Media Watch... *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in* ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

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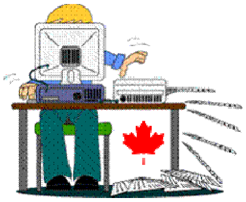


Compiled & Annotated by Barry R. Ashpole

Psychosocial aspects of end-of-life care: Scroll down to Specialist Publications and 'Social work assessment and outcomes measurement in hospice and palliative care' (p.6), in *American Journal of Hospice & Palliative Medicine.*

Canada

In an era of assisted death, we need palliative care more than ever

ONTARIO | *The Ottawa Citizen* – 16 July 2018 – Based on recent news reports, there is a strong, arguable case that, only two years after federal assisted dying legislation was passed, the lack of palliative care (PC) is influencing people to choose assisted death when they would have chosen PC had it been available. If we allow the most vulnerable among us to choose assisted death because they lack PC, what kind of society will we have built? What kind of people will our children say we were? What about compassion and love by accompaniment on the journey towards a chosen natural death? We need to give people the option of strong PC so that they can choose to live until their last dying breath, instead of taking their last dying breath while living. https://goo.gl/R5Vc6d

Extract from *The Ottawa Citizen* article

Of those who have already died by assisted death, did they opt for assisted death to relieve them of the shame they felt at seeing themselves as a burden to others, i.e., "shame relief"? This information should be publicly available; otherwise how will we ever know if the absence of palliative care was an overriding and undue influence?

Noted in Media Watch 25 June 2018 (#569, p.1):

- *MACLEAN'S* | Online – 22 June 2018 – **'Assisted dying was supposed to be an option. To some patients, it looks like the only one.'** Canadians were asked in 2016 to accept what is now called medical assistance in dying (MAiD) as standard practice in the health-care system. But as the second anniversary of the federal law sanctioning assisted suicide passes this month, ambiguities embedded in the new regulatory regime are turning end-of-life care into a troubling leap of faith for doctors and patients alike. Even the Collège des Médicins in Quebec, which sped ahead with its own statute in advance of Ottawa's Bill C-14, has sounded a strong warning note about patients "choosing" MAiD purely because their preference for palliative care isn't available. https://goo.gl/7TdFZa

N.B. There were 1,523 medically assisted deaths in Canada in the last six-month reporting period.[1] Since Quebec's assisted death law and the federal legislation came into force two years ago, 3,714 Canadians have received medical aid in dying.

1. 'Third Interim Report on Medical Assistance in Dying,' Health Canada, June 2018. **Download/view at:** https://goo.gl/gY3MJy

U.S.A.

America is running out of family caregivers, just when it needs them most

THE WALL STREET | Online – 20 July 2018 – For generations, the nation has relied on family members to keep aging loved ones in their homes. Today, many Americans are growing older without family nearby, offering a glimpse of what the future may hold for the cohort of Americans who are approaching retirement. The caregiving crunch comes at a time when Americans reaching retirement age are in a squeeze unseen in generations. Their median incomes, including Social Security and retirement fund receipts, haven't risen in years. They have high average debt, some incurred from taking care of their own aging parents. And if they're counting on family to care for them, too, they may well find their families too small and far-flung to meet the task. Today, an estimated 34.2 million people provide unpaid care to those 50 and older. These caregivers, about 95% family, and long the backbone of the nation's long-term care system, provide an estimated $500 billion worth of free care annually – three times Medicaid's professional long-term care spending – and help keep people out of costly institutions... But the supply of these caregivers is shrinking just as the nation needs them most. Every day, 10,000 people turn 65. In 2020, there will be 56 million people 65 and older, up from 40 million in 2010. https://goo.gl/gZ1ff8

End-of-life care isn't where to find savings

BLOOMBERG | Online – 18 July 2018 – In the quest to reduce health spending without harming health outcomes, one area has always loomed large: end-of-life care (EoLC). But it turns out that the share of total outlays that occurs near the end of life is small, and in any case it is difficult to predict when that stage is near, as a new analysis shows.[1] This issue is typically presented as the ultimate Ebenezer Scrooge dilemma: huge opportunities for reducing costs, but at significant moral cost. The misleading debate over non-existent "death panels" as part of the Affordable Care Act followed this pattern. Yet both dimensions of the story are flawed because the savings from altering EoLC are more modest than conventional wisdom suggests, and many people actually prefer lower-cost, at-home options to dying in a hospital. First, on the potential for cost savings, historical figures showed that more than 25% of total Medicare expenditures occurred in the last year of a beneficiary's life. That suggested significant opportunity to wring out costs from the care delivered near the end of life. The share of Medicare spending on those at the end of their lives has, however, declined somewhat over time. More importantly ... about 5% of Medicare beneficiaries die each year, compared with about 1% of the total population. As a result, EoLC represents a smaller share of total health-care spending than of Medicare spending. Indeed, the most recent estimates suggest that less than 9% of total U.S. health-care spending occurs in the final year of life.[2] And that share is actually lower than in many other developed countries. A new study points to an even more challenging issue: We have little idea who is on the verge of death, so knowing after the fact that a certain amount of spending occurred in the last year of life doesn't provide much insight to practitioners or policy makers. https://goo.gl/1NqD3g

Specialist Publications

'The status of end-of-life care in the U.S.: The glass is half full' (p.10), in *Journal of the American Medical Association*.

'Complaints about hospice care in the U.S., 2005-2015' (p.10), in *Journal of Palliative Medicine*.

