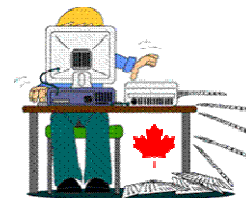


Media Watch...

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.

22 February 2016 Edition | Issue #450



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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Recruitment and reasons for non participation in a family-coping-orientated palliative home care trial' (p.15), in *Journal of Psychosocial Oncology*.

Canada

The do's and don'ts of end-of-life planning

CBC NEWS | Online – 21 February 2016 – Canadians can appoint a friend or family member to make health-care decisions on their behalf, like whether to have surgery or be placed in a retirement home, if they are incapacitated. But even with proper planning there isn't a 100% guarantee that these appointed decision makers will follow someone's wishes. The terminology and legal documents required to appoint a decision maker vary by province and territory. Speak Up, an initiative by the National Advance Care Planning Task Group, lists resources specific to each one. In Ontario, for example, people can designate someone through a power of attorney for personal care. People can write what's often called a letter of wishes, which includes information on what kind of treatments they do and don't want, along with the power of attorney document. In British Columbia, meanwhile, people can do essentially the same thing, but through what's called a representation agreement, the kind of document that carries similar legal weight. <http://goo.gl/PJO49o>

More palliative care patients should get medical marijuana: Doctors

CTV NEWS | Online – 15 February 2016 – Canada is in the midst of drawing up guidelines for end-of-life care, but some doctors believe that the medical system isn't doing enough to offer high-quality pain relief to patients, including the option to use medical marijuana. Though researchers are learning that cannabis can offer many benefits in pain relief, less than 10% of palliative care (PC) patients are able to access the drug, in part because of outdated restrictions that make it hard to access, some doctors say. PC patients in most hospitals or hospices still can't use medical marijuana because very few facilities have policies for its use. It can't easily be prescribed or dispensed because it is not a drug with DIN [Drug Identification Number] number. And there are questions about how to use it.

Smoking marijuana is not an option in hospitals or hospices, since such facilities have no-smoking policies. Most also have not yet developed policies on the use of vapourizers or oil. <http://goo.gl/Co2ouY>

Specialist Publications

'Developing institutional medical marijuana guidelines: Understanding law and science' (p.14), in *Journal of Pain & Symptom Management*.

'Waiting for the body to fail: Limits to end-of-life communication in Canadian hospitals' (p.9), in *Mortality*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Edmonton Journal* – 19 February 2016 – ‘**Alberta government to hold consultations on doctor-assisted death.**’ Albertans will soon get the chance to have their say on how the provincial health system should implement doctor-assisted death. “Death impacts every one of us and we all have strong opinions about this, so we want to make sure that the actual way (the service) is delivered here in Alberta is one that Albertans have an opportunity to give their feedback on, in terms of where, how and when the procedure is carried out,” Health Minister Sarah Hoffman said... In addition to the province, the College of Physicians & Surgeons of Alberta has also been wrestling with the issue. The college has developed a set of guidelines for doctors, including a suggested process to follow when a patient makes a request to die. Some of the issues that could be discussed through the consultation include: how to determine a patient’s competency, how quickly a request must be carried out, what sort of health staff must be present, whether opposing doctors should be forced to make a referral to a physician who will provide the service, and whether Catholic operated Covenant Health facilities should be exempt from the practice. <http://goo.gl/1D43R3>
- QUEBEC | CJAD News (Montreal) – 17 February 2016 – ‘**10 Quebecers have died with the assistance of doctors: Report.**’ Quebec’s Health Minister has put a number on how many people have taken advantage of the province’s new right-to-die legislation. In an interview with Radio-Canada, Gaétan Barrette said ten people have died with the assistance of doctors since the law allowing the practice was adopted in December. <http://goo.gl/rT3P5b>
- *THE GLOBE & MAIL* | Online – 16 February 2016 – ‘**A dignified death for dementia patients: Who makes that call?**’ The advocacy organization Dying With Dignity believes that new laws currently being drafted by federal and provincial legislators and guidelines being formulated by the bodies overseeing medical professionals should allow for people diagnosed with dementia to make a request for assisted death ahead of time. A poll commissioned by the group suggests that 80% of Canadians agree with them on the concept of advanced consent. The idea is compelling, at least superficially. After all, no one relishes the thought of gradually losing their memory, their intellect, their ability to function independently. Shouldn’t we be able to end it all? Practically though, letting someone choose to die at some undetermined future date is perilous, both legally and ethically. <http://goo.gl/Z57M5z>

Specialist Publications

‘**Doctor, can we get this over with?**’ (p.18) in *BC Medical Journal*.



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://goo.gl/5CHoAG>

U.S.A.

Dartmouth Atlas Project

Study: Care for San Diego's dying patients needs to improve

CALIFORNIA | KPBS News (San Diego) – 18 February 2016 – Health care providers in the San Diego region rank poorly in how they care for older, dying patients in three important ways, according to a national report...¹ First, Medicare beneficiaries with dementia should not have feeding tubes inserted during their last six months of life. Yet among those patients treated here, 7.8% had that unpleasant experience, more than the 6% national average. The region scored lower than 208 of the 306 hospital regions in the country. Second, during their last six months of life, more beneficiaries spent time receiving aggressive, expensive care in intensive care units here than did beneficiaries in 252 other regions of the country, 4.4 days compared to the national average of 3.6. And third, dying Medicare patients should not have to wait until their last three days of life before being enrolled in hospice services. Yet in San Diego, 16.8% did not receive hospice services until then. Despite the large number of hospice services available here, the region's rating was equal to the national average. <http://goo.gl/uKqW3N>

Extract from Dartmouth Atlas Project report

Late hospice referral at the end of life

Rates of hospice referral across the U.S. often do not reflect patient preferences, which tend to favor comfort measures over medical intervention. Referrals to hospice care that are done too late also adversely affect the quality of care, the reported experiences of patients and families, and their satisfaction with the health care system. The percentage of Medicare decedents who were enrolled in hospice care within three days of their deaths varied more than fourfold across hospital referral regions in 2012.

Specialist Publications

'Transitions between healthcare settings of hospice enrollees at the end of life' (p.9), in *Journal of the American Geriatrics Society*.

