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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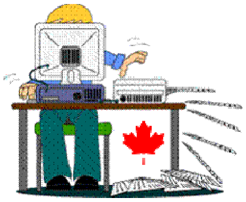

Compiled & Annotated by Barry R. Ashpole

Encompassing the holistic philosophy of palliative care: Scroll down to Specialist Publications and 'Addressing sexual issues in palliative care: A qualitative study on nurses' attitudes, roles and experiences' (p.13), in *Journal of Advanced Nursing*.

Canada

We are ignoring a key part of "dying with dignity"

ONTARIO | *The National Post* (Toronto) – 27 March 2018 – Ing Wong-Ward is disabled, dependent on a wheelchair and afflicted with colon cancer, accompanied, for the past year, by a stubbornly persistent abdominal abscess. This seems a depressing scenario, but Wong-Ward presents as anything but depressed in her promotional article for palliative care (PC) in *The Globe & Mail*...[1] Wong-Ward writes she was surprised to discover that PC – which, like many Canadians, she identified as meaning "you are about to die" – is more about guidance and protection for patients "who are coping with the most difficult time of their lives," which may or may not include the prospect of imminent death. In fact, Wong-Ward was told she may have years to live in spite of her cancer. But through consultation with a PC expert, her fears of a gruesome death (for although she wants no heroic measures at the end, she also does not wish to be euthanized) were assuaged, and she was given "the window I need to live my life, as compromised as it now is." Wong-Ward resists the freighted term "dying with dignity." She is well aware that many euthanasia proponents would not consider the constrained circumstances she grapples with "dignified," but that troubles her, as well it should. She is "trying to live with dignity as I always have, despite the very real medical indignities" she endures. It "dismays" her that the state makes it easy for people without terminal conditions to end their lives, and that lobby groups such ... are not "actively lobbying for increased access to palliative and hospice care." They aren't, because according to my reading of the literature, activists for euthanasia regard activists for PC as rivals for the same "customers," rather than purveyors of an equally worthy but different "product." https://goo.gl/RmN1qz

Specialist Publications

'A technology-enabled solution to manage referrals to hospice and palliative care beds: The Ottawa SMART system as a case study' (p.12), in *Healthcare Quarterly*.

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1. 'There is more than one way to die with dignity,' *The Globe & Mail* (Toronto, Ontario), 23 March 2018. https://goo.gl/mxuQsM

Supreme Court rejects son's appeal over dying mother's pain meds, sides with doctor

BRITISH COLUMBIA | *The Vancouver Sun* – 26 March 2018 – An 80-year old double amputee, who spent her last months between a Nanaimo hospital and a nursing home, was in so much pain that a highly distinguished palliative care (PC) doctor was consulted on ways to make her daily wound care dressing changes more tolerable with narcotics like morphine. Thomas William Sanders, the son of Arleane ... Sanders, had a health representation agreement on behalf of his mother, but wouldn't consent to heavy-duty pain medications for her. Dr. Robin Love, an internationally recognized PC doctor, was brought in to see the patient. Love, who has been honoured with numerous awards, overruled Sanders and prescribed a fentanyl patch and other medications for his mother. Eileen Sanders died on 22 March 2015. Her son had gotten the representation agreement the year before his mom died from complications of her peripheral vascular disease. Sanders' end-of-life experiences have played out in numerous legal hearings for three years because her son has filed complaints to every authority he could, starting with the College of Physicians & Surgeons of B.C. which dismissed his complaint about Love, finding he was diligent and attentive. The court reserved its decision after a three-day hearing last fall in Victoria, but has now issued its decision, ruling against Sanders.[1]
https://goo.gl/9iPD4D

1. *Sanders v. College of Physicians and Surgeons of British Columbia*, Supreme Court of British Columbia, March 2018**. Download/view ruling at:** https://goo.gl/fgYuCz

U.S.A.

Hospice providers get high marks on Centers for Medicare & Medicaid Services satisfaction surveys, but do they reflect reality?

MODERN HEALTHCARE | Online – 31 March 2018 – Interim is one of more than 4,000 hospice providers across the country required by the Centers for Medicare & Medicaid Services (CMS) since 2015 to send out the Consumer Assessment of Healthcare Providers & Systems (CAHPS) Hospice Survey to family members or risk a 2% Medicare payment cut. The requirement is part of the larger Hospice Quality Reporting Program mandated under the Affordable Care Act in an effort to move the sector to value-based payment. Along with the CAHPS hospice survey, the CMS program requires hospices to publicly report data on quality measures. In late February, the CMS for the first time posted findings on Hospice Compare from the CAHPS hospice surveys, which were gathered from April 2015 to March 2017. The results at first glance are a success story. A *Modern Healthcare* analysis shows that for each of the eight measures the CMS uses in the survey, on average at least 75% of respondents indicated they received a positive experience. The CMS dataset displays "top box" scores to show the CAHPS results, which is the percentage of respondents who gave the most positive responses for each measure. But experts are questioning the value of the surveys for consumers considering the overwhelmingly positive results and modest response rates. The results come after the CMS had to implement a correction to the Hospice Compare site last year because of inaccurate reporting regarding hospice locations and for-profit status. https://goo.gl/s8gczi

Specialist Publications

'The determinants of palliative care use in patients with colorectal cancer: A national study' (p.8), in *American Journal of Hospice & Palliative Medicine.*

'Improving psychological well-being and quality of life among palliative care nurses: Literature review' (p.14), in *American Journal of Nursing Research.*

'Availability of patient-centered cancer support services: A state-wide survey of cancer centers' (p.15), in *Plos One.*

'Death with dignity and mental disorder' (p.17), in *Arizona Law Review.*

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Related

- NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 28 March 2018 – **'Facts & Figures: Hospice Care in America.'** Hospice Medicare beneficiaries with a principal diagnosis of cancer dropped to 27.2% in 2016 while patients with Alzheimer's or dementia rose to 18% – up from 16.5% the previous year. When hospice first became available as a covered benefit under Medicare in 1983, the overwhelming majority of patients had cancer. That has changed in recent years with hospices caring for more people with a cardiac or circulatory diagnosis (18.7%), a respiratory illness (11%), and the fastest growing diagnosis of dementia. Hospice professionals continue to be concerned about the number of people who receive hospice care for a short period of time. The national organization's report indicates that that just over 40% of Medicare beneficiaries accessing hospice received care for 14 days or less in 2016, which is considered too short a period for patients to fully benefit from the person-centered care available from hospice. **Download/view at:** https://goo.gl/Kg28nN

Dying in prison

CONNECTICUT | WNPR News (Hartford) – 28 March 2018 – "Compassionate release" of our sickest and oldest prisoners is a way to reduce the federal prison population. It's also meant to save on the high cost of health care for aging inmates, and show some – well, compassion, to prisoners closing in on the end of their lives. Yet, the Bureau of Prisons approves few of the thousands of applications they receive from inmates – even with bipartisan support in Congress, and regardless of recommendations from prison doctors, counselors, and wardens recommend release. As a result, hundreds die in jail awaiting approval, many of them incarcerated for non-violent offenses. https://goo.gl/R4NAJE

Specialist Publications

'The health of America's aging prison population' (p.10), in *Epidemiologic Reviews*.

