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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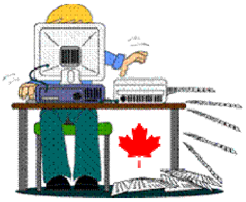

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Compiled & Annotated by Barry R. Ashpole

The specific phrase "goals-of-care" is pervasive in the discourse about serious illness care. Yet, the meaning of this phrase is ambiguous.

'Use and meaning of "goals-of-care" in the healthcare literature: A systematic review and qualitative discourse analysis' (p.9), in *Journal of General Internal Medicine*.

Canada

Specialist Publications

'**Canadian Guideline for Parkinson Disease – clarification on palliative care and medical assistance in dying**' (p.14), in *Canadian Medical Association Journal*.

New tool helps start conversations about end of life

ALBERTA | *Folio* (University of Alberta) – 23 October 2019 – A series of questions called the Life Conversation Tool is designed to help people with chronic, life-limiting illnesses gently make their wishes known, while they can still express them. Treatment needs to go beyond the standard medical forms about feeding tubes and resuscitation, to address patients' needs, goals and wishes, and to "normalize" conversations about end of life (EoL), said University of Alberta medical researcher Meena Kalluri, a pulmonary doctor who worked with Faculty of Extension researchers Diane Laverty and Kyle Whitfield to develop the tool. "We change the focus of medical decision-making to be more patient-focused and on how to live with the disease day-by-day – that's what the patients want," Kalluri said. People living with chronic illnesses … often haven't had those important conversations with their families, and wishes about EoL care risk going unfulfilled if a patient suffers a life-threatening event that leaves critical decisions up to a family member… http://bit.ly/2ByD6cn

No-CPR orders: Recent legal developments

ONTARIO | *Lexology* – 21 October 2019 – The College of Physicians & Surgeons (CPSO) recently amended its policy 'Planning for and Providing Quality End-of-Life Care' in light of a decision of the Ontario Superior Court in a medical malpractice lawsuit.[1] In the case of *Wawrzyniak v. Livingstone*, the plaintiff,

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who was the substitute decision-maker for her father, alleged that her father's physicians failed to meet an acceptable standard of care when they made the decision to write a do not resuscitate (DNR) order without her knowledge and consent in September 2008. In August 2019, her lawsuit was dismissed and no appeal is being taken. The foundational facts of the case involved a medical consensus of a critical care physician and an internist that the patient's death was imminent (meaning within days), and that he would almost certainly not benefit from aggressive ICU care or CPR, which would only increase his suffering at the end of his life, and co-signed a DNR order in his chart. The Court's decision to some extent runs counter to revisions, which had been made to the CPSO's policy in 2015 and 2016. The CPSO has therefore recently reconsidered and amended its policy effective 20 September 2019. With eleven years having passed since the events in this case, the CPSO takes the position that its standard of care today would not permit a no-CPR order to be written until after notification of the patient/SDM and, if no consensus, the completion of a dispute resolution process. The newly amended policy, however, would allow for a bedside exercise of clinical judgment as to benefit/harm, and would not expect the medical team to act contrary to the standard of care in the circumstances. http://bit.ly/2MYEIBo

1. 'Planning for and Providing Quality End-of-Life Care,' College of Physicians & Surgeons, September 2019: **Download/view at:** http://bit.ly/2W0WHeH

N.B. Selected news media reports on the *Wawrzyniak v. Livingstone* case noted in 26 August 2019 issue of Media Watch (#628, pp.1-2).

U.S.A.

Should family members see patients die in the ICU?

THE NEW YORK TIMES | Online – 25 October 2019 – A well-run code is like a dance, where any new member can threaten to disrupt the balance. So we would ask families to leave, banishing them to the waiting room until we could offer a verdict, alive or dead. It seemed safer that way. But a growing body of research argues we might have been wrong.[1] Studies suggest relatives don't distract the medical team or interfere with decision-making in a code. Doctors don't feel pushed to continue CPR longer than we would otherwise or to stop sooner. Nor are there increases in legal ramifications. Perhaps more important, allowing relatives to be present for CPR doesn't leave them with higher rates of anxiety, depression or post-traumatic stress disorder (PTSD). To the contrary, some studies suggest when family members watch the medical team attempt to bring a loved one back from the brink, they're actually less likely to suffer PTSD in the months that follow. Maybe there is value in knowing that we tried, and in seeing our efforts, in all their devastating detail. Maybe there is some reassurance in that reality. https://nyti.ms/32M0tLt

1. 'Family presence during cardiopulmonary resuscitation,' *New England Journal of Medicine*, published online 14 March 2013. **Full text:** http://bit.ly/31RGauY

Noted in Media Watch 1 January 2018 (#544, p.16):

- *JOURNAL OF CLINICAL NURSING* | Online – 20 December 2017 – **'How do clinicians practice the principles of beneficence when deciding to allow or deny family presence during resuscitation?'** The decision to allow or deny family presence during resuscitation is complex and often impacted by personal preferences and beliefs, setting norms and tensions between clinicians and consumers. As a result, many families are missing the chance to be with their loved ones at the end of life. This study highlights current deficits in decision-making around family presence during resuscitation and could prompt introduction of clinical guidelines and policies, in turn promote the equitable provision of safe, effective family-centred care during resuscitation events. **Abstract:** http://bit.ly/31QoXme

N.B. Additional articles on family presence during cardiopulmonary resuscitation are noted in 7 August 2017 issue of Media Watch (#524, p.13).