1. 'Our Parents, Ourselves: Health Care for an Aging Population,' A Report of the Dartmouth Atlas Project, February 2016. <http://goo.gl/dcXa6C>

Related

- *THE WALL STREET JOURNAL* | Online – 18 February 2016 – **'Lengthy hospice care boosts Medicare bills.'** Medicare pays hospice agencies to care for patients who are close to death. For some beneficiaries of the taxpayer-funded program, hospice has become a way of life. Between 2005 and 2013, about 107,000 patients received hospice care for an average of nearly 1,000 days spread out over four or more calendar years, according to a *Wall Street Journal* analysis of Medicare billing records. Medicare's hospice program ... is supposed to be only for patients who doctors certify are likely to die within six months, or about 180 days. <http://goo.gl/uzC0sl>

Report: Connecticut could save \$657 million by caring for elderly in their homes

CONNECTICUT | *The Hartford Courant* – 17 February 2016 – Currently about 60% of the state's population requiring long-term care (LTC) is being taken care of in their home with 40% in nursing homes or other institutions.¹ The state has set a goal of having 75% of people needing LTC being able to stay in their homes. Reaching that goal would net the hundreds of millions in savings due to less costly care. Since many of the patients use Medicaid, the lower costs for care translate to lower costs for state government. According to data ... a private room in a nursing home cost more than \$12,000 in 2012, with that number expected to rise 73% by 2027. For in-home care, a homemaker costs about \$3,600 a month while a home health aide runs \$4,000 a month. <http://goo.gl/NbPeFo>

1. 'Assessment of Connecticut's Long-Term Care System – An Update, February 2016,' Connecticut Institute for the 21st Century. <http://goo.gl/eN3V7X>

What dying looks like in America's prisons

THE ATLANTIC | Online – 16 February 2016 – Mohawk had once been a residential home for the developmentally disabled. It occupied the southernmost corner of the 150-acre Mohawk-Oneida campus and was converted to a medium-security prison in 1988. Today, it houses about 1,400 inmates, 112 of whom are inside the “skilled nursing facility,” Walsh Regional Medical Unit, which takes in prisoners from the central and western parts of New York State. What the hospice program at Mohawk did was prevent patients from dying alone. Terminal patients, particularly those dying inside prison, need human contact, companionship, and a chance to talk about their lives, the nurses told me. The program also provided healthy prisoners who had good behavior records the chance to train as volunteers, to give back to their fellow inmates. The program provided a real “sense of satisfaction to our guys,” according to the daytime hospice nurse. “They’re proud of what they’re doing. They’re putting someone ahead of themselves. They’ve put themselves first until

now.” Volunteer training took place once a year (and lasted one week), but applications came in throughout the year. <http://goo.gl/1uCEUC>

Extract from *The Atlantic* article

The old hospice directive – that patients should be helped to think reflectively and reckon with how they’ve lived their lives – fits surprisingly well in prison.

[Prison Hospice Backgrounder](#)

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: <http://goo.gl/ggd4hp>

Noted in Media Watch, 15 February 2016, #449 (p.8):

- *AMERICAN JOURNAL OF NURSING* | Online – 11 February 2016 – ‘**End-of-life care behind bars: A systematic review.**’ Nineteen articles, all published between 2002 and 2014, met the inclusion criteria. Of these, 53% were published between 2009 and 2014, and 58% reported findings from qualitative research. One article reported on research conducted in the U.K.; the remaining 18 reported on research conducted in the U.S. Capacity (that is, the number of prisoners requiring end-of-life care (EOLC) and the ability of the prison to accommodate them) and the site of EOLC delivery varied across studies, as did the criteria for admission to end-of-life or hospice services. <http://goo.gl/zgocdi>

“Right to try” drug bill advances to Iowa Senate floor

IOWA | *The Des Moines Register* – 15 February 2016 – The Iowa Senate State Government Committee voted ... to approve a bill that would allow Iowans facing terminal illness to have access to medicines that have passed Phase I of the Food & Drug Administration’s approval process but are not yet on pharmacy shelves. The action sends Senate Study Bill 1264 to the Senate floor, where it will be eligible for debate... Twenty-four states have already adopted similar legislation, according to the Phoenix-based Goldwater Institute, a conservative and libertarian think tank that is leading a national effort for passage of such laws. The Food & Drug Administration (FDA) has an existing process that allows people to ask permission to access investigational medicines. However, the federal “Com-

passionate Use” process takes hundreds of hours of paperwork and months to navigate, according to the Goldwater Institute. While many people ultimately receive FDA permission, there are dozens of documented cases of people dying while waiting on their approval, lobbyists said. The proposed legislation is aimed at patients who are not eligible or are unable to get into clinical trials of drugs. <http://goo.gl/92LF4u>

[Specialist Publications](#)

‘**The ethical challenges of compassionate use**’ (p.12), in *Journal of the American Medical Association*.

Cont.

Noted in Media Watch, 5 October 2015, #430 (p.7):

- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – ‘**Right-to-try laws: Hope, hype, and unintended consequences.**’ Most right-to-try laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. <http://goo.gl/JWjfyu>

Family caregivers may be sacrificing their own health to help loved ones

REUTERS | Online – 15 February 2016 – Many family caregivers in the U.S. provide unpaid medical aid and other services to loved ones at the expense of their own financial, physical and mental health, a study suggests.¹ Nationwide, an estimated 14.7 million family caregivers assist 7.7 million older adults who live in the community rather than in institutions like nursing homes. These family members often help with daily activities like eating, bathing and dressing. Many also provide medical support such as scheduling physician checkups, managing medications, cleaning wounds and giving injections. “This issue is not a small or isolated issue, but is widespread,” said Jennifer Wolff of Johns Hopkins Bloomberg School of Public Health in Baltimore, who led the study. “There is no silver bullet easy solution to simplify the management of meeting complex care needs – this is an issue that is experienced by individuals but is the result of the fragmented and complex health care system and long-term care system that families often are left navigating without any formal preparation,” Wolff added... Researchers estimated that 6.5 million family and unpaid caregivers provide substantial assistance with medical needs, another 4.4 million offer some help and 3.8 million don’t handle health care. Almost half of the caregivers surveyed – 46% – helped an elderly person with

Alzheimer’s disease or dementia. Another 34% assisted a loved one with a severe disability... <http://goo.gl/lbDKjT>

The high cost of cancer care may take physical and emotional toll on patients

THE WALL STREET JOURNAL | Online – 15 February 2016 – Doctors who supervise cancer treatments have long been concerned about side effects, including fatigue, hair loss and depression. To that list, some now add the potentially harmful effects of costly treatments. Researchers call it “financial toxicity.” The financial burdens that some patients suffer as a result of the cost of their treatments can cause damage to their physical and emotional well-being. Repercussions can include delaying or forgoing the treatment and only partly filling or even avoiding taking prescribed medication. <http://goo.gl/SZX6TZ>

[Specialist Publications](#)

‘**Recruitment and reasons for non-participation in a family-coping-orientated palliative home care trial (FamCope)**’ (p.15), in *Journal of Psychosocial Oncology*.

