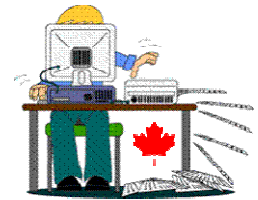


Media Watch...

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

Patient-centred care: Scroll down to [Specialist Publications](#) and ‘The “other” in end-of-life care: Providers’ understandings of patients with migrant backgrounds’ (p.11), in *Journal of Intercultural Studies*.

Canada

Why we need better end-of-life policies in seniors’ residences

ONTARIO | *The Globe & Mail* – 12 April 2016 – About 15% of all deaths in Ontario occur in long-term care facilities. With a rapidly aging population and soaring dementia figures, those numbers are likely to rise despite our hopes of aging and dying at home. Yet none of the \$75-million recently pledged by the Ontario government to bolster end-of-life care across the province is earmarked for long-term care facilities. Instead, the money is going to support hospices, caregivers and health-care practitioners who are providing palliative care in patients’ homes, according to Member of the Provincial Parliament John Fraser, parliamentary assistant to Eric Hoskins, Minister of Health & Long Term Care.¹ That focus leaves some of our most vulnerable

patients ... *in extremis*. The lack of adequate medical support on site means that many frail, elderly and cognitively impaired residents who develop urinary tract infections, breathing problems or other end-of-life issues are routinely shipped by ambulance to crowded hospital emergency wards. <http://goo.gl/XBvEVJ>

Specialist Publications

‘Measuring staff perception of end-of-life experience of older adults in long-term care’ (p.6), in *Applied Nursing Research*.

1. ‘Palliative & End-Of-Life Care Provincial Roundtable Report,’ Ontario Ministry of Health & Long-Term Care, March 2016. [Noted in Media Watch, 14 March 2016, #453 (p.2)] <http://goo.gl/eRyw8K>

Noted in Media Watch, 3 February 2014, #343 (p.9):

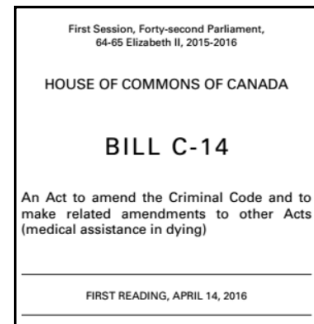
- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 24 January 2014 – ‘Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers.’ Study participants had a relatively positive attitude toward more than one-half of selected aspects of interdisciplinary practice and end-of-life palliative care for long-term residents. Overall, however, there are significant differences between upper-level professionals and managers (registered nurses, physicians, rehabilitation staff, and clinical managers) versus the hands-on caregivers (nursing assistants, patient assistants and volunteers) with regard to some aspects of the care of the dying. <http://goo.gl/B5rwp1>



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 14 April 2016 – ‘**New assisted suicide law will be limited to Canadians to prevent suicide tourism.**’ Canada’s new assisted suicide law ... will exclude non-Canadians, which means Americans won’t be able to travel to Canada to die. A senior government official told The Associated Press late Wednesday the new law will exclude non-Canadians, precluding the prospect of suicide tourism from the U.S. and elsewhere. The official spoke on condition of anonymity because they were not authorized to discuss details ahead of the Thursday morning announcement. The law will also will exclude those who experience mental illness or psychiatric conditions. It will also ban advance consent. That is, it won’t allow requests to end one’s life in the future. <http://goo.gl/IGON9t>



