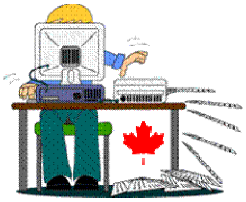
Media Watch...

*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.*

17 April 2017 Edition | Issue #508



Compiled & Annotated by Barry R. Ashpole

Preferred place to die: Scroll down to Specialist Publications and 'When it comes to death, there is no place like home… Or is there?' (p.12), in *Palliative Medicine*.

Canada

Nursing home residents with dementia often get unneeded drugs at end of life

ONTARIO | CBC News – 10 April 2017 – People nearing the end of life often receive medications they may no longer need, and that's true even in nursing homes, researchers say. Nearly 9,300 Ontario nursing home residents with dementia received at least one medication of questionable benefit during the last year of life, a study found.[1] About one in three nursing home residents in the study didn't see any specialists during the last year of life. https://goo.gl/HyHXD6

1. 'Use of medications of questionable benefit at the end of life in nursing home residents with advanced dementia,' *Journal of the American Geriatrics Society*, 29 March 2017. https://goo.gl/mUT9b5

Noted in Media Watch 4 July 2016, #469 (p.7):

- AUSTRALIA | ABC News (Sydney) – 27 June 2016 – **'High number of terminal patients unnecessarily treated, study finds.'** Doctors have called for the public to discuss end-of-life care with their loved ones after a study revealed one third of elderly patients with an advanced or terminal illnesses receive unnecessary treatment in the last six months of their lives.[1] http://goo.gl/rBeFJ2

    1. Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem,' *International Journal for Quality in Healthcare*, 27 June 2016. http://goo.gl/4mwpLS

Federal government changes policy to ensure women giving birth away from reserve aren't alone

THE WINNIPEG FREE PRESS | Online – 9 April 2017 – Health Minister Jane Philpott says Ottawa will now pay for someone to travel with indigenous women who need to leave their communities to give birth – a change to what she called an "extremely unhelpful" policy. Indigenous women without proof of a medical need to have someone escort them have long been forced to have their children alone and far from from their land, language and heritage... https://goo.gl/4gjiHF

N.B. Listed in the 6 February 2017 issue of Media Watch (#498, p.1) are selected articles on end-of-life care for Canada's indigenous peoples.

Extract from *The Winnipeg Free Press* report

Indigenous people needing to leave communities for end-of-life care still have to travel alone said Dr. Michael Kirlew, a family physician in Sioux Lookout, Ontario.

U.S.A.

Should the Federal Drug Administration relax rules on compassionate access to new drugs?

THE WALL STREET JOURNAL | Online – 11 April 2017 – A patient faces a potentially fatal illness and the treatments available just aren't working. Should he or she be allowed to turn to a drug that hasn't been approved? And if so, how easy should it be to obtain it? It's an emotionally charged question that has swirled around the Food & Drug Administration (FDA) for years. Supporters of the agency argue its "compassionate use" program for as-yet unapproved drugs can have delays. But they say the FDA approves almost all requests, and quickly, and that delays are caused by drug companies. Others argue the blame for delays rests with the agency, and they have won big battles. They have gotten easier compassionate-use bills – called "right to try" – passed in more than 30 states that eliminate the requirement for an application to the FDA. https://goo.gl/4wqmww

Specialist Publications

'Palliative care training in cardiology fellowship: A national survey of the fellows' (p.6), in *American Journal of Hospice & Palliative Medicine.*

'Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities' (p.10), in *Journal of Racial & Ethnic Health Disparities.*

'Inconsistent state laws may complicate medical decision-making' (p.12), in *Medical Express.*

'Role of psychiatrists in assisted dying: A changing trend' (p.14), in *American Journal of Psychiatry.*

Noted in Media Watch 3 April 2017, #506 (p.4):

- *THE WASHINGTON TIMES* | Online – 26 March 2017 – **'Are right-to-try laws a last hope for dying patients – or a false hope?'** The anti-regulatory mood dominating Washington is boosting efforts to allow patients to take experimental medicines outside of clinical trials. But the increased momentum is raising alarms, with opponents saying that such laws largely offer false hope. That's because many drug companies are reluctant to provide medications outside of clinical trials – and why critics insist that the FDA is not the problem. https://goo.gl/SzY1UK

N.B. Listed in the 6 March 2017 issue of Media Watch (#502, p.6) are selected articles on "right-to-try" laws.

Withdrawing care for developmentally disabled persons: New Idaho standards

IDAHO | *The National Law Review* – 10 April 2017 – Under Idaho law, the guardian or personal representative of an incompetent person may generally authorize the medically appropriate withdrawal of treatment for the patient. In the case of developmentally disabled persons, however, the former law prohibited guardians and physicians of developmentally disabled persons from withholding or withdrawing artificial life-sustaining treatment unless the treating physician and one other physician certified that the person had a terminal condition such that the application of artificial life-sustaining treatment would only serve to prolong death for a period of hours, days or weeks, and that death was imminent regardless of the life-sustaining procedures. Unfortunately, this standard looked only at the length of the patient's life without considering the pain that the patient may be forced to endure in the meantime. Because of advances in medicine, healthcare providers are often able to keep persons alive for months or years, but at a terrible cost in suffering to the patient and their loved ones. Application of the former standard sometimes resulted in heartbreaking situations in which developmentally disabled persons – often with little or no cognition – were relegated to an existence that offered nothing more than perpetual pain or discomfort instead of allowing the medically appropriate withdrawal treatment. By so doing, the standard deprived developmentally disabled persons of rights that were offered to others. https://goo.gl/C25mnk

The patients were saved. That's why the families are suing.

