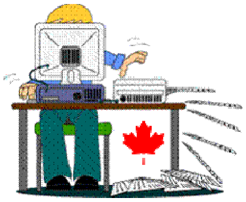
Media Watch…

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.*

29 August 2016 Edition | Issue #477



Compiled & Annotated by Barry R. Ashpole

Patient misunderstandings about the intentions of treatment and their overall prognosis: Scroll down to Specialist Publications and 'Palliative care in cancer: Managing patients' expectations' (p.10), in *Journal of Medical Radiation Sciences*.

Canada

Paramedics treating patients at home eases end-of-life journey, caregiver says

NOVA SCOTIA | CBC News (Halifax) – 24 August 2016 – The daughter of a cancer patient in Nova Scotia says a new program, which allows paramedics to care for palliative care patients in their homes instead of rushing them to the hospital, has helped make her father's final days a little bit easier. The Paramedics Providing Palliative Care at Home Program[1] is funded by the Canadian Partnership Against Cancer and is currently available in both Nova Scotia and Prince Edward Island. Although program development and training began in 2014, the program didn't officially launch until June. Funding expires at the end of 2016. Martin said the paramedics assessed her father and discussed the treatment plan with a medical resident over the phone. They gave him an IV, and even stayed with him while she ran out to buy his antibiotics. She said her father received the same treatment he would have had in hospital, "but it was more efficient and timely," and it meant the family could avoid a lengthy wait in the emergency room. http://goo.gl/7HGivZ

1. Paramedics Providing Palliative Care at Home Program, Nova Scotia: http://goo.gl/Txru6I

Noted in Media Watch, 1 August 2016, #473 (p.2):

- PRINCE EDWARD ISLAND | CBC News (Charlottetown) – 26 July 2016 – '**Palliative home care program big success so far, says province.**' The province said paramedics have responded to 76 calls from in-home palliative care patients at night, and 27 patients – or 35% – have been able to remain in their home with support from paramedics, while 49 patients – 65% – asked to be taken to the Provincial Palliative Care Centre in Charlottetown or the nearest hospital. http://goo.gl/ac2MVI

Noted in Media Watch, 30 March 2015, #403 (p.3):

- ONTARIO | CBC News (Toronto) – 24 March 2015 – '**Community paramedicine program aims to keep chronic illness patients out of emergency.**' The community paramedicine program, which aims to keep people at home and out of the emergency room, allows paramedics to visit patients with chronic and complex illnesses without the prompt of a 911 [emergency] call. http://goo.gl/iRM4Lt

Changes needed to boost end-of-life care, ranked 18th in world: Doctors

THE GLOBE & MAIL | Online – 22 August 2016 – A group of doctors says Canada's approach to palliative care (PC) must be broadened to provide end-of-life support to patients with serious chronic illnesses, not just those with cancer. Their analysis suggests much needs to be done to improve access to PC, especially for patients with such conditions as heart failure and chronic obstructive pulmonary disease, or chronic obstructive pulmonary disease.[1] The authors say Canada is ranked 18th worldwide by the Economist Intelligence Unit for provision of PC, and it lags behind Mongolia and Panama in strategies to develop and promote such services to patients. Co-author Dr. Graeme Rocker of Dalhousie University says two-thirds of the 250,000 Canadians who die each year have illnesses other than cancer, yet most don't have access to the same types of support as cancer patients. The authors suggest all physicians need to be educated about providing PC to their patients, and that services should be home- or community-based rather than delivered primarily in hospitals. Rocker says most Canadians prefer to die at home or in a hospice, but too often a lack of community-based services means they end their lives in a hospital bed. http://goo.gl/HG2t7l

Clarification *vis-à-vis The Globe & Mail* report

Canada was ranked 11th overall of the 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, commissioned by the Lien Foundation of Singapore, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/JsSbW3

Specialist Publications

'Medical assistance in dying in Canada: An ethical analysis of conscientious and religious objections' (p.14), in *BioéthiqueOnline.*

1. 'Palliative care for chronic illness: Driving change,' *Canadian Medical Association Journal*, 22 August 2016. http://goo.gl/UtPz17

Related

- ONTARIO | *The Sarnia Observer* – 26 August 2016 – **'MP's bill calls for a national palliative care framework.'** The Conservative MP for Sarnia-Lambton has introduced a private member's bill she's hoping will pave the way for better palliative care service. Bill C-277, the 'Framework on Palliative Care in Canada Act,' was introduced in May and is set for first reading in September. The Canadian Medical Association is the latest group to lend its support to [Marilyn] Gladu's bill, which also has backing from the Canadian Society of Palliative Care Physicians, the Canadian Nurses Association, and St. Joseph's Hospice in Sarnia, among other groups. http://goo.gl/UgcN8R

More federal funds needed to deal with aging population's health costs: Canadian Medical Association

THE GLOBE & MAIL | Online – 21 August 2016 – Ottawa should provide a financial "top-up" to help provinces and territories deal with the additional health costs caused by an aging population, the president of the Canadian Medical Association (CMA) says. At least $1.6-billion a year more is needed to meet the ever-growing health needs of seniors, notably better access to prescription drugs, home care and long-term care, Dr. Cindy Forbes, president of the CMA, said in an interview. It is the most direct advice yet from the CMA to the federal government as talks heat up around a new Health Accord between Ottawa and the provinces and territories. An Ipsos poll commissioned by the CMA as part of its annual report care on the state of health care found that three in four Canadians agree with the notion that provinces with a significant elderly population should get additional funding. The same survey shows that only one in seven Canadians even knows that the federal government is currently in intense negotiations about cash transfers to the provinces and territories. http://goo.gl/hShnuC

N.B. According to the CMA/Ipsos Reid survey, palliative care ranked fourth in terms of priorities behind an overall strategy for seniors health, mental health services, and prescription drugs. Homecare and caregiver support were rated 5th and 6th, respectively. http://goo.gl/OqFWwY

U.S.A.

