No place like home? Investigating Ontario’s home-care shortcomings

ONTARIO | The Globe & Mail – 10 July 2015 – More aggressively than any other province, Ontario is shifting health care out of hospitals and long-term-care facilities, and into people’s homes. It now has the fewest hospital beds per capita of any province in Canada – if Ontario were a country, only Chile and Mexico would rank lower in beds per capita among the 34 nations of the Organization for Economic Co-operation & Development. In a cascade effect, the resulting spike in demand for home care is leading some cash-strapped community-care centres to change assessment standards, reduce services and cut clients off. In some cases, the CCACs [Community Care Access Centres] are pressuring reluctant patients and their family caregivers to dress wounds, change intravenous medicine bags, and perform other medical tasks in a bid to cut back on expensive in-home nursing visits. Meanwhile, more than 4,500 people across the province are languishing on waiting lists for publicly funded personal-support services in their homes – some of them high-needs patients. The result is a perverse “postal-code lottery” in which Ontario patients win or lose for no reason other than their addresses and how generously their local agencies are funded – funding rates are different for agencies across the province – according to Samir Sinha, director of geriatrics at two of Toronto’s largest hospital networks. He was also a member of an expert panel that earlier this year excoriates the province for its approach to caring for people in their homes.1


Provincial end-of-life care strategy

Valley Hospice Foundation’s plans have been delayed for 1 year

NOVA SCOTIA | CBC News (Halifax) – 6 July 2015 – The Valley Hospice Foundation hopes it can help make a difficult time for families a little easier, but the project to build a residential hospice facility has been delayed for about a year. In last year’s annual report, foundation chair Diana Patterson wrote that 97% of the foundation’s financial goals had been achieved. That was 11 June 2014. The reason for the delay ... is the [provincial] Liberal government’s move this spring to merge nine district health authorities into one provincial health authority. The province is working on a framework for palliative care whether it’s at home, a hospital or a hospice facility.

http://www.cbc.ca/news/canada/nova-scotia/valley-hospice-foundation-s-plans-have-been-delayed-for-1-year-1.3137961

Noted in Media Watch, 12 May 2014, #357 (p.1):

- NOVA SCOTIA | The Truro Daily News – 6 May 2014 – ‘Strategy to improve palliative care for Nova Scotians.’ The provincial government is releasing a new strategy to help provide Nova Scotians with choices about how they are cared for as they approach the end of life.†


Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NATIONAL POST | Online – 9 July 2015 – ‘Assisted suicide candidates should be required to talk to a judge.’ It remains for future courts to decide exactly which life situations are to be solved by suicide or euthanasia, but the experience elsewhere suggests the answer is “more and more.” These three points – the wide potential eligibility for state-endorsed suicide created by the Court, the professed need for rigor and transparency, and the wise absence of compulsion for any individual doctor to be involved in such a practice – give us direction. Death-seekers who think they fit within the Court’s wide scope of eligibility could – themselves – notify a judge who would ensure the Supreme Court’s instructions were going to be honored. The requirement for a court order would ensure that alternatives to suicide had been effectively presented to the person and that the possibility of coercion had been questioned.

  http://news.nationalpost.com/full-comment/will-johnston-assisted-suicide-candidates-should-be-required-to-talk-to-a-judge

- THE NATIONAL POST | Online – 7 July 2015 – ‘Calls give insight into those who may seek assisted death: “What are my options?”’ Some are terminal cancer patients who have been told they have less than six months to live. Others are living with a slow moving disease that will take away their ability to walk and talk before ultimately killing them. Some are simply depressed. Some are healthy. An analysis of calls made to Dying with Dignity [DWD] Canada from Canadians seeking information on hastening their deaths is offering a rare glimpse into the people who may be most likely to seek doctor assisted suicide once the practice becomes legal in Canada. The summary of the DWD calls was based on only a few people and is far from an exhaustive or scientific survey.

Aid-in-dying laws are just a start

THE NEW YORK TIMES | Online – 11 July 2015 – About seven out of 10 of us now live long enough to die from chronic conditions like heart disease, emphysema, dementia, diabetes, cancer and kidney failure. Many will spend years in a “gray zone” where medical choices aren’t black and white. We will each have to decide when to allow a natural death and when to say yes to yet another medical technology that might fend off death without restoring health: implantable defibrillators, dialysis, feeding tubes, ventilators and the like. We will need brave, truthful doctors willing to discuss when to stop fighting for maximum longevity and explore, instead, what may matter more to us. Like living independently at home for as long as possible. Like forgoing treatments that are worse than the disease. Like managing pain. Like living a meaningful life despite physical limitations, and dying a good death, surrounded by one’s family. This is the province of palliative care, currently medicine’s tin-cup specialty. Its doctors integrate curative medicine, symptom management and shared decision making. Their numbers are too small to meet the need and their comparatively thin pay checks are often covered by philanthropies rather than insurance.


