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

Towards end of life: Scroll down to <u>Specialist Publications</u> and 'Slow medicine: The barrier on the bridge' (p.11), in *Journal of Gerontological Nursing*.

Canada

Canadian seniors now outnumber children for 1st time, 2016 census shows

CBC NEWS | Online – 3 May 2017 – There are now 5.9 million Canadian seniors, compared to 5.8 million Canadians 14 and under.¹ This is due to the historic increase in the number of people over 65 – a jump of 20% since 2011 and a significantly greater increase than the five per cent growth experienced by the population as a whole. The increase in the share of the oldest Canadians was even bigger – up 19.4% for those over 85 and up 41.3% among those over 100. The aging of the population is due to the first baby boomers turning 65 over the last five years, as well as the increasing life expectancy of Canadians and a low fertility rate. https://goo.gl/nJLqE1

1. 'Age and sex, and type of dwelling data: Key results from the 2016 Census,' Statistics Canada, May 2017. <u>https://goo.gl/5O0agb</u>

Noted in Media Watch 5 September 2011, #200 (p.1):

 BRITISH COLUMBIA | CBC News – 29 August 2011 – 'Cost of aging population on health care "overblown."' Fears Canada's aging population could lead to soaring health-care costs may be greatly exaggerated, say researchers, who suggest that the predicted "grey tsunami" may turn out to be more like a "grey glacier." <u>https://goo.gl/LGsbMP</u>

Saskatchewan budget cuts hospital chaplain services

SASKATCHEWAN | CKOM Radio News (Saskatoon) – 29 April 2017 – The move to eliminate [funding for] chaplains and other religious leaders from health care facilities is expected to save the province \$1.5 million dollars. Spiritual care providers visit with patients and their families facing end-of-life, major surgeries, and mental health concerns. The Canadian Association of Spiritual Care is calling for a moratorium to eliminate funding until the [proposed, single] province-wide health region is in place. According to a provincial spokesperson, spiritual care can continue in health care facilities through non-profit groups and churches, but not at the cost of taxpayers. https://goo.gl/a7U0CX

Specialist Publications

'Hooray for chaplains! How do we prove their value' (p.14), in *Journal of Palliative Medicine.*

'In the chaplain's shadow' (p.14), in *Journal of Palliative Medicine.*

<u>U.S.A.</u>

Out-of-hospital do-not-resuscitate orders

"Clock ticking" as bill named for dying teen passes the Alabama House

ALABAMA | Alabama Media (Montgomery) - 3 May 2017 – Rene Hoover has rarely missed an opportunity to advocate for her terminally-ill son - 16-year-old Alex, who was born with a condition that's slowly causing his heart to fail. But on Tuesday, she missed a critical vote in the Alabama House on a bill named for Alex. The bill was born 18 months ago, when Hoover began to fight for her son's right to attend public school without the risk of receiving unwanted medical treatment if his heart failed on campus. Alex's Law would do just that, creating portable medical orders for children younger than 19 that can be honored by schools, churches and other organizations. It passed the Alabama House of Representatives with 98 votes... Members of the Senate still need to approve the measure before sending it to the governor... During the historic vote. Hoover remained at home in Athens near her son. His condition has deteriorated during the last month. His heart can barely keep up with the demands of his body. Alex may not live long enough to find out whether his bill will become law. <u>https://goo.gl/3ljh5J</u>

Specialist Publications

'The changing landscape of palliative care' (p.13), in *Generations*.

'Lessons from the Hospice benefit for advanced illness care' (p.13), in *Generations.*

'Are we making progress?' (p.13), in *Journal of Palliative Medicine.*

'A qualitative study of the emotional and spiritual needs of Hispanic families in hospice' (p.13), in *Palliative & Supportive Care.*

Noted in Media Watch 5 September 2016, #478 (p.17):

PEDIATRIC CLINICS OF NORTH AMERICA, 2016;63(5):899-911. 'Integrating pediatric palliative care into the school and community.' When a child has an out-of-hospital do-not-resuscitate order, heath care providers should partner with schools to provide support to the child and family, as well as to school professionals, to ensure a positive outcome for all parties. http://goo.gl/wpZl26

Noted in Media Watch 25 January 2016, #446 (p.3):

 ALABAMA | The Decatur Daily – 21 January 2016 – 'Mother, school district reach agreement on terminally ill student.' Limestone County Schools ... has never denied Alex Hoover access to school, but the district refused to comply with an advanced directive, which essentially requested Alex not be provided lifesaving medical care if he had medical problems at school. <u>http://goo.gl/KxOIxd</u>

Five imitation-worthy palliative care programs

OHIO | *Managed Healthcare Executive* – 3 May 2017 – Palliative care (PC) is looking more and more like hospice care, moving programs from the site of treatment – a hospital, nursing home or extended care facility – to the home. While both services provide compassionate care, what often separates them is the curative services offered in a palliative program. Under Medicare, patients with six months or fewer to live who are in hospice cannot receive concurrent care, a combination of treatment and compassionate service; however, seniors in private plans are not bound by the ruling. The Medicare Care Choices Model, which began in January 2016, is a demonstration initiative under the Centers for Medicare & Medicaid Innovation for patients with advanced cancer, congestive heart failure, and chronic obstructive pulmonary disease who are eligible for Medicare hospice benefits. The study is testing whether allowing concurrent care in hospice leads to additional care coordination, better quality of life, a decrease in hospitalizations and avoidance of preventable health expenditures. https://goo.gl/000ecB

Noted in Media Watch 20 June 2016, #467 (p.9):

• AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 16 June 2016 – 'First Medicare demonstration of concurrent provision of curative and hospice services for end-of-life care.' The authors provide background and analysis of the first Medicare hospice demonstration in 35 years that will test the concurrent provision of curative and hospice services for terminally ill individuals with a life expectancy of six months or less. This demonstration is a harbinger of potential policy changes to hospice and palliative care in the U.S. that could reduce barriers to end-of-life care that aligns with patient and family preferences as demand for care increases with an aging population. http://goo.gl/hEuGQG

Many seniors who qualify for home-based care under Medicare aren't receiving it. Why?

