

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

Meeting unmet needs: Scroll down to [Specialist Publications](#) and 'Creating a sacred space in the intensive care unit at the end of life' (p.10), in *Dimensions of Critical Care Nursing*.

Canada

Review of health care in Manitoba recommends massive changes

MANITOBA | CBC News (Winnipeg) – 8 February 2017 – A comprehensive review of health-care delivery in Manitoba calls for dramatic changes to service delivery, but the Progressive Conservative (PC) government has its own review on the go and may not commit to the sweeping changes. The report was ordered by the previous National Democratic Party government and co-authored by Dr. David Peachey, a Nova Scotia-based principal with Health Intelligence Inc. The report calls for a reorganization of service delivery on a massive scale, especially in the Winnipeg Regional Health Authority. The report recommends consolidating surgery at three hospitals and using the remaining facilities for convalescent and rehabilitation services. Emergency departments in three of Winnipeg's community hospitals would be closed and converted into urgent-care centres. Money for health is tight. The PC government and other Canadian provinces are in a battle with Ottawa over the funding formula. <https://goo.gl/yQ9YgZ>

N.B. To access 'Provincial Clinical & Preventive Services Planning for Manitoba: Doing Things Differently and Better' click on 'Read the full report here' (embedded in the CBC report).

Extract from 'Provincial Clinical & Preventive Services Planning for Manitoba: Doing Things Differently and Better' (p.99)

Palliative care in Manitoba is provided by a relatively small number of physicians, nurses, and home care aides. It is evident that palliation is responding to demand and that a strengthened provincial model will be required to respond to need, especially with the shifting sands of Medical Assistance in Dying (MAiD). MAiD will restore a focus on palliation across Canada. The other important component of care is the Palliative Care Drug Access Program. Minister of Health, Seniors & Active Living operates the drug access program, and the regional health authorities provide the service. As with most services in the vast Manitoba geography, the more remote the site, the less the access and equity of care.

Specialist Publications

'End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward' (p.13), in *Journal of Palliative Medicine*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 5 February 2017 – **‘More Canadians travelling to Switzerland to end their lives.’** A growing number of Canadians are travelling to Switzerland to end their own lives, after Parliament passed a new law permitting doctor-assisted death that was widely criticized as too restrictive. According to figures from Dignitas, a Swiss organization that assists patients with chronic or terminal illness to die, 131 Canadians became “members” last year. That’s the highest in number in the last five years. <https://goo.gl/Qq0vih>

U.S.A.

Finding solutions to the growing caregiver crisis

FORBES | Online – 7 February 2017 – We are facing an extraordinary demographic shift that will create new challenges for our society and demand new policy solutions. Each day, 10,000 boomers turn 65 and over the next 30 years, the population of older adults will nearly double – growing from 48 million to 88 million, with the largest percentage increase among those 85 and older. This shift will profoundly impact families all across America. As more Americans face these challenges, we need to create a social infrastructure that will help families manage their caregiving responsibilities. In addition to adopting family-friendly workplace policies – for example, guaranteed paid family leave – we need to ensure that growing numbers of family caregivers can supplement the care they provide with the services of professional home care aides who are compassionate, skilled and reliable. But finding these workers is becoming increasingly difficult. <https://goo.gl/35UVoC>

Specialist Publications

‘Longer periods of hospice service associated with lower end-of-life spending in regions with high expenditures’ (p.8), in *Health Affairs*.

‘Hospice access for undocumented immigrants’ (p.10), in *JAMA Internal Medicine*.

‘U.S. clergy religious values and relationships to end-of-life discussions and care’ (p.13), in *Journal of Pain & Symptom Management*.

‘Does religiosity account for lower rates of advance care planning by older African Americans?’ (p.14), in *The Journals of Gerontology*.

Humor may be an antidote for pain of death for patients and survivors

KAISER HEALTH NEWS | Online – 6 February 2017 – Just weeks before Christmas some years ago, Shirley Rapp and her family faced the devastating news that she had what appeared to be a terminal illness. But that didn’t stop Rapp from wanting to do one last round of Christmas shopping for her kids. Her daughter, Karyn Buxman, a self-described neuro-humorist and registered nurse, went along. When the mother-daughter duo stepped into a St. Louis-area stationery store, Rapp picked up a day planner that she admired, turned to her daughter and quipped: “If I make it past 1 January, will you buy this one for me?” That’s when Mom and daughter burst into laughter that attracted every eye in the store. For some folks, the process of dying comes with less stress when it’s something of a laughing matter. Not a yuk-yuk laughing matter. But, at its simplest, a willingness to occasionally make light of the peculiarities – if not absurdities – that often go hand-in-hand with end-of-life situations. <https://goo.gl/i74ypD>

N.B. Additional articles on humour in the context of end-of-life care are noted in Media Watch 29 February 2017, #451 (pp.7-8).