1. 'Predictive modeling of U.S. health care spending in late life,' *Science*, 2018;360(6296):1462-1465. [Noted in the 2 July 2018 issue of Media Watch (#570, p.3)] **Abstract:** https://goo.gl/LioPPT

2. 'End-of-life medical spending in last twelve months of life is lower than previously reported,' *Health Affairs*, 2017;36(7):1211-1217. [Noted in the 10 July 2017 issue of Media Watch (#520, pp.10-11)] **Full text:** https://goo.gl/3dfoJp

N.B. The focus of the July 2017 issue of *Health Affairs* is advance illness and end-of-life care. Journal contents page: https://goo.gl/snqj35

International

Cicely Saunders Institute

Dying patients are being neglected by councils, with budgets for end-of-life care as low as £52 per person

U.K. (England) | *The Daily Mail* (London) – 17 July 2018 – Dying patients are still being neglected by councils, researchers said yesterday. End-of-life (EoL) care is being prioritised by only 4% of town halls in England, according to analysis by experts at King's College London.[1] Councils, which have responsibility for social care, face increasing numbers of elderly people needing EoL support. The scientists said demand is set to increase 42% by 2040. They said quality of care and resources varied hugely around the country, with budgets ranging from £52 to £2,329 per patient per year for PC. Lead author Dr. Katherine Sleeman, of the Cicely Saunders Institute at King's [College], said: "What we found is that while half of health and wellbeing strategies mention EoL care, few prioritise it, and none cite evidence for effective interventions. This is concerning, especially as EoL care has been highlighted as a priority for policy makers. This research underscores the need for greater scrutiny of local health and care strategies to avoid the unintended creation of a palliative care postcode lottery." https://goo.gl/2Ey6tH

Two patients affected as doctor shortage forces St Clare's Hospice to close for three weeks

U.K. (England) | *The Shields Gazette* – 19 July 2018 – The move has been taken after two doctors have left the team and a third doctor has had to reduce their hours as they undergo training to become a palliative care consultant. https://goo.gl/tB4W9K

Katharine House Hospice faces staff funding crisis

U.K. (England) | *The Banbury Gazette* – 19 July 2018 – Banburyshire's hospice is facing a £250,000 shortfall over the next three years because of new government rules on National Health service pay. The Adderbury hospice is one of the majority in England that do not meet 'Agenda for Change' criteria for staff pay... https://goo.gl/JbFPoB

N.B. See 'Charities warn that National Health Service pay award could hit hospices hard,' Hospice UK, noted in the 16 July 2018 issue of Media Watch (#572, p.4)] https://goo.gl/PYPZW2

1. 'Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies,' *Palliative Medicine*, published online 17 July 2018. **Full text:** https://goo.gl/dVrfKj

Noted in Media Watch 6 March 2017 (#502, p.5):

- U.K. (England) | BT.com – 1 March 2017 – **'Researchers warn of postcode lottery in care for the dying.'** Dying people are being left with inadequate round-the-clock pain relief and poor access to specialist help, according to new research.[1] They are caught in a postcode lottery which affects whether their families are able to secure proper National Health Service end-of-life care on weekends and during the night, it suggests. In some parts of England, NHS bosses only provide a telephone advice line to cater for people in their last days of life. Meanwhile, others have full palliative care teams with expertise in areas such as controlling cancer pain or lessening distress. https://goo.gl/0x1Ptz

    1. 'Commissioning of specialist palliative care services in England,' *BMJ Supportive & Palliative Care*, published online 28 February 2017. **Full text:** https://goo.gl/SnmBW0

Noted in Media Watch 23 May 2016, #463 (p.8):

- U.K. (England) | *The Northern Echo* (Buckinghamshire) – 19 May 2016 – **'Councils and GP groups "overlooking local end-of-life care needs."'** The charity Hospice UK used the Freedom of Information Act to find out how well councils and National Health Service groups assessed the needs of dying people in their communities. The results showed that more than a third of health and wellbeing boards, which are run by councils, do not consider the needs of dying people in their assessments of local needs.[1] Some 57% do not include the needs of dying adults and children in their key strategies that inform local service planning. http://goo.gl/1K8sDk

Cont.

1. ‘A low priority? How local health and care plans overlook the needs of dying people,’ Hospice UK, May 2016. **Download/view at:** https://goo.gl/xkFsBg

N.B. See the 20 November 2017 issue of Media Watch (#539, pp.7-8) for news media coverage on various reports by, for example, the Institute for Policy Research, the National Institute for Health & Care Excellence and the charity Together for Short Lives, on the “patchy and inconsistent” approach in the U.K. to end-of-life care for infants, children and young people.

End-of-life care in China

Demand for palliative care outstrips supply

CHINA | China News Service (Beijing) – 16 July 2018 – Most of the patients received by physician Qin Yuan, director of the hospice ward at Beijing Haidian Hospital, have an expected life span of two weeks or less. With just six beds available for terminally ill patients, Qin has no option but to impose the time limit. “Some patients die while waiting for a bed,” she said, leafing through the pages of a notebook filled with patients’ names, phone numbers and details of their illnesses. Despite the high demand for palliative care, there are only a few dedicated hospices in the country, and they are struggling to survive. Having worked as a cancer specialist for more than 30 years, she has witnessed many terminally ill patients die in the hospital while attached to tubes and drips, even though there is no medical reason for them to suffer. Death is still a taboo subject in China, though, so to avoid discussing the topic some families pay for expensive treatment until the patient dies, despite them having no chance of recovery, according to Qin. Cultural concerns about death run deep in China. For instance, most people try to avoid living on the fourth floor of a building because “four” in Chinese has a similar pronunciation to “death.” People are always reluctant to discuss the subject. https://goo.gl/3cfZCP

Noted in Media Watch 28 May 2018 (#565, p.13):

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 May 2018 – ‘**Current research status of palliative care in Mainland China.**’ The current research status of palliative care (PC) in Mainland China remains at an early stage with minimal PC services used. Although several knowledge gaps were identified, the first step, which should be addressed, is assessing the PC needs. An appropriate and ongoing needs assessment could provide important information for constructing comprehensive education and training programs of PC, identifying prognostic factors of timely PC referral, and developing evidence-based and tailored PC services. **Abstract:** https://goo.gl/Kyorw4

N.B. Additional articles on palliative care in China noted in the 15 January and 14 May 2018 issues of Media Watch (#546, pp.7-8, and #563, p.3, respectively).