Noted in Media Watch 26 March 2018 (#556, p.2):

- *PSYCHOLOGY, PUBLIC POLICY & LAW* | Online – 24 March 2018 – **'Extraordinary and compelling: The use of compassionate release laws in the U.S.'** In 1984, federal compassionate release laws were established, allowing for the release of inmates given "extraordinary and compelling circumstances" not present at sentencing. Many states established similar laws. Despite possible financial and ethical benefits of compassionate release, few inmates have been released under these laws. This research explores why. **Abstract:** https://goo.gl/Vjo1zc

N.B. 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 (last updated 1 February 2018) can be downloaded/view at Palliative Care Network-e: https://goo.gl/YLckx6

You've detailed your last wishes, but doctors may not see them

THE NEW YORK TIMES | Online – 27 March 2018 – In the absence of nationwide standards, there's significant variability among hospitals and among electronic records. Some have worked to make end-of-life (EoL) documentation more easily accessible. At my hospital, for example, clicking on an 'Advance Care Planning' tab will bring you to a record of all advance care planning (ACP) notes, health care proxy forms, scanned directives and code status orders. Without a clear set of incentives, training and ongoing education, doctors (myself included) continue to record information about EoL conversations in progress notes, where they are not readily available, particularly when they are urgently needed. Recently, a handful of start-ups have stepped in, trying to offer a solution to the fact that different electronic records can't communicate with each other. There's software and clever patient apps that work outside the electronic record, promising to build a repository of directives, proxy forms, even conversations. What could really make a meaningful difference ... is standards for sharing, or "interoperability" across all electronic records

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that would benefit every patient, everywhere. At least, all related ACP documentation should be in one place in the medical record and accessible with one simple click of the mouse. Beyond that, maybe all health systems could require identification of a health care proxy for all patients, so we would know who should make decisions if the patient can't. Maybe patients should be able to access their health records through a patient-facing interface, send in their own directives, or even update related notes. Ideally, the electronic record isn't just a clunky online version of a paper chart, but actually a tool to help us do our jobs better. https://goo.gl/UMYSqs

Noted in Media Watch 12 May 2018 (#554, p.13):

- *SUPPORTIVE CARE IN CANCER* | Online – 4 March 2018 – **'A qualitative descriptive study on the use of electronic patient-physician communication in patients with advanced cancer.'** The authors identify five themes relating participants' perspectives on electronic communication to their experience of care: 1) Apparent gaps in care; 2) Uncertainty in defining the circle of care; 3) Relational aspects of communication; 4) Incongruence between technology and social norms of patient-physician communication; and, 5) Appreciation but apprehension about the team-based communication tool for improving the experience of care. **Abstract (inc. list of references):** https://goo.gl/SKTSJu

Noted in Media Watch 20 February 2017 (#500, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 February 2017 – **'Provider perspectives on advance care planning documentation in the electronic health record: The experience of primary care providers and specialists using advance health-care directives and Physician Orders for Life-Sustaining Treatment.'** The authors' findings imply the need for improved interoperability between hospital and outpatient electronic health records systems, consensus about which providers should document advance care planning (ACP), and widespread standardized clinic workflows for ACP. **Abstract:** https://goo.gl/jtWCrH

Federal advisory panel urges creation of palliative care model

MODERN HEALTHCARE | Online – 26 March 2018 – A federal advisory panel is recommending that the Department of Human & Health Services (HHS) pursue new models of care for Medicare patients in need of palliative care. The Physician-Focused Payment Model Technical Advisory Committee (PTAC), voted to forward proposals for two alternative payment models for review by the HHS secretary. The panel believes the ideas can be merged into one as both involve forming multidisciplinary care teams for patients in advanced stages of illnesses, but who are not yet ready for hospice care. While this population only makes up 4% of Medicare beneficiaries, it accounts for 25% of annual Medicare expenditures, according to researchers. Better coordination between providers could not only improve quality of care, but reduce costs, advocates for the new pay models argued. https://goo.gl/JvrncC

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | KHON 2 News (Honolulu) – 29 March 2018 – **'Medical aid-in-dying passes Senate, heads to governor.'** It's never come this far before. Now a measure that would legalize medical aid in dying heads to the governor. The Senate passed the measure in a 23-2 vote... Hawaii is close to becoming the seventh state to allow terminally ill adults with only six months to live the option to make their own end-of-life decisions. Lawmakers have closely examined this issue a number of times over the past two decades. https://goo.gl/SJ2pQL

- MASSACHEUSETTS | *The Telegram* (Worchester) – 28 March 2018 – **'Assisted suicide bill dies in Massachusetts legislature.'** For at least the fifth consecutive legislative session, bills that would open the door to doctors prescribing lethal doses for terminally ill patients were dropped from consideration by the Public Health Committee. Bills ... that would have legalized medical aid in dying ... were sent to study by the Joint Committee on Public Health, effectively spelling the end of the issue for this session. https://goo.gl/LKq2ws

International

Palliative care in Africa

Submission to the Universal Periodic Review of Senegal

AFRICA (Senegal) | Human Rights Watch – 29 March 2018 – In 2013, Human Rights Watch (HRW) found that only a few hospitals in the Senegalese capital provided palliative care (PC) for patients with end-stage cancer. The amount of morphine used was enough to treat just 179 patients with advanced cancer or AIDS – although about 70,000 people there required PC each year. During Senegal's 2013 Universal Periodic Review review, states recommended the improvement of living standards and further and continuous efforts to guarantee access to health. HRW recognizes the government's efforts to improve access to PC by boosting its estimate for morphine from 1,180 grams in 2012 to 40,329 grams; starting to supply oral morphine tablets to public hospitals; changing regulations limiting the prescription of morphine to seven days at a time to 28 days; and, working with the World Health Organization to train physicians, pharmacists, and health workers on using morphine. Moreover, the country's largest adult cancer unit hired a PC specialist. But much remains to be done. A recently published needs assessment, on which the health ministry cooperated with HRW, found that nearly half of hospitalized patients in four hospitals needed PC, and that many suffered from inadequately treated pain. The study recommends that the government prioritize training of health care workers and ensuring availability of relevant medications throughout the healthcare system.[1] https://goo.gl/2Z8F7R

1. 'Palliative care need and availability in four referral hospitals in Senegal: Results from a multi-component assessment,' *Journal of Pain & Symptom Management*, 2018;55(4):1122-1130. **Abstract (w. link to references):** https://goo.gl/4wsrgb

Specialist Publications

'What is the British Medical Association's advice on dropping unfunded work?' (p.11), in *GP*.

