

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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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

Royal Society of Medicine palliative care competition: Scroll down to Specialist Publications and 'How can patient and carers' experiences shape services?' (p.8), in *BMJ Supportive & Palliative Care*.

Canada

Beyond the scalpel: Why “virtual” autopsies may be the way of the future

CBC NEWS | Online – 4 October 2018 – Autopsies offer valuable information about how injury or disease affected a body, how that disease spread inside the body, and which treatments were (or weren't) working. But the number of autopsies being done in Canada – and around the world – has been dropping steadily for decades, due to tightening budgets, as well as reluctance from loved ones over the intrusiveness of the procedure. According to Statistics Canada, autopsies were conducted in about 17% of all deaths in 1991, compared to less than 6% in 2016. A new study suggests a high-tech, less-invasive version of an autopsy ... performs just as well as a conventional post-mortem exam.¹ The researchers hope their findings will eventually help more next of kin to consent to an au-

topsy, particularly those who may object to the traditional procedure for cultural or religious reasons. <https://goo.gl/rm6Hxf>

Specialist Publications

'Readability of advance directive documentation in Canada: A cross-sectional study' (p.18), in *Canadian Medical Association Journal Open*.

'Bearing witness: Exploring the end-of-life needs of homeless persons and barriers to appropriate care' (p.17), in *OMEGA – Journal of Death & Dying*.

'Acute-care hospital use patterns near end-of-life for cancer patients who die in hospital in Canada' (p.14), in *Journal of Global Oncology*.

1. 'Conventional autopsy versus minimally invasive autopsy with post-mortem MRI, CT, and CT-guided biopsy: Comparison of diagnostic performance,' *Radiology*, published online 25 September. **Full text:** <https://goo.gl/TCDXir>

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Noted in Media Watch (Under 'Worth Repeating') 21 August 2017 (#526, p.19):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 December 2014 – **'Interpreting educational evidence for practice: Are autopsies a missed educational opportunity to learn core palliative care principles?'** The autopsy enables students to learn about death and dying in a social context. Increasing communication and collaboration between medical school curriculum designers and disciplines such as palliative medicine as well as pathology could address concerns regarding student/doctor competencies to deal with death and dying. **Abstract:** <https://goo.gl/AGWgYV>

Noted in Media Watch 3 March 2014 (#347, p.12):

- *RELIGIONS*, 2014;5(1):165-178. **'Death investigations, objections to autopsy, and the religious and cultural "other."** Sudden, violent and otherwise unexplained deaths are investigated in most western jurisdictions through a coronial or medico-legal process. The authors explore the disjuncture between medico-legal discourses, which position the body as corpse, and the rise of more "therapeutic" discourses which recognise the family's wishes to reposition the body as beloved and lamented. **Abstract:** <http://www.mdpi.com/2077-1444/5/1/165>

Noted in Media Watch 7 March 2011 (#191, p.4):

- U.K. | BBC News – 1 March 2011 – **'New post-mortem method developed.'** A non-surgical autopsy technique which could remove the need to open up the body to determine a cause of death has been developed. Conventional post-mortem examinations require cutting open the body so the vital organs can be inspected. The method has been developed by the University of Leicester. The conventional autopsy process can be distressing for the family and is opposed by some communities on religious grounds. <http://www.bbc.co.uk/news/science-environment-12616550>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SASKATCHEWAN | CBC News (Saskatoon) – 5 October 2018 – **'Medical assistance in dying deaths of terminally ill patients will now be marked as "unclassified."** The Saskatchewan government has changed its practice of recording medically assisted deaths as suicides. The deaths of terminally ill patients who ask for medical assistance to avoid a painful end to their lives will now be recorded as "unclassified." A total of 123 medically assisted ... deaths were recorded as suicides in Saskatchewan before the change was made. The change was made through an amendment to Section 14 of the Vital Statistics (Medical Certificate of Death) Amendment Regulations. <https://goo.gl/LvqGEK>

U.S.A.

Congress targets misuse of hospice drugs

KAISER HEALTH NEWS | Online – 5 October 2018 – Hospice workers would be allowed to destroy patients' unneeded opioids, reducing the risk that families misuse them, according to one little-noticed provision in the bi-partisan opioids bill... The bill would empower hospice staff to destroy opioid medications that are expired, no longer needed by the patient because of a change in treatment or left over after the patient dies. Last August, a *Kaiser Health News* (KHN) investigation found that as more people die at home on hospice, some of the addictive drugs they are prescribed are being stolen by neighbors, relatives and paid caregivers – contributing to an opioid epidemic that kills an average 115 people a day in the U.S.¹ The article quoted a Washington state woman named Sarah B. who stole hundreds of pills ... that were left on her father's bedside table after he died at home on hospice care. The hospice staff never talked about addiction or how to safely dispose of drugs after a person dies... <https://goo.gl/zBcEfx>

1. 'Dying at home in pain doesn't keep relatives from stealing the pills,' *The Washington Post*, published online 21 August 2017 (#527, p.4). <https://goo.gl/LPxhWF>

Cont.

N.B. Leslie Blackhall, head of palliative medicine at the University of Virginia Health System's palliative care clinic, sounded the alarm about drug diversion in 2013, when she found that most of the 23 Virginia hospices she surveyed didn't have mandatory training and policies on the misuse and theft of drugs. Her study spurred Virginia's hospice association to create guidelines encouraging its members to assess the risk of misuse, and it prompted national discussion among hospice experts.¹

1. 'Risk Evaluation & Mitigation Tool-Kit: Strategies to Promote the Safe Use of Opioids,' Virginia Association for Hospices & Palliative Care. **Download/view at (scroll down to 'Risk Evaluation & Mitigation Tool-Kit'):** <https://goo.gl/ntPm8s>

The hospital says she's brain-dead. Her parents say she's alive. Who decides when to take her off the ventilator?

TEXAS | *The Texas Tribune* (Austin) – 3 October 2018 – If 9-year-old Payton Summons were lying in a hospital bed in Oklahoma, her parents would have more control over the ventilator that's currently breathing for her. But 100 miles south in Fort Worth, it's largely left up to her doctors. Summons' doctors want to take her off the ventilator. Her parents are adamantly opposed. And Texas law ... favors the positions of the doctors. Summons' parents won an emergency court order to temporarily block the hospital from shutting off the ventilator that is maintaining her breathing. But, unless the family and their lawyers are able to find a different physician at a different hospital that's willing to take on Summons despite her difficult situation ... the Cook Children's Medical Center doctors have the legal right to set the course of Summons' treatment. That's the result of a controversial 1999 state law, near-unique in the country, that allows doctors in Texas to withdraw some forms of life-sustaining treatment even over the wishes of the patient's family, as long as the physician has the backing of her hospital's ethics committee. Doctors in Texas are also protected from any civil or criminal liability – meaning grieving family members can't easily take physicians to court after

their loved ones have been taken off ventilators. In states such as Oklahoma, by contrast, doctors are explicitly forbidden from withdrawing life-sustaining treatment without agreement from the patient or patients' legal surrogates. Just two other states, California and Virginia, offer broad, "green light" protections like those in Texas, experts said. <https://goo.gl/kVBcyM>

Specialist Publications

'What do transplant physicians think about palliative care? A national survey study' (p.9), in *Cancer*.

'Changes in end-of-life care in the Medicare Shared Savings Program' (p.10), in *Health Affairs*.

'Nursing homes increasingly pushing patients into rehab at end-of-life' (p.16), in *MedicalXPress*.

'The genealogy of death: A chronology of U.S. organizations promoting euthanasia and assisted suicide' (p.21), in *Palliative & Supportive Care*.