Humanists UK campaign for more non-religious National Health Service “chaplains”

U.K. (England & Wales) | *The Observer* (London) – 15 July 2018 – For people of faith, when they face serious ill-health or an operation, being able to seek solace in their beliefs is vital. Even more so when they reach the end of life. Now humanists are campaigning to end what they see as discrimination against non-religious people being treated by the National Health Service (NHS), by urging that chaplains – or what they term non-religious pastoral carers – are hired to cater for non-believers. Humanists UK has been advertising ... to raise funds to support pastoral workers and train them, because it says there is a disproportionate number of religious chaplains in the NHS, given how many people in the U.K. do not have religious beliefs. 53% of Britons have no religion, according to the 2017 Social Attitudes Survey conducted by the National Centre for Social Research. https://goo.gl/TZLmSh

N.B. In April 2018, a humanist was appointed to lead a team of NHS chaplains at the world-renowned spinal injuries unit at Stoke Mandeville Hospital in Aylesbury, England, in a move that reflects growing demand for emotional and spiritual support from people who do not identify with any organised religion. Although there are two other humanists among the NHS’s paid chaplains, it is the first time that chaplains in hospitals and hospices will work under a non-religious leader.

Cont.

Noted in Media Watch 30 October 2017 (#536, p.7):

- U.K. (England) | *The Guardian* (London) – 25 October 2017 – **'Having an atheist chaplain is about patient choice.'** Jane Flint's role as a member of the chaplaincy at University Hospitals of Leicester National Health Service trust is to offer emotional and spiritual support to patients, visitors and staff. The difference between her and the other 12 chaplains is that she is an atheist. Duties are the same as for the other chaplains bar offering prayers, rituals or a religious perspective. https://goo.gl/RQiiEK

Noted in Media Watch 2 October 2017 (#532, p.4):

- U.K. (Wales) | BBC News (Cardiff) – 28 September 2017 – **'"Demand up" for humanist pastoral care in Wales.'** Humanist pastoral carers are being trained in Wales after research showed demand was up. Charity Humanists UK said almost 70% of those surveyed thought non-religious carers should be provided alongside religious chaplains at hospitals, prisons and universities. It found 93% of non-religious people did not make use of chaplains. https://goo.gl/UvTGJn

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM / *The Brussels Times* – 18 July 2018 – **'Euthanasia up by 13% as three minors elect for early exit.'** The majority of the increase was accounted for by patients aged between 60 and 89 years, who were suffering from polypathology – a combination of different illnesses, such as blindness, hearing loss and incontinence, which together make life for the patient unbearable. "We are seeing more and more people who no longer accept that condition," said Professor Wim Distelmans, chair of the federal control commission. "In addition, we are getting older and older, so the figures also go up. This is in fact the first generation to be confronted with polypathology." Polypathology patients requesting euthanasia have almost doubled in the last four years from 232 tot 444, although cancer remains the primary reason. Men and women are equally represented. The introduction of the right to euthanasia for minors ... led to three cases in 2016 and 2017. In all three cases, the patients were suffering from insufferable and incurable conditions which were already in a terminal phase. https://goo.gl/svjXFb

Specialist Publications

Incorporating bereaved parents as faculty facilitators and educators in teaching principles of palliative and end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 16 July 2018 – The objective of this study is to present an innovative palliative care educational program facilitated by trained bereaved parents who serve as volunteer educators in local and national PC educational forums and to describe how incorporation of bereaved parents in these educational forums affects participant comfort with communication and management of children at the end of life. Parent educators underwent both general and session-specific training and participated in debriefings following each session. Survey tools were developed or adapted to determine how bereaved parent educators affected participant experiences in three different educational forums. Involvement of trained parent educators across diverse, interdisciplinary educational forums improved attendee comfort in communicating with, and caring for, patients and families with serious illness. Importantly, parent educators also derive benefit from involvement in educational sessions with interdisciplinary clinicians. **Abstract:** https://goo.gl/YpSZ2q

St. Jude Children's Research Hospital

"It's very humbling": The effect experienced by those who facilitate a legacy project session within palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 July 2018 – The creative arts can be utilized within palliative care (PC) to facilitate the creation of a legacy project, an object which will reflect the unique experiences and interests of the creator. This can be bestowed to a loved one, thereby providing an opportunity to leave something tangible behind. However, there is a paucity of evidence exploring the impact experienced by those who facilitate the legacy generation session. "From The HEart" is a volunteer operated program that offers creative arts based legacy projects to PC patients. Five volunteers were interviewed to understand their personal experiences. Five themes emerged [from interviews with volunteers]: "providing a benefit," "internal validation," "it's all been positive," "self-awareness," and "if you need support. This study provides confirmation that facilitators do not report any negative experiences while assisting a PC client in creating a legacy project. These activities can provide meaning while working in the field of PC. **Abstract:** https://goo.gl/JpCyzi

Social work assessment and outcomes measurement in hospice and palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 July 2018 – While psychosocial assessment is required in hospice, no requirement exists for documentation of psychosocial outcomes. Social work research has identified the psychosocial and spiritual domains most often and appropriate for social workers to address, and standardized assessment tools have been developed by social workers based on this research. The aims of this study were to document the current use of standardized assessment measures for assessment and documenting outcomes and specifically the use of the Social Work Assessment Tool. A national sample of 203 hospice and palliative care (PC) social workers was recruited for this mixed methods study. Results indicated that most social workers used a form developed by a non-social worker in the agency for the initial assessment, and many PC social workers were not responsible for the assessment. Fewer conducted a follow-up assessment or documented outcomes. No common standardized measure was used. This study confirmed anecdotal evidence about lack of standardized social work assessment and outcomes measurement occurring in hospice and PC. As the Centers for Medicare & Medicaid Services is likely to select a standardized tool to measure psychosocial outcomes, social workers have an opportunity to contribute a quantitatively driven outcomes measure, developed by social workers, that will demonstrate effectiveness of social work intervention and lead to a better understanding of the social work role in hospice and PC. **Abstract:** https://goo.gl/v2cwNa