THE NEW YORK TIMES | Online – 10 April 2017 – Physicians and hospitals have grown accustomed to the threat of lawsuits when they fail to save a patient's life. Now, some face legal action for failing to let a patient die. Several ... lawsuits around the country say that health care providers disregarded or overrode advance directives, resuscitating people whose instructions clearly said not to. Historically, the practice has been "if in doubt, err on the side of aggressive, life-sustaining treatment," said Thaddeus Pope, who directs the Health Law Institute at Mitchell Hamline School of Law in St. Paul, Minnesota. After all, resuscitated patients in intensive care can later be disconnected from ventilators, he pointed out, but "you can't reverse death." Courts have seemed unreceptive to what might be labeled wrongful-life cases. Dr. Pope sees that changing, however, and has published several recent examples...[1] "Courts increasingly accept that unwanted life is also a harm," he said. "Families were showing up at plaintiffs' attorneys offices in the past and getting turned away. Now, plaintiffs' attorneys are taking these cases." For decades, since the bitter legal battles surrounding Karen Ann Quinlan and Terri Schiavo,[2,3] Americans have been continually urged to put their end-of-life wishes in writing. https://goo.gl/nflei2

1. 'Legal briefing: New penalties for ignoring advance directives and do-not-resuscitate orders,' *Journal of Clinical Ethics*, 2017;28(1):74-81. https://goo.gl/nxN3qF

2. 'Karen Ann Quinlan, 31 dies, focus of '76 right-to-die case,' *The New York Times*, 12 June 1985. https://goo.gl/RQ4Vpn

3. 'From private ordeal to national fight: The case of Terri Schiavo,' *The New York Times*, 20 April 2014. [Noted in Media Watch 28 April 2014, #355 (p.3)] https://goo.gl/YLkD9r

Noted in Media Watch 10 April 2017, #507 (p.9):

- *ANNALS OF THE AMERICAN THORACIC SOCIETY*, 2017;14(4):491-492. **'Interpreting "do not resuscitate": A cautionary tale of physician influence.'** Care intensity at the end of life is known to vary across geography and health care systems, yet very little work has identified mechanisms that drive such variation. Existing literature has been unable to attribute such differences consistently to patient characteristics, raising the possibility that individual health care center factors or physicians' practice patterns drive much of the variation. https://goo.gl/YGDMGP

International

End-of-life care in Australia

New South Wales government addresses Australia's "unseen crises"

AUSTRALIA (New South Wales | *The Sydney Morning Herald* – 16 April 2017 – When patients turn 18, they are no longer covered by this special service and their parents are faced with a stark choice; place their children in an aged care palliative facility or become 24/7 carers without rest or respite. Australia has no dedicated palliative care facilities ... for young adults, although there are a few specialised care units for children. The New South Wales (NSW) government is trying to plug the gap in care by announcing a $2 million funding commitment that will recur year-on-year starting in 2018. A senior NSW government source told Fairfax Media that with the newly announced funding model the "best case scenario" to get a facility for young adults up and running was "three to four years away." https://goo.gl/OWzjvC

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

We need a rethink on palliative care – it works best if started early

U.K. | *The Daily Mirror* – 14 April 2017 – Most of us think palliative care (PC) is for people in the terminal stage of cancer. It is often delayed until the last few weeks or days of life when treatments are no longer effective. However, we need to rethink that as up to 80% of people who die could benefit from PC earlier. In fact a 2014 World Health Organization guideline proposes early PC should be considered from diagnosis onwards. There are many benefits of early PC for families as well as patients. Outpatient specialist PC in particular improves quality of life and, for some, longevity. It can also help avoid uncomfortable interventions that have little benefit. Studies of older people in Australia and people with chronic disease in Canada show significantly fewer hospital admissions for those who have early PC. Although trials don't explain which aspects of PC are the most important, helping people to make choices that fit with their own priorities seems to be key. https://goo.gl/XEpn1F

Elder care in Australia

Shrinking home care workforce raises concerns: Report

COMMUNITY CARE REVIEW | Online – 13 April 2017 – Despite continued growth in government-funded home care and home support, the sector's full-time equivalent direct care workforce has shrunk by 19% since 2012, official figures show.[1] The latest aged care workforce census found the community care workforce overall has reduced by 13% in the last four years. In 2012, 6.7% of community care workers were employed on permanent a full-time contract, which has dropped to 5.7% in 2016. The report's authors, researchers at the National Institute of Labour Studies at Flinders University, said the findings point to an increase in the proportion of workers employed for fewer hours. https://goo.gl/egrkA1

Extract from aged care workforce report

Priority areas identified for future training included dementia, palliative care and (in home care and home support) mental health.

