Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

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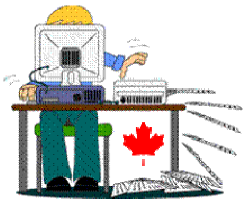


Compiled & Annotated by Barry R. Ashpole

Public health approaches to palliative care: Scroll down to Specialist Publications and 'Integrating palliative care into the community: The role of hospices and schools' (p.6), in *BMJ Supportive & Palliative Care.*

Canada

Canada's prisoners face too many injustices

THE TORONTO STAR | Online – 10 August 2016 – The 'Mandela Rules' on the treatment of prisoners call for health care to be provided by agencies ordinarily responsible for health and not by agencies specifically responsible for prisons.[1] Canada falls short of meeting that standard, except in Nova Scotia and Alberta. Too often security and prison management issues lead to prescribed medicines being unavailable, limited, or arbitrarily changed by the prison. Prisoners wait long periods for illnesses to be diagnosed since access to medical services are limited. Chronic diseases, such as diabetes, are not managed with the same care as in the community, which can lead to serious complications. The process of dying behind bars is a sad one. The tragedy of a terminal prognosis is compounded for family members and prisoners when they receive palliative care in custody. Now that Canadians have the right to receive physician-assisted death to relieve suffering, prisoners should have equal access to this option without delays. It would be even more just and humane to allow compassionate releases of those terminally ill so they could die with the support of loved ones. Other countries routinely allow such releases, so why can't Canada? https://goo.gl/nJxvVw

1. Known as the 'Mandela Rules,' the UN Standard Minimum Rules for the Treatment of Prisoners were initially adopted by the UN Congress on the Prevention of Crime and the Treatment of Offenders in 1955, and approved by the UN Economic & Social Council in 1957. https://goo.gl/nnpJgG

N.B. There is no mention of end-of-life care (EOLC) in the recent report by Canada's Office of the Correctional Investigator, 'In the Dark: An Investigation of Death in Custody Information Sharing and Disclosure Practices in Federal Corrections': http://goo.gl/lVyzno. EOLC in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly repo is available on the Palliative Care Community Network website: http://goo.gl/qgd4hp. ***BRA***

CSPCP SCMSP
Canadian Society of Palliative Care Physicians Société canadienne des médecins de soins palliatifs

The 1 August 2016 issue of Media Watch (#473, p.2) included a report on the Ontario government's new policy on access to opioids ('Palliative care doctors decry Ontario's new opioid policy,' *The Globe & Mail*, 25 July 2016: http://goo.gl/CldjNX). Since, the Canadian Society of Palliative Care Physicians has published 'Access to Opioids for Patients Requiring Palliative Care': http://goo.gl/McHoou.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- 610 CKTB NEWSTALK (St. Catharines, Ontario) | Online – 11 – August 2016 – **'Canadian bar society wants expansion of assisted dying law.'** The Canadian Bar Association is urging the federal government to expand its new law on assisted dying, allowing mature minors, people suffering strictly from psychological illnesses, and those diagnosed with competence-eroding conditions like dementia to get medical help to end their suffering. But even as the country's lawyers seek to extend the right to medical assistance in dying, the government is digging in its heels, maintaining that the findings on which the Supreme Court decided to strike down the ban on assisted dying are no longer applicable. http://goo.gl/FL5WTm

Specialist Publications

'A sign of the changing times? Perceptions of Canadian psychologists on assisted death' (p13), in *Canadian Psychology.*

U.S.A.

American Cancer Society

New report has praise, criticism for states in fight against cancer

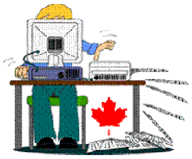
PENNSYLVANIA | CBS NEWS – 11 August 2016 – A new report has praise and some criticism for how Pennsylvania stacks up in the fight against cancer.[1] In Pennsylvania alone, more than 28,000 people will die of cancer this year. The American Cancer Society says ten specific laws could cut cancer rates, but not every state has them all. The Society applauded Pennsylvania's efforts to fund breast and cervical cancer screenings in its new report on how state legislatures are fighting cancer. But the report gave Pennsylvania low marks on regulating palliative care for cancer patients... http://goo.gl/Cmo4Mg

Palliative Care Advisory Councils

The Society has created model state legislation that establishes a Palliative Care Advisory Council comprised of state experts and that also empowers the state health department to provide palliative care information. This legislation has consistently received bipartisan support and has been passed in 13 states.

N.B. Palliative Care Advisory Councils in Connecticut and Rhode Island are profiled in the Society report (p.50).

1. 'How do you measure up? A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality,' American Cancer Society, August 2016. http://goo.gl/KMy6pY



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.[1] 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

1. Ashpole BR. 'Communications with the Public, Politicians, and the News Media,' *Oxford Textbook of Palliative Medicine*, 5th Edition (pp.357-359), Oxford University Press, 2015. https://goo.gl/Vi07RS.