<https://goo.gl/ysCQMG>

Related

- CBC NEWS | Online – 16 April 2016 – ‘**Aboriginal communities not ready for “rushed” assisted-dying regulations: Doctor.**’ Health experts say there are still many unanswered questions about how remote Northern communities will be able to offer medical assistance in dying – especially since most are already in dire need of proper palliative care and culturally appropriate services. <http://goo.gl/Yomuyl>
- THE CANADIAN PRESS | Online – 14 April 2016 – ‘**Legislation mandates both nurse practitioners and MDs to provide assisted death.**’ Nurse practitioners – not just doctors – would be allowed to provide medically assisted death to eligible patients under proposed legislation tabled ... by the federal government. Their inclusion in Bill C-14 is being welcomed by both nursing and physician groups, which say that nurse practitioners are often the only medical professionals working in rural and remote communities who could provide patients with aid in dying. <http://goo.gl/ba0NN7>
- CTV NEWS | Online – 14 April 2016 – ‘**Five ways the assisted dying legislation strays from parliamentary recommendations.**’ The proposed legislation satisfies many of the recommendations from the Special Joint Committee on Physician-Assisted Dying, which released 21 recommendations back in February to guide the government in drafting the legislation.¹ But there are at least five keys [sic] in which the legislation strayed from what parliamentarians called for. <http://goo.gl/a7ZgU4>
 1. ‘Medical Assistance in Dying: A Patient-Centred Approach,’ The Special Joint Committee on Physician-Assisted Dying, February 2016. [Noted in Media Watch, 29 February 2016, #451 (p.3)] <http://goo.gl/Lo7RP3>
- *THE TORONTO STAR* | Online – 14 April 2016 – ‘**Palliative care supports necessary to live and die with dignity.**’ We must ensure the palliative care supports are in place for people to live and die with dignity. A decision to opt for physician assisted death should not be driven by the fact a patient lacks other options. <http://goo.gl/Ho1uz7>
- BRITISH COLUMBIA | *The Vancouver Sun* – 10 April 2016 – ‘**Palliative care and physician-hastened death: Whose role is it anyway?**’ Palliative care (PC) physicians see firsthand how serious illnesses can lead to intense suffering for both the patient and their loved ones. Their working lives are dedicated to relieving that suffering. In Canada, PC physicians recognize the choice to die must be legally respected. Some have even publicly advocated for this as a right. And by 6 June, the Canadian government must have crafted a law to regulate assisted death. Would it not be a failure of new legislation if patients resorted to ending their lives without first being offered quality care as a choice? PC physicians feel it is critical that Canadians have access to quality PC so that they can confidently seek treatment to improve their quality of life without fear of an accelerated demise. PC is often misunderstood as being appropriate only at the very end of life when there may be only days or weeks to live; often too little and too late. Many believe that PC leads to an accelerated demise despite clear evidence to the contrary. Fear and misinformation abounds. Sadly, a large proportion of the province’s residents and Canadians die from chronic progressive illnesses without any contact with a PC service at any point in their illness; a life unsupported. <http://goo.gl/s3PfPM>

U.S.A.

Perinatal hospice care prepares parents for the end, at life's beginning

THE WASHINGTON POST | Online – 16 April 2016 – Last month, Indiana became the sixth state to require doctors to counsel women who have received fatal fetal diagnoses about perinatal hospice before they terminate a pregnancy. The care model is a bundle of services, untethered to a hospital or medical center. Hospice nurses and social workers help families prepare for loss, coaching parents on what to say to siblings and co-workers. They take calls at 2 a.m. They recommend family therapists for couples whose relationships strain under grief. They teach mothers how to deliver painkillers to a dying infant, should the baby live long enough to go home. A children's hospital in Denver became the first in the U.S. nation to develop hospice care for terminally ill infants in 1980... Psychiatrists instructed nurses on how to talk to

parents in moments of stress. Perinatal hospice grew as more parents connected online and learned about what has since become a flourishing community... Most hospitals will accommodate a parent's end-of-life wishes, if they ask. But hospice care creates an especially gentle environment with professionals trained to handle despair. <https://goo.gl/SOLR30>

Specialist Publications

'Neonatal death in the emergency department: When end-of-life care is needed at the beginning of life' (p.8), in *Clinical Pediatric Emergency Medicine*.

The Older Americans Act finally clears congress

FORBES | Online – 14 April 2016 – Congress finally just passed bipartisan legislation renewing the Older Americans Act for three years... Passage comes almost 10 years since the Act was last reauthorized, a delay which has been a source of great consternation to older adults and their advocates. Why should you care? Simply because the legislation keeps core Older Americans Act programs intact, while adding improvements to the law. In essence, the bill allows older adults to remain at home and in the community by providing them with necessary services to maintain their independence. The Older Americans Act also saves Medicaid and Medicare untold millions each year. <http://goo.gl/zHCdsZ>

Most doctors unsure how to discuss end-of-life care, survey says

KAISER HEALTH NEWS | Online – 14 April 2016 – Doctors know it's important to talk with their patients about end-of-life care (EOLC). But they're finding it tough to start those conversations – and when they do, they're not sure what to say, according to a national poll.¹ Such discussions are becoming more important as baby boomers reach their golden years. By 2030, an estimated 72 million Americans will be 65 or over, nearly one-fifth of the U.S. population. Medicare now reimburses doctors \$86 to discuss EOLC in an office visit that covers topics such as hospice, living wills and do-not-resuscitate orders. Known as advance care planning (ACP), the conversations can also be held in a hospital. Among the poll's findings: while 75% of doctors said Medicare reimburse-

ment makes it more likely they'd have ACP discussions, only about 14% said they had actually billed Medicare for those visits; three quarters also believe it's their responsibility to initiate end-of-life conversations; fewer than one-third reported any formal training on end-of-life discussions with patients and their families; and, more than half said they had not discussed EOLC with their own physicians. <http://goo.gl/7SNNEh>

Specialist Publications

'Discussing long-term prognosis in primary care: Hard but necessary' (p.10), in *JAMA Internal Medicine*.