When patients can't be cured: Massachusetts medical schools teaching more end-of-life care

MASSACHUSETTS | WBUR News (Boston) – 1 October 2018 – Last year, all four medical schools in Massachusetts agreed to work together to improve the way they teach students to care for seriously ill patients, especially near the end of life (EoL). Students at the University of Massachusetts Medical School are learning to treat gravely ill patients in the school's simulation lab, examining "patients" – paid actors – and talking to them and their "relatives" about their worsening illnesses. At Harvard Medical School, professors also hope to add lessons about EoL wishes to the school's simulated teaching sessions. At Boston University, students are visiting patients with a hospice nurse for the first time this year. Fourth-year students like Mendelsohn and Vellanki will be questioned on the principles of palliative care – a medical specialty that seeks to improve seriously ill patients' quality of life – that they've learned on rotations like Young's, part of the effort to measure what they're learning. The new EoL training for medical students grew from the Massachusetts Coalition for Serious Illness Care, a group created in 2016. <https://goo.gl/RyvKR5>

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Noted in Media Watch 1 January 2018 (#544, p.23):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 December 2017 – ‘**Experiences of female and male medical students with death, dying and palliative care: One size does not fit all.**’ Medical students learn about death, dying and palliative care (DDPC) through formal curricular and informal clinical experiences; however, the lessons learned in the clinic may be at odds with the formal curriculum. Males and females have different perceptions of DDPC experiences, and female students appear to be more deeply impacted. **Abstract:** <https://goo.gl/4LXNSH>

Noted in Media Watch 14 March 2016 (#453, p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2016;34(6):559-565. ‘**A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015.**’ At 5-year intervals, U.S. medical schools were surveyed via a questionnaire. The inclusion of end-of-life topics has expanded over the 40-year period as findings reveal that U.S. undergraduate medical students are currently exposed in over 90% of programs to death and dying, palliative care and geriatric medicine, with the emphasis on these topics varying with the medical programs. **Abstract:** <http://goo.gl/pa3cCV>

International

More people are choosing to die at home or in a hospice

U.K. (England) | The *Swindon Advertiser* – 5 October 2018 – The latest data from Public Health England reveals about 23% of the deaths registered in 2016 happened at home – up from 22% five years earlier. The data identifies the four most common places of death as hospitals, care homes, hospices and homes. Although most deaths in Swindon occur in hospitals, the number that happen at home has risen in five years, from 762 in 2011 to 778 four years later. About 23% were at care homes and 10% took place at hospices. A study by King’s College London last year pointed out that most people prefer to die in the place they are usually cared for, including home, rather than in a hospital.¹ Anna Bone, lead author of the study, warned that hospital deaths could rise further unless capacity continues to increase in care homes. She said: “The projected rise of deaths in care homes is striking and warns of the urgent need to ensure adequate bed capacity, resources and training of staff in palliative care (PC) in all care homes in the country. If we are to continue enabling people to die in their preferred place, it is essential to invest more in care homes and community health services. Without this investment, people are likely to seek help from hospitals, which puts pressure on an already strained system and is not where people would rather be at the end of their lives. <https://goo.gl/nMFpCd>

Specialist Publications

‘**End-of-life situations in cardiology: A qualitative study of physicians’ and nurses’ experience in a large university hospital [in France]**’ (p.8), in *BMC Palliative Care*

‘**Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review**’ (p.8), in *BMJ Supportive & Palliative Care*.

‘**Role of clinical psychology in U.K. hospices**’ (p.18), in *BMJ Supportive & Palliative Care*.

‘**Cancer Council New South Wales – policy & advocacy: “I Care for Palliative Care” campaign to increase government investment in specialist publications**’ (p.13), in *Journal of Global Oncology*.

‘**Development and implementation of an advance care planning program in Catalonia, Spain**’ (p.18), in *Palliative & Supportive Care*.

‘**Technical-efficiency analysis of end-of-life care in long-term care facilities within Europe: A cross-sectional study of deceased residents in 6 European Union countries**’ (p.19), in *PLoS One*.

‘**Last chance to care: An autoethnography of end-of-life care in Indonesia**’ (p.20), in *The Qualitative Report*.

Cont.

1. 'What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death,' *Palliative Medicine*, published online 10 October 2017. [Noted in 23 October 2017 issue of *Media Watch* (#535, p.6)] **Full text:** <https://goo.gl/nhXAVS>

N.B. Cicely Saunders Institute statement on palliative care and the long term plan for the National Health Service (posted 3 October 2017): **Download/view at:** <https://goo.gl/zhfMDY>

Related

- U.K. (England) | PoliticsHome (London) – 5 October 2018 – '**Patients aren't the ones reluctant to talk about death and dying...**' Evidence shows that supporting people to plan ahead in a timely fashion results in better person-centred care at the end of life – a commitment for the National Health Service; and, reduces unwanted and unwarranted hospital admission – a target for Clinical Commissioning Groups (CCGs) across England. However, a new report reveals a worrying mismatch between the advance care planning policies of CCGs and the suboptimal reality experienced by patients.¹ <https://goo.gl/xDTPGA>
1. 'Advance care planning in general practice – does policy match reality?' *Compassion in Dying*, October 2018. **Download/view at:** <https://goo.gl/xDTPGA>

New research shows bereaved people in Scotland are not receiving enough help

U.K. (Scotland) | *The Press & Journal* (Aberdeen) – 4 October 2018 – According to research commissioned by Sue Ryder and Hospice UK, bereaved people in Scotland are not receiving enough help and assistance.¹ The organisations believe this is of particular concern with Scotland passing the six-month mark of the implementation of the Carer's Act, which places a duty on authorities to signpost bereaved carers to support groups. More than 230,000 people are bereaved every year in Scotland and the study highlights how many of whom feel isolated in the aftermath. Almost a quarter of the respondents said they would have liked some kind of support beyond family and friends, but didn't access it. This was because they didn't know how (12%),

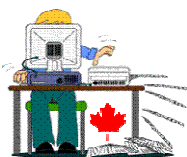
felt uncomfortable asking for it (8%), or couldn't get the type of support they wanted (3%). <https://goo.gl/hcGjFU>

[Specialist Publications](#)

'Coping with bereavement online? An overview of web-based interventions for the bereaved' (p.10), in *Grief Matters: The Australian Journal of Grief & Bereavement*.

'When those who need it most use it least: Facilitating grief support for those at greatest risk' (p.10) in *Grief Matters: The Australian Journal of Grief & Bereavement*.

1. 'Bereavement Support in Scotland: A joint report by Sue Ryder and Hospice UK,' October 2018. **Download/view at:** <https://goo.gl/fRcD2E>



[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>

Paediatric palliative care

Asking and answering the hard questions

SOUTH AFRICA | *Oncology Buddies Magazine* (Florida Park, Gauteng Province) – 26 September 2018 – Children are among the most marginalised and vulnerable members of society and, in many instances, are not consulted on decisions that affect them directly. This becomes even more prevalent when a child has a serious, life-threatening or life-limiting illness. A “conspiracy of silence” often begins at the point of a life-threatening or life-limiting diagnosis. Understandably, parents feel a strong urge to protect their child from the difficult reality of a poor prognosis. Reasons for this include: not wanting their child to be burdened with thoughts of the possibility or certainty of their death; discussing death may be contrary to their religious or cultural belief systems. They may believe that talking about the possibility of death means giving up, or that their faith is not strong enough, or it may just be too difficult. Parents will often insist that the medical team also keep the truth from the child, drawing them into the conspiracy. The sick child often, unwillingly, becomes a co-conspirator to this silence in a courageous and selfless effort to comfort and protect their parents and loved ones. Research has revealed that most children who are dying are aware of it but quickly realise that certain topics are upsetting to their loved ones, so they avoid them. They may resist asking questions or raising distressing concerns. This breakdown in honest communication usually creates even greater suffering for everyone, particularly the child. <https://goo.gl/nRGYF3>

Related

- U.K. | *Charity News* (Peterborough) – 3 October 2018 – ‘**Charity supporting more families than ever before.**’ Together for Short Lives impact report for 2017-2018 shows the difference the charity has made, including raising and sharing over £1,000,000 for lifeline support for children and families in children’s hospices and palliative care charities, and to kick-start innovative new projects to support seriously ill young people.¹ The charity saw a 31% rise in calls from families and a 52% increase in calls from professionals seeking one-to-one support for their work with seriously ill children. The report shows that Together for Short Lives has secured policy changes that will directly improve the lives of seriously ill children and their families. <https://goo.gl/wYQk8T>

1. ‘Our Value and Impact, 2017-2018,’ Together for Short Lives, October 2018. **Download/view at:** <https://goo.gl/PFePHQ>

N.B. See ‘A Guide to Children’s Palliative Care,’ Together for Short Lives, September 2018. [Noted in 1 October 2018 issue of *Media Watch* (#583, p.6)] **Download/view at:** <https://goo.gl/fRmnMr>

Specialist Publications

‘**Not the whole story – considering children’s spirituality and advance care planning**’ (p.7), in *Archives of Disease in Childhood*.

‘**Integrating palliative care into the ongoing care of children with central nervous system tumors**’ (p.14), in *Brain Tumors in Children*.

‘**Are we creating ethical dilemmas where there are none?**’ (p.9), *Clinic Ethics*.

‘**Pilot of a paediatric palliative care early intervention instrument**’ (p.14), in *Journal of Hospice & Palliative Nursing*.