Poll: Sandwich generation worried about own long-term care

THE NEW YORK TIMES | Online – 10 July 2015 – Caught between kids and aging parents, the sandwich generation worries more than most Americans their age about how they’ll afford their own care as they grow older, a new poll shows.¹ But most aren’t doing much to get ready. Nearly 1 in 10 people age 40 and over are “sandwiched” – they’re supporting a child while providing regular care for an older loved one... Another 8% may join the ranks of double-caregivers in the next five years, citing declining health of an older relative or close friend. Dwelling responsibilities can make some days feel like a tug-of-war. After age 65, government figures show nearly 7 in 10 Americans at some point will need long-term care — from a relative, home aide, assisted living or nursing home. http://www.nytimes.com/aponline/2015/07/10/health/ap-us-med-healthbeat-long-term-care-poll.html?_r=0


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://www.ipcrc.net/barry-r-ashpole.php
Teens dying of cancer face intensive treatments in the final days

NATIONAL PUBLIC RADIO | Online – 9 July 2015 – For 68% of patients, interventions include chemotherapy, treatment in the intensive care unit or emergency department, or hospitalization in their final month. The study1 ... is the first of its kind to study end-of-life care for people ages 15 through 39. They either had stage 1 to 3 cancer, with evidence that cancer came back, or stage 4 cancer when they were first diagnosed. They died between 2001 and 2010 before reaching the age of 40. Eleven percent of patients received chemotherapy within 14 days of death. In their last month, 22% of patients received care in the ICU and 22% had more than one trip to the emergency department [ED]. Sixty-two percent were hospitalized. In comparison, the desired standard rate for intensive end-of-life care in cancer patients among older adults is less than 4% when it comes to both ICU and ED visits. Are higher numbers necessarily bad? “We don’t know,” says Jennifer Mack, a pediatric oncologist at Dana-Farber/Boston Children’s Cancer & Blood Disorders Center and lead author of the study. “For a patient who is well-informed and wishes to pursue all possible measure to prolong life, it may be a very reasonable choice. It may be these patients are receiving the exact care they wanted.” At the same time, these medically intensive measures can undermine the quality of life in patients’ last days. And it’s worrying to Mack, because some of these patients might have benefited from having hospice care and being at home surrounded by loved ones rather than hooked up to machines in the ICU. http://www.npr.org/sections/health-shots/2015/07/09/421450470/teens-dying-of-cancer-face-intensive-treatments-in-the-final-days


Palliative care law rolling out slowly, as those in need wait

CALIFORNIA | California Health Report – 6 July 2015 – Palliative care ... is not widely available in California. A new law, SB 1004, passed by the Legislature last August, directs the state to create a palliative care program for people enrolled in Medi-Cal, California's low-income health plan. Nearly a third of Californians – about 12.3 million people – are enrolled in Medi-Cal. Advocates hope the law will open the gates to palliative care for all Californians, including those with private insurance. The Department of Health Care Services, which operates Medi-Cal, is chipping away at ideas for the program and ways to measure the effectiveness of it, and expects to release draft guidelines this summer, spokesman Anthony Cava said. http://www.healthycal.org/palliative-care-law-rolling-out-slowly-as-those-in-need-wait/

Hospice care ... “It’s not giving up”

ILLINOIS | WGN Radio (Chicago) – 6 July 2015 – We have talked recently about all the advancements that have been made in medicine in the last decade. Many of these advancements save lives, and allow for cures. Other advancements we make extend life in the hopes that we can buy time to get to a cure. Unfortunately there are times when we can’t cure an illness, when everything we have in our options will not cure the disease. In some of these cases the treatment we use to extend life take away from the quality of life the patient has at the end of life. It is at these moments where a discussion about hospice comes in to play. The decision to extend care that will keep the patient comfortable and let them share their final days with loved ones free of pain and often in the comfort of their home. http://wgnradio.com/2015/07/06/hospice-care-doctor-kevin-most-explains-its-not-giving-up/

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**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.16.
With Palin “death panels” debunked, Congress pushes end-of-life planning

FORBES | Online – 5 July 2015 – The politics of end-of-life care are beginning to disappear in Washington six years after Tea Party darling Sarah Palin injected false claim that Congressional health reform legislation included “death panels.” Bipartisan legislation introduced in the U.S. Senate ... to help patients suffering serious illness with advanced care planning is gaining momentum. The Care Planning Act of 2015, would have Medicare reimburse doctors and other health professionals for consulting with their patients about end-of-life care. It’s the first major push to pay doctors and other health care providers for consultations about end-of-life care since Palin, the former GOP [Republican Party] vice presidential candidate and Alaska governor, and other Republicans accused the Obama administration and Democrats in Congress of creating “death panels.” Even though she was wrong as several organizations pointed out at the time, the political hubbub contributed to lawmakers’ decision to strip Medicare reimbursement of doctors for end-of-life consultations from the legislation that eventually became the Affordable Care Act.


N.B. The Tea Party is an American political movement known for its conservative positions and its role within the Republican Party. The movement’s name refers to the Boston Tea Party of 16 December 1773, a turning-point in the American struggle for independence from Great Britain.

Noted in Media Watch, 30 March 2015, #403 (p.7):

- REUTERS | Online – 23 March 2015 – ‘Reimburse doctors for helping patients plan end-of-life care, experts say.’ Physician incentives are needed to improve end-of-life care in the U.S., health experts said at an Institute of Medicine forum convened to discuss action on the recommendations of the Institute’s seminal fall [2014] report... When people fail to plan for end-of-life care, they may suffer through ultimately futile, invasive and often unwanted treatments.


1. ‘Dying in America: Improving Quality & Honoring Individual Preferences Near the End of Life,’ Institute of Medicine, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)]


International

Is Asia ready to face a “grey tsunami”? 

