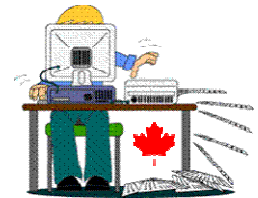


Media Watch...

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

Emotional, physical, spiritual and social wellbeing at the end of life: Scroll down to [Specialist Publications](#) and ‘Psychosocial interventions for end-of-life care...’ (p.7), in a special issue of the *Australian Psychologist* on the subject.

Canada

Dr. Susan MacDonald on what the dying can teach the living

ONTARIO | CBC News (Ottawa) – 30 September 2017 – The dying can teach the living a lot about what is truly important in this world, according to Dr. Susan MacDonald. As the medical director of palliative care (PC) for Eastern Ontario Health, she says her work has taught her to be more mindful and to live in the moment without letting the trivial stuff get in the way. MacDonald said people often don’t understand what PC actually is and think it is a place of care – when actually it is a philosophy of care. “It’s a philosophy about the physical symptoms that somebody experiences when they have an illness that will eventually take their life, but also the emotional and psychosocial and spiritual aspects of whatever kind of suffering they’re having,” she said. “Good PC is focused on helping people live as well as they possibly can for as long as they possibly can.” Sometimes people don’t consider PC early enough, MacDonald said, and assume it is a negative thing that is only for the end-of-life scenario. <https://goo.gl/Apv7ZF>

N.B. CBC interview with Dr. MacDonald: <https://goo.gl/RELn5R>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | CBC News (Halifax) – 24 September 2017 – **‘Most people seeking euthanasia in Nova Scotia in early 2017 didn’t get it: Agency.’** Nearly two-thirds of Nova Scotians seeking assisted suicide in the first six months of 2017 did not receive a lethal injection, with doctors saying the province’s system is short of available physicians and payments are low. The Nova Scotia Health Authority reports that of 64 referrals made for medical assistance in dying, 23 were completed between 1 January and Canada Day [i.e., 1 July]. The remaining patients either dropped the request, lost the mental ability to agree – a requirement under Canada’s Bill C-14 – or died before anyone could carry out the euthanasia. <https://goo.gl/gmaE5h>

IPCRC.NET International Palliative
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Back Issues of Media Watch
<http://goo.gl/frPgZ5>

U.S.A.

Many kids dying of cancer get intense care at end of life

CALIFORNIA | Reuters – 28 September 2017 – Nearly two-thirds of children and teens with terminal cancer receive intense care at the end of life (EoL), often in hospitals and intensive care units, a study suggests.¹ Certain patients, including kids under age 5 and teens aged 15 to 21 as well as ethnic minorities and patients with blood malignancies were more likely to receive aggressive care than other children, the study also found. “The rates of medically intense end-of-life care (EoLC) we found in our study and the disparities we found raise the question: Are we providing a palliative approach to EoLC for these patients?” said lead study author Dr. Emily Johnston of Stanford University School of Medicine in California. “I hope this study makes pediatric oncologists and others taking care of these patients reflect on the EoL discussions they are having, particularly with these high-intensity groups,” Johnston said by email. “I also hope it lets families experiencing the loss of a child due to cancer know that there are different ways for that death to happen, so they can think about and advocate for what is best for their child and their family.” Many adult patients with cancer who know they are dying choose less intense care, and aggressive treatment is associated with worse outcomes for families and caregivers, Johnston and colleagues write. But less is known about treatment choices for children, Johnston told Reuters. <https://goo.gl/Z5V3o1>

1. ‘Disparities in pediatric palliative care: An opportunity to strive for equity,’ *Pediatrics*, published online 28 September 2017. **Abstract:** <https://goo.gl/fdYkoj>

Specialist Publications

‘End-of-life care for World War II, Korea, and Vietnam-era veterans’ (p.10) in *Home Healthcare Now*.

‘Three barriers to voluntary stopping eating and drinking by advance directive: A critical assessment’ (p.14), in *Seattle Journal for Social Justice*.

More people than ever are dying in prison. Their caregivers? Other inmates

PENNSYLVANIA | *The Inquirer* (Philadelphia) – 27 September 2017 – “The death squad.” Or, “the executioners.” That’s what many inmates used to call the inmate-volunteers who work the Graterford state prison hospice unit, a bleak row of isolation rooms – each one-part hospital room, one-part jail cell – where inmates with terminal illnesses are placed to die. Then, they saw how the inmates cared for dying men in shifts, undertaking the intimate tasks of feeding, cleaning and comforting them. For many, it is a calling. Over time, attitudes changed, said James, a 51-year-old inmate who volunteers to do this work. “There’s a lot of progress in this place. There is more humanity here now.” It’s needed, given that far more people are dying in prison than ever before. In Pennsylvania, 483 state inmates have died since January 2015. That’s about 180 deaths in prison each year. From 2005 to 2014, the average was 150 deaths per year. <https://goo.gl/oH47nW>

Specialist Publications

‘Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: A cross-sectional study’ (p.12), in *Palliative Medicine*.

Palliative Care Network Community

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 31 July 2017) can be downloaded/viewed at: <http://goo.gl/ZpEjyQ>

Cont.