1. 'Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?' John A. Hartford Foundation, California Health Care Foundation & Cambia Health Foundation, April 2016. <http://goo.gl/NTzOpZ>

Hospice plus treatment: Medicare should cover palliative and curative measures for terminal patients

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 12 April 2016 – Many terminally ill people with a prognosis of six months or less to live choose to go into hospice. As defined by the National Hospice & Palliative Care Organization, hospice is specialized care for those facing a life-limiting illness and for their families and caregivers. High quality hospice care can be wonderful because it focuses on palliative care (PC) to maximize comfort and minimize suffering at the end of life. There is access to an interdisciplinary team that caters to the physical, social and the spiritual well-being of the dying person. And yet, at the core of hospice care is a paradox. People who elect hospice now must choose between PC with support services or curative treatment that hospice does not provide. Fewer than half of eligible Medicare beneficiaries use hospice care and most do so only for the last few days of their lives. As a result, they get minimal benefit from hospice because there is not enough time to

evaluate their needs. Medicare beneficiaries currently are not eligible to receive concurrent palliative and curative treatments. The result is that we are all too familiar with stories of people who enroll in hospice only after the conclusion of long bouts of aggressive, excruciating treatment because they and/or their doctors did not want to give up on curative treatment. Who can blame them? <http://goo.gl/s29BFk>

Specialist Publications

'Homeward bound, not hospital rebound: How transitional palliative care can reduce readmission' (p.9), in *Heart*.

'Patterns of palliative care consultation among elderly patients with cancer' (p.11), in *Journal of the National Comprehensive Cancer Network*.

Noted in Media Watch, 27 April 2016, #407 (p.5):

- *U.S.A. TODAY* | Online – 20 April 2015 – **'Medicare considers changing hospice care policy.'** Medicare is considering changes in the hospice benefit to stop the federal government from paying twice for care given to dying patients. But patient advocates and hospice providers fear a new policy could make the often difficult decision to move into hospice care even tougher. <http://goo.gl/cBSD0Y>

Noted in Media Watch, 19 May 2014, #358 (p.3):

- REUTERS | Online – 14 May 2014 – **'Under new Medicare model, members may not have to choose between treatment and hospice.'** A new program from the Centers for Medicare & Medicaid Services may remove a barrier that makes patients hesitate to opt for hospice care near the end of life. <http://goo.gl/7E4X3U>

End-of-life care in rural communities and remote regions

Alone on the range, seniors often lack access to health care

WYOMING | *The New York Times* – 8 April 2016 – Through his 95th summer, Bill Kolacny was tending the tomato patch on the 400-acre Wyoming ranch where he and his wife, Beverly, had lived for 25 years. When he began to weaken from heart failure in December, all he wanted was to die in their log home on the Clark Fork River. But, the nearest hospice organization, in Red Lodge, Montana, isn't licensed to care for patients in Wyoming. And the closest Wyoming hospice said it couldn't afford to send staff members 60 miles to the Kolacny ranch. So Bart Kolacny and his two sisters, who all live at least an hour away, took turns caring for their father at home with the help of their family physician, Dr. Bill George, also certified in palliative care. The family managed until Bill Kolacny died last month at 95, but "it wasn't easy," Bart Kolacny said. When it comes to attention and medical resources, "we're kind of underrepresented," said Dr. George, who practices at Beartooth Billings Clinic in Red Lodge. "People sometimes feel forgotten." The rural American population is older: About 15% of residents are 65 or older, compared with 12 percent in urban areas... Among those over 65, poverty rates run higher outside of metropolitan counties, the Department of Agriculture reports. <http://goo.gl/yHaFw8>

Cont.

Related

- *THE WASHINGTON POST* | Online – 10 April 2016 – ‘**Life expectancy study: It’s not just what you make, it’s where you live.**’ White women have been dying prematurely at higher rates since the turn of this century, passing away in their 30s, 40s and 50s in a slow-motion crisis driven by decaying health in small-town America, according to an analysis of national health and mortality statistics by *The Washington Post*. Analysis ... shows a clear divide in the health of urban and rural Americans, with the gap widening most dramatically among whites. The statistics reveal two Americas diverging, neither as healthy as it should be but one much sicker than the other. <http://goo.gl/ucHmL6>

N.B. Additional articles on end-of-life care in rural communities and remote regions are noted in the issues of *Media Watch* of 4 April 2016, #456 (pp.2,12); 8 February 2016, #448 (p.9); 4 January 2016, #443 (p.9); 30 November 2015, #438 (p.12); 14 September 2015, #427 (p.8); 7 September 2015, #426 (p.17); 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE ATLANTIC* | Online – 14 April 2016 – ‘**Legalizing assisted suicide in Canada.**’ Americans interested in ending their lives through medical-assisted suicide will not be allowed to take advantage of new Canadian legislation ... that would legalize the practice. The law, aimed to aid people with terminal, painful, and grievous conditions, excludes non-Canadians interested in so-called “suicide tourism.” The proposed legislation would allow people who have a serious and incurable medical condition in an advanced stage, where their death “reasonably foreseeable,” to seek medical assistance in dying. That may come through a physician administering a substance or prescribing a medication that will lead to a person’s death. The bill requires a 15-day reflection period, unless a physician decides to speed up the process. Canadian officials on Thursday said the law would ensure the “autonomy” of people to make this decision. <http://goo.gl/IAHMvo>