As the for-profit world moves into an elder care program, some worry

KAISER HEALTH NEWS | Online – 24 August 2016 – With the support of private equity money, InnovAge aims to aggressively expand a little-known Medicare program that will pay to keep older and disabled Americans out of nursing homes. Until recently, only non-profits were allowed to run programs like these. But a year ago, the government flipped the switch, opening the program to for-profit companies as well, ending one of the last remaining holdouts to commercialism in health care. The hope is the profit motive will expand the services faster. Hanging over all the promise, though, is the question of whether for-profit companies are well-suited to this line of work, long the province of non-profit do-gooders. Critics point out the business of caring for poor and frail people is marred with abuse. Already, new ideas for lowering the cost of the program have started circulating. In Silicon Valley, for example, some eager entrepreneurs are pushing plans that call for a higher reliance on video calls instead of in-person doctor visits. Medicare enrollment is expected to grow by 30 million people in the next two decades, and many of those people are potential future clients. http://goo.gl/gfG4YZ

Extract from *Kaiser Health News* article

Even the program's supporters acknowledge that the movement needs fresh momentum. But they worry that commercial operators will tarnish their image in the same way many for-profits eroded trust in hospice care and nursing homes. Three decades ago, after Congress authorized Medicare to pay for hospice care, commercial operators displaced the religious and community groups that had championed the movement. As recently as 2014, government inspectors found that for-profit hospice companies cherry-picked patients and stinted on care.

Mission creep doesn't benefit patients at the end of life

THE WASHINGTON POST | Online – 22 August 2016 – Here in America, there is a deeply held belief that advances in medicine will eventually conquer or cure the chronic scourges of cancer, dementia, heart disease, lung disease and diabetes. This notion leads many elderly patients to seek aggressive treatment not only to spare their loved ones grief but because they hope (and expect) to be cured, if only they hold on just a little longer. This is one reason that every year more than 75,000 people older than 85 die in intensive care units seeking care that proves to be futile ... and why more than 65% of our senior citizens die in institutions when a significant majority say they would prefer to die at home, according to a 2014 report by the Institute of Medicine.[1] The impulse to treat often prompts us to forget that many elderly patients have multiple medical problems brought on by chronic organ system weaknesses. Focusing aggressive therapy on one serious diagnosis can complicate another to the point of death, disability or prolonged hospitalization. Beyond that, too many doctors succumb to research from drug and device makers that show incrementally positive results for therapies that mean little to someone at the end of a long life. https://goo.gl/OZ0hVQ

Specialist Publications

'American Society of Health-System Pharmacists Guidelines on the Pharmacist's Role in Palliative and Hospice Care' (p.5), in *American Journal of Health-System Pharmacy.*

'Racial differences in hospitalizations of dying Medicare-Medicaid dually eligible nursing home residents' (p.9), in *Journal of the American Geriatric Society.*

'A survey of perinatal palliative care programs in the U.S.: Structure, processes, and outcomes' (p.12), in *Journal of Palliative Medicine.*

---

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Reuters – 26 August 2016 – **'Judge keeps in place California law allowing physician-assisted suicide.'** A California judge ... refused to suspend a new state law allowing physician-assisted suicide for terminally ill patients, citing the need to protect them from pain, but he allowed a legal challenge to proceed. The mixed ruling portends a continued debate over the highly contested law in the first months of its implementation. http://goo.gl/sLc7us

International

Schools are organising "death clubs" to teach children how to manage their feelings

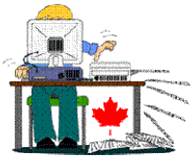
U.K. (Scotland) | *The Sunday Post* (Dundee) – 21 August 2016 – Children as young as nine are being given school lessons about death in a radical scheme to help them cope better with bereavement. School trips to hospices, class talks about dead relatives and even school "death clubs" are being trialled under the scheme. The move has been launched to make children better equipped to cope when someone they know dies. Experts say children have unmet needs around death and bereavement and that including the subject in schools will promote end-of-life and bereavement experiences to children. Parents' groups said any move to teach children about death must be done in an age-appropriate way and should not be forced on anyone. Trials were carried out by the University of Strathclyde, using expert staff from a hospice working with two schools in the Falkirk area, and backed by the Scottish Government. Researchers consulted with teachers, parents, pupils and hospice staff about how they could include the subject in the curriculum. Results put into practice included creating an education programme about death, illness and bereavement alongside health in the school curriculum as well as raising awareness of the role of the local hospice. The research was led by Dr. Sally Paul, lecturer in the School of Social Work & Social Policy at the University of Strathclyde and former hospice social worker.[1] https://goo.gl/yhRGHR

Specialist Publications

'What is in a name? Evidence of impact in palliative and end-of-life care in the 2014 Research Excellence Framework is difficult to find' (p.6), in *BMJ Supportive & Palliative Care.*

'Likelihood of death within one year among a national cohort of hospital inpatients in Scotland' (p.12), in *Journal of Pain & Symptom Management.*

1. 'Integrating palliative care into the community: The role of hospices and schools,' *BMJ Supportive & Palliative Care*, 11 August 2016. http://goo.gl/LqbYkL [Noted in Media Watch, 15 August 2016, #475 (p.6). Additional articles on initiatives to introduce dying and death into school curriculums noted in this issue of the weekly report.]



