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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The removal of the pathway has not remedied the issues attributed to it. Further, the way in which the Liverpool Care Pathway was removed indicates that the non-expert media can play a negative role in how palliative care is perceived, which inhibits the care process.

‘Palliative care after the Liverpool Care Pathway: A study of staff experiences’ (p.6), British Journal of Nursing.

U.S.A.
Palliative care still relatively unknown among the general public: Shows education for consumers and physicians necessary to make a difference

CENTER TO ADVANCE PALLIATIVE CARE | Online – 8 August 2019 – New opinion research confirms that once educated with the correct definition of palliative care (PC), understanding and favorability greatly increase among consumers and physicians. “All organizations and clinicians must proactively align themselves in defining PC correctly,” said Diane E. Meier, the Center’s director. “With an aging population increasing exponentially, it is more important than ever that both the field of PC and the referring clinicians evolve their rhetoric. The point must always be made that PC is based on need, not prognosis.” http://bit.ly/2ZXaHXK

Specialist Publications
‘Forgiveness and reconciliation processes in dying patients with cancer’ (p.5), in American Journal of Hospice & Palliative Medicine.

‘Honoring the moral concerns of caregivers afraid of giving morphine’ (p.5), in American Journal of Nursing.

‘Trends and racial disparities of palliative care use among hospitalized patients with end-stage kidney disease on dialysis’ (p.8), in Journal of the American Society of Nephrology.

Terminally ill military kids can now receive both treatment and hospice

MILITARY.COM | Online – 6 August 2019 – The parents of children with terminal illnesses covered by Tricare no longer have to choose between treatment and end-of-life care, thanks to a policy update issued today. The policy change, ordered by the 2018 National Defense Authorization Act, will allow military dependents under 21 to receive both medical treatment for their terminal illness, such as medication, radiation or surgeries; and care that falls under the umbrella of “hospice,” which includes pain relief and symptom control. Under previous law and policy, a patient could only receive one or the other. While the either-or policy might work for adults whose terminal illnesses lead to predictable declines, studies have shown that integrating hospice with ongoing recovery treatments can actually increase sick kids’ chances of survival... http://bit.ly/2yMLVh2
House Committee seeks answers from CMS on OIG hospice reports

HOSPICE NEWS | Online – 5 August 2019 – Leaders in the influential Ways & Means Committee in the U.S. House of Representatives have called for stronger supervision of hospice regulatory programs in a letter to ... the U.S. Centers for Medicare & Medicaid Services (CMS). The first report of Office of the Inspector General (OIG), in the Department of Health & Human Services, indicated that about 20% of hospices surveyed by regulators or accreditors between 2012 and 2016 had a condition-level deficiency that posed a serious safety risk. A second report discussed 12 examples of those deficiencies in-depth. OIG examined state agency and accreditor survey findings as well as complaint data from 2012 through 2016. Regulators and accreditors surveyed nearly all hospice providers in the nation during those years. The reports garnered widespread media attention and elicited strong reactions from hospice organizations. In addition to bringing attention to safety incidents in hospices, the reports called into question the effectiveness of CMS’ enforcement strategies.

N.B. Links to the two OIG reports, noted in 15 July 2019 issue of Media Watch (#622, p.2), are embedded in the Hospice News article.

Cancer treatment at the end of life

THE NEW YORK TIMES | Online – 5 August 2019 – Too often, people with incurable cancers pursue therapy beyond any hope of benefit except perhaps to the pockets of Big Pharma. There are many reasons this happens. Some patients won’t acknowledge that their death is imminent, and some doctors won’t admit to them that nothing more can be done to contain the disease. Others with unstoppable cancers think that if they hang in there long enough, a new treatment may come along to reverse their fate. And some patients hope to ward off the Grim Reaper until after a special event, like a child’s graduation or wedding or birth of a grandchild. Still others succumb to the urging of family members to try everything modern medicine can offer. Even when people with advanced cancer are relatively healthy, attempting yet another round of treatment often worsens quality of life (QoL) in their final weeks, according to a 2015 study of patients with metastatic solid tumors and a prognosis of six months or less to live. About half the patients ... opted for end-stage chemotherapy. For those who were sickest at the start, QoL in their last week was no worse than if they had skipped further treatment. But among the 122 patients in the best shape initially, QoL was significantly worse for the 56% who opted for further chemotherapy. Holly G. Prigerson of Weill Cornell Medical College, who directed the study, expected the healthier patients to do better and was surprised by the results. As Dr. Charles D. Blanke wrote about the study ... “Chemotherapy is supposed to either help people live better or help them live longer, and this study showed that chemotherapy did neither.” Sometimes, however, chemotherapy or radiation is offered to patients near the end of life to alleviate debilitating symptoms. But the goal of such palliative therapy should be made clear to patients lest it give them false hopes for a cure. https://nyti.ms/2GOeW0x