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How oncologists can ethically navigate the 'Right-To-Try' drug law

MEDICALXPRESS | Online – 22 October 2019 – The 2018 federal Right-to-Try Act allows patients with a life-threatening illness to be treated with drugs that have not yet been approved by the Food & Drug Administration. Many in the oncology community say Right-to-Try strips away important regulatory protections and view the move as a risky step bound to create ethical dilemmas for physicians whose goal is to guide patients toward safe and appropriate treatment decisions. Oncology is one field at the forefront of requests for unapproved drugs. An interdisciplinary team of bioethicists, oncologists, and lawyers from Penn Medicine and other institutions … penned a commentary published online … to offer recommendations to help oncologists navigate this new 'Right-to-Try' world, while maintaining their ethical obligations to patients.[1] **Full text:** http://bit.ly/2BFgaYL

1. 'Right-to-try requests and oncologists' gatekeeping obligations,' *Journal of Clinical Oncology*, published online 15 October 2019. **Full text:** http://bit.ly/2Jlk9y4

N.B. Selected articles on "right-to-try" laws noted in 16 September 2019 issue of Media Watch (#631, p.3).

International

Grief in the workplace research: Preliminary results released

IRELAND | Irish Hospice Foundation (IHF) – 22 October 2019 – In 2018, the IHF began the two-part research project looking at how bereaved employees are currently supported in the Irish workplace. The preliminary results (employees' experiences) will now be used to inform Part 2 of the research, which will examine the experiences of organisations when an employee is bereaved. It will be released in early 2020. Preliminary results of Part 1 of the research show: 1) Being treated with compassion by an employer was identified as the most important support for employees who are bereaved; 2) "Soft" supports like compassionate treatment and acknowledgement of loss are more important on the whole than "hard" supports like flexible working hours and extra leave entitlements; 3) 3 in 10 Irish adults [of 1,000 survey respondents] said their employer has a bereavement policy; 4) 25% of people are not satisfied with the support received from their employer; 5) More than half of respondents would feel less committed to their job if they were not appropriately supported following a bereavement; 6) Inadequate support has implications for absenteeism and morale: 46% would take more sick days if they were not appropriately supported, and 45% feel disgruntled and talk to other employees about it; 7) Almost a third would think about leaving the job; and, 8) Almost a quarter of respondents would actually leave the job if not appropriately supported. This research has significant implications for best practice in workplaces in supporting bereaved employees. http://bit.ly/2Jd4bWE

Specialist Publications

'How to help researchers in palliative care improve responsiveness to migrants and other underrepresented populations: Developing and testing a self-assessment instrument' (p.6), in *BMC Palliative Care*.

'Palliative care within universal health coverage: The Malawi Patient & Carer Cancer Cost survey' (p.6), in *BMJ Supportive & Palliative Care*.

'Healthcare professionals' perceptions about the Italian law on advance directives' (p.14), in *Nursing Ethics*.

Cont. next page

Noted in Media Watch 18 March 2019 (#606, p.4):

- U.K. | *HuffPost* – 12 March 2019 – **'Should offices have bereavement first aiders to help with grief at work?'** Bereavement first aiders should be trained by employers to help people in the workplace struggling with grief, according to the Sue Ryder charity.[1] The majority of U.K. adults are not getting any formal support after the loss of a loved one. Around seven in 10 U.K. adults have been bereaved at least once in the last five years. Sue Ryder suggests a number of measures to improve support for the bereaved, including a call for employers to consider training "bereavement first aiders" in the workplace, to give people the skills to help colleagues who want to return to work. http://bit.ly/2HfOrD6

    1. 'A Better Grief,' Sue Ryder, March 2019. **Download/view at:** http://bit.ly/2Hh9x3G

Noted in Media Watch 22 December 2014 (#389, p.16):

- *BEREAVEMENT CARE*, 2014;33(3):111-112. **'Handling bereavement in the workplace: A guide for employers.'** Grief cannot be left at the door by staff when they come to work, and how they are treated by their employers at this vulnerable time will have important consequences for both. If bereavement is handled well in the workplace the employer will always be remembered – if it is handled badly it will never be forgotten. The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.[1] **First page view (w. link to references):** http://bit.ly/2XRzmeV

    1. 'Managing bereavement in the workplace: A good practice guide,' Advisory, Conciliation & Arbitration Service, U.K., 2014 [Noted in 22 September 2014 issue of Media Watch, #376, p.15] **Download/view at:** http://bit.ly/2UZ57pz

Ageing prison population "sees officers working as carers"

U.K. (England & Wales) | BBC News (London) – 21 October 2019 – The ageing jail population has left prison officers providing care for a growing number of older inmates "dying in front of them," officers have said. The warning from the Prison Officers' Association (POA) has come as new figures revealed the oldest prisoner in England & Wales was 104 years old. The data showed there were 13,617 inmates aged above 50 out of a prison population of 82,710 in June 2019.[1] The Prison Service said it was working to meet the needs of elderly prisoners. More and more inmates were frail, incontinent or had dementia, the POA said. https://bbc.in/2qBkg20

Extract from Prisons & Probation Ombudsman 2017 report

It is not only prisoners who are ageing – often our facilities are older and not designed to adequately accommodate disability or palliative care needs. We recommend that prisons try to ensure the terminally ill are treated in a suitable environment. We also identify a lesson to improve healthcare coordination at the end of life, by ensuring that care plans are initiated at an appropriate, and ideally early, stage for those who are diagnosed with a terminal illness.[1]

1. 'Learning from Prisons & Probation Ombudsman Investigations' ('Palliative and end-of-life care, pp.19-20), Prisons & Probation Ombudsman, June 2017. [Noted in 31 July 2017 issue of Media watch (#523, p.6)] **Download/view at:** http://bit.ly/2Jte30q

1. 'Prison population figures: 2019,' Her Majesty's Prison Service (Public Sector Prisons), October 2019. **Download/view at:** http://bit.ly/2BBopVL

N.B. A compilation of selected articles, etc., on end-of-life care in the prison system noted in past issues of Media Watch can be downloaded/viewed from/at the Palliative Care Network website: http://bit.ly/2RdegnL