Related

- PENNSYLVANIA | Montgomery Patch – 27 September 2017 – ‘**Graterford inmate who stole \$1 of lemonade almost couldn’t come home to die.**’ When an inmate at Graterford State Prison found out he was going to die, all he wanted to do was go home. That’s allowed in Pennsylvania, under something called the compassionate-release law. The paperwork, however, can be unbelievably slow. This was what happened this summer with 57-year-old Frank Rodriguez. Rodriguez, of Bethlehem, who was dying of colon cancer, petitioned months before his death to be allowed to return home to die. But his case was so administratively tangled that he wasn’t allowed to come home until 25 August. He died 27 August. His crime? He stole \$1 worth of lemonade, and then was caught smoking marijuana while on parole, the report states. <https://goo.gl/RToBMG>

Hospice in crises

POLITICO (Arlington, Virginia) | Online – 27 September 2017 – It might seem odd to talk about “innovations in dying,” but in recent decades the hospice movement has become an important new pathway for the most difficult phase of life. As American health care has become ever more high-tech and expensive, the hospice model of home-based care for terminally ill patients has enabled millions of Americans to die peacefully in their own houses, without painful medical procedures – often greatly reducing stress on both the families and the health care system. Now, however, the hospice model is coming under stress of its own. Some of that’s because the industry has changed, with a lot more for-profit hospice agencies and investor-owned chains, which are coming under scrutiny from regulators. But much of the stress comes from shifts in how we die, how we live – and with whom. These are big demographic changes that make the original conception of hospice harder to carry out as it was once intended. With baby boomers aging and likely to live with serious illness for several years, understanding how best to take care of the aged and the dying is becoming an ever more pressing issue in America – emotionally, morally, and financially. <https://goo.gl/JvXX22>

Extract from *Politico* article

Even strong advocates of hospice know that it’s time for changes to match the complex medical needs of today’s patients and the demographic realities of the country – as well as trends arising from long-term use of hospice in existing institutions like nursing homes. But in the near future, there aren’t a whole lot of fabulous solutions, at least not ones that don’t cost a lot of money.

South Carolina Rural Health Research Center

Hospice services in rural areas can reduce need for more expensive services

SOUTH CAROLINA | *The Daily Yonder* (Knoxville, Tennessee) – 26 September 2017 – Expanding the use of hospice services among rural residents in the last six months of their lives could reduce patients’ need for more expensive and inconvenient medical treatments, a new report suggests.¹ About 44% of rural Medicare patients who died in the second half of 2013 used hospice services, according to the study. By comparison, just over half of urban Medicare patients at the same stage of life used hospice services. Patients who use hospice services are less likely to visit a doctor’s office, be admitted to hospitals, or require an ambulance, the study said. That can save money and allow patients to spend less time going to and from appointments and undergoing exams and treatments. The biggest difference between hospice and non-hospice patients was in their use of skilled nursing facilities. Rural Medicare patients who did not receive hospice care were 22% more likely to use a skilled nursing facility than patients who did get hospice care. The difference was less pronounced, but still obvious for urban patients. For them, non-hospice patients were 12% more likely to use a skilled nursing facility than patients who received hospice care. Both urban and rural non-hospice patients were less likely to receive in-home health-care services. <https://goo.gl/yJJ9JV>

1. ‘Rural-Urban Differences in Medicare Service Use in the Last Six Months of Life,’ South Carolina Rural Health Research Center, University of South Carolina, August 2017. <https://goo.gl/mqT5Po>

Cont.

Noted in Media Watch 25 April 2016 (#459, p.3):

- **POLITICAL NEWS** | Online – 18 April 2016 – ‘**Legislation to expand rural hospice care.**’ Bipartisan legislation to improve access to hospice care in rural America has been tabled in the Senate. Only 32% of those eligible in rural areas utilize hospice compared to 48% in urban areas, according to a report from the Medicare Payment Advisory Commission. The Rural Access to Hospice Act of 2016 aims to level the playing field. <http://goo.gl/paarBo>

N.B. Additional articles on the provision and delivery of hospice and palliative care in rural and remote regions of the U.S. are noted in the 12 June 2017 issue of Media Watch (#516, p.8).

International

Patients “dying alone” due to lack of National Health Service staff, report finds

U.K. (England, Northern Ireland, Scotland & Wales) | Sky News (London) – 29 September 2017 – Patients are dying alone in National Health Service hospitals because there are not enough staff to look after them, according to a new report.¹ A survey of more than 30,000 nurses found many felt stressed or burnt out, with a quarter saying they had to care for 14 or more patients at a time. Nurses described being reduced to tears at the end of shifts, patients being left to die alone when they did not have any family and said managing patients was like “spinning plates.” One nurse said: “Patient care is seriously compromised when there are not enough staff. Patients at the end of life have no one to sit with them. It is very upsetting when they have no family. Too many patients are dying alone.” Another said: “Being unable to attend to a dying patient as quickly as they need is soul-destroying.” The Royal College of Nursing report is based on the experience of U.K. nurses on their last shift. <https://goo.gl/5wtfSb>



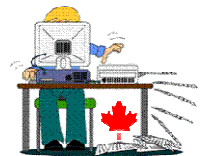
1. ‘Safe and Effective Staffing: Nursing Against the Odds,’ Royal College of Nursing, September 2017. <https://goo.gl/U4TNmv>