Doctors ask for state-wide approach to patient care

MONTANA | *Daily Inter Lake* (Kalispell) – 6 February 2017 – Kalispell doctors are keeping their eyes on a state legislative bill that would set goals for how health facilities provide care to patients with a chronic illness beyond filling their immediate medical needs. House Bill 285 states that people facing complex, chronic health issues that affect their quality of life should be able to use palliative care (PC), or supportive care, throughout their treatment. If passed, House Bill 285 would require Montana's Department of Public Health & Human Services to establish a PC access initiative. The department would appoint and operate an advisory council created to survey PC services in Montana and improve people's access to that type of treatment. The bill would also develop an education program for patients and health providers to understand what PC is and how to tap into resources across the state. <https://goo.gl/JyyzPM>

Terminally ill obese people less likely to get hospice care

UNITED PRESS INTERNATIONAL | Online – 6 February 2017 – Obesity affects many facets of life, and now a new study suggests that carrying a great deal of extra weight also may affect the way a person dies.¹ Obese people are less likely to spend their last days in hospice care and more likely to die at home, the new research found. It's not yet clear why the difference exists or exactly what it means for the quality of life for obese people in the final stages of their lives. But theories include potential bias against the obese and the unique challenges obese people face in getting proper medical treatment, the study authors said. <https://goo.gl/Pk2LSH>

1. 'The relationship of obesity to hospice use and expenditures: A cohort study,' *Annals of Internal Medicine*, published online 7 February 2017. <https://goo.gl/OfxCWB>

International

End-of-life care in Australia

Aged care providers central to community-led palliative care: Expert

AUSTRALIA | *Australian Ageing Agenda* – 10 February 2017 – A grassroots campaign of care professionals and services is pushing to embed community-based palliative care (PC) in Australia to provide more inclusive end-of-life care (EoLC) – and they say aged care providers have a key role to play. With Australia's ageing population, increasing pressure on health and aged care budgets and mounting rates of social isolation in the community, they say a new approach to EoLC is needed. The "compassionate communities" movement aims to promote and integrate social approaches to dying, death and bereavement by building community capacity around EoLC and support. Not only does the model provide for more inclusive and person-centered PC, the experience in Europe has shown it also reduces unnecessary and costly hospital treatment. <https://goo.gl/Dc1YWY>

Noted in Media Watch 30 January 2017, #497 (p.12):

- *UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE* | Online – Accessed 28 January 2017 – '**Compassionate communities and their role in end-of-life care.**' Given the need for support throughout all aspects of end-of-life care, an emerging paradigm shift shows compassionate communities as a new standard for placing responsibility back in the community and promoting respectful and compassionate care. Development of Compassionate Communities promotes quality end-of-life care designed to meet the individualized needs of the dying as well as their caregivers. <https://goo.gl/rrqQDj>

Palliative Care Tasmania

Clearing air on palliative care's future direction

AUSTRALIA (Tasmania) | *The Mercury* (Hobart) – 9 February 2017 – It has been reported that Palliative Care Tasmania is closing as its Federal funding had ceased. This is not the case. <https://goo.gl/tQk5fu>

The doctor's dilemma: Is it ever good to do harm?

U.K. | *The Guardian* – 9 February 2017 – Medical knowledge changes swiftly, and technological changes make new and expensive investigations and treatments possible only theoretical a few years ago. Life has been extended in length, but not in quality, and the debates about end-of-life decisions show us how much the notion of a “good life” is bound up with the absence of disease, illness and suffering. The practice of medicine is not purely technical. It involves a relationship between a person who is seeking help, and who may be vulnerable, and a person who has the skills and knowledge to help. Relationships that involve disparities of power, knowledge and vulnerability require some degree of external oversight and regulation. Traditionally, in medicine, this oversight has taken the form of codes of ethics, starting with the Hippocratic Corpus. Today, bodies such as the General Medical Council and the Royal Colleges define the standards of good medical practice. There has been much discussion of how we make moral choices, but what do we mean by a “moral” decision in medicine? Conventionally, we are distinguishing what is clinically and technically possible from whether it is “right” to intervene at all. For example, if a person's heart stops, we know we can resuscitate them, but should we do so? <https://goo.gl/XLY10c>

Better Care Fund for England

Government's £5.3 billion plan to integrate health and social care “failing to save money”

U.K. (England) | *The Independent* – 8 February 2017 – A Government plan to integrate health and social care is failing to save money or stem the rise in hospital admissions, a report has warned.¹ The National Audit Office (NAO) said the Department of Health and National Health Service (NHS) England were both over-optimistic about what the Better Care Fund for England could achieve. It was set up with £5.3 billion of NHS and local authority funding in 2015 to better integrate health and social care. The NHS is suffering due to record-high numbers of delayed discharges, where patients are medically fit to leave hospital but there are delays to arranging their social care in the community. Councils, which arrange and pay for some of the care, are also under huge pressure due to budget cuts. The NAO report found the Department of Health expected to achieve savings of £511 million in the first year of the Better Care Fund, but this was not realised. It also expected a reduction in hospital admissions, but in fact they increased. <https://goo.gl/hmAeoU>

1. ‘Health and Social Care Integration,’ National Audit Office, 8 February 2017. <https://goo.gl/7W6Xz7>

Noted in Media Watch 23 February 2015, #398 (p.5):

- U.K. (England) | *The Guardian* – 17 February 2015 – ‘**Good communication is essential to successful integration of health and social care.**’ Most people involved in delivering health and social care are committed to making integration happen. They know it's a good thing and can see the benefits for care and for the people who use services. A new guide, soon to be produced by the consortium that is delivering the national Better Care Fund support programme argues that better integrated care can only happen with good engagement and communication. <https://goo.gl/ReWqvq>

Related

- U.K. (England) | BBC News – 8 February 2017 – ‘**Reality check: Who gets social care and who pays for it?**’ Directors of adult social services in England say they have had to cut £4.6 billion from their budgets since 2010. So who is getting care, what kind of care are they getting, and who is paying for it? In England social care is not free at the point of delivery – a lot of people have to pay for at least some of their care, and a lot of that care is delivered by private providers. <https://goo.gl/z4r6N9>
- U.K. (England) | *The Daily Telegraph* – 7 February 2017 – ‘**Finding solutions to the growing care-giver crisis.**’ Elderly people are waiting more than a year to receive the care they need from local councils an investigation has found. Seven councils have admitted to waits of more than six months for promised help, with one local authority leaving an elderly person in limbo for over a year before their care package could begin. <https://goo.gl/2G9CD0>