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

Specialist Publications

A dedicated palliative care nurse improves access to palliative care and hospice services in an urban emergency department

AMERICAN JOURNAL OF EMERGENCY MEDICINE | Online – 18 August 2016 – Patients with advanced and end-stage disease in need of symptom management, pain relief, and care coordination often present to the emergency department (ED). Moreover, a large proportion of patients with chronically progressive and terminal illnesses lack coordination of care, especially among the elderly and underserved. Thus, their healthcare needs are often episodic and unplanned, with the ED being a primary source of medical care. However, for many of these patients traditional life-prolonging treatments offered by ED providers may not be concordant with their goals, and may not address the symptoms for which they sought care. goo.gl/RLF04V

Noted in Media Watch, 2 May 2016, #460 (p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – **'Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review.'** Emergency departments (EDs) are seeing more patients with palliative care (PC) needs, but evidence on best practice is scarce. There is yet no evidence that ED-based PC affects patient outcomes except for indication from one study of no association with 90-day hospital readmission, but a possible reduction in length of stay if integrated PC is introduced early at ED rather than after hospital admission. http://goo.gl/J18JG6

N.B. Additional articles on end-of-life care in the emergency department noted in Media Watch 18 April 2016 issue of Media Watch (#458, p.10).

American Society of Health-System Pharmacists Guidelines on the Pharmacist's Role in Palliative and Hospice Care

AMERICAN JOURNAL OF HEALTH-SYSTEM PHARMACY, 2016;73(17):1351-1367. Specialized training programs and board certification opportunities exist for most members of the palliative care (PC) interdisciplinary team. As the model of PC has progressed, so too has each team member's potential for contributions. Despite representation within the first hospice demonstration project in the U.S.,[1] participation of the pharmacist as an essential member of the interdisciplinary team has been traditionally overlooked. Evidence of the pharmacist's contribution to the delivery of PC and supportive care services beyond the original role of medication dispensing and compounding has garnered growing recognition across numerous practice settings. Perhaps no other practice setting presents as diverse a collection of potential roles and responsibilities for the affiliated palliative and hospice care pharmacist. Here, the pharmacist may provide support in an administrative role (policy and procedure, formulary management), in a consultative role (order set development, treatment algorithm development, best practices education), and in advanced clinical practice (medication therapy management services, pain and symptom management consultations, and interdisciplinary team participation). http://goo.gl/gV9VcJ

1. 'Medicare reconsiders rule that leaves dying patients facing a stark choice,' *The Washington Post*, 25 August 2015. [Noted in Media Watch, 31 August 2015, #425 (p.4)] http://goo.gl/3rB9Ho

Noted in Media Watch, 15 September 2014, #375 (p.12):

- *JOURNAL OF PHARMACY PRACTICE & RESEARCH* | Online – 5 September 2014 – **'Forging an advanced practice role for pharmacists in palliative care.'** This paper describes incorporation of an advanced practice pharmacist into a large metropolitan palliative care service. http://goo.gl/Zw1wWr

End-of-life care in Norway

Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: A cross-sectional study

BMC PALLIATIVE CARE | Online – 24 August 2016 – In Norway, palliative care (PC) is provided by a public healthcare system in primary or community care (CC), and specialist healthcare (SH) contexts (tertiary and secondary care). CC and SH provide non-specialized PC ... as an integrated part of the services, in addition specialized PC services are offered. CC is responsible for and serves patients both in nursing homes and at home, via home care or their general practitioner. Specialized PC is provided by palliative units or beds in nursing homes and cancer nurses/coordinators in the community. The State is responsible for patients in SH and serves patients in hospitals and specialist services. Specialized PC in the SH system is organized through palliative centres, palliative units in nursing homes and PC teams. As part of the PC provided, dedicated hospice care services are specialized PC services using "hospice" by name, indicating special dedication to the hospice philosophy and values. Hospice services are organised within CC as palliative units in nursing homes and within the SH system as PC units, PC teams or day care centres led by the hospitals. PC has been criticized for being developed to include mainly patients with cancer. Consequently, the care for patients with other life-threatening illnesses does not equal the care for patients with cancer. http://goo.gl/sENwIe

Noted in Media Watch, 6 July 2015, #417 (p.12):

- *OPEN JOURNAL OF NURSING*, 2015;5(6):538-547. **'To die at home or to end life in an institution.'** This study aimed to determine the main causes for the low proportion of deaths at home in Norway. A retrospective cohort study was conducted in six municipalities. This study showed how challenging it is for the family and health personnel in the last steps of life. However, when physical distress is under control, and when a dying patient and his/her significant other genuinely wish for death at home, it is necessary to control physical distress. Greater holistic well-being may then be achieved at home than in the hospital. http://goo.gl/03lz5J

  N.B. Click on 'Download as PDF' to access complete text.