'Psychometric properties of the suffering assessment questionnaire in adults with chronic diseases or life-threatening illness' (p.15), in *Scandinavian Journal of Caring Sciences.*

Caring for the chronically ill in Bangladesh's Rohingya camps

BANGLADESH | IRIN Association (Formerly the UN's Integrated Regional Information Network) – 28 March 2018 – Along with the [Rohingya] refugees, medical workers flooded into Cox's Bazar [a town on the southeast coast of Bangladesh]. They treated traumatic injuries, raced to reverse severe malnutrition exacerbated by displacement and disease, and set up an emergency medical care system in the chaotic first weeks of the influx. But despite the scale of the response, healthcare advocates say thousands of people with incurable diseases are still ignored by a system that overlooks the needs of the dying or gravely ill. "I saw people were treating only acute patients and palliative care (PC) was being neglected," said Farzana Khan, a doctor who founded the Bangladesh-based Fasiuddin Khan Research Foundation, a private group that set up the programme that helps Sanjida and 200 other severely ill patients. Advocates of PC say it's the first programme to offer dedicated help for people with chronic or life-threatening illnesses during a humanitarian response. "There's absolutely no reason why PC can't be there as part of the health system," said Joan Marston, co-founder of PalCHASE (Palliative Care in Humanitarian Aid Situations & Emergencies Network), a U.K.-based organisation that advocates for such assistance to be included in responses to disasters and conflict.[1] "It really is about the dignity of the individual. There's enough indignity within these humanitarian situations." There's no allotment for PC in the recently released $950-million Rohingya [international] response plan, which outlines the aid sector's priorities through the end of the year.[2] But Marston said the scarcity of this kind of care during humanitarian emergencies reaches far beyond the current crisis in Bangladesh. https://goo.gl/WeHRQ6

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1. Palliative Care in Humanitarian Aid Situations & Emergencies Network: https://goo.gl/QdEAUz

2. 'JRP for Rohingya Humanitarian Crisis: March-December 2018.' International Organization for Migration, UN High Commissioner for Refugees, UN Resident Coordinator for Bangladesh & Inter Sector Coordination Group. **Download/view at**: https://goo.gl/WyaEyU

Noted in Media Watch 4 December 2017 (#541, p.13):

- *MEDICINE, CONFLICT & SURVIVAL* | Online – 4 December 2017 – **'What do humanitarian emergency organizations do about palliative care? A systematic review.'** Humanitarian emergency organizations have only recently integrated care for non-communicable diseases into their relief action. The needs for palliative care (PC) in emergencies are still largely unmet. A systematic review was undertaken of health programmes run by international humanitarian organizations that take (PC) and/or enhanced pain control into account. **Abstract (w. link to references):** https://goo.gl/7dahXr

N.B. Additional articles on the provision of palliative care during humanitarian emergencies noted in the 22 May 2017 issue of Media Watch (#513, p.19).

Alfie Evans: European Court of Human Rights rejects case

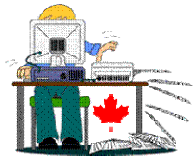
U.K. (England) | BBC News (London) – 28 March 2018 – A mother and father fighting a decision to switch off their toddler son's life support have lost their last-ditch legal bid. Tom Evans and Kate James want to take 22-month-old Alfie abroad for treatment. The couple took their case to the European Court of Human Right after exhausting all legal avenues in the U.K. But three judges ruled the submission "inadmissible." The panel's decision was final, the court said, adding that a request for an interim measure to stay a High Court order allowing medics to switch off his life support was also refused. Judges found no appearance of a violation of the European Convention on Human Rights, the court said. https://goo.gl/GKcPQQ

N.B. Earlier news media coverage of the Alfie Evans case noted in the 12 March 2018 issue of Media Watch (#554, p.3).

Survey reveals over 80% of families caring for seriously ill children feel alone

U.K. | *Charity Today News* – 28 March 2018 – 84% of families caring for a child with a life-limiting or life-threatening condition say they have felt isolated and alone since their child's diagnosis, according to a survey carried out by a U.K. children's palliative care charity.[1] There are over 49,000 babies, children and young people with life-limiting or life-threatening conditions across the U.K., and the number is rising. Most of these children have complex health conditions and need constant support and care 24 hours a day. The charity's report shows that a child's diagnosis can have negative effects on families' relationships with family, friends, neighbours and their wider community. Most of the families who took part in the survey said that they often felt isolated and their social life had suffered considerably because of their child's condition. The reasons cited for not going out socially ranged from exhaustion to a fear of being away from their child. https://goo.gl/njf7qi

1. "Hidden Lives: Tackling the social exclusion of families caring for a seriously ill child, Together for Short Lives, March 2018. **Download/review at:** https://goo.gl/7sx7Ts



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

Let Australians die as they want to, says Productivity Commission

AUSTRALIA (Victoria) | *The Sydney Morning Herald* – 26 March 2018 – Tens of thousands of terminally ill Australians are dying in hospitals when they would rather be dying at home, a highly critical Productivity Commission report has found.[1] A wide-ranging inquiry into ways to introduce competition and informed user choice into human services has found that most people want to die in surroundings that are familiar to them, surrounded by their family. Instead they are often rushed to hospital, even though it would be cheaper and more dignified to treat them where they lived. "Aged care facilities are Commonwealth government funded and the Commonwealth considers palliative care (PC) a state funding issue, so aged care facilities receive very little funding for PC," inquiry chairman Stephen King explained. "It means that if you are in an aged care facility, and you are getting towards the end of life and need an intervention, you will most likely be popped in an ambulance and sent off to hospital." The Commission also recommends that health insurance regulations be amended to make clear that patients can choose their own specialists rather than the ones their general practitioners (GPs) refer them to. The right is already enshrined in law, but many GPs and specialists are unaware of it. https://goo.gl/iHPWeu

Extract from Productivity Commission report

Providing community-based palliative care (PC) instead of hospital care to those who would prefer it is potentially cost effective. Available evidence indicates that the savings from avoiding a single hospital admission for PC (costing about $11,000) would more than cover the cost of providing community-based care over a period of months (costing between $6,000 and $10,000). However, the net cost to State and Territory Governments of increasing the availability of community-based PC will ultimately depend (amongst other things) on the extent of unmet demand, which is currently unknown.

Specialist Publications

'A qualitative evaluation of Australian palliative care services' participation in National Palliative Care Standards self-assessment' (p.16), in *Progress in Palliative Care.*

'Insights from linking routinely collected data across Australian health jurisdictions: A case study of end-of-life health service use' (p.16), in *Public Health Research & Practice*.

1. 'Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services' (See 'Caring for people at the end of life,' pp.8-13), Productivity Commission, Australian Government, 26 March 2018. **Download/view at:** https://goo.gl/Rq12qb

Noted in Media Watch 12 January 2018 (#546, p.4):

- AUSTRALIA (Victoria) | *The Sydney Morning Herald* – 9 January 2018 – **'"Not the way they wanted to die": Final wishes of thousands of Australians going unmet.'** The desire of thousands of gravely ill Australians to die without pain and surrounded by family is going unmet because palliative care services fall badly short. Just one palliative medicine specialist is available for every 704 deaths each year, according to Palliative Care Australia. The plea comes six months after a draft Productivity Commission report predicted without a significant policy overhaul, "tens of thousands of Australians will die in a way and in a place that does not reflect their values or their choices."[1] https://goo.gl/AW8Ex1

  1. 'Reforms to Human Services,' Productivity Commission, Australian Government, June 2017. [Noted in the 5 June 2017 issue of Media Watch (#515, p.4)] **Download/view at:** https://goo.gl/VoBZBX

N.B. Additional articles on palliative and end-of-life care in Australia noted in the 27 November and 18 December 2017 issues of Media Watch (#540, p.7 and #543, p.9, respectively).