“Demand up” for humanist pastoral care in Wales

U.K. (Wales) | BBC News (Cardiff) – 28 September 2017 – Humanist pastoral carers are being trained in Wales after research showed demand was up. Charity Humanists UK said almost 70% of those surveyed thought non-religious carers should be provided alongside religious chaplains at hospitals, prisons and universities. It found 93% of non-religious people did not make use of chaplains. Humanists believe the universe is a natural phenomenon with no supernatural or religious side, and trust scientific methods and evidence to understand it. Kathy Riddick, who coordinates pastoral care in Wales for Humanists UK, said: “The traditional chaplains are based around religious needs, but we are finding more and more people are not comfortable receiving that care, particularly in hospices where the view of a non-religious person at the end of their life can be very different.” <https://goo.gl/UvTGJn>

N.B. A series of viewpoints published in *The Lancet* in 2005 explores contrasting end of life perspectives, e.g., ‘End of life: The humanist view’ <https://goo.gl/rJPY5Q>.

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>

Multi-hospital Australian study

Push to consider organ donation for all end-of-life patients in ICU after untapped pool of donors discovered

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 25 September 2017 – Australia has large untapped pool of potential deceased organ donors that could save the lives of hundreds of patients waiting on transplant lists, suggests a new study...¹ Less than 2% of Australians die in a way that allows them to donate their organ. Most deceased organ donors come from brain-dead patients, but the number of donations after circulatory death (DCD) has been growing. In 2016 DCD made up one-quarter of all deceased organ donors. The researchers analysed data of patients who died in an intensive care unit or emergency department across the 75 Australian hospitals between 2012 and 2014. They identified DCD patients whose organs were donated, those who would have been ideal DCD donors but did not have their organs donated, and patients who met a set of expanded criteria to become DCD donors but did not become donors. “That’s potentially another 416 kidney transplants, 117 lungs, 41 livers and seven potential heart transplant recipients,” senior author and intensive care specialist at the Alfred Hospital in Melbourne Professor David Pilcher said. <https://goo.gl/vPv8hs>

1. ‘Untapped potential in Australian hospitals for organ donation after circulatory death,’ *Medical Journal of Australia*, published online 25 September 2017. **Abstract:** <https://goo.gl/TsNEFK>

N.B. Additional articles on organ transplantation in the context of end-of-life care are noted in the 15 May 2017 issue of Media Watch (#512, p.7).

“Why won’t they let the dead rest?”

U.K. (England) | *The Daily Mail* (London) – 25 September 2017 – Emergency call handlers are routinely issuing “grotesque” instructions ordering callers to attempt to resuscitate the bodies of loved ones who are obviously beyond help... In horrific accounts given to this newspaper, readers have told how they were commanded to perform futile chest compressions on corpses already blackened with decomposition, stiff with rigor mortis or badly damaged. Some told how operators “shouted” at them, despite protestations that a parent, spouse or other family member had “been dead for hours.” Others were told they would “get into trouble” if they did not comply with instructions, and they spoke of how they were made to feel “guilty” for not doing enough if they objected to carrying out CPR attempts. But one 999 insider admitted they felt they had no option but to follow the protocols to avoid legal cases against them for “lack of duty of care.” The revelations led senior medics to call for an urgent overhaul of emergency call rules, saying they “lacked common sense” and were inhumane. <https://goo.gl/vnCWLA>

Specialist Publications

‘Case conferencing for palliative care patients: A survey of South Australian general practitioners’ (p.7), in *Australian Journal of Primary Health*.

‘Psychosocial interventions for end-of-life care...’ (p.7), in *Australian Psychologist*.

‘Implementation of national palliative care guidelines in Swedish acute care hospitals: A qualitative content analysis of stakeholders’ perceptions’ (p.9), in *Health Policy*.

‘Development of the international guidelines for home health nursing’ (p.9), in *Home Healthcare Now*.



Media Watch Online

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (New South Wales) | *The Guardian* (Surry Hills) – 27 September 2017 – ‘**A reading of past assisted dying debates records breathtaking ignorance and lies.**’ With the law to permit voluntary assisted dying introduced to the Victorian and New South Wales parliaments this month, it is interesting to reflect on past contributions on the same subject. Since the federal parliament overturned the first voluntary euthanasia law, the 1995 Northern Territory Rights of the Terminally Ill Act, in 1997, there have been 28 failed attempts to pass similar legislation in the states. Unlike the Victorian bill, all of them were private members’ bills. Each one of the bills was opposed by a well organised and funded religious lobby. Interestingly, their campaigns played down the religious arguments and concentrated on spreading a plethora of lies and innuendo – what Andrew Denton calls FUD, fear of uncertainty and doubt. <https://goo.gl/eMQSVZ>

Specialist Publications

Deaths and end-of-life decisions differed between neonatal and paediatric intensive care units at the same children’s hospital