PUBLIC BROADCASTING SERVICE | NewsHour – 3 May 2017 – One of the greatest gaps in Medicare coverage is that it does not help to pay for home-based care unless such care is requested by a physician as medically necessary. Medicaid will cover such long-term custodial care for people with little to no income or assets. But Medicaid covers fewer than one in five of the roughly 55 million people on Medicare, leaving the rest to fend for themselves or, for a small group of mostly better-off folks, purchase private long-term care insurance. Now, it appears that even Medicare's limited home-based coverage benefits for those with medical needs are also not possible for many people. The non-profit Center for Medicare Advocacy says it been researching the availability of Medicare enrollees that they are being denied home-based care even though they are qualified to receive it and it is covered by Medicare. Like nearly every-thing about Medicare, this is a complex topic. But it appears that Medicare is not keen to encourage use of allowable home care benefits. Home care providers don't much like this benefit either. They don't make much money on it, and under new Medicare rules, they can actually lose money providing such care. https://goo.gl/RaUAKW

Death rate among black Americans declines, especially for elderly people

NATIONAL PUBLIC RADIO | Online – 2 May 2017 – For decades, black Americans have been dying at a higher rate than white Americans. That's still true overall. But now there's some good news about this long, disturbing trend: The overall death rate for black Americans fell 25% between 1999 and 2015, according to a report released ... by the U.S. Centers for Disease Control & Prevention.¹ The overall death rate dropped for white people as well, but the decrease among black Americans was far greater, narrowing the gap in the death rate between white and black Americans from 33% in 1999 to 16% in 2015, the report shows. https://goo.gl/nJ8hCr

1. 'Vital Signs: Racial Disparities in Age-Specific Mortality Among Blacks or African Americans – U.S., 1999-2015,' U.S. Centers for Disease Control & Prevention, May 2016. <u>https://goo.gl/8Hmyhb</u>



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/SCHoAG

International

Record number of U.K. care homes declared insolvent

U.K. (England, Northern Ireland & Wales) | *The Guardian* – 5 May 2017 – Seventy-five companies failed in 2016 as councils cut contributions and wage increases raised cost of frontline staff. A record number of care home businesses failed last year as the financial pressure on social care in Britain took its toll. New government figures show that 75 care home businesses were declared insolvent in 2016, up from 74 the previous year. The failures mean that in total 421 care home businesses have collapsed since 2010. https://goo.gl/pe7JSw

Noted in Media Watch 27 March 2017, #505 (p.5):

Specialist Publications

'The ABCDE of good care: A thematic analysis on the art of caring for terminally ill patients in Malaysia' (p.5), in *Advances in Modern Oncology Research.*

'Palliative care in Brazil: With a view to future needs?' (p.8), in *International Archives of Medicine*.

'Nursing home physicians' assessments of barriers and strategies for end-of-life care in Norway and The Netherlands' (p.8), in *Journal of the American Medical Directors Association.*

- U.K. (England, Northern Ireland & Wales) | *The Financial Times* 20 March 2017 'U.K. home care industry "on the brink of collapse," says report.' The U.K.'s home care industry is "on the brink of collapse" with companies either going bankrupt or pulling out of contracts, according to a report by the Local Government Information Unit and one of the country's biggest providers.¹ <u>https://goo.gl/1BQQTE</u>
 - 1. 'Paying for it: the human cost of cut-price care,' Local Government Information Unit, March 2017. https://goo.gl/qSI02u

More [Japanese] college students study the meaning of death

JAPAN | *The Japan News* (Tokyo) – 30 April 2017 – Classes in which students examine death, and in the process consider the way they have lived until that point, are becoming more common at universities and junior colleges. Known as thanatology, this study has received more attention since the Great East Japan Earthquake in 2011, which brought the concept of death strongly to the forefront of many young people's minds. Changes in family structure and other societal shifts mean people today encounter death less often. Studying death academically can help students discover benchmarks for their lives. Thanatology covers the study of death through the humanities, such as its philosophy and history, as well as from a scientific or clinical perspective, such as considering how to provide end-of-life care. This field of study gained popularity in the U.S. in the 1960s. https://goo.gl/lYzbYn

Noted in Media Watch 10 April 2017, #507 (p.16):

 PASTORAL CARE IN EDUCATION | Online – 28 March 2017 – 'Making death, compassion and partnership "part of life" in school communities.' Death can be considered a social taboo, a common source of fear and public avoidance. School communities are not immune to this, as the topic of death is constantly avoided. It is vital to understand how we can socially and culturally cultivate a positive regard for death, dying and bereavement in our school communities. <u>https://goo.gl/V4H7NR</u>

N.B. Selected articles on the inclusion of the topic of dying and death in school curriculums are noted in the 27 February 2017 issue of Media Watch (#501, pp.1-2).



Back Issues of Media Watch <u>http://goo.gl/frPgZ5</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | Seven News (Melbourne) 4 May 2017 'Victoria could become the first state to legalise euthanasia.' Seven News understands the state government received an interim report from the Independent Ministerial Advisory Panel... The initial parliament committee report into assisted dying talked about the process to start when a patient was weeks or months from the estimated end of their life. But the advisory panel wants to extend the timeline and the government is believed to be considering three options: 24 months, 12 months or six months. If a 12 months timeline was chosen, that would mean doctors would have to confirm the patient is expected to die within that time and that would allow the patient to start the process. A final report is expected to go to the Health Minister by July with parliament having a conscience vote by the end of 2017. https://goo.gl/dVil.pp
- BELGIUM | Catholic News Service 3 May 2017 'Belgian Brothers to allow euthanasia for nonterminal psych patients.' A group of psychiatric care centers run by a Catholic religious order in Belgium has announced it will permit doctors to undertake the euthanasia of "non-terminal" mentally ill patients on its premises. In a nine-page document, the Brothers of Charity Group stated that it would allow doctors to perform euthanasia in any of its 15 centers, which provide care to more than 5,000 patients a year, subject to carefully stipulated criteria. https://goo.gl/yO3H0r