End-of-life wishes not always guaranteed

CALIFORNIA | *The North Coaster* (Inverness) – 10 August 2016 – In 1990, Congress enacted the Federal Patient Self-Determination Act. In response, California ethics committees and state legislators developed advance directives. Like an *à la carte* checklist, the directive forms allow the public to name an agent or two to act on their behalf should they become incapacitated. The agent can make all health care decisions, including decisions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of health care. Yet problems arise because the directive is not legally binding. When the end of life becomes imminent, doctors are often the ones who introduce the discussion. Patients must quickly learn a massive new lexicon: terminal illness, living will, advance directive, compassionate care, comfort care, true wishes, palliative care, code blue, no code, no CPR, do not resuscitate, do not intubate, chemical code, slow code, etc. Even after Congress passed the self-determination act to facilitate communication between physicians and patients, the medical profession remains unable to distinguish between those terms themselves, so communication frequently breaks down. Disagreements between health care professionals occur outside hospice patients' homes or hospital rooms, and nurses, who are most likely to be present at the moment of death, struggle with internal cultural and ethical decisions. As a result, the fulfillment of end-of-life wishes is not always guaranteed. http://goo.gl/I5e0Wt

Specialist Publications

'A bioethicist and a journalist discuss end-of-life care' (p.15, under 'Worth Repeating') in *The Hastings Center Report.*

'Senate committee holds hearing on palliative and hospice care' (p.8), in *Journal of the American Medical Association.*

Most sick, aging Americans live far from in-home care

UNITED PRESS INTERNATIONAL | Online – 9 August 2016 – Most older Americans struggling with chronic illnesses live too far from "in-home" medical care providers to get the help they need to stay in their homes, a new study finds.[1] At least 2 million Medicare beneficiaries are homebound, compared to fewer than 2 million beneficiaries who receive care in nursing homes, the researchers said. Yet, seven times more primary-care providers visited nursing homes than patients at home during the two-year study period. And more than half of Americans live more than 30 miles from a high-volume provider of "home-based medical care," the study also revealed. These services are mostly concentrated in large urban areas. Home-based medical care is a modern twist on the old-fashioned doctor's house call. It involves a team-based approach to managing the care of functionally limited, chronically ill older adults, the researchers explained. Physicians, nurse practitioners and physician assistants manage patients' medical needs in collaboration with nurses, social workers and subspecialists. http://goo.gl/jYm5ni

1. 'Geographic concentration of home-based medical care providers,' *Health Affairs*, 2016;35(8)8:1404-1409. http://goo.gl/JD1Oef

Related

- CALIFORNIA | *Kaiser Health News* – 11 August 2016 – **'Teaching in-home caregivers seems to pay off.'** Low-income Californians who are elderly and disabled were less likely to go to the emergency room or be hospitalized after their in-home caregivers participated in an intensive training program, according to a new report. The rate of repeated emergency room visits declined on 24%, on average, in the first year after caregivers were trained and 41% in the second year... http://goo.gl/m3tfVa

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.13.

We need to be frank about death with terminal patients

NEWSWEEK | Online – 8 August 2016 – One recent survey of patients with advanced cancers found only 5% knew their projected life expectancy was just a few more months. Another found only about half of patients dying from renal and pulmonary conditions had been offered consultations on palliative care. Denied a clear understanding of their situation, terminal patients often pursue invasive treatments that actually make their lives worse. Over 70% of patients with incurable colorectal, breast, lung, pancreatic and prostate cancers continue to receive aggressive care in their last months of life, treatments which typically induce vomiting, mouth sores and other torturous side effects. This collective denial of the inevitable imposes a huge cost on patient well-being and too often, it's for little or no return. Over the past five years ... nearly 70% of cancer drugs were approved without proof they extended or improved life.[1] While cost should never be a factor in a doctor's treatment recommendation or a regulator's decision the collective denial of death's reality is putting a financial burden on patients and their families. http://goo.gl/HtVG8I

1. 'Cancer drugs approved on the basis of a surrogate end point and subsequent overall survival: An analysis of five years of U.S. Food & Drug Administration approvals,' *JAMA Internal Medicine*, 2015; 175(12):1992-1994. http://goo.gl/BfHLmF

N.B. See 'End of Life: Helping With Comfort & Care,' National Institute on Aging, Bethesda, Maryland, July 2016. https://goo.gl/MUlq7t

International

Bereavement teams to be placed in all maternity hospitals

IRELAND | *The Irish Times* (Dublin) – 10 August 2016 – Bereavement specialist teams will be established in all maternity hospitals to support parents dealing with a pregnancy loss or the death of a baby with a fatal foetal anomaly. Minister for Health Simon Harris published 'National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death'[1] ... and said they marked a new beginning for bereavement care services for parents who suffered such a "devastating" experience. http://goo.gl/NkDHoM

1. 'National Standards for Bereavement Care Following Pregnancy Loss,' Health Services Executive, August 2016. http://goo.gl/bkb4lx

Peak death

JAPAN | *The Economist* – 6 August 2016 – A 2008 film, "Departures," movingly depicted the beauty and dignity of *nokan*, the (Buddhist-derived) ritual cleansing ceremony for the recently deceased, carried out at home before laying the body in a coffin for cremation. The film's success led to a wave of job applications to perform *nokan*. Not long after, *Asahi*, a magazine, began promoting the idea of *shukatsu*, planning for the end of life, in the hope of interesting readers and attracting advertisers. And then the devastating tsunami of 2011 made many Japanese wonder openly: if I die, who will take care of my funeral, sort out my affairs, and carry out my wishes? Although Japanese are living longer, healthier lives, the huge baby-boom generation born after the second world war is starting to die just as younger Japanese are having fewer children. The population of 127 million has already peaked and is set to fall below 100 million by 2050. This year around 1 million Japanese will be born, and around 1.3 million will die. By 2040 annual deaths may approach 1.7 million. Call it peak death. It is already changing families. Traditionally, offspring would handle their deceased parents' affairs, with neighbours helping with funeral ceremonies at home. But many more Japanese, particularly in depopulated rural areas and coastal towns, are now dying alone, with few to help them into the next world. http://goo.gl/p2pK2v

Specialist Publications

'Rituals at end-of-life' (p.9), in *Nursing Clinics of North America*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | Stuff.co.nz – 11 August 2016 – **'More than 21,000 New Zealanders to have their say on euthanasia – MPs to hold roadshow.'** A petition to hold a parliamentary inquiry into euthanasia has pulled in a staggering 21,000 submissions from across New Zealand. It's an issue more than 1,800 submitters felt strongly enough about, that they also wanted to appear in front of Parliament's Health Select Committee to speak to MPs directly. Committee chair Simon O'Connor said the MPs would hold hearings around New Zealand, to allow as many as possible the chance to submit in person. http://goo.gl/AUAWbX