Related

- *PROFESSIONAL CASE MANAGEMENT*, 2018;23(4):228-230. **'The social worker case manager: "Owning" the psychosocial issues.'** A change of terminology is occurring as social workers elevate their expertise in identifying and addressing psychosocial issues... and recognize the influence of these factors on health status... That term is "social worker case manager." Among those of us who specialize in end-of-life care, this title is becoming standard, in part, because it is commonly used in widely deployed software for recording information and managing cases. But the change is more powerful than the words alone. **First page view:** https://goo.gl/aDJCWM

Noted in Media Watch 18 June 2018 (#568, p.7):

- *THE GERONTOLOGIST* | Online – 13 June 2018 – **'Nursing home residents' legal access to onsite professional psychosocial care: Federal and state regulations do not meet minimum professional social work standards.'** The federal government [in the U.S.] holds nursing homes (NHs) responsible for assessing and addressing resident psychosocial needs. The staff person most responsible for psychosocial care planning is the social worker. However, the federal government requires only NHs with 120+ beds to employ one full-time social worker, and that person need not hold a social work degree. **Abstract (inc. list of references):** https://goo.gl/LF9iVt

N.B. Additional articles on psychosocial interventions in end-of-life care noted in the 2 October 2017 issue of Media Watch (#532, pp.7-8).

Editorial

Now Gosport: What next?

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 16 July 2018 – The patients investigated in the Gosport inquiry were not admitted for end-of-life care (EoLC), and opioids were prescribed and administered to them without appropriate clinical indication. Thus, although these patients were not imminently dying ... we can expect some filtering down to the beliefs, prescribing culture, and practices of GPs. This highlights an urgent need for further training to address these anxieties and prevent a potential negative impact on the quality of EoLC being provided by generalists in the community. Recent work by Selman *et al* identified several educational barriers to GPs providing EoLC, including inadequate exposure during training, the challenge of keeping knowledge up to date and maintaining skills, and low confidence in their abilities.[1] Their work suggests a move away from formal education methods and identifies the need for practice-based mentorship and/or apprenticeship models in education in EoLC. With a national drive to enable more people who are dying to be cared for and to die at home, GPs and their community nursing colleagues will, once again, be in a position of greater responsibility for managing care at the end of life. To achieve this, good relationships with specialist palliative care services will be required, in addition to appropriate guidance and the confidence to put it in place – which we think will be shaken by the Gosport report.[2] Good communication with patients and their families will also be necessary, because some of the mainstream press coverage is likely to have increased lay misunderstanding and escalated their concerns about the use of medication in the dying patient. **Full text:** https://goo.gl/mdTJvi

1. 'Primary care physicians' educational needs and learning preferences in end-of-life care: A focus group study in the U.K.,' *BMC Palliative Care*, published online 9 March 2017. [Noted in the 13 March issue of Media Watch (#503, p.8). **Full text:** https://goo.gl/yNXvBY

2. 'Gosport War Memorial Hospital: The Report of The Gosport Independent Panel,' June 2018. [Noted in the 9 July 2018 issue of Media Watch (#571, p.5)] **Download/view at:** https://goo.gl/XZeJkH

N.B. Noted in this issue of Media Watch: 1. 'Gosport deaths: Lethal failures in care will happen again,' and 2) 'Lessons from Gosport,' *British Medical Journal*, published online 4 July 2018. 1. **Full text:** https://goo.gl/iBKf51; 2. **Abstract:** https://goo.gl/dsH9Gm

Discourses reproducing gender inequities in hospice palliative home care

CANADIAN JOURNAL OF NURSING RESEARCH | Online – 19 July 2018 – This critical analysis sheds light on institutional discourses that reproduce gender inequities: discourses of difference and denial; discourses of individuality, autonomy, and choice; and, discourses of efficiency, objectivity, and rationality. Although gender was discounted, these neoliberal discourses reinforced traditional gender relations. Neoliberal discourses frame health and health-care experiences as resulting primarily from individual behaviors and biomedical factors, permitting health-care providers and policy makers to overlook power relations and the socio-political forces that obscure gender inequities. A critical perspective is needed to consider how social structures significantly shape everyday gendered experiences in hospice palliative home care. **Abstract:** https://goo.gl/huYH4D

A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease

CARDIOLOGY IN THE YOUNG, 2018;28(4):561-570. The authors hypothesised that early palliative care (PC) in the single-ventricle population may have the same benefit for mothers. In this pilot randomised trial, mothers of infants with prenatal single-ventricle diagnoses completed surveys measuring depression, anxiety, coping, and quality of life at a prenatal visit and neonatal discharge. Infants were randomised to receive early PC – structured evaluation, psychosocial/spiritual, and communication support before surgery – or standard care. The results of this study show that mothers of infants with single-ventricle disease experience significant depression and anxiety prenatally. Early PC resulted in decreased maternal anxiety, improved maternal positive reframing, and improved communication and family relationships. **Abstract (inc. list of references):** https://goo.gl/FxZu2H

The role of resilience in the sibling experience of pediatric palliative care: What is the theory and evidence?