International

End-of-life care in England

Nearly 80 care homes praised for cutting crisis admissions and deaths in hospital

U.K. (England) | Carehome – 13 April 2016 – Seventy-seven care homes across England have been honoured for the ‘Gold Standard’ level of care they give dying residents, including efforts to reduce hospital deaths. Offering advance care planning, reducing the number of crisis admissions and deaths in hospital, meeting residents’ end-of life care (EOLC) preferences and a high level care in residents’ final days, were some of the 20 standards the care homes had to meet before receiving a Gold Standards Framework (GSF) accreditation. Many have halved the number of their residents dying in hospital as well as halving crisis hospital admissions, in response to the wishes of residents, their loved ones and staff. The rise in job satisfaction experienced by staff at GSF-accredited homes has also resulted in reduced staff turnover and better relationships between staff and residents. The National Gold Standards Framework Centre trains care workers to identify early whether a resident requires EOLC, assess and plan for it and clarify early their preferences. Homes must also submit a portfolio of evidence and undertake an independent visit from a trained assessor. More than 3,000 homes across England and Wales have completed the GSF in Care homes training programme and almost a quarter of all care homes in England having undertaken the training. <http://goo.gl/soM1B5>

[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.13.

Elder and home care in Northern Ireland

Independent providers issue a stark warning on the cost of home care

U.K. (Northern Ireland) | BBC News (Belfast) – 13 April 2016 – Northern Ireland's independent health care providers are warning that it is becoming increasingly difficult to provide home care packages to the sick and elderly. The problem has worsened since the introduction of the national living wage... The majority of care packages in Northern Ireland are administered by about 233 independent care companies. They deliver about 170,000 hours of domiciliary care each week. This amounts to 70% of the total – the rest is provided “in-house” by the five health trusts. <http://goo.gl/9FxnwD>

[Specialist Publications \(e.g., in-print and online journal articles, reports, etc.\)](#)

Ageing in Finland

Do you want to live to be 100? Answers from older people

AGE & AGEING | Online – 13 April 2016 – One-third (32.9%) of home-dwelling older people [i.e., survey respondents] wanted to live to be 100. Those who did were older, more often male and self-rated their health better than those who did not. Often the desire for long life was conditional: “Yes, if I stay healthy.” Among the reasons is that many were curious to see what would happen. Many stated that they loved life, they had twinkle in their eye or significant life roles. Those who did not want to live extremely long lives gave various rationales: they would become disabled, life would be meaningless, they were reluctant to become a burden to others or they feared loss of autonomy or suffering pain or loneliness. Some people also shared the view that they should not intervene in destiny or they felt that they had accomplished what they wanted in life. <http://goo.gl/fHl6ab>

Measuring staff perception of end-of-life experience of older adults in long-term care

APPLIED NURSING RESEARCH, 2016;30:245-251. A questionnaire measuring staff perception of their patient's end-of-life experience (SPELE) was developed. Content validity was assessed by a panel of experts and piloting conducted with healthcare assistants and nurses. The SPELE captured facets of the quality of the death and dying experience from healthcare staff's perspective. Good group inter-rater reliability was observed among sub-scales. Kappa values, however, showed little agreement between nurses and healthcare assistants for certain symptoms, including pain. Further testing of the questionnaire is required. However it was described as a useful mechanism to enable researchers and clinicians to explore quality of care at end of life. <http://goo.gl/KP4coc>

The badness of death and priorities in health

BMC MEDICAL ETHICS | Online – 14 April 2016 – The state of the world is one with scarce medical resources where longevity is not equally distributed. Given such facts, setting priorities in health entails making difficult yet unavoidable decisions about which lives to save. The business of saving lives works on the assumption that longevity is valuable and that an early death is worse than a late death. There is a vast literature on health priorities and badness of death, separately. Surprisingly, there has been little cross-fertilisation between the academic fields of priority setting and badness of death. The authors aim is to connect philosophical discussions on the badness of death to contemporary debates in health priorities. <http://goo.gl/aoFjzQ>

[Media Watch: Back Issues](#)

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://goo.gl/frPgZ5>

Development and pilot evaluation of a home-based palliative care training and support package for young children in southern Africa

BMC PALLIATIVE CARE | Online – 9 April 2016
– This home-based paediatric palliative care (PC) training and support package is designed to help home- and community-based care (HCBC) workers who are in a position to support families in provision of quality PC. The comprehensive training and support package is presented within an adult-friendly learning framework that is accessible to a range of literacy levels. The underlying principle is to facilitate learning through practice in the home environment and to build partnerships between professional health care workers, HCBC workers, families, sick children and caregivers. The training guide contains practical guidance, techniques and tips.