Assisted (or facilitated) death

Representative sample of recent news media coverage:

• U.S. NEWS & WORLD REPORT | Online – 9 August 2019 – ‘Who uses medical aid to die in Oregon and Washington?’ The outcomes of medical in dying laws in the two states with the longest-running programs in the U.S. show many similarities in who is using the option, a new study finds. With more states implementing laws to assist terminally ill patients in taking their lives, researchers from across the U.S. examined empirical data of Oregon and Washington to find out if there were similarities in who’s asking for and taking medical aid-in-dying prescriptions. The data came from published...
annual reports from the Oregon Health Authority and Washington State Department of Health that ranged from 1998 to 2017 in Oregon and from 2009 to 2017 in Washington. They found that 2,558 – 76% – of the 3,368 written prescriptions resulted in patients’ deaths, with patients more likely to be non-Hispanic white (94.8%) and 65 years or older (72.4%). The most common underlying illnesses were cancer (76.4%), neurologic illness (10.2%), lung disease (5.6%) and heart disease (4.6%), with loss of autonomy, impaired quality of life and loss of dignity the most common reasons reported by clinicians for patients who pursue medical aid in dying. Ages of all participants over the time periods ranged from 20 to 102, and participation was nearly equally split between males and females.


International

Reports highlights impact of A&E admissions on cancer patients

U.K. (Northern Ireland) | Belfast Telegraph – 8 August 2019 – Almost three in four of those who died from cancer in Northern Ireland in 2015 had at least one emergency admission in the last year of their life. Outcomes for more than 4,300 patients were examined in their last year of life by Macmillan Cancer Support and the Northern Ireland Cancer Registry at Queen’s University Belfast in a new report on emergency admissions in 2015. It found that one in six patients died within seven days of their last admission, almost all in hospital despite research showing that most people would prefer to die at home. The report demonstrates the significant pressures on emergency departments within the health and social care system, in supporting the 1 in 4 who currently die of cancer in Northern Ireland. It was also discovered that late diagnosis is an issue, with one in nine people admitted in an emergency receiving a cancer diagnosis the same day. Another quarter were admitted one to three months before their cancer diagnosis. Those with at least one emergency admission were twice as likely to die while in hospital. The report contains recommendations to focus on more “person-centred care” – which includes the early identification of patients who are in their last year of life and continuing to promote early detection of cancer. It also recommended additional training for healthcare professionals to improve advance care planning and establishing a direct point of contact for patients and their carers. http://bit.ly/2yJG787

Specialist Publications

‘Visiting nurses’ perspectives on practices to achieve end-of-life cancer patients’ wishes for death at home: A qualitative study’ (p.11), in Asia-Pacific Journal of Oncology Nursing.

‘Palliative care for people living with heart failure – European Association for Palliative Care Task Force expert position statement’ (p.7), in Cardiovascular Research.

‘Agreement of nursing home staff with palliative care principles: A PACE cross-sectional study among nurses and care assistants in five European countries’ (p.10), in Journal of Pain & Symptom Management.

‘Global survey of the roles, satisfaction, and barriers of home healthcare nurses on the provision of palliative care’ (p.11), in Journal of Palliative Medicine.

‘An analysis of Charlie’s Law and Alfie’s Law’ (p.11), in Medical Law Review.

‘Physician-assisted suicide: Reflections on the possibility of legalization on the basis of the Polish legal system’ (p.15), in Internetowy Przegląd Prawniczy.