1. ‘A national profile of family and unpaid caregivers who assist older adults with health care activities,’ *JAMA Internal Medicine*, 15 February 2016. <http://goo.gl/rTLsq1>

Related

- *THE WASHINGTON POST* | Online – 17 February 2016 – ‘**How to cope with caring for baby boomer parents while raising small children.**’ The term “sandwich generation” was coined in the 1980s to describe people who are squeezed between taking care of their children and their parents. Now, as members of the baby boom generation are entering their 70s... There are about 75 million baby boomers in the U.S., and many are beginning to experience the changes nobody wants and nobody likes to talk about: disease and chronic conditions. <https://goo.gl/Zck6PQ>

Cont.

Selected articles on different aspects of family caregiving

- MASSACHUSETTS | *The Boston Globe* – 7 September 2015 – **‘The real costs of unpaid family caregiving.’** 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 [Noted in Media Watch, 14 September 2015, #427 (p.2)] <https://goo.gl/eVp4U6>
 1. ‘Valuing the Invaluable 2015: Update,’ Public Policy Institute, American Association of Retired Persons, July 2015. <http://goo.gl/Dg5oNg>
- *THE GERONTOLOGIST*, 2015;55(2):302-308. **‘Improving policies for caregiver respite services.’** Federal initiatives and state-level policies and programs affecting respite are reviewed and directions for policy advancement are highlighted. Much more work is needed to educate caregivers and the general public about the necessity for respite beginning early in the caregiving career to prevent burnout and other adverse effects. [Noted in Media Watch, 27 April 2015, #407 (p.11)] <http://goo.gl/dufWG8>
- *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. [Noted in Media Watch, 29 September 2014, #377 (p.9)] <http://goo.gl/bHWZCx>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE PATRIOT POST* | Online – 16 February 2016 – **‘10,000 deaths if assisted suicide legalized nationwide.’** According to numbers crunched by [the The Heritage Foundation’s] *The Daily Signal* [Washington DC], America could easily see over 10,000 deaths a year if assisted suicide were legalized nationwide. Recently, the Oregon Public Health Division released numbers about assisted suicide in its state, a jurisdiction that legalized the practice in 1997 and where the numbers have steadily climbed. In 2014, 105 people used a physician to help end their life. In 2015, that number climbed to 132. While proponents of assisted suicide argue that the number of people that choose to end their life will always be low, their argument doesn’t take into account how the practice will grow when introduced to a nation of 300 million. <http://goo.gl/JoE5L1>

Media Watch: Back Issues – <http://goo.gl/frPqZ5>



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Please feel free to share this weekly report with your colleagues.
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MW 444: Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?

[Download the complete issue \(PDF 540 KB\)](#)

CLINICAL ONCOLOGY | Online – 14 December 2015 | The authors describe documentation of prognosis, treatment benefit and goals of care discussions in outpatients with advanced cancer. [read more...](#)

Media Watch Archives

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

International

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

New 'Building on the best' programme aims to improve end of life hospital care across the U.K.

U.K. | National Council for Palliative Care – 18 February 2016 – Ten acute hospital trusts have been selected to take part in the 'Building on the best' programme, which will support improvements in quality and experience of palliative and end-of-life care (EOLC) across the U.K. Almost half of people who die in England & Wales currently die in hospital, yet there are considerable variations in the quality of EOLC in hospitals. This programme will see support, knowledge and leadership provided to hospital settings in order that people experience good quality and safe care, and are able to make the choices that

meet theirs and their family's wishes, wherever they are. The programme, which is U.K.-wide, will initially roll-out in England ... and ... will run for two-and-a-half years. <http://goo.gl/aLmJj6>

Specialist Publications

'After the Liverpool Care Pathway clear guidance and support on end-of-life care is needed' (p.11) in *Evidence Based Nursing*.

Related

- U.K. | *The Daily Mail* – 18 February 2016 – **'End-of-life form could leave vulnerable at risk, say doctors...'** Hospital patients may be left to die because a new form for Do Not Resuscitate cases is too complicated, experts warn. The two-page Emergency Care & Treatment Plans are being introduced later this year to encourage staff to talk to patients and relatives about dying. They are intended to replace DNR orders which have often been slipped into patients' notes by doctors without consulting families. But experts say the new forms are so confusing that doctors will not fill them in properly or have the sensitive discussions required. Some campaigners say they will encourage more box-ticking and repeat the mistakes of the controversial Liverpool Care Pathway. <http://goo.gl/yl5362>
- U.K. | Together for Short Lives – 17 February 2016 – **'Nursing shortage threatens to cut care for seriously ill children.'** A shortage of nurses has resulted in two thirds of voluntary sector children's palliative care (PC) services reducing their offer of care to families. This is resulting in reduced care for families such as: fewer available beds in children's hospices; a reduction in short breaks on offer to families; and, preventing children from being cared for and forming meaningful relationships with their nurse as agency nurses change from day to day. Our Nursing Vacancy Survey 2015 has found that, on average, 10% of nursing posts within voluntary children's PC organisations remain vacant... <http://goo.gl/42r0nK>

Elder care in England

Almost half of all older people in care homes are depressed and think condition is a "normal part of ageing"

U.K. (England) | *The Daily Telegraph* – 15 February 2016 – Almost half of all older people in care homes are depressed and most think that the condition is now a "normal part of ageing," a landmark National Health Service (NHS) report has warned.¹ Four in 10 people in nursing homes are depressed while one in five older people who live in their own homes suffer from the condition, with rates among older women even higher. The report ... found that "older people's needs are neglected," with most of them not even seeking treatment. The report concludes that people with mental health conditions suffer from poor physical health and that those with severe mental illnesses die on average 15-20 years earlier than the rest of the population. <http://goo.gl/Q2euz1>

1. 'The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England.' <https://www.england.nhs.uk/mentalhealth/taskforce/>

Cont.