ACTA PAEDIATRICA | Online – 25 September 2017 – Most of the studies on neonatal deaths in the Western world have focused on preterm infants and have identified four major causes of mortality: prematurity, congenital malformations, perinatal asphyxia, and sepsis. In The Netherlands, full-term neonates who suffer from critical illnesses are commonly admitted to a neonatal intensive care unit (NICU) or paediatric intensive care unit (PICU) depending on the nature of their illness. Although the major causes of neonatal deaths are known, there have been no studies that have compared the mortality and causes and timing of neonatal deaths in NICUs and PICUs. There are different factors that can have an impact on the neonatal mortality rate, including birth weight and gestational age. The postnatal age at death and length of intensive care stay may be simultaneously influenced by the underlying illness, but this has not been studied in much detail. In addition, neonatologists who work in a NICU may have different attitudes towards end-of-life (EoL) decisions than the paediatric intensivists or paediatric anaesthesiologists who work in a PICU. EoL decisions can be classified using different systems and have been widely studied in NICUs. However, little is known about the process of EoL decision-making for neonates in PICUs. This study, which was carried out in the same children’s hospital in The Netherlands from 2003 to 2013, found that full-term neonates died sooner after being admitted to the NICU than PICU, which may have been due to underlying disease. In the NICU, most full-term neonates died due to the results of perinatal asphyxia, and in the PICU, neonates mainly died due to congenital cardiac malformations. EoL decisions were remarkably different between both units and were guided by the patient population rather than their age. **Full text:** <https://goo.gl/Q3Zw6G>

End-of-life care preferences in patients with severe and persistent mental illness and chronic medical conditions: A comparative cross-sectional study

AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY | Online – 25 September 2017 – Physicians rarely engage severe and persistent mental illness (SPMI) patients in end-of-life care (EoLC) discussion despite an increased risk of debilitating medical illnesses and mortality. Whereas access to quality palliative care (PC) and medical assistance in dying (MAiD) has become a priority in Canada and many jurisdictions, the authors 1) Compared SPMI and chronic medically-ill (CMI) patients’ (EoLC) preferences and comfort level with EoLC discussion; and, 2) Identified potential predictors of interest in MAiD. SPMI was not correlated to any EoLC intervention, except for MAiD where SPMI patients were less likely to support its use. Religiosity was also correlated with interest in MAiD. Patients in both groups were comfortable talking about EoLC. SPMI patients are able to voice their EoLC preferences, and contrary to some fears, do not want MAiD more than CMI patients. **Abstract:** <https://goo.gl/ubHCoV>

Case conferencing for palliative care patients: A survey of South Australian general practitioners

AUSTRALIAN JOURNAL OF PRIMARY HEALTH | Online – 26 September 2017 – Despite a growing evidence base for the benefits, the uptake of case conferencing (CC) has been limited in South Australia (SA). The aim of this study is to explore the beliefs and practice general practitioners (GPs) towards CC for people with palliative care (PC) needs. Using an online survey, participants were asked about demographics, attitudes towards CC and details about their most recent case conference for a person with PC needs. Responses were received from 134 GPs (response rate 11%). In total, 80% valued CC for people with PC needs; however, <25% had been involved in CC in the previous 2 years. The major barrier was time to organise and coordinate case conferences. Enablers included GP willingness or interest, strong relationship with patient, specialist PC involvement and assistance with organisation. Despite GPs' beliefs of the benefits of CC, the barriers remain significant. Enabling case conferencing will require support for organisation of case conferences and review of Medicare Benefits Schedule criteria for reimbursement.

Abstract: <https://goo.gl/EAmX1k>

Noted in Media Watch 4 September 2017 (#528, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 September 2017 – ‘**The development of practice guidelines for a palliative care multidisciplinary case conference.**’ In Ontario, Canada, the authors identified that few hospitals have developed multi-disciplinary case conferences or forums for discussion of patients with palliative care issues. A literature search focusing on multidisciplinary case conferences (pMCCs) and their implementation was completed as well as a current state assessment to understand challenges with existing pMCCs. A working group was assembled to draft a recommendation report that was finalized by an expert panel. **Abstract:** <https://goo.gl/eMmv7e>

Psychosocial interventions for end-of-life care

AUSTRALIAN PSYCHOLOGIST, 2017;52(5):340-345. End-of-life care (EoLC) impacts on emotional, physical, spiritual, and social wellbeing for both the individual and their family. Despite remarkable medical advances in the field, the empirical evidence regarding the development and efficacy of psychosocial interventions at EoLC is lagging behind. A number of psychosocial interventions are promising and represent important progress in the field. Psychologists have a range of suitable skills and knowledge, however, the profession is underutilised in EoLC. This special issue on EoLC highlights the need for more research into this area and could act as a call to action to accelerate our understanding of the role of psychology in EoLC. **Abstract:** <https://goo.gl/W2LUa3>



N.B. Contents page of special issue on psychology and end-of-life care: <https://goo.gl/b1dDKW>

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14 October 2017

Universal health coverage and palliative care – Don't leave those suffering behind

<https://goo.gl/diYn7i>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 September 2017 – ‘**The effectiveness of psychosocial interventions for psychological outcomes in paediatric oncology: A systematic review.**’ Nine studies reported statistically significant improvements on psychological outcomes. These findings suggest that psychosocial interventions are effective at reducing anxiety and depressive symptoms as well as improving quality of life. Additionally, six studies found psychosocial interventions to have positive impact on physical symptoms and wellbeing, including a reduction in procedural pain and symptom distress. **Abstract:** <https://goo.gl/TXpZYe>