Related

- U.K. | The National Catholic Reporter 5 May 2017 'Vatican launches Belgium euthanasia investigation.' The Vatican is investigating the decision of a group of psychiatric care centers run by a Catholic religious order in Belgium to permit doctors to perform euthanasia of "non-terminal" mentally ill patients on its premises. <u>https://goo.gl/5rxgAK</u>
- U.K. (Scotland) | The Herald (Glasgow) 30 April 2017 'New poll shows huge split between MSPs and public opinion on right-to-die law.' Scottish politicians [i.e., Members of the Scottish Parliament (MSPs)] are hugely out of synch with public opinion over the issue of the right-to-die for terminally ill people... A survey shows that 56% of MSPs either "strongly oppose" or "somewhat oppose" proposals which would give patients with less than six months to live the choice to be prescribed life-ending medication. Only 27% of MSPs support a change in the law while 17% say they would abstain, did not know how they would vote, or declined to answer. The results of the poll ... highlight the gulf in opinion between politicians and the public with the most recent survey of adults finding 83% in favour of right-to-die legislation. https://goo.gl/EWOzgk

Specialist Publications

The ABCDE of good care: A thematic analysis on the art of caring for terminally ill patients in Malaysia

ADVANCES IN MODERN ONCOLOGY RE-SEARCH, 2017;3(S1):65-72. The results if this study show that the core elements of good care consist of <u>attitude</u>, <u>b</u>ehaviour, <u>c</u>ommunication, <u>d</u>uty and <u>environment</u> (ABCDE). Among the examples of attitude perceived as important in good care, positive attitudes related to social relations were described most in the study, such as being approachable, friendly, kind, caring and helpful. Other examples included being gentle, careful, cheerful, committed, passionate, empathetic, honest, patient, respectful, etc. Examples of core attitudes in palliative care were empathy, honesty, acceptance, openness, authenticity and mindful-



ness. Staff with more work experience or previous experience caring for terminally ill patients tended to have more positive attitude towards caring for dying patients. A stronger fear of death was associated with negative attitudes towards caring at the end-of-life. Behaviour is influenced by attitude, since attitude is a predisposition for a person to think, feel and behave in a certain manner. A friendly attitude will manifest as friendly behaviour, and a cheerful attitude will give rise to cheerful behaviour. Caring behaviour was perceived when healthcare providers work with care, love and patience. good care did not mean doing extraordinary work for patients but doing ordinary tasks correctly with extraordinary attention, a smile and the capacity to tolerate trouble without getting angry or upset. reported mostly in the nursing literature, top caring behaviours included putting the patient first no matter what happened, responding when needed without being prompted, being honest with the patient, speaking in understandable terms, knowing how to perform one's duty, taking care of patient's needs... https://goo.gl/py9cu2

N.B. Click on 'Full Text: PDF' to download complete article.

Noted in Media Watch 25 April 2016, #459 (p.5):

- MALAYSIA | *The Malay Mail* (Jalan) 22 April 2016 'Four out of 10 Malaysians need palliative care each year.' This translates to an estimated 56,000 patients each year and this number is growing as the population ages. More than 60% of the needs arise from patients suffering from non-cancer ill-nesses. And even more worrisome, less than 10% of them have access to this essential aspect of medical care. Hospis Malaysia has produced a report...¹ http://goo.gl/6lfsrJ
 - 1. 'Palliative Care Needs Assessment: Malaysia,' April 2016. Hospis Malay. https://goo.gl/NSQqFQ

N.B. Malaysia was ranked 38th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch 12 October 2015, #431 (p.6)] <u>http://goo.gl/JsSbW3</u>

Palliative care in surgery: Defining the research priorities

ANNALS OF SURGERY | Online – 3 May 2017 – Given the acute and often life-limiting nature of surgical illness, as well as the potential for treatment to induce further suffering, surgical patients have considerable palliative care () needs. Yet these patients are less likely to receive PC than their medical counterparts and PC consultations often occur when death is imminent, reflecting poor quality end-of-life care. [In the U.S.] the National Institutes of Health and the National Palliative Care Research Center convened researchers from several medical sub-specialties to develop a national agenda for palliative care research. To date, evidence to support the role of PC in surgical practice is sparse and PC research in surgery is encumbered by methodological challenges and entrenched cultural norms that impede appropriate provision of PC. Priorities for future research on palliative care in surgery include: 1) Measuring outcomes that matter to patients; 2) Communication and decision making; and 3) Delivery of PC to surgical patients. https://goo.gl/iVP8M3

Noted in Media Watch 3 April 2017, #506 (p.13):

JOURNAL OF PALLIATIVE MEDICINE | Online – 24 March 2017 – 'Palliative care in surgery: Defining the research priorities.' To date, evidence to support the role of palliative care (PC) in surgical practice is sparse and PC research in surgery is encumbered by methodological challenges and entrenched cultural norms that impede appropriate provision of PC. The authors describe the existing science of PC in surgery within three priority areas and expose specific gaps within the field. They propose a research agenda to address these gaps and provide a road map for future investigation. https://goo.gl/RGRopi

Noted in Media Watch 16 May 2017, #462 (p.7):

 ANNALS OF SURGERY | Online – 9 May 2016 – 'Palliative care and surgical training: Are we being trained to be unprepared?' The current system for educating surgical trainees enjoys welldeserved acclaim for producing thoughtful and technically skilled individuals, but continues to inadequately prepare and train young surgeons to care for seriously ill and dying patients. Accordingly, a dramatic change to structure palliative and end-of-life care into surgical training and the willingness of practicing surgeons to actively participate in this care are essential http://goo.gl/YilC36

Communication in end-of-life care for people with dementia: An Admiral Nurse case study

BRITISH JOURNAL OF NEUROSCIENCE NURSING, 2017;13(2):70-75. Dementia is largely a disease of old age and many people with a diagnosis of dementia will also have other illnesses or disabilities for which they may be admitted to an acute hospital. However, the lack of recognition of when a person with dementia is nearing the end of life (EoL) can pose challenges and may lead to a failure to provide good palliative care (PC). There is a need for effective communication with families who are affected by dementia, from the point of diagnosis through to EoL. Good communication with all parties involved, including discussions about prognosis and advance care planning, is essential to a shared PC approach that enables families to have an understanding of the goals of care and to be a part of the decision-making process. https://goo.gl/Uxr3dN

N.B. Admiral Nurses are specialist dementia nurses who give expert practical, clinical and emotional support to patients and families living with dementia.