Shortage of nurses and doctors in England hitting care for seriously ill children

U.K. (England) | Together for Short Lives – 20 October 2019 – A growing shortage of skilled children's palliative care (PC) doctors and nurses across England has reached crisis point, a new report reveals. It is leading to seriously ill children and their families missing out on crucial out of hours care and vital short respite breaks. 'A workforce in crisis: Children's palliative care in 2019' shows a children's PC workforce

Cont.

at breaking point: **1)** There are just 15 children's PC consultants in the U.K. (the Royal College of Paediatrics & Child Health suggests there should be 40-60); **2)** The nursing vacancy rate in children's hospices is growing, with posts increasingly difficult to fill; **3)** There are too few skilled children's nurses to fill vacant posts in the National Health Service (NHS) and children's hospices; **4)** There are too few community children's nurses employed by the NHS; and, **5)**There are shortages among other important health and care professionals. These staff shortages are having a direct impact on terminally ill children and their families. Despite being assessed as needing 24-hour support by the NHS, some children and young people are not getting around the clock care. **Download/view report at:** http://bit.ly/33RWkG6

Specialist Publications

How prepared are we to address sexuality in palliative care?

ACTA MÉDICA PORTUGUESA, 2019;32(10):625-627. Sexuality, as one of the determinants of quality of life (QoL), includes different subjective dimensions related to identity, communication and intimacy. According to the World Health Organization (WHO), sexuality "is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction." In this sense, WHO considers intimacy as an important element of the expression of sexuality. This includes individual satisfaction with his/her affective, loving, and sexual relationships. Moreover, in concordance with WHO, and distinct from sexuality and intimacy, sex "refers to the biological characteristics that define humans as female or male." However, in general use, the term sex is often used to mean "sexual activity." For many patients, sexual health is an essential component of their QoL, providing a sense of normality and closeness within the couple. Studies show that terminally ill patients continue to crave intimacy, although the type of intimate relationship may change along with their illness. At this stage, patients' intimacy reinforces their emotional bond. **Full text:** http://bit.ly/2BvpQ8s

N.B. Click on 'Select Language" to access full text in either English or Portuguese. .

Noted in Media Watch 1 July 2019 (#620, p.6):

- *BRITISH JOURNAL OF NURSING* | Online – 26 June 2019 – **'Addressing sexuality and intimacy in people living with Parkinson's during palliative care and at the end of life.'** Sexuality and intimacy are poorly researched in both people living with Parkinson's and in older people. Triggers for discussion usually centre on sexual dysfunction and hypersexuality in relation to Parkinson's. However, there are many more factors that impact on physical and emotional connectedness. Despite highlighting this unmet need there are limited tools or comprehensive assessments available to help improve quality of life. **Abstract:** http://bit.ly/320uFCL

Definition of a good death, attitudes toward death, and feelings of interconnectedness among people taking care of terminally ill patients with cancer: An exploratory study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 October 2019 – The concept of a good death is crucial in palliative care, but its relationship with attitudes toward death and feelings of interconnectedness needs to be further deepened. The first aim of this study was to explore the concept of good death, attitudes toward death, and feelings of interconnectedness among family caregivers and healthcare providers of terminally ill patients with cancer. The second aim was to analyze associations of good death concept with attitudes toward death and feelings of interconnectedness. Participants were asked to assess the importance of features that characterize a good death. Nine good death features were considered essential by more than 70% of participants. These referred to the physical (e.g., symptoms control), social (e.g., loved ones' presence), emotional (e.g., sharing emotions), and spiritual (e.g., inner peace) dimensions. Importance attributed to components of a good death such as patient's awareness and acceptance of death, meaning, respect for the patient's wishes, and inner peace were found to be associated with lack of avoidance and acceptance toward death and feelings of interconnectedness. **Abstract:** http://bit.ly/365MAKg

How to help researchers in palliative care improve responsiveness to migrants and other underrepresented populations: Developing and testing a self-assessment instrument

BMC PALLIATIVE CARE | Online – 21 October 2019 – European migrant populations are aging and will increasingly be in need of palliative and end-of-life care. However, migrant patients are often underrepresented in palliative care (PC) research populations. This poses a number of drawbacks, such as the inability to generalize findings or check the appropriateness of care innovations amongst migrant patients. With this study the authors aimed to develop and test a self-assessment instrument to help researchers assess and find ways to improve their PC projects' responsiveness to diversity in light of the aging migrant population. By implementing all changes and omitting some items the self-assessment instrument includes a list of 23 measures to be taken at varying stages of a project and targets all groups at risk of being underrepresented in PC research and underserved by PC services. The measures cover topics important during project set-up: describing the diversity of the patient population in the project proposal; monitoring engagement of a diverse patient population; establishing a representative project team; project execution (patient and caregiver participation); access to and quality of care within the project and, follow-up (responsive implementation of project results); and, sharing experiences on responsiveness in PC projects. **Full text:** http://bit.ly/2MCcfIV

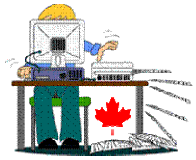
Assessing the validity of the clinician-rated distress thermometer in palliative care

BMC PALLIATIVE CARE | Online – 17 October 2019 – The distress of patients suffering from a terminal illness can lead to a state of despair and requests for euthanasia and assisted suicide. It is a major challenge for palliative care (PC) workers. The Distress Thermometer is recommended by the National Comprehensive Cancer Network as a means of more easily assessing distress. It is available as a Self-assessment Reported Distress Thermometer, but for a wider use in PC it should also be implemented in the form of a clinician-reported outcome. Clinicians need to rate patient's distress when the patient is not able to do so (subject that cannot be addressed, defensive patient…). Results of this study demonstrate that a subjective feeling like distress can be externally evaluable. **Full text:** http://bit.ly/32yehsG