Specialist Publications

Palliative care for patients with heart failure: Facilitators and barriers – a cross sectional survey of German health care professionals

BMC HEALTH SERVICES RESEARCH | Online – 8 August 2016 – A lack of knowledge about the content and measures of palliative care (PC), poor communication and unclear responsibilities between medical disciplines, difficulties in determining the right time to initiate PC, and the feeling of not being prepared to discuss end-of-life issues with patients were identified by survey respondents. Further, survey respondents believed that patients and relatives do not possess adequate knowledge about the disease and its progression and are therefore unprepared in asking questions regarding PC. They tend to demand everything possible to be done in order to prolong life, and are reluctant to accept that life is limited. Overall, survey respondents perceived that dying is a taboo subject within our society placing PC on the same level as assisted dying. http://goo.gl/8vK2Be

Selected articles on communications with heart failure patients

- *CANADIAN JOURNAL OF CARDIOLOGY* | Online – 13 May 2016 – **'End-of-life decisions and palliative care in advanced heart failure.'** Future care planning for heart failure patients should incorporate the basic tenets of shared decision-making. These include understanding the patient's perspective and care preferences, articulating what is medically feasible, and integrating these considerations into the overall care plan. [Noted in Media Watch, 23 May 2016, #463 (p.11)] http://goo.gl/rtboJB

- *AMERICAN JOURNAL OF CARDIOLOGY* | Online – 17 March 2016 – **'Choosing words wisely in communication with heart failure patients and families.'** The complex and often unpredictable course of heart failure provides many opportunities for communication between clinicians and patients about advance care planning, disease-state education, therapeutic options and limitations, and end-of-life care. [Noted in Media Watch, 28 March 2016, #455 (p.7)] http://goo.gl/BFrgnA

- *JOURNAL OF CLINICAL OUTCOMES MANAGEMENT*, 2015;22(2):73-82. **'Advance care planning among patients with heart failure: A review of challenges and approaches to better communication.'** Although most patients with heart failure (HF) prefer to receive thorough and honest information about their condition and prognosis, the unpredictability of the HF trajectory coupled with physician barriers, including discomfort with emotionally-laden topics and difficulty identifying the "right" time to engage in advance care planning, impede timely engagement in discussion. [Noted in Media Watch, 23 February 2015, #398 (p.10)] http://goo.gl/2UeN30

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

Patients' perception of types of errors in palliative care: Results from a qualitative interview study

BMC PALLIATIVE CARE | Online – 11 August 2016 – In times where more and more studies are conducted to generate "hard facts" and high-grade evidence to develop standards that define right and wrong, the authors consider this study as an important counterbalance to this development through the integration of the patients' perspective, especially in the area of medical error management. Errors in PC touch similar aspects as in other areas of medicine, but there are also aspects specific to PC mainly related to issues such as communication, professionalism or advance care planning. The issue of errors in PC, and particularly errors from the patients' perspective, needs much more clinical and scientific engagement and this study may be seen as a baseline and index of important aspects. Therefore, the three level model developed – including 1) Definition of and differences between errors; 2) Types of errors; and, 3) Causes, consequences, recognition, meaning, handling and prevention of errors – gives a specification of issues to explore in more depth and detail in future projects. http://goo.gl/eZrBxQ

Noted in Media Watch, 12 November 2012, #279 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2012 – **'Errors in palliative care: Kinds, causes, and consequences – A pilot survey of experiences and attitudes of palliative care professionals.'** Professionals acknowledge errors – in particular errors in communication – to be a common and relevant problem in palliative care, one that has, however, been neglected in training and research. http://goo.gl/2Pc8dA

Noted in Media Watch, 20 December 2010, #180 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2010;13(12):1469-1474. **'Medical errors and patient safety in palliative care: A review of current literature.'** Although patients in palliative care (PC) are more vulnerable to errors and their consequences, there is little theoretical or empirical research on the subject. The authors propose a specific definition for errors in PC and analyze the challenges of delineating, identifying and preventing errors in such key areas as prognostication, advance care planning and end-of-life decision-making. http://goo.gl/xdH2gn

End-of-life care in Scotland

Integrating palliative care into the community: The role of hospices and schools

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 11 August 2016 – Palliative care (PC) services have, up to now, paid insufficient attention to social aspects of dying and bereavement and this has affected how patients and their families experience end of life (EOL) and bereavement within their communities. New public health approaches to PC offer a different way forward by seeking to develop communities that support death and bereavement. Such approaches are now a priority for the majority of hospices in the U.K. and work with schools has been identified as a key area of work. Practice that engages schools and children on issues concerning EOL care is, however, underdeveloped and under-documented. The research was conducted in one hospice and two primary schools in Scotland. Participants included children, parents and school and hospice staff. Seven innovations were identified that were found to be useful for the school curriculum and the relationship between hospices, school communities and wider society. A model for integrated practice between hospices and schools is suggested. http://goo.gl/LqbYkL

Extract from *BMJ Supportive & Palliative Care* article

This research adds to knowledge about how hospices might engage in community engagement activities that encourage school staff to develop greater openness and support around EOL and bereavement care for their children. This will require a rethinking of normal hospice services to also participate in community capacity building.

Cont.