‘**Top ten tips palliative care clinicians should know about caring for children**’ (p.15), in *Journal of Palliative Medicine*.

‘**Modes of death within a children’s hospital**’ (p.15), in *Pediatrics*.

‘**A day in the life of a paediatric palliative care pharmacy technician**’ (p.12), in *The Pharmaceutical Journal*.

‘**Studying children’s experiences in interactions with clinicians: Identifying methods fit for purpose**’ (p.15), in *Qualitative Health Research*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | Scoop (Wellington) – 3 October 2018 – **‘Poll: 68% want binding referendum on medical aid in dying.’** New Zealanders want a binding referendum on proposed End-of-Life Choice law. A Horizon Poll finds 68% say yes to having a binding referendum, 33% say no. The referendum would be held if the bill passes in Parliament, but before it is given Royal assent to become law. The bill, expected to be reported back to Parliament by the Justice select committee on March 27 next year, would give adults with a terminal illness or a grievous and irremediable medical condition the option of requesting assisted dying. <https://goo.gl/ey9uBF>

Specialist Publications

Not the whole story – considering children’s spirituality and advance care planning

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 28 September 2018 – In a society of diverse views, faiths and beliefs, what can paediatric palliative care contribute to our understanding of children’s spirituality? By failing to recognise and respond to their spirituality in this work, we risk missing something of profound importance to children and their families. We overlook their search for wholeness in the absence of cure and fall short of offering truly holistic care. The authors explore how developments in advance care planning and related documentation are addressing these issues. Since children’s spirituality is elusive and rarely explored in practice, they aim to clarify our understanding of it with a variety of examples and contains suggestions for hearing the voice of the child amid the needs of parents and professionals. **Abstract:** <https://goo.gl/1KYnUm>

Related

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 September 2018 – **‘The spiritual concerns of people experiencing homelessness at the end of life.’** Studies report the primacy of religious beliefs and spiritual experience for people experiencing homelessness considering end-of-life issues. The findings of the studies reviewed are not necessarily transferable to the other populations of people experiencing homelessness. It cannot be assumed the spiritual needs of people experiencing homelessness mirror those of the housed population. **Abstract:** <https://goo.gl/PQRfAL>

“Non-palliative care” – A qualitative study of older cancer patients’ and their family members’ experiences with the health care system

BMC HEALTH SERVICES RESEARCH | Online – 29 September 2018 – Encounters with health services can become a challenge to family life. This was especially true for the passing on of the responsibility for keeping in contact with the health services to close family members, for the patients’ and family members’ various information needs, and for the patients’ and family members’ various needs for help and support from the home care nurse. Cancer patients’ and family members’ preferences regarding content, timing, and delivery of information may vary. Van Eechoud *et al* found that when family members’ wishes for involvement in older patients’ advanced care planning did not agree with those of the patient, relations might become

Journal Watch

‘The role of mainstream publishers in eliminating the threat of predatory publishing’ (p.21), in *Canadian Journal of Diabetes*.

‘On the role of religion in articles this journal seeks to publish’ (p.21), in *Developing World Bioethics*.

‘How to read an ethics paper’ (p.22), in *Journal of Medical Ethics*.



**Western Norway
University of
Applied Sciences**

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tense.¹ The abovementioned challenges connected to family life may be related to the families' lack of knowledge of and lack of involvement in the health care system. Family members who were not trained in some health care profession did not know what was expected from them, what to expect or whom to contact. Established routines at hospitals for dialogue on expectations and need for family involvement will most likely contribute to a common understanding within the family and in meetings between the family and the health services on how the individual family should become involved to secure the best possible follow-up of the patient. **Full text:** <https://goo.gl/tGWzXB>

1. 'Perspectives of family members on planning end-of-life care for terminally ill and frail older people,' *Journal of Pain & Symptom Management*, published online 16 September 2013. [Noted in 23 September 2013 (#324, p.10)] **Full text:** <https://goo.gl/cVrxEj>

End-of-life situations in cardiology: A qualitative study of physicians' and nurses' experience in a large university hospital [in France]

BMC PALLIATIVE CARE | Online – 5 October 2018 – Physicians and nurses have different, yet complementary attitudes to end-of-life (EoL) issues. Both approaches must align towards a common goal, namely integrating discussions about EoL goals of care across the disease spectrum where possible, with a view to improving communication and maximizing patient comfort at the EoL. Practices in the authors' department are heterogeneous, and fall short of the objectives outlined by professional societies in this regard, particularly in patients with advanced heart failure. There is a compelling need for a minimum of training in palliative care (PC) skills among cardiologists. Improved training would help provide clinicians with the ability to anticipate EoL discussions, and improve communication skills. A change in the paradigm of what the discipline of cardiology encompasses is also warranted, in order to integrate PC in a systematic and standardized manner. **Full text:** <https://goo.gl/7ZojJ9>

Royal Society of Medicine palliative care competition

How can patient and carers' experiences shape services?

BMJ SUPPORTIVE & PALLIATIVE CARE | online – 3 October 2018 – Quality improvement can be difficult to assess and monitor in palliative care (PC) due to the nature of the specialty. This essay investigates ways in which this is currently carried out by assessing the benefits of patient-centred outcome measures. Potential technological improvements which could be implemented in the future are also discussed. This is an award-winning essay which subsequently complemented a separate project which analysed the use of the Integrated Palliative Care Outcome Scale in an inpatient PC unit. **Abstract:** <https://goo.gl/7CoMmU>

Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 October 2018 – Of the 40 million people globally in need of palliative care (PC), just 14% receive it, predominantly in high-income countries. Within fragile health systems that lack PC, incurable illness is often marked by pain and suffering, as well as burdensome costs. In high-income settings, PC decreases healthcare utilisation, thus enhancing value. Similar cost-effectiveness models are lacking in low-income and middle-income countries and with them, the impetus and funding to expand PC delivery. Despite the small number of included studies, wide variety of study types and lack of high-quality studies, several patterns emerged: 1) Low-cost PC delivery in low-income and middle-income countries is possible; 2) Patient-reported outcomes are favourable; and, 3) PC is less costly than the alternative. This review highlights the extraordinary need for robust cost-effectiveness analysis of PC in low-income and middle-income countries in order to develop health economic models for the delivery of PC, direct resource allocation and guide healthcare policy for PC delivery in low-income and middle-income countries. **Abstract:** <https://goo.gl/ZhSCg7>

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Noted in Media Watch 20 February 2017 (#500, p.8):

- *BMJ GLOBAL HEALTH* | Online – 14 February 2017 – ‘**What is the value of palliative care provision in low-resource settings?**’ While proven to be “cost-effective” in high-income settings based on principles of cost avoidance, the costs of illness for incurable disease in low-resource settings is largely unknown. The critical absence of palliative care (PC) services in low-resource settings results in significant costs being absorbed by the individual, family and local community. In considering the direct, indirect and broader societal costs of incurable disease in low-resource countries, PC should be considered as a poverty-reduction strategy. **Full text:** <https://goo.gl/nMsqQu>

What do transplant physicians think about palliative care? A national survey study

CANCER | Online – 5 October 2018 – Despite its established benefits, palliative care (PC) is rarely utilized for hematopoietic stem cell transplant (HSCT) patients. The majority of transplant physicians trust PC, but have substantial concerns about PC clinicians’ knowledge about HSCT and patients’ perception of the term “palliative care.” Interventions are needed to promote collaboration, improve perceptions, and enhance integration of PC for HSCT recipients. **Abstract:** <https://goo.gl/cc7vxS>

N.B. Selected articles on organ transplantation in the context of palliative and end-of-life care noted in 13 August 2018 (#576, p.13).

Are we creating ethical dilemmas where there are none?

CLINIC ETHICS | Online – 30 September 2018 – This case study focuses on decision-making for minors who are permanently unconscious and dependent on life-sustaining therapies. Cases of this type often cause anguish and angst for health care providers and caregivers and can lead to mistrust, moral distress, and communication problems. After presenting a particular case, an ethical analysis is applied to determine whether there is an apparent course of action or an ethical dilemma. The ethical analysis focuses on the currently accepted guidance principle for surrogate decision-making for minors and applies them to the case. The conclusion drawn shows that the case was not, in fact, an ethical dilemma by definition and that there is a reasonable course of action to be taken. **Abstract:** <https://goo.gl/GjuskS>

Examining the transitions between living and dying roles at end-of-life

DEATH STUDIES | Online – 4 October 2018 – Improvements in the diagnosis and disclosure of dying mean that nowadays dying people typically live with an awareness of their status for longer than they have previously. However, little is known regarding how transitions between living and dying roles occur during this time. In this grounded theory study, the authors investigated role transitions at end-of-life (EoL). They found that dying people periodically foreground and background living and dying selfhoods, focus on living day-by-day and goal-by-goal and reframe dying roles with an orientation to living. The authors argue that with better understanding of role transitions at EoL more compassionate and responsive care becomes possible. **Abstract:** <https://goo.gl/yxYmeB>



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.23.