ASIA | East Asia Forum Quarterly – 10 July 2015 – In Asia, where the elderly population is projected to reach 922.7 million by the middle of this century, countries such as India and Indonesia will still reap the population dividend until 2030, but the rate of ageing of some countries is as fast as in the West. Increasing longevity is one of humanity’s greatest achievements. Indeed, population ageing is cause for celebration. Look at the rapid increase of life expectation even among low-income countries – 10-15 years over the last 50. The opportunities that this presents are as endless as the contributions that a socially and economically active, secure and healthy ageing population can bring to society. But the opportunities come with challenges. Population ageing presents social, economic and cultural challenges to individuals, families and society.

http://www.eastasiaforum.org/2015/07/10/is-asia-ready-to-face-a-grey-tsunami/

Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at:

Low-key ruling puts sharp focus on sensitive end-of-life care debate

IRELAND | The Independent (Dublin) – 10 July 2015 – In the tragic canon of end-of-life cases that have come before our courts, yesterday’s ruling involving a profoundly disabled 10-year-old girl was remarkably low key. The child’s life was marked by tragedy. Born with a congenital heart defect, she suffered serious and extensive brain damage when she was four months old. The brain damage was the result of a non-accidental injury and the child has been State care since. Irish courts have refused to authorise positive steps to accelerate death or terminate life. But the Supreme Court has – when it authorised the withdrawal of treatment in the case of a woman in a near-persistent vegetative state – ruled that the right to life includes the right to die a dignified and natural death. The ethical dilemma facing doctors treating this child is somewhat different from previous cases. Death is not immediately imminent, but the court heard it is “absolutely inevitable” that she will have another life-threatening illness soon. Rather than seeking withdrawal of life-saving treatment, clinicians – supported by the Child & Family Agency and the child’s mother – sought permission not to provide aggressive treatment including resuscitation, essentially approval to form a palliative care plan. http://www.independent.ie/irish-news/courts/lowkey-ruling-puts-sharp-focus-on-sensitive-endoflife-care-debate-31366036.html

Extract from The Independent report

In her ruling, Ms. Justice Iseult O’Malley said it was necessary for the court to attempt to see the quality-of-life issues raised in the case from the child’s perspective. Judge O’Malley also applied the best interests of the child principle which has gained greater force since the passing of the Children’s Rights Referendum. Noting that there is a strong presumption in favour of authorising life-saving treatment, the judge said that in exceptional circumstances, authorisation can be given to steps not being taken to prolong life. The ruling is discreet, but it will no doubt contribute to the sensitive end-of-life care debate.

Russia’s economic crunch puts pain drugs out of reach, even for the sickest

RUSSIA | The Guardian (U.K.) – 10 July 2015 – Diagnosed with virulent neuroblastoma at 4 months, Artyom – now 5 – has had multiple surgeries and rounds of chemotherapy. As a Russian citizen whose family has state-mandated health insurance, he is, in theory, entitled to all the benefits of the Russian public health-care system. But in practice, while doctors treat his cancer, the burden of treating his pain has fallen on his family. And as the Russian economy has faltered, pain management for people with severe illnesses, like Artyom, has become all but unaffordable. The fall of the ruble has driven the price of drugs – many of which are imported – nearly out of reach for many. And that has complicated an already bleak outlook for palliative-care patients in Russia, who are often thwarted in their quest to lessen their pain by entrenched cultural prejudices and doctors' legitimate fears of legal repercussions for prescribing controlled narcotics. https://www.washingtonpost.com/world/europe/russias-economic-crunch-puts-pain-drugs-out-of-reach-even-for-the-sickest/2015/07/09/cdff9af8-1142-11e5-a0fe-dccfea4653ee_story.html

Noted in Media Watch, 15 September 2014, #375 (p.9):

- БЮЛЛЕТЕНЬ МЕДИЦИНСКИХ ИНТЕРНЕТ-КОНФЕРЕНЦИЙ | Online – Accessed 10 September 2014 – 'Palliative medicine: Overview and statistics.' Palliative care developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. Yet the economic constraints of the 1990s have left health services chronically under-funded. In what is the largest geographic country of the world, the combined hospice and palliative care services are currently estimated at around 125 and the challenges are acknowledged as considerable. http://cyberleninka.ru/article/n/palliative-medicine-overview-and-statistics

N.B. Russian language article.
End-of-life care in England

End-of-life care lowest in hospital

U.K. (England) | BT.com – 9 July 2015 – People whose friend or relative died in a hospital have rated their end-of-life care “significantly lower” than those whose loved ones died in a hospice, care home or at home. Figures published by the Office for National Statistics show seven out of 10 (69%) rated the care received in hospital as outstanding, excellent or good, with hospices receiving the top score of 83%, followed by care homes (82%) and at home (79%). One aspect of care measured was how much staff treated the patient with dignity and respect, with hospitals again receiving the lowest rating. Just 53% of those asked said they “always” felt hospital nurses treated their loved one with dignity and respect, while the figure was 59% for hospital doctors. This was in contrast to doctors in hospices (88%) and hospice nurses (85%). Overall, one in 10 (10%) people rated the care their friend or relative received as poor. One in every eight (13%) said they felt the patient did not have enough support to eat or receive nutrition while a third (33%) of those questioned said they felt the hospital services did not work well together with GP and other services outside the hospital. http://home.bt.com/news/uk-news/end-of-life-care-lowest-in-hospital-11363991419873


Of related interest:


- U.K. (England) | The Daily Mail – 8 July 2015 – ‘Getting over a bereavement “takes more than two years.”’ The average person grieves for two years, one month and four days before they start to move on with their lives. Research, for hospice charity Sue Ryder, also showed women mourn for longer than men, taking six months longer to get through the experience.¹ http://www.dailymail.co.uk/news/article-3154241/Getting-bereavement-takes-two-years-Survey-questioned-considered-suicide-felt-heartbroken.html


- U.K. (England) | The Guardian – 6 July 2015 – ‘Terminally ill benefit claimants asked when they expect to die, MP says.’ Terminally ill welfare claimants are being asked by benefit assessors when precisely they are expected to die, according to evidence seen by Frank Field, the newly elected chairman of the [parliamentary] Work & Pensions Select Committee. http://www.theguardian.com/politics/2015/jul/06/terminally-ill-benefit-claimants-asked-when-they-expect-to-die-mp-says

- U.K. (England) | The Leicester Mercury – 6 July 2015 – ‘GP call to protect jobs for terminally ill patients.’ A Leicestershire GP is backing a national campaign to secure more rights for workers with terminal illness.¹ Dr. Terri Eynon fears some patients are facing discrimination from employers and sometimes end up being sacked from their job. She wants to see legal protection, similar to that of maternity leave, to cover workers. Glenis Willmott, Member of the European Parliament for the East Midlands, has taken the campaign to the European Parliament. http://www.leicesterm mercury.co.uk/GP-protect-jobs-terminally-ill-patients/story-26842062-detail/story.html

1. ‘Dying to Work,’ Trade Union Congress: http://www.dyingtowork.co.uk/
U.K. (England) | National End-of-Life Care Intelligence Network – 6 July 2015 – ‘End-of-life care profiles for clinical commissioning groups.’ These profiles, launched in April 2014, updated in July 2015 with new data, draw together a wide range of information to give an overview of variations in cause and place of death, by age and sex, for each clinical commissioning group in England. The profiles will help commissioners and providers of end-of-life care get a clearer picture of the end-of-life care needs of their local populations. They will help with the planning and delivery of services and will support drives locally towards improving end of life care. There are 170 indicators, presented in four separate tools, using Office for National Statistics mortality data from 2011 to 2013. The cause of death ... tool gives breakdowns for selected causes of death where they were recorded as the underlying cause or a contributory cause.


N.B. Clinical commissioning groups are National Health Service (NHS) organisations set up by the Health & Social Care Act 2012 to organise the delivery of NHS services in England.

Noted in Media Watch, 29 June 2015, #416 (p.8):

U.K. (England) | National End-of-Life Care Intelligence Network – 26 June 2015 – ‘New information collated by the National End-of-Life Care Intelligence Network.’ The report, ‘What we know now 2014’, summarises the key findings of the network and its partners over the last year. Although much of the research has been published previously, this is the first time it has been brought together in one place. New findings show there is a growing understanding within the health sector of what is important to people at the end of life. http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014

Living with dementia in England

Dementia 2015: Aiming higher to transform lives

U.K. (England) | Alzheimer’s Society – 6 July 2015 – The Society’s fourth annual report looks at quality of life for people living with dementia in England, a snapshot of what support they are receiving, and what barriers they face to living well. It offers practical recommendations. Key findings: 1) 68% of people who responded to the survey said that they felt they were living well with dementia, 15% said that they were not, and 17% said that they did not know; 2) Despite this positive outlook, 53% of survey respondents said that they had felt anxious or depressed recently, 36% said they that had not, and 11% said that they didn’t know; 3) The feeling of anxiety or depression was highest among those who had started experiencing symptoms [of dementia] most recently; 4) 49% of respondents said that their carer did not receive help, 39% said that they did, and 12% said that they didn’t know; 5) Half of people living with dementia said that they were not getting enough support from government; and, 6) 75% of survey respondents said that they had another health condition in addition to dementia.


Extract from Alzheimer’s Society report

In December 2014, Marie Curie and Alzheimer’s Society published a report examining the issues with people with dementia and end-of-life care. It found that there were still barriers in identification, access to palliative care, and in the quality of care that was received... The Health Select Committee inquiry into end-of-life care found that round-the-clock palliative care in the community was important, but was too often difficult to access, especially for people with dementia... It recommended early planning among this group and that social care at the end-of-life should not be charged for. Equally, the review ... found that while some people were offered choices in their end-of-life care, many, including many with dementia, are not...

1. ‘Living and Dying with Dementia in England...’ Marie Curie Cancer Care & Alzheimer’s Society, 2014. [Noted in Media Watch, 8 December 2014, #393 (p.7)]

2. ‘End-of-Life Care,’ House of Commons Health Committee, 15 March 2015. [Noted in Media Watch, 16 March 2015, #401 (p.4)]
http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf

Cont.

N.B. Selected articles on end-of-life care for people living with dementia listed in past issues of Media Watch are noted in the issue of the weekly report of 15 June 2015, #414 (pp.13-14).

**Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- **ARGENTINA | The Buenos Aires Herald** – 6 July 2015 – ‘Supreme Court allows death with dignity.’ In a historic ruling, the Supreme Court upheld “the right of every patient to choose a dignified death,” drawing a sharp distinction between halting treatment and euthanasia. Justices confirmed a lower court’s decision to allow the end of extraordinary measures to preserve the life of a person, who had remained in a persistent vegetative state since 1995. Yesterday’s decision breaks new ground, since patients in previous situations, in which the judiciary authorized the termination of medical treatment, had to have set down in writing their wishes not to be kept alive artificially.  