Selected articles on initiatives to introduce dying and death into the school curriculum

- U.S. (Hawaii) | KITV 4 News (Honolulu) – 10 February 2015 – **'Iolani School offers hospice course to students.'** As a teacher, Bob Kane began pondering ways he could use the subjects of death and terminal illness to boost the self-esteem of his students. He devised a year-long hospice course where students could be trained in caring for those facing life-limiting illnesses. [Noted in Media Watch, 23 February 2015, #398 (p.4)] http://goo.gl/gSVu3K

- U.S. (Minnesota) | *International Falls Daily Journal* – 29 October 2011 – **'The journey from life to death: Students participate in end-of-life simulation.'** After learning about hospice in the community, Rainy River Community College students were given 12 pieces of paper on which they wrote the names of three important people in their lives, three prized possessions, three favorite activities and three attributes about themselves of which they were most proud. After being told they had a life-threatening illness with six months to live, they were given thirty seconds to rip up three pieces of paper, signifying things they had to give up. Later, one-by-one, they had torn up all their papers except two. The exercise is intended to show students when your life is ending, you can't always control what you lose first. [Noted in Media Watch, 31 October 2011, #225 (p.3)] http://goo.gl/cr7w5K

- THE NETHERLANDS | TheAge.com.au – 14 February 2007 – **'Lesson in life and death: Pupils build dying teacher's coffin.'** Eri van den Biggelaar has just a few weeks to live after being diagnosed with an aggressive form of cervical cancer. She asked the woodwork teacher, a friend, to build a coffin for her. "Why don't you let the children make it?" he replied. Now pupils ... have been helping with the finishing touches. "Life and death belong together," van den Biggelaar said. "The children realised that when I explained it to them. I didn't want to be morbid about it; I wanted them to help me. None of the children considered it creepy ... and nobody felt traumatised. Parents of the children involved all gave their consent. [Noted in Media Watch, 8 August 2011, #213 (p.9, under 'Worth Repeating')] http://goo.gl/6R3Tl1

Supportive care: Communication strategies to improve cultural competence in shared decision making

CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY | Online – Accessed 12 August 2016 – Historic migration and the ever-increasing current migration into Western countries have greatly changed the ethnic and cultural patterns of patient populations. Because health care beliefs of minority groups may follow their religion and country of origin, inevitable conflict can arise with decision making at the end of life. The principles of truth telling and patient autonomy are embedded in the framework of Anglo-American medical ethics. In contrast, in many parts of the world, the cultural norm is protection of the patient from the truth, decision making by the family, and a tradition of familial piety, where it is dishonourable not to do as much as possible for parents. The challenge for health care professionals is to understand how culture has enormous potential to influence patients' responses to medical issues, such as healing and suffering, as well as the physician-patient relationship. This paper provides a framework of communication strategies that enhance cross-cultural competency within nephrology teams. Shared decision making also enables clinicians to be culturally competent communicators by providing a model where clinicians and patients jointly consider best clinical evidence in light of a patient's specific health characteristics and values when choosing health care. The development of decision aids to include cultural awareness could avoid conflict proactively, more productively address it when it occurs, and enable decision making within the framework of the patient and family cultural beliefs. http://goo.gl/kfpGaF

Noted in Media Watch, 18 April 2016, #458 (p.11):

- *JOURNAL OF INTERCULTURAL STUDIES*, 2016;37(2):103-117. **'The "other" in end-of-life care: Providers' understandings of patients with migrant backgrounds.'** The analysis brings to the fore three themes: 1) The expectation that the existence of difference and uncertainty is a given when caring for patients with migrant backgrounds; 2) The expectation that the extension of responsibility that difference entails creates a variety of dilemmas; and, 3) The expectation that difference will bring about misunderstandings and that patients' needs can go unmet as a result of this. http://goo.gl/35jYcU

Talking about sex, relationships and intimacy: New guidance and standards for nurses and other health and social care professionals working with young people with life-limiting and life-threatening conditions

JOURNAL OF ADVANCE NURSING | Online – 3 August 2016 – In 2013 the Open University Sexuality Alliance was established. This is a collaborative partnership which brings together young people and adults with life-threatening and life-limiting conditions, representatives from the public and third sector, policy makers, doctors, lawyers, academics and nurses with particular expertise in addressing the sexuality of young people with an uncertain life-course. http://goo.gl/HM8Xgr

> **N.B.** Additional articles on sexuality and intimacy in terminal illness are noted in Media Watch, 16 May 2016, #462 (p.12).

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

Senate committee holds hearing on palliative and hospice care

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2016;316(6):575. Physicians and family members must talk with seriously ill adults about the kind of care they'd like to receive before they are too sick to make their preferences known, Senator Susan Collins said at a recent hearing of the Senate Special Committee on Aging, which she chairs. "Federal policies must then support efforts to relieve suffering, respect personal choice, provide opportunities for people to find meaning and comfort during serious illness, and – most important – remain in control of their own care," Collins said at the hearing, titled 'The Right Care at the Right Time: Ensuring Person-Centered Care for Individuals With Serious Illness.' Approximately 90 million adults in the U.S., or more than 1 in 4, live with a serious, life-threatening illness, according to the committee, and that number will grow with the aging of the population. While an increasing number of Medicare beneficiaries are opting for hospice care, more than a quarter of them don't receive it until their last week of life, according to the committee. http://goo.gl/vS3VcE

> **N.B.** The U.S. Senate Special Committee on Aging website: http://goo.gl/jXB47Y

A tissue, a tissue, we all fall down

JOURNAL OF HEALTHCARE COMMUNICATIONS | Online – Accessed 11 August 2016 – Most health professionals would consider it standard practice to offer a patient a tissue if the patient started crying during a consultation. In this context, it can be surprising that are tissue boxes are not always in the rooms of hospitals and clinics where such conversations occur. Some more advanced practitioners in communication will sometimes argue this should not be our sole response to a patient who is crying. At the heart of such a clinical encounter with a patient who is crying is to determine what this means and how best to respond to their crying and distress. A flexible approach is required, and it may be more the intention behind handing a patient a tissue that is more important than whether a tissue is actually given or not. One of the challenges with having to leave the room to find a box of tissues (if a tissue box is not already in the room) is that it becomes a barrier to you being with present with the patient in their distress. In one sense, it can allow you to escape from the patient's distress. Alternatively, it can also be tempting to change the topic of the conversation to something lighter (e.g., speaking about a less intense topic, for example, medicines) or more technical (e.g., description of a medical investigation or procedure) and this should be avoided. Allowing the patient to cry, and giving them time to do this, shows the patient you are aware of their level of distress and that "it is okay to cry." http://goo.gl/uhPlhR