CHILDREN | Online – 16 July 2018 – Siblings of children with life-limiting conditions (LLC) are an important part of the broader family system and require consideration in the holistic care of the family. There can be considerable variation in the functioning and adjustment of these siblings. The current paper explores the resilience paradigm, particularly in the context of siblings of children with LLC and serious medical conditions. The potential impact of children living with a seriously ill brother or sister is overviewed, and a range of functional outcomes considered. Factors contributing to sibling resilience are detailed, including individual, family, and broader external and social factors. Given the limited research with siblings of children with LLC, literature has also been drawn from the siblings of children with serious and/or chronic medical conditions. Implications for clinical practice and future research are considered. Pediatric palliative care services may be well placed to contribute to this body of research as they have commonly extended relationships with the families of children with LLC, which span across the child's disease trajectory. **Full text:** https://goo.gl/7JmHa4

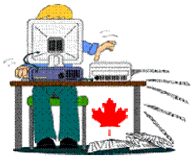
CANADIAN Virtual Hospice Portail CANADIEN EN SOINS palliatifs

Supporting Grieving or Bereaved Children

A 2015 literature search undertaken for the Children & Youth Grief Network of the Regional of Peel, Ontario, Canada, includes many *articles vis-á-vis* the experiences of siblings of children living with a life-limiting condition. More recent articles on the subject noted in the 18 December 2018 issue of Media Watch (543, p.5). **Download/view at:** http://goo.gl/ydHfq9

Cultural considerations at end of life in a geriatric inpatient rehabilitation setting

COLLEGIAN | Online – 14 July 2018 – There is little doubt that in Australia, like many other Western cultures, dying in geriatric inpatient rehabilitation settings remains problematic. When the goal of care is ultimately about life prolongation, dying does not fit. Furthermore, with increasing rates of specialisation amongst clinicians coupled with the multidisciplinary approach to care as seen in this geriatric inpatient rehabilitation setting, coordination of end-of-life (EoL) care in settings other than specialist palliative care (PC) settings appears to be lacking. Issues of cultural diversity further compound this. This highlights the need for greater recognition and acceptance of the potential sensitivities associated with aspects of cultural diversity and how it may influence patients' and families' needs at the EoL. This study has emphasised the need for health service organisations to prioritise and make explicit the importance of early referral and utilisation of existing support services, such as professional interpreters, specialist PC and pastoral care personnel in the provision of EoL care. If use of a dying care pathway for all dying patients was promoted, or possibly mandated, these issues would likely be addressed. **Full text:** https://goo.gl/Turpnf



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

PALLIMED A HOSPICE & PALLIATIVE MEDICINE BLOG

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

International Group for Reducing Inappropriate Medication Use & Polypharmacy: Position statement and 10 recommendations for action

DRUGS & AGING | Online – 14 July 2018 – This first International Group for Reducing Inappropriate Medication Use & Polypharmacy (IGRIMUP) position statement briefly details the causes, consequences, and extent of inappropriate medication use and polypharmacy. This article outlines current strategies to reduce inappropriate medication use, provides evidence for their effect, and then proposes recommendations for moving forward with 10 recommendations for action and 12 recommendations for research. The authors conclude that an urgent integrated effort to reduce inappropriate medication use and polypharmacy should be a leading global target of the highest priority. The cornerstone of this position statement ... is the understanding that without evidence of definite relevant benefit, when it comes to prescribing, for many older patients "less is more." This approach differs from most other current recommendations and guidance in medical care, as the focus is on what, when, and how to stop, rather than on when to start medications or interventions. Disrupting the framework that indiscriminately applies standard guidelines to older adults requires a new approach that better serves patients with multi-morbidity. This transition requires a shift in medical education, research, and diagnostic frameworks, and re-examination of the measures used as quality indicators. In achieving this objective, the authors promote a return to some of the original concepts of evidence-based medicine: which considers scientific data (where it exists), clinical judgment, patient/family preference, and context. A shift is needed: from the current model that focuses on single conditions to one that simultaneously considers multiple conditions and patient priorities. **Full text:** https://goo.gl/zj4Q3Y

Extracts from IGRIMUP position statement

The **Palliative & Therapeutic Harmonization Program** was developed in Canada.[1] One goal of this program is to achieve frailty-specific treatment guidelines to replace conventional clinical practice guidelines using an evidence review of common chronic conditions... The guidelines consider the clinical relevance of commonly accepted outcomes when there is frailty and suggest that even the outcome of reduced mortality may not be relevant with frailty owing to multiple competing risks for mortality. Based on an evidence review, the panel of experts conclude that rigid blood pressure, serum glucose, and cholesterol targets may be harmful in patients with severe frailty.

1. 'Palliative and therapeutic harmonization: A model for appropriate decision-making in frail older adults,' *Journal of the American Geriatrics Society*, 2012; 60(12):2326-2332. [Noted in the 5 November 2012 issue of Media Watch (#278, p.8)] **Request full text at:** https://goo.gl/gWdKur

The **Good Palliative Geriatric Practice Algorithm** is a proactive process that simultaneously discontinues as many "non-life saving" medications as possible where there is an absence of evidence in older people. Attention is paid to a patient's circumstances and preference for care, and to providing follow-up monitoring. In nursing homes, the discontinuation of 2.8 drugs per patient led to a significant 24% reduction in mortality and 18% in referral to acute care facilities. In community-dwelling elderly individuals, discontinuation of 4.4 drugs per patient led to an improvement of global health and well-being in 88% of the patients; only 2% of the discontinued drugs had to be re-administered and no significant adverse events were recorded as a result of de-prescribing. This approach is translatable into any setting; but requires knowledge of the limitations of standard guidelines.