**Specialist Publications (e.g., in-print and online journal articles, reports, etc.)**

**Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians**

**AMERICAN HEART JOURNAL | Online – 2 July 2015** – From a hospice clinician perspective, caring for patients with heart failure is unique compared to other hospice populations. This study suggests potential opportunities for hospice clinicians and referring providers who seek to collaborate to improve care for patients with heart failure during the transition to hospice care. Hospice clinicians identified three themes regarding care for patients with heart failure. First, care for patients with heart failure involves clinical complexity and a tailored approach to cardiac medications and advanced cardiac technologies. Second, hospice clinicians describe the difficulty patients with heart failure have in trusting hospice care due to patient optimism, prognostic uncertainty, and reliance on pre-hospice healthcare providers. Third, hospice clinicians described opportunities to improve heart failure-specific hospice care, highlighting the desire for collaboration with referring cardiologists.  
http://www.ahjonline.com/article/S0002-8703(15)00393-2/abstract

Of related interest:

- **BRITISH JOURNAL OF CARDIAC NURSING | Online – 3 July 2015** – ‘Understanding palliative care needs in heart failure.’ Although patients report little understanding of palliative care, it is clear that individuals living with heart failure have a number of palliative care needs. Among these are education, communication, symptom management and psychosocial needs. In particular, this literature review found that clinicians often struggled to discuss palliation with heart failure patients owing to the unclear disease trajectory and cardiac-specific barriers to identifying palliation needs.  
http://www.magonlinelibrary.com/doi/abs/10.12968/bjca.2015.10.7.348

- **HEART FAILURE CLINICS, 2015;11(3):479-498**. ‘Team-based palliative and end-of-life care for heart failure.’ Clinical practice guidelines endorse the use of palliative care in patients with symptomatic heart failure. However, the optimal content and delivery of palliative care interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. Therefore, this article comments on the current state of multidisciplinary care for such patients, explores evidence supporting a team-based approach to palliative and end-of-life care for patients with heart failure, and identifies high-priority areas for research.  
http://www.heartfailure.theclinics.com/article/S1551-7138(15)00024-0/abstract

N.B. Selected articles on palliative care in patients with heart failure noted in past issues of Media Watch are listed in the issue of the weekly report dated 19 January 2015, #393 (pp.11-12).
Use of the word “cure” in the oncology literature

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2015;32(5):477-483. “Cure” is an important word in oncology, but its use in the published literature has not been examined. The author investigated all oncology articles using cure in the title field and published in 2012. The definition of cure was examined, specifically whether or not authors use the word to connote some surviving subset of patients who go on to experience outcomes similar to age-matched, normal controls – a definition favored by researchers and employed in survival function analyses. Twenty-nine oncology articles used the word cure in their title in 2012. Nearly half, 14 (48%) of 29, used the term in situations (cancer type, stage/grade) currently considered incurable.

http://ajh.sagepub.com/content/32/5/477.abstract

Behavioral and educational interventions to support family caregivers in end-of-life care: A systematic review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 July 2015 – The demand for family caregivers steadily increases as the number of people receiving hospice and palliative care rises. Family caregivers play a significant role in supporting their loved ones in end-of-life care. However, there is limited evidence about the effectiveness of the interventions for supporting family caregivers. This article synthesizes behavioral and educational interventions that support family caregivers in end-of-life care. Fourteen studies were identified: 4 educational studies, 6 cognitive behavioral therapy studies, and 4 psycho-educational studies. All educational and behavioral interventions had developed structures and treatment manuals and improved family caregivers’ outcomes. The cognitive behavioral therapy resulted in more positive outcomes than the other two interventions. Future studies need to develop tools for assessing family caregivers’ needs, create consistent and specific tools to effectively measure family caregivers’ outcomes, incorporate a cost-effectiveness analysis, and find the most efficient intervention format and method.

http://ajh.sagepub.com/content/early/2015/07/07/1049909115593938.abstract

Clinical psychology for cancer patient: The key role of clinical psychology

FRONTIERS IN PSYCHOLOGY | Online – 6 July 2015 – Psychological issues take on great importance in oncology settings from the communication of the diagnosis to the management of the end-of-life phase. When diagnosed with cancer, about 30% of patients can suffer from psychological distress or other important mental health conditions. The papers of the present research topic give an insight into what taking care of a cancer patient means at the individual, relational, and socio-cultural levels. The topics of the papers range from the importance of personality and the psychological distress/psychopathology which cancer patients may experience to the essential role of the caregiver and the relevance of socio-cultural factors. It is now well-proven that psychological distress is a key variable in taking care of cancer patients. A meta-analytic review investigating the longitudinal associations between stress and cancer evidenced in 165 studies that stress-related psychosocial factors are associated with higher cancer incidence in initially healthy populations. A further 330 studies showed that stress in patients with cancer was related to a poorer rate of survival.