Palliative care within universal health coverage: The Malawi Patient & Carer Cancer Cost survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – Evidence of the role of palliative care (PC) to reduce financial hardship and to support wellbeing in low/middle-income countries is growing, though standardised tools to capture relevant economic data are limited. The authors describe the development of the Patient & Carer Cancer Cost Survey (PCCCt survey) that is being used to gather prospective data on healthcare use, household out-of-pocket expenditure and well-being among households affected by advanced cancer in Southern Malawi. The PCCCt survey is currently only suitable for households affected by cancer-related illnesses. Further validation of this instrument should be prioritised. The authors invite others to adapt this survey for their own settings and for other life-limiting conditions. Such data are critical to inform future economic evaluations and to influence global health policy dialogues on universal health coverage with the aim of improving access to services for the many in need of PC. **Full text:** http://bit.ly/32R4UVi

> **N.B.** Additional articles, etc., on palliative care as a "facet of universal health coverage" noted in 21 October 2019 issue of Media Watch (#636, p.15).



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://bit.ly/2RPJy9b

Deprescribing in end-of-life care

BRITISH JOURNAL OF COMMUNITY NURSING | Online – 10 October 2019 – The aim of deprescribing in end-of-life care (EoLC) is to improve the patient's quality of life by reducing their drug burden. It is essential to engage the patients and enable them to make choices about medications by discussing their preferences and implement a pharmacy management plan. Withdrawing medications during the end stages of life is extremely complex because the period of care varies substantially. The author discusses polypharmacy within EoLC and reviews which medications should be stopped by examining the non-essential and essential drugs. **Abstract:** http://bit.ly/2qHDnY8

Noted in Media Watch 22 July 2019 (#623, p.9):

- *CLINICAL MEDICINE*, 2019;19(4):311-314. **'Deprescribing in palliative care.'** The use of multiple medications is common in palliative care, putting patients at risk of adverse events and a high tablet burden. Barriers to deprescribing exist meaning many patients will take multiple medications despite being in the final months of life. The OncPal deprescribing guideline is a useful tool to support the process for patients with a limited life expectancy. There is evidence for the safety of stopping certain medications, particularly those aimed at primary prevention. A systematic process of reviewing individual medications and their appropriateness is recommended. **Abstract:** http://bit.ly/32GrX5E

N.B. Additional articles on medications with questionable benefit at the end of life noted in 1 April 2019 issue of Media Watch (#608, pp.7-8).

Palliative care interventions for people with multiple sclerosis

COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 22 October 2019 – The authors assessed the effects (benefits and harms) of palliative care (PC) interventions compared to usual care for people with any form of multiple sclerosis: relapsing-remitting MS, secondary-progressive MS, and primary-progressive MS. They also compare the effects of different PC interventions. The studies included in this review compared PC delivered in home visits versus usual care for people with MS. Interventions focused on assessment and management of symptoms and end-of-life planning. The authors are uncertain about differences between PC versus usual care for the following outcomes assessed at long-term follow-up: change in health-related quality of life (QoL), adverse events, and hospital admission. The included studies did not assess fatigue, cognitive function, relapse-free survival or sustained progression-free survival. There is low- or very low-certainty evidence regarding the difference between PC interventions versus usual care for long-term health-related QoL, adverse events and hospital admission. **Abstract:** http://bit.ly/2qvW94C

Noted in Media Watch 5 August 2019 (#625, p.12):

- *MULTIPLE SCLEROSIS & RELATED DISORDERS* | Online – 20 July 2019 – **'Accessing palliative care for multiple sclerosis: A qualitative study of a neglected neurological disease.'** Improving access to palliative care (PC) for multiple sclerosis (MS) requires a contextual understanding of how PC is perceived by patients and health professionals, the existing care pathways, and barriers to the provision of PC. Patients and neurologists [i.e., study participants] mostly associated PC with the end-of-life and struggled to understand the need for PC in MS. Another barrier was the lack of understanding about the PC needs of MS patients. PC physicians also identified the scarcity of resources and their lack of experience with MS as barriers. **Abstract:** http://bit.ly/2Mnv2lj

  N.B. Additional articles on PC for people living with MS.

Specific challenges in end-of-life care for patients with hematological malignancies

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 21 October 2019 – The prevalence of hematological malignancies (HM) is expected to increase in the next 20 years because of better

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therapeutic options with longer survival and because of the aging population. However, patients with HM are underrepresented in palliative care (PC) as these diseases are associated with special care needs and prognostic uncertainty, which differ from the unambiguity of terminally ill patients with solid tumors. Recent research covers prognostic uncertainty, challenges in terms of the acute death setting, and blood transfusions in the terminally ill as well as interdisciplinary collaboration. In addition to qualitative approaches exploring reasons for these challenges, criteria that indicate the approaching end of life in HM were systematically developed and tested. Further, the effectiveness of PC addressing the hematopoietic stem cell transplantation setting was further analyzed. The patients' perspective needs to be involved in future research to examine whether the connotation of PC is a barrier for patients, families or healthcare professionals. Communication culture and skills have already been identified as goals for medical training. Further studies should identify the effective elements of PC specific for HM and develop feasible support models, including informal caregivers. **Abstract:** http://bit.ly/33WCKYX

How simple steps can help practices improve end-of-life care

GP | Online – 23 October 2019 – One person dies every minute in the U.K. each year, most of whom have an advanced serious illness. With our ageing population, this number is set to rise along with increased need for palliative and end of life care by 2030. Evidence tells us most people want to be cared for and die in their own home or in a care home, where possible. Most people who die in the community receive palliative and end-of-life care from a general practice, without involvement of hospice or specialist palliative care. We can make a bigger impact on people's experiences towards the end of their lives with high quality, consistent, planned care across GP practices and their networks. The Daffodil Standards provide evidence-based guidance, tools and resources to test what you are doing well and spot where you can make improvements.[1] They are important as GPs and their teams play a vital role in caring for terminally ill or dying patients. **Full text:** http://bit.ly/32GVCuO