Back Issues of Media Watch

<http://goo.gl/frPgZ5>

Coping with bereavement online? An overview of web-based interventions for the bereaved

GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT, 2018; 21(1):10-14. Over the past years Internet-based support for bereaved people has been established via social media, including online support groups, memorial websites and discussion forums. Parallel to the use of social media, web-based bereavement interventions have also been developed in recent years. The interventions are delivered in various forms, from text-based approaches with therapist feedback to self-help treatments delivered without therapist guidance. The author describes these different treatment approaches, beginning with the efficacy of bereavement interventions, continuing with web-based interventions that include therapist support, and finally discussing self-help bereavement interventions. She presents the procedures and key components of web-based grief

interventions for different types of losses, and discusses important indications and contraindications for web-based interventions. **Abstract:** <https://goo.gl/xLsceQ>



Related

- *DEATH STUDIES* | Online – 4 October 2018 – ‘**How religious and spiritual beliefs explain prolonged grief disorder symptoms.**’ This study investigated the importance of religious and spiritual beliefs in daily life in explaining prolonged grief disorder (PGD) symptomatology. Participants were 588 bereaved adults who completed a questionnaire. The importance of spiritual beliefs in daily life explained a small to medium, significant 3% of variance in PGD symptoms, but religious beliefs in daily life did not. Individuals who placed moderate importance on spiritual beliefs in their daily life may experience more intense grief. **Abstract:** <https://goo.gl/YaGLdN>
- *GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT*, 2018;21(1):27-31. ‘**When those who need it most use it least: Facilitating grief support for those at greatest risk.**’ The authors highlight research demonstrating the underuse of mental health services among those who may benefit from support. They describe efforts to improve bereavement risk screening, reduce barriers to accessing professional care, improve clinical assessment and therapeutic fit, disseminate empirically supported bereavement interventions, and to increase and sustain the workforce specializing in grief and loss to facilitate grief support for those in greatest need. **Abstract:** <https://goo.gl/hiXjko>

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

Changes in end-of-life care in the Medicare Shared Savings Program

HEALTH AFFAIRS, 2018;37(10):1693-1700. End-of-life care (EoLC) is often overly aggressive and inconsistent with patients’ preferences. Although EoLC could therefore be a natural target for accountable care organizations (ACOs) in their efforts to reduce spending, identifying and curbing wasteful care for patients at high risk of death may be challenging. To date, the impact of ACOs on EoLC has not been quantified. Using fee-for-service Medicare claims through 2015 and a difference-in-differences approach, the authors found evidence of some changes in EoLC associated with providers’ participation in the Medicare Shared Savings Program among both decedents and patients at high risk of death. Although generally suggestive of less aggressive care, most effects were small and inconsistent across cohorts of ACOs entering the program in different years. This suggests ACOs have not yet substantially altered EoLC patterns and additional incentives, time, or both may be needed. Alternatively, curbing wasteful EoLC might not be a viable source of substantial savings under population-based payment models. **Abstract:** <https://goo.gl/bsjCyr>

Cont.

Noted in Media Watch 28 August 2017 (#527, p.9):

- *HEALTH AFFAIRS* | Online – 25 August 2017 – ‘**Variation in end-of-life care is an open invitation for accountable care organization innovation.**’ End-of-life care (EoLC) is ripe for transformation by accountable care organizations (ACOs), which have the right incentives to tackle the widespread variation in use, quality and costs that now characterize health care at the end of life. Despite significant attention to ACOs from researchers and policy makers, little is known about how ACOs are approaching EoLC. While ACOs have been shown to affect the use of certain health care services ... discussions of the impact of ACOs on EoLC are conspicuously absent. **Full text:** <https://goo.gl/pNtjEd>

Noted in Media Watch 5 June 2017 (#515, p.10):

- *HEALTH SERVICES RESEARCH* | Online – 30 May 2017 – ‘**End-of-life care planning in accountable care organizations: Associations with organizational characteristics and capabilities.**’ In this is a cross-sectional survey study, 21% accountable care organizations (ACOs) had few or no end of life care (EoLC) planning processes, 60% had some processes, and 19.6% had advanced processes. ACOs with a hospital in their system, and ACOs with advanced care management, utilization management and shared decision-making capabilities were more likely to have EoLC planning processes than those with no hospital or few to no capabilities. **Abstract:** <https://goo.gl/8W2uB6>

Needs of immigrants at the end of life

HEILBERUFESCIENCE | Online – 4 October 2018 – Questionnaires from 28 patients and 26 relatives were analyzed by the authors. Hospice and palliative care was carried out in 63% of the patients as out-patients. Important themes for the participants were professional care, physical contact, self-determination of place of dying, care in native language, family contact, adherence to spiritual/religious rituals, adequate pain management and traditional food. Patients showed satisfaction with the care received but less satisfaction with opportunities to live out according to their own spirituality. The expressed needs essentially correspond to those of all patients in end-of-life care, regardless of migration status. **Abstract:** <https://goo.gl/2Gu9EA>

N.B. German language article.

Noted in Media Watch 7 August 2017 (#524, p.14):

- *PLOS ONE* | Online – 1 August 2017 – ‘**End-of-life care for immigrants in Germany...**’ Immigrants are underrepresented in the hospice and palliative care institutions of Berlin. Despite this, a need for services exists as immigrants on average make use of care younger than non-immigrants. In this regard, Turkish immigrants in particular are hardly found, despite being the largest immigrant population in the country. The data presented in this study should also give rise to an urgency of action. **Full text:** <https://goo.gl/UoBav7>

Noted in Media Watch 26 June 2017 (#518, p.13):

- *ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 14 June 2017 – ‘**Considering diversity in nursing and palliative care – the example of migrants.**’ Currently, one fifth of the population in Germany is considered to be of immigrant origin. Healthcare needs of immigrants are often not sufficiently taken into account by healthcare institutions. This may result in many barriers encountered by immigrants in the healthcare system, which may affect the utilization and quality of care. These barriers are particularly pronounced in nursing and palliative care. <https://goo.gl/odVvuu>

N.B. German language article.

Current perspectives on pharmacist home visits: Do we keep reinventing the wheel?

INTEGRATED PHARMACY RESEARCH & PRACTICE | Online – 1 October 2018 – The scope of clinical pharmacy services available in outpatient settings, including home care, continues to expand. This review sought to identify the evidence to support pharmacist provision of clinical pharmacy services in a home care setting. Seventy-five reports were identified in the literature that provided evaluation and description of clinical pharmacy home visit services available around the world. Based on results from randomized controlled trials, pharmacist home visit interventions can improve patient medication adherence and knowledge, but have little impact on health care resource utilization. Other literature reported benefits of a pharmacist home visit service such as patient satisfaction, improved medication appropriateness, increased persistence with warfarin therapy, and increased medication discrepancy resolution. Current perspectives to consider in establishing or evaluating clinical pharmacy services offered in a home care setting include: staff competency, ideal target patient population, staff safety, use of technology, collaborative relationships with other health care providers, activities performed during a home visit, and pharmacist autonomy. **Abstract:** <https://goo.gl/4QN5Ah>

Related

- *THE PHARMACEUTICAL JOURNAL* | Online – 1 October 2018 – ‘**A day in the life of a paediatric palliative care pharmacy technician.**’ A role that is a first in the U.K., Lisa Smith is a member of Children’s Hospices Across Scotland (CHAS) medical team, which offers palliative and supportive care, end-of-life care, step down care, short planned breaks, family support, spiritual care, and bereavement care. CHAS operates a ‘Hospice at Home’ service and has a dedicated nursing and medical team providing paediatric palliative care within hospitals. **Full text:** <https://goo.gl/4hXdHL>

Noted in Media Watch 9 July 2018 (#571, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018;21(7):1017-1023. ‘**Ten tips palliative care pharmacists want the palliative care team to know when caring for patients.**’ As palliative care (PC) moves upstream in the course of serious illness and the development of drugs and their indications rapidly expand, PC providers must understand common drug indications and adverse effects to ensure safe and effective prescribing. Pharmacists, experts in the nuances of medication management, are valuable resources and colleagues for PC providers. **Abstract:** <https://goo.gl/uZsva4>