Related

- DEMENTIA | Online 28 April 2017 'Perception and communication of risk in decision making by persons with dementia.' Actual or feared risks were identified relating to: 1) Daily activities; 2) Hobbies and socialising; 3) Mental health and medicines; and, 4) Risks to and from others. Effective risk communication in informed decision-making processes about health and social care is discussed. https://goo.gl/1xVDSK
- NURSING OLDER PEOPLE, 2017;29(4):19. 'How can I broach the subject of advance care planning with families, when the person with dementia lacks capacity and is near the end of life?' Advance care planning is a structured discussion about a person's wishes and thoughts for the future, and is recognised as a vital part of good care at the end of life. <u>https://goo.gl/ccSzpD</u>

Providing palliative care for patients with lung cancer

CLINICAL PULMONARY MEDICINE, 2017; 24(3):105-111. Because of severe and progressive symptoms, co-existing lung disease, anxiety, and depression, lung cancer (LC) patients derive robust benefit from palliative care (PC). Multiple studies have shown that PC in LC improves quality of life, survival, mental health outcomes, and caregiver satisfaction. Despite proven benefit, PC is very often viewed as a therapy of last resort, and opportunities to reduce suffering are missed. To be most effective, PC should be provided by generalists and specialists, implemented early, involve multidisciplinary teams, and be malleable to the needs of patients and caregivers. This paper reviews the literature to improve the understanding and dissemination of best palliative practices in LC care. https://goo.gl/W08yfW

Implementing evidence-based palliative care programs and policy for cancer patients: Epidemiologic and policy implications of the 2016 American Society of Clinical Oncology Clinical Practice Guideline update

EPIDEMIOLOGIC REVIEWS | Online – 2 May 2017 – This review demonstrates that to have clinicians implement these guidelines, there is a need for support from stakeholders across the health-care continuum, health system and institutional change, and changes in health-care financing. Because of rising costs and the need to improve value, the need for coordinated care, and change in end-of-life care patterns, many of these changes are already underway. https://goo.gl/v7RrPe

Noted in Media Watch 30 January 2017, #497 (p.10):

CLINICAL LUNG CANCER | Online – 20 January 2017 – 'Addressing the palliative setting in advanced lung cancer should not remain a barrier: A multicentre study.' When comparing presumed treatment goals between patients who were aware that their treatment could not cure them, and patients likely to think that their treatment could cure them, 39% of the former chose quality of life versus 9% of the latter; whereas 36% of the former chose cure versus 13% of the latter. 75% never had a conversation about EoLC. https://goo.gl/gUeH8R

Noted in Media Watch 17 October 2017, #483(p.16):

SEMINARS IN RESPIRATORY & CRITICAL CARE MEDICINE, 2016;37(05):750-759. 'Palliative care
in lung cancer: A review.' Palliative care (PC) has shown multiple benefits to cancer patients such as
better quality of life, higher patient and family satisfaction, improved disease understanding, less symptom burden, fewer depressive symptoms, less aggressive end-of-life care, and even improved survival
with early implementation. Unfortunately, utilization of PC is both low and often near the end of life, increasing risk for suffering. https://goo.gl/lueGMp

Related

 JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 May 2017 – 'End of life place of care, health care settings and health care transitions among cancer patients: Impact of an integrated cancer palliative care plan.' Frequent end-of-life health care setting transitions can lead to an increased risk of fragmented care and exposure to unnecessary treatments. A well-integrated palliative care approach can be effective in further reducing the percentage of patients who spent many days in hospital and/or undergo frequent and inopportune changes of their care setting during their last month of life. https://goo.gl/lsT2Hb

Palliative care in Brazil: With a view to future needs?

INTERNATIONAL ARCHIVES OF MEDICINE | Online – 25 April 2017 – Traditionally, palliative care (PC) in Brazil has been offered most often to people suffering from cancer in the advanced stage. The needs for people who have other life-limiting chronic diseases are not being fulfilled in a stable approach. The concept of PC only at the end of life (EoL) limits access for many people and carers that could benefit from this mode of health assistance during the trajectory of the disease; from diagnosis, continuing to benefit from treatments that alter the progress of the disease, until the EoL. Despite the fact that PC structures and resources have had a significant increase in recent years in Brazil, the distribution of services are concentrated in some regions, but the health care for people with chronic advanced or life-limiting diseases is fragmented and also there exists differences in the level of access and kind of care. The authors propose guidelines based on integration of several existing policies, trigger and strengthen actions, and integral care to patients with PC needs that are synergistic, sustainable, and respectful of the specificities of each area as well as to support decision-making and the development of actions in health, in particular to the definition of needs and priorities, the construction of prospective scenarios, and the assessment of ongoing actions. https://goo.gl/GGuPhY

N.B. The Kaiser Family Foundation, in partnership with *The Economist*, recently conducted a crosscountry survey of adults in the U.S., Italy, Japan, and **Brazil** about people's views and experiences related to aging and end-of-life care (EoLC). Reports on the survey are noted in the 1 May 2017 issue of Media Watch (#510, pp.3, 5-6). Selected articles on EoLC in Brazil are noted in the issues of Media Watch of 6 June 2016, #465 (p.10) and 21 March 2016, #454 (p.9). Brazil was ranked 42nd of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch 12 October 2015, #431 (p.6)] http://goo.gl/JsSbW3 **BRA**

Nursing home physicians' assessments of barriers and strategies for end-of-life care in Norway and The Netherlands

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 29 April 2017 – Working conditions in nursing homes (NHs) may hamper teamwork in providing quality end-of-life care (EoLC), especially the participation of NH physicians. Dutch NH physicians are specialists or trainees in elder care medicine with NHs as the main workplace. In Norway family physicians usually work part time in NHs. Most survey respondents in both countries reported inadequate staffing, lack of skills among nursing personnel, and heavy time commitment for physicians as important barriers; this was more pronounced among Dutch respondents. Approximately 30% of the respondents in both countries reported their own lack of interest in EoLC as an important barrier. Suggested improvement strategies were routines for involvement of patients' family, pain and symptom assessment protocols, EoLC guidelines, routines for advance care planning, and education in EoLC for physicians and nursing staff. <u>https://goo.gl/4IFznZ</u>

Noted in Media Watch 24 April 2017, #509 (p.12):

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 13 April 2017 – 'Palliative care development in European care homes and nursing homes: Application of a typology of implementation.' The authors identified three levels of palliative care (PC) implementation: 1) Macro (national/regional policy, legislation, financial and regulatory drivers); 2) Meso (implementation activities, such as education, tools/frameworks, service models, and research); and, 3) Micro (PC service delivery). This typology was applied to data collected from 29 European countries and demonstrates the diversity of PC implementation activity across Europe with respect to the scope, type of development, and means of provision. https://goo.gl/h35EXR

N.B. Noted in this issue of Media Watch are selected articles on palliative and end-of-life care in care homes and nursing homes.