1. 'Daffodils set the standard for end-of-life care,' Royal College of General Practitioners and Marie Curie UK, February 2019. [Noted in 18 February 2019 issue of Media Watch (#602, p.11)] **Download/view at:** http://bit.ly/2JgtkzH

When death with dementia is "a memory seared in my brain": Caregivers' recommendations to healthcare professionals

JOURNAL OF APPLIED GERONTOLOGY | Online – 23 October 2019 – The purpose of this study is to determine family caregivers' recommendations for healthcare professionals on how to help prepare them for the death of an elder with dementia. Purposive criterion sampling was employed to identify 30 bereaved caregivers of family members aged 65 and older who died with a dementia-related diagnosis. In-depth, qualitative interviews were conducted over a 12-month period, and qualitative content analysis was used to analyze the data. Three primary themes emerged: 1) Educate caregivers; 2) Lead caregivers; and, 3) Provide a caring and compassionate presence. The results highlight the importance of various healthcare professionals' roles in preparing family caregivers for a death. In doing so, both the dying and their caregivers may have a better end-of-life experience with improved bereavement outcomes. **Abstract:** http://bit.ly/2JiywDg

Related

- *BMC PALLIATIVE CARE* | Online – 24 October 2019 – **'Context, mechanisms and outcomes in end-of-life care for people with advanced dementia: Family carers perspective.'** This study adds to the existing literature by providing a comprehensive picture of the context and mechanisms influencing end-of-life care (EoLC) in dementia. During the advanced stages of dementia people have limited capacity and verbal communication and so open communication and trusting relationships between family, care staff and healthcare professionals become paramount in providing a coordinated approach to EoLC. In addition to good relationships, increased provision of resources such as Admiral Nurses, staff training and advance care planning may help to reassure family carers that their relative will have a comfortable and peaceful death in a homelike environment. **Full text:** http://bit.ly/341f1XO

N.B. Selected articles on palliative and end-of-life care for people living with dementia noted in 21 October 2019 issue of Media Watch (#636, p.12).

Use and meaning of "goals-of-care" in the healthcare literature: A systematic review and qualitative discourse analysis

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 21 October 2019 – The specific phrase "goals-of-care" (GoC) is pervasive in the discourse about serious illness care. Yet, the meaning of this phrase is ambiguous. The authors sought to characterize the use and meaning of the phrase GoC within the healthcare literature to improve communication among patients, families, clinicians, and researchers. An operational definition emerged from consensus within the published literature: the overarching aims of medical care for a patient that are informed by patients' underlying values and priorities, established within the existing clinical context, and used to guide decisions about the use of or limitation(s) on specific medical interventions. Application of the GoC concept was described as important to the care of patients with serious illness, in order to: 1) Promote patient autonomy and patient-centered care; 2) Avoid unwanted care and identify valued care; and, 3) Provide psychological and emotional support for patients and their families. **Abstract (w. list of references):** http://bit.ly/2PbYaNN

Goal-concordant care – searching for the Holy Grail

NEW ENGLAND JOURNAL OF MEDICINE, 2019; 381(17):1603-1606. The importance of delivering goal-concordant care to seriously ill patients is widely recognized. Yet there are no methods that can reliably and accurately be used to measure whether care that was provided to patients was concordant with their goals. **Introductory paragraph:** http://bit.ly/2MJf6JL

Delivering advance care planning support at scale: A qualitative interview study in twelve international healthcare organisations

JOURNAL OF LONG-TERM CARE | Online – 17 October 2019 – Globally, populations are ageing, with people increasingly likely to die with chronic progressive illness. In this context, there is widespread interest in advance care planning (ACP), where people are supported to think about and express preferences concerning their future care. However, to date there has been limited systematic implementation. In a purposive sample of 12 international health and care organisations [in five countries: Australia, Canada, New Zealand, the U.K., the U.S.] working to provide system-wide ACP support, the authors examined organisational aims, leaders' perspectives on the economic case and promising approaches for efficiently delivering ACP support at scale. Organisational aims for ACP support were multiple and complex; they included optimizing patient and family care, supporting staff and mitigating risks of complaints from bereaved families, reputational damage, poor staff morale and potential legal challenges. The economic case comprised intrinsic benefits for patients, families and staff; averting costs associated with potential risks; and making best use of resources by reducing reactive care and provision of unwanted, low-value treatments. A degree of staff specialism, team-based delivery, use of decision aids, group-based facilitations, public health approaches and supportive parallel system changes and initiatives appear likely to support the efficient and effective delivery of ACP support at scale. The authors identify various approaches for delivering ACP support more efficiently at scale. **Full text:** http://bit.ly/2o7SeKy

Long-Term Care

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE (IAHPC) | Online – October 2019 – Older persons living in long-term care (LTC) facilities have palliative care needs, but it is only in recent years that the quality of end-of-life care (EoLC) in these settings has gained what might be termed "serious" attention. A selection of articles on palliative and EoLC in LTC, from past issues of Media Watch, are noted in the current issue of the IAHPC's newsletter [scroll down to 'Media Watch: Long-Term Care'] at: http://bit.ly/2p0p68g

Missed opportunities when communicating with limited English proficient patients during end of life conversations: Insights from Spanish and Chinese speaking medical interpreters