Systematic review and meta-analysis of cannabinoids in palliative medicine

JOURNAL OF CACHEXIA, SARCOPENIA & MUSCLE, 2018;9(2):220-234. The most common and troublesome symptoms for patients in palliative care (PC) are pain, nausea, poor appetite, weight loss, and anxiety. The effectiveness of cannabinoids in treating these symptoms has not yet been established by comparison to other therapies, a task complicated by the lack of specific criteria and indications for treatment. The situation is further complicated by the active cannabis legalization advocates effectively lobbying to change political and public opinions that cannabinoids of various formulations are highly effective in PC and a range of other conditions. As more jurisdictions across different countries begin to consider using cannabis and cannabinoids as a therapy during end-of-life care, it is important to evaluate the current evidence for the effectiveness, tolerability, and safety of cannabinoids. The aim of this study is to evaluate the efficacy, tolerability, and safety of cannabinoids as an adjunct or complementary therapy in palliative medicine. Following the Grading of Recommendations Assessment, Development & Evaluation methodology, no recommendations can be made for the use of cannabinoids in PC treatment for cancer, HIV-AIDS, or dementia. In view of this finding, further research is urgently needed to identify the efficacy and safety of cannabinoids as adjunctive or complementary therapies and to provide evidence-based recommendations on their clinical utility in PC. **Full text:** <https://goo.gl/hQHd1u>

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Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Noted in Media Watch 25 June 2018 (#569, p.11):

- *BRITISH JOURNAL OF CLINICAL PHARMACOLOGY* | Online – 20 June 2018 – ‘**Medicinal cannabinoids in palliative care.**’ There is strong public support for the availability of medicinal cannabis, particularly for people with palliative diagnoses. There are several areas where there is potential for symptom benefits through modulation of the endocannabinoid system, though clinical data to date has been inconclusive in key symptoms such as pain and nausea, and data from other settings such as chemotherapy-induced nausea and vomiting not readily extrapolated. **Abstract:** <https://goo.gl/Qjj7iH>

Noted in Media Watch 7 May 2018 (#562, p.13):

- *JOURNAL OF PSYCHOACTIVE DRUGS* | Online – 1 May 2018 – ‘**Cannabis in end-of-life care: Examining attitudes and practices of palliative care providers.**’ Of interest, cannabis use appears low in palliative care (PC) settings, with few guidelines available to PC providers. Results of an online survey demonstrated that PC providers endorse cannabis for a wide range of symptoms, end-of-life care generally, and as an adjuvant medication. Nevertheless, the gap between these beliefs and actual recommendation or prescription appears vast. **Abstract:** <https://goo.gl/8AQ1Bp>

Noted in Media Watch 22 February 2016 (#450, p.14):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2016;51(2):396-397. ‘**Developing institutional medical marijuana guidelines: Understanding law and science.**’ A large network of hospitals in the U.S. state of Massachusetts assembled a multidisciplinary workgroup to generate institutional guidelines for medical marijuana. This workgroup completed comprehensive scientific literature reviews before generating guidelines reflective of this evidence base as well as federal and state legal climates. **Abstract:** <http://goo.gl/5luOOn>

End of life: A focus upon making doing the right thing easier in challenging conversation

JOURNAL OF CLINICAL ONCOLOGY, 2018;36(30):Suppl.174. A multidisciplinary task force developed a communication tool to guide clinicians in discussions with patients and improved upon the electronic health record (EHR) to make documentation clearer, easier and more meaningful. “Words that Matter” with scenarios and suggestions for clinicians to introduce palliative care or hospice to patients were established. EHR enhancements included structured fields for hospice discussion and referral based upon network defined objective clinical criteria. A hospice referral field was also created to allow physicians to place an order along with discontinuing chemotherapy without leaving the note. Education was provided to clinicians in various formats. Structured fields allow for easier electronic data pulls for reports to measure process improvement and communication. Outcome measures of interest include chemotherapy administered in the last 14 days of life and timeliness of referral to hospice. Additional process metrics are in place to measure utilization of supporting resources. Communication tools and criteria prompt our physicians to engage in discussions and refer patients earlier in their journey, when appropriate. Providing structured fields in the EHR has made documentation more complete. **Abstract:** <https://goo.gl/jbk3w9>

Cancer Council New South Wales – policy & advocacy: “I Care for Palliative Care” campaign to increase government investment in specialist palliative care services

JOURNAL OF GLOBAL ONCOLOGY | Online – 1 October 2018 – The campaign was developed and delivered between November 2015 and July 2017 in recognition of the fact that the state had fewer palliative care (PC) physicians and nurses than were needed to meet demand. This meant that some people with life-limiting cancer were being denied quality of life and were unable to die in the place of their choosing. Moreover, Aboriginal people remained disadvantaged by limited access to specialist PC that fits with their community values, beliefs, rituals, heritage and place. Various tactics were used, including collection and sharing of engaging community stories via media and online channels, mobilizing community support via training and events, and tar-



Cont.

geted engagement of decision-makers and members of parliament (MPs), which took into consideration marginal electorates, personal experiences with cancer, and geography, noting the issue disproportionately impacts regional and rural communities. An online and offline “pledge” activity was also used, providing the public and MPs with an opportunity to support the campaign. An independent qualitative evaluation confirmed that the campaign was undoubtedly a success. It noted that the campaign created an environment in which the New South Wales government made a historic decision to provide an additional \$100 million in funding for PC services over four years. Without the campaign, PC could well have lost out to other healthcare and government spending priorities. **Abstract:** <https://goo.gl/hCZkeE>

N.B. ‘I Care for Palliative Care’: Campaign Resources: <https://goo.gl/5GXmXH>

Acute-care hospital use patterns near end-of-life for cancer patients who die in hospital in Canada

JOURNAL OF GLOBAL ONCOLOGY | Online – 1 October 2018 – Acute care utilization at end-of-life remains commonplace. In Canada (excluding Québec), 43% (48,987) of deaths from cancer occurred in acute-care hospitals, with 70% admitted through the emergency department (ED). Despite previous patient surveys indicating that patients would prefer to receive care and spend their final days at home or in a hospice, there appears to be overuse of and overreliance on acute care hospital services near the end-of-life (EoL) in Canada. The high rates of hospital deaths and admissions through the ED at the EoL for cancer patients may signal a lack of planning for impending death and inadequate availability of or access to community- and home-based palliative and EoL care services. Acute care hospitals may have a role in managing the health care needs of people affected by cancer; however, EoL care should be an option in other settings that align with patient preferences. Standards or practice guidelines to identify, assess and refer patients to palliative care services earlier in their cancer journey should be developed and implemented to ensure optimal quality of life. **Abstract:** <https://goo.gl/ACrbab>

Pilot of a pediatric palliative care early intervention instrument

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(5):486-491. Given that physicians or nurse practitioners are responsible for initiating palliative care (PC) referrals, it is incumbent upon registered nurses to advocate when improved symptom management care is needed. The pediatric PC screening instrument pilot provides a centralized instrument to document and quantify a patient’s symptom profile, giving registered nurses the opportunity to objectively communicate and track a patient’s need for improved symptom management care within the areas of pain, secretions, dyspnea, intractable seizures, nausea, vomiting, constipation, diarrhoea, anorexia, cachexia, sleep disturbance, lethargy, anxiety, depression, and/or agitation. The 4-week quality improvement project at an academic teaching hospital formally incorporated the bedside registered nurses’ symptom assessment into a centralized document. Fifty-three patients were identified as having an uncontrolled symptom burden in at least one of the symptom domains, indicating that excessive and untreated symptom burden was present on the acute care floor. The pediatric PC screening instrument could act as a conduit between bedside registered nurses and the PC team, serving to reduce the time between onset of excessive symptom burden and initiation of symptom management services. **Abstract:** <https://goo.gl/bQYeFc>