Cont
GPs in the U.K. lack sufficient awareness and understanding of living wills

U.K. | Compassion in Dying (London) – Accessed 7 August 2019 – Five themes emerged from the organization’s recent research: 1) GPs had significant gaps in knowledge about advance decisions and how they can benefit people. [This included a lack of awareness that a valid and applicable advance decision (AD) is legally binding and must be followed and, conversely, an assumption it requires the involvement of a solicitor. Some GPs acknowledged their limited knowledge, while others wrongly believed they were well-informed.]; 2) GPs imposed a financial barrier by charging for appointments to discuss advance decisions. [Some GPs classified supporting a person to make an AD as private work that should be charged for.]; 3) GPs felt that conversations about death, dying and planning for the end of life (EoL) would be too upsetting or difficult. (This resulted in some GPs failing to initiate conversations about people’s wishes for EoL care and treatment and opportunities to support people to express their wishes for care and treatment being missed. One GP commented that broaching the topic of an AD or do not attempt resuscitation form would be “opening up a can of worms.”); 4) GPs had negative preconceptions about refusing treatment. (GPs were concerned about repercussions if an AD they supported a person to make was followed at a later date. One worried that “some long lost son is going to turn up and say you got mum to sign this”. Some GPs also felt an AD could be in conflict with their duty to provide medical care.); and, 5) GPs had practical concerns about the ease and process of supporting a person to make an AD. [GPs felt there wasn’t enough time to support someone to make an AD in the standard appointment slot] Download/view report at: http://bit.ly/2YOeDMM

More people are dying from dementia in England and Wales than ever before as official figures also reveal the mortality gap between men and women is shrinking

U.K. (England & Wales) | The Daily Mail (London) – 6 August 2019 – More people than ever died of dementia last year in England & Wales, official statistics have revealed. A total of 69,478 people were killed by the brain-destroying disorder, making up around one in eight of all deaths. Charities have called for better funding from the Government and branded current investment in finding a treatment for the condition “pitiful.” Figures also suggested the life expectancy gender gap, which has seen women traditionally live longer than men, is closing. Figures showing how many people died and what they died of were released today by the Office for National Statistics. The death rate for women has risen for a third time in the past 15 years, while men’s has only risen once during the same time frame. Scientists have for years been scrambling to find a way to treat or prevent Alzheimer’s disease, which accounts for around two thirds of the 50 million dementia patients worldwide. But attempts to tackle the brain-destroying disease have been beset with failures. https://dailym.ai/31ilCLW

N.B. Selected articles on palliative and end-of-life care for people living with dementia noted in 29 July 2019 issue of Media Watch (#624, p.13).
The Royal Commission into Aged Care Quality & Safety has released three more background papers...

AUSTRALIA | Royal Commission into Aged Care Quality & Safety – 5 August 2019 – The fifth, and latest, background paper focuses on advance care planning in Australia, the sixth centres around informal and unpaid carers who are critical for the sector to work efficiently and sustainably, and the seventh background paper summarises the legislative framework for Aged Care Quality & Safety Regulation and the complexities around the current system. The papers are part of a series of background papers the Office of the Royal Commission is issuing following public hearings around the aged care sector. Download/view background papers at: http://bit.ly/2Jf4TDf

Specialist Publications

Forgiveness and reconciliation processes in dying patients with cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 August 2019 – This article … focuses on the end of life, when family conflicts resurface and unfinished business challenges patients and causes spiritual distress. Forgiveness and reconciliation may intensify patient-family relationships and facilitate peace of mind and peaceful death. Existing forgiveness models and interventions focus on coping in life, yet no study has examined forgiveness and reconciliation (F/R) processes until death. Three interdisciplinary units at a major Swiss hospital observed 50 dying patients with cancer experiencing severe conflicts with relatives, themselves, and/or with fate/God. The authors found that conflicts were complex and involved relational, biographical, and spiritual layers. In 62% of patients, F/R processes occurred repeatedly. Many patients died after finding F/R (22 within 48 hours). Patients indicated that imminent death, a mediating third party, acceptance, and experiences of hope motivated them to seek F/R. Although deep relationships may support F/R processes, the limited data on near-death experience/spiritual experiences restrict interpretation. Forgiveness and reconciliation processes oscillate between five phases: 1) Denial; 2) Crisis; 3) Experience of hope; 4) Decision; and, 5) Finding F/R. Understanding F/R processes, empathy, hope, and a neutral third party may support patients in seeking forgiveness. Abstract: http://bit.ly/2YMNxSP