No matter the species

Companion-animal caregiver knowledge, attitudes, and beliefs regarding end-of-life care

JOURNAL OF APPLIED ANIMAL WELFARE SCIENCE | Online – 3 May 2017 – Although awareness of end-of-life care (EoLC) is growing within the veterinary field and there appears to be consumer demand for these services, it is unclear exactly what caregivers know about end-of-life (EoL) options for their companion animals. Are companion-animal caregivers aware of the range of options for their non-human animals? What do they value most highly for their non-human animals at the EoL? Answers to these and other related questions about caregiver perceptions are important because what they know about EoLC and how they approach decision-making for their companion animals will shape the kind of care an animal receives. This article presents the results of a large survey exploring companion-animal caregivers' knowledge, attitudes, and beliefs about EoLC, including in-home euthanasia, hospice and palliative care, financial commitment to EoL, insurance usage, and level of comfort in providing care (e.g., subcutaneous fluids) in the home. https://goo.gl/2hK2LL

N.B. The parallel to be drawn between the practice and philosophy of hospice and palliative care and how end-of-life care for domestic animals has evolved in recent years has occasionally been highlighted in Media Watch, e.g., 10 April 2017 (#507, p.17), 19 December 2016 (#492, p.9); 3 October 2016 (#482, p.13); and, 11 April 2016 (#457, p.14).

Advance care planning communication: Oncology patients and providers voice their perspectives

JOURNAL OF CANCER EDUCATION | Online -29 April 2017 – Advance care planning (ACP) ... has ethical implications for providers, yet evidence suggests that these conversations are not always occurring, particularly in underserved populations. This study took place at an urban, multispecialty cancer center in the [U.S.] mid-Atlantic region where approximately 1,400 patients are treated each year. Findings revealed differences among both patients and providers in terms of their ACP knowledge, preferences, and practices. Overall, 70% of patients were familiar with advance directives (100% of White patients and 45.5% of Black patients), yet only 35% of them reported having completed one (55.6% of White patients and 18.2% of Black patients, although not statistically significant). Most providers (70%) held ACP conversations with patients with advanced illness only. They tended to make assumptions about the amount of information that patients desired and noted the significant challenges that were inherent with these types of conversations. Ethical implications are inherent in ACP as patients are making medical decisions without always having necessary information. There are various reasons why providers may not supply information regarding potential outcomes and end-of-life planning and why patients may not request (or know to request) more medical information. <u>https://goo.gl/ibUcX2</u>

Quotable Quotes

The single biggest problem in communication is the illusion that it has taken place. George Bernard Shaw (1856-1950)

Noted in Media Watch 1 May 2017, #510 (p.6):

 JOURNAL OF ONCOLOGY PRACTICE | Online – 26 April 2017 – 'REMAP: A framework for goalsof-care conversations.' Conversations regarding goals-of-care with patients who have advanced cancer still occur too late, and oncologists say they lack the training to have these conversations effectively. Experts recommend a number of strategies when having these discussions, including discussing prognosis, responding to patient emotion, exploring values, and often making a recommendation for medical treatments that fit those values. https://goo.gl/P7KJbw

Noted in Media Watch 6 February 2017, #498 (p.10):

JOURNAL OF CLINICAL ONCOLOGY | Online – 30 January 2017 – 'Promoting end-of-life discussions in advanced cancer: Effects of patient coaching and question prompt lists.' Most patients with advanced cancer say they want honest, sensitive communication about end-of-life issues. These conversations help patients and their families prepare, make informed decisions, and avoid potentially burdensome aggressive medical treatments near death. Yet, patients are often misinformed about cancer survival and curability, and those with over-optimistic prognosis estimates are more likely to die in a hospital and receive burdensome aggressive care. https://goo.gl/cM068b

The Cystic Fibrosis-CARES primary palliative care model: A Cystic fibrosisspecific structured assessment of symptoms, distress, and coping

JOURNAL OF CYSTIC FIBROSIS | Online – Accessed 3 May 2017 – Current palliative care (PC) tools do not address distressing chronic symptoms that are most relevant to cystic fibrosis (CF). A CF-specific structured assessment based on a primary PC framework was administered to 41 adolescents and adults with CF. Patients reported numerous physical and psychological symptoms, with psychological symptoms rated as more distressing. Anxiety and depression were prevalent and correlated with distress attributable to physical symptoms and difficulty with CF self-management, but did not correlate with disease severity. The CF-CARES (<u>C</u>oping, goal <u>A</u>ssessment, and <u>R</u>elief from <u>E</u>volving CF <u>Symptoms</u>) primary PC assessment model provides a framework for patients experiencing chronic symptoms to explore interventional options with their clinicians. https://goo.gl/wk9rn4