Care staff “at breaking point” over end-of-life provision

U.K. (Scotland) | *The Herald* (Glasgow) – 7 February 2017 – Older people at the end of their lives are being let down by the care system, with too many unable to achieve a “good death” and dying alone, according to a survey from Scottish Care. The umbrella organisation for independent care providers says staff in care homes or providing care in people’s own homes are stretched to breaking point by the needs of terminally ill residents. Calling for more investment in palliative care (PC) services, Dr. Donald Macaskill, chief executive of Scottish Care, said that death and dying are often taboo subjects, but that means planning for end-of-life care is often inadequate. The report ... is based on nationwide focus groups with people working on the frontline of elderly care. It says more than 100,000 people work in independent care homes and home care services, supporting more than 63,000 people, including around 52,000 aged over 65. Scots are dying older, often affected by frailty, dementia and multiple other conditions, Scottish Care says, and by 2037 deaths will have gone up by 12% to 61,600 with more than eight out of ten of those people likely to have a need for end-of-life PC. <https://goo.gl/jfjq62>



End-of-life care in England

How National Health Service and hospice teamwork can make end-of-life care as easy and painless as possible

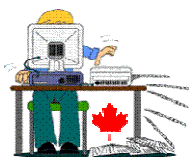
U.K. (England) | *The Daily Telegraph* – 6 February 2017 – Previous research by Hospice UK has shown that, of the 250,000 people who die in hospital every year, many would have much preferred to die at home. Understanding what people want and building a relationship with them, as soon as an illness is diagnosed as terminal, allows hospice care to be taken to the patient’s home, even if that is a care home or sheltered accommodation – away from the noise and bustle of a hospital ward. The success of Hospice-at-Home care has persuaded National Health Service England to fund the first stage of a new project by Hospice UK to evaluate yet more of the initiatives led by hospices. It will identify how hospice-led services can help to offer more choice to people over where they die. <https://goo.gl/dJA4zY>

Extract from *The Daily Telegraph* article

While there are a few National Health Service (NHS) hospices in the U.K., the great majority rely on charitable donations to fund their work. They need to raise £1 billion annually and to this amount the NHS contributes a mere £300,000.

Specialist Publications

‘Discharging patients home from hospital at the end of life’ (p.7), in *British Journal of Hospital Medicine*.



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>

Specialist Publications

End-of-life care in Australia

The association of community-based palliative care with reduced emergency department visits in the last year of life varies by patient factors

ANNALS OF EMERGENCY MEDICINE | Online – 3 February 2017 – Emergency department (ED) use increases significantly toward the end of life (EoL). Numerous studies have reported that community (home)-based PC for people with life-limiting conditions is associated with reduced use of acute care health services. Although multidisciplinary palliative care (PC) has been demonstrated to reduce acute care service use, not all use of the ED is unwarranted. A study of cancer patients receiving outpatient PC in the U.S. reported that 77% of ED visits were unavoidable.¹ However, even if most ED visits of cancer patients in the last two weeks of life result in hospital admission, it does not necessarily mean that the patient could have been managed only in the acute care setting. Ideally, high-quality PC should be able to manage the most common acute symptoms of the dying person without hospitalization. Historically, PC evolved to meet the EoL needs of cancer patients. It has since become apparent that it benefits non-cancer terminal conditions such as renal failure, heart failure, chronic obstructive pulmonary disease, and liver failure, although access to and quality of PC for these conditions could be improved. In Australia, there has been evidence of this improved access to PC in non-cancer conditions during the last 10 years. <https://goo.gl/C296Ey>

1. 'Avoidable and unavoidable visits to the emergency department among patients with advanced cancer receiving outpatient palliative care,' *Journal of Pain & Symptom Management*, 2015;49(3):497-504. <https://goo.gl/DtTFzJ>

Noted in Media Watch 5 December 2016, #490 (p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 November 2016 – **“They shouldn’t be coming to the ED, should they?”: A descriptive service evaluation of why patients with palliative care needs present to the emergency department.** There is no international agreement on which patients are best cared for in the emergency department (ED), compared to the primary care setting or direct admission to the hospital. Findings of this single centre study challenge the misconception that patients known to a palliative care team should be cared for outside the ED. <https://goo.gl/qQL7qS>

End-of-life care in The Netherlands

From concept to practice, is multidimensional care the leading principle in hospice care? An exploratory mixed method study


BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 6 February 2017 – The aim of this study is to gain insight into multidimensional care (MC) provided to hospice inpatients by a multi-professional team (MT) and identify facilitators, to ameliorate multidimensional hospice care (HC). First a quantitative study of 36 patient records (12 hospices, 3 patient records/hospice) was performed. Second, MC was qualitatively explored using semi-structured focus group interviews with multi-professional hospice teams. The physical dimension was most prevalent in daily care, reflecting the patients’ primary expressed priority at admission and the nurses’ and physicians’ primary focus. The psychological, social and spiritual dimensions were less frequently described. Assessment tools were used systematically by 4/12 hospices. Facilitators identified were interdisciplinary collaboration, implemented methods of clinical reasoning and structures. MC is not always verifiable in patient records; however, it is experienced by hospice professionals. The level of MC varied between hospices. <https://goo.gl/PO106B>