Related

- *BRAIN TUMORS IN CHILDREN* | Online – 30 September 2018 – ‘**Integrating palliative care into the ongoing care of children with central nervous system tumors.**’ Children with brain tumors continue to experience high rates of morbidity and mortality and a substantial symptom burden, necessitating the integration of palliative care (PC) principles and practices throughout their illness trajectory. These patients experience a high number of hospital deaths, and there is often only a short interval between the initial PC consultation and death. Early introduction of PC is essential, and a broad-based approach that does not exclusively rely on consult-based PC services can help optimize the integration of PC into the continuum of care for pediatric neuro-oncology patients. **Abstract (inc. list of references):** <https://goo.gl/cdG3Zx>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 October 2018 – ‘**Top ten tips palliative care clinicians should know about caring for children.**’ Given the limited number of pediatric-specific palliative care (PC) programs, PC providers of all disciplines may be called on to care for infants, children, and adolescents with serious illness. This article provides a review of the unique components of pediatric PC, including key roles within an interdisciplinary team, pediatric developmental considerations, use of medical technology and complexities of symptom management in children with serious illness, hospice utilization, as well as pointers for discussions with families regarding a patient’s quality of life and goals of care. **Abstract:** <https://goo.gl/AsU6q6>
- *PEDIATRICS*, 2018;142(4). ‘**Modes of death within a children’s hospital.**’ Knowledge about how children die in pediatric hospitals is limited and this hinders improvement in hospital-based end-of-life care. Among the 5 modes of death [in the patient population studied], the most common was the withdrawal of life-sustaining technology (40.2%), followed by non-escalation (25.6%), failed resuscitation (22.8%), code then withdrawal (6.0%), and death by neurologic criteria (5.3%). Patients who received a palliative care consultation were less likely to experience a code death, although African American patients were more likely than white patients to experience a code death, mostly because of code events occurring in the first 24 hours of hospitalization. **Abstract:** <https://goo.gl/QbBFZ2>
- *QUALITATIVE HEALTH RESEARCH* | Online – 1 October 2018 – ‘**Studying children’s experiences in interactions with clinicians: Identifying methods fit for purpose.**’ Drawing on the authors’ experiences in a study of children with leukemia in hospital, this article explains the challenges and opportunities that arise in the use of five commonly used methods in a study of hospitalized children’s experiences with health care professionals, including the “Draw and Write” technique, a sticker activity, a paper-person exercise, informal interviews, and participant observation. Each of these methods was examined with regard to ease of use, data generation, and utility of data for accessing children’s perspectives and development of initial clinical guidance. **Abstract:** <https://goo.gl/9ENwd8>

Noted in Media Watch 4 June 2018 (#566, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 29 May 2018 – ‘**Researching children’s perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research.**’ Qualitative research is pivotal in gaining understanding of individuals’ experiences in pediatric palliative care (PC). In the past few decades, the number of qualitative studies on pediatric PC has increased slightly, as has interest in qualitative research in this area. Nonetheless, a limited number of such studies have included the first-person perspective of children. The aim of this article is to understand the contribution of previous qualitative research on pediatric PC that included the voices of children. **Abstract:** <https://goo.gl/2iPNKP>

N.B. Additional articles on the patient’s voice in paediatric palliative care noted in this issue of Media Watch.

A systematic review of training in symptom management in palliative care within postgraduate medical curriculums

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 October 2018 – Symptom management is a priority area within palliative care (PC) core competencies for generalist providers. While several educational initiatives exist, a comprehensive evidence synthesis on the effectiveness of symptom management training on trainees’ learning and patient-reported outcomes is lacking. Six studies met the [authors’] inclusion criteria: two randomised controlled trials and four quasi-experimental. Pain management, use of opioids and their side effects were most frequently covered. Clinical decision support tools, web-based teaching, PC rotation and mixed educational methods were used. Most studies used self-reported, original or modified evaluation instruments, though psychometric properties were seldom reported. Despite methodological considerations, all educational methods improved trainees’ learning outcomes. However, the effects on trainees’ behaviour and patient-related outcomes were not evaluated. **Abstract:** <https://goo.gl/gLxT2F>



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

Vicarious post-traumatic growth in end-of-life care: How filling gaps in knowledge can foster clinicians' growth

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 3 October 2018 – Vicarious post-traumatic growth is a term used to describe the positive benefits from working with trauma patients who themselves have experienced a highly stressful or traumatic event and resultant growth. Research on vicarious post-traumatic growth remains in its initial stages and findings are inconsistent, leading to the need for additional research. A literature review was performed to ascertain the methodologies guiding research on vicarious post-traumatic growth and identify gaps in knowledge. This study found that 71% of research studies examined used survey instruments to measure vicarious post-traumatic growth and 87% of these studies utilized the Posttraumatic Growth Inventory. This instrument was not designed to measure secondary trauma. In order to support clinicians who are at high risk of adverse outcomes, the knowledge of vicarious post-traumatic growth must be broadened by conducting research with varying methodologies, among other populations, and by developing effective survey instruments to operationalize this concept. **Abstract:** <https://goo.gl/2BfzPh>

Elder care in the U.S.

Nursing homes increasingly pushing patients into rehab at end-of-life

MEDICALXPRESS | Online – 3 October 2018 – A new [U.S.] study reveals a growing trend of potentially unnecessary – and harmful – high intensity rehabilitation services for residents of nursing homes.¹ The study finds that this trend ... is on the rise for patients in the last 30 days of life, indicating that these services may be interfering with appropriate end-of-life care. Nursing home Medicare reimbursement rates are based on categories that place patients into resource utilization groups based on the complexity, intensity, and amount of staff time dedicated to their care. Patients who receive high levels of rehabilitation services fall into a category that makes these facilities eligible to collect the highest level of reimbursement for their care. This phenomenon has been on the radar of federal regulators for some time. The authors of the current study analyzed data from 647 nursing home facilities in New York State to better understand the patterns and growth of rehabilitation services. Specifically, they focused on residents who had received very high to ultrahigh rehabilitation services ... during the last 30 days of life. They found that residents receiving ultrahigh rehabilitation had increased by 65% between 2012 and 2015 and that most of the rehabilitation therapy residents received was concentrated in the last seven days of life. They also found that there was a significantly higher use of these services in for-profit nursing home compared to not for profit homes. **Full text:** <https://goo.gl/SyGf6x>

1. 'Rehabilitation therapy for nursing home residents at the end-of-life,' *Journal of the American Medical Directors Association*, published online 1 October 2018. **Abstract:** <https://goo.gl/xYVntG>

Qualitative study on the influence of the physical environment in patients admitted to a palliative care unit after its remodelling

MEDICINA PALIATIVA, 2018;25(4):222-229. The patients [interviewed] attached great importance to privacy and intimacy in single rooms both at a personal and a family level. Common spaces, nature and art favour interpersonal relationships, emotional and spiritual experiences and generated positive memories in the patients. Considering the participants' answers, the authors highlight several categories related to the environment created in the unit and its effect on the patient's social and physical wellbeing. The humanization of infrastructures and material structures is part of the humanization of health care. Environment influences people's behaviour. It is important to create spaces that provide a balance between intimacy, physical and psychological comfort and to promote social relationships and experiences of connection and life. **Abstract:** <https://goo.gl/aKEfsA>

N.B. Spanish language article.

Bearing witness: Exploring the end-of-life needs of homeless persons and barriers to appropriate care

OMEGA – JOURNAL OF DEATH & DYING | Online – 2 October 2018 – Traditional models of palliative care (PC) are largely inaccessible to homeless persons, and their preferences regarding end-of-life care (EoLC) are poorly understood. This review summarizes the burgeoning gray and academic literature on EoLC for homeless persons. Five medical databases, seven social science databases, and four gray literature databases were searched, resulting in 57 relevant titles. Six themes emerged: 1) Characteristics of homeless persons who require EoLC; 2) Preferences and concerns of homeless persons approaching the end of life; 3) The role of spirituality for homeless persons at the end of life; 4) Barriers to care at the patient, provider and institutional or structural levels; 5) Inclusive models of PC; and, 6) Implications for policy and practice. Practitioners and homeless persons must negotiate many obstacles in the provision and receipt of PC. There is tremendous potential and opportunity to improve the quality of life at

the end of life for this vulnerable population. **Abstract:** <https://goo.gl/uD9YCb>



European Journal of
Palliative Care 
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The homeless: a vulnerable population with poor access to palliative care

■ In his regular column, **Barry Ashpole** presents a selection of abstracts that highlight new findings and trends in the diverse and rapidly expanding body of research in the field of palliative and end-of-life care.

See March/April 2018 issue of the *European Journal of Palliative Care* (p.89). **Contents page (and access options):** <https://goo.gl/7w8HS9>

N.B. Additional articles on palliative and end-of-life care for the homeless in Canada noted in 30 July 2018 issue of Media Watch (#574, p.1).