Selected articles on palliative care for people living with cystic fibrosis

- EUROPEAN RESPIRATORY JOURNAL, 2016;47(2):420-428. 'Report of the European Respiratory Society/European Cystic Fibrosis Society Task Force on the care of adults with cystic fibrosis.' Adult cystic fibrosis (CF) centres should ensure they have adequate skills and facilities to deal with palliative care for people with CF. End-of-life care is ideally delivered in an adult centre where appropriate discussions and arrangements can be facilitated and the autonomy of the individual is respected and protected. [Noted in Media Watch 8 February 2016, #448 (p.13)] http://goo.gl/8UDedM
- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 26 January 2016 'A service evaluation of an integrated model of palliative care of cystic fibrosis.' Patients with advanced cystic fibrosis (CF) have severe symptoms with a complex trajectory of exacerbations and recovery. They are often awaiting lung transplantation, and many die without receiving specialist palliative care (PC). The authors introduced an integrated model whereby palliative specialists joined the CF team to provide PC in parallel with standard care. [Noted in Media Watch 1 February 2016, #447 (p.7)] http://goo.gl/VCVEoD
- JOURNAL OF CYSTIC FIBROSIS | Online 8 September 2015 'Cystic fibrosis healthcare workers feel unprepared in providing suitable end-of-life care and desire more education: Results of a nationwide survey.' The majority of non-physician cystic fibrosis care providers [i.e., survey respondents] reported that they felt "somewhat" or "very" involved in palliative or end-of-life care in their current role. Yet only 18% reported that they were "fully prepared" and 45% felt that they were only "minimally" or "not" prepared. [Noted in Media Watch 14 September 2015, #427 (p.10)] http://goo.gl/pBBKTc

Slow medicine: The barrier on the bridge

JOURNAL OF GERONTOLOGICAL NURSING, 2017;43(5):449-50. Slow medicine (SM) is a common sense, yet somewhat revolutionary, take on end-of-life (EoL) planning and care that can help patients and families prepare for challenging issues that arise during the last stages of life. After considering use of SM, it can be seen that the process is less stressful and more meaningful than acute, traumatic EoL experiences. SM allows for a deeper respect of the previous generation. Moreover, it helps strengthen the family unit emotionally and relationally. For nurses, SM will help them view the older adult population with empathy and respect, and see the road that they have traveled and have ahead as they walk alongside them to their next phase of life. In effect, the pace of medicine will slow and tear down the barrier on the bridge. <u>https://goo.gl/UEdhXI</u>

Healthcare professionals' experiences of perinatal loss: A systematic review

JOURNAL OF HEALTH PHILOSOPHY | Online – 3 May 2017 – Healthcare professionals' psychological involvement in perinatal loss is a largely overlooked subject by healthcare systems, scientific research and prevention policies. A systematic scientific review has been carried out about emotional experiences, attributed meanings and needs conveyed by healthcare professionals in relation to perinatal loss. The authors identified 213 studies between 1985 and 2015, 20 of which were included in the present study for qualitative analysis. The authors' results point out the need for a targeted vocational training in perinatal loss, enabling healthcare professionals to achieve a proper management of their own internal states. https://goo.gl/qUGMSv

Noted in Media Watch 10 August 2015, #422 (p.8):

AMERICAN JOURNAL OF MATERNAL CHILD NURSING, 2015;40(1):44-50. 'Clinician perspectives
of barriers in perinatal palliative care.' Among the study participants, both nurses and physicians
expressed similar feelings of distress and helplessness when caring for families expecting a fetal or
neonatal demise. Participants in the study also reported a lack of societal support and understanding
about perinatal palliative care. <u>https://goo.gl/Tb44j8</u>

Is higher acceptance associated with less anticipatory grief among patients in palliative care?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 May 2017 – Patients in palliative care (PC) can experience substantial psychological suffering. Acceptance based interventions from approaches like Acceptance & Commitment Therapy have demonstrated effectiveness in helping people cope with a range of life challenges. However, there is a dearth of research examining mechanisms of therapeutic change for patients in PC. This study provides preliminary data suggesting that interventions that target acceptance may be indicated in patients in PC. <u>https://goo.gl/wBvz5L</u>

A survey of hospice and palliative care Clinician's experiences and attitudes regarding the use of palliative sedation

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 May 2017 – A variety of terms and attitudes surround palliative sedation (PS) with little research devoted to hospice and palliative care (HPC) clinicians' perceptions and experiences with PS. These factors may contribute to the wide variability in the reported prevalence of PS. Nine hundred thirty-six [members of the American Academy of Hospice & Palliative Medicine] responded to the survey. About 83.21% preferred the terminology of PS compared with other terms. A majority felt that PS is a bioethically appropriate treatment for refractory physical and nonphysical symptoms in dying patients. Most felt PS was not an appropriate term in clinical scenarios when sedation occurred as an unintended side effect from standard treatments. Hospice clinicians use PS more consistently and with less distress than non-hospice clinician respondents. [Among respondents] there is a lack of clear agreement about what is included in PS and how the practice of PS should be best delivered in different clinical scenarios. https://goo.gl/BrGdEV

Noted in Media Watch 24 April 2017, #509 (p.9):

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 20 April 2017 – 'International variations in clinical practice guidelines for palliative sedation: A systematic review.' In this review, the authors identify and compare national/regional clinical practice guidelines on palliative sedation (PS) against the European Association for Palliative Care (EAPC) palliative sedation framework and assess the developmental quality of these guidelines using the Appraisal Guideline Research & Evaluation (AGREE II) instrument. There were striking differences in terminologies used and in life expectancy preceding the practice. https://goo.gl/c8NhbR

Noted in Media Watch 11 July 2016, #470 (p.13):

 CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 1 July 2016 – 'A systematic literature review on the ethics of palliative sedation: An update (2016).' In a 2010 review of palliative sedation (PS), the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of PS may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. http://goo.gl/qWxPgk

End-of-life care in Canada

Supportive cardiology: Moving palliative care upstream for patients living with advanced heart failure

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 May 2017 – Heart failure (HF) affects 600,000 Canadians and is a chronic, life-limiting illness marked by exacerbations of distressing symptoms requiring acute medical management, typically sought in Canada's emergency departments. HF often has an unpredictable illness trajectory and is a chronic terminal illness with a poor prognosis. Patients living with advanced HF have difficulty in accessing palliative care (PC) supports, which can result in unnecessary suffering as their HF progresses and they near end of life (EoL). This is, in part, due to a lack of research, helping clinicians to identify patients who are approaching EoL. In addition, the unpredictable nature of illness progression often precludes access to most EoL resources in our current prognosis-dependent healthcare system. PC teams focus on optimizing quality of life through symptom management and ensure that care plans are congruent with patient and family preferences. Findings show that integration of an embedded model of PC delivery for patients living with advanced HF led to overwhelming positive patient and family feedback while providing timely advance care planning discussions that may be associated with beneficial patient, family, and system outcomes. These outcomes can be used to inform public policy and speak to a cost-effective patient and family-centered approach for providing care to individuals and families living with advanced HF. <u>https://goo.gl/iFC2Ab</u>

Noted in Media Watch 24 April 2017, #509 (p.11):

JOURNAL OF CARDIOLOGY | Online – 17 April 2017 – 'Potential palliative care quality indicators in heart disease patients: A review of the literature.' The authors summarize seven potential categories of quality indicators in heart disease: 1) Presence and availability of a palliative care (PC) unit, PC team, and outpatient PC; 2) Human resources such as number of skilled staff; 3) Infrastructure; 4) Presence and frequency of documentation or family survey; 5) Patient-reported outcome measure data and disease-specific patient quality of life; 6) Questionnaires and interviews about the quality of PC after death, including bereaved family survey; and, 7) Admission-related outcomes such as place of death and intensive care unit length of stay. https://goo.gl/1yFtCf



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.17.