Discharging patients home from hospital at the end of life

BRITISH JOURNAL OF HOSPITAL MEDICINE | Online – 6 February 2017 – This article provides an overview of important considerations for the non-palliative care specialist when discharging a dying person home to his or her preferred place of care. A highly practical framework is included for identifying and assessing the patient's needs, and devising a tailored care plan. Rapid discharges at the end of life are complex processes which require the input of multiple health care professionals at every stage. With appropriate assessment and a framework to work from, such discharges can be successful. Key components for a rapid discharge are explored: 1) Recognition that the person has a deteriorating condition and may be dying, and communication with the person and/or carers such that they are aware of the situation; 2) Finding out what the person wants, including options around preferred place of care and death; 3) Assessment of clinical and care needs; 4) Provision of an individually-tailored care plan and package of care to support the person's needs; 5) Effective liaison with and communication of the person's needs and wishes to appropriate community services; and, 6) Exceptional circumstances or unusual situations (emergency department, outpatients, abroad, addiction, homelessness). <https://goo.gl/NKZLgP>

Related

- *JOURNAL OF AGING & HEALTH* | Online – 5 February 2017 – **'Death following recent admission into nursing home from community living: A systematic review into the transition process.'** Eleven cohort studies met the inclusion criteria. Mortality within the first 6 month post-admission varied from 0% to 34%... Causes of deaths were not reported. Heightened mortality was not wholly explained by intrinsic resident factors. Only two studies investigated the influence of facility factors, and found an increased risk in facilities with high antipsychotics use. Transition of care to the nursing home environment from the community is hazardous. A safer transfer is a duty care nursing home executives, managers, the government, and health and aged care professionals owe to residents. Answers are needed to the questions of whether, and to what extent, excess mortality is linked to the transfer process itself, to the environment and practices at destination, or to the fact that it is a significant stressful life event. This knowledge will contribute to providing optimal care for older people. Initiatives to make transitions safer are now possible by acting on the knowledge that there are modifiable risk factors. <https://goo.gl/c2Xin6>



Improving the Last Stages of Life

The Commission recently released the research paper 'Improved Care Setting Transitions in the Last Year of Life.' <http://goo.gl/anPjz>

Noted in Media Watch 17 October 2016, #483 (p.15):

- *PALLIATIVE MEDICINE* | Online – 7 October 2016 – **'Managing risk during care transitions when approaching end of life: A qualitative study of patients' and health care professionals' decision making.'** This study highlights how the concept of risk is used in decision making about transitions in care, raising the importance of more open dialogue between the patients and health care staff on discussing patient choice in this area of decision making. Further research is needed to understand how community-based staff and allied health professionals can be better integrated into decision making in this area. <https://goo.gl/4eUm7x>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.

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

Critical care nurses' perceptions of end-of-life care obstacles: Comparative 17-year data

DIMENSIONS OF CRITICAL CARE NURSING, 2017;36(2):94-105. A random, geographically dispersed sample of 2,000 members of the American Association of Critical Care Nurses was surveyed. Five obstacle items increased in mean score and rank as compared with 1999 data including: 1) Family not understanding what the phrase "lifesaving measures" really means; 2) Providing lifesaving measures at families' requests despite patient's advance directive listing no such care; 3) Family not accepting patient's poor prognosis; 4) Family members fighting about the use of life support; and, 5) Not enough time to provide end-of-life care (EoLC) because the nurse is consumed with lifesaving measures attempting to save the patient's life. Five obstacle items decreased in mean score and rank compared with 1999 data including: 1) Physicians differing in opinion about care of the patient; 2) Family and friends who continually call the nurse rather than calling the designated family member; 3) Physicians who are evasive and avoid families; 4) Nurses having to deal with angry families; and, 5) Nurses not knowing their patient's wishes regarding continuing with tests and treatments. Obstacles in EoLC, as perceived by critical care nurses, still exist. Family-related obstacles have increased over time. Obstacles related to families may not be easily overcome as each family, dealing with a dying family member in an ICU, likely has not previously experienced a similar situation. <https://goo.gl/xDNcEK>

Related

- *HEALTH AFFAIRS*, 2017;36(2):328-336. '**Longer periods of hospice service associated with lower end-of-life spending in regions with high expenditures.**' The authors examined 103,745 elderly Medicare fee-for-service beneficiaries in the Surveillance, Epidemiology & End Results Program Medicare database who died from cancer in 2004-2011. Longer periods of hospice service were associated with decreased EoL expenditures for patients residing in regions with high average expenditures, but not for those in regions with low average expenditures. Hospice use accounted for 8% of the expenditure variation between the highest and the lowest spending quintiles, which demonstrates the powers and limitations of hospice use for saving on costs. <https://goo.gl/8VWXPB>
- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 5 February 2017 – '**Planning ahead: Using the theory of planned behavior to predict older adults' intentions to use hospice if faced with terminal illness.**' Higher hospice knowledge, normative beliefs that support hospice utilization, higher perceived control to use hospice, and preferences for end-of-life care that favor comfort and quality of life over living as long as possible were significant predictors of intentions to use hospice. In spite of being a sample of mostly highly educated older adults, almost half did not know about funding for hospice. These results provide better understanding of where to focus interventions to educate older adults about hospice, ideally in advance of a crisis. <https://goo.gl/3Lxb2A>

Palliative care triggers in the intensive care unit: A pilot success story

DIMENSIONS OF CRITICAL CARE NURSING, 2017;36(2):106-109. There is growing recognition that electronic medical record triggers in the ICU have led to an increase in palliative care consultations. One suburban health care system adopted triggers unique to their culture and setting in a pilot study and saw an increase in palliative consultations in the ICU. Implementing triggers is often a complex and multifaceted process to adopt. This review shares the steps from concept to implementation of establishing palliative prompts in one ICU within an integrated health care system. <https://goo.gl/GE1R3L>

Noted in Media Watch 2 May 2016, #460 (p.6):

- *JOURNAL OF CRITICAL CARE* | Online – 22 April 2015 – '**Developing triggers for the surgical intensive care unit for palliative care integration.**' This article provides insight into a model for palliative care integration into the surgical intensive care unit (SICU), utilizing triggers. Factors significantly associated with hospital death or hospice discharge were: 1) Repeat SICU admission; 2) Metastatic/advanced cancer; 3) SICU physician referral; and, 4) The matching of two or more secondary criteria. <http://goo.gl/TIsEnz>

Cont.