1. '2016 National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016,' Department of Health, Government of Australia, April 2016. https://goo.gl/2jzEiB

End-of-life care in Singapore

New wards for dementia patients and critically ill children launched at Assisi Hospice

SINGAPORE | *The Straits Times* – 12 April 2017 – New wards dedicated to end-of-life care for dementia patients and critically ill children were launched at Assisi Hospice... They are the first inpatient hospice programmes for such patients, and will feature new models of care to meet the needs of these groups. The dementia hospice programmes will be piloted for two years, while the paediatric programme will be piloted for three years. Patients in the dementia ward will receive care from staff trained to be attuned to verbal and non-verbal cues, in order to better understand patients' needs. Out of 16 beds, 10 are currently taken. In the paediatric ward there are five single beds and one patient. The ward is designed to accommodate families... There is also space within each single room for parents to stay over with their children. Patients in both wards pay $295 a day before subsidies. Up to 75% of the cost can be subsidised by the Government, with further subsidies available from Assisi Hospice. https://goo.gl/K27i33

Media Watch Online

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

Court rulings in England

Dying man Noel Conway can fight right-to-die law

U.K. (England) | BBC News – 12 April 2017 – A terminally ill man has won the right to bring a High Court challenge over the law on assisted dying. Noel Conway, 67, asked the Court of Appeal to overturn a decision that prevented a judicial review over the blanket ban on providing a person with assistance to die. The retired college lecturer, who has motor neurone disease, is not expected to live for more than 12 more months. https://goo.gl/dHfBJZ

Charlie Gard case: Doctors can withdraw baby's life support

U.K. (England) | BBC News – 11 April 2017 – Doctors can withdraw life support from a sick baby with a rare genetic condition against his parents' wishes, a High Court judge has ruled. Specialists at Great Ormond Street Hospital said eight-month-old Charlie Gard has irreversible brain damage and should be moved to palliative care. His parents Connie Yates and Chris Gard, from London, had wanted to take him to the US for a treatment trial. https://goo.gl/nzOZCr

Coroner criticises Junee Correctional Centre after paedophile Keith Howlett dies from cancer

AUSTRALIA (New South Wales) | *The Southern Cross* (Adelaide, South Australia) – 10 April 2017 – A coroner has hit out at the operators of Junee jail for allowing a terminally ill paedophile to "suffer greatly" and not be afforded access to proper palliative care (PC). Keith Howlett, who was serving a minimum two-year sentence for child sex offences, collapsed and died at the prison in mid-2013. In her findings of a coronial inquest ... Deputy State Coroner Harriet Grahame said the prisoner had not been "adequately assessed" and had "suffered greatly" before his death. Howlett was being treated for lung cancer ... and had been diagnosed HIV-positive, the inquest heard. "All of these issues should have been explored by a practitioner skilled in recognising PC needs," Magistrate Grahame said. The deputy coroner also recommended a specialist PC unit for prisoners and said medical staff in the state's prisons should be better trained in providing care for cancer patient prisoners. https://goo.gl/WKKwX9

Specialist Publications

'"We call it jail craft": The erosion of the protective discourses drawn on by prison officers dealing with ageing and dying prisoners in the neoliberal, carceral system' (p.13), in *Sociology*.

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 4 April 2017) is posted on the Palliative Care Community Network website at: http://goo.gl/ZpEJyQ

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *Dutch News* (Amsterdam) – 12 April 2017 – **'Number of official cases of euthanasia rise 10% in The Netherlands.'** The number of official cases of euthanasia in The Netherlands rose 10% last year to 6,091 and euthanasia now accounts for 4% of total deaths... In 10 cases, the rules for euthanasia were not followed correctly, most of which involved a failure to properly consult a second doctor... In one case, a doctor was reprimanded for "crossing the line" with a patient suffering from severe dementia. Of the total, 87% of assisted deaths involved people with cancer, serious heart or lung problems or diseases of the nervous system such as ALS. There were 32 more cases of assisted suicide involving people with dementia, most of whom were in the early stages of the disease. In addition, there were 60 cases involving people with severe psychiatric problems, a rise of four on 2015. https://goo.gl/Qa0T9r

Specialist Publications

Palliative care training in cardiology fellowship: A national survey of the fellows

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 11 April 2017 – Fellows [i.e., survey respondents] reported discordance in the quality of education between general cardiology and palliative care (PC) principles as it relates to care of the patient approaching the end of life (EoL). Fellows infrequently received explicit training nor were observed or mentored in delivering EoL discussions. Respondents reported an underutilization of PC and hospice resources during fellowship training and also a perception that attending faculty were not routinely addressing goals of care. The survey results highlight a need for enhanced PC and EoL training experiences for cardiology fellows and also suggest underutilization of hospice and PC resources for patients with advanced cardiac diseases. These findings create a platform for future work that might: 1) Confirm this training deficit; 2) Lead to exploration of educational models that could reconcile this deficit; and, 3) Potentially help improve PC support for patients and families facing advanced heart disease. https://goo.gl/mBeUSo

Noted in Media Watch 19 December 2016, #492 (p.10):

- *JOURNAL OF CARDIAC FAILURE* | Online – 9 December 2016 – **'Palliative care in heart failure: Architects needed.'** The role of palliative care (PC) in heart failure has gained increased attention in recent years, with an emphasis on providing patients with this complex syndrome an additional layer of support. This includes a focus on quality of life and relief from pain and other distressing symptoms. Expert and public opinion, as well as professional and policy organizations are increasingly calling for the expansion of PC into the care of patients with heart failure. https://goo.gl/tc4vt5

Related

- *EUROPACE* | Online – Accessed 10 April 2017 – **'Ethics and the cardiac pacemaker: More than just end-of-life issues.'** For many years, ethical debate about pacemakers has focused on whether and under what circumstances they may be turned off in end-of-life care. Several other important ethical issues have been neglected, perhaps because the dilemmas they pose for cardiologists are not so immediate. This paper analyses these issues in order to facilitate a more comprehensive approach to ethics and the cardiac pacemaker. Cardiologists should be aware of all of these issues and contribute to ongoing discussions about how they are resolved. https://goo.gl/vagKz6