American perspective

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 August 2017 – ‘**Palliative care gaps in providing psychological treatment: A review of the current state of research in multidisciplinary palliative care.**’ The authors reviewed 59 multi-component palliative care (PC) intervention articles and analyzed the mental health components of PC interventions and their outcomes in order to better understand the current state of psychological care in PC. The majority did not provide details regarding the psychological component delivered as part of the PC intervention. Most did not specify which provider on the team was responsible for providing the psychological intervention. [Noted in Media Watch 14 August 2017 (#525, p.5)] **Abstract:** <https://goo.gl/MVXij3>

European perspective

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):114-118. ‘**Psychological ideas in palliative care: Diagnosis and formulation.**’ Not every patient needs, wants or has access to formal contact with a psychologist. What’s more, all members of a multidisciplinary team are likely to experience the impact of psychological matters in their daily practice with patients and colleagues, whether or not their role is to explicitly address those. This article, the third in a series, aims to summarise some of the “big ideas” in psychology and translate them into practical advice to promote psychologically informed practice for those providing PC, whether as doctor, nurse, allied health professional or in any other clinical or non-clinical role. [Noted in Media Watch 17 July 2017, #521 (p.11)]

N.B. Earlier articles in this series: ‘**Attachment theory**’ in the 27 February 2017 issue of Media Watch (#501, p.7) and ‘**Emotional regulation**’ in the 3 April 2017 issue of the weekly report (#506, p.11). Access to articles in the *European Journal of Palliative Care* requires a subscription. Journal website: <https://goo.gl/bmq5E5>.

Emotional impact of end-of-life decisions on professional relationships in the ICU: An obstacle to collegiality?

CRITICAL CARE MEDICINE | Online – 21 September 2017 – During the end-of-life (EoL) decision-making process, families and patients restructure the decision-making frame by introducing a strong emotional dimension. This results in the emergence of new challenges quite different from the immediacy often associated with intensive care. In response to changes in decision frames, physicians rely on their relationship with the patient’s family to assist with advanced care decisions. Nurses, however, draw on their relationship and proximity to the patient to denounce therapeutic obstinacy. This study suggests that during the EoL decision-making process, nurses’ feelings toward their patients and physicians’ feelings toward nurses’ families influence the decisions they make. Although these emotional dimensions allow nurses and physicians to act in a manner that is consistent with their professional ethics, the professionals themselves seem to have a poor understanding of these dimensions and often overlook them, thus hindering collegial decisions. **Abstract:** <https://goo.gl/k1N6JA>

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Related

- *INTENSIVE CARE MEDICINE*, 2017;43(10):1529-1531. ‘**Life after death in the ICU: Detecting family-centered outcomes remains difficult.**’ Family members of patients who die in the ICU experience significant and lasting psychological burdens... Among the contributors to these adverse bereavement outcomes are the circumstances surrounding and processes of limiting life support. This hypothesis is supported by evidence that ICU deaths are commonly preceded by decisions to withdraw life support, and evidence that both ICU processes of care and behaviors of ICU clinicians near the end of life can influence family members’ post-ICU psychological outcomes. **Full text:** <https://goo.gl/k9Lb6Z>
- *INTENSIVE CARE MEDICINE* | Online – 20 September 2017 – ‘**Focus on palliative care in the ICU.**’ Included in a broad overview of research on palliative care in the ICU, the authors emphasize that there is increasing attention on the way that health professionals frame treatment options to family members. Choice architecture, they point out, is a term discussed by Anesi and Halpern in a 2016 editorial that articulates the importance of presentation and framing.¹ They describe how choice architecture is inevitable in discussions with family, and understanding this can provide a powerful tool to improve health-care decisions. **Full text:** <https://goo.gl/UZkvsJ>

1. ‘Choice architecture in code status discussions with terminally ill patients and their families,’ *Intensive Care Medicine*, 2016;42(6):1065-1067. **Access options:** <https://goo.gl/5msYku>

N.B. Additional articles on palliative care in the intensive care unit are noted in the 17 July 2017 issue of *Media Watch* (#521, p.12).

Implementation of national palliative care guidelines in Swedish acute care hospitals: A qualitative content analysis of stakeholders’ perceptions

HEALTH POLICY | Online – 20 September 2017 – In high-income countries a large proportion of all deaths occur in hospitals. A common way to translate knowledge into clinical practice is developing guidelines for different levels of health care organisations. During 2012, national clinical guidelines for palliative care (PC) were published in Sweden. Later, guidance for PC was issued by the National Board of Health & Welfare. The aim of this study was two-fold: to investigate perceptions regarding these guidelines and identify obstacles and opportunities for implementation of them in acute care hospitals. Interviews were conducted with local politicians, chief medical officers and health professionals at acute care hospitals. The results showed little knowledge of the two documents at all levels of the health care organisation. PC was primarily described as end-of-life care and only few of the participants talked about the opportunity to integrate PC early in a disease trajectory. The environment and culture at hospitals, characterised by quick decisions and actions, were perceived as obstacles to implementation. Health professionals’ expressed need for PC training is an opportunity for implementation of clinical guidelines. There is a need for further implementation of PC in hospitals. One option for further research is to evaluate implementation strategies tailored to acute care. **Abstract:** <https://goo.gl/pfiysU>