Related

- *NURSE EDUCATION TODAY*, 2018;71(12):135.144. **‘Evaluation of training on palliative care for staff working within a homeless hostel.’** Training around how to support hostel residents with deteriorating health is currently largely absent from the training received by hostel staff in the U.K. This study suggests that training can be beneficial for improving knowledge, confidence, openness and work related stress for hostel staff that support people with deteriorating health who are homeless. Recommendations for implementing changes in how people experiencing homelessness are supported include embedding training into routine practice, promoting multidisciplinary working, incorporating flexibility within the recovery focused approach of services and recognising the need for emotional support for staff. **Full text:** <https://goo.gl/Yf1vGh>

Advance care planning for frail older adults: Findings on costs in a cluster randomised controlled trial

PALLIATIVE MEDICINE | Online – 1 October 2018 – Advance care planning (ACP) did not significantly affect the costs of medical care for frail older adults. In a cluster randomised trial, 16 residential care homes in The Netherlands were randomly allocated to the intervention group, where frail, older participants were offered facilitated ACP conversations or to the control group. The authors calculated variable costs of ACP per participant including personnel and travel costs of facilitators. They assessed participants’ healthcare use during 12 months applying a broad perspective (including medical care, inpatient days in residential care homes, home care) and calculated costs of care per participant. Average variable ACP costs were €76 per participant. The average costs of medical care were not significantly different between the intervention and control group (€2,360 vs €2,235, respectively). Costs of inpatient days in residential care homes (€41,551 vs €46,533) and of home care (€14,091 vs €17,361) were not significantly different either. **Abstract:** <https://goo.gl/GS2S3n>

Cont.

Related

- *CANADIAN MEDICAL ASSOCIATION JOURNAL OPEN* | Online – 28 September 2018 – ‘**Readability of advance directive documentation in Canada: A cross-sectional study.**’ Provincial and territorial health agencies oversee the distribution of advance directive (AD) documentation, and the results of this study demonstrate the different approaches used to create and administer ADs in terms of authorship, publication year, length, density of information and intended audience. Taken together, the readability and comparative document analysis presented here support the observation that there are significant differences among the English language AD documents commonly used in Canada. The authors recommend that newly created AD documents be written and distributed on the basis of clearly articulated benchmarks that control for, among other things, the readability of the language they contain. Both health literacy and AD completion rates could be improved by standardizing these documents across Canada or perhaps even working toward producing a single AD form that could be used across the country. **Full text:** <https://goo.gl/bWoinu>
- *PALLIATIVE MEDICINE* | Online – 4 October 2018 – ‘**Advance care planning in community dwellers: A constructivist grounded theory study of values, preferences and conflicts.**’ Most participants claimed at the outset that they had engaged in advance care planning, but they were unfamiliar with contemporary life-sustaining interventions and had not factored these into their decisions. Participants’ confidence in their substitute decision makers precluded them from having explicit discussions with these individuals. Participants expressed their values and preferences in terms of unacceptable functional outcomes from serious illness, rather than desired interventions. The process of articulating their preferences within the interviews was subject to decision conflicts, which in turn helped them re-evaluate and refine their decisions. **Abstract:** <https://goo.gl/wk8KTX>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 October 2018 – ‘**Development and implementation of an advance care planning program in Catalonia, Spain.**’ This project was led by the Catalan Ministry of Health. The strengths of the project development include the contribution of a wide range of professionals from the entire region, approval by the Catalan Bioethics Committee and the Social Services Ethics Committee, and ongoing validation by members of the community. A standardized online training course was offered to all primary care professionals and included as a quality indicator for continuing education for those professionals in the period 2016–2020. **Abstract:** <https://goo.gl/rHFshr>

Meaning-centered psychotherapy integrated with elements of compassion: A pilot study to assess feasibility and utility

PALLIATIVE & SUPPORTIVE CARE | Online – 1 October 2018 – The main objective of this study was to establish emotional benefits of promoting and maintaining meaning in palliative care (PC) patients in the final weeks of life and to assess the benefits of including the compassion and self-compassion constructs in the Meaning-Centered Psychotherapy Model (MCP). Of the 51 patients that began one of the three interventions, 30 completed the three-session interventional program, as well as the pre- and post-treatment questionnaires. No significant differences were found between therapies in terms of the positive feedback of patients regarding the structure, focus, and length of the all three psychotherapeutic interventions. The most helpful elements or constructs reported by patients were meaning, self-compassion, compassion, legacy, and courage and commitment. An abbreviated version of MCP-PC tailored to the needs of PC patients appears to be feasible, acceptable, and helps patients cope with the process of dying. **Abstract (inc. a list of references):** <https://goo.gl/ebW3Zm>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 October 2018 – ‘**Role of clinical psychology in U.K. hospices.**’ Eighteen clinical psychologists responded to an anonymous online survey and there was considerable variance in how their roles were organised. The tasks undertaken by most respondents were direct work with and consultation for hospice patients, and teaching and training staff. However, the findings demonstrated that clinical psychologists can undertake a wide range of tasks and draw on a range of therapeutic approaches including cognitive behavioural therapy, acceptance and commitment therapy, and compassion focused therapy, in their hospice work. **Abstract:** <https://goo.gl/P8jzy7>

Technical-efficiency analysis of end-of-life care in long-term care facilities within Europe: A cross-sectional study of deceased residents in 6 European Union countries

PLOS ONE | Online – 25 September 2018 – An ageing population in the European Union leads to a higher need of long-term institutional care at end of life (EoL). At the same time, healthcare costs rise while resources remain limited. Consequently, an urgency to extend knowledge on factors affecting efficiency of long-term care facilities (LTCFs) arises. This study investigated and explains variation in technical efficiency of EoL care within and between LTCFs of Belgium (Flanders), England, Finland, Italy, The Netherlands and Poland. In this study, technical efficiency reflects the LTCFs' ability to obtain maximal quality of life and quality of dying for residents from a given set of resource inputs (personnel and capacity). 133 LTCFs of only one type (onsite nurses and offsite GPs) were considered in order to reduce heterogeneity. Variation in LTCF efficiency was found across as well as within countries. This variation was not explained by country, ownership, availability of palliative care or opioids. However, in the "hands-on care at the bedside" scenario, i.e., only taking into account nursing and care assistants as input, Poland and Finland seemed to be most efficient. Efficiency of LTCFs differed extensively across as well as within countries, indicating room for considerable efficiency improvement. The authors findings should be interpreted cautiously, as comprehensive comparative EU-wide research is challenging as it is influenced by many factors. **Full text:** <https://goo.gl/aUPnif>



Related

- *PALLIATIVE MEDICINE* | Online – 1 October 2018 – ‘**Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study.**’ A considerable proportion of nursing home residents are perceived by staff [i.e., study participants] as dying with physical and emotional distress. Problems were reported in all countries, including those with high levels of palliative care (PC) integration in nursing homes such as Belgium, The Netherlands or England. The study findings point to an urgent need to review whether improvements can be made in the systematic assessment, recognition and management of EoL symptoms and underline the importance of further integration of PC in nursing home care. **Full text:** <https://goo.gl/NHkBFG>

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

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

The analysis of results of sociological survey concerning attitude to palliative care support in the Russian Federation

PROBLEMY SOTSIAL'NOI GIGIENY, ZDRAVOOKHRANENIYA I ISTORII MEDITSINY, 2018;28(1):32-35. The palliative care (PC) is a regulatory determined form of medical care in the Russian Federation since 2011. Until now, no complex analysis was applied to problems occurring during provision of the given form of care. The actual study provides analysis of the results of questionnaire survey of population of Russia with the purpose of determining public demand in development of PC – level of awareness, social cultural attitudes and main needs of population – concepts of effective forms of its development. **Abstract:** <https://goo.gl/R8nCko>

N.B. Russian language article.