Noted in Media Watch dated 30 May 2011, #203 (p.5):

- *BMC PALLIATIVE CARE* | Online – 27 May 2011 – ‘**Expert opinion on detecting and treating depression in palliative care: A Delphi study.**’ This study evaluated expert opinion on the choice of screening tool, choice of antidepressant, and choice of psychological therapy. The aim was to inform the development of best practice recommendations for the European Palliative Care Research Collaborative clinical practice guideline on managing depression in palliative care. <http://goo.gl/9UiNqC>

End-of-life care in South Korea

Terminal cancer patients to get home hospice services

SOUTH KOREA | *The Korea Times* (Seoul) – 14 February 2016 – Terminal cancer patients will be able to receive hospice services at home starting next month. The Ministry of Health & Welfare ... will run a pilot service ... to allow late-stage cancer patients to spend their last days with their families at home while receiving professional care. Korea offers such services at hospice wards or hospitals; but this is the first time for the home hospice services to be introduced. The measure is in line with the recent passage of a bill on death with dignity, which allows patients with no hope of recovery to end their lives by refusing life-sustaining treatment. <http://goo.gl/F8PhJe>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

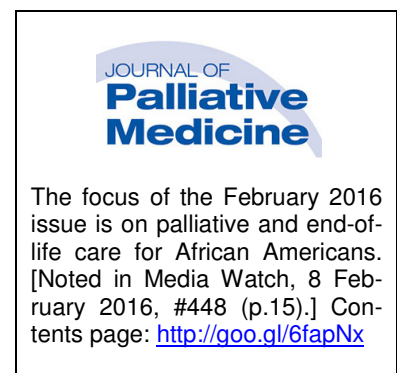
- U.K. (Scotland) | *Scottish Legal News* – 19 February 2016 – ‘**Lord Advocate’s prosecution policy on assisted suicide is “in accordance with law.”**’ The failure by the Lord Advocate to adopt and publish a policy identifying the facts and circumstances which he will take into account in deciding whether or not to authorise the prosecution in Scotland of a person who assists another to commit suicide does not breach human rights law, appeal judges have ruled. <http://goo.gl/oeS3IH>

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

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

The desires of their hearts: The multidisciplinary perspectives of African Americans on end-of-life care in the African American Community

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 February 2016 – The goal of this study was to examine perceptions of advance care planning (ACP), palliative care (PC), and hospice among a diverse sample of African Americans with varying degrees of personal and professional experience with end-of-life care (EOLC) and use these responses to inform a culturally sensitive intervention to promote awareness of these options. Several themes emerged. Participants felt that ACP, PC, and hospice can be beneficial to African American patients and their families but identified specific barriers to completion of advance directives and hospice enrollment, including lack of knowledge, fear that these measures may hasten death or cause providers to deliver inadequate care, and perceived conflict with patients’ faith and religious beliefs. Providers described approaches they use to address these barriers in their practices. Findings, which are consistent with and further elucidate those identified from previous research, will inform design of a culturally sensitive intervention to increase awareness and understanding of ACP, PC, and hospice among members of the African American community. <http://goo.gl/E8zLgH>



Cont.

Noted in Media Watch, 8 February 2016, #448 (p.15):

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2016;27(1):219-237. **‘Toward eliminating hospice enrollment disparities among African Americans: A qualitative study.’** Participants identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative goals for hospice care, and relying on information obtained outside the formal health system. Finally, participants offered suggestions for eliminating barriers and providing salient information about hospice care to other African Americans. <http://goo.gl/Q6XS8f>

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2016;64(2):314-322. **‘Transitions between healthcare settings of hospice enrollees at the end of life.’** Of 311,090 hospice decedents, 31,675 (10.2%) had at least one transition after hospice enrollment, and this varied substantially across the U.S.; 6.6% of all decedents had more than one transition in care after hospice enrollment (range 2-19 transitions). Of hospice users with transitions, 53.4% were admitted to hospitals, 17.7% were admitted to skilled nursing facilities, 9.6% used home health agencies, and 25.8% had transitions to home without receiving the services from the healthcare settings examined. decedents who were younger, non-white, enrolled in a for-profit or small hospice program, or had less access to hospital-based palliative care had significantly higher odds of having at least one transition. <http://goo.gl/p6gGpM>

Exploring health care providers’ views about initiating end-of-life care communication

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 February 2016 – This study explores the perspectives of physicians, nurses, social workers, and chaplains on engaging seriously ill patients and families in end-of-life care communication. Qualitative data were from 79 (medical and non-medical) providers practicing at two medical centers in Central Los Angeles. Three themes that describe providers’ perceptions of their roles and responsibility in talking with seriously ill patients emerged: 1) Providers’ roles for engaging in end-of-life discussions; 2) Responsibility of physicians for initiating and leading discussions; and, 3) Need for team co-management patient care. Providers highlighted the importance of beginning discussions early by having physicians lead them, specifically due to their medical training and need to clarify medical information regarding patients’ prognosis. Although physicians are a vital part of leading end-of-life communication, and are at the center of communication of medical information, an interdisciplinary approach that involves nurses, social workers, and chaplains could significantly improve patient care. <http://goo.gl/arQ6ot>

Related

- *MORTALITY* | Online – 8 February 2016 – **‘Waiting for the body to fail: Limits to end-of-life communication in Canadian hospitals.’** The DECIDE (DECISION-making about goals of care for seriously ill, hospitalised medical patients) study was conducted with the aims of identifying barriers and ideas for improving end-of-life communication and decision-making with seriously ill patients in Canadian hospitals. Its qualitative component involved interviews with 30 physicians and nurses asking them to recall and describe hospital-based goals of care communication and decision-making incidents that had gone “well” or “unwell.” This article explores a dominant pattern in participants’ accounts, which is a norm of waiting to initiate end-of-life discussions until seriously ill patients are within days or even hours of death. Attending to clinicians’ explanations of when and why goals of care discussions are routinely delayed provides opportunity to clarify and critically consider important and normally unarticulated rationales underlying end-of-life discussion practices between health care teams and patients/families in Canadian hospitals. <http://goo.gl/xSx60p>

[Media Watch: Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

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

Research challenges in palliative and end of life care

BMJ SUPPORTIVE & PALLIATIVE CARE, 2016;6(1):2-4. As the number of older people increases across the world, and more people approach the end of their lives with chronic and complex conditions, the need for robust and relevant research in palliative and end of life care has never been greater. An estimated 19 million people need palliative care (PC) worldwide each year, and evidence to help provide relief from symptoms and offer support to patients and those close to them at the end of their lives is an ongoing priority. The U.K. is considered a world leader in palliative and end of life care provision and research, and has influenced end of life care around the world. However, in the U.K. and all the more advanced countries, there is evidence of shortfalls, highlighting the challenges facing all countries. PC is a high priority for the U.K. National Health Service and many other countries; several national guidelines have been developed over recent years. A review of end-of-life care in the U.K. expressed serious concerns about a lack of research in this field and underuse of existing research. However, research in this area is underfunded compared with studies into the prevention and cure of life-limiting conditions. Less than 0.3% of the

£500 million spent on cancer research is allocated to PC, with funding for non-cancer conditions likely to be even less. <http://goo.gl/WNJJeLB>

The forgotten people in British public health: A national neglect of the dying, bereaved and caregivers

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 February 2016 – The clinical and social epidemiology of living with a life-threatening or life-limiting illness, frail ageing, long-term caregiving, and grief and bereavement is well documented in the palliative care, psycho-oncology and psychiatric literature but this investigation asks what interest exists from the mainstream public health sector in these health and illness experiences. This paper reports a content analysis of 7 key British public health journals, 14 major public health textbooks and 3 public health websites ... to assess the size and quality of interest in populations related to ageing, dying, caregiving, and grief and bereavement. Compared with other public health issues, such as obesity and tobacco use, for examples, interest in the social experience and epidemiology of end-of-life experiences is extremely low. Reasons for this lack of interest are explored. <http://goo.gl/sv0i6p>

N.B. Selected articles on evidenced-based end-of-life care are listed in Media Watch of 8 February 2016, #448 (p.9).