Extract from *Journal of Healthcare Communications* article

Health professionals also need to be able to deal with their own discomfort when a patient cries. Health professionals need to be able to be comfortable with the expression of emotions and to just let them be. This is in contrast to the perceived need to "fix" the problem which is causing the emotional distress. "Constantly checking in with ourselves, rather than moving on auto-pilot to offer a tissue for instance, can sometimes reveal that what we are doing is more about attending to our own needs and discomfort rather than theirs."

Deprescription in advanced cancer patients referred to palliative care

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 5 August 2016 – In palliative care (PC), drugs are considered futile if they do not have a short-term benefit in symptom control or quality of life. The authors examined pharmacotherapy prescribed for patients referred to PC to identify futile drugs. This was a retrospective analysis of patients referred over 6 months, focusing on the prescription of gastric protectants, antidiabetic agents, bisphosphonates, anticoagulants, antidementia drugs, statins, and antihypertensive agents. The sample consisted of 448 patients. Gastric protectants were prescribed futilely in 50% of cases (125/248), statins in 97% (69/71), antihypertensive agents in 27% (42/155), antidiabetic drugs in 1% (1/70), bisphosphonates in 27% (4/15), and antidementia drugs in 100% (9/9). This study reveals that many patients with advanced cancer continue to be treated with inappropriate drugs and points to the need for medical training in PC, drawing attention to the need for therapeutic review at each medical visit. http://goo.gl/Fk22Rs

Noted In Media Watch, 11 January 2016, #444 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 January 2016 – **'Inappropriate prescribing of preventative medication in patients with life-limiting illness: A systematic review.'** The way in which preventative medication appropriateness is assessed in patients with life-limiting illness varies considerably with some methodologies utilising criteria previously developed for elderly populations. Given this lack of standardisation, improving the prescribing in this context requires an approach specifically designed and validated for populations with life-limiting illness. http://goo.gl/rhYmzW

Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 August 2016 – Classification of family types has been shown to identify patients at risk of poor psychosocial function. However, little is known about how family relationships affect caregiver psychosocial function. Three family types emerged [in this study]: 1) Low-expressive; 2) Detached; and, 3) Supportive. The study identified supportive, low-expressive and detached family types among caregivers of advanced cancer patients. The supportive family type was associated with the best outcomes and detached with the worst. These findings indicate that family function is related to psychosocial function of caregivers of advanced cancer patients. Therefore, paying attention to family support, and family members' ability to share feelings and manage conflicts may serve as an important tool to improve psychosocial function in families affected by cancer. http://goo.gl/tFNpD8

Rituals at end-of-life

NURSING CLINICS OF NORTH AMERICA, 2016;51(3):471-487. One of the major themes to emerge from reports of dying patients and their surviving family members is the extreme importance of rituals at end of life (EOL). A ritual has been defined as a sequence of activities involving gestures, words, and objects performed in a specific place and sequence of time. Rituals help participants to cross from their present situation to another and, therefore, describe an important change in status. Rituals encase memories and link the past with the present. Rituals are an antidote to powerlessness. Rituals help patients find meaning in life, enter into a comfort zone, create memories that confirm life accomplishments, assuage a sense of loss, and create a roadmap for dying "the right way." Rituals address the need to comprehend existence in a meaningful way, establish relationships, attach order, and posit a place in the wonder and the mystery of life. Rituals can help the dying focus on living rather than the processes of dying, giving richer meaning to each day of life. The meaning of rituals for the dying not only are important to patients but also to family members and caregivers. http://goo.gl/QDnQsr

Cont.

Related

- *NURSING CLINICS OF NORTH AMERICA*, 2016;51(3):459-469. '**Family care during end-of-life vigil.**' This article reviews seminal and current research regarding the meaning and structure of the lived experience of vigil keeping for a dying family member, and translates this research to inform nursing practice regarding family care during the transition at end of life. http://goo.gl/IhHEBc

Seeing the light end-of-life experiences: Visions, energy surges, and ether death bed phenomena

NURSING CLINICS OF NORTH AMERICA, 2016;51(3):489-500. Death bed phenomena are common within the last days and weeks of life and can include visions, dreams, hallucinations, and pre-mortem energy surges. These end-of-life experiences have been under-recognized and unappreciated by health care providers, often discounted as the results of medical delirium. General consensus among those describing these death bed occurrences is that they are a source of consolation to dying patients and families. Qualitative studies show that patients and families are often more likely to talk about these experiences to nurses than to other health care providers. Nursing interventions to normalize and validate these phenomena and open channels of communication can impact care during this period and facilitate a more peaceful passing. http://goo.gl/Z6b3gI

Selected articles on deathbed phenomena

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 January 2016 – '**Unusual perceptions at the end of life: Limitations to the diagnosis of hallucinations in palliative medicine.**' Conclusions from interdisciplinary (as opposed to single discipline) hallucination studies suggest that the way forward for clinical and research work in palliative medicine may lie in a more biographical and cultural approach to unusual perceptions at the end of life. [Noted in Media Watch, 8 February 2016, #448 (p.8)] http://goo.gl/yEerLt