N.B. Norway was ranked 13th overall of the 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, commissioned by the Lien Foundation of Singapore, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/JsSbW3

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

What is in a name? Evidence of impact in palliative and end-of-life care in the 2014 Research Excellence Framework is difficult to find

BMJ SUPPORTIVE & PALLIATIVE CARE, 2016;6(3):248-250. The U.K. Research Excellence Framework (REF) replaced the Research Assessment Exercise to become the new system for assessing the quality of academic research in the U.K. The results of REF help the four U.K. higher education funding bodies allocate research funds. The 2014 REF was the first exercise of this kind to collect information on the impact of research as an outcome measure, defining impact as "any effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia." Impact was assessed in terms of reach and significance, using information provided in 6,975 impact case studies. Impact case studies contributed to 20% of the total assessment of U.K. higher education institutions in 2014 and were submitted as four page documents describing the impacts between January 2008 and July 2013. To submit an impact case study, the university had to prove that it had produced high-quality research which resulted in tangible impact. The fact that impact case studies were given such a high weighting indicates a cultural shift, part of a wider impact agenda, suggesting that the social benefit of research is now more widely regarded. http://goo.gl/NRYmWm

Very old people dying: What would relatives like to have seen managed differently?

BMJ SUPPORTIVE & PALLIATIVE CARE, 2016;6(3):392. As people live longer, dying in very old age is becoming more common. Palliative care is trying to adapt, from models that evolved predominantly from cancer care origins, to better meet the needs and priorities of frail older people. From one of the longest-running studies of ageing, the authors have already described disability and cognition in the last year of life of a population-representative sample of men and women who died aged and their end-of-life place of care transitions, showing most died away from home, with markedly higher dependency levels amongst people dying. From interviews with relatives after the study participants' deaths, reportedly dying comfortably was associated with avoiding transitions, particularly with staying in care homes that had become home. Qualitative research in the same study found participants aged ≥95 were willing to discuss their end-of-life care preferences. The authors also sought to understand bereaved family members' perspectives on their "older old' relatives" deaths. http://goo.gl/1JbQ4G

Select articles on end-of-life care for the oldest old

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 25 April 2016 – **'Meeting the needs of the growing very old population: Policy implications for a global challenge.'** The authors outline several promising approaches for policy makers and professionals to develop evidence-based policies and programs that are tailored to the needs of very old adults and their families. They focus their discussion on three key topics essential to life care: 1) The importance of integrated care to meet the complex care needs of the very old; 2) The balance between formal and informal care; and, 3) The development of suitable places for living. [Noted in Media Watch, 2 May 2016, #460 (p.6)] http://goo.gl/v2wBsi

- *PLOS ONE* | Online – 5 April 2016 – **'Death and the oldest old: Attitudes and preferences for end-of-life care: Qualitative research within a population-based cohort study.'** This study's rare data show ≥95-year-olds are willing to discuss dying and end-of-life care, but seldom do. Formal documentation of wishes is extremely rare and may not be welcome. Although being "ready to die" and preferring a palliative approach predominated, these preferences cannot be assumed. [Noted in Media Watch, 11 April 2016, #457 (p.6). http://goo.gl/UFaCvc

- *AGE & AGING* | Online – 24 March 2016 – **'A good death for the oldest old.'** People aged over 85 are the fastest growing segment of the population, both in the U.K. and across all high-income countries. This is also the group of people who are most likely to die. So it is pertinent to consider how we can ensure that for the oldest old, their deaths, as well as their lives, are as good as we can help them to be. [Noted in Media Watch, 28 March 2016, #455 (p.6)] http://goo.gl/jmj0yG

End-of-life care for people with alcohol and other drug problems: An exploratory study

BMJ SUPPORTIVE & PALLIATIVE CARE, 2016;6(3):392-393. The problematic use of substances is linked to many forms of chronic and life threatening conditions, the majority of which affect people in later life. In part as a consequence of population ageing and with evidence suggesting that older people's substance use is increasing, this complex and heterogeneous group is growing. Thus greater numbers will require palliative care and present new challenges to end of life services. This study explores the nature and extent of these changes and the needs of service users and providers. http://goo.gl/EM7WcD

Noted in Media Watch, 16 November 2015, #436 (p.15):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(6):292-295. **'What you need to know about alcohol in palliative care: A brief review of the literature.'** Overall, it seems that, in the palliative care (PC) setting, the main concern is to identify whether or not a patient has alcohol dependence. Detoxification may not be needed, but identification is crucial so that any symptoms potentially exacerbated by alcohol dependence can be appropriately managed. It is also important to identify alcohol dependence in order to manage any psychological problems that the patient may be self-managing with alcohol.