Noted in Media Watch, 11 May 2015, #409 (p.8):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(3):114-117. '**Identifying palliative and end-of-life care research priorities: A U.K. approach to consult end users.**' Launched in 2013 the Palliative and End-of-Life Care Priority Setting Partnership (PeolcPSP) has enabled end users of research – patients, carers and clinicians – to identify their priorities in order to inform future end-of-life care research. A "long list" of 83 questions was compiled and 1,300 patients, current and bereaved carers and healthcare professionals took part in the second phase of the survey to select their most important priorities. The top ten research priorities were determined.

N.B. Access to the contents of the *European Journal of Palliative Care* requires a subscription. Contents page: <http://goo.gl/63tZAn>

Haematologists question timing of end-of-life discussions

CANCER NURSING PRACTICE, 2016;15(1). A postal survey of just over 600 North American haematologists has been undertaken to understand their experience of introducing initial discussions about end-of-life care with patients with life-threatening illness. More than half of the sample surveyed responded to the questionnaire, which looked at the timing of conversations about end of life and hospice care, resuscitation status and respondents' insight into the quality of such interactions. <http://goo.gl/ISBLs0>

Cont.

Noted in Media Watch, 28 December 2015, #442 (pp.3-4)]:

- U.S. | *U.S. NEWS & WORLD REPORT* | – 21 December 2015 – ‘**End-of-life talk often comes too late for blood cancer patients.**’ Many doctors wait too long to have end-of-life discussions with blood cancer patients, a new study finds.¹ The lack of a clearly defined point when there is no remaining hope for blood cancer patients may contribute to delays in end-of-life discussions, the researchers said. The findings show that blood cancer specialists are aware of gaps in end-of-life care for their patients, but are uncertain how to tackle the issue...² <http://goo.gl/01tJ87>
 1. ‘Timeliness of end-of-life discussions for blood cancers: A national survey of hematologic oncologists,’ *JAMA Internal Medicine*, 21 December 2015. <http://goo.gl/kuElHb>
 2. ‘Addressing end-of-life quality gaps in hematologic cancers: The importance of early concurrent palliative care,’ *JAMA Internal Medicine*, 21 December 2015. <http://goo.gl/VlnSBt>

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

After the Liverpool Care Pathway clear guidance and support on end-of-life care is needed

EVIDENCE BASED NURSING, 2016;19(1):27. The authors recommend that future end-of-life care (EOLC) planning approaches should ensure patient and family involvement; that guidance should be issued around key palliative care decisions; and, that education and mentorship should be available to critical care practitioners. It would be hard to disagree with these proposals, but they may not be enough to produce the desired changes. After all, the Liverpool Care Pathway (LCP) documentation and surrounding processes were designed to provide for all these, so it seems unlikely that the problems experienced stem principally from the nature of the pathway itself. In fact, the evidence is that the National Health Service (NHS) has struggled to provide high-quality EOLC before, during and after the implementation of the LCP – a reality reflected in this paper. Present herculean efforts to improve on the LCP are unlikely to succeed as hoped without attention to hindering cultural, professional and organisational issues that are endemic to the NHS. <http://goo.gl/D7IVzb>

N.B. The author is commenting on ‘Life after the Liverpool Care Pathway: A qualitative study of critical care practitioners delivering end-of-life care,’ *Journal of Advanced Nursing*, 13 May 2015. [Noted in Media Watch, 25 May 2015, #411 (p.10)] <http://goo.gl/FPA00F>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 February 2016 – ‘**Transferring patients home to die: What is the potential population in U.K. critical care units?**’ Medical notes of all patients who died in or within 5 days of discharge from seven critical care units across two hospital sites over a 12-month period were reviewed. A little over 20% of patients dying in critical care demonstrated potential to be transferred home to die. Staff should actively consider the practice of transferring home as an option for care at end of life for these patients. <http://goo.gl/fcw6mF>

Media portrayal of the nursing homes sector: A longitudinal analysis of 51 U.S. newspapers

THE GERONTOLOGIST | Online – 16 February 2016 – Most Americans’ low opinion of the nursing home (NH) sector could derive, in part, from the way in which it is portrayed in the media. This study furthers understanding of media portrayal of the NH sector... Findings reveal considerably less NH coverage in the Western U.S. and a steady decline in NH coverage nationally over time. Most articles were news stories; more than one third were located on the front page of the newspaper or section. Most articles focused on NH industry and government interests, very few on residents/family and community concerns. Most articles were neutral or negative in tone; very few were positive or mixed. Common themes included quality, financing, and legal concerns. Tone, themes, and other article attributes varied across region, market type, and over time. <http://goo.gl/V2Wo2p>

The ethical challenges of compassionate use

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 11 February 2016 – Granting access to drugs, vaccines, biologics, and devices that have not yet been approved by governmental regulatory authorities is a growing challenge for physicians, public officials, patient advocacy groups, institutional review boards, and patients. Although the issue of rapid access to investigational agents is not new ... the pace of requests has increased. This is attributable to many factors, including greater awareness of compassionate use on the part of patients and their physicians; more information available through the Internet and websites describing clinical trials; an increase in promising interventions; threats from potential epidemics such as Ebola, cholera, and influenza; and, an increased willingness to try novel agents by patients who are chronically ill or dying. <http://goo.gl/Llu1iO>

Palliative care, hospice, and advance care planning: Views of people living with HIV and other chronic conditions

JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE | Online – 11 February 2016 – People living with HIV who survive to older adulthood risk developing multiple chronic medical conditions. Health policymakers recognize the role of early palliative care (PC) and advance care planning (ACP) in improving health quality for at-risk populations, but misperceptions about PC, hospice, and ACP are common. Overall, [focus group] participants were unfamiliar with the term PC, confused concepts of PC and hospice, and/or associated hospice care with dying. Participants misunderstood ACP, but valued communication about health care preferences. Accepting PC was contingent on distinguishing it from hospice and historical memories of HIV and dying. <http://goo.gl/xBPYfY>