Specialist Publications

The use of humor in palliative care: A systematic literature review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 March 2018 – Humor has its own place in the context of medicine. Nevertheless, its acceptance by terminal stage patients and health-care professionals has not been studied in depth and is not free from controversy. A total of 156 studies were identified, which were then filtered in pairs by means of an established hierarchy, selecting studies that discussed the use of humor specifically in palliative care (PC) from all perspectives and designs, and finally published in Spanish, English, French, or Portuguese. Critical reading of all the selected studies took place, with no exclusions due to quality evaluation. Thirty-four studies were included. Five main topics were identified: 1) Definition of humor; 2) Use and functions of humor in PC; 3) How to use humor; 4) When not to use humor; and, 5) Humor before and after the diagnosis of terminal illness. **Abstract:** https://goo.gl/Qp8nP1

Noted in Media Watch 26 February 2018 (#552, p.13):

- *HOLISTIC NURSING PRACTICE*, 2018;32(2):98-106. **'Grieving with humor: A correlational study on sense of humor and professional grief in palliative care nurses.'** The aim of this study was to explore the relationship between humor and professional grief. Findings confirm that these are not independent phenomena. Using humor as a coping mechanism emerged as a response to death-related work. Likewise, positive attitudes toward humor seem to alleviate the distress associated with end-of-life care. **Abstract:** https://goo.gl/3qyyEG

N.B. Additional articles on humour in the context of palliative care noted in Media Watch 29 February 2016, #451 (pp.7-8).

The determinants of palliative care use in patients with colorectal cancer: A national study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 March 2018 – A total of 287,923 patients were analyzed. Overall, 4.3% of the patients received palliative care (PC). Patients who received PC were more likely to be younger, recently diagnosed, treated at academic hospitals, and have Stage IV disease. Patients living in Mountain and Pacific regions had higher odds of PC receipt than those in the East Coast. Patients without insurance had higher odds of PC if they survived <24 months. Insurance coverage through Medicaid was associated with increased PC use among patients who survived 6 to 24 months. Patients who survived <6 months and lived >9 miles from the institution received more PC. **Abstract:** https://goo.gl/u59k5x

Noted in Media Watch 19 March 2018 (#555, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 March 2018 – **'Surgeons' perceived barriers to palliative and end-of-life care: A mixed methods study of a surgical society.'** Nearly 20% of colorectal cancer patients present with potentially incurable (Stage IV) disease, yet their physicians do not integrate cancer treatment with palliative care. Compared with patients treated by primary providers, surgical patients with terminal diseases are significantly less likely to receive palliative or end-of-life care. **Full text:** https://goo.gl/2qXbeV

From a good death to a better bereavement? The impact of the end of life experience on bereavement adjustment, a thematic analysis

BEREAVEMENT CARE | Inprint – 27 March 2018 – To date, the majority of research into a good death has focused on the experience of the person who is dying. Taking the perspective of bereaved individuals, this qualitative study explores which elements of the end of life (EoL) experience constitute a good death and how these elements influence the process of bereavement adjustment. Following interviews

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With ten bereaved adults four themes were identified which together define a good death: 1) A lack of physical distress; 2) Emotional resolution; 3) "Naming death as death"; and, 4) Death at "the right time." The value of open communication prior to death is highlighted. For those working with bereaved individuals these results support an understanding of the impact of the manner of death on bereavement adjustment. For those in palliative care settings, potentially modifiable elements of the EoL experience which may support better bereavement are suggested. **Abstract:** https://goo.gl/rM4W5x

Palliative care for people with schizophrenia: A qualitative study of an under-serviced group in need

BMC PALLIATIVE CARE | Online – 27 March 2017 – This study builds on previous literature to confirm that Western Australian people with schizophrenia at the end of life (EoL) are at risk of not receiving good medical and psycho-social care, including palliative care (PC). They have complex needs that challenge the general health workforce as well as the more sympathetic practitioners in mental health and PC. Barriers to PC are outlined, but more importantly facilitators to PC are presented that identify key indicators needed to ensure good care. These include identifying a carer or nominating an advocate for the person, case conferencing in multidisciplinary and cross sector teams, and building capacity within the pre-existing workforce and care providers through education and advocacy. Inclusive and collaborative models of care are required and resources should be allocated to both specialised PC and mental health services so that people with schizophrenia can claim their right to have their EoL needs addressed with compassion and skill. **Full text:** https://goo.gl/HxhSVC

Noted in Media Watch 9 June 2014 (#361, p.14):

- *JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH SERVICES*, 2014;52(8):32-38. **'Palliative care for terminally ill individuals with schizophrenia.'** Individuals with schizophrenia are often medically undertreated and experience symptoms that interfere with communication and the capacity to make medical decisions. These issues complicate quality end-of-life care for this population and are of particular concern for hospice and palliative care nurses and health care providers. **Abstract:** https://goo.gl/13zi8r

N.B. Additional articles on palliative care for people living with schizophrenia noted in this issue Media Watch.

A review of paper-based advance care planning aids

BMC PALLIATIVE CARE | Online – 27 March 2018 – This study identifies a need for paper-based aids that support and empower patients to initiate meaningful advance care planning (ACP). All examined aids presented ACP solely within an end-of-life (EoL) framing. The findings suggest that to meet patients' needs and create patient-centered ACP aids, active patient involvement is a necessary, and often missing, component and ACP aids need to explore framing beyond specific EoL care situations. By identifying and classifying different categories of paper-based ACP aids, the study provides a useful framework that clinicians might use to help inform the selection of an ACP aid that is most appropriate to their patients and to alternative decision makers. Additionally, these findings have helped guide the development of a new ACP aid, and have provided a framework by which future ACP aids might be measured. **Full text:** https://goo.gl/fXWkED

Value-impregnated factual claims may undermine medical decision-making

CLINICAL ETHICS | Online – 27 March 2018 – Clinical decisions are expected to be based on factual evidence and official values derived from healthcare law and soft laws such as regulations and guidelines. But sometimes personal values instead influence clinical decisions. One way in which personal values may influence medical decision-making is by their affecting factual claims or assumptions made by

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healthcare providers. Such influence, which the authors call "value-impregnation," may be concealed to all concerned stakeholders. They suggest as a hypothesis that healthcare providers' decision making is sometimes affected by value-impregnated factual claims or assumptions. If such claims influence e.g., doctor-patient encounters, this will likely have a negative impact on the provision of correct information to patients and on patients' influence on decision making regarding their own care. The authors explore the idea that value-impregnated factual claims influence healthcare decisions through a series of medical examples. **Full text:** https://goo.gl/8c7Xm2