Noted in Media Watch 2 July 2018 (#570, p.8):

- *EUROPEAN JOURNAL OF CLINICAL PHARMACOLOGY* | Online – 23 June 2018 – **'Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: A European expert consensus.'** The expert panel reached consensus on a set of 14 drug classes deemed as "often adequate," 28 drug classes deemed "questionable," and 10 drug classes deemed "often inadequate" for continuation during the last 3 months of life. Regarding the initiation of new drug treatments, the panel reached consensus on a set of 10 drug classes deemed "often adequate," 23 drug classes deemed "questionable," and 23 drug classes deemed "often inadequate." Consensus remained unachieved for some very commonly prescribed drug treatments... **Full text:** https://goo.gl/wtWTJ7

Health professionals' dealing with hope in palliative patients with cancer, an explorative qualitative research

EUROPEAN JOURNAL OF CANCER CARE | Online – 18 July 2018 – Three focus group discussions were held, each consisting of five to ten health professionals working with palliative patients recruited in a general Dutch hospital and homecare organisation. The ways in which the participating health professionals interpret hope in palliative individuals with cancer and their behaviour towards these hopeful palliative patients are shaped by their reliance on their own normative ideas. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. Hope that does not correspond with the medical facts is experienced as problematic by Dutch health professionals who therefore believe they should intervene and do something about it. Health professionals are challenged to face and address patients' and families' perceptions of hope, especially when those perceptions might differ from their own as professionals. **Abstract:** https://goo.gl/LwCYri

Noted in Media Watch 13 April 2009 (#92, p.6):

- *CLINICAL ETHICS*, 2009;4(1):38-43 **'Hope and terminal illness: False hope versus absolute hope.'** Sustaining hope in patients is an important element of health care, allowing improvement in patient welfare and quality of life. However in the palliative care (PC) context it might seem that in order to maintain hope the PC practitioner would sometimes have to deceive the patient about the full nature or prospects of their condition by providing a "false hope." **Abstract:** https://goo.gl/mAfLon

N.B. Additional articles on hope in the context of palliative and end-of-life care noted in the 18 June 2018 issue of Media Watch (#568, p.8).

The status of end-of-life care in the U.S.: The glass is half full

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2018;320(3):239-241. Almost everyone has a story about end-of-life care (EoLC) gone bad. The available data reveal many reasons for frustration with how care for dying patients is currently delivered. But rather than see the glass as half empty, the historical perspective offered by Teno and colleagues in this issue of the journal is a reminder of how far the U.S. health care system has come on EoLC.[1] This study suggests four important messages about the status of EoLC. **Introduction:** https://goo.gl/H92Mi6

1. 'Site of death, place of care, and health care transitions among U.S. Medicare beneficiaries, 2000-2015,' *Journal of the American Medical Association*, published online 25 June 2018. [Noted in the 2 July issue of Media Watch (#570, p.4)] **Full text:** https://goo.gl/1Pa4Zv

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 July 2018 – **'Complaints about hospice care in the U.S., 2005-2015.'** Retrospective analyses merged hospice complaints from 2005-2015 with agency characteristics from Medicare Cost Reports and Provider of Service files. Although the number of complaints was low overall, these data have the potential to convey insights about the care that hospice agencies provide. Greater attention to the perspectives of patients and their families, even when focused on shortcomings in care, can help ensure transparency and accountability and promote higher quality hospice care. **Abstract:** https://goo.gl/GvLQfu

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.

Prior trauma exposure and serious illness at end of life: A national study of children in the U.S. foster care system from 2005 - 2015

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – Accessed 16 June 2018 – Children in foster care suffer with serious illness at end of life (EoL). However, the relationship between prior trauma exposure and serious illness has received little empirical attention. Sixty-eight percent of children [of the patient population studied] experienced maltreatment, 28% exposure to parental drug/alcohol misuse, and 39% psychosocial stressors before entering foster care. Maltreatment was positively associated with physical health and developmental disabilities, whereas parental drug/alcohol exposure was inversely related to developmental disabilities. Psychosocial stressors contributed to the prediction of poor physical, mental, and developmental health. These findings suggest that trauma-informed EoL care may be a critical need among children in foster care with serious illness. Future directions are discussed, including collaboration between EoL clinicians and social service workers and the importance of future research to understand and improve the quality of health at EoL for this underserved population. **Abstract: (w. link to list of references)**: https://goo.gl/iwNAfQ

Place of care trajectories in the last two weeks of life: A population-based cohort study of Ontario decedents

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 July 2018 – Place of death is a commonly reported indicator of palliative care (PC) quality, but does not provide details of service utilization near end of life (EoL). This study aims to explore place of care trajectories in the last two weeks of life in a general population and by disease cohorts. The authors identified 235,159 decedents. Of which, 215,533 represented the major cohorts of our analysis – cancer (32%), frailty (29%), and organ failure (31%). Sixty-one percent of all decedents died in hospital-based settings. Place of care utilization trends show us a marked increase in use of palliative-acute hospital care (13-26%) and acute hospital care (12-25%) and a small decrease in community care use (15-12%) in the last two weeks of life. Those with cancer were the largest users of palliative-acute hospital care, while those with organ failure were the largest users of acute-hospital care. Place of care trajectories show a marked rise in care in hospital-based settings from 29% to 61% in the last two weeks of life. Nearly half of all hospital deaths had PC as the main service provided. Place of care trajectories differ greatly by disease cohort. Exploring place of care trajectories in the last two weeks of life can illuminate EoL utilization patterns not evident when reporting solely place of death. **Abstract:** https://goo.gl/kmnNrV

Noted in Media Watch 9 April 2018 (#558, p.7):

- *BMJ OPEN* | Online – 5 April 2018 – **'Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.'** This study quantifies a large disparity in access to palliative care (PC) for those dying from organ failure and frailty trajectories. Decedents with a terminal illness trajectory, exemplified by a cancer diagnosis, are significantly more likely to receive PC services than the other dying trajectories; they receive more services (intensity) both in hospital and community, and these services are initiated earlier in the dying trajectory. **Full text:** https://goo.gl/duyQma