One of the main strengths of the package is it can be used in its entirety or the individual components can be used separately as resources and need dictates. <http://goo.gl/C00svR>

Extract from *BMC Palliative Care* article

The model of home-based care works well only when there is a home that is materially appropriate, where an individual or individuals are able to consistently care for the child, and an home- and community-based care worker...

Noted in Media Watch, 7 March 2016, #452 (p.11):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 29 February 2016 – ‘**Evaluating a pilot paediatric hospice-at-home service: A literature review.**’ This literature review aims to offer practitioners an overview of the key components involved in designing the evaluation of a paediatric hospice-at-home pilot that will assess the effectiveness, efficiency and sustainability of the programme. <http://goo.gl/5oJYKv>



Related

- *BANGLADESH JOURNAL OF MEDICAL SCIENCE*, 2016;15(1):51-56. ‘**Pediatric palliative care in Kelantan [Malaysia]: A community engagement model.**’ The authors describe a novel approach where an individual doctor ensured his own training, obtained a substantial grant from a national university that had a campus in the region, and worked closely together with an established foundation for people with disabilities to establish palliative care service for children. This care is among the first one in Malaysia with its own unique model of integration at different levels of care. <http://goo.gl/Xo7jeB>

A palliative care link nurse programme in Mulago Hospital, Uganda: An evaluation using mixed methods

BMC PALLIATIVE CARE | Online – 9 April 2016
– The programme has been successful in meeting its aims of equipping nurses from different wards with knowledge and skills enabling them to provide generalist palliative care (PC) alongside their clinical team and improving links between the wards and the Makerere/Mulago PC unit. It has radically improved PC within Mulago Hospital, Uganda Heart Institute and Uganda Cancer Institute both in reaching more people, but also in providing care according to extent of needs, enabling specialist PC practitioners to concentrate more on those with complex needs, as well as offering training and mentor-ship. PC need in hospitals such as Mulago Hospital are great, and integrated models of care that

strengthen health systems need to be developed in order to meet that need and to ensure that all patients in the hospitals who need it have access to PC services, through both generalist and specialist provision. <http://goo.gl/id3vQa>

Extract from *BMC Palliative Care* article

The programme demonstrates that nurses working in the wards of busy hospitals in sub-Saharan Africa can be trained and supported to provide generalist PC to patients, working with and referring to the specialist PC team as needed and working as a focal point for the core clinical teams.

Many people in Scotland now benefit from anticipatory care before they die: An after death analysis and interviews with general practitioners

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 April 2016 – Key Information Summaries (KIS) were introduced throughout Scotland in 2013 so that anticipatory care plans written by general practitioners (GPs) could be routinely shared electronically and updated in real time, between GPs and providers of unscheduled and secondary care. Overall, 60% of patients were identified for a KIS, a median of 18 weeks before death. The numbers identified were highest for patients with cancer, with 75% identified compared with 66% of those dying with dementia/frailty, and only 41% dying from organ failure. Patients were more likely to die outside hospital if they had a KIS. GPs identified professional, patient and societal challenges in identifying patients for palliative care (PC), especially those with non-cancer diagnoses. GPs are identifying patients for anticipatory and PC more equitably across the different disease trajectories and earlier in the disease process than they were previously identifying patients specifically for PC. Many patients still lack care planning, particularly those dying with organ failure. <http://goo.gl/83tc2N>

Perinatal palliative care in the U.S.

Neonatal death in the emergency department: When end-of-life care is needed at the beginning of life

CLINICAL PEDIATRIC EMERGENCY MEDICINE | Online – 8 April 2016 – Each year, critically-ill neonates present to emergency departments across the U.S. These infants require acute medical interventions with a goal of stabilization. Despite these efforts, hundreds of infants die every year in emergency departments across the U.S. Emergency providers, unaccustomed to providing neonatal end-of-life care, may feel unsure about how to best care for families during resuscitative measures and after neonates die. There is literature to suggest that increased knowledge and advance preparation can calm fears of providers caring for patients in such tragic situations. The authors aim to provide in this article a broad overview of a variety of topics related to neonatal death and bereavement care. <http://goo.gl/uNTjSK>