Organization-level principles and practices to support spiritual care at the end of life: A qualitative study

BMC PALLIATIVE CARE | Online – 11 April 2017 – Though most models of palliative care (PC) specifically include spiritual care as an essential element, secular health care organizations struggle with supporting spiritual care for people who are dying and their families. Organizations often leave responsibility for such care with individual care providers, some of whom are comfortable with this role and well supported, others who are not. This study looked to hospice programs founded and operated on specific spiritual foundations to identify, if possible, organizational-level practices that support high-quality spiritual care that then might be applied in secular healthcare organizations. Nine principles for organizational support for spiritual care emerged from the interviews [conducted]. Three principles identify where and how spiritual care fits with the other aspects of PC; three Principles guide the organizational approach to spiritual care, including considerations of assessment and of sacred places; and, three principles support the spiritual practice of care providers within the organizations. https://goo.gl/Lhwzzb

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

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 February 2017 – **'Multidisciplinary training on spiritual care for patients in palliative care trajectories improves the attitudes and competencies of hospital medical staff: Results of a quasi-experimental study.'** The authors describe a training program for healthcare professionals that had a positive effect on staff attitudes and competencies, improved attention to the spiritual dimension. https://goo.gl/VLkjbr

Cont.

Noted in Media Watch 2 January 2017, #493 (p.19):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2016;19(8):814-821. **'Efficacy of training interprofessional spiritual care generalists.'** A day-long workshop of concentrated instruction, including didactics, a visual slideshow, simulation of clinical scenarios, and debriefing/discussion components, was effective in training clinicians from varied disciplines to learn basic generalist-level spiritual care skills and to collaborate more effectively with chaplains, the spiritual specialists. https://goo.gl/wMgyza

Decision-making and future planning for children with life-limiting conditions: A qualitative systematic review and thematic synthesis

CHILD: CARE, HEALTH & DEVELOPMENT | Online – 12 April 2017 – In the last decade, the number of children with life-limiting and life-threatening conditions in England has almost doubled and it is estimated that worldwide there are 1.2 million children with palliative care needs. Families and professionals caring for children with life-limiting conditions are likely to face a number of difficult treatment decisions and develop plans for future care over the course of the child's life, but little is known about the process by which these decisions and plans are made. The purpose of this review is to synthesize findings from qualitative research that has investigated decision-making and future planning for children with life-limiting conditions. Nineteen descriptive themes were identified, and these were further synthesized into four analytical themes – analytical themes were "decision factors," "family factors," "relational factors" and "system factors." Review findings indicate that decision-making and future planning is difficult and needs to be individualized for each family. However, deficits in understanding the dynamic, relational and contextual aspects of decision-making remain and require further research. https://goo.gl/aC2F1J

Related

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(3):174-181. **'Translating research to practice: Providing critically ill children the opportunity to go home or to hospice for end-of-life care.'** A free-standing quaternary pediatric hospital in New England has been facilitating parents' requests to take their child home or to a hospice facility from an intensive care unit (ICU) at end of life (EoL) for the withdrawal of life sustaining measures for the past 16 years. However, knowledge of the aftermath of this decision was very limited. Before responding to a growing interest in making this service more available, an exploratory study was done to learn about the parents' perceptions of the experience over time. https://goo.gl/lPRFCa

- *NORDIC JOURNAL OF NURSING RESEARCH* | Online – 7 April 2017 – **'An obligation to care for seriously ill children in their homes: A qualitative study of community nurses' perceptions.'** The aim of this study was ... to describe community nurses' perceptions of caring for seriously ill children at home. A content analysis was conducted of 11 semi-structured interviews with nurses. One theme, "obligation to care," was found, followed by three categories: 1) Making an impact; 2) Feeling confident; and, 3) Emotional processing. The authors found collaboration with paediatric staff in the hospital is important for community nurses in order to gain confidence, which would optimise care at home for seriously ill children and their families. https://goo.gl/I0f3Yo

Integrating quality palliative and end-of-life care into the geriatric assessment

CLINICS IN GERIATRIC MEDICINE | Online – 6 April 2017 – This article provides an overview of how integrating quality palliative and end-of-life care (P&EoLC) into geriatric assessment can be a tremendous benefit to older adult patients and their families. Although the quality of P&EoLC for older adults has improved greatly, there are still many opportunities to improve the quality of life and function for older adult patients in the last few years of their life. More clinical expertise in comprehensive P&EoLC must be developed and maintained. There also must be greater focus on and more direct reimbursement developed for physicians and health system providers. https://goo.gl/5vhdzr

Cont.

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

- *GERONTOLOGY & GERIATRICS EDUCATION* | Online – 27 January 2017 – '**Geriatric education utilizing a palliative care framework.**' The dramatic growth of persons over 65 and the increased incidence of multiple, chronic illness has resulted in the need for more comprehensive healthcare. Geriatrics and palliative care are medical specialties pertinent to the elderly, yet neither completely addresses the needs of older adults with chronic illness. https://goo.gl/KZn9Cw

N.B. Noted in this issue of Media Watch are selected articles on the common ground shared by geriatric and palliative medicines.