Palliative care as an essential component of the HIV care continuum

THE LANCET HIV | Online – 16 July 2018 – Although antiretroviral therapy has reduced mortality among people with HIV, inadequate treatment coverage, ageing, and the increasing incidence of organ failure and malignancies mean that high-quality care should include care at the end of life (EoL). This review summarises the epidemiology of HIV in relation to mortality, and the symptoms and concerns of people with AIDS and those living with HIV who have either related or unrelated advanced comorbidities. In response to the evidence of a need for palliative care (PC), the principles and practice of PC are described, and the evidence for its effectiveness and cost-effectiveness is appraised. The core practices of PC offer

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a mechanism to enhance the person-centred nature of HIV care; the author identifies the gaps in this type of care, and presents evidence for effective models of care to address these. He details the policies that prompt governments and health systems to respond to the PC needs of their population. Finally, the author concludes with evidence-based recommendations to improve the delivery of, and access to, high-quality HIV care until the EoL, reducing unnecessary suffering while optimising person-centred outcomes. **Abstract:** https://goo.gl/teTgcY

> **N.B.** Additional articles on palliative care for people living with HIV noted in the 7 May 2018 issue of Media Watch (#562, p.6).

Demystification of palliative care: What palliative care teams don't want you to think about them

MEMO – MAGAZINE OF EUROPEAN MEDICAL ONCOLOGY | Online – 17 July 2018 – There is robust data that palliative care (PC) is prolonging life while there are still prejudices towards this discipline that have to be demystified. Patients, relatives and caregivers benefit from the concept of early integration of PC and therefore, PC should not be mainly regarded as end-of-life care. The primary goal of PC is to consider the individual priorities and values of patients through specialized, interdisciplinary care and communication . The "pallium" stands as a synonym for a coat in which the patients can slip into and that consists of individual, medical and psychosocial care, as well as spiritual care. This multimodal treatment should help patients and their relatives to gain a better understanding of the disease, its prognosis and possible treatment options. PC should not be understood as a discontinuation of therapy, but more as a change in therapy goals. Although there are many non-malignant, chronic palliative disorders, the majority of patients receiving PC suffer from advanced oncological diseases. There are still prejudices against the concept of PC that can be mitigated by well-published scientific studies. The authors of this article report upon some common myths towards PC: 1) PC only deals with dying; 2) PC mainly deals with talking; and, 3) PC is demoralizing. **Full text:** https://goo.gl/hjJvST

Assessing the validity of proxy caregiver reporting for potential palliative care outcome measures in Parkinson's disease

PALLIATIVE MEDICINE | Online – 17 July 2018 – There is increasing interest in applying palliative care (PC) approaches for patients with Parkinson's disease (PD). Methodological studies are needed to validate PC outcome measures for PD to build this evidence base. As many patients with PD have cognitive and/or communication issues, proxy outcome measures may improve the inclusivity and relevance of research. A cross-sectional study of PD patients and caregivers completed a battery of outcome measures relevant to PC... Caution is indicated when considering caregiver proxy reporting for most outcomes assessed, particularly in PD patients with advanced disease. **Abstract:** https://goo.gl/b2Ja9i

> **N.B.** Additional articles on the palliative care needs of patients and families living with Parkinson's disease noted in the 28 May 2018 issue of Media Watch (#565, pp.10-11).

What do hospitalists experience as barriers and helpful factors for having advance care planning conversations? A systematic qualitative evidence synthesis

PERSPECTIVES IN PUBLIC HEALTH | Online – 16 July 2018 – Hospitalists seem to struggle with advance care planning (ACP) implementation. One strategy to help them is to understand which barriers and helpful factors they may encounter. [In this systematic synthesis of the qualitative literature] hospitalists report lacking communication skills which lead to difficulties with exploring values and wishes of patients, dealing with emotions of patients and families and approaching the conversation about letting a patient die. Other barriers are related to different interpretations of the concept ACP, cultural factors, like being lost in translation, and medico-legal factors, like fearing prosecution. Furthermore, hospitalists report that decision-making is often based on irrational convictions, and it is highly personal. Physician and patient characteristics, like moral convictions, experience, and personality play a role in the decision-making process. Hospitalists report that experience and learning from more experienced colleagues is helpful. Furthermore, efficient multidisciplinary co-operation is helping. **Abstract:** https://goo.gl/14PD2Z

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Noted in Media Watch 10 April 2017 (#507, p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 April 2017 – **'Confidence with and barriers to serious illness communication: A national survey of hospitalists.'** On most or every shift, many participants reported having concerns about a patient's or family's understanding of prognosis (53%) or the patient's code status (63%). Most participants were either confident or very confident in discussing goals of care (93%) and prognosis (87%). Fewer were confident or very confident in responding to patients or families who had not accepted the seriousness of an illness (59%) or in managing conflict (50%). **Abstract:** https://goo.gl/ofIMKZ

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 July 2018 – **'Advance care planning with patients who have end-stage kidney disease: A systematic realist review.'** Advance care planning is hindered by a lack of training, administrative complexities, pressures of routine care, patients overestimating life-expectancy, and when patients, family, and/or clinical staff are reluctant to initiate discussions. It is more likely to succeed where organisations treat it as core business; when the process is culturally appropriate and takes account of patient perceptions; and when patients are willing to consider death and dying with suitably trained staff**. Abstract (w. link to list of references):** https://goo.gl/9Qv9gw

- *JOURNAL OF PROFESSIONAL NURSING* | Online – 9 July 2018 – **'Nurses preparation for advanced directives: An integrative review.'** This review integrates 19 studies published between 1990 and 2018 of the knowledge or confidence of nurses and nursing students regarding advance directives (ADs) or of education on ADs in nursing curricula. Fewer than half of working nurses demonstrated knowledge, confidence, or both regarding ADs, and nursing programs which cover ADs at all typically devote only 1.5 h or less to this legal document, which potentially has impact on patient care and outcomes. **Abstract (w. link to list of references):** https://goo.gl/rX1Pjb