Noted in Media Watch 27 January 2014 (#342, p.14):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – Accessed 24 January 2014 – **'Are physicians' estimations of future events value-impregnated? Cross-sectional study of double intentions when providing treatment that shortens a dying patient's life.'** The authors used questionnaire based cross-sectional design and described a situation where an imminently dying patient was provided with alleviating drugs which also shortened life and, additionally, were intended to do so. They asked what would happen to physicians' own trust if they took the action described, and also what the physician estimated would happen to the general publics' trust in health services. **Abstract (inc. list of references):** https://goo.gl/88DFtS

The health of America's aging prison population

EPIDEMIOLOGIC REVIEWS | Online – 23 March 2018 – In this systematic review, the authors summarize the epidemiologic evidence of the health challenges facing the aging U.S. prison population. Their comprehensive literature search focuses on health outcomes, including diseases, comorbid conditions, mental health, cognition, and mobility. From 12,486 articles identified from the literature search, the authors reviewed 21 studies published between 2007 and 2017. All were observational and cross-sectional, and most were based on regional samples. Sample sizes varied widely, ranging from 25 to 14,499 incarcerated people... In general, compared with their younger counterparts, older incarcerated individuals reported high rates of diabetes mellitus, cardiovascular conditions, and liver disease. Mental health problems were common, especially anxiety, fear of desire for death or suicide, and depression. Activities of daily living were challenging for up to one-fifth of the population. The authors found no empirical data on cognition among older incarcerated individuals. The findings of this review reveal few empirical data in this area and highlight the need for new data to drive policy and practice patterns that address critical health issues related to the aging prison population. **Full text:** https://goo.gl/TmdFXK

Extract from *Epidemiologic Reviews* article

Researchers ... evaluated preferences for end-of-life care, reporting that ethnic minority incarcerated individuals who did not have a life sentence, and who had greater anxiety about death, had a greater desire for a feeding tube, whereas white incarcerated individuals were more likely to seek palliative care. Loneliness and lower valuation of life were associated with greater depressed mood, which, in turn, was associated with more medical co-morbidity.

Noted in Media Watch 26 May 2018 (#556, p.16):

- *PSYCHOLOGY, PUBLIC POLICY & LAW* | Online – Accessed 24 March 2018 – **'Extraordinary and compelling: The use of compassionate release laws in the U.S.'** In 1984, federal compassionate release laws were established, allowing for the release of inmates given "extraordinary and compelling circumstances" not present at sentencing. Many states established similar laws. Despite possible financial and ethical benefits of compassionate release, few inmates have been released under these laws. This research explores why. **Abstract:** https://goo.gl/Vjo1zc

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 beginning on p.19.

The association between assisted living direct care worker end-of-life training and hospice use patterns

GERONTOLOGY & GERIATRIC MEDICINE | Online – 27 March 2018 – The Institute of Medicine's report on Dying In America recommends non-physician direct care workers to have evidence-based educational programs available to them so as to be equipped to provide quality of end-of-life care (EoLC).[1] The results from this small pilot study data are encouraging related to EoLC training and the increase in hospice use. Assisted living (AL) communities will continue to serve an increasingly large portion of the older adult population in need of EoLC. The direct care workforce who cares for this older adult population needs to be prepared to provide end-of-life and palliative care. Given the growing demand for EoLC in ALs, the regulation of requiring some type of educational program related to providing care for the terminally ill for direct care staff as is done in some states with competency evaluations by a nurse or hospice agency should become a common practice for all states. Because hospice care is widely accepted as the gold standard for EoLC for dying persons, any end-of-life educational program should incorporate information about hospice as a key resource for residents in need of this type of care. **Full text:** https://goo.gl/syFA6K

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** http://goo.gl/mm4o6W

What is the British Medical Association's advice on dropping unfunded work?

GP | Online – 26 March 2018 – Some 70% of *GP* partners responding to a GPonline poll say that their practice provides some non-core services, for which they receive no extra funding. Given the shortage of GPs, increased demand from patients, and practices' ballooning workloads, unsurprisingly 59% of partners say that they are considering dropping unfunded work in the coming 12 months. However, GPonline's figures suggest that practices find it difficult to stop providing these services. GPonline has been tracking this issue since 2015 when the the British Medical association (BMA) published its guidance...[1] In each survey across the years the proportion of partners saying their practice provides some work for free has remained broadly similar, as has the number saying they plan to drop unfunded work, suggesting little has changed in the last three years. Comments from this year's survey highlight why practices often feel they have no choice but to provide some services for free. What do we mean by unfunded work? Part of the problem is that GPs – and commissioners – are often unclear about what work should be classed as non-core and therefore attract extra payment under an enhanced service or other local funding arrangement. The BMA issued guidance last year ... which details a list of 88 enhanced services "that have been commissioned somewhere in the U.K."[2] **Full text:** https://goo.gl/k38rM5

Extract from *GP* report

We have an elderly population – there is no extra funding for dealing with masses of frailty and co-morbidities, nor for all the hours we put into providing excellent palliative care – a cornerstone of general practice.

1. 'Quality first: Managing workload,' February 2018. **Download/view at:** https://goo.gl/vziYcp

2. 'Enhanced services," May 2016. **Download/view at:** https://goo.gl/75QLTw

Palliative Care Network

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

Nudge or grudge? Choice architecture and parental decision-making

THE HASTINGS REPORT, 2018;48(2):33-39. Much has been written about the ethics of nudging competent adult patients. Less has been written about the ethics of nudging surrogates' decision-making and how the ethical considerations and arguments in that context might differ. Even less has been written about nudging surrogate decision-making in the context of pediatrics, despite fundamental differences that exist between the pediatric and adult contexts. Yet, as the field of behavioral economics matures and its insights become more established and well-known, nudges will become more crafted, sophisticated, intentional, and targeted. Thus, the time is now for reflection and ethical analysis regarding the appropriateness of nudges in pediatrics. The authors argue that there is an even stronger ethical justification for nudging in parental decision-making than with competent adult patients deciding for themselves. They give three main reasons in support of this: 1) Child patients do not have autonomy that can be violated (a concern with some nudges), and nudging need not violate parental decision-making authority; 2) Nudging can help fulfill pediatric clinicians' obligations to ensure parental decisions are in the child's interests, particularly in contexts where there is high certainty that a recommended intervention is low risk and of high benefit; and, 3) Nudging can relieve parents' decisional burden regarding what is best for their child, particularly with decisions that have implications for public health. **Abstract:** https://goo.gl/k9wM7g

> **N.B.** Additional articles on the ethics of nudging noted in the 8 January 2018 issue of Media Watch (#545, pp.6-7).
>
> **Related**
>
> - *ARCHIVES OF DISEASE IN CHILDHOOD: EDUCATION & PRACTICE* | Online – 24 March 2018 – '**Fifteen-minute consultation: Developing an advance care plan in partnership with the child and family.**' When performed well, the process provides all those involved with the opportunity to talk honestly about the future allowing children and their families to retain autonomy and to influence how they are looked after. While this may represent a difficult area of practice for healthcare professionals, both staff and families appear to benefit when the process is fully informed and the child and family are actively involved. **Full text:** https://goo.gl/QgtACy

A technology-enabled solution to manage referrals to hospice and palliative care beds: The Ottawa SMART system as a case study