Honoring the moral concerns of caregivers afraid of giving morphine

AMERICAN JOURNAL OF NURSING, 2019;119(8):64-65. Beyond its potential side effects and potency (especially when warnings about opioid medications seem to come daily), many associate morphine’s use in terminally ill patients with the last days of life. Though not necessarily true, it often is. But what people often see, or have heard, is that when morphine is given, patients die soon thereafter. This can create two potential barriers: a belief that morphine kills or a belief that if one agrees to it, she or he is giving up on a loved one, surrendering hope or even displaying insufficient faith in God’s ability to heal. Moreover, for caregivers who are not used to giving medication and who are providing care at home, simply giving morphine with a dropper can be frightening. What if I give the wrong dose? What if she has a bad reaction? What if she dies because of me? What if she goes to sleep and never wakes up again? What if this clouds her mind and I never get to talk with her again? Such moral concerns can activate powerful ideas of loyalty, responsibility, and protectiveness that override education and reassurances from healthcare professionals. If we see resistance to morphine as rooted solely in knowledge deficits, emotions, or misconceptions, we may dismiss caregivers as oppositional or irrational. We may miss these deeper moral imperatives. Full text: http://bit.ly/2YqaFev

Publishing Matters

‘Predatory journals: A potential threat to nursing practice and science’ (p.15), in Critical Care Nursing.
Noted in Media Watch 18 February 2019 (#602, p.13):

- **MEDSCAPE** | Online – 13 February 2019 – ‘Dying at home: The burden of medication management.’ A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home. The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as over-medicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** [https://wb.md/2X43MeD](https://wb.md/2X43MeD)


**Related**

- **TRANSLATIONAL MEDICINE@UNISA**, 2019;19:54-59. ‘Care for carers: An investigation on family caregivers’ needs, tasks, and experiences.’ Family caregivers (FCGs) play a key role in the management of patients and provide some caregiving activities once provided only by professional caregivers. Often they are not adequately trained or prepared, however a systematic assessment of their needs is rarely practiced. For these reasons, this preliminary investigation was designed to better identify the needs and changes in the lifestyles of FCGs of home cancer palliative care. The results confirmed that cancer caregiving is burdensome. Large proportions of caregivers experienced substantial caregiving workload as well as a range of negative consequences, e.g., lack of time for social relations. Furthermore, considerable proportions of caregivers experienced problems or had unmet needs regarding the interaction with health care professionals. **Full text:** [http://bit.ly/31UkbN](http://bit.ly/31UkbN)

“...I go into crisis when ...”

**Ethics of care and moral dilemmas in palliative care**

*BMC PALLIATIVE CARE* | Online – 9 August 2019 – The results of this study suggest that for health professionals (HPs) recognizing moral principles, dealing with ethical dilemmas and giving importance to dialogue and communication is paramount in the care relationship. This requires developing and implementing effective educational programs focused on step-by-step moral training. The program should include at least the following objectives: empowering HPs with the ability to recognise ethical dilemmas and analyse conflicts; promoting sensitiveness to principles, values, goals and wishes of patients; and, ensuring the ability of HPs to come to reasoned decisions in daily clinical practice. Different ethical approaches can help in reaching the objectives described; the ethics of care framework also includes the belief systems of HPs; moreover, it allows the values of the patients and HPs to come to light through the relationship of care. **Full text:** [http://bit.ly/2MTN1y](http://bit.ly/2MTN1y)

**Palliative care after the Liverpool Care Pathway: A study of staff experiences**

*BRITISH JOURNAL OF NURSING*, 2019;28(15):1001-1007. The objective of this study was to explore nurses’ perceptions of end-of-life care following the withdrawal of the Liverpool Care Pathway (LCP). Thirteen semi-structured interviews were conducted with nurses working in palliative care (PC). Three themes emerged: 1) Perceptions of the LCP; 2) Prevailing issues; and, 3) Patients’ and families’ experiences. This study suggested that the removal of the pathway has not remedied the issues attributed to it. Further, the way in which the LCP was removed indicates that the non-expert media can play a negative role in how palliative care (PC) is perceived, which inhibits the care process. In this respect it is important that “insider” voices are also heard, in order to educate and also redress disinformation. Similarly, broader, persisting, contextual challenges facing staff need addressing in order to prevent a repeat of the issues leading to the removal of the LCP. **Abstract:** [http://bit.ly/2M9ivm5](http://bit.ly/2M9ivm5)