Noted in Media Watch 25 November 2013, #333 (p.7):

- *AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE* | Online – 21 November 2013 – ‘**Estimates of the need for palliative care consultation across U.S. ICUs using a trigger-based model.**’ In this study approximately one in seven ICU admissions met triggers for palliative care consultation using a single set of triggers, with an upper estimate of one in five patients using multiple sets of triggers; these estimates were consistent across different types of ICUs and individual units. <http://goo.gl/oRY1RQ>

Related

- *THE PERMANENTE JOURNAL*, 2017;21(1):16-37. ‘**Use of improving palliative care in the ICU (intensive care unit) guidelines for a palliative care initiative in an ICU.**’ Despite the numerous resources available, the Improving Palliative Care in the ICU project guidelines are an effective tool and provide specific tailored recommendations toward initiating a palliative care (PC) program in an ICU. The successful use of these guidelines resulted in the integration of PC standards and the incorporation of basic PC principles into the daily routine in our ICU. <https://goo.gl/xpTavl>

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

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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.



Media Watch: Behind the Scenes
<http://goo.gl/XDjHxz>

Creating a sacred space in the intensive care unit at the end of life

DIMENSIONS OF CRITICAL CARE NURSING, 2017;36(2):110-115. At least one-third of deaths in the U.S. occur in the hospital; nearly half of the Americans who die in the hospital will have spent time in the intensive care unit during the last 3 days of life. Critically ill patients and their families identify significant unmet spiritual, environmental, and communication needs. Although the Society of Critical Care Medicine recommends that the spiritual needs of critically ill patients be addressed by the health care team and be incorporated in patients' plans of care, spiritual concerns are infrequently addressed during goals-of-care discussions. The American Association of Critical-Care Nurses' Synergy Model recognizes the central importance of spirituality to the provision of patient-centered care. Furthermore, the model highlights the value of the relationship between the patient and the nurse to a healing environment. The privileged connection between patients and nurses, foundational to the creation of a healing environment, may be understood as a sacred space. Critical care nurses are uniquely positioned to improve end-of-life care by focusing on the spiritual, environmental and communication needs of their patients through the creation of a third space in the intensive care unit, a sacred space. <https://goo.gl/LRAJ5L>

Noted in Media Watch 22 August 2016, #476 (p.8):

- *AMERICAN JOURNAL OF RESPIRATORY CRITICAL CARE MEDICINE* | Online – 15 August 2016 – **'Experiences and expressions of spirituality at the end of life in the intensive care unit.'** The austere setting of the intensive care unit (ICU) can suppress expressions of spirituality. Participants [in this study] characterize dying as a spiritual event. Spirituality is an integral part of the life narrative of the patient before, during, and after death. Experiences and expressions of spirituality for patients, families and clinicians during end-of-life care in the ICU are supported by eliciting and implementing wishes in several ways. <http://goo.gl/oUD9IL>

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

Hospice access for undocumented immigrants

JAMA INTERNAL MEDICINE | Online – 6 February 2017 – The 11.2 million undocumented immigrants living in the U.S. are not covered by the Medicare Hospice Benefit, and most are uninsured. Aging of undocumented patients owing to increasing lengths of residence in the U.S. is likely to increase hospice demand, and undocumented immigrants are the largest demographic group explicitly excluded from Affordable Care Act provisions. Clinicians have reported challenges in obtaining hospice for undocumented immigrants; however, little is known about hospice access in this population. This study examined hospice agency practices and access for undocumented immigrants. <https://goo.gl/rb4ocl>

Commentary on 'Hospice access for undocumented immigrants'

Comprehensive immigration reform is needed to address national policies so that clinicians and health care systems can deliver standard of care to patients without regard to their immigration status. Until then, state and local health care leaders must find creative solutions to alleviate the pain and suffering of the patients we serve, regardless of their immigration status. <https://goo.gl/gBO7KU>

Selected articles on undocumented immigrants in the U.S. in the context of end-of-life care

- *MORTALITY* | Online – 30 June 2016 – **'Coping with dying and deaths at home: How undocumented migrants in the U.S. experience the process of transnational grieving.'** The paper argues that the grieving process is unique for a group like this, where the undocumented status means that the migrants cannot go back home to help the dying, support the ones left behind, or receive consolation. [Noted in Media Watch 4 July 2016, #469 (p.16)] <http://goo.gl/g7y8n8>

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- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 December 2015 – ‘**End-of-life care for undocumented immigrants with advanced cancer: Documenting the undocumented.**’ It is important for clinicians and policy makers to have a better understanding of the issues surrounding end-of-life care (EoLC) for undocumented immigrants and together work to improve the quality of life and quality of EoLC for these disadvantaged individuals. [Noted in Media Watch 14 December 2015, #440 (p.9)] <https://goo.gl/jnBE3R>
- *NARRATIVE INQUIRY IN BIOETHICS*, 2014;4(2)83-85. ‘**Undocumented and at the end of life.**’ Three of the most contentious issues in contemporary American society – allocation of medical resources, end-of-life care, and immigration – converge when undocumented immigrant patients are facing the terminal phase of chronic illness. The lack of consistent, pragmatic policy in each of these spheres leaves us with little guidance for how to advocate for undocumented patients at the end of life. [Noted in Media Watch 18 August 2014, #371 (p.13)] <https://goo.gl/kHBZvo>