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

Are we making progress?

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 April 2017 – Measuring the quality of what we do is of paramount importance as we move forward, not just about ourselves, but about the larger healthcare systems in which we work. We have moved beyond, "the nurse who trained me did it this way" to a series of quality measures. The major objection has been the burden of the measurement – to patients, families, and staff. Of interest is to move beyond process measures to patient-centered measures that are not burdensome. To that end, the report in this issue of evidence for the validity of a single item approach is of real interest (Conrad *et al*).¹ Although more work needs to be done, I take heart that this takes work from the research realm to something that could be of utility in daily practice. One of my pet peeves is the report by a healthcare provider that the patient "wants everything done" versus "comfort care only" as if there were just two flavors of ice cream: vanilla and chocolate. The report that preferences for aggressive medical treatment are not associated with healthcare utilization in the very old is heartening (Albert *et al*).² It suggests that patients, families, and their healthcare professionals are able and willing to engage in nuanced discussion and planning to achieve the right treatments for the patient at the time. In other words, we can move away from slogans toward patient-centered care with confidence. https://goo.gl/BdV5wn

- 1. 'Measurement of quality of life in palliative care: Evidence for criterion-oriented validity of a single-item approach,' published online 5 January 2017. <u>https://goo.gl/h5Qlvu</u>
- 'Are preferences for aggressive medical treatment associated with healthcare utilization in the very old?' published online 23 March 2017. <u>https://goo.gl/Op7hbg</u>

Related

GENERATIONS, 2017;41(1):74-80. 'The changing landscape of palliative care.' As the number of Americans living with serious illness grows, how will our fragmented, top-heavy healthcare system respond? How can we ensure high-quality care for our most vulnerable patients? The evolution of palliative care provides insight into efficient, effective models of care for seriously ill patients in their communities, and the system redesign and workforce repositioning that will be necessary to respond to our seriously ill patients' needs and preferences at a national scale. https://goo.gl/BXWvwl



 GENERATIONS, 2017;41(1):58-67. 'Lessons from the Hospice Benefit for advanced illness care.' This article reviews the origins and progression of hospice care, including the difficult issue of everincreasing prognostic uncertainty. The authors conclude this benefit for patients living with chronic progressive illnesses needs to be updated to assure more timely access, less regulatory ambiguity, and more seamless integration into mainstream healthcare delivery systems. https://goo.gl/xYIKch

N.B. The focus of the Spring 2017 issue of *Generation*, the journal of the American Society on Aging, is on end-of-life care (EoLC). Topics include the policy and politics of EoLC, education, family caregiving, and advance care planning. Journal contents page: <u>https://goo.gl/jZy9jT</u>

 PALLIATIVE & SUPPORTIVE CARE | Online – 2 May 2017 – 'A qualitative study of the emotional and spiritual needs of Hispanic families in hospice.' Participant narratives fell into five main themes: 1) The influence of Hispanic culture in the relationship with hospice care providers; 2) Types of social support received from hospice; 3) Barriers to receiving support; 4) Lack of health literacy regarding hospice care; and, 5) Cultural preferences for religious/spiritual support in hospice. These findings provide insight into the specific emotional and spiritual needs of Hispanic families receiving hospice services. https://goo.gl/ttpTRa

N.B. Selected articles on end-of-life care in the Hispanic community in the U.S. are noted in the issues of Media Watch of 18 January 2016 (#445, p.10) and 1 June 2015 (#412, p.8).

Hooray for chaplains! How do we prove their value

JOURNAL OF PALLIATIVE MEDICINE | Online - 7 April 2017 -What does it mean to address an existential or spiritual issue? How do we study the work of the chaplain when he or she is doing this most important task? What is the difference between religiosity and spirituality? Certainly as healthcare becomes increasingly expensive, services such as chaplaincy are going to need to justify their activities to assure ongoing support. The research community can help. From a brief perusal of the literature, it appears that proving the obvious - that chaplains help patients and families - is both hard research to do and hard research to fund. However, there are lots of people thinking about this. The importance of understanding and proving the sacred work of chaplains is only becoming more important lest we risk losing them as members of the team. As another chaplain once taught me, distinguishing between fears that occur before the last breath and fears that occur after the last breath is a great way to help determine whose expertise is needed at the bedside. https://goo.gl/neitQ2

In the chaplain's shadow

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 April 2017 – I saw the chaplain in a different light, saw how he – not the doctors – had positioned himself to help the man at the very crux of his suffering. He was in the right place. And the clearer the light, the sharper the shadow. For the first time, I recognized that for many patients, we doctors, whether we perceive it or not, live in the chaplain's shadow. <u>https://goo.gl/qov69w</u>

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.' Half of survey respondents reported frequently participating in palliative care rounds. Primary chaplain activities were relationship building, care at the time of death, and helping patients with existential issues or spiritual distress. Over half reported addressing goals of care 60% of the time or more. https://goo.gl/hpZOyu

Mourning and memory in the twittersphere

MORTALITY | Online – 2 May 2017 – Emerging work in the field of social media and mourning suggests that social media spaces have changed the landscape of grief by encouraging mourners to form communities online, post public statements about loss, and maintain continuing bonds with the deceased. While existing studies restrict their analyses to public or private online spaces, The authors examine a space that is suited to both private communication and information broadcast. They analyse mentions of deceased Twitter users and find that Twitter facilitates multiple types of mourning behaviours previously identified in isolation within other online spaces. While some Twitter users engage directly with the deceased and display evidence of continuing bonds, others use Twitter to comment on the death of high profile individuals or individuals whose death sparked their interest – often connecting these deaths to broader topics, including current events and calls for social change. Overall, the authors' findings suggest that Twitter is a unique online space that encourages users to engage in a variety of personal and public communication that ranges from highly personal and intimate interaction to abstracted and impersonal commenting. https://goo.gl/emsYyn