Palliative and end-of-life care in nephrology: Moving from observations to interventions

CURRENT OPINION IN NEPHROLOGY & HYPERTENSION | Online – 7 April 2017 – In comparison with patients who have other serious illnesses, patients with advanced kidney disease have a higher rate of intensive care utilization at the end of life (EoL) and receive palliative care (PC) less frequently. Consensus and clinical practice guidelines have therefore recommended the incorporation of PC earlier in the disease trajectory. This review summarizes recent literature on this aspect of care and will highlight future directions for patient-centered care within palliative nephrology. Patients with advanced kidney disease and their families frequently do not engage effectively with their clinicians to make informed treatment decisions or plan for care at the EoL. Furthermore, racial and ethnic minority patients continue to receive a lower rate of PC services compared to other racial groups. Interventions that promote better PC communication and education among nephrology clinicians, patients and their families are becoming increasingly more common in nephrology. Overall, improved understanding of the unique care needs of patients with advanced and end-stage kidney disease provides a solid foundation to improve palliative and EoL care delivery among diverse populations in nephrology. https://goo.gl/QGfH50

Cont. next page

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.

Noted in Media Watch 2 May 2016, #460 (p.9):

- *NEPHROLOGY* | Online – 26 April 2016 – **'Providing supportive care to patients with kidney disease.'** The field of medicine is recognizing the importance of patient-centered care and quality of life, thoughtfully considering patients' values and goals so care can be effectively tailored to support those goals, which may include the delivery of supportive or palliative care, when necessary. To this end, three "best practices" are provided: 1) Nurture a shared decision-making relationship; 2) Provide meticulous pain and symptom management; and, 3) Provide or collaborate with supportive care or hospice in the treatment of seriously ill kidney disease patients. http://goo.gl/uAZ8dm

N.B. Listed in the 14 March 2016 issue of Media Watch (#453, p.10) are selected articles on end-of-life care for people living with kidney disease.

Falling together: A conceptual paper on the complexities of information interactions and research gaps in empathetic care for the dying

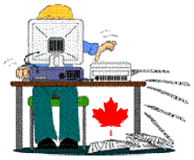
INFORMATION RESEARCH | Online – Accessed 10 April 2017 – Palliative care (PC) embraces the plight of patients and caregivers. Cognitive and emotional empathy, empathetic care, and the information environment at a time of dying influence caregivers' experiences of information interactions and emotional well-being. Understanding empathetic care, and the need for empathy in caregiver information interaction experiences in both PC and information behaviour, is still too limited. Visceral autoethnographic sharing combined with other qualitative research methods may help. This paper intends to push the boundaries of research on the complexities of information interactions experienced by caregivers in empathetic care for the dying. Themes for further research are deducted from the subject literature, recorded experiences of caregivers, and the authors' own experiences and insight gained from dual sharing experiences as information behaviour researchers and caregivers (i.e., collaborative autoethnography). They allow for *etic* (outsider) and *emic* (insider) perspectives. Information behaviour, collaborative autoethnography, and the philosophy of PC served as research lens. https://goo.gl/m0oZId

Extract from *Information Research* article

Since conventional research designs alone cannot address the complexities of information interactions, and there has been a failure to meet with the expectations of caregivers at the time of dying, alternative designs such as inter-disciplinary collaborative autoethnography supplemented by qualitative mixed methods research must be considered.

Related

- *INFORMATION RESEARCH* | Online – Accessed 10 April 2017 – **'An exploratory review of research on cancer pain and information-related needs: What (little) we know.'** The literature is scant on cancer pain information-related needs. This review reports on research themes, research designs and research gaps. Suggestions are offered for further research embracing the commitment for palliative care of cancer pain and ensuring quality of life, enhanced research designs, the need to address the issue of differing terminologies on a broader extent between disciplines and in a narrower context, between patients and healthcare practitioners, and to explore means to address the complexity of cancer pain and cancer pain information-related needs. https://goo.gl/uWkL4B



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

Team functioning in hospice interprofessional meetings: An exploratory study of providers' perspectives

JOURNAL OF INTERPROFESSIONAL CARE | Online – 13 April 2017 – Interprofessional collaboration is the foundation of hospice service delivery. In the U.S., hospice agencies are required to regularly convene interprofessional meetings during which teams review plans of care for the patients and families they serve. A small body of research suggests that team functioning could be significantly enhanced in hospice interprofessional meetings; however, systematic investigation of this possibility has been limited to date. The purpose of this qualitative study was to better understand the experiences and perspectives of hospice providers who regularly participate in interprofessional meetings as a first step toward improving teamwork in this setting. Participants [in this study] recognised the ways meetings supported high-quality, holistic patient and family care, but voiced frustrations over meeting inefficiencies, particularly in light of caseloads they perceived as overly demanding. Time constraints were often viewed as prohibiting the inclusion of interprofessional content and full participation of all team members. https://goo.gl/sKGr6V

Related

- *JOURNAL OF CREATIVITY IN MENTAL HEALTH* | Online – 7 April 2017 – **'Creative supervision for counselors working in a hospice setting.'** Many individuals who suffer from debilitating health issues use the care of helping professionals in a hospice environment. Supervision approaches for counselors who encounter grief, loss, death, and bereavement issues in hospice settings are needed. The authors introduce three creative interventions for use with supervisees in one of the four stages of the integrative developmental model of supervision. One intervention, the "rock talk," is more thoroughly explained and then demonstrated in a case illustration of a supervisee using the intervention to say goodbye to a hospice client. https://goo.gl/EnAJ5e

Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities

JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES | Online – 13 April 2017 – Racial and cultural barriers inherent in health systems have made the delivery of culturally relevant end-of-life care (EoLC) that aligns with patient preferences a particular challenge across African American patient populations. The end of life experience has been cited as a public health crisis by the Institute of Medicine,[1] and this crisis is one felt even more acutely by patients of this minority race. Structural racism has limited access to planning mechanisms proven to result in quality EoLC; thus, health systems must initiate remedies in the face of dire need, as African Americans face a disproportionate burden of morbidity and mortality from many serious illnesses. Recognizing education is essential to overcoming barriers to quality care access, development of new and culturally appropriate models of community engagement surrounding advance care planning is needed to serve and empower African American patients. https://goo.gl/FvKT3m

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

Noted in Media Watch 10 April 2017, #507 (p.3):

- U.S. (Massachusetts) | STAT News (Boston Globe Media) – 5 April 2017 – **'Against a history of medical mistreatment, African Americans are distrustful of hospice care.'** Why should African Americans continue to suffer more at life's end than others? There's a lot to sift through, starting with the medical industry's long and at times ugly history of neglect and abuse of blacks. Doctors can also fail to account for the pervasive belief among many African American faithful that God has an ability to heal the sick through miracles. Finally, there's the reality that some in tighter-knit African American communities can direct harsh judgments toward those who choose hospice. https://goo.gl/mU0b6v

N.B. Noted in this issue of Media Watch are selected articles on the disparities in the provision and delivery of hospice and palliative care within African American communities.

Palliative care in humanitarian crises: Always something to offer

THE LANCET | Online – 15 April 2017 – More than 128·6 million people across 33 countries require life-saving humanitarian assistance, 92·8 million of whom are particularly vulnerable. Palliative care (PC), however, has been omitted from efforts to tackle humanitarian crises. PC is, according to the World Health Organization, "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering." The authors propose holistic PC as an integral component of relief strategies. PC is especially applicable in four humanitarian scenarios. First, in protracted humanitarian crises for patients with life-limiting illnesses whose pre-crisis PC is interrupted and for those whose PC needs are unmet or exacerbated as a result of the crises. Older people are the most prominent group here, given their vulnerability and poorly identified and understood health-care needs. Second, in mass casualty events where resources are overwhelmed by acute injuries and individuals are triaged according to their likelihood of survival. Third, in communicable disease outbreaks with high mortality and limited therapeutic interventions where relief of suffering can be the main treatment option available... Fourth, in camps for refugees and displaced people where some individuals need PC during transition through the camp. https://goo.gl/vnGfgr

Noted in Media Watch 13 March 2017, #503 (p.2):

- HUMANITARIAN HEALTH ETHICS RESEARCH NETWORK | Online – Accessed 8 March 2017 – **'Palliative care in humanitarian situations – is it achievable?'** While we have estimates of the need for palliative care (PC) in relatively stable populations, we have no similar assessments in humanitarian situations. We can assume that where populations experiencing humanitarian emergencies remain in their home country, any pre-existing level of need for PC would persist or even increase under the additional strains of the emergency (depending on the humanitarian situation). There is a growing realization that it is precisely in these situations where there is a high level of physical and emotional trauma and death that PC is needed. https://goo.gl/MSvXTT

Home hospice care in Nepal: A low-cost service in a low-income country through collaboration between non-profit organisations

THE LANCET GLOBAL HEALTH Online – Accessed 12 April 2017 – In 2015, Binaytara Foundation, a U.S.-based non-profit organisation, collaborated with a Nepal-based non-profit organisation, Cancer Care Nepal, to develop a home hospice programme in Kathmandu. The authors interviewed 150 terminally ill patients and their family to investigate the need for a hospice programme. A project leader (a Nepali physician) was appointed. In the second phase of the programme, health-care providers were trained and electronic medical records implemented. A hospice nurse practitioner from Idaho, U.S. travelled to Nepal to train 15 Nepali nurses. A motorbike was provided for the hospice nurse to travel to patients' homes. The hospice programme was launched in January 2016. By September 2016, 65 patients had been enrolled in home hospice care. The service is provided free of charge to the patients and their family. The cost of running the hospice programme is US$17 per day. All costs, including equipment, salary, staff training, electronic medical records, fuel, and other monthly expenses have been paid for by Binaytara Foundation. Home hospice programmes are very important in low-income countries like Nepal where most patients with cancer are diagnosed at late stages, and many patients do not have access to cancer centres. To make a home hospice project successful, several factors, such as the selection of an appropriate local partner organisation, training, and financial support are necessary and the project should respect local cultural contexts. https://goo.gl/Kv9btC

Cont.

Noted in Media Watch 9 February 2015, #396 (p.15):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2015;49(1):110-116. **'Opioid availability and palliative care in Nepal: Influence of an International Pain Policy Fellowship.'** In 2008, an oncologist from Nepal, one of the poorest countries in the world, was selected to participate in the International Pain Policy Fellowship, a program to assist low- and middle-income countries (LMICs), to improve patient access to pain medicines. Following the World Health Organization public health model for development of pain relief and palliative care (PC), the Fellow, working with colleagues and mentors, has achieved initial successes. https://goo.gl/rrkAi0