Development of the international guidelines for home health nursing

HOME HEALTHCARE NOW, 2017;35(9):494-506. Throughout the world, healthcare is increasingly being provided in home and community-based settings. There is a growing awareness that the most effective, least costly, patient-preferred setting is patients’ home. Thus, home healthcare nursing is a growing nursing specialty, requiring a unique set of nursing knowledge and skills. Unlike many other nursing specialties, home healthcare nursing has few professional organizations to develop or support its practice. This article describes how an international network of home healthcare nurses developed international guidelines for home healthcare nurses throughout the world. It outlines how the guidelines for home healthcare nursing practice were developed, how an international panel of reviewers was recruited, and the process they used for reaching a consensus. It also describes the plan for nurses to contribute to future updates to the guidelines. **Abstract:** <https://goo.gl/9xn2qt>

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

End-of-life care for World War II, Korea, and Vietnam-era veterans

HOME HEALTHCARE NOW, 2017;35(9):485-493. It is estimated that only 4% of veterans die in a Veterans Affairs setting. Home care and hospice clinicians should ask “Are you a veteran?” or “Have you ever served in the military?” so that appropriate care considerations can be made. Elliott (2015) also suggested several strategies to identify if a patient is a veteran, such as observing for military-related memorabilia around the home or military-related tattoos on the patient. Clinicians might be able to create an immediate connection with a patient who is a veteran by taking the time to inquire about prior military service. Although military experiences and subsequent post-military experiences vary between individuals, many veterans carry the “values, attitudes, and behaviors that are distinctly military” into the civilian world. Not making assumptions about how one views their military service is a good approach. Acknowledging military service is important and may be especially important when caring for a veteran at the end of life. Honoring and respecting the veteran and their family for the service and sacrifice to our country can help build trust and rapport. Highlighted are a variety of ways in which home care and hospice clinicians and agencies can honor and respect veterans. Listening to a patient reminisce and observing for potential complications can facilitate the clinician in seeking the right care or support for the patient, their families, and their caregivers. Asking the patient, their families, and caregivers what their wishes are is important to providing patient-centered care. Knowing not all veterans want to share their stories is important too. **Full text:** <https://goo.gl/FKEL2b>

Noted in Media Watch 14 August 2017 (#525, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 August 2017 – ‘**Addressing the challenges of palliative care for homeless veterans.**’ Care of veterans at the end of life (EoL) without homes may be substantially improved through policy changes to facilitate access to appropriate housing and care; better dissemination of existing policy; cross-discipline and cross-system education; facilitated communication among Veterans Affairs (VA), community, homeless and EoL providers; and, pilot testing of VA group homes or palliative care facilities that employ harm reduction strategies. **Abstract:** <https://goo.gl/sXwLf7>

N.B. Selected articles on end-of-life care of veterans in a Veterans Affairs setting are noted in the 24 April 2017 issue of Media Watch (#509, pp.10-11).

Care at end of life influences grief: A nationwide long-term follow-up among young adults who lost a brother or sister to childhood cancer

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 September 2017 – A majority of cancer-bereaved siblings report long-term unresolved grief, thus it is important to identify factors that may contribute to resolving their grief. Several predictors for unresolved grief were identified: siblings’ perception that it was not a peaceful death, limited information given to siblings the last month of life, information about the impending death communicated the day before it occurred, siblings’ avoidance of the doctors, and lack of communication with family and people outside the family about death. Depressive symptoms and time since loss also predicted unresolved grief. Together, these predictors explained 54% of the variance of unresolved grief. **Abstract:** <https://goo.gl/YnVGV8>



Related

- *BEREAVEMENT CARE*, 2017;36(2):58-64. ‘**Rumination following bereavement: An overview.**’ The authors provide an overview of rumination (i.e., thinking repetitively and recurrently about negative events and/or negative emotions) in adjustment to bereavement. First, they summarise a growing literature on rumination and mental health outcomes of bereavement. Next, they compare two main theories explaining the maladaptive effects of rumination after loss, which hold conflicting implications for clinical practice. **Full text:** <https://goo.gl/RjYp68>

Patient-centredness and consumerism in healthcare: An ideological mess

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 25 September 2017 – Two concepts appear to permeate political rhetoric concerning healthcare in the U.K. and elsewhere: patient-centred care and consumerism. Concerned that these two important ideas should not get conflated in public debates about healthcare, the authors outline their different philosophical origins and note their differences and similarities. They argue that both can be used in ways that are muddled or insincere, with implications for healthcare delivery. **Introduction:** <https://goo.gl/NKoUM8>

Noted in Media Watch 18 September 2017 (#530, p.11):

- *BRITISH MEDICAL JOURNAL* | Online – 11 September 2017 – ‘**Implementing person-centred approaches.**’ Although there is widespread agreement that person centredness is important, the concept itself remains subject to debate, with different perspectives attaching different meanings and with different implications. **Introduction:** <https://goo.gl/nVDRV5>
- *HEALTH POLICY* | Online – 8 September 2017 – ‘**An exploration of person-centred concepts in human services: A thematic analysis of the literature.**’ There is no common definition of what it means to be person-centred, despite being a core feature of contemporary health and human service policy. This suggests its inclusion facilitates further misunderstanding and misinterpretation. **Abstract:** <https://goo.gl/W8r6fw>