Physicians’ responsibilities for deaths occurring at home

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 6 February 2017 – Deaths occurring at home are increasing in the U.S. Primary care physicians and trainees may not be explicitly taught about management of deaths in the home. Physician responsibilities for expected and unexpected deaths at home are summarized. The medical examiner should be contacted if death was due to natural disease processes but occurred suddenly or when a physician was not treating the decedent. Police and emergency personnel are often called after terminally ill individuals have died at home, which may cause significant family distress and is typically not necessary if the death was expected. Clinicians should counsel patients and families on managing expected deaths without involving emergency personnel. There is also the question of autopsy, which has become less common throughout the country. Although there are no requirements for physicians to ask families whether they want an autopsy if the death occurred at home, unexpected deaths should be referred to the medical examiner for possible forensic or medico-legal autopsy. If the medical

examiner declines the case, the family can be offered private-pay autopsy; costs can exceed \$3,000. Regarding the completion of death certificates, it is appropriate for the physician to write “probable” or “presumed” for diagnoses when the precise cause of death at home is uncertain. After a person has died, clinicians can still offer significant post-mortem guidance and closure to the family. <https://goo.gl/jn2ZZa>

Understanding palliative care and hospice: A review for primary care providers

MAYO CLINIC PROCEEDINGS, 2017;92(2):280-286. Even among patients and health care professionals who understand the value of hospice, many still equate hospice to “giving up” and/or agreeing to shorten one’s life. Reframing hospice as a choice to focus on how one lives rather than how long one lives sometimes can help patients and families accept hospice. Interestingly, care focused on comfort and quality may allow patients to live both better and perhaps a little longer. <https://goo.gl/UG2zHN>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 February 2017 – ‘**What matters most? A mixed methods study of critical aspects of a home-based palliative program.**’ This study presents a conceptual model of the critical services in home-based palliative care and why these services are important to high-risk patients. Four major themes of critical services reported by distinct populations of participants were described: 1) Medical support endorsed by nearly every participant; 2) Emotional and spiritual support, endorsed by those with serious illness and symptom burden; 3) Practical assistance, endorsed by those with functional disability and isolation; and; 4) Social services, endorsed by those in poverty. Medical monitoring was also described as critical, but only by healthier participants. <https://goo.gl/AjtOlx>
- *GERIATRICS & GERONTOLOGY INTERNATIONAL* | Online – 8 February 2017 – ‘**Comparative economic evaluation of home-based and hospital-based palliative care for terminal cancer patients.**’ Despite similar treatment durations between the groups [studied], treatment costs were substantially lower in the home-care group. These findings might inform the policymaking process for improving the home-care support system. <https://goo.gl/LN4lyk>

Assessment and intervention for patients with hearing loss in hospice

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(1):97-103. Hearing loss is the third most chronic condition in older adults and is often untreated. Such losses can interfere with critical communication exchanges that occur during admissions to hospice as well as during home or inpatient care. Three case scenarios are provided to illustrate these points. A comprehensive plan of options from screening to specific interventions is summarized. Options can be implemented to improve the overall communication for persons with hearing loss and their providers and family members. Improving communication may lead to improved quality of life and quality of care at end of life. <https://goo.gl/ldo27B>

Noted in Media Watch 4 April 2016, #456 (p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 April 2016 – ‘**Hearing loss in hospice and palliative care: A national survey of providers.**’ Age-related hearing loss can impair patient-provider communication about symptom management, goals of care, and end-of-life decision making. <http://goo.gl/DCC813>

N.B. Additional articles on hearing loss in the context of end-of-life care are noted in this issue of Media Watch.

Pediatric palliative care in Australia

Preparing pediatric healthcare professionals for end-of-life care discussions: An exploratory study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 February 2017 – Healthcare professionals, including medical, nursing, and allied health professionals working in pediatric palliative care settings across Queensland, Australia, participated in this study. Settings included major tertiary hospitals, general practice, community, and non-government organizations. Seven themes were identified that had relevance for preparing for an end-of-life (EoL) discussion: 1) Communication; 2) Healthcare professional perspectives; 3) Interdisciplinary team role; 4) Patient and family perspectives; 5) Practical issues; 6) Addressing mistakes; and, 7) Healthcare professional education. The findings support a need for further research in two areas. First, a systematic review of interdisciplinary resources that are available to support healthcare professionals in preparing for EoL discussions is recommended. Second, evidence-based interdisciplinary interventions to support pediatric EoL discussions need to be developed and evaluated. <https://goo.gl/A4c4fi>

Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 February 2017 – Clinician burnout reduces the capacity for providers and health systems to deliver timely, high quality, patient-centered care and increases the risk that clinicians will leave practice. This is especially problematic in hospice and palliative care (PC): patients are often frail, elderly, vulnerable and complex; access to care is often outstripped by need; and, demand for clinical experts will increase as PC further integrates into usual care. Efforts to mitigate and prevent burnout currently focus on individual clinicians. However, analysis of the problem of burnout should be expanded to include both individual- and systems-level factors as well as solutions; comprehensive interventions must address both. As a society, we hold organizations responsible for acting ethically, especially when it relates to deployment and protection of valuable and constrained resources. We should similarly hold organizations responsible for being ethical stewards of the resource of highly trained and talented clinicians through comprehensive programs to address burnout. <https://goo.gl/q2i0Te>

N.B. Additional articles on clinician burnout in the context of hospice and palliative care are noted in Media Watch 23 January 2017, #496 (p.11).