HEALTHCARE QUARTERLY, 2018;20(4):63-67. Ottawa has a 31-bed palliative care unit (PCU) and two residential adult hospices (total 19 beds). In 2013, the authors initiated a project to improve the referral and triage processes to these beds. Previously, there were two separate paper-based systems with duplication, inefficiencies, delays and inappropriate patient placements. The multipronged approach included clarifying the respective roles of the PCU and hospices, creating a single referral and triage office and developing an e-platform. The authors leveraged technology that was available in the public-funded system. This paper describes the development processes, lessons learned, and the final system, referred to as System to Manage Access, Referrals & Triage (SMART). **Abstract:** https://goo.gl/ASrV7a

The effect of hospice on hospital admission and readmission rates: A review

HOME HEALTH CARE MANAGEMENT & PRACTICE | Online – 23 March 2018 – Symptom control may become challenging for terminally ill patients as they near the end of life. Patients often seek hospital admission to address symptoms, such as pain, nausea, vomiting, and restlessness. Alternatively, palliative medicine focuses on the control and mitigation of symptoms, while allowing patients to maintain their quality of life, whether in an outpatient or inpatient setting. Hospice care provides, in addition to inpatient care at a hospice facility or in a hospital, the option for patients to receive symptom management at home. This option for symptom control in the outpatient setting is essential to preventing repeated and expensive hospital readmissions. This article discusses the impact of hospice care on hospital readmission rates. **Abstract (inc. list of references):** https://goo.gl/ms4GoU

Addressing sexual issues in palliative care: A qualitative study on nurses' attitudes, roles and experiences

JOURNAL OF ADVANCED NURSING | Online – 25 March 2018 – Patients and their partners in palliative care (PC) might experience dramatic changes in their sexuality and want nurses to provide the opportunity to address them. Moreover, it is argued that the holistic philosophy of PC encourages nurses working in this area to include sexual issues in their daily care. In this study, the way PC nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying PC. The different interpretations of these principles create tensions for nurses about how to address sexual issues in the daily practice of PC and nurses vary in their reactions to these tensions. The present findings show that PC nurses – when they were able to overcome these tensions – use a "sex-positive approach" that fits with their tendency to focus on quality of life. **Abstract:** https://goo.gl/DiWJ82

Noted in Media Watch 11 September 2017 (#529, p.5):

- *AUSTRALIAN HOSPITAL & HEALTHCARE BULLETIN* | Online – 1 September 2017 – **'Sexuality, intimacy and palliative care.'** "Sexuality and dying are considered taboo subjects, and most people feel that people in this stage of their lives are too ill to think about sex," says Brigitte Karle, clinical nurse educator with HammondCare. "But our palliative care staff – and our patients – recognise that sexuality is part of the holistic care of patients, and this has resulted in the 'Let's Talk About It' program. We need to make it easier for patients, their partners and staff to feel that they can have the conversation without being uncomfortable," she said. **Full text:** https://goo.gl/desUWQ

N.B. Additional articles on sexuality and intimacy in the context of living with a life-limiting or terminal illness noted in the 13 March 2017 issue of Media Watch (#503, pp.4,16).

The role of healthcare chaplains in resuscitation: A rapid literature review

JOURNAL OF RELIGION & HEALTH | Online – 22 March 2018 – This review found few studies that directly explored the topic. Certainly many view the chaplain as a key member of the resuscitation team, although this role has not been fully explored. Chaplains likely have a key role in supporting families during decisions about not for resuscitation and in supporting families during and after resuscitation procedures. Chaplains are key personnel, already employed in many healthcare organisations, who are in a pivotal position to contribute to future developments of spiritual and pastoral care provision and support. Their role at the end of life (EoL), despite well described and supported, has received little empirical support. There is an emerging role for chaplains in healthcare ethics, supporting EoL decisions and supporting family witnessed resuscitation where relevant. Their role needs to be more clearly understood by medical staff, and chaplain's input into undergraduate medical education programmes is becoming vital. **Abstract (inc. list of references):** https://goo.gl/6mg2sc

The competence of families in paediatric palliative care

MÉDECINE PALLIATIVE | Online – 30 March 2018 – In general, a huge number of different actors and caregivers are involved in pediatric palliative care (PC) and in particular when a child has multiple disabilities. While each actor has an area of competence, that of the family is the most difficult to make exist and to acknowledge. The authors share their vision, with a critical look on the caregivers' postures and by going beyond the usual perception attributed to the families. They first establish the asymmetry and the different ways of thinking of caregivers and the families. Furthermore, the authors develop various family skills and their evolution during the often-long period of paediatric PC. The recognition of families' various competences increases their development, but it also facilitates the collaboration between caregivers and families and therefore paediatric PC. **Abstract:** https://goo.gl/1jSkhj

N.B. French language article.

When a mobile palliative care team arrives at a residence for people with disabilities: What questions does that raise? What's at stake?

MÉDECINE PALLIATIVE | Online – 28 March 2018 – The palliative care (PC) support team mission is to spread the palliative culture wherever patients need this care, including in the structures in charge of people with disabilities. Those centres are increasingly soliciting the PC support team. The experiences presented in this study illustrate the challenge faced by these teams, as well as the ethical issues raised by the palliative approach in the handicap world. Both of these fields, the handicap and the PC, often attest a mutual improvement of such collaboration. **Abstract:** https://goo.gl/k2S42b

N.B. French language article.

Communication of genetic information in the palliative care context: Ethical and legal issues

MEDICAL LAW INTERNATIONAL | Online – 23 March 2018 – In the palliative care (PC) context, the question of when and how to disclose a patient's genetic information raises a host of ethical, legal, and social issues, including the challenges of communicating during the end-of-life (EoL) stage and complex familial and cultural dynamics. The authors outline the legal components of these issues in three civil law jurisdictions with similarly comprehensive approaches to healthcare and PC – Quebec, Belgium, and France – and provide insights from bioethics literature and normative documents on the disclosure of genetic information at the EoL. From this research, they propose a strategy for PC providers who are considering available options to communicate hereditary health information. **Abstract:** https://goo.gl/1VgvUV

Noted in Media Watch 27 November 2017 (#540, p.13):

- *JOURNAL OF COMMUNITY GENETICS* | Online – 20 November 2017 – **'Mainstreaming genetics in palliative care: Barriers and suggestions for clinical genetic services.'** Palliative healthcare professionals (PHCPs) frequently do not refer their eligible patients for genetic testing. After the death of the affected individual, clinically relevant information for family members is lost. In previous research, PHCPs stated that the end-of-life setting is not appropriate to discuss genetic issues. It is unclear if this has changed due to increasing awareness of genetics in the media and efforts to mainstream genetic testing. **Abstract:** https://goo.gl/yXYgBQ

The psychological and spiritual dimensions of palliative care: A descriptive systematic review

NEUROPSYCHIATRY, 2018;8(2):484-494. Lack of definitional consensus of spirituality is still evident. Nevertheless, spiritual well-being was considered an important component of quality of life, closely related to physical and psychological distress symptoms, therefore highlighting the importance of psychological and psychiatric care in enhancing the wellbeing of palliative care (PC) patients. Understanding the interface of the psychological and spiritual dimensions of adult PC patients may contribute to a more efficient therapeutic practice. Training healthcare professionals to improve spiritual support and appropriately addressing these issues should be of great importance in PC settings, thus promoting an appropriate response to the patients' needs and dying process. **Full text:** https://goo.gl/NkUGwA

Improving psychological well-being and quality of life among palliative care nurses: Literature review

AMERICAN JOURNAL OF NURSING RESEARCH, 2018;6(3):82-86. The authors identify the most commonly reported problems associated with the psychological well-being and quality of life (QoL) among palliative care (PC) nurses. This study provides important recommendations to support PC nurses and overcome different challenges that they face. Considering the authors' recommendations, improving nurses' psychological health and QoL is essential to help them provide quality PC for patients. However, additional research is needed to identify the most effective methods for improving PC nurses' psychological health and QoL. **Full text:** https://goo.gl/EL8Spb

Cont.