An elderly couple dies of natural causes on the same day

NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online – 8 September 2017 – A 77-year-old woman died of metastatic colorectal cancer. On that same day, her 82-year-old husband, who had stayed in bed next to her during the last days of her life, also died. The authors describe their two separate trajectories to death: anticipated dying and unexpected death with diagnostic uncertainty. They analysed the general practitioner’s role in this scenario. Existential suffering was partly the reason for commencing palliative sedation for the husband after his wife had died. GPs might find it difficult to change their course in care management for terminal patients from “life preserving” to “letting go.” An effective handover between physicians is essential in the palliative phase. No evidence was found in the literature for the hypothesis that dying people can influence their own time of death. **Abstract:** <https://goo.gl/nhhDhD>

N.B. Dutch language article.

Advance care planning for mechanical ventilation: A qualitative study on health-care providers’ approaches to cross-cultural care

OMEGA – JOURNAL OF DEATH & DYING | Online – 25 September 2017 – With growing ethno-cultural diversity in Canada health-care providers are managing an increasing number of diverse beliefs and values that are commonly associated with preferences for intensive mechanical ventilation (MV) treatment at the end of life. Semi-structured interviews were conducted with healthcare providers from acute care settings. Using a value-based approach in advance care planning (ACP) was deemed an effective method of practice for managing and interpreting diverse beliefs and values that impact decisions for MV. However, personnel, organizational, and systemic barriers that exist continue to hinder the provision of ACP across cultures. **Abstract:** <https://goo.gl/5TbCPN>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: A cross-sectional study

PALLIATIVE MEDICINE | Online – 27 September 2017 – Overall, 745 incarcerated and 370,086 non-incarcerated individuals died in California hospitals [between 2001 and 2013]. Incarcerated decedents were more often male, Black, Latino, younger, had shorter hospitalizations, and fewer had an advance care plan. Incarcerated decedents had higher rates of cancer, liver disease, HIV/AIDs, and mental health disorders. Cause of death was disproportionately missing for incarcerated decedents. The average age of incarcerated decedents rose between 2001 and 2013, while it remained stable for others. Palliative care (PC) services in correctional facilities should accommodate the needs of relatively young patients and those with mental illness. Given the simultaneous growth in the older prisoner population with the rising age of incarcerated hospital decedents, community hospital clinicians should be prepared to care for seriously ill, incarcerated patients. Significant epidemiologic differences between incarcerated and non-incarcerated decedents in this study suggest the importance of examining the differential PC needs of incarcerated patients in all communities. **Abstract:** <https://goo.gl/yv6ydp>

When to provide palliative care: The challenge of (re)searching where the light is dim

PALLIATIVE MEDICINE, 2017;31(9):778-780. In the last decade, there has been a sea change in the direction of research and practice in palliative care (PC). The first wave of trials of specialised PC interventions, beginning in the 1980s, aimed to show the effectiveness of involvement of PC for patients with life-threatening illness at the end of life (EoL), when PC was traditionally provided. These studies had methodological challenges that were virtually insurmountable, including difficulties with recruitment, attrition, and cross-over from the control to the intervention group. Many, if not all, of these challenges were related to the time of recruitment, which occurred when referral to PC was normally contemplated (i.e., late in the disease course), or even after referral – with subsequent randomisation to PC or to a waiting list. Not surprisingly, many studies had negative results, particularly for patient-reported outcomes. Did this mean that PC at the EoL was ineffective? Definitely not. Did it mean that methodology needed to change? Certainly yes. **Full text of editorial:** <https://goo.gl/K6R9Em>

Palliative care research: State of play and journal direction

PALLIATIVE MEDICINE, 2017;31(1):3-4. While there are an increasing number of atlases of palliative care (PC), international, regional and national, few explicitly map PC research resource, although its importance is often acknowledged. The latest EAPC Atlas of Palliative Care in Europe does outline research capacity in each country, but this tells us little about the type, quality and quantity of research undertaken. In the U.K., the academic PC research groups have been called “fragile,” with little growth noted during the 2000s. Studies of PC research tell us a little more about focus, quality and type of research. National studies, such as those in Sweden and Ireland, identify upward trends in publication numbers, and an increase in quantitative research approaches and studies outside cancer, although there remain critiques of the small scale of studies. International studies are also increasing in number, although they are predominantly observational rather than interventional. Trials in PC remain small, with low quality of reporting. **Full text of editorial:** <https://goo.gl/A1rqdL>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 September 2017 – ‘**Update in hospice and palliative care.**’ The objective of this update ... is to identify, summarize, and critique a sampling of research from the prior year that has the potential for marked impact on hospice and palliative clinical practice. Articles were ranked based on the study’s methodological quality, appeal to a breadth of palliative care clinicians across different settings, and potential clinical practice impact. The authors summarize the eight articles with the highest ratings and give recommendations for clinical practice. **Abstract:** <https://goo.gl/NahSyH>

Cont.

