listen, good communication, provision of information, empowerment, and timeliness. Honoring choices included those pertaining to treatment, spirituality, and family needs. Health care providers must be compassionate and empathetic and possess skills in listening, connecting, and interacting with patients and families. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0155>

"Conditional candour" and "knowing me": An interpretive description study on patient preferences for physician behaviours during end-of-life communication

BMJ OPEN | Online – 8 October 2014 – A total of 16 participants were recruited, most of whom (69%) were women and 70% had a non-cancer diagnosis. Two major concepts regarding helpful physician behaviour during end-of-life conversations emerged: 1) "knowing me," which reflects the importance of acknowledging the influence of family roles and life history on values and priorities expressed during end-of-life communication; and, 2) "conditional candour," which describes a process of information exchange that includes an assessment of patients' readiness, being invited to the conversation, and sensitive delivery of information. The authors' findings suggest that patients prefer a nuanced approach to truth telling when having end-of-life discussions with their physician. This may have important implications for clinical practice and end-of-life communication training initiatives. <http://bmjopen.bmj.com/content/4/10/e005653.full>

Decisions relating to cardiopulmonary resuscitation

BRITISH MEDICAL ASSOCIATION, (U.K.) RESUSCITATION COUNCIL & THE ROYAL COLLEGE OF NURSING | Online – Accessed 8 October 2014 – This new edition takes into account developments in clinical practice and developments in the law regarding anticipatory decisions about cardiopulmonary resuscitation. The guidance identifies key ethical and legal principles that should inform all CPR decisions. The high-level ethical principles are the same for all people, in all settings, but differences in clinical and personal circumstances make it essential that all CPR decisions are made on an individual basis. How these individual decisions are made is also guided by law, which differs between adults and children, and differs in England & Wales, in Scotland, and in Northern Ireland. For example, a central tenet of the mental capacity legislation in England & Wales is "best interests" and in Scotland it is "benefit." These terms ... for the purposes of this guidance ... are used interchangeably in parts... This guidance also provides a framework to support decisions relating to CPR and effective communication of those decisions. It also highlights relevant legal requirements and differences. <https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf>

The new edition of 'Decisions relating to cardiopulmonary resuscitation' emphasises:

The value of making anticipatory decisions about CPR as an integral part of good clinical practice. A clear plan should be made to explain and/or discuss the decision with the person and/or their representatives at the earliest practicable opportunity. Leaving people in the default position of receiving CPR should their heart or breathing stop, regardless of their views and wishes, denies them of the opportunity to refuse treatment that for many may not offer overall benefit and that many may not want.

The importance of involving people (or their representatives if they are unable to make decisions for themselves) in the decision-making process. This often involves a person making a shared decision with their healthcare professionals, but where CPR has no realistic chance of success it may involve informing people of the decision and explaining the basis for it.

That when CPR has no realistic chance of success it is important to make decisions that are in the best interest of the patient, and not to delay a decision because a person is not well enough to have it explained to them or because their family or other representatives are not available.

The importance of careful documentation and effective communication of decisions about CPR

Source: *Anesthesia UK*

<http://www.frca.co.uk/content.aspx?content=2099>

Noted in Media Watch, 23 June 2014, #363 (p.6):

- U.K. (England) | BBC News – 17 June 2014 – '**Legal duty over resuscitation orders.**' Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate order on medical notes, the Court of Appeal in England has ruled. <http://www.bbc.com/news/health-27886265>

A bimonthly interdisciplinary state-wide palliative care case conference promotes education, networking, and emotional support

HAWAII JOURNAL OF MEDICINE & PUBLIC HEALTH, 2014;73(9 Suppl 1):40. Meeting emotional, educational, and professional development needs for palliative care practitioners is a priority of clinical practice guidelines for quality palliative care. Here, the authors introduce and evaluate Palliative Pupus, a novel, state-wide, interdisciplinary, case conference designed to meet these needs. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4175964/?report=classic>

Of related interest:

- *QUALITY HEALTH RESEARCH* | Online – 3 October 2014 – '**Cancer care decision making in multidisciplinary meetings.**' Members of the meetings [i.e., study participants] categorized cases in varying ways, drew on a range of sources of authority, expressed different value positions, and utilized a variety of strategies to justify their actions. An important dimension of authority was encountered authority – the authority a clinician has because of meeting the patient. <http://qhr.sagepub.com/content/early/2014/10/01/1049732314553010.abstract#aff-1>

The practical wisdom gained in the provision of end-of-life care

HU LI ZA ZHI: THE JOURNAL OF NURSING, 2014;61(5):33-42. The findings [of this study] show practicing and engaging in end-of-life care provide nurses opportunity to acquire practical care wisdom: 1) the emotional difficulties of patient care; 2) the limitations of the self; and, 3) learning to adjust to the needs and pace of the patient. End-of-life care is an opportunity for both dying patients and nurses to transform and grow spiritually. Dealing with the emotional difficulties of end-of-life care, recognizing their self-limitations in care, and adjusting their care provision to meet the needs and pace of their patients help increase the awareness of nurses to the ethical responsibility they have toward patients. <http://europepmc.org/abstract/med/25271031>

N.B. Chinese language article.

The effect of hospice on hospitalizations of nursing home residents

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 7 October 2014 – Hospice enrollment is known to reduce risk of hospitalizations for nursing home residents who use it. The authors examined whether residing in facilities with a higher hospice penetration: 1) reduces hospitalization risk for non-hospice residents; and, 2) decreases hospice-enrolled residents' hospitalization risk relative to hospice-enrolled residents in facilities with a lower hospice penetration. In the last 30 days of life, 37.63% of non-hospice and 23.18% of hospice residents were hospitalized. Every 10% increase in hospice penetration leads to a reduction in hospitalization risk of 5.1% for non-hospice residents and 4.8% for hospice-enrolled residents. [http://www.jamda.com/article/S1525-8610\(14\)00543-X/abstract](http://www.jamda.com/article/S1525-8610(14)00543-X/abstract)

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

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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.

Evaluating palliative care needs in Middle Eastern countries

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 October 2014 – Cancer incidence in Middle Eastern countries, most categorized as low- and middle-income, is predicted to double in the next 10 years, greater than in any other part of the world. While progress has been made in cancer diagnosis/treatment, much remains to be done to improve palliative care for the majority of patients with cancer who present with advanced disease. Improved pain management services are key facilitators. Top barriers include lack of designated palliative care beds/services, community awareness, staff training, access to hospice services, and personnel/time. The nonexistence of functioning home-based and hospice services leaves families/providers unable to honor patient wishes. [Survey] respondents were least satisfied with discussions around advance directives and wish to learn more about palliative care focusing on communication techniques. Populations requiring special consideration comprise: patients with ethnic diversity, language barriers, and low literacy; pediatric and young adults; and the elderly. The majority of Middle Eastern patients with cancer are treated in outlying regions; the community is pivotal and must be incorporated into future plans for developing palliative care services. Promoting palliative care education and certification for physicians and nurses is crucial; home-based and hospice services must be sustained. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0194>

Noted in Media Watch, 21 July 2014, #367 (p.12):

- *SUPPORTIVE CARE IN CANCER* | Online – 18 July 2014 – '**Developing a palliative care service model for Muslim Middle Eastern countries.**' Palliative Care (PC) was first introduced to Muslim Middle Eastern (MME) countries in 1992, but growth has been slow and access is still limited. While most PC models have been developed in Western countries, MME societies have different cultural and religious values that are not incorporated in Western models. <http://link.springer.com/article/10.1007/s00520-014-2347-4>

Noted in Media Watch, 10 June 2013, #309 (p.15):