N.B. Access requires a subscription. Journal home page: http://goo.gl/WkSR8a

Where is God in my dying? A qualitative investigation of faith reflections among hospice patients in a secularized Society

DEATH STUDIES | Online – 25 August 2016 – Despite increased focus on the role of spiritual care in palliative care, there is limited knowledge about spirituality/religiosity among dying patients in secularized cultures such as Denmark. This study aims through semi-structured interviews with Danish hospice patients and participant observation to elucidate how hospice patients reflect and act upon their potential faith. The results demonstrate three dimensions of faith: 1) "Knowing" (cognition); 2) "doing" (praxis); and; 3) "Being" (meaning). The article concludes that most patients had a hesitant, but according to their situation, important faith although it was not something they knew much about, let alone discussed or practiced much. http://goo.gl/ngZGhf

"Spiritual care is not the hospital's business"

A qualitative study on the perspectives of patients about the integration of spirituality in healthcare settings

JOURNAL OF MEDICAL ETHICS | Online – 24 August 2016 – This study critically analyses the idea that we ought to take care of the spiritual dimension of patients. Does this interest for spirituality not come from healthcare professionals' desire more than from the patients themselves? Findings demonstrated that participants do not expect help from the hospital to handle spiritual issues, but they wish for their spiritual dimension to be simply recognised as a part of their identity and dignity. http://goo.gl/ERxXPl

End-of-life care in England

Practice rated outstanding after helping 97% of palliative care patients die at home

GP | Online – 24 August 2016 – The Baslow Health Centre in Bakewell, Derbyshire ... was rated "outstanding" by the Care Quality Commission, marking it among the top 4% of practices in the country, according to inspectors. Evidence presented during inspection showed that 97% of the practice's patients who died in the previous 12 months had died within their preferred place as a result of the planning and support provided by the practice. Inspectors said the practice's "significant efforts" had yielded "excellent outcomes" for patients. The service sees GPs visiting patients in the evenings and at weekends, responding immediately to requests for assistance with end-of-life care and acquiring particular medicines. The GPs also provide personalised bereavement support to families and carers. The scheme has now evolved into a charity called Helen's Trust, named after one of the surgery's patients, Helen Louise Lyon, who passed away in 2001 after being diagnosed with terminal cancer. http://goo.gl/9uVW8n

Related

- *PLOS ONE* | Online – 23 August 2016 – **'Place of death in patients with lung cancer: A retrospective cohort study from 2004-2013.'** Of 143,627 patients identified 40% (57,678) died in an acute hospital, 29% (41,957) died at home and 17% (24,108) died in a hospice. Cause of death in the majority was lung cancer (86%), with other malignancies, chronic obstructive pulmonary disease and ischaemic heart disease comprising 9% collectively. http://goo.gl/Z5a6b7

Effect of primary care involvement on end-of-life care outcomes: A systematic review

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 22 August 2016 – Of 2,812 studies screened, 13 were included in this study. The studies were mostly conducted in the U.S. and Canada and analyzed data collected from 1989 to 2010. Almost all studies used different definitions of primary care providers (PCP) involvement in care, but in general, individuals who received more care from PCPs were more likely to be discharged or die with supportive care (home or hospice) than those receiving less PCP care. A few studies indicated that individuals seeing a PCP were less likely to have hospital or emergency department admissions, although the evidence for this was mixed. Studies linking PCP involvement to resource use, symptom management, and survival had mixed results or showed no association. http://goo.gl/YjnRA6

Racial differences in hospitalizations of dying Medicare-Medicaid dually eligible nursing home residents

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 22 August 2016 – End-of-life (EOL) hospitalization rate was 31.7% for whites and 42.8% for blacks. For participants without do not hospitalize (DNH) orders, adjusted probability of EOL hospitalization was higher for blacks than for whites... For those with DNH orders, adjusted racial differences in EOL hospitalization were not statistically significant in those with moderate ... cognitive impairment, but blacks had a higher probability of EOL hospitalization than whites if they had relatively intact cognitive status. http://goo.gl/9kJUlj

> **N.B.** The focus of the February 2016 issue of the Journal of Palliative Medicine is on palliative and end-of-life care for African Americans. [Noted in Media Watch, 8 February 2016, #448 (p.15).] Contents page: http://goo.gl/6fapNx

Making sense of bereavement in people with profound intellectual and multiple disabilities: Carer perspectives

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 24 August 2016 – People with intellectual disabilities are thought to have a reduced capacity for understanding death. Drawing on cognitive theory, researchers have suggested that those with profound intellectual and multiple disabilities mainly perceive loss as a mismatch between past and present experiences. However, very little research has considered how carers conceptualize bereavement in relation to this group. Two superordinate themes emerged [in this study]: "difficulty articulating the experience of loss" and "making sense of bereavement through familiar patterns." Carers [i.e., study participants] conceptualize bereavement primarily in cognitive terms, but also take account of relational factors mediating loss. Implications for training and further research are outlined. http://goo.gl/NVarvf

Noted in Media Watch, 11 April 2016, #457 (p.9):

- *INTERNATIONAL JOURNAL OF DEVELOPMENTAL DISABILITIES* | Online – 28 March 2016 – '**Overcoming barriers to grief: Supporting bereaved people with profound intellectual and multiple disabilities.**' Although there are some similarities between people with profound intellectual and multiple disabilities PIMD and their more able peers, there are additional factors which may place people with PIMD at greater risk of complicated grieving. This paper identifies the socio-contextual factors that can mediate experiences of and reactions to loss in this group. http://goo.gl/POczcq

Noted in Media Watch, 7 December 2015, #439 (p.14):