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 October 2019 – There is limited research evaluating the views of medical interpreters on best interpreter practices when they are utilized to break bad news or participate in end-of-life (EoL) conversations. The objectives of this study were: 1) Develop insights from medical interpreters about their role when interpreting discussions regarding EoL issues; 2) Identify practices interpreters perceive as helping to improve or hinder patient-provider communication; and, 3) Obtain suggestions on how to improve communication during EoL conversations with Spanish and Chinese speaking patients. Six themes were identified: 1) Medical interpreters' perceived comfort level during EoL interpretation; 2) Perception of interpreter role; 3) Communication practices perceived as barriers to effective communication; 4) Communication practices felt to facilitate effective communication; 5) Concrete recommendations how to best utilize medical interpreters; and, 6) Training received/perceived training needs. Medical interpreters provide literal interpretation of the spoken word. Due to cultural nuances in Chinese and Spanish speaking patients/family members during EoL conversations, medical interpreters can translate the meaning of the message within a specific cultural context. Conducting pre-meetings and debriefings after the encounter are potentially important strategies to maximize communication during EoL conversations. **Abstracts (w. link to references):** http://bit.ly/31NL5gb

Noted in Media Watch 10 April 2017 (#507, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – **'Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.'** The authors present a case that generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. **Abstract (w. list of references):** http://bit.ly/2JqsyjL

Conceptualizing and counting discretionary utilization in the final 100 days of life: A scoping review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 October 2019 – There has been surprisingly little attention to conceptual and methodological issues that influence the measurement of **d**iscretionary utilization **a**t the end-of-**l**ife (DIALs), an indicator of quality care. The authors extracted data from 254 articles published in 79 journals covering research conducted in 29 countries, mostly on cancer (69.1%). More than 100 DIALs have been examined. Relatively crude, simple variables (e.g., ICU admissions [56.9% of studies], chemotherapy [50.8%], palliative care [40.0%]) have been studied more frequently than complex variables (e.g., burdensome transitions; 7.3%). The authors found considerable variation in the assessment of DIALs, illustrating the role of norms and disciplinary habit. Variables are typically chosen with little input from the public (including patients or caregivers) and clinicians. Fewer than half the studies examined age (44.6%), gender (37.3%), race (26.5%), or socioeconomic (18.5%) correlates of DIALs. Unwarranted variation in DIALs assessments raises difficult questions concerning how DIALs are defined, by whom, and why. The authors recommend several strategies for improving DIALs assessments. Improved metrics could be used by the public, patients, caregivers, clinicians, researchers, hospitals, health systems, payers, governments, and others to evaluate and improve end-of-life care. **Abstract (w. link to references):** http://bit.ly/2J7OPmd

In the child's best interests: Should life be sustained when further treatment is futile?

NURSING CHILDREN & YOUNG PEOPLE | Online – 22 October 2019 – The authors explore the concept of medical futility and the withdrawal of care for children in intensive care units. There have been several recent cases where medical staff have considered that there was no possibility of recovery for a child, yet their clinical judgments were challenged by the parents. The private anguish of these families became public, social media heightened emotions and this was followed by political and religious intru-

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sion. Innovations in medical treatment and technological advances raise issues for all those involved in the care of children and young people especially when decisions need to be made about end-of-life care. Healthcare professionals have a moral and legal obligation to determine when treatment should cease in cases where it is determined to be futile. The aim should be to work collaboratively with parents but all decisions must be made in the best interests of the child. However, medical staff and parents may have differing opinions about care decisions. In part, this may be as a result of their unique relationships with the child and different understanding of the extent to which the child is in discomfort or can endure pain. **Abstract:** http://bit.ly/2oWIfbD

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 October 2019 – '**Artificial nutrition and hydration for children and young people towards end of life: Consensus guidelines across four specialist paediatric palliative care centres.**' There is a paucity of evidence on the role, use, benefit and challenges of artificial nutrition and hydration (ANH) in children at end of life (EoL). Parents express the difficulty they face with making the decision to withdraw ANH. Decision-making on the role of ANH in an individual child requires careful multidisciplinary team deliberation and clear goals of care with children and families. **Abstract:** http://bit.ly/2pxYbku

Noted in Media Watch 22 April 2019 (#611, p.3):

- *ARCHIVES OF DISEASE IN CHILDREN* | Online – 18 April 2019 – '**Achieving consensus: Advice for paediatricians and other health professionals on prevention, recognition and management of conflict in paediatric practice.**' Conflict is damaging, stressful and emotionally challenging for all involved. Taking the correct early steps may prevent early disagreements reaching conflict. If conflict is reached, families must continue to be supported even if there is a breakdown of trust between families and clinicians. As the voice of the child and what is in their best interest remains paramount, the families' wishes and needs must also be taken into consideration. **Full text:** http://bit.ly/2T4Zwd6

Moral identity and palliative sedation: A systematic review of normative nursing literature

NURSING ETHICS | Online – 21 October 2019 – In the last two decades, nursing authors have published ethical analyses of palliative sedation (PS), an end-of-life care (EoLC) practice that also receives significant attention in the broader medical and bioethics literature. This nursing literature is important, because it contributes to disciplinary understandings about nursing values and responsibilities in end-of-life care. Two different tones are apparent in the extant nursing ethics literature. One is educational, while the other is critically reflective. Irrespective of tone, all authors agree on the alleviation of suffering as a fundamental nursing responsibility. However, they differ in their analysis of this responsibility in relation to other values in EoLC, including those that depend on consciousness. Finally, authors emphasize the importance of subjective and experience-based understandings of PS, which they argue as depending on nurses' proximity to patients and families in EoLC. Based on their findings, the authors develop three recommendations for future writing by nurses about PS. These relate to the responsibility of recognizing how consciousness might matter in (some) peoples' moral experiences of death and dying, to the importance of moral reflectiveness in nursing practice, and to the value of a relational approach in conceptualizing the nursing ethics of PS. **Abstract:** http://bit.ly/2pMpYNU

N.B. Additional articles on PS noted in 30 September 2019 issue of Media Watch (#633, p.12).