Selected articles on end-of-life care for people living with HIV

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2015;50(3):350-361. '**Implementation of HIV palliative care: Interprofessional education to improve patient outcomes in resource-constrained settings, 2004-2012.**' This article is an historical description of how basic palliative competencies were observed to be acceptable for health workers providing outpatient HIV care and treatment during eight years of U.S. implementation of "care and support," a term coined to represent palliative care for persons living with HIV in resource-constrained settings. [Noted in Media Watch, 31 August 2015, #425 (p.31)] <http://goo.gl/kX0hVx>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 September 2014 – '**Integrating early palliative care for patients with HIV: Provider and patient perceptions of symptoms and need for services.**' The authors began a program to integrate early palliative care (PC) into HIV inpatient care. Providers ranked their patients' fatigue, sadness, anxiety, sexual dysfunction, and body image significantly higher than patients did for themselves. Patients ranked medical care, pharmacy, social work, physical therapy, and housing as significantly more important to them than providers estimated them to be. Early PC may narrow this gap between providers' and patients' perceptions of needs through good communication and targeting barriers, such as housing instability, which are vital to overcome for consistent long-term follow up. [Noted in Media Watch, 15 September 2014, #375 (p.6)] <http://goo.gl/3TKtyo>
- *THE LANCET INFECTIOUS DISEASES* | Online – 11 June 2012 – '**Integration of palliative care throughout HIV disease.**' People with HIV have a high burden of pain and physical, psychological, and social difficulties that can be managed effectively with palliative care (PC). However, most individuals do not have access to this type of care. Historically, PC and HIV care were linked closely, but misconceptions divide the two disciplines today. [Noted in Media Watch, 18 June 2012, #258 (p.15)] <http://goo.gl/oEEoe9>

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

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>

Medical maternalism: Beyond paternalism and antipaternalism

JOURNAL OF MEDICAL ETHICS | Online – 18 February 2016 – This paper argues that the concept of paternalism is currently overextended to include a variety of actions that, while resembling paternalistic actions, are importantly different. The author uses the example of Japanese physicians' non-disclosures of cancer diagnoses directly to patients, arguing that the concept of maternalism better captures these actions. To act paternalistically is to substitute one's own judgement for that of another person and decide in place of that person for his/her best interest. By contrast, to act maternally is to decide for another person based on a reasonable understanding of that person's own preferences. The concept of maternalism allows for a more thorough assessment of the moral justification of these types of actions. I conclude that it is possible, at least in principle, to justify Japanese physicians' non-disclosures, and that this justification must be based on an understanding of these actions as maternalistic. <http://goo.gl/IODwGe>

Noted in Media Watch, 7 September 2015, #426 (p.9):

- *ETHICAL THEORY & MORAL PRACTICE* | Online – 27 August 2015 – '**Mandatory disclosure and medical paternalism.**' The author argues that, depending on the context, the disclosure of medical information can undermine the patient's ability to exercise her autonomy or have therapeutically detrimental effects. In the light of these insights, the author goes on to develop a context-sensitive approach to medical disclosure. <http://goo.gl/ysgK3I>

Noted in Media Watch, 10 March 2014, #348 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 March 2014 – '**When open-ended questions don't work: The role of palliative paternalism in difficult medical decisions.**' Autonomy is the current gold standard approach to patient communication and has grown to the point that patient preference dictates care, even when their choices are not possible or are medically non-beneficial. <http://goo.gl/p2sr7h>

Case study

Hospice – Where peace and turmoil coexist

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 10 February 2016 – It is often said that a hospice is much more than just a place providing supportive care for the terminally ill. This narrative describes a young mother who found her solace in the hospice and spent her last days there by choice. It reinforces the fact that the hospice is truly a philosophy of care where powerful and contrasting emotions do coexist. <http://goo.gl/1Q5nXP>

Chemotherapy use in the months before death and estimated costs of care in the last week of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 February 2016 – Chemotherapy for end-stage cancer patients is associated with higher estimated end-of-life care costs (EOLC). Half (50.5%) of the patients [studied] were receiving chemotherapy at baseline [i.e., median four months before death]. Estimated EOLC costs for patients with baseline chemotherapy use (median=\$2,681) were significantly higher than for patients without baseline chemotherapy use (median=\$1,092). This relationship persisted after adjusting for socio-demographic and clinical characteristics... None of the psychosocial variables accounted for the relationship between chemotherapy use and estimated care costs. Given evidence of limited benefit and potential harm of chemotherapy for end-stage cancer patients, the cost-effectiveness of such care is questioned and further study warranted. <http://goo.gl/RG3aqX>

Cont.

Selected articles on chemotherapy at the end of life

- U.S. | *The New York Times* – 23 July 2015 – ‘Benefit of end-stage chemotherapy is questioned.’ A multi-national study suggests even stronger patients may not benefit from end-of-life chemotherapy, and for many their quality of life may worsen in their final weeks compared with patients who forego last-ditch treatment.¹ [Noted in Media Watch, 27 July 2015, #420 (p.4)] <http://goo.gl/CZ8lWF>
 1. ‘Chemotherapy use, performance status, and quality of life at the end of life,’ *JAMA Oncology*, 23 July 2015. <http://goo.gl/Z1Cgij>
- *CANCER* | Online – 11 February 2015 – ‘Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer.’ A third of the patients [i.e., study participants] recognized chemotherapy was “not at all” likely to cure their cancer. Such patients were no less likely than other patients to receive end-of-life chemotherapy... [Noted in Media Watch, 23 February 2015, #398 (p.10)] <http://goo.gl/5Vhp4y>
- *BRITISH MEDICAL JOURNAL* | Online – 5 March 2014 – ‘Chemotherapy near the end of life.’ Even as cancer treatments become more effective, we can still wonder about the symbolic meaning behind decisions to pursue chemotherapy near the end of life. Although most patients with metastatic cancer choose to receive palliative chemotherapy, evidence [from a 2012 study¹] suggests most do not clearly understand its intent. [Noted in Media Watch, 10 March 2014, #348 (p.10)] <http://goo.gl/uBfAMS>
 1. ‘Patients’ expectations about effects of chemotherapy for advanced cancer,’ *New England Journal of Medicine*, 2012;367(17):1616-1625. [Noted in Media Watch, 29 October 2012, #277 (p.2)] <http://goo.gl/JRR2jZ>

Developing institutional medical marijuana guidelines: Understanding law and science

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2016;51(2):396-397. The scientific evidence for cannabis’ therapeutic potential is limited, yet expanding. There is a lack of coherence between the scientific evidence and regulations in several states. The immature evidence base does not negate cannabis’ exciting therapeutic potential. The authors’ ... guidelines remind providers that they need not issue certifications; encourages them to exhaust conventional symptom management first; advises prudence with regard to patients with milder forms of qualifying conditions or conditions without strong evidence; requests that providers avoid certifying regularly or as the bulk of practice; asks that they communicate to patients indications, risks, benefits, and alternatives; recommends that they warn against operating heavy machinery while under

the influence; encourages consideration of baseline and/or periodic drug testing and, in the case of patients with addiction history, psychiatric consultation; and, emphasizes the need for caution if history of psychosis. Finally, the guidelines outline that network hospitals will neither dispense marijuana nor allow it in any form on hospital premises. <http://goo.gl/5luOOn>

Extract from *Journal of Pain & Symptom Management* article

The evidence to support the use of medical marijuana is limited but highly relevant to hospice and palliative medicine providers.