Noted in Media Watch 4 September 2017 (#528, p.7):

- *EUROPEAN JOURNAL OF BIOETHICS*, 2017;8(15):31-57. **‘Does the distinctiveness of palliative care research require distinct ethical guidelines?’** Palliative care (PC) research is essential in order to continue providing effective treatments to those suffering in the last stages of life. Indeed, the goal of good PC research is to relieve suffering and to improve quality of life. Similar to any other field, PC programs must develop on a research base, and patient care will suffer if it is not backed by sound research. However, weighted against this need are some who maintain that the ethical and practical challenges of PC research are unique and insurmountable. **Abstract:** <https://goo.gl/hhEQ9o>

Noted in Media Watch 9 March 2009 (#87, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2009;12(3):215-217. **‘The culture of research in palliative care: “You probably think this song is about you.”** “But is it right?” If my memory can be trusted, the question came after a presentation by Eduardo Bruera on the importance of research in palliative care. The nurse asking this question did so, not in a way that felt dismissive or punitive, but rather, with a sense of genuine caring and concern. After all, people approaching death have limited time and energy; did we really want to be asking them, indeed, was it right to be asking them to expend effort in answering our research questions? **Abstract:** <https://goo.gl/KKhdFT>

N.B. Selected articles on evidence-based palliative care are noted in the 22 May issue of Media Watch (#513, p.11).

American Academy of Physical Medicine & Rehabilitation

Integrating function-directed treatments into palliative care

PM&R, 2017;9(9):S335-346. The growing acceptance of palliative care (PC) has created opportunities to increase the use of rehabilitation services among populations with advanced disease, particularly those with cancer. Broader delivery has been impeded by the lack of a shared definition for palliative rehabilitation (PR) and a mismatch between patient needs and established rehabilitation service delivery models. The authors propose the definition that, in the advanced cancer population, PR is function-directed care delivered in partnership with other clinical disciplines and aligned with the values of patients who have serious and often incurable illnesses in contexts marked by intense and dynamic symptoms, psychological stress, and medical morbidity to realize potentially time-limited goals. Although PR is most often delivered by inpatient physical medicine and rehabilitation consultation/liaison services and by physical therapists in skilled nursing facilities, outcomes in these settings have received little scrutiny. In contrast, outpatient cancer rehabilitation programs have gained robust evidentiary support attesting to their benefits across diverse settings. Advancing PR will require attention to historical barriers to the uptake of cancer rehabilitation services, which include the following: patient and referring physicians’ expectation that effective cancer treatment will reverse disablement; breakdown of linear models of disablement due to presence of concurrent symptoms and psychological distress; tension between reflexive palliation and impairment-directed treatment; palliative clinicians’ limited familiarity with manual interventions and rehabilitation services; and, challenges in identifying receptive patients with the capacity to benefit from rehabilitation services. **Abstract:** <https://goo.gl/P6zuvn>

Caregivers needing care: The unmet needs of the family caregivers of end-of-life cancer patients

SUPPORTIVE CARE IN CANCER | Online – 27 September 2017 – The family caregivers (FCGs) of end-of-life (EoL) cancer patients take on the responsibility of many aspects of care for their patient, but many of their own needs remain unmet. The findings of this study can be used for healthcare policy planning and the development of palliative interventions, particularly for the FCGs of EoL cancer patients. The analysis of the data led to the formation of three main categories, including social needs, cognitive needs, and psychological needs. The social needs category comprised of the sub-categories of support for care, effective communication and financial support. The cognitive needs category comprised of educational support and support in decision-making. The psychological needs category comprised of support for psychological trauma, preparation to confront the reality of the death of a loved one, and support for mourning. **Abstract:** <https://goo.gl/JJ1bVM>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *NURSING ETHICS* | Online – 25 September 2017 – ‘**Nurse leaders’ role in medical assistance in dying: A relational ethics approach.**’ Recent changes to the Criminal Code of Canada have resulted in the right of competent adult Canadians to request medical assistance in dying (MAiD). The moral dilemmas raised by MAiD provide an opportunity to look at a relational ethics approach to nursing leadership both for MAiD and other difficult situations that arise in nursing practice. Relational ethics is a framework that proposes that the ethical moments in healthcare are based on relationships and fostering growth, healing, and health through the foundational concepts of mutual respect, engagement, embodiment, and environment. **Abstract:** <https://goo.gl/grCqFp>
- *SEATTLE JOURNAL FOR SOCIAL JUSTICE*, 2017;15(3). ‘**Three barriers to voluntary stopping eating and drinking by advance directive: A critical assessment.**’ Competent persons have the right to voluntarily stop eating and drinking as a means of hastening death, just as they have the right to refuse lifesaving medical treatment. If people do not lose their rights merely by becoming incompetent, then arguably their right to stop eating and drinking is not lost when they become incompetent. Such a right could be exercised on their behalf pursuant to an advance directive (AD). However, such directives to withhold food and fluids by mouth face significant legal and moral barriers. Among them are that consent is no defense to a charge of criminal homicide for failure to feed, that an incompetent person’s willingness to eat constitutes a change of mind revoking her directive, and that oral feeding is basic personal care that falls outside the legitimate scope of ADs. None of these three objections is persuasive. Strong reasons for rejecting them bolster the case for permitting the implementation of adequately clear directives to withhold food and fluids by mouth. **Full text:** <https://goo.gl/DuvBrC>

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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/nZMuK7>

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