Experiences from the first 10 years of a perinatal palliative care program: A retrospective chart review

PAEDIATRICS & CHILD HEALTH | Online – 18 October 2019 – Perinatal palliative care (PC) is a relatively new component of paediatric PC which supports families who are expecting the birth of a child with a life-limiting condition. This study seeks to understand the characteristics of the infants and families referred for perinatal PC and the context for referrals in terms of diagnoses, referral characteristics, inter-

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ventions, and outcomes. This study confirms previously observed characteristics of diagnosis, referrals, and outcomes, while providing the most detailed account of lifespans for particular diagnoses to date. The findings validate the need for perinatal PC, as 99% of those referred continued with the service. Future research should adopt a prospective approach to identify critical factors affecting decision making of families and physicians in the wake of a life-limiting diagnosis. **Abstract:** http://bit.ly/2qusoRT

N.B. Additional articles on neonatal and perinatal PC noted in 22 July 2019 and 10 December 2018 issues of Media Watch (#625, pp.11-12 and #593, p.13, respectively).

Case report

When the patient says no to transplant: A life well lived and well ended

PSYCHOSOMATICS | Online – 16 October 2019 – There is a paucity of literature on the clinician–patient dynamics when a patient declines referral to transplantation despite the team's recommendation. This case report describes a young woman with cystic fibrosis (CF) who declined referral to lung transplantation and relevant literature review. Although initially the CF team struggled with the patient's decision, the embedded psychiatrist was consulted and a multidisciplinary team meeting between patient, her family, and the medical team enabled the team to fully appreciate the patient's viewpoint and to embrace and support her goals towards the end of life. The case also describes a modified dignity therapy conducted with this patient. Finally, the case describes the patient's last phase of life with a dignified dying experience. This report documents the first published case of modified dignity therapy work in people with CF. In addition, it provides an illustrative example of the team working with a patient declining life-prolonging transplantation and providing the patient with a dignified experience of last stages of life according to her goals and values. **Abstract:** http://bit.ly/31FqKJY

Noted In Media Watch 8 October 2018 (#584, p.8):

- *CANCER* | Online – 5 October 2018 – **'What do transplant physicians think about palliative care? A national survey study.'** Despite its established benefits, palliative care (PC) is rarely utilized for hematopoietic stem cell transplant (HSCT) patients. The majority of transplant physicians trust PC, but have substantial concerns about PC clinicians' knowledge about HSCT and patients' perception of the term "palliative care." Interventions are needed to promote collaboration, improve perceptions, and enhance integration of PC for HSCT recipients. **Abstract:** http://bit.ly/31NpNPH

N.B. Selected articles on organ transplantation in the context of PC noted in 13 August 2018 (#576, p.13).

Nurses defending the autonomy of the elderly at the end of life

REVISTA BRASILEIRA DE ENFERMAGEM | Online – 21 October 2019 – Interaction among nurses, other health team members and family of the elderly is an important action to promote their autonomy at the end of life, especially when hospitalized. Family nucleus plays a fundamental social role because, once participatory and integrated, it generates a feeling of brotherhood, security and dignity. In order for the family to play this role in the hospital, the health team must insert it into the caring process and consider it a unit of care, since it may require different needs. Communication is emphasized as an important work tool that, based on sensitivity and compassion, makes it possible to clarify doubts about the elderly's health in a simple and objective way. This study's participants expressed concern that the information be transmitted in a clear way, based on truthfulness, respecting the capacity of understanding and the moment of acceptance of each person. It is necessary to pay attention to the elderly's emotional state and their relatives, who, depending on it, can interfere in the interpretation of the information. This requires caution on the part of the health team, since communication may need to be developed gradually over hospitalization. Nurses play an important role in sharing information, since it occupies a strategic position in the hospitalization setting, acting as mediator between other team members, in order to meet the elderly's and their relatives' needs. **Full English language text:** http://bit.ly/2p93VRK

N.B. Click on pdf icons to access the full text in Portuguese.

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Noted in Media Watch 7 January 2019 (#596, p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2019 – **'Patients' autonomy at the end of life: A critical review.'** The authors identified two core structural domains of autonomy: 1) Being normal; and, 2) Taking charge. By analysing these domains they described 8 and 13 elements, respectively, which map the conceptual structure of autonomy within this population of patients. The review shows that maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients' engagement in daily activities, in contributing to others, and in active preparation for dying. **Full text:** http://bit.ly/2N8fhgV

From hospitalization to grief: Meanings parents assign to their relationships with pediatric oncology professional

REVISTA DA ESCOLA DE ENFERMAGEM DA USP | Online – 14 October 2019 – This study showed an intimate association between relationships and meanings. Both are complex, since they allow for a diversity of possible outcomes, but rich in information about a very particular universe and difficult to unravel when parents experience the loss of a child from cancer in the hospital. Various meanings are intertwined in the memories of the relationships lived at the time the parents [interviewed] were in the hospital, whether with their child, with friends, with relatives or with professionals. Over the years, the emotions involved in these memories can change, as new meanings are integrated into the experience. These meanings, when recognized during the end of the child's life in the hospital, give nurses the opportunity to act in the prevention of future complications related to bereavement process. **Full English language text:** http://bit.ly/32KSwpK

N.B. Click on pdf icons to access the full texts in either Portuguese or Spanish.