Related

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 26 March 2018 –'**Psychometric properties of the suffering assessment questionnaire in adults with chronic diseases or life-threatening illness.'** Suffering has been considered by many authors to be a difficult concept to assess and measure, as it is subjective and unique. However, to guide the diagnosis and decision-making of healthcare professionals, it is important to develop an instrument that differentiates the different suffering dimensions, namely, intra- and interpersonal suffering, awareness of suffering and spiritual suffering. The aim of this study was to design and validate an instrument for the assessment of the dimensions of suffering in adult patients with chronic diseases or life-threatening illnesses.. **Abstract:** https://goo.gl/qkWMf8

Noted in Media Watch 19 March 2018 (#555, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 March 2018 – **'Spiritual distress within inpatient settings: A scoping review of patient and family experiences.'** Within the 37 articles meeting inclusion criteria, the authors identified six themes: 1) Conceptualizing spiritual distress (SD); 2) Diagnosis and prevalence; 3) Assessment instrument development; 4) Experiences; 5) Associated variables; and, 6) Barriers and facilitators to clinical support. The majority of studies focused on patients; two studies focused on family caregivers. The most common clinical settings were oncology and advanced disease. **Abstract (inc. list of references):** https://goo.gl/JguF67

N.B. The *European Journal of Palliative Care* published a series of articles, 'Psychology in palliative practice,' each noted in past issues of Media Watch. Access to the journal, however, requires a subscription. **Journal website:** https://goo.gl/mDQWH7

Availability of patient-centered cancer support services: A state-wide survey of cancer centers

PLOS ONE | Online – 27 March 2018 – No systems exist in the U.S. to support state-level data collection on availability of support services for cancer patients. Developing a mechanism to systematically collect these data and document service availability is essential for guiding comprehensive cancer control planning efforts. This study was carried out to develop a protocol for implementing a state-wide survey of all Commission on Cancer (CoC) accredited cancer centers in South Carolina and to implement the survey to examine availability of patient support services within the state. We conducted a cross-sectional survey of CoC-certified cancer centers in South Carolina. An administrator at each center completed a survey on availability of five services: 1) Patient navigation; 2) Distress screening; 3) Genetic risk assessment and counseling; 4) Survivorship care planning; and, 5) Palliative care (PC). Completed surveys were received from 16 of 17 eligible centers (94%). Of the 16 centers, 44% reported providing patient navigation; 31% reported conducting distress screening; and, 44% reported providing genetic risk assessment and counseling. Over 85% of centers reported having an active PC program, PC providers and a hospice program, but fewer had palliative outpatient services (27%), palliative inpatient beds (50%) or inpatient consultation teams (31%). This was a small, yet systematic survey in one state. This study demonstrated a practical method for successfully monitoring state-wide availability of cancer patient support services, including identifying service gaps. **Full text:** https://goo.gl/PrSkZC

Palliative care initiatives in South Carolina

Most cancer centers in this survey had service components such as an active palliative care (PC) program, a PC nurse, and/or physician and a hospice program either available onsite or by referral. This finding suggests that some level of basic PC is available to patients across the state. However, the lack of a hospice outpatient program, dedicated PC beds and an inpatient consultation team at many centers suggests that additional components are needed in many areas across the state to be able to provide comprehensive palliative services. For example, PC beds and an inpatient consultation team would be needed to promote transition of patients from curative to PC to enhance comfort and support earlier in their illness. Similarly, hospice outpatient programs would be needed to meet the needs of terminally ill patients in their home environment, perhaps after a transition from inpatient PC. Together these findings pinpoint clear areas for improvement to support holistic and streamlined systems for delivery of PC.

Cont.

Noted in Media Watch 16 October 2017 (#534, p.16):

- *SUPPORTIVE CARE IN CANCER* | Online – 9 October 2017 – **'Palliative care content on cancer center websites.'** The authors conducted a content analysis of 62 National Cancer Institute designated cancer center websites. 10% had no webpage with palliative care (PC) information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. **Abstract (inc. list of references):** https://goo.gl/6vEYhL

End-of-life care in Australia

A qualitative evaluation of Australian palliative care services' participation in National Palliative Care Standards self-assessment

PROGRESS IN PALLIATIVE CARE | Online – 27 March 2018 – The National Standards Assessment Program (NSAP) is an Australian initiative for monitoring and supporting specialist palliative care (PC) services to align with Standards for providing quality PC for all Australians. It comprises evaluation of 13 National Palliative Care Standards and their elements with the purpose of identifying priority areas to focus improvement activities; strategies include peer mentor visits (PMVs) and use of evidence-based resources. Monitoring of participants' organizational quality is structured into the program. A key strength of NSAP was the cycle between data collection, identification of key improvement areas, and development of strategies for improvement. An understanding of NSAP as a continuous quality improvement process and the potential for the integration of other national programs were noted as key service improvement strategies. The use of resources to promote best practice largely relied upon access to the Internet. PMVs were considered successful, contingent on careful matching of mentors to services. The presence of a "champion" within services was perceived as a success factor. **Abstract:** https://goo.gl/nCjWKx

Related

- *PUBLIC HEALTH RESEARCH & PRACTICE,* 2018;28(1):e2811806. **'Insights from linking routinely collected data across Australian health jurisdictions: A case study of end-of-life health service use.'** In Australia, there are currently barriers to accessing and using comprehensive linked health data crossing community and hospital care. Similar challenges are faced internationally. For example, a recent comparison of end-of-life care in seven developed countries using health administrative data was limited to hospital-based care, and only two of the seven countries were able to report data after 2010.[1] **Full text:** https://goo.gl/Fkrxt7

[1] 'Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries,' *Journal of the American Medical Association*, 2016;315(3):272-283. [Noted in the 25 January 2016 issue of Media Watch (#446, p.14). **Full text:** http://goo.gl/UWG881

About the good use of illusions in oncology. End-of-life experiences and communications in adolescent patients

RECENTI PROGRESSI IN MEDICINA, 2018;109(3):166-173. This article aims to describe the psychological mechanisms which affect teenage patients with terminal cancer in order to allow the best quality of life possible. The adaptation of teenager patients suffering from terminal illnesses is also related to other non-medical issues such as psychological, legal and ethical considerations. A correct and balanced communication with such patients is needed in order of maintaining a positive mental approach ("hope") so that the teens are able to come to terms with the hard reality. Several case studies are presented that ... show the importance of developing an area of illusion, which allows patients to face up to the extreme distress and anxiety of their reality, without completely denying the reality itself. These hypotheses at the moment need more empirical evidences, but they demonstrate the complex mental process involved with terminally ill adolescent patients coming to terms with their situations and show the importance of considering such process in all aspects of clinical care and treatment, in order to best address their physical and psychological well-being. **Abstract:** https://goo.gl/RqAhke

N.B. Italian language article.