Analysis of the U.S.'s medical decision-making statutes

Inconsistent state laws may complicate medical decision-making

MEDICAL EXPRESS | Online – 12 April 2017 – A patchwork of state laws can make it confusing to navigate incapacitated patients' medical wishes. Without clear national standards, the problem may worsen as the nation's 75 million baby boomers continue to age, according to medical ethics research led by investigators at Beth Israel Deaconess Medical Center, the Mayo Clinic and the University of Chicago's MacLean Center for Clinical Medical Ethics...[1] "Decisions about withdrawing or withholding life-sustaining care are incredibly emotional and challenging," said Erin Sullivan DeMartino MD, a pulmonary and critical care medicine physician at Mayo Clinic in Minnesota who led the study... "But when there is ambiguity about who is responsible for decision-making, it adds much more stress to that moment." Fewer than 30% of Americans have "advance directives" or legal documents outlining their treatment preferences that can also grant someone power to make medical decisions on their behalf. On average, 40% of hospitalized adults can't make their own medical decisions. In some intensive care units, that figure reaches 90%. For patients without advance directives, most states have laws dictating that medical decisions fall to someone else – typically a spouse, parent or child. But the legal surrogate may not always be someone who understands the patient's specific values and wishes. That presents both ethical and health care policy problems, researchers say. https://goo.gl/rg5aZO

Australian perspective

Advance care planning: Is quality end-of-life care really that simple?

INTERNAL MEDICINE JOURNAL | Online – 11 April 2017 – Routine implementation of advance care planning (ACP) is a prominent feature of policy directed at improving end-of-life care (EoLC) in Australia. However, while complex ACP interventions may modestly reduce medical care at the end of life and enable more people to die at home or outside of acute hospital settings, existing legal, organisational, cultural and conceptual barriers limit the implementation and utility of ACP. https://goo.gl/GoZRg5

1. 'Who decides when a patient can't? Statutes on alternate decision makers,' *New England Journal of Medicine*, 2017;376(15):1478-1482. https://goo.gl/SYQsj4

When it comes to death, there is no place like home… Or is there?

PALLIATIVE MEDICINE | Online – 6 April 2017 – The studies discussed in this article have added to the corpus of evidence demonstrating the value of palliative care (PC); however, they also reveal on-going challenges and priority areas for discovery and dissemination. Two questions readily come to mind: How can we support family caregivers (FCGs) who can have a major influence on patients' acute care resource use? And, what are the most effective and scalable models to provide the same level of PC expertise and availability to all, and especially to patients and their clinicians in the most rural areas? Relative to FCGs, despite international consensus and guidelines about the critical need for support, few PC models have been identified that accomplish this routinely and effectively. https://goo.gl/07EdaG

Cont.

Noted in Media Watch 12 October 2015, #431 (p.9):

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – **'Is home always the best and preferred place of death?'** Death at home is not necessarily good, and just because a patient did not die at home does not necessarily mean their death occurred in the wrong place. It is important to recognise and accommodate the diversity of patient preferences for place of death, especially in the context of a cultural heterogeneity that is rarely researched or recognised. When home death becomes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences. Normalising home as the best and natural place to die promotes a sense of guilt and failure if death occurs elsewhere. https://goo.gl/GPkyeO

"We call it jail craft": The erosion of the protective discourses drawn on by prison officers dealing with ageing and dying prisoners in the neoliberal, carceral system

SOCIOLOGY | Online – 7 April 2017 – The U.K. prison population has doubled in the last decade, with the greatest increases among prisoners over the age of 60 years, many of whom are sex offenders imprisoned late in life for "historical" offences. Occurring in a context of "austerity" and the wider neoliberal project, an under-researched consequence of this increase has been the rising numbers of "anticipated" prison deaths; that is, deaths that are foreseeable and that require end-of-life care (EoLC). The authors focus on "jail craft"; a nostalgic, multi-layered, narrative or discourse, and set of tacit practices which are drawn on by officers to manage the affective and practical challenges of working with the demands of this changed prison environment. Utilising findings from an empirical study of EoLC in prisons, they propose that the erosion of jail craft depletes protective resources and sharpens the practical consequences of neoliberal penal policies. https://goo.gl/OQkmDR

Palliative care in Huntington disease: Personal reflections and a review of the literature

TREMOR & OTHER HYPERKINETIC MOVEMENTS | Online – 11 April 2017 – Huntington disease (HD) is a fatal, autosomal dominant, neurodegenerative disorder manifest by the triad of a movement disorder, behavioral disturbances, and dementia. At present, no curative or disease modifying therapies exist for the condition and current treatments are symptomatic. There is increasing evidence of the benefit of palliative care (PC) throughout the course of neurodegenerative conditions including Parkinson disease and amyotrophic lateral sclerosis. However, beyond its application at the end of life, little is known about the role of PC in HD. The authors discuss what is known about HD, specifically related to early disease burden, caregiver burnout, advance care planning, and end-of-life care. https://goo.gl/HpvS9H

Noted in Media Watch 6 October 2014, #378 (p.13):

- *JOURNAL OF HUNTINGTON'S DISEASE* | Online – 25 September 2014 – **'Perhaps the subject of the questionnaire was too sensitive: Do we expect too much too soon?'** Wishes for the end of life in Huntington disease – the perspective of physicians in 15 European countries. No abstract available. https://goo.gl/P9KwDG

Noted in Media Watch 24 December 2012, #285 (p.11):

- *JOURNAL OF MEDICAL ETHICS* | Online – 22 December 2012 – **'A plea for end-of-life discussions with patients suffering from Huntington disease: The role of the physician.'** From a qualitative study based on interviews with 15 physicians experienced in treating Huntington disease (HD), several ethical issues emerged. Consideration of these aspects leads to a discussion about the professional role of a physician in relation to the personal autonomy of a patient. Such a discussion can raise awareness that talking about end-of-life wishes with an HD patient is part of the legal, professional and moral responsibility of the physician... https://goo.gl/LK4EGS