- *INTELLECTUAL & DEVELOPMENTAL DISABILITIES,* 2015;53(6):394-405. '**A Delphi study on staff bereavement training in the intellectual and developmental disabilities field.**' Results showed that training should help staff identify and support service users experiencing grief. Importantly, staff also needs help in managing their own grief. Organizational policies and resources should be instituted to support the grief processes of both service users and staff. http://goo.gl/YZx0ar

<u>**Literature review**</u>

Palliative care in cancer: Managing patients' expectations

JOURNAL OF MEDICAL RADIATION SCIENCES | Online – 9 August 2016 – Advanced cancer patients commonly have misunderstandings about the intentions of treatment and their overall prognosis. Several studies have shown that large numbers of patients receiving palliative radiation or chemotherapy hold unrealistic hopes of their cancer being cured by such therapies, which can affect their ability to make well-informed decisions about treatment options. This review aimed to explore this discrepancy between patients' and physicians' expectations by investigating three primary issues: 1) The factors associated with patients developing unrealistic expectations; 2) The implications of having unrealistic hopes and the effects of raising patients' awareness about prognosis; and, 3) Patients' and caregivers' perspective on disclosure and their preferences for communication styles. The discrepancy between patients' and doctors' expectations was associated with many factors including doctors' reluctance to disclose terminal prognoses and patients' ability to understand or accept such information. The majority of patients and caregivers expressed a desire for detailed prognostic information; however, varied responses have been reported on the preferred style of conveying such information. Communication styles have profound effects on patients' experience and treatment choices. Patients' views on disclosure are influenced by many cultural, psychological and illness-related factors, therefore individuals' needs must be considered when conveying prognostic information. http://goo.gl/kkvGvc

End-of-life planning with frail patients attending general practice: An exploratory prospective cross-sectional study

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 1 September 2016 – The British Medical Association and the National Health Service acknowledge the benefits of identifying patients approaching the end of life, to address their care needs and the needs of their families. There is much policy in this area, across many health systems. In the current study, Supportive & Palliative Care Indicators Tool was helpful in prompting GPs to raise end-of-life issues systematically. Given the known inaccuracies of healthcare professionals in predicting death, and in recognising the clear risks of misinterpreting patients' wishes if they are not provided with the opportunity to express their preferences, the approach used in this exploratory study may be useful in further studies. http://goo.gl/JTQZoF

Related

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 22 August 2016 – **'Challenge of prognostic uncertainty in the modern era of cancer therapeutics.'** Advances in cancer therapy make it significantly more challenging for clinicians to provide an accurate prognosis, especially if we approach prognostic disclosure as a one-time event. Describing the nature of this uncertainty to patients and revisiting discussions about prognosis over time are essential strategies for overcoming challenges in communicating prognosis in the modern era. In addition, data show that the integration of palliative care early in the course of illness enables patients to understand their prognosis more accurately and improves clinician-patient communication about end-of-life care preferences. http://goo.gl/eIiZOT

- *PLOS ONE* | Online – 25 August 2016 – **'A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts?'** Wide variation was shown with categorical estimates (range 23% to 78%) and continuous estimates ranged between an underestimate of 86 days to an overestimate of 93 days. Overall, there was no clear "expert" sub-group of clinicians identified. Studies of prognostic accuracy in palliative care are heterogeneous, but the evidence suggests that clinicians' predictions are frequently inaccurate. No sub-group of clinicians was consistently shown to be more accurate than any other. http://goo.gl/mUzCsH

Cont.

Selected articles on the accuracy of prognosis

- U.S. | Madison.com – 16 July 2016 – **'Cancer patients, doctors often disagree about prognosis.'** Cancer patients and their doctors often hold different opinions about the patient's chances for survival and how long he or she might live, according to a new study.[1] And, in many cases, patients are unaware there's any misunderstanding. Almost all patients were more optimistic than their doctor. Of the 68%, only 10% understood their views and their doctor's differed. [Noted in Media Watch, 18 July 2016, #471 (p.3)] http://goo.gl/wA8QSl

    1. 'Determinants of patient-oncologist prognostic discordance in advanced cancer,' *JAMA Oncology*, 14 July 2016. http://goo.gl/CEvikm

- *BMC PALLIATIVE CARE* | Online – 12 July 2016 – **'Communicating prognostic uncertainty in potential end-of-life contexts: Experiences of family members.'** This study found nearly half of all family members [i.e., study participants] wanted more information about possible outcomes of care, including knowledge that the patient was "sick enough to die." Prognostic uncertainty was often poorly communicated, if at all. Inappropriate techniques included information being cloaked in confusing euphemisms, providing unwanted false hope, and incongruence between message and the aggressive level of care being provided. [Noted in Media Watch, 18 July 2016, #471 (p.9)] http://goo.gl/xfQIHy

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 January 2016 – **'Accuracy of physician prognosis in heart failure and lung cancer: Comparison between physician estimates and model predicted survival.'** Cardiologists [i.e., study participants] were more accurate in predicting survival in heart failure symptoms and reduced ejection fraction compared to generalists and oncologists, but no different at predicting heart failure symptoms and preserved ejection fraction. Physicians felt more uncomfortable discussing palliative care with heart failure patients compared to lung cancer. [Noted in Media Watch, 18 January 2016, #445 (p.5)] http://goo.gl/Fp686D