Related

- *APPLIED NURSING RESEARCH* | Online – 20 October 2019 – **'Social media as a recruitment method to reach a diverse sample of bereaved parents.'** Online platforms, such as Facebook and Twitter, may be one potential method to reach and recruit a diverse group of bereaved parents. The authors describe: 1) How the social media platforms of Facebook and Twitter were used to recruit bereaved parents into a cross-sectional, online survey; and, 2) The effectiveness of social media as a recruitment tool for this population. More research is needed, however, to determine the best methods to reach fathers as well as racial and ethnic minorities. **Abstract:** http://bit.ly/2PkAlUa

Wife against advance directive: A case-inspired legal and ethical clarification

ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE | Online – 18 October 2019 – Advance directives (ADs) and durable powers of attorney are two increasingly used tools for patients' precedent autonomy; however, their combined use, as recommended by major institutions in Germany, might in reality result in various discrepancies between the wording and interpretation of the directive and the surrogate's understanding of the patient's relevant will. In one of the possible conflict constellations, the surrogate wants to overrule a relevant and unambiguous AD by reference to a privileged access to the patient's "real" treatment preferences or the presumed will of the patient. Such cases, which must be strictly distinguished from cases with real or alleged leeway for interpretation in the AD, can lead to normative uncertainty as well as to substantial psychological distress for all persons involved. Based on an exemplary real clinical case from 2015 (which did not go to court) legal, ethical and pragmatic aspects of the described constellation are discussed. Ethically, caution should be exercised against a relapse into a masked treatment paternalism, which currently seems to be partly caused by judicial exegesis. **Abstract (w. list of references):** http://bit.ly/2pfFOAN

N.B. German language article.

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Related

- *EINSTEIN (SÃO PAULO)* | Online – 4 October 2019 – **'Variables that influence the medical decision regarding advance directives and their impact on end-of-life care.'** The main factors that influenced physicians [in the literature reviewed] to implement an advance directive (AD) were patients prognosis, medical paternalism and patients understanding of their medical condition. Respect for autonomy, lack of knowledge and experience with directives, legal concerns, family influence, cultural and religious factors also contributed to medical decision. Most studies showed that having a directive led to lower rates of invasive interventions in the last days of patient´s life. Physicians were interested in respecting their patients' autonomy and agreed that having an AD helped in the decision-making process... **Abstract:** http://bit.ly/31MfCez

  N.B. Click on 'Full Text' icon to access full text in either English or Portuguese.

- *NURSING ETHICS* | Online – 20 October 2019 – **'Healthcare professionals' perceptions about the Italian law on advance directives.'** In the variegated legislative framework on advance directives (ADs), the first specific regulation in Italy on this issue came into force only in 2018. This qualitative study aimed to investigate the implications of the new Italian law on ADs in clinical practice from the perspective of those who deal with this delicate ethical issue on an everyday basis, that is, Italian healthcare professionals. The authors identified a main overall category, 'Pros and Cons of the Italian law on advance directives,' composed of six constituent categories: 1) Positive welcome; 2) Self-determination and protection; 3) Prompts for future betterment; 4) Uncertainties; 5) Lack of knowledge; and, 6) Neutrality and no suggestions. **Abstract:** http://bit.ly/2P8JXRD

  N.B. Additional articles on Italy's law on the "provisions for informed consent and ADs treatment" noted in 11 March 2019 issue of Media Watch (#605, p.6).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 21 October 2019 – **'Assisted dying: Restricting access to people with fewer than six months to live is discriminatory.'** The Australian state of Victoria has become the latest jurisdiction to legalise assisted dying, joining Belgium, Luxembourg, The Netherlands, Canada and the U.S. states including Oregon, California, Colorado, Hawaii, New Jersey and Washington. In the U.K., assisted dying remains illegal. But there are signs that indicate that the U.K. is inching towards legalisation. For example, in March 2019 the Royal College of Physicians adopted a position of neutrality, and the British Medical Association and Royal College of General Practitioners have both decided to consult their members on whether the official position of these organizations should change from opposition. Much of the public debate around the legalisation of assisted dying remains binary: yes or no. But this is a dangerous oversimplification. Assisted dying laws exist along a continuum. For example, in Oregon, assisted dying is only available to people who have a terminal illness expected to result in death within six months. In Belgium, by contrast, assisted dying is available to people with unbearable and unrelievable mental or physical suffering, regardless of predicted life expectancy. The most recent three Bills to appear before the U.K. parliament have advocated a law similar to Oregon's, with assisted dying restricted to those expected to die within six months. **Introductory paragraphs:** http://bit.ly/33V9TEJ

  N.B. Access the full text (via BMJ's blog) at: http://bit.ly/2JcR6Nc

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 17 October 2019 – **'Canadian Guideline for Parkinson Disease – clarification on palliative care and medical assistance in dying.'** The Canadian Society of Palliative Care Physicians (CSPCP) welcomes the inclusion of palliative care (PC) in the new 'Canadian Guideline for Parkinson Disease' and commends the authors for making it one of their five key recommendations.[1] Early integration of a palliative approach to care is essential for all persons with serious and life-threatening illnesses, including those with neurological illnesses. However, the CSPCP strongly disagrees with the way that medical assistance in dying (MAiD) is portrayed throughout the Guideline as being an option included under PC. PC and MAiD are distinct, as recognized in Canadian Medical Association General Council Resolution GC 15-35, which states that: "As-

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sisted death as defined by the Supreme Court of Canada is distinct from the practice of PC." National and international standards for PC, including the World Health Organization's definition of PC, clearly state that PC focuses on providing support to enable people to live as well as possible until they die but "does not hasten death." MAiD is a legal option for some patients who qualify and choose to pursue it but is not part of a palliative approach, as described in CSPCP's 'Key Messages: Palliative Care and MAiD.'[2] **Full text:** http://bit.ly/2VV6iDP

1. 'Canadian Guideline for Parkinson Disease [Section on palliative care],' *Canadian Medical Association Journal*, 2019;191(36):E989-E1004. [Noted in 16 September 2019 issue of Media Watch (#631, p.6)] **Download/view at:** http://bit.ly/2kniP4B

2. 'Key messages: Palliative care and medical assistance in dying (MAiD),' Canadian Society of Palliative Care Physicians, May 2019. [Noted in 27 May 2019 issue of Media Watch (#615, p.15)] **Download/ view at:** http://bit.ly/2QdIGre

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