U.S. clergy religious values and relationships to end-of-life discussions and care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 6 February 2017 – While clergy interact with approximately half of U.S. patients facing end-of-life (EoL) medical decisions, little is known about clergy-congregant interactions or clergy influence on EoL decisions. A mailed survey to a nationally representative sample of clergy completed in March 2015 with 1,005 of 1,665 responding (60% response rate). Most U.S. clergy are Christian (98%), and affirm religious values despite a congregant's terminal diagnosis. Endorsement included God performing a miracle (86%), pursuing treatment because of the sanctity of life (54%), postponement of medical decisions because God is in control (28%), and enduring painful treatment because of redemptive suffering (27%). Life-prolonging religious values in EoL medical decisions were associated with fewer clergy-congregant conversations about considering hospice, stopping treatment, and forgoing future treatment, but not associated with congregant receipt of hospice or ICU care. Clergy with lower medical knowledge were less likely to have certain EoL conversations. The absence of a clergy-congregant hospice discussion was associated with less hospice and more ICU care in the final week of life. American clergy hold religious values concerning EoL medical decisions, which appear to decrease EoL discussions. Clergy EoL education may enable better EoL care for religious patients. <https://goo.gl/aj2qRX>

Noted in Media Watch 6 February 2017, #498 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 February 2017 – ‘**Chaplains working in palliative care: Who they are and what they do.**’ The authors report on [survey] respondents who were full-time chaplains. Half (52%) reported frequently participating in palliative care (PC) rounds. Primary chaplain activities were relationship building (76%), care at the time of death (69%), and helping patients with existential issues or spiritual distress (49%). Over half (55%) reported addressing goals of care 60% of the time or more. This study suggests when chaplains are more involved in PC teams, they provide more comprehensive support to PC patients and their families. <https://goo.gl/hpZOyu>

End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward

JOURNAL OF PALLIATIVE MEDICINE | Online – 8 February 2017 – Increasing longevity for Inuit living in Nunavik, northern Quebec, has resulted in heightened rates of cancers and chronic diseases necessitating complex treatments. Consequently, end-of-life (EoL) care, once the domain of Inuit families and communities, has come to include professionalized healthcare providers with varying degrees of awareness of factors to consider in providing care to Inuit populations. Socio-cultural, historical, and geographic factors shape EoL care in Nunavik, presenting a complex set of challenges for Inuit patients, families, and healthcare providers. A sustainable model of EoL care requires building on shared initiatives, capitalizing on the existing strengths in communities, and attending to the multiple bereavement needs in the region. Building a sustainable model of EoL care requires respectful collaboration among governing structures, healthcare institutions, and community members. It must centrally value local knowledge and initiatives. To ensure Inuit families and patients are supported throughout the dying process, future initiatives must centrally include local stakeholders in both the design and evaluation of any changes to the current healthcare system. <https://goo.gl/HMbbgO>

End-of-life conversations and hospice placement: Association with less aggressive care desired in the nursing home

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 8 February 2017 – Education about end-of-life care and treatment options, communication between family and health care providers, and having advance directives and medical orders in place are important for older adults with chronic, progressive decline and end-stage disease who spend their last days in the nursing home. Findings [of this study] showed for almost all decedents, do not resuscitate and do not intubate orders were in

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place, and just over one-half had do not hospitalize and no artificial feeding orders in place. A small proportion had no artificial hydration or no antibiotic orders in place. Overall, there was congruence between documented medical orders and treatment received. Use of hospice and discussions about particular life-sustaining treatments each had significant associations with having less aggressive medical orders in place. These results can inform best practice development to promote high quality, person-directed, end-of-life care for nursing home residents. <https://goo.gl/xshUi5>

Related

- *CONTINUUM: LIFELONG LEARNING IN NEUROLOGY*, 2017;23(1):254-258. **‘Discussing life-sustaining therapy with surrogate decision makers.’** Clinicians caring for patients with severe stroke in intensive care units often grapple with requests from surrogate decision makers for life-prolonging treatment that members of the care team may believe to be futile. An example is a surrogate decision maker’s request to place a tracheostomy and feeding tube in a patient who, in the clinical judgment of the neurocritical care team, is very unlikely to recover interactive capacity. This article presents a case, discusses definitions of medical futility, and summarizes recommended steps for mediating conflict regarding potentially inappropriate treatment. <https://goo.gl/5eLn1y>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 8 February 2017 – **‘Cultural influences upon advance care planning in a family-centric society.’** Collusion and familial intervention in the decision-making process are part of efforts to protect the patient from distress and are neither solely dependent on cultural nor an “all-or-nothing” phenomenon. The response of families are context-dependent and patient-specific, weighing the patient's right to know and prepare and the potential distress it is likely to cause. In most cases, the news is broken gently over time to allow the patient to digest the information and for the family to assess how well they cope with the news. Furthermore, the actions of families are dependent upon their understanding of the situation, highlighting the need for continued engagement with healthcare professionals. <https://goo.gl/bxJRVl>

Does religiosity account for lower rates of advance care planning by older African Americans?