Of related interest:

- PALLIATIVE & SUPPORTIVE CARE | Online – 9 July 2015 – ‘Cancer patients’ emotional distress, coping styles and perception of doctor-patient interaction in European cancer settings.’ About one out of three patients have moderate to high level of emotional distress and about one out of four clinically significant maladaptive coping. Also, patients showing hopelessness and distress tended to perceive their doctors as both disengaged and less supportive.

http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9840808&fulltextType=RA&fileId=S1478951515000760

pg. 10
Let’s talk about death: Data collection for verbal autopsies in a demographic and health surveillance site in Malaysia

GLOBAL HEALTH ACTION | Online – 1 July 2015 – Verbal autopsies have gained considerable ground as an acceptable alternative to medically determined cause of death. Unlike with clinical or more administrative settings for data collection, verbal autopsies require significant involvement of families and communities, which introduces important social and cultural considerations. The objectives of this study were to: 1) Explore the range of bereavement rituals within the multi-ethnic, multi-faith population of the district; 2) Investigate the preparedness of communities to talk about death; 3) Describe the verbal autopsy process; 4) Assess the effects of collecting verbal autopsy data on data collectors; and, 5) Determine the most accurate sources of information about deaths in the community. Consideration of cultural bereavement practices is important to acceptance and response rates to verbal autopsies. They are also important to the timing of verbal autopsy interviews. Well trained data collectors, regardless of health qualifications are able to collect good quality data, but debriefing is important to their health and well being. This article contributes to guidance on the data collection procedures for verbal autopsies within community settings.  
http://www.globalhealthaction.net/index.php/gha/article/view/28219

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

- RELIGIONS, 2014;5(1):165-178. ‘Death investigations, objections to autopsy, and the religious and cultural “other.”’ Sudden, violent and otherwise unexplained deaths are investigated in most western jurisdictions through a Coronial or medico-legal process. This paper explores the disjuncture between medico-legal discourses, which position the body as corpse, and the rise of more “therapeutic” discourses which recognise the family’s wishes to reposition the body as beloved and lamented.  
http://www.mdpi.com/2077-1444/5/1/165

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

- U.K. | BBC News – 1 March 2011 – ‘New post-mortem method developed.’ The conventional autopsy process can be distressing for the family and is opposed by some communities on religious grounds. A non-surgical autopsy technique which could remove the need to open up the body to determine a cause of death has been developed ... at the University of Leicester.  

Thinking all wrong about how you die

THE HASTINGS CENTER REPORT | Online – 7 July 2015 – How do we approach our deaths? By avoidance, for one thing – death, especially our own death, is hard to talk about, think about, even imagine in the dimmest way. Or we dwell on it, that black, feared vortex that will eventually engulf us, swallowing our identity and personhood. Mostly, we distract ourselves with things of the moment. But in our rational moments we make preparations. We write advance directives. We execute durable powers of attorney. We give instructions to loved ones: “No tubes, no machines.” That’s the wrong approach... All this stuff we put together doesn’t guarantee what we say we want will actually happen or that we’ll have what we’d call a “good death” – what you would think of as a good death for you.  

Of related interest:

- JAMA ONCOLOGY | Online – 9 July 2015 – ‘Trends in advance care planning in patients with cancer: Results from a national longitudinal survey.’ Use of durable power of attorney increased significantly between 2000 and 2012, but was not associated with end-of-life care decisions. Importantly, there was no growth in key advance care planning domains such as discussions of care preferences. Efforts that bolster communication of care preferences and incorporate surrogate decision makers are critically needed to ensure receipt of goal-concordant care.  
http://oncology.jamanetwork.com/article.aspx?articleid=2383145&resultClick=3
Hospice care in assisted living facilities versus at home: Results of a multi-site cohort study

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2015;63(6):1153-1157. The assisted living population was more likely than the home hospice population to have a diagnosis of dementia ... and enrol in hospice closer to death... Assisted living residents were less likely to receive opioids for pain ... and less likely to die in an inpatient hospice unit ... or a hospital... There are several differences between residents of assisted living receiving hospice care and individuals living at home receiving hospice care. A better understanding of these differences could allow hospices to develop guidelines for better coordination of end-of-life care for the assisted living population. http://onlinelibrary.wiley.com/doi/10.1111/jgs.13429/abstract

Noted in Media Watch, 8 December 2014, #387 (p.9):

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 December 2014 – ‘Knowledge, skills, and attitudes in caring for older adults with advanced illness among staff members of long-term care and assisted living facilities.’ An needs assessment was conducted to determine the learning needs and preferences of staff members related to providing care for patients with life-limiting illnesses. They placed importance on understanding [the] principles of palliative care, pain assessment, pain management, and non-pain symptom management. http://ajh.sagepub.com/content/early/2014/12/02/1049909114561996.abstract

N.B. ‘Medicare Hospices Have Financial Incentives to Provide Care in Assisted Living Facilities,’ Office of the Inspector General, Department of Health & Human Services, January 2015. [Noted in Media Watch, 8 June 2015, #413 (p.5)] https://oig.hhs.gov/oei/reports/oei-02-14-00070.pdf

The spirit of “Ubuntu” in children’s palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 July 2015 – The concept of “Ubuntu”, a Nguni word, is found in many Southern African cultures and means that we are part of all humanity and we are who we are through our interconnectedness with others. Children with life-limiting conditions often become isolated and take on a new identity in the eyes of others, linked to their illness and treatment. Terms that are used can de-humanize the child. The concept of Ubuntu can help the child, the family and the community to ensure the child remains connected to society. Programs providing palliative care for children often say they feel isolated; Ubuntu principles are relevant to effective network development. http://www.jpsmjournal.com/article/S0885-3924(15)00328-0/abstract