End-of-life care in Wales

Royal Pharmaceutical Society Wales' evidence on palliative and end-of-life care shared in Welsh Assembly report

THE PHARMACEUTICAL JOURNAL | Online – 17 July 2018 – Community pharmacists are frequently not made aware if a patient has been placed on a palliative care (PC) register, a cross-party group of Welsh Members of Parliament has heard. The issue was raised in ... a report from the National Assembly for Wales's Cross-Party Group on Hospices & Palliative Care...[1] The inquiry leading to the new report aimed to identify gaps in the provision of equal access to hospice and PC in Wales. PC registers are used to identify patients with PC needs and to coordinate multidisciplinary PC for those patients. But in a recent survey by the Royal Pharmaceutical Society Wales, two-thirds of respondents said they had not been informed that a patient was on such a register. **Full text:** https://goo.gl/Vqsdoo

1. 'Inequalities in access to hospice and palliative care,' Cross Party Group Hospices & Palliative Care, July 2018. [Noted in the 16 July issue of Media Watch (#572, p.4)] **Download/view at (scroll down to 'Inquiry Report 2018'):** https://goo.gl/gVA7sS

Social bonds with the dead: How funerals transformed in the twentieth and twenty-first centuries

PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B | Online – 16 July 2018 – Evolutionary thanatology includes the study of necrophoresis – the removal of dead individuals by the living among social insects. In human societies, "necrophoresis" is performed via the funeral ceremony. In pre-modern societies, relatives and local community members helped to conduct funerals. In this way, holding a funeral was a form of mutual help, a social exchange of duty and responsibility essential to individuals. These societies developed systems to ensure the survival of humans as social animals based on mutual

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trust built over long periods of time within the same community. Contemporary societies are undermining these systems. Compared to funerals in pre-modern societies, holding a funeral in a modern society is a complicated process that requires professionals with specialized knowledge and skills. If people feel they can face mortality without support from relatives or the local community, and that they cannot necessarily expect a future return on the effort invested in community-based social relationships, they may begin to disengage from such relationships. In the context of modernization, the clearest changes in collective funerary behaviours include decreased funeral attendance and the above-mentioned outsourcing of funerary services. As such, it can be said that bonds with the dead changed completely under modernization, especially in the twentieth and twenty-first centuries. **Full text:** https://goo.gl/23wbzx

Caring for patients at the end of life: Experiences and needs of physicians

THERAPEUTISCHE UMSCHAU, 2018;75(2): 135-144. The author provides an overview of the aspects that characterise physicians' attitudes, experiences and needs when dealing with dying patients, with a view to provide information on useful approaches to communication at the end of life (EoL), as well as to encourage the development of strategies to better integrate EoL conversations and self-care practices into everyday practice. Medical training has favoured overtime a detached approach to emotions and death and dying as an isolating experience. While some patient deaths may be more confronting than others, and some conversations more difficult to start than others, turning the view to oneself can help to not only understand where the discomfort comes from, but also to improve communication patterns, stay healthy, and derive job satisfaction. By sharing perspectives and learning how other colleagues deal with similar issues, there is an opportunity for medical practitioners to develop a well-rounded approach to dealing with death and dying, which may enhance personal and professional relationships and may ultimately influence future generations of medical practitioners, as well as societal expectations. **Abstract:** https://goo.gl/rHYBav

Therapeutische Umschau

The focus of the current issue of the German language health journal is palliative care. Contents page: https://goo.gl/vXetPQ

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDICAL ANTHROPOLOGY QUARTERLY* | Online – 16 July 2018 – '**Choreographing death: A social phenomenology of medical aid-in-dying in the U.S.**' This article draws on ethnographic research on the implementation of Vermont's 2013 medical aid-in-dying (AID) law to explore a fundamental paradox: While public discourse characterizes AID as a mechanism for achieving an individually controlled autonomous death, the medico-legal framework that organizes it enlists social support and cultivates dependencies. Therefore, while patients pursuing AID may avoid certain types of dependency – such as those involved in bodily care – the process requires them to affirm and strengthen other bureaucratic, material, and affective forms. By tracing the social phenomenology of several AID deaths, the author illustrates how AID results in distinctive forms of sociality and dependency that require terminally ill people and caregivers to embrace a collaborative stance toward choreographing death. She argues that assisted dying offers an opportunity to resist dominant U.S. cultural narratives that view dependency in purely negative terms and re-imagine the relationships between disability, dependency, and care at the end of life. **Abstract:** https://goo.gl/8gByrm

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- *PSYCHIATRIC TIMES* | Online – 18 July 2018 – **'Two misleading myths regarding "medical aid in dying."'** "Assisted dying," "medical aid in dying" (MAiD), "physician assisted suicide" (PAS) – by whatever label we attach to it controversy continues to swirl around the practice of prescribing a lethal drug for a patient with a putatively terminal illness. To be clear: people of conscience, including many physicians, are sharply divided regarding whether, and under what conditions, MAiD/PAS may be ethically justified – even when it is legal. The challenges of providing end-of-life care that preserves the patient's humanity and minimizes pain and suffering are complex and daunting. There are no simple, universally applicable clinical or ethical options for addressing these challenges. However, the authors argue that support for "assisted dying" as the preferred option is founded on numerous misconceptions regarding existing MAiD/PAS statutes, among both the general public and many physicians. They discuss two fundamental misconceptions: the myth of the patient's autonomy, and the myth of the incurability of the patient's illness. **Full text:** https://goo.gl/PxtQNS

Media Watch: Editorial Practice

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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13 October 2018

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[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at https://goo.gl/6vdk9v]

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[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']

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ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

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ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

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EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/KjrR6F

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population...]

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/L7D2hw

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

South America

Academia Nacional de Cuidados Paliativos (Brazil): https://goo.gl/b5CV31