Pediatric oncologists’ coping strategies for dealing with patient death

JOURNAL OF PSYCHOSOCIAL ONCOLOGY | Online – 11 February 2016 – Pediatric oncologists [i.e., study participants] used engagement coping strategies with primary and secondary responses including emotional regulation (social support and religion), problem solving (supporting families at end of life), cognitive restructuring (making a difference and research), and distraction (breaks, physical activity, hobbies and entertainment, spending time with own children). They also used disengagement coping strategies that included voluntary avoidance (compartmentalization and withdrawing from families at end of life). Given the chronic nature of patient death in pediatric oncology and the emotionally difficult nature of this work, medical institutions such as hospitals have a responsibility to assist pediatric oncologists in coping with this challenging aspect of their work. <http://goo.gl/fNp4wl>

Recruitment and reasons for non-participation in a family-coping-orientated palliative home care trial (FamCope)

JOURNAL OF PSYCHOSOCIAL ONCOLOGY, 2016;33(6):655-674. The FamCope intervention was developed to test if a nurse-led family-coping-orientated palliative home care intervention would help families cope with physical and psychosocial problems at home – together as a family and in interaction with health care professionals. However, an unexpectedly high number of families declined participation in the trial. A total of 65.9% of the families [approached] declined participation. Two main categories for declining emerged: 1) That the “burden of illness is too great,” and, 2) That it was “too soon” to receive this kind of support. Men were more likely to participate than women. Timing of interventions and readiness of patients and their relatives seems to affect willingness to receive a family-coping-orientated care approach and impeded recruitment to this trial. Our findings can be used in further research and in clinical practice in order to construct interventions and target relevant populations for early family-coping-orientated palliative care. <http://goo.gl/ftdQcl>

Morocco’s long road to comprehensive palliative care

THE LANCET, 2016;387(10019):620. In May 2014, the World Health Assembly unanimously adopted the resolution on strengthening of palliative care (PC) as a component of comprehensive care throughout the life course and called on member states to ensure that it is integrated into all levels of the health-care system. Many countries – not only low-income and middle-income ones – struggle with the provision of comprehensive PC. Morocco is no exception, but an assessment of its progress and failures highlights important areas for others to consider. <http://goo.gl/Tgl8IY>

Noted in Media Watch, 8 February 2016, #448 (p.8):

- HUMAN RIGHTS WATCH | Online – 4 February 2016 – ‘**Morocco: Thousands face needless suffering at end of life.**’ While the Moroccan government has taken important steps to improve end-of-life care, Human Rights Watch found only two public hospitals, in Casablanca and Rabat, have specific units that offer this essential health service, and only to cancer patients.¹ <https://goo.gl/1JRxNm>

1. ‘Pain Tears Me Apart: Challenges and Progress in Ensuring the Right to Palliative Care in Morocco,’ Human Rights Watch, February 2016. <https://goo.gl/7ifssc>

N.B. Morocco was ranked 52nd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015, commissioned by the Lien Foundation of Singapore. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/nuPWII>

Prolonging life at all costs: Quantity versus quality

THE LANCET RESPIRATORY MEDICINE | Online – 15 February 2016 – Medical advances have meant that people are living longer but, as the 2015 Global Burden of Disease data showed,¹ the corresponding increase in healthy life expectancy was significantly less, meaning that people are also living with illness for longer. This situation creates an increased burden on health-care resources and more challenging discussions around appropriate medical interventions and intensive treatment near the end of life. <http://goo.gl/ZIKkYF>

1. ‘Global, regional, and national disability-adjusted life years (DALYs) for 306 diseases and injuries and healthy life expectancy (HALE) for 188 countries, 1990–2013: quantifying the epidemiological transition,’ *The Lancet*, 2015;386(10009):2145-2191. <http://goo.gl/G1HFVa>

Incorporating palliative care concepts into nutrition practice: Across the age spectrum

NUTRITION IN CLINICAL PRACTICE | Online – 17 February 2016 – A practice gap exists between published guidelines and recommendations and actual clinical practice with life-sustaining treatments not always being based on the patient's wishes, including the provision of nutrition support therapies. Closing this gap requires an interdisciplinary approach that can be enhanced by incorporating basic palliative care (PC) concepts into nutrition support practice. In the fast-paced process of providing timely and effective medical treatments, communication often suffers and decision making is not always reflective of the patient's quality-of-life goals. The current healthcare clinical ethics model does not yet include optimum use of advance directives and early communication between patients and family members and their healthcare providers about treatment choices, including nutrition support. A collaborative, proactive, integrated process in all healthcare facilities and across levels of care and age groups, together with measurable sustained outcomes, shared best practices, and preventive ethics, will be needed to change the culture of care. Implementation of a better process, including basic PC concepts, requires improved communication skills by healthcare professionals. Formalized PC consults are warranted early in complex cases. An education technique, as presented in this article, of how clinicians can engage in critical and crucial conversations early with patients and family members, by incorporating the patient's values and cultural and religious diversity in easily understood language, is identified as an innovative tool. <http://goo.gl/aj1pcr>

Noted in Media Watch, 19 December 2011 #237 (p.12):

- *PSYCHO-ONCOLOGY* | Online – 8 December 2011 – ‘**Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.**’ Decrease in oral intake, weight loss, and muscular weakness in the last phases of a terminal illness, particularly in the context of the cachexia-anorexia syndrome, can be an important source of anxiety for the triad of patient, family, and health staff. The present literature review examines the emotional impact of reduced oral intake as well as perceptions and attitudes toward assisted nutrition and hydration for terminally ill patients at the end of life, among patients, family, and health care staff. <http://onlinelibrary.wiley.com/doi/10.1002/pon.2099/full>

Language and understanding of cardiopulmonary resuscitation amongst an aged inpatient population