Paediatric Palliative Care Service in Queensland, Australia

Respite needs of families receiving palliative care

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 23 August 2016 – The care of a child with a life-limiting condition proves an emotional, physical and financial strain on the family that provides care for their child. Respite care is one way which allows carers to receive some relief and support in the context of this burden of care. The provision of and the requirements for respite in this context is poorly understood. This survey aims to describe the types of respite care families receive, the respite that they would ideally receive and the barriers that prevent this. Three of the 34 families interviewed (15%) reported receiving no respite in the previous 12 months. Families who received respite received a combination of formal respite (a structured care provider) and informal respite (family or friends). Ten families (50%) reported that they would want the time of respite changed. Barriers to receiving adequate respite included complexity of care of the child, financial barriers and lack of a respite provider. There is disparate provision of respite care with the main perceived barrier to attaining "ideal respite" being the lack of a provider able to meet the complex care needs of their child. The provision of respite across diversity in geography; medical condition; social and cultural needs remains a challenge. http://goo.gl/NVyHVQ

Noted in Media Watch, 14 March 2016, #453 (p.11):

- *PALLIATIVE MEDICINE* | Online – 7 March 2016 – **'Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study.'** Four themes represented the prevalent experiences of parents: 1) Trapped inside the house; 2) The protector; 3) Living with the shadow; and, 4) Travelling a different pathway. They describe parents' physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being. Limited professional and diminished social supports resulted in full ownership of care responsibility. Yet, parents embraced their role as "protector," reporting acquired meaning and purpose. http://goo.gl/We37gb

Likelihood of death within one year among a national cohort of hospital inpatients in Scotland

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2016;52(2):e2-e4. In an earlier study,[1] the authors took a census of all inpatients in the 25 teaching and general hospitals of Scotland on a single date in 2010 and then linked the hospital patient records to records of death registration. They found that almost one-third of the patients in hospital on the census date died within 12 months. Could we assume that these findings would be replicated on any other day in Scotland's hospitals? To assess the robustness of the original findings of our census, the authors sought to test whether the results from the 2010 cohort of inpatients in Scotland would be repeated on a subsequent census date, three years later, in 2013. Answering this question would help us to build on the significant policy and public impact of the original study and might also assist in national policy efforts to identify patients for palliative and advance care planning conversations in the hospital setting. The 2013 repeat of the study from 2010 demonstrated no significant differences between the two cohorts of inpatients in Scotland, both in their overall characteristics and in their propensity to die within one year. http://goo.gl/C3La5U

1. 'Imminence of death among a national cohort of hospital inpatients,' *Palliative Medicine*, 17 March 2014. [Noted in Media Watch, 24 March 2014, #350 (p.5)] http://goo.gl/5XfShG

A survey of perinatal palliative care programs in the U.S.: Structure, processes, and outcomes

JOURNAL OF PALLIATIVE MEDICINE | Online – 25 August 2016 – Perinatal palliative care (PPC) programs are proliferating nationwide, but little is known about their structure, process, or desired outcomes, to inform future program development. The majority of programs have a care coordinator, but roles vary from direct patient care to program administration. Participants described a range of topics discussed during family meetings to determine parental goals across the perinatal period. Support and respect for parent preferences and choices were the most important components of care. Desired program outcomes include parental satisfaction with physical and psychosocial support, help with the decision-making process, opportunity to parent their infant, infant comfort, and positive personal and family growth. While PPC programs do not often measure quality, their goals are family centered, with a focus on parent satisfaction with decision making and psychosocial support. PPC programs coordinate interdisciplinary care by arranging meetings and advocating for families. More research is needed to understand parent perspectives on care provided. http://goo.gl/opbeOt

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

Pediatric palliative care and child psychiatry: A model for enhancing practice and collaboration

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 August 2016 – As the field of pediatric palliative care (PC) continues to develop, it is important to consider the scope of practice and the utility of collaboration with other specialties, including child and adolescent psychiatry. The integration of psychiatry and palliative medicine has been explored in adult practice, but has not yet been elaborated in pediatrics. This article proposes a clinical model of care that highlights the overlapping and unique expertise that each discipline brings, in a continuum of collaboration, and proposes an integrated care model for the most complex patients and families. Case examples are used to define specific professional skills and roles, and to describe shared and distinct clinical approaches used by pediatric PC and child psychiatry. Effective collaboration provides opportunities for cross-disciplinary educational exchange and enhanced care of children and families with co-morbid mental health issues and serious illness. http://goo.gl/zZP3cp

Cont.

Noted in Media Watch, 28 May 2016, #455 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 March 2016 – **'The role of psychology in pediatric palliative care.'** Results from a recent survey of pediatric palliative care (PC) programs across the U.S. indicate that team composition almost never included a psychologist. This article argues that psychology brings specialized skills in assessment, intervention, and research that fit with the premise of PC as a holistic approach that relieves symptoms. http://goo.gl/IGqMEm

U.K. Mental Capacity Act 2005

Do not resuscitate: Lawful or unlawful?