"Being with" or "doing for"? How the role of an end-of-life volunteer befriender can impact patient wellbeing: Interviews from a multiple qualitative case study

SUPPORTIVE CARE IN CANCER | Online – 29 March 2018 – Impacts from volunteer befriending or neighbour services may be achieved through volunteers taking a more practical/goal-based orientation to their role and/or taking a more relational and emotional orientation based on conversation, sharing stories and expressing feelings. The exact combination and weighting given to both of these aspects of the role must be determined by the needs of the patient and their relationship with the volunteer. Training of volunteers must equip them to be aware of these differing elements of the role and sensitive to when it is necessary to depend on one facet of the role or the other. Clinicians can support volunteer provided befriending services, as these appear to have emotional and social benefits which clinical services may struggle to provide. This research identifies the domains these services have influence in, and the challenge for future researchers is to identify how to measure impact across these domains to enable targeting of services where resources (e.g. volunteers) may be limited. This is one of the largest qualitative studies of volunteers providing care towards the end of life and has particular strengths in its focus on the voice of people being supported as well as those of staff or volunteers. **Full text:** https://goo.gl/E3jvaw

Related

- *SYMBOLIC INTERACTION* | Online – 26 March 2018 – **'"They are just like you and me": Cultivating volunteer sympathy.'** This study demonstrates the centrality of emotion work, especially sympathizing with beneficiaries of help, to sustaining volunteerism. Drawing on data from in-depth interviews with 42 volunteers and paid volunteer coordinators, it explains how volunteers cultivate sympathy, and thus commitment to helping, by framing beneficiaries as deserving. Volunteers constructed recipients as "deserving" along three dimensions: neediness, blamelessness, and impressionability. **Abstract:** https://goo.gl/fY9CgH

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ARIZONA LAW REVIEW*, 2018;60(1):115-161. **'Death with dignity and mental disorder.'** Legal scholars and bioethicists are divided over whether someone with a mental disorder should have access to physician-assisted dying. Some object to physician-assisted dying itself, while others support a right to assisted dying for people with terminal illnesses, but are unwilling to extend that right to people with mental illnesses. The author argues that when a person requests the assistance of a physician to hasten her death, the only concern should be whether he/she is competent to consent to physician-assisted dying. A large empirical literature has shown that mental disorder is not synonymous with incompetence. **Full text:** https://goo.gl/yHmqKa

- *INTERNATIONAL JOURNAL OF HUMAN RIGHTS IN HEALTHCARE* | Online – Accessed 31 March 2018 – **'Transcendence/religion to immanence/non-religion in assisted dying.'** The purpose of this paper is to draw attention to the ways in which the Supreme Court of Canada has shifted away from transcendent/religious to non-religious conceptualizations of assisted-dying. The research points to a shift away from religious to non-religious understandings in the way the Court conceptualizes suffering, pain, illness and assisted-dying. **Abstract:** https://goo.gl/muYUnJ

- *THEORETICAL MEDICINE & BIOETHICS* | Online – 20 March 2018 – **'Physician-assisted dying: Thoughts drawn from Albert Camus' writing.'** Hopelessness, as a basic aspect of the human condition, is a central topic in Albert Camus' philosophical work *The Myth of Sisyphus*, which addresses the question of suicide. Suffering in the face of a hopeless situation, and the way doctors approach this suffering, is the topic of *The Plague*... The author draws philosophical and ethical conclusions about physician-assisted dying based on an analysis of central concepts in the work of Camus – specifically, those treated in *The Myth of Sisyphus* and *The Plague*. On the basis of her interpretation of Camus' work, the author argues that hopelessness and unbearable suffering are useless as eligibility criteria for physician-assisted dying, given that they do not sufficiently elucidate where the line should be drawn between patients who should to be eligible for assistance and those who should not. **Abstract (inc. list of references):** https://goo.gl/rcUKnd

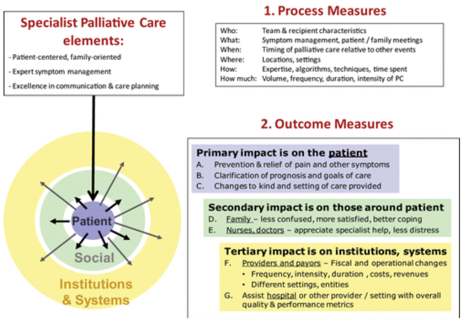
N.B. French-born Albert Camus (1913-1960) was a philosopher, author and journalist.

Worth Repeating

The importance of following the money in the development and sustainability of palliative care

PALLIATIVE MEDICINE, 2013;27(2):103-104. Questions about cost-effectiveness and efficiency of health care are universal across developed economies, regardless of the under-lying political economy of a given country or the financing of its health care system. The articles from Klinger *et al* regarding home-based palliative care (PC) in rural Ontario, and from Roberts and Hurst,[1,2] regarding inpatient PC unit staffing in England, are two cases in point. As our field continues to mature and develop, we can expect to see more of such studies taking place worldwide, because they shed much-needed light on management and sustainability issues in specialist PC. The study from Roberts and Hurst makes salient the point that sustainability in our field involves not only monetary inputs (resources, represented as costs) but also workforce availability. Availability is influenced by many factors across the world, including funding for specialist education and training, as well as issues of satisfaction, burnout, and turnover among specialist staff. Klinger *et al* go beyond a snapshot of current practices and attempt projections of what future, broader utilization could look like. [Noted in the 11 February 2013 issue of Media Watch (#292, p.11)] **Full text:** https://goo.gl/P4MpLv

Measurement model for specialist palliative care



1. 'Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life *Shared-Care Project,' Palliative Medicine*, 2013;27(2):115-122 (first published online 16 January 2012). [Noted in Media 23 January 2012 issue of Media Watch (#237, p.10)] **Abstract (w. list of references):** https://goo.gl/6UXx4j

2. 'Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data,' *Palliative Medicine*, 2013;27(2):123-130. **Abstract (w. list of references):** https://goo.gl/SPWG5N

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/38NX5H

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

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ

[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’; see also ‘Media Watch: Behind the Scenes’ at https://goo.gl/6vdk9v]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/ZRngsv

[Scroll down to ‘Resource Collection’ and ‘Media Watch Barry Ashpole]

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

[Scroll down to ‘Are you aware of Media Watch?’]

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

[Scroll down to ‘Additional Resources’]

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

Cont.

Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/jjCHez

[January/February 2018 issue (Scroll down to ‘Paediatric palliative care; the patient’s voice’]

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

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

South America

Academia Nacional de Cuidados Paliativos (Brazil): https://goo.gl/b5CV31

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