Noted in Media Watch, 21 December 2015, #441 (p.15):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 December 2015 – ‘**Provision of services in perinatal palliative care: A multicenter survey in the U.S.**’ Congenital anomalies account for 20% of neonatal and infant deaths in the U.S. Perinatal palliative care programs are housed in academic medical centers, regional or community hospitals, local hospices, or community-based organizations. Significant differences by program setting were observed for type of fetal diagnoses seen, formal training in communicating bad news to parents, mechanisms to ensure continuity of care, and reimbursement mechanisms. <http://goo.gl/JeGbxP>

Availability of caregiver-friendly workplace policies: An international scoping review

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 12 April 2016 – Little research has been done to summarise: what is currently available to caregiver-employees (CEs), what types of employers are offering caregiver-friendly workplace policies (CFWPs), and the characteristics of employers offering CFWPs. The authors applied an iterative method of determining study search strings, study inclusion and data extraction, and qualitative thematic analysis of the search results. Searches were performed in both the academic and grey literature, published between 1994 and 2014. Four main qualitative themes were identified: 1) Diversity and inclusiveness; 2) Motivation; 3) Accessibility; and, 4) Workplace culture. Policy recommendations are discussed. <http://goo.gl/TT0BMU>

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>

Homeward bound, not hospital rebound: How transitional palliative care can reduce readmission

HEART | Online – 11 April 2016 – Despite therapeutic advances in the management of heart failure (HF), approximately 25% of hospitalised patients with HF are readmitted within 30 days. These costly episodes of care have given rise to numerous policy initiatives, such as the Medicare Hospital Readmissions Reduction Programme, which fiscally penalises hospitals with “excess” readmissions. Transitional care programmes have emerged as a potential solution to avert HF readmissions by monitoring and supporting patients and caregivers for a limited period of time post-discharge. A recent meta-analysis of these interventions suggests that programmes which incorporate home visits are effective at reducing all-cause re-admission and mortality, whereas less-intensive programmes of structured telephone support alone can reduce HF-related readmissions and mortality. <http://goo.gl/5ErH1H>

End-of-life care in ICU

Addressing uncertainty: What is the role of consensus in end-of-life care

INTENSIVE CARE MEDICINE | Online – 7 April 2016 – Uncertainty is a familiar companion in the practice of medicine, and this lack of certainty is abundant in end-of-life care (EOLC). Medical decision-making at the end of life occurs in a complex milieu of personal values and beliefs, where tensions between patient autonomy, sanctity of life, quality of life, and social justice abound. Efforts to attenuate this uncertainty through rigorous scientific investigation may be met with legal and ethical challenges, and high-quality evidence is often absent. Without high-quality evidence to guide decision-making, the importance of consensus in EOLC becomes readily apparent. Although it may be impractical to establish a universal understanding of what is “beneficial” or what it means to “do no harm” at the end of life, achievement of consensus is possible in many different areas of EOLC. When driven by a desire to improve the quality of dying and death for patients and their family members, consensus in EOLC can serve as an important source of direction for clinicians. <http://goo.gl/Qt7O2l>

Related

- *INTENSIVE CARE MEDICINE* | Online – 8 April 2016 – ‘**Guidelines for the withdrawal of life-sustaining measures.**’ A total of 39 experienced clinicians completed an initial workshop and 36 were involved in the subsequent Delphi rounds. The group developed a series of guidelines to address 1) Preparing for withdrawal of life-sustaining measures; 2) Assessment of distress; 3) Pharmaceutical management of distress; and, 4) Discontinuation of life-sustaining measures and monitoring. <http://goo.gl/t6fQFC>
- *INTENSIVE CARE MEDICINE* | Online – 7 April 2016 – ‘**The importance and challenge of measuring family experience with end-of-life care in the ICU.**’ The ICU is a setting where death is common, and the majority of these deaths involve decisions to withhold or withdraw life-sustaining treatments. These two facts highlight the importance of addressing the quality of end-of-life care in the ICU, as well as the need to support patients and family members through this process. Unfortunately, both quality of care and support for patients and families vary markedly from hospital to hospital, influenced in large part by physician attitudes and hospital norms. <http://goo.gl/h6pRUj>

Cont. next page



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>

- *JOURNAL OF CRITICAL CARE* | Online – 9 April 2016 – ‘**How is life support withdrawn in intensive care units: A narrative review.**’ This review describes current practices and opinions about withdraw life-sustaining therapy (WDLs), and also demonstrates the significant practice variation that currently exists. The authors believe that the development of guidelines to help increase transparency and standardize the process will be an important step to ensuring high quality care during WDLs. <http://goo.gl/O032eF>

Discussing long-term prognosis in primary care: Hard but necessary

JAMA INTERNAL MEDICINE | Online – 11 April 2016 – Primary care practitioners (PCPs), including physicians and nurse practitioners, strongly influence whether older adults are screened for cancer, treated aggressively for diabetes mellitus, and/or given statins for primary prevention of cardiovascular disease. Meanwhile, guidelines increasingly encourage PCPs to consider patient life expectancy when deciding whether to recommend these and other medical interventions to older adults. For example, several organizations recommend that older adults with less than a 10-year life expectancy not be screened for cancer. The rationale for this recommendation is that these patients will not live long enough to experience the possible life-prolonging benefits of cancer screening. <http://goo.gl/HL0FZ0>