MEDICO-LEGAL JOURNAL | Online – 12 August 2016 – The doctor puts or causes to be put the instruction in the hospital notes or on the clinical record at the end of the patient's bed: 'Do not resuscitate' (DNR), or 'Do not attempt to resuscitate' (DNAR) or 'Do not attempt cardiopulmonary resuscitation' (DNACPR). Is this lawful or unlawful? In essence, the basic test to be applied is the best interests of the patient (the common law and the Mental Capacity Act 2005). The problem of the doctor wishing not to give treatment or to discontinue treatment is not confined to DNR, but DNR is the classic stark pre-emptive situation. http://goo.gl/u2Blhf

Selected articles on resuscitation policies and practices

- *RESUSCITATION* | Online – 11 March 2016 – **'Themes and variations: An exploratory international investigation into resuscitation decision-making.** Eight-eighty percent of survey respondents reported a method for implementing do not attempt cardiopulmonary resuscitation (DNACPR) decisions, 90% of which discussed resuscitation wishes with patient at least half of the time; 94% of respondents thought that national guidance for DNACPR order implementation should exist, with 53% of countries surveyed reporting existence of such guidance. [Noted in Media Watch, 21 March 2016, #454 (p.13)] http://goo.gl/sNCM0G

- *RESUSCITATION* | Online – 14 January 2016 – **'A survey of key opinion leaders on ethical resuscitation practices in 31 European Countries.'** The authors report the responses to a survey covering four domains of resuscitation: 1) Approaches to end-of-life care and family presence during CPR; 2) Determinants of access to best resuscitation and post-resuscitation care; 3) Diagnosis of death and organ donation; and, 4) Emergency care organisation. [Noted in Media Watch, 25 January 2016, #446 (p.16)] http://goo.gl/me0mUy

- *BMJ OPEN* | Online – 13 January 2015 – **'Variation in local trust do not attempt cardiopulmonary resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.'** There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of National Health Service Trusts used the recommended Resuscitation Council record form (or a modification of the form). There was variation in the terminology used, which included DNAR (Do Not Attempt Resuscitation), DNACPR (Do Not Attempt CPR), CPR, and AND (Allow Natural Death). [Noted in Media Watch, 19 January 2015, #393 (p.9)]http://goo.gl/cxZMNM

'Dignity therapy.' A promising intervention in palliative care: A comprehensive systematic literature review

PALLIATIVE MEDICINE | Online – 26 August 2016 – Of 121 studies, 28 were included. Quality of studies is high. Results were grouped into effectiveness, satisfaction, suitability and feasibility, and adaptability to different diseases and cultures. Two of five randomized control trials applied dignity therapy to patients with high levels of baseline psychological distress. One showed statistically significant decrease on patients' anxiety and depression scores over time. The other showed statistical decrease on anxiety scores pre-post dignity therapy, not on depression. Non-randomized studies suggested statistically significant improvements in existential and psychosocial measurements. Patients, relatives and professionals perceived it improved end-of-life experience. http://goo.gl/QwWRLb

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BIOÉTHIQUE ONLINE* | Online – 17 August 2016 – **'Medical assistance in dying in Canada: An ethical analysis of conscientious and religious objections.'** The Supreme Court of Canada (SCC) has ruled that the federal government is required to remove the provisions of the Criminal Code of Canada that prohibit medical assistance in dying (MAiD). The SCC has stipulated that individual physicians will not be required to provide MAiD should they have a religious or conscientious objection. Therefore, the pending legislative response will have to balance the rights of the patients with the rights of physicians, other health care professionals, and objecting institutions. The objective of this paper is to critically assess, within the Canadian context, the moral probity of individual or institutional objections to MAiD that are for either religious or conscientious reasons. The discussion of religious or conscientious objections to MAiD has not explicitly considered the competing duties of the conscientious objector. It has focussed on the fact that a conscientious objection exists and has ignored the normative question of whether the duty to respect one's conscience or religion supersedes the duty to respect the patient's right to life. https://goo.gl/9LS4wF

  N.B. Click on pdf icon to access full text.

- *MEDSCAPE* | Online – 25 August 2016 – **'Should physicians help terminal patients die?'** 'Both Sides Now,' a Medscape program, discusses the highly complex question of whether physicians should be allowed to assist patients in ending their lives. Two physicians who are in favor of physicians helping terminally ill patients to hasten their death and two physicians who are adamantly opposed to it air their views. http://goo.gl/yLLuhV

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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

Worth Repeating

An exploration of the word "palliative" in the 19th century: Searching the *British Medical Journal* archives for clues

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 November 2012 – Palliative care (PC) went through a significant evolution in the 20th century, but the 19th century has been seen by some scholars as the real turning point toward the more modern concept of hospices and PC. Search results brought up a number of case reports, and the word was employed to describe medicines ("use of palliatives") as well as passive, non-active treatment approaches, probably best described as a watch-and-wait strategy. Of note is that the first recorded use of the word in the archives is by a surgeon. Some doctors associated the word palliative with there not being any prospect for cure and only for the relief of symptoms and greater comfort of the patient. There were, however, early reflections on whether palliative treatments may in some cases increase the length of patients' lives. [Noted in Media Watch, 19 November 2012, #280 (p.8)] http://goo.gl/1Yuu2y

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/vjGQws

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/5d1l9K

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

PALLIMED
A HOSPICE & PALLIATIVE MEDICINE BLOG

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

Barry R. Ashpole
Guelph, Ontario CANADA

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