Last chance to care: An autoethnography of end-of-life care in Indonesia

THE QUALITATIVE REPORT, 2018;23(9):2238-2250. In Australia, palliative care (PC) is an accepted and expected part of contemporary health care service provision. Efficacious PC focuses on managing pain and symptoms and making the patient as comfortable as possible... As well, PC focuses on the spiritual and psycho-social dimensions of life, providing the opportunity for the patient and their family to continue to be engaged with life and self-determined decision making throughout palliation. In this account, the Australian author describes her experience of caring for her Indonesian father-in-law in the last week of his life. She explores emerging tensions associated with local end-of-life care and Western care which trigger deeper feelings associated with losing a loved one, complicated by the recent and sudden loss of her own parents. Narration is a powerful tool for capturing the verisimilitude of everyday experiences, evoking in the reader a powerful resonance into a very personal inner life which is often not spoken about in academic texts. This account, a cultural story of dying in East Java, Indonesia, also provides insight into the author's expectations, as an Australian and concludes with some reflections about the emerging position of PC services in Indonesia. **Full text:** <https://goo.gl/NQ9BMc>

A survey of respiratory therapist preparedness for end-of-life care

RESPIRATORY CARE | Online – 1 October 2018 – Respiratory therapists (RTs) are often called upon to stop treatments or life support for patients who are near death. Like all professionals, RTs struggle with emotions in EoL. These issues are further magnified when the patient dying is a child. Most RTs have not had specific training in dealing with EoL... This has forced the RTs to encounter EoL situations ill prepared. The lack of preparation may add anxiety to an already tense and stressful situation. 42% of survey respondents cited ineffective hospital orientation about EoL and 44% cited no hospital orientation about EoL. When asked about EoL training in RT school, 50% (18/39) responded with ineffective training and 36% (13/39) stated that they did not get any training in RT school. **Abstract:** <https://goo.gl/SUgwpX>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDICAL JOURNAL OF AUSTRALIA*, 2018;209(7): 286-287. **'Medical assistance in dying: A disruption of therapeutic relationships.'** Medical assistance in dying, whether voluntary euthanasia or physician-assisted suicide (PAS), has been a recurring topic for societal debate. Voluntary euthanasia is the deliberate and intentional act to end a competent person's life, at their request, to relieve their suffering. PAS relates to the medical provision of the means or knowledge for someone to commit suicide via the self-administration of a prescribed medication. Amid growing societal support and stability of worldwide medical opinion, there has been a 66% increase in the legalisation of PAS since 2015, which indirectly legitimises such practices through the broad influence it has on societal support. Canada and the American states of California and Colorado legalised PAS in 2016. In Australia, the Victorian Parliament passed a Bill in 2017 to legalise PAS, while the debate currently continues in other Australian states and New Zealand. By contrast, in May 2018 Guernsey failed to become the first place in Britain to permit PAS. **Abstract:** <https://goo.gl/m944ns>
- *NARRATIVE INQUIRY IN BIOETHICS* | Online – Accessed 1 October 2018 – **'Responding to requests for aid-in-dying: Rethinking the role of conscience.'** This case study illustrates the complex role that a physician's conscience can play in end-of-life care. The authors examine a case from [the U.s. state of] Vermont in which a terminally ill patient requests aid-in-dying from her primary care physician under the state's 'Patient Choice and Control at End of Life Act.' The physician feels conflicted: she is opposed to prescribing death-hastening medication, but does not want to abandon her patient. Much of the medical ethics literature on conscience focuses on whether health care professionals should be permitted to abstain from providing morally contested medical services. The authors analysis highlights the interplay of conflicting values that inform the physician's engagement with aid-in-dying, demonstrating that the issue is often more nuanced than the question of whether or not a physician can (or should) opt out. **Abstracts:** <https://goo.gl/P7c7ci>

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- *PALLIATIVE & SUPPORTIVE CARE* | Online – 1 October 2018 – ‘**The genealogy of death: A chronology of U.S. organizations promoting euthanasia and assisted suicide.**’ In the early 20th century, a political movement to secure access to euthanasia and assisted suicide began in the U.S. The multitude of organizations associated with this effort has undergone an array of mergers, splits, and name changes, channeled through two progenitor organizations – the Euthanasia Society of America and the Hemlock Society. A few chronologies mapping the metamorphoses of these organizations are available, but they are not accessible in the medical literature. Moreover, they are not comprehensive, lack consistency, and are not rigorously validated. As debates about the legalization of euthanasia and assisted suicide continue, it is important to have a common understanding of the history behind these developments, including recognition of the factors driving these adaptations. The authors offer a comprehensive and definitive history to aid those interested in knowing the roots of these organizations and those that are still active today. **Abstract (inc. a list of references):** <https://goo.gl/RD2EM9>
- *THE PROFESSIONAL COUNSELOR*, 2018;8(3):249-261. ‘**Resolving value conflicts with physician-assisted death: A systemic application of the counselor values-based conflict mode.**’ Counselors are becoming more involved with clients pursuing physician-assisted death (PAD) as legislation for legalization increases. PAD may present complex values-based conflicts that can challenge counselors to maintain ethical practice in counseling. When conflicts arise, counselors must engage in ethical decision making that considers systemic influences on personally held beliefs and values. The authors merge ecological systems theory with the counselor values-based conflict model to offer a holistic approach to resolving values-based conflicts surrounding PAD. The authors review PAD and counselors’ roles in the hastened death process, discuss sources and impacts of personal and professional values through an ecological systems lens, and provide an applied method of managing values-based conflicts with PAD through a case illustration. **Full text:** <https://goo.gl/g96exz>
- *PUBLIC DISCOURSE* | Online – 19 September 2018 – ‘**Making death easier makes life Harder.**’ Easing access to suicide continues to be debated, usually in discussions of the legalization of assisted suicide (now often called euphemistically “aid in dying”). But there is an argument that may not be heard in such debates: by making death easier, we make life harder. Once suicide becomes readily available and accepted, dependent persons who refuse to choose death will be blamed for voluntarily burdening their caregivers, and for burdening society as well, thus filling the end of their lives with new sorts of suffering. Yet this is not the harm ordinarily articulated by opponents of assisted suicide. They most commonly argue, rightly, that making a deadly drug available to dependent persons risks life itself by exposing vulnerable persons to pressure or coercion aiming at death. But they often fail to mention the other great harm that results from any “right to die”: facilitating suicide endangers not just ailing or moribund bodies but the quality of ongoing human relationships. **Full text:** <https://goo.gl/QhYvfE>

Journal Watch

The role of mainstream publishers in eliminating the threat of predatory publishing

CANADIAN JOURNAL OF DIABETES, 2018;42(5):457-458. The phenomenon of open-access publication has drastically altered the business landscape of scientific publishing and aided in the emergence of smaller publishing houses. Open access has the potential to be a very positive development with increased accessibility of research. While several of these publishers maintained a requisite level of review integrity on what they publish, others used this opportunity to prey on authors. The exponential growth of such journals transpired over the past decade with the sole intent of financial gains from article processing charges and total negligence to scholarly publishing standards. **Full text:** <https://goo.gl/cHQLyL>

On the role of religion in articles this journal seeks to publish

DEVELOPING WORLD BIOETHICS, 2018;18(3):207. Bioethics as a field of inquiry has many parents, its writers come from a wide variety of academic disciplines. What they all have in common, whether they are historians, lawyers, philosophers or social scientists, is an understanding that the arguments presented must be a variety of public-reason based arguments. Religion based arguments are, by definition,

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Arguments that do not fall into the category of public-reason based arguments. They rely on premises involving the existence of unobservable supernatural powers giving us direction in terms of how we must live our lives. Typically their guidance is provided in religious documents the content of which is credited to said unobservable supernatural powers. This, of course, is a very much simplified description of the world's major monotheistic religions, but its key elements are pretty much like this. Secular societies cannot possibly function as arbiters of the truth or otherwise of their diverse citizenries religious beliefs. The reasons for this are well-known and reflected in myriad highest courts' judgments delivered across liberal societies' jurisdictions. As a consequence of this, while debates in such societies will countenance in varied ways religious arguments, ultimately only views that can be defended within the analytical frameworks of public-reason based arguments can succeed in secular societies. **Full text:** <https://goo.gl/t8YZtk>

How to read an ethics paper

JOURNAL OF MEDICAL ETHICS | Online – 2 October 2018 – In recent decades, evidence-based medicine has become one of the foundations of clinical practice, making it necessary that healthcare practitioners develop keen critical appraisal skills for scientific papers. Worksheets to guide clinicians through this critical appraisal are often used in journal clubs, a key part of continuing medical education. A similar need is arising for health professionals to develop skills in the critical appraisal of medical ethics papers. Medicine is increasingly ethically complex, and there is a growing medical ethics literature that modern practitioners need to be able to use in their practice. In addition, clinical ethics services are commonplace in healthcare institutions, and the lion's share of the work done by these services is done by clinicians in addition to their usual roles. Education to support this work is important. The authors present a worksheet designed to help busy healthcare practitioners critically appraise ethics papers relevant to clinical practice. In the first section, they explain what is different about ethics papers. They then describe how to work through the steps in their critical appraisal worksheet: identifying the point at issue; scrutinising definitions; dissecting the arguments presented; considering counter arguments; and finally deciding on relevance. Working through this reflective worksheet will help healthcare practitioners to use the ethics literature effectively in clinical practice. **Abstract:** <https://goo.gl/xMtKKS>

Of related interest:

- **'An open letter to all of the medical journals who send me daily offers to publish my "high-impact research in next month's issue,"'** *Canadian Medical Association Journal*, 2018;190(39): E1172. **Access options:** <https://goo.gl/xE4kCj>

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South America



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