- *PSYCHOLOGY & PSYCHOTHERAPY: THEORY, RESEARCH & PRACTICE* | Online – 16 July 2015 – '**Experiences of continued presence: On the practical consequences of "hallucinations" in bereavement.**' Experiences of continued presence were meaningfully connected to the immediate environments in which they happened, but also to the personal histories of the bereaved. [Noted in Media Watch, 27 July 2015, #420 (p.16)] http://goo.gl/N82VXr

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 March 2015 – '**Deathbed phenomena reported by patients in palliative care: Clinical opportunities and responses.**' The authors systematically reviewed the literature on deathbed phenomena and provide suggestions for a clinical response to dying patients' recounts of these hard-to-explain phenomena. [Noted in Media Watch, 6 April 2015, #404 (p.7)] http://goo.gl/DCYj2p

Experiences and perspectives of older people regarding advance care planning: A meta-synthesis of qualitative studies

PALLIATIVE MEDICINE | Online – 11 August 2016 – Studies have indicated that family members or health professionals may not know or predict their older relatives' or patients' health preferences. Although advance care planning (ACP) is encouraged for older people to prepare end-of-life care (EOLC), it is still challenging. Four themes were identified: 1) Life versus death; 2) Internal versus external; 3) Benefits versus burdens; and, 4) Controlling versus being controlled. The view of life and death influenced older people's willingness to discuss their future. The characteristics, experiences, health status, family relationship, and available resources also affected their plans of ACP. Older people needed to balance the benefits and burdens of ACP, and then judge their own ability to make decisions about EOLC. http://goo.gl/UsQGqC

Cont.

Related

- *PATIENT EDUCATION & COUNSELLING* | Online – 10 August 2016 – **'Advance care planning for nursing home residents with dementia: Influence of 'we DECide' on policy and practice.'** Advance care planning (ACP) policy was significantly more compliant with best practice after 'we DECide'; policy in the control group was not. ACP was not discussed more frequently, nor were residents and families involved to a higher degree in conversations after 'we DECide.' Barriers to realizing ACP included staff's limited responsibilities; facilitators included support by management staff, and involvement of the whole organization. http://goo.gl/mteikl

End-of-life care in Canada

Palliative homecare is associated with reduced high- and low-acuity emergency department visits at the end of life: A population-based cohort study of cancer decedents

PALLIATIVE MEDICINE | Online – 9 August 2016 – Prior work shows palliative homecare services reduce the subsequent need for hospitalizations and emergency services; however, no study has investigated whether this association is present for emergency department (ED) visits of high acuity or whether it only applies to low-acuity ED visits. There were 54,743 decedents (i.e., patient population studied) who received homecare nursing in the last 6 months of life. The receipt of palliative homecare nursing decreased the rate of low-acuity ED visits ... and was significantly associated with a larger decrease in the rate of high-acuity ED visits... http://goo.gl/9FaH5W

Noted in Media Watch, 16 May 2016, #462 (p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 12 May 2016 – **'"They shouldn't be coming to the ED, should they?" A qualitative study of why patients with palliative care needs present to the emergency department.'** Previous studies define the "reason" as the "presenting symptom," which ignores the perspectives of service users. This paper addresses an acknowledged gap in the literature, which fails to examine the decision-making process that brings patients to the emergency department. http://goo.gl/nTEq85

Noted in Media Watch, 29 February 2016, #451 (p.12):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 February 2016 – **'Why do adults with palliative care needs present to the emergency department? A narrative review of the literature.'** Given the increasing emphasis on community-based provision of palliative care (PC) and the view that good dying should occur at home, it is unsurprising that policy in many countries has started focusing on preventing hospital admissions at the end of life. http://goo.gl/H2ko6X

Discontinuation and non-publication of randomized clinical trials conducted in children

PEDIATRICS | Online – 4 August 2016 – Of 559 trials, 104 (19%) were discontinued early, accounting for an estimated 8,369 pediatric participants. Difficulty with patient accrual (37%) was the most commonly cited reason... Trials were less likely to be discontinued if they were funded by industry compared with academic institutions... Of 455 completed trials, 136 (30%) were not published, representing 69,165 pediatric participants. Forty-two unpublished trials posted results on ClinicalTrials.gov. Trials funded by industry were more than twice as likely to result in non-publication at 24 and 36 months ... and had a longer mean time to publication compared with trials sponsored by academia... http://goo.gl/0dv4ji

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Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website: http://goo.gl/frPgZ5

Noted in Media Watch, 6 June 2016, #465 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 June 2016 – **'The spectrum of caregiving in palliative care for serious, advanced, rare diseases: Key issues and research directions.'** The National Institute of Nursing Research, the lead institute at the National Institutes of Health for End-of-Life Research, in conjunction with the National Center for Advancing Translational Sciences, Office of Rare Diseases Research, held an interdisciplinary workshop on the unique challenges of caregiving and palliative care in adult and pediatric rare diseases. This report presents a summary of the workshop. http://goo.gl/yXwMOr

Noted in Media Watch, 16 May 2016, #462 (p.15):

- *PALLIATIVE MEDICINE* | Online – 13 May 2016 – **'A call for increased paediatric palliative care research: Identifying barriers.'** Challenges faced by researchers aiming to recruit children and young people with life-limiting conditions or life-threatening illnesses and their families are numerous, including small sample sizes and limited funding as well as difficulties with research ethics committees, the unpredictable nature of the illnesses and society's perceptions of the potential physical and psychological burden for participants and their families. http://goo.gl/EVPHs5

Physicians' identification of the need for palliative care in people with intellectual disabilities

RESEARCH IN DEVELOPMENTAL DISABILITIES, 2016;59(12):55-64. Identification of people with intellectual disabilities (ID) in need for palliative care (PC) mostly results from a process in which multiple signals from different information sources converge and lead to a growing awareness. As a result, ID-physicians do not expect people to return to their prior level of health or functioning, but rather expect an irreversible decline leading to death. The presence, stage and prognosis of the disease, physician-patient interaction, and communication with proxies who provide contextual information are factors influencing the process. Distinctive for a population of people with ID are the frequent diagnostic uncertainty in people with ID, the patients' communicational abilities and the reliance of ID-physicians on close proxies. The authors argue for a proactive attitude of physicians regarding care and support of people with ID with PC needs. http://goo.gl/0AuHy9

N.B. Additional articles on palliative care for people living with intellectual disabilities are noted in Media Watch, 1 August 2016, #473 (p.14), and 8 February 2016, #448 (p.12).