Noted in Media Watch 13 June 2016, #466 (p.4):

U.S. | The Atlantic – 8 June 2016 – 'The space between mourning and grief.' Some argue that the likes of Facebook and Twitter have opened up public space for displays of grief that had been restricted to private spheres of secular culture. But rather than reconstructing an outlet for public grief, social media often reproduces the worst cultural failings surrounding death, namely platitudes that help those on the periphery of a tragedy rationalize what has happened, but obscure the uncomfortable, messy reality of loss. http://goo.gl/VMUX9p

Double vision: When a dying patient's family member is also a nurse

NURSING, 2017;47(5):59-54. When a patient who's dying has a family member who's a nurse, that nurse may have *double vision*, or a misalignment between the nurse's view and the family member's view. This article provides nurses with strategies to help nurse-family members cope and participate in decision making and caregiving for a family member who's actively dying in the hospital. <u>https://goo.gl/Fu4yvt</u>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- JOURNAL OF MEDICAL LAW & ETHICS, 2017;5(1):57-79. 'Losing our grip on death: What now for assisted dying in the U.K.?' Recent developments on assisted dying in England and Wales are a unique opportunity to engage academics, healthcare professionals, and the public in a fresh round of debate on one of the most controversial subjects of modern times. This article engages in a discussion and evaluation of these developments, namely, the establishment of the Commission on Assisted Dying in 2010 and the publication of its Report in 2012, the ground-breaking Supreme Court case of Nick-linson in 2014, and the Private Members' Bill, the Assisted Dying Bill (2013-2015). In particular, although the Bill's progress was significant, the U.K.'s Parliament and the government were again reluctant and failed to use the Bill as an opportunity to deal with difficult questions. In an area of conflicting societal and individual interests and of great importance for medicine, ethics, and law, this article suggests that a balance between the "protection" of "vulnerable" groups potentially affected by the legalisation of assisted dying, and "choice" in the context of life-expectancy should be considered in future reform. https://goo.gl/w5IFUJ
- SOUTH AFRICAN JOURNAL OF PHILOSOPHY | Online 25 April 2017 'Assisted dying: Why the argument from sufficient palliation fails.' Opponents of legalising assisted dying often make the argument from sufficient palliation. On the premise that advances in palliative treatment (PT) have made it possible to free terminal patients from pain and distress, the argument concludes that assisted dying is unnecessary. The author assert that this argument fails. Firstly, the premise is false because patients respond differently to analgesics and many continue to experience intractable pain even on medication. Secondly, the premise fails to acknowledge the extreme discomfort (for many patients) of the side effects of PT. Thirdly, the conclusion would only follow from the premise if the overwhelming majority of patients had access to PT, and this is patently not the case. Finally, the argument completely overlooks the enormous distress experienced by terminal patients, arising from perceived loss of dignity and concerns about being a burden to others. https://goo.gl/mBRnEr
- SOUTH AFRICAN MEDICAL JOURNAL, 2017;107(5):383-385. 'Human dignity and the future of the voluntary active euthanasia debate in South Africa.' The issue of voluntary active euthanasia was thrust into the public policy arena by the *Stransham-Ford* lawsuit.¹ The High Court legalised voluntary active euthanasia however, ostensibly only in the specific case of Mr. Stransham-Ford. The Supreme Court of Appeal overturned the High Court judgment on technical grounds, not on the merits. This means that in future the courts can be approached again to consider the legalisation of voluntary active euthanasia. As such, *Stransham-Ford* presents a learning opportunity for both sides of the legalisation divide. In particular, conceptual errors pertaining to human dignity were made in *Stransham-Ford*, and can be avoided in future. https://goo.gl/v18zt2
 - 'Assisted suicide and assisted voluntary euthanasia: Stransham-Ford High Court case overruled by the Appeal Court – but the door is left open,' *South African Medical Journal*, 2017;107(5):381-382. <u>https://goo.gl/92uouy</u>



Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8l

Worth Repeating

Last offices neglected in over half of hospital deaths

NURSING TIMES (U.K.) | Online - 11 May 2010 - A dearth of training and guidance means nurses are failing to follow "last offices," the simple procedures for treating dead patients with dignity and respect, a Nursing Times investigation has found. In more than half of hospital deaths, nurses neglect to follow procedures such as straightening patients' limbs or closing their eyes and mouth before rigour mortis sets in, according to evidence gathered by hospital trusts and shared with Nursing Times. Such failures can mean patients have tubes and lines wrongly removed or are left with loose dressings, resulting in fluid leaks which can be distressing for relatives. On occasions patients are not cleaned properly or are left with marks on their bodies. Audits of how last offices are performed are rare. But Nursing Times has seen details of an audit at North Tees and Hartlepool Foundation Trust, carried out in January last year, which found problems in the way 47 out of 80 deceased patients were dealt with. The most common error - found in 15% of cases - was leakage from unsecured dressings. [Noted in Media Watch 16 June 2014, #362 (p.14, under 'Worth Repeating')] https://goo.gl/LPsH5J

What should last offices involve?

If the patient is not catheterised, apply gentle pressure over the bladder to allow it to drain

Remove and record jewellery and any personal items, unless requested or advised otherwise

Attend to hygiene needs, particularly hair, nail and mouth care

Replace dentures

Attempt to close the eyes, using a small piece of clinical tape if required

Attach identification labels

Dress the patient in a gown/shroud or own clothes, as required

Place an incontinence pad under the buttocks to contain any soiling

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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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: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/j46LpJ

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

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: <u>HTTP://GOO.GL/JNHVMB</u>

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: <u>http://goo.gl/o7kN3W</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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

Barry R. Ashpole Guelph, Ontario CANADA ⁶phone: 519.837.8936 e-mail: <u>barryashpole@bell.net</u>