- *JOURNAL OF PALLIATIVE CARE MEDICINE* | Online – Accessed 6 June 2013 – '**Palliative care training gains ground in Middle Eastern countries.**' The responses and observations gleaned from two American Society of Clinical/Middle East Cancer Consortium workshops in the Middle East provide further support for the notion that additional efforts are needed to improve the management of cancer-related physical and emotional symptoms by means of ongoing training sessions for all care givers, in particular physicians and nurses, as has been recently advocated. <http://www.omicsgroup.org/journals/2165-7386/2165-7386-S3-e001.pdf>

Pediatric palliative care consultation services in California hospitals

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 October 2014 – The American Academy of Pediatrics recommends that palliative care be available to seriously ill hospitalized children, yet little is known about how these services are structured. All 8 children's hospitals in the state reported having a pediatric PCS [palliative care service], and 36 pediatric PCSs were in mixed hospitals. Mixed hospitals saw fewer children per year than pediatric-only PCSs. Pediatric-only PCSs treated more patients for non-cancer-related illness than pediatric PCSs in mixed hospitals or adult-only PCSs. All PCSs were universally available (100%) during weekday business hours and half were available during weekend business hours. Better understanding of the palliative care needs of seriously ill children in mixed hospitals and assessment of the quality of care provided will help ensure that children seen in these hospitals receive necessary care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0190>

Cont.

Of related interest:

- *CHILDREN* | Online – 1 October 2014 – '**The role of play in children's palliative care.**' The role and value of play increase proportionately when a child is made more vulnerable through illness or disability. Despite this, providing time and opportunities to play can be overlooked or considered to be of little importance or relevance when the focus of the adult carers is the amelioration of clinical symptoms of the illness and on lessening the psychological impact the illness may have on the child. This paper outlines the role and the value of play as an integral component in the provision of palliative care for children with chronic, life-threatening and life-limiting conditions. <file:///C:/Users/Barry/Downloads/children-01-00302.pdf>

Palliative care for the newborn

Changing the focus of care: From curative to palliative care

JOURNAL OF PEDIATRIC & NEONATAL INDIVIDUALIZED MEDICINE, 2014;3(2):e030261. The improvements in the obstetrical and neonatal diagnosis and therapies have resulted into an increase in the survival rate of infants previously considered as non-viable. Debate is focusing on professionals' behaviour about withdrawal or withholding of life sustaining treatment (LST) and administration of palliative care for newborns whose conditions are incompatible with a prolonged life. Decisions about treatment should be made jointly by the professionals' team and the family, placing the interest of the baby at the very heart of the decision process. It is very important that the environment in which the family has to make the decision is characterized by openness, dialogue and frankness. A proper and effective communication with parents is always necessary and can resolve any conflict caused by disagreement. Furthermore, parents need time in the decision making process. Other supports, which could help the family in the final decision are the possibility to ask for a specialist's second opinion and the involvement of religious leaders and of an independent clinical ethics committee. Withholding or withdrawal of LST does not mean cessation of care for the baby, it means to change the focus of care from curative to palliative care. <http://www.jpnm.com/index.php/jpnm/article/viewFile/030261/189>

Strategies for handling ethical problems in end-of-life care: Obstacles and possibilities

NURSING ETHICS | Online – 6 October 2014 – In end-of-life care, ethical problems often come to the fore. Little research is performed on ways or strategies for handling those problems and even less on obstacles to – and possibilities of using – such strategies. All the studied strategies for handling of ethical problems were found to have both obstacles and possibilities. Uncertainty is shown as a major obstacle and unanimity as a possibility in the use of the strategies. The findings [of this study] also illuminate the value of the concept "the patient's best interests" as a starting point for the carers' ethical reasoning. The concept "the patient's best interests" used as a starting point for ethical reasoning among the carers is not explicitly defined yet, which might make this value difficult to use both as a universal concept and as an argument for decisions. <http://nej.sagepub.com/content/early/2014/10/01/0969733014547972.abstract>

Of related interest:

- *ONCOLOGY TIMES* | Online – 5 October 2014 – '**Understanding the emotions of patients who refuse treatment.**' Emotions that drive refusal for treatment may stem from exhaustion, depression, or a desire not to be a burden to loved ones. Or patients might unreasonably request continuing treatment because of a profound fear of death, the pressure of their families, or because they want to be with the family to celebrate some milestone such as a child's graduation from college. There is an emotional impact on the oncologist and the palliative care team as well, who may feel saddened or angered by the fact that patients are not taking advantage of their recommendations and knowledge. <http://journals.lww.com/oncology-times/blog/onlinefirst/pages/post.aspx?PostID=1164>

Why families matter

PEDIATRICS, 2014;134:S97-S103. Serious illness puts pressure not only on individual family members but also on the family itself. The care of an acutely ill child requires the family to channel many of its resources toward a single member – an arrangement that can usually be sustained for a while but that cannot continue indefinitely while the other members do without. Illness disrupts ordinary familial functions and, if it is serious enough, threatens to break the family altogether. The author argues there are situations in which the threat to family integrity is so real and serious the interests of parents or siblings or sometimes grandparents may override the interests of the pediatric patient. http://pediatrics.aappublications.org/content/134/Supplement_2/S97.short

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://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>

Of related interest:

- *PEDIATRICS*, 2014;134:S81-S186. **'Four models of family interests.'** The author distinguishes between four models for thinking about how to balance the interests of parents, families, and a sick child: 1) the oxygen mask model; 2) the wide interests model; 3) the family interests model; and, 4) the direct model. While there is room for all four models at the bedside, the author argues that the direct model should be highlighted in clinical decision-making. http://pediatrics.aappublications.org/content/134/Supplement_2/S81.abstract

Palliative Network for Severely Affected Adults (Italy)

Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention

PLOS ONE | Online – 6 October 2014 – The Palliative Network for Severely Affected Adults with MS in Italy ... developed a home palliative care program for MS patients and carers, preceded by a literature review and qualitative study (here reported). Patients had difficulties expressing needs; experiences of burden and loneliness were prominent, chiefly in dysfunctional, less affluent families, and among parent carers. Needs differed across Italy with requirements for information and access to services highest in the South. All participants voiced a strong need for qualified personnel and care coordination in day-to-day home care. Personal hygiene emerged as crucial, as did the need for a supportive network and preservation of patient/carer roles within family and community. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0109679>

Noted in Media Watch, 4 August 2014, #369 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 July 2014 – **'Palliative care for severely affected patients with multiple sclerosis: When and why? Results of a Delphi Survey of health care professionals.'** Results clearly identified specific areas in which palliative care will likely prove to be a valuable asset in the treatment course of multiple sclerosis. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0667>

Realist review to inform development of the electronic advance care plan for the personally controlled electronic health record in Australia

TELEMEDICINE & e-HEALTH | Online – 7 October 2014 – Australia has invested heavily to introduce an opt-in personally controlled electronic healthcare record (PCEHR), which incorporates an element of advance care planning (ACP). A further investment of \$10 million AUD has been made to increase capability to a fully integrated electronic ACP (eACP). Australia has an aging population, the majority of whom will live, be cared for, and die in the community. ACP in the community setting can support older people to navigate their illness trajectories and health decision-making. Sharing this information with care providers across different healthcare settings is crucial. The authors developed a model informed by six core themes from the literature: 1) information sharing; 2) process; 3) initiating conversations; 4) dignity of life (individualized approach); 5) education (individual and community); and, 6) collaborative practice (engagement). <http://online.liebertpub.com/doi/abs/10.1089/tmj.2013.0341>

Of related interest:

- *THE NURSE PRACTITIONER* | Online – 3 October 2014 – **'Advance directives: Empowering patients at the end of life.'** Unfortunately, these directives have been inadequately incorporated into healthcare decisions due to less-than-optimal execution and implementation. Authors explore challenges to implementing advance directives and propose potential solutions. http://journals.lww.com/tnpj/Abstract/publishahead/Advance_directives_Empowering_patients_at_the_end.99854.aspx

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