Implementation of a life-sustaining management and alternative protocol for actively dying patients in the emergency department

JOURNAL OF EMERGENCY NURSING | Online – 7 April 2016 – The aging population and the growing number of home hospice patients have resulted in increased utilization of emergency departments (ED). This situation poses a clinical challenge to the ED staff in determining when lifesaving treatment is indicated and when end-of-life care (EOLC) begins. A best practice initiative, Life Sustaining Management & Alternatives, was developed and implemented to provide palliative care services and comprehensive care for patients who are actively dying in the ED. The ED became better equipped to handle EOLC, providing adequate pain management, optimal comfort measures, and emotional support with respect and dignity for the dying patient and family. The practices implemented resulted in improved patient care, increased patient satisfaction, and reduced overall hospital admissions. <http://goo.gl/d1gpK4>

Selected articles on palliative care in the emergency department

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 February 2016 – ‘**Why do adults with palliative care needs present to the emergency department? A narrative review of the literature.**’ Given the increasing emphasis on community-based provision of palliative care (PC) and the view that good dying should occur at home, it is unsurprising that policy in many countries has started focusing on preventing hospital admissions at the end of life. However, little attention has been paid to the role of the emergency department (ED) in this regard, despite the fact that a high proportion of hospital admissions among patients with PC needs originate in the ED. [Noted in Media Watch, 29 February 2016, #451 (p.12)] <http://goo.gl/H2ko6X>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 August 2015 – ‘**Palliative care screening and assessment in the emergency department: A systematic review.**’ The authors identify multiple studies demonstrating that screening and referral for palliative care consultation is feasible. They recommend a screening framework based on a synthesis of available evidence. [Noted in Media Watch, 7 September 2015, #426 (p.13)] <http://goo.gl/LbYL6Q>
- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – ‘**What’s in a name? A qualitative exploration of what is understood by “palliative care” in the emergency department.**’ There are entrenched contradictions and tensions surrounding the term “palliative care” and confronting these is likely to require more than “re-branding,” and will promote better care for this vulnerable patient group... [Noted in Media Watch, 9 February 2015, #396 (p.11)] <http://goo.gl/nLdAKQ>

The “other” in end-of-life care: Providers’ understandings of patients with migrant backgrounds

JOURNAL OF INTERCULTURAL STUDIES, 2016;37(2):103-117. This article explores end-of-life care (EOLC) providers’ understandings of patients with migrant backgrounds... The analysis brings to the fore three themes: 1) The expectation that the existence of difference and uncertainty is a given when caring for patients with migrant backgrounds; 2) The expectation that the extension of responsibility that difference entails creates a variety of dilemmas; and, 3) The expectation that difference will bring about misunderstandings and that patients’ needs can go unmet as a result of this. On the basis of these themes the authors suggest that the EOLC providers interviewed regard patients with migrant backgrounds as “others” and themselves as providers that cannot deliver so called culture-competent care. The findings are problematised using the lens that the debate on patient-centredness offers. The article suggests that if the uniqueness of all patients is to be seriously taken into account then “othering” is perhaps what patient-centredness actually entails. <http://goo.gl/35jYcU>

The logo for the Journal of Intercultural Studies, featuring the text "JOURNAL OF INTERCULTURAL STUDIES" in a serif font, with "JOURNAL OF" in smaller letters above "INTERCULTURAL STUDIES".

The focus of this issue is on end-of-life care in the context of post-migration diversity in Europe. <http://goo.gl/ZQ6IR1>

Decision-making in a death investigation: Emotions, families and the coroner

JOURNAL OF LAW & MEDICINE, 2016;23(3):571-581. The role of the coroner in common law countries such as Australia, England, Canada and New Zealand is to preside over death investigations where there is uncertainty as to the manner of death, a need to identify the deceased, a death of unknown cause, or a violent or unnatural death. The vast majority of these deaths are not suspicious and thus require coroners to engage with grieving families who have been thrust into a legal process through the misfortune of a loved one’s sudden or unexpected death. In this research, 10 experienced coroners discussed how they negotiated the grief and trauma evident in a death investigation. They articulated two distinct ways in which legal officers engaged with emotions, which are also evident in the literature. <http://goo.gl/vAmnu7>