JOURNALS OF GERONTOLOGY (Series B) | Online – 1 February 2017 – Older African Americans are less likely to complete advance directives (ADs) or discuss life-sustaining treatment preferences. This study examined whether religiosity accounts for race disparities. Whites were twice as likely to engage in ACP. Including religiosity predictors did not close these gaps. Frequency of service attendance was positively associated with AD completion for both White and African American participants. Relationships between religious affiliation and advance care discussion varied by race. For White participants only, more frequent prayer was associated with higher odds of advance care discussion. Although religiosity is often proposed as a reason for low rates of ACP among African Americans, religiosity measures did not explain race differences. Distinct aspects of religiosity were associated with ACP both negatively and positively, and these relationships varied by type of ACP and by race. <https://goo.gl/iK3CsX>

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

- *JOURNAL OF PALLIATIVE MEDICINE*, 2016;19(2):143-148. **‘The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members.’** African Americans underuse palliative care (PC) and hospice services because of a combination of factors including faith beliefs. As the spiritual family for many African Americans, the church presents an opportunity to improve communication about PC and hospice services and end-of-life decision making. <http://goo.gl/hO0qUe>

N.B. The focus of the February 2016 issue of the *Journal of Palliative Medicine* is on palliative and end-of-life care for African Americans. Contents page: <http://goo.gl/6fapNx>



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8l>

Primary palliative care in neonatal intensive care

SEMINARS IN PERINATOLOGY | Online – 4 February 2017 – This article explores the 2014 Institute of Medicine's recommendation concerning primary palliative care (PC) as integral to all neonates and their families in the intensive care setting.¹ The authors review trends in neonatology and barriers to implementing PC in intensive care settings. Neonatal primary PC education should address the unique needs of neonates and their families. The neonatal intensive care unit needs a mixed model of PC, where the neonatal team provides primary PC and the palliative sub-specialist consults for more complex or refractory situations that exceed the primary team's skills or available time. <https://goo.gl/G3Eu1p>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine of the National Academy of Sciences, September 2014. [Noted in Media Watch 22 September 2014, #376 (p.4)] <https://goo.gl/W9Dy0Q>

Noted in Media Watch 23 January 2017, #496 (p.9):

- *CURRENT OPINION IN PEDIATRICS* | Online – 13 January 2017 – '**Neonatal palliative care.**' The aim of this article is to review the most recent and relevant literature regarding neonatal palliative care (NPC). A variety of perinatal and NPC programs are described, but most programs focus exclusively on end-of-life care. Moreover, there is a great need to standardize practices and obtain follow-up quality measures. <https://goo.gl/iJmS19>

Noted in Media Watch 19 December 2016, #492 (p.9):

- *JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2016;14(11):99-105. '**Parents' and families' experiences of palliative and end-of-life neonatal care in neonatal settings: A systematic review protocol.**' The overall objective of this systematic review is to identify, critically appraise, and synthesize the parents' and families' experiences of palliative and end-of-life neonatal care at facilities/services globally. <https://goo.gl/jzHQLW>

Interventions at the end of life: A taxonomy for “overlapping consensus”

WELLCOME OPEN RESEARCH | Online – Accessed 7 February 2017 – An unprecedented number of people dying in future decades will put new strains on families, communities, services and governments. It will also have implications for representations of death and dying within society and for the overall orientation of health and social care. What interventions are emerging in the face of these challenges? The authors classify the range of end-of-life (EoL) interventions into ten substantive categories: 1) Policy; 2) Advocacy; 3) Educational; 4) Ethico-legal; 5) Service; 6) Clinical; 7) Research; 8) Cultural; 9) Intangible; and, 10) Self-determined. They distinguish between two empirical aspects of any EoL intervention: the “locus” refers to the space or spaces in which it is situated; the “focus” captures its distinct character and purpose. The authors also contend that EoL interventions can be seen conceptually in two ways – as “frames” (organized responses that primarily construct a shared understanding of an EoL issue) or as “instruments” (organized responses that assume a shared understanding and then move to act in that context). Their taxonomy opens up the debate about EoL interventions in new ways to provide protagonists, activists, policy makers, clinicians, researchers and educators with a comprehensive framework in which to place their endeavours and more effectively to assess their efficacy. <https://goo.gl/sM2sVF>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL FOR NURSE PRACTITIONERS*, 2017;13(2):150-155. '**The emerging role of nurse practitioners in physician-assisted death.**' This article explores the role of the nurse practitioner (NP) and raises the awareness of the potential for NPs to be called on to participate in physician-assisted death. The authors identify the ethical and legal dilemmas that NPs may face when dealing with patients who have requested physician-assisted death. The article further defines the ethical and legal responsibilities of the NP who cares for patients requesting physician-assisted death and provides recommendations if future legislation allows NP involvement in the physician-assisted death process. <https://goo.gl/JAUDoH>

Worth Repeating

Bad words: Clinical case study about the desires of a patient to prolong her life and the doctors to communicate with her only using “positive” language

THE HASTINGS REPORT, 2014;44(2):13-14. The clinical ethicist met with Ms. H to clarify what information she wants and does not want to know. She wants to receive any treatment that could prolong her life, regardless of how the treatment affects her ability to engage in activities of daily living. She wants to be included in the decision-making process as much as possible, as long as clinicians use only “positive” language. Ms. H. considers the words “dying,” “chemotherapy,” “radiation” and “cancer” to be “bad words.” For conversations in which these words cannot be avoided, she wants her clinicians to talk to her son. Her desired engagement includes hearing about risks, benefits, and alternatives to treatments if clinicians use only “positive” language. Finally, she says that she rarely sees doctors and that she is “very scared” of hospitals, despite exhibiting a comfortable demeanor. <https://goo.gl/z37tpg>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/o9wzNe>

Link updated 02.10.2017

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): <https://goo.gl/JL3j3C>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

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>

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