Evolution of medical ethics in resuscitation and end of life

TRENDS IN ANAESTHESIA & CRITICAL CARE | Online – 3 August 2016 – Medical ethics has evolved from paternalistic to patient-centred. Emergency and end-of-life situations are frequently associated with inability to make informed decisions. Respect for advance directives, proxy informed consent for therapeutic/research interventions, do-not-attempt resuscitation orders, and withdrawal of life-sustaining treatment focus on autonomy and nonmaleficence. Beneficence is increasingly interpreted in terms of "achieved quality of life" following emergency treatment/resuscitation. Justice pertains to equality of access to best available care, which depends on patient age, co-morbidity, preferences, socioeconomic status, race, ethnicity, and religion. Dignity includes the concept of "dignified death," the still-debated practice of physician-assisted death is gaining ground. Honesty/transparency augments patient participation in shared decision-making and treatment selection. http://goo.gl/kuDVqC

The DNR order after 40 years

NEW ENGLAND JOURNAL OF MEDICINE, 2016; 375(6):504-506. In the 40 years since its introduction, the do-not-resuscitate order has become part of our society's ritual for dying. The concept expanded the domain of informed consent, while contributing to ongoing controversy over appropriate care for dying patients. http://goo.gl/Ifkuou

Cont.

Noted in Media Watch, 25 January 2016, #446 (p.16):

- *RESUSCITATION* | Online – 14 January 2016 – **'A survey of key opinion leaders on ethical resuscitation practices in 31 European Countries.'** The authors report the responses to a questionnaire covering four domains of resuscitation: 1) Approaches to end-of-life care and family presence during CPR; 2) Determinants of access to best resuscitation and post-resuscitation care; 3) Diagnosis of death and organ donation; and, 4) Emergency care organisation. http://goo.gl/me0mUy

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN PSYCHOLOGY*, 2016;57(3):188-192. **'A sign of the changing times? Perceptions of Canadian psychologists on assisted death.'** This research topic is of significant value given that there have been few published data on this topic specific to this target population. Further, changes to Canada's current legislation surrounding assisted death may require psychologists to develop familiarity with this issues surrounding end-of-life care. The data demonstrated that [study] participants support physician-assisted death for terminal, but not mental, illness. In addition, these psychologists had limited confidence in their ability to assess the competency of terminally ill individuals to provide informed consent to the receipt of physician-assisted death. Implications for this study include a new perspective being added to the debate on assisted death as well recognition that psychologists may have an important role to play in the legalization and regulation of these controversial practices. http://goo.gl/tAV4Xk

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Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/vjGQws

IAHPC link updated 08.10.2016

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

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/5d1l9K

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

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(6):656-657. **'The controversial issue of euthanasia in patients with psychiatric illness.'** This commentary discusses a study published in *JAMA Psychiatry* that investigated the characteristics of patients receiving euthanasia or assisted suicide for psychiatric conditions and how the practice is regulated in The Netherlands.[1] http://goo.gl/S6ynb9

    1. 'Euthanasia and assisted suicide of patients with psychiatric disorders in The Netherlands 2011 to 2014,' *JAMA Psychiatry*, 2016;73(4):362-368. http://goo.gl/VGxZJL

- *JOURNAL OF MEDICAL ETHICS* | Online – 5 August 2016 – **'Developments in the practice of physician-assisted dying: Perceptions of physicians who had experience with complex cases.'** The authors conducted ... in-depth interviews with 28 Dutch physicians who had experience with a complex case of euthanasia and physician-assisted suicide (EAS). First, they experienced a change in what (family of) patients would expect from them: from a role as an involved caregiver to being the mere performer of EAS. Second, interviewees said that requests for EAS based on non-medical reasons came up more frequently and wondered if EAS was the right solution for these requests. Last, respondents had the impression that the standards of EAS are shifting and that the boundaries of the EAS regulation were stretched. http://goo.gl/gopeS8

- *NEUROLOGY* | Online – 5 August 2016 – **'Cognitive impairment, behavioral impairment, depression, and wish to die in an ALS cohort.'** While the authors found no association between cognitive impairment and depression or any measure of distress, behavioral impairment was strongly associated with depressive symptoms and diagnoses although seldom addressed by clinicians. Thoughts about ending life were unrelated to either cognitive or behavioral changes, a finding useful to consider in the context of policy debate about physician-assisted death. http://goo.gl/pj3ybz

    N.B. Editorial: 'Hastened death in ALS: Damaged brains and bad decisions?' http://goo.gl/nfMY7e

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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
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.