Ethics for Muslim physicians in the light of recent biomedical advancements

JOURNAL OF PUBLIC HEALTH IN DEVELOPING COUNTRIES, 2015;1(1):31-39. Rapidly changing scenario of modern health care because of the scientific and technological advancements has generated a never ending debate among socio-religio-ethical segments of the society. Physicians working in traditional societies with religious inclination constantly face a dilemma due to the lack of guidelines on the issues of ethics of creation, therapeutic and reproductive cloning, assisted reproductive techniques, abortions, contraception, transplantation and euthanasia. As in all other fields, Islamic teachings on ethics of patient care are primarily based on Qur’anic directives and the actions and guidance of the Prophet of Islam known as ‘Sunnah.’ This article analyzes some of the religio-ethical issues surrounding the modern health care system in the light of recent biomedical improvements, with relevance to Muslim physicians. There is an urgent need to have clear local and national guidelines in addition to universal ethical codes on this subject. http://jphdc.org/index.php/jphdc/article/view/7

N.B. Click on ‘Download as PDF’ to access complete text.
GLOBAL BIOETHICS | Online – 9 February 2015 – ‘Islam and palliative care.’ Palliative care is experiencing an upsurge in interest and importance. This is driven, paradoxically, by modern medicine’s increased ability to provide effective pain relief on the one hand and an acknowledgement of its limitation in delivering a cure for certain diseases on the other. With many Muslims suffering from such incurable diseases worldwide, they too are now faced with the decision of whether to avail themselves of pain relief offered within the framework of scientific medicine. http://www.tandfonline.com/doi/abs/10.1080/11287462.2015.1008752#.VOCMaebF_YQ

AMERICAN JOURNAL OF BIOETHICS, 2015;15(1):3-13. 'Ethical obligations and clinical goals in end-of-life care: Deriving a quality-of-life construct based on the Islamic concept of accountability before God (Taklīf).’ In order to determine whether it is ethically justifiable to forgo medical treatment in such scenarios, clinical data must be interpreted alongside patient values, as well as in light of the physician’s ethical commitments. Though much has been written about this ethical issue from religious perspectives ... little work has been done from an Islamic point of view. http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.974769

An assessment of the court’s role in the withdrawal of clinically assisted nutrition and hydration from patients in the permanent vegetative state

MEDICAL LAW REVIEW | Online – 6 July 2015 – The authors reassess the court’s role in the withdrawal of clinically assisted nutrition and hydration from patients in the permanent vegetative state (PVS), focussing on cases where health-care teams and families agree that such is in the patient’s best interest. As well as including a doctrinal analysis, the reassessment draws on empirical data from the families of patients with prolonged disorders of consciousness, on economic data about the costs of the declaratory relief process to the National Health Service (NHS), and on comparative legal data about the comparable procedural requirements in other jurisdictions. The authors show that, following the decision in the Bland case [i.e., Airedale National Health Service Trust v Bland (1993)], the role of the Court of Protection is now restricted to the direct supervision of the PVS diagnosis as a matter of proof. They argue that this is an inappropriate role for the court, and one that sits in some tension with the best interests of patients. http://medlaw.oxfordjournals.org/content/early/2015/07/06/medlaw.fwv026.full.pdf+html

MEDICAL LAW REVIEW | Online – 11 March 2014 – “Moving on from Bland: The evolution of the law and minimally conscious patients.” This article seeks to critically appraise the evolution of the law in regard to withdrawing treatment from MCS [minimally conscious state] patients ... explaining differences between persistent vegetative state and MCS ... and defines the law from the starting point of Bland [i.e., Airedale National Health Service Trust v Bland (1993)]. http://medlaw.oxfordjournals.org/content/early/2014/03/11/medlaw.fwu003.abstract

MEDICAL LAW REVIEW | Online – 12 January 2014 – ‘Does withdrawing life-sustaining treatment cause death or allow the patient to die?’ The authors argue that traditional medical ethics, and the law, are mistaken to take the view that withdrawal merely allows the patient to die, rather than causing the patient’s death, describing such a view as “patently false.” They argue that the law’s continued position to the contrary stems from a moral bias, resulting in the moral and legal fiction that withdrawal does not cause death but lets the patient die. http://medlaw.oxfordjournals.org/content/early/2014/01/15/medlaw.fwt034.abstract
End-of-life care in Portugal

Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world

PALLIATIVE MEDICINE | Online – 10 July 2015 – In one of the most ageing countries in the world, there is a long standing trend towards hospitalised dying, more pronounced among the oldest old. To meet people’s preferences for dying at home, the development of integrated specialist home palliative care teams is needed. There were 2,364,932 deceased adults in Portugal from 1988 to 2010. Annual numbers of deaths increased 11.1%, from 95,154 in 1988 to 105,691, mainly due to more than doubling deaths from people aged 85+ years. Hospital deaths increased by a mean of 0.8% per year, from 44.7% in 1988 to 61.7% in 2010. This rise was largest for those aged 85+ years. Regardless of the scenario considered, and if current trends continue, hospital deaths will increase by more than a quarter until 2030 (minimum 27.7%, maximum 52.1% rise) to at least 83,293 annual deaths, mainly due to the increase in hospital deaths in those aged 85+ years.

http://pmj.sagepub.com/content/early/2015/07/10/0269216315594974.full.pdf+html

Noted in Media Watch, 23 December 2013, #337 (p.6):

- PORTUGAL | The Portugal News (Lagoa) – 19 December 2013 – ‘Palliative care in Portugal is “clearly insufficient,” says nurse championing change.’ A Portuguese nurse who has set up an association to promote palliative care in the Algarve [the southernmost region of mainland Portugal] has told The Portugal News that government resources currently available to patients are “clearly insufficient” and that society must unite to fill the voids being left by waning health and support services. Maria José Pachaco has worked in primary health care since 1999.