PSYCHOLOGY, HEALTH & MEDICINE | Online – 12 February 2016 – The authors demonstrated that although medical inpatients have some familiarity with terms relating to resuscitation, there is a lack of understanding of the context, process and outcomes of CPR. The predominant sources of information were television and print media. Examination of the English language corpora revealed a paucity of the use of terms related to resuscitation. This finding indicates that physicians have a duty of care to determine patients' understanding around resuscitation language, and terms used, in discussions of their preferences before assuming their engagement in shared decision-making. More open public discussion around death and resuscitation would increase the general knowledge of the population and would provide a better foundation for the discussions in times of need. <http://goo.gl/8cf8Ce>

Selected articles on terminology *vis-à-vis* resuscitation

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 March 2015 – ‘**“Allow Natural Death” versus “Do Not Resuscitate”: What do patients with advanced cancer choose?**’ All 93 of the participants who completed a survey were considered by their attending physician to have a terminal illness, but only 42% believed they were terminally ill. Only 25% thought that their primary oncologist knew their end-of-life wishes. Participants were equally likely to choose either of the “no code” options in all hypothetical scenarios. A similar proportion of patients who had a living will chose AND [Allow Natural Death] and DNR [Do Not Resuscitate] orders instead of “full code” in all the scenarios. In contrast, among patients who did not have a living will, 52% chose DNR, while 19% opted for AND. [Noted in Media Watch, 6 April 2015, #404 (p.9)] <http://goo.gl/LQmDf2>

Cont.

- *BMJ OPEN* | Online – 13 January 2015 – ‘**Variation in local trust Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.**’ There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council record form (or a modification of the form). There was variation in the terminology used, which included DNAR (Do Not Attempt Resuscitation), DNACPR (Do Not Attempt CPR), CPR, and AND (Allow Natural Death). [Noted in Media Watch, 19 January 2015, #393 (p.9)] <http://goo.gl/cxZMNM>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 28 April 2014 – ‘**A communication training perspective on AND versus DNR directives.**’ The term “do not resuscitate” (DNR) is challenging to use in end-of-life discussions because it omits the goals of care. Allow Natural Death (AND) has been proposed as a better way of framing this palliative care discussion. [Noted in Media Watch, 5 May 2014, #356 (p.15)] <http://goo.gl/C3yCPD>

Life and treatment goals of patients with advanced, incurable cancer

SUPPORTIVE CARE IN CANCER | Online – 11 February 2016 – Goals of care conversations have been suggested as a strategy for helping patients with advanced cancer manage the uncertainty and distress associated with end-of-life care. However, knowledge deficits about patient goals limit the utility of such conversations. The authors described the life and treatment goals of patients with incurable cancers, including goal values and expectancies. They examined the associations between paramount goals and patient prognosis, performance status, and psychological adjustment. Patient life goals resembled goals among healthy populations; whereas, treatment goals were perceived as separate and more important. Cure and fight cancer emerged as the most important goals. Patients who valued cure the most had worse performance status ... and more depressive symptoms... Patients who valued fight cancer the most had worse self-prognosis..., fewer treatment goals ..., and lower optimism... <http://goo.gl/1iPiqK>

Noted in Media Watch, 25 March 2015, #411 (p.4):

- MASSACHUSETTS | WBUR News (Boston) – 18 May 2015 – ‘**Ending “the war” and giving up “the fight”**: How not to talk about cancer.’ A visit to the American Cancer Society website asks you to join the “fight against cancer”; and a majority of public cancer-related media is packed with more war imagery. While the war description of cancer has resulted in unprecedented attention and fundraising for cancer care, research and survivorship, a balance should be reached between these successful efforts and language that is a realistic assessment of what can be accomplished today, for the patient, right now. <http://goo.gl/Kr6d4s>

Noted in Media Watch, 10 November 2014, #383 (p.8):

- U.K. | *The Independent* – 3 November 2014 – ‘**Mind your language: “Battling” cancer metaphors can make terminally ill patients worse.**’ Media portrayals of cancer as a “battle to be fought” are leading to feelings of failure and guilt among terminally ill patients, experts in language and end-of-life care have said. <http://goo.gl/uL4lge>

Understanding global end-of-life care practices: International Hospital Federation 2014 research project

WORLD HOSPITALS & HEALTH SERVICES, 2015;51(4):4-10. This first-of-its kind survey of global end-of-life practices uncovered major differences in how end-of-life care (EOLC) is defined, delivered, and measured. According to respondents from university hospitals and cancer centers in 17 countries, the primary challenges to providing effective EOLC are communication between clinicians and patients/families, cultural beliefs about death, entrenched staff beliefs about prolonging life, and lack of funding. However, many organizations are implementing improvements in end-of-life services that support hospital-wide identification of patients for whom such services are appropriate, screening to avoid needless aggressive therapies, enhanced provider education, and ways to assess quality of life for terminally ill patients. <http://goo.gl/fZLTuL>

- **N.B.** This issue includes several articles on end-of-life care from a global perspective. Listing of contents: <http://goo.gl/m3bPG8>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BC MEDICAL JOURNAL* (Canada), 2016;58(1):30-31. **‘Doctor, can we get this over with?’** In 2016 physician-assisted death will become legal in Canada. Studies of general public knowledge about refusing or withdrawing life-sustaining therapy suggest people may be confused about their right to make life-determining decisions when they are seriously ill, and support for physician-assisted death is enhanced by stories of negative experiences associated with dying – poorly controlled symptoms, patients who feel a lack of dignity, and deaths that are drawn out due to repeated rescue by a medical system that assumes prolonging life is more important than the quality of living and dying. Palliative care (PC) arose as a response to patient experiences of poor quality dying. People were dying in hospital surrounded by machines that provided futile treatment rather than being comfortable in a loving and supportive community. Following a long period of evidence building, the benefits of PC in improving quality of living and dying are now relatively robust. However, making physicians aware of what PC can do for their patients and why it should be incorporated into disease management at an early stage is still an ongoing struggle. The toughest part is convincing physicians and surgeons that if they care for patients who have serious illnesses, they are obliged to have basic skills and knowledge in PC. <http://goo.gl/M7BxRm>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 February 2016 – **‘Attitudes among patients with advanced cancer towards euthanasia and living wills.’** Euthanasia has been invariably discussed throughout Europe. In some countries, euthanasia has been legalized under specific conditions that must be fulfilled. These include a properly reported request to be considered carefully, unbearable suffering, no other reasonable alternatives, and a consultation with an independent physician. <http://goo.gl/XC30hv>

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/zluyY9>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://GOO.GL/JNHVMB](http://goo.gl/JNHVMB)

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

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, research and teaching tool.

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. 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.
6. 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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