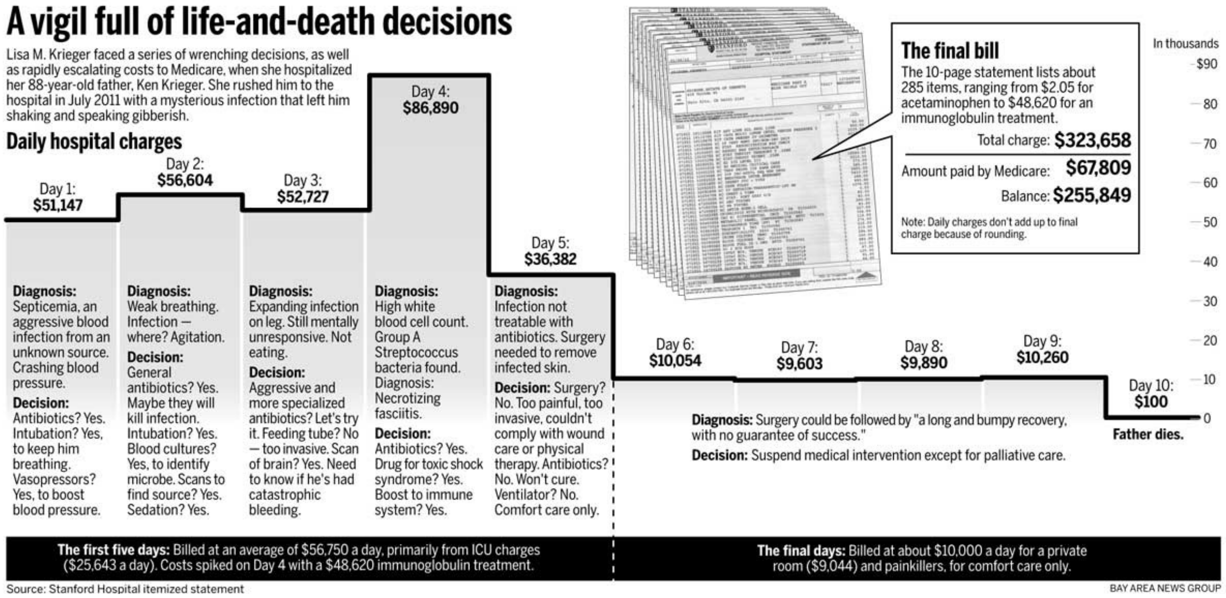
Worth Repeating

A bioethicist and a journalist discuss end-of-life care

THE HASTINGS CENTER REPORT | Online – 21 February 2012 – Writers always hope for a response from their readers. But when Lisa Krieger, a science and medicine writer for the *Mercury News* in San Jose, California, wrote ... about the death of her 88 year-old father[1] – a death that was prolonged, at a cost of $323,000, despite his “do not resuscitate” and “desire for a natural death” directives – she was stunned by the flood of reactions. One of them was from Daniel Callahan, co-founder of The Hastings Center, who was interviewed in the article. Callahan, who has been writing about end-of-life issues for more than 40 years, was so impressed by the article that he proposed to Krieger that they “reverse roles” – he would interview her about her article and, particularly, the response that it got. “I would like to ask you, on looking back, at what point should the life-sustaining efforts have been stopped,” he told her. “It was as if people just wanted permission to talk about dying,” she told Callahan. “I opened the door.” The interview, which includes Krieger’s advice to people in a situation similar to the one she described, appears in *Bioethics Forum*.[2] [Noted in Media Watch, 20 February 2012, #241 (p.7)] http://goo.gl/kcH78O

1. ‘The cost of dying: It’s hard to reject care even as costs soar,’ *The San Jose Mercury News*, 6 February 2012 [Noted in Media Watch, 13 February 2012, #240 (p.4)]. http://goo.gl/yasXpa

2. ‘The trial of “Death by Medicine”: An interview with Lisa Krieger,’ *Bioethics Forum*, The Hastings Center, 13 February 2012. http://goo.gl/J4nDhu



A vigil full of life-and-death decisions

Lisa M. Krieger faced a series of wrenching decisions, as well as rapidly escalating costs to Medicare, when she hospitalized her 88-year-old father, Ken Krieger. She rushed him to the hospital in July 2011 with a mysterious infection that left him shaking and speaking gibberish.

Diagnosis: Septicemia, an aggressive blood infection from an unknown source. Crashing blood pressure.
Decision: Antibiotics? Yes. Intubation? Yes, to keep him breathing. Vasopressors? Yes, to boost blood pressure.

Diagnosis: Weak breathing. Infection — where? Agitation.
Decision: General antibiotics? Yes. Maybe they will kill infection. Intubation? Yes. Blood cultures? Yes, to identify microbe. Scans to find source? Yes. Sedation? Yes.

Diagnosis: Expanding infection on leg. Still mentally unresponsive. Not eating.
Decision: Aggressive and more specialized antibiotics? Let's try it. Feeding tube? No — too invasive. Scan of brain? Yes. Need to know if he's had catastrophic bleeding.

Diagnosis: High white blood cell count. Group A Streptococcus bacteria found. Diagnosis: Necrotizing fasciitis.
Decision: Antibiotics? Yes. Drug for toxic shock syndrome? Yes. Boost to immune system? Yes.

Diagnosis: Infection not treatable with antibiotics. Surgery needed to remove infected skin.
Decision: Surgery? No. Too painful, too invasive, couldn't comply with wound care or physical therapy. Antibiotics? No. Won't cure. Ventilator? No. Comfort care only.

Diagnosis: Surgery could be followed by "a long and bumpy recovery, with no guarantee of success."
Decision: Suspend medical intervention except for palliative care.

The final bill

The 10-page statement lists about 285 items, ranging from $2.05 for acetaminophen to $48,620 for an immunoglobulin treatment.

Total charge: **$323,658**

Amount paid by Medicare: **$67,809**

Balance: **$255,849**

Note: Daily charges don't add up to final charge because of rounding.

The first five days: Billed at an average of $56,750 a day, primarily from ICU charges ($25,643 a day). Costs spiked on Day 4 with a $48,620 immunoglobulin treatment.

The final days: Billed at about $10,000 a day for a private room ($9,044) and painkillers, for comfort care only.

Source: Stanford Hospital itemized statement

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