Noted in Media Watch, 24 December 2012, #285 (P.5):

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 December 2012 – 'A cross-sectional survey of the activity of palliative care teams in Portugal.' Of the 21 teams identified, 10 accepted to participate in the study. A total of 164 patients were included with a median of 15.5 per team: 60 (37%) were identified as inpatients in palliative care units; 59 (36%) by an intra-hospital support team; 26 (16%) as outpatients; and 19 (12%) at home.
  http://ajh.sagepub.com/content/early/2012/12/20/1049909112469718.abstract

N.B. Portugal was rated 31st (of the 40 countries surveyed) in The Quality of Death: Ranking End of-life-Care Across the World, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010.

End-of-life care in Australia

Outcomes from applying a palliative care satisfaction survey instrument in Victoria, Australia

PROGRESS IN PALLIATIVE CARE | Online – Accessed 4 July 2015 – Attempts to develop tools to measure client satisfaction in the palliative care sector have identified a number of challenges, including the lack of common definition of “satisfaction.” In response the Victorian Palliative Care Satisfaction Instrument (VPCSI) was developed and trialed. This paper reports on the utilization of the VPCSI in three Victoria-wide surveys over 3 years... Satisfaction state-wide rated very high, ranging from 66% for patients to 74% for bereaved carers. Items given priority to improve varied across respondent type but included: 1) Opportunities to talk to other carers; 2) Activities to pass the time; 3) Minimizing financial burden; and, 4) Training for carers to perform specific care tasks. The top rated items overall were: 1) Level of respect shown as an individual; 2) Nurse responses, expertise of staff; 3) Overall palliative care team performance; and 4) Support for physical care.
  http://www.maneyonline.com/toc/ppc/0/0

Cont.
Of related interest:

- **CANCER FORUM, 2015;39(2):90-94.** ‘Role of palliative care in survivorship.’ There is consensus that survivorship care should be integrated, risk or needs stratified, individualised, coordinated and multidisciplinary. Further work is needed to determine the key elements within models of care configured to support cancer survivors that positively influence outcomes, and how these elements can be best delivered across a diverse range of care settings. In the meantime, adopting a needs based approach to care at the individual patient level will ensure that those in most need have access to relevant support and care from specialist palliative care services. [http://www.cancerforum.org.au/file/2015/July/7.Role-of-palliative-care-in-survivorship.pdf](http://www.cancerforum.org.au/file/2015/July/7.Role-of-palliative-care-in-survivorship.pdf)

**Therapeutic weekend gatherings for bereaved parents**

**SCANDINAVIAN PSYCHOLOGIST** | Online – 7 July 2015 – Many grief groups are conducted without any attempt at systematic evaluation or learning. This study indicates that a systematic program with weekend gatherings aimed at helping the bereaved with complicated grief can have a beneficial effect. The results show that the participants reported good effects on several levels, influencing complicated grief, posttraumatic reactions and general psychic distress. However, the study requires replication with a larger group of parents and a more rigorous methodological design. Although the bereaved commonly report both a strong desire to meet others and to benefit from this interaction, some bereaved benefit less from grief groups. People with complicated grief reactions view grief support groups less favourably, mainly because they do not meet their requirements or expectations. The presented format may be better tailored to meet the needs of this specific subgroup of people experiencing bereavement. [http://psykologisk.no/sp/2015/07/e12/](http://psykologisk.no/sp/2015/07/e12/)

**Prison hospice**

**From the warehouse to the deathbed: Challenging the conditions of mass death in prison**

**THEMIS: RESEARCH JOURNAL OF JUSTICE STUDIES & FORENSIC SCIENCE** | Online – Accessed 7 July 2015 – The purpose of this project is to analyze the crisis of mass incarceration by placing the conditions faced by elderly, terminally ill, and dying prisoners, as its main point of focus. Much of this crisis was built through post-1970s American penal policies which set in place tough sentencing laws, increased prosecutorial power, and ultimately, led to a significant growth in the prisoner population. Today, elderly and terminally ill prisoners make up the fastest growing population inside of prisons. Few of these prisoners are approved for early release, and instead die while incarcerated. This has resulted in a condition of mass death within a system of mass incarceration. In order to manage the crisis of mass death, many prisons have constructed specialized hospice care units, internal to the prison facility. As the practice of providing hospice care inside of prisons becomes more and more commonplace, it is crucial to document their functions. This project attempts to provide a critical analysis of the origins of prison-hospice care, the benefits and limitations of these facilities, and the experiences of prisoners within these spaces. [http://scholarworks.sjsu.edu/cgi/viewcontent.cgi?article=1022&context=themis](http://scholarworks.sjsu.edu/cgi/viewcontent.cgi?article=1022&context=themis)

** Prison Hospice Backgrounder **

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: [http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons](http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons)

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**HIDDEN LIVES, HIDDEN PATIENTS**

World hospice & palliative care day

10 October 2015

pg. 15
Assisted (or facilitated) death

Representative sample of recent news media coverage:


Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2015/06/media-watch/


PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ [Scroll down to ‘International Websites’ and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://hpccommonwealth.ca/general-resources/in-the-news/

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to ‘Additional Resources’]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

U.K. | Omega, the National Association for End-of-Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b6237568904ba11300f652267fd7f90c

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