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Noted in Media Watch 5 March 2018 (#553, p.13):

- **WELLCOME OPEN RESEARCH | Online – Accessed 27 February 2018 – ‘The Liverpool Care Pathway for the Dying Patient: A critical analysis of its rise, demise and legacy in England.’** The Liverpool Care Pathway for the Dying Patient (“the LCP”) was an integrated care pathway recommended by successive governments in England & Wales to improve end-of-life care (EoLC), using insights from hospice and palliative care. It was discontinued in 2014 following mounting criticism and a national review. The ensuing debate among clinicians polarised between “blaming” of the LCP and regret at its removal. The authors aimed to address three questions: 1) Why and how did the LCP come to prominence as a vehicle of policy and practice; 2) What factors contributed to its demise; and, 3) What immediate implications and lessons resulted from its withdrawal? **Full text:** [http://bit.ly/2ZIiYyY](http://bit.ly/2ZIiYyY)

A critical perspective on advance care planning for older people

**BRITISH JOURNAL OF SOCIAL WORK | Online – 8 August 2019 – How older people plan ahead for ageing in relation to accommodation, care arrangements, healthcare and medical treatment, and end of life decisions has attracted particular attention in recent years and as a result there has been considerable promotion of the importance of planning ahead and executing planning instruments with the aim of making one’s wishes and preferences known in advance. Planning ahead is promoted as allowing older people to have their voices heard, to advance their autonomy, choice and self-determination and to allow them to decide what treatment they may not want to receive. This article provides a critique of advance care planning (ACP), based on a subset of findings from a qualitative intergenerational study on ageing in Australia. The findings suggest that ACP is a much more complex and at times problematic endeavour, compared to what is promoted about ACP, in particular with regard to the use of planning instruments.** **Abstract:** [http://bit.ly/2ZNqUFI](http://bit.ly/2ZNqUFI)

**Related**

- **JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 5 August 2019 – ‘Would you be surprised if this patient died this year? Advance care planning in substance use disorders.’** Though substance use disorders (SUDs) are widely acknowledged to be chronic diseases associated with an increased risk of mortality, there has been little discussion on advance care planning (ACP) in this population. Studies in other vulnerable populations have shown that marginalized and high-risk individuals may be less likely to receive ACP. Similarly, patients with SUDs may employ different decision-makers than that defined by law (i.e., friend vs. family member), increasing the importance of discussing patient values and social structure. Physicians should routinely conduct ACP conversations with patients with SUDs, especially those with chronic, progressive medical conditions and/or severe, uncontrolled substance use disorders. **Abstract:** [http://bit.ly/2Ysco2Z](http://bit.ly/2Ysco2Z)

**N.B.** Additional articles on terminal ill patients with drug and alcohol addictions noted in 15 July 2019 issue of Media Watch (#622, pp.9-10).

Palliative care for people living with heart failure – European Association for Palliative Care Task Force expert position statement

**CARDIOVASCULAR RESEARCH | Online – 6 August 2019 – Contrary to common perception, modern palliative care (PC) is applicable to all people with an incurable disease, not only cancer. PC is appropriate at every stage of disease progression, when PC needs emerge. These needs can be of physical, emotional, social or spiritual nature. This document encourages the use of validated assessment tools to recognise such needs and ascertain efficacy of management. PC interventions should be provided alongside cardiologic management. Treating breathlessness is more effective, when cardiologic management is supported by PC interventions. Treating other symptoms like pain or depression requires predominantly PC interventions. Advance care planning aims to ensure that the future treatment and care the person receives is concordant with their personal values and goals, even after losing decision-making capacity. It should include also disease specific aspects, such as modification of implantable device activity at the end of life.**

Cont.
The “whole person care” concept describes the inseparability of the physical, emotional and spiritual dimensions of the human being. Addressing psychological and spiritual needs, together with medical treatment, maintains personal integrity and promotes emotional healing. Most PC concerns can be addressed by the usual care team, supported by a PC specialist if needed. During dying, the persons’ needs may change dynamically and intensive PC is often required. Following the death of a person