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ALBERTA LAW REVIEW* | Online – Accessed 12 April 2017 – **'Autonomy and beneficence in assisted dying in Canada: The eligibility of mature minors.'** The Supreme Court of Canada's unanimous decision in *Carter v. Canada (Attorney General)* transformed euthanasia and assisted suicide from criminal acts to health services. This transformation occurred because the Supreme Court focused on individuals and their desire to escape intolerable suffering caused by grievous and irremediable illness. Promoting the ethical principles of autonomy and beneficence (acting with the best interests of the person in mind), the Carter decision effectively recognizes that Canadian law must respect the autonomous choice of competent adults to relieve intolerable suffering by seeking assistance in dying and that such a choice can be beneficent. The Carter decision has profound significance for end-of-life care for many Canadians including grievously and irremediably ill youth who seek aid in dying. https://goo.gl/3NiCD8

- *AMERICAN JOURNAL OF PSYCHIATRY* | Online – 6 April 2017 – **'Role of psychiatrists in assisted dying: A changing trend.'** Perhaps what is prolonging the debate about the legalization of physician-assisted death is the current conceptualization of what constitutes a "good" or "appropriate" death. This includes resolution of internal conflicts, sustenance of one's personal sense of identity, and reduction of fear of loss of control. However, there is no reliable and effective guiding principle to achieve all these ideals in the care of a dying person. As the momentum builds for autonomy at the end of life, concerns over adequacy of mental capacity in such cases abound. Psychiatric consultation is imperative to determine whether a patient's psychopathology, however covert, is influencing his or her judgment. Since physician-assisted death is becoming more widely accepted, its legal status, as well as ethical issues surrounding end-of-life care, should be formally taught in medical schools and psychiatry residencies. https://goo.gl/Qq6OtW

  Noted in Media Watch 20 February 2017, #500 (p.17):

  - *PSYCHIATRIC SERVICES* | Online – 15 February 2017 – **'Should mental disorders be a basis for physician-assisted death?'** Among the problems seen in countries that have legalized assisted death for mental disorders are difficulties in assessing the disorder's intractability and the patient's decisional competence, and the disproportionate involvement of patients with social isolation and personality disorders. Legitimate concern exists that assisted death could serve as a substitute for creating adequate systems of mental health treatment and social support. https://goo.gl/5tQ3to

- *DEATH STUDIES* | Online – 11 April 2017 – **'Declarations on euthanasia and assisted dying.'** Declarations on end-of-life issues are advocacy interventions that seek to influence policy, raise awareness and call others to action. Despite increasing prominence, they have attracted little attention from researchers. This study tracks the emergence, content and purpose of declarations concerned with assisted dying and euthanasia, in the global context. The authors identify 62 assisted dying/euthanasia declarations covering 1974-2016, and analyse them for: originating organization, geographic scope, format, and stated viewpoint on assisted dying/euthanasia. The declarations emerged from diverse organizational settings and became more frequent over time. https://goo.gl/CCpZRA

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2017;317(14):1476-1477. **'Potential number of organ donors after euthanasia in Belgium.'** Organ donation after euthanasia involves patients whose request to undergo euthanasia has been granted and who voluntarily want to donate their organs after death. It requires patients to undergo euthanasia in the hospital, and organ donation is performed after circulatory death. The practice is controversial and currently only allowed in Belgium and The Netherlands. Even in these countries, it is rarely performed; as of August 2016, 43 patients undergoing euthanasia had donated organs. https://goo.gl/Yo6miQ

Worth Repeating

Rhetoric and reality: Matching palliative care services to meet the needs of patients of all ages, with any diagnosis

PALLIATIVE MEDICINE, 2016;30(1):3-5. In the 21st century the major expenditure for health services worldwide is on chronic, non-communicable disease and the disabling *sequelae* of acute illness, with its attendant multi-morbidity and incapacity. Persistent illness and disability also present the greatest challenges to effective service design. Successful care requires services to couple responsiveness to unavoidable acute on chronic deterioration with long-term, continuous efforts to prevent avoidable further complications and maximise quality of life. These approaches require different skills. The evidence is clear that in chronic, symptomatic illness a psychologically-informed approach is necessary to inform and motivate people to change established beliefs and habits, giving themselves the greatest chance of the best possible physical and psychological health in the longer term. This impact is going to be greatest in those overcoming the greatest disease burden, at the youngest age, to contain accumulating morbidity on morbidity. There are frequent policy restatements regretting that hospitals are still only designed to meet the needs of those with acute conditions where life-saving treatment or single interventions are required, but not suited to managing chronicity: little changes. The significant advances in the effective acute medical management of myocardial infarction, stroke, and chronic respiratory illness, the care of trauma patients, and the transition of cancer to a chronic illness for many, are impressive achievements. Sadly the quality of survival of people with chronic, progressive disease does not yet reliably match the standard of their acute care, with increasing evidence in the literature of hidden distress and blighted lives for both patient and family. [Noted in Media 28 December 2016, #442 (p.11)] https://goo.gl/LxJp14

Media Watch: Online

International

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

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): https://goo.gl/JL3j3C

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): https://goo.gl/IOSNC7

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/5d1l9K

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

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