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

Patterns of palliative care consultation among elderly patients with cancer

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2016;14(4):439-445. Palliative care (PC) consultation rates increased from 3.0% in 2000 to 12.9% in 2009, with most consultations occurring in the last 4 weeks of life (77%) in the inpatient hospital setting. The rates of PC delivery were highest in the West (7.6%) and lowest in the South (3.2%). The likelihood of PC consultation increased with decreasing numbers of regional acute care hospital beds *per capita*. The use of PC consultation increased with increasing numbers of regional physicians ... [and] ... decreased with increasing regional Medicare expenditure with a \$1,387 difference per beneficiary between the first and fourth quartiles of PC use. <http://goo.gl/0VVw5Z>

A campaign to change end-of-life care in India

NEUROLOGY TODAY, 2016;16(7):8. For most of his career as a consulting neurologist at PD Hinduja National Hospital in Mumbai, Roop Gursahani MD, has specialized in treating epilepsy. But five years ago, he found himself in quite a different position – testifying before the Supreme Court in India, not about seizure disorders, but about end-of-life care (EOLC). The case involved a once young and vibrant nurse – Aruna Shanbaug – who had been in a persistent vegetative state 42 years after barely surviving a brutal strangulation and sexual assault in the hospital where she worked. In 2011, her caretakers fought to continue the care (she was nourished through a feeding tube) that was keeping her alive. The apex court asked Dr. Gursahani and two other doctors to assess her physical and mental state and confirm that she

Cont.

was in a persistent vegetative state – which they did. Although the Supreme Court of India ruled for passive euthanasia in 2011, which meant that life support could be withdrawn from patients in a persistent vegetative state, it did not change the situation for Shanbaug. The court did not grant permission to remove her feeding tube since both her doctors and caregivers were in agreement about continuing care. She died naturally of pneumonia in May 2015. “The laws in India are archaic,” and typically families care for their loved ones at home, Dr. Gursahani told *Neurology Today*. “In a country where talking about one’s death with your loved ones is often considered a bad omen or taboo, it is an uphill task for doctors and caregivers to discuss EOLC with patients and their families,” he added. <http://goo.gl/RXKAfX>

Selected articles on ethics and the law in the context of end-of-life care in India

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2015;21(3):258-261. ‘**Constitutional and legal protection for life support limitation in India.**’ The perceived lack of legal guidance is the greatest barrier to taking a treatment limiting decision in India. The physician approach seems to be hampered by misperceptions of legal liability linked to treatment limitation, in major part due to the unclear signals from the legal community. [Noted in Media Watch, 14 February 2015, #427 (p.8)] <http://goo.gl/zmWzW0>
- *THE TIMES OF INDIA* | Online – 19 May 2015 – ‘**India needs a complete law on “end-of-life” care.**’ India does not have a comprehensive legal framework that lets patients and families take control of their last days and do the right things. As a default option, doctors tend to follow the safest option, which is to do nothing. [Noted in Media Watch, 25 May 2015, #411 (p.8)] <http://goo.gl/GnPHMx>
- *MEDICAL JOURNAL ARMED FORCES INDIA*, 2013;69(1):2-3. ‘**End-of-life care: Should we struggle on, or let go?**’ Numerous studies have found that the medical care of the dying to be unnecessarily prolonged, painful, expensive and emotionally burdensome to both patients and their families. [Noted in Media Watch, 29 April 2013, #303 (p.14)] <http://goo.gl/a3UXmq>

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.

Health workers coping with having a relative in palliative care for cancer

REVISTA GAÚCHA DE ENFERMAGEM, 2016;37(1):e55080. This study shows that being a family member and a health professional at the same time demands greater involvement in care and decision-making regarding treatment since these workers have the scientific and technical knowledge that the other family members do not have. The participants of this study claimed that witnessing a family member suffering from a disease and the final stage of their lives caused distress, whereas their professional knowledge helped them make decision through this process. <http://goo.gl/EH76QJ>

N.B. For full text in either Portuguese or English click on  [pdf](#) icon.

Related

- *JOURNAL OF GERONTOLOGICAL NURSING* | Online – 11 April 2016 – ‘**Functional and existential tasks of family caregiving for end-of-life, hospitalized older adults.**’ Findings [of this study] show that engagement in end-of-life existential tasks and motivations, such as life review, spirituality, multi-generational family relationships, and preparation for death, acted as a coping resource and was positively related with caregivers’ sense of self-benefit. <http://goo.gl/SGnGaM>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JAMA INTERNAL MEDICINE*, 2016;176(4):427-428. ‘**The challenge of new legislation on physician-assisted death.**’ This Viewpoint discusses the need for international cooperation in deciding how professional societies, academic medical centers, medical groups, and health care systems can best integrate physician-assisted death into their practices. <http://goo.gl/SSQcH3>

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/0Q1Mh4>

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

Canada

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

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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

Barry R. Ashpole
Guelph, Ontario CANADA

‘phone: 519.837.8936
e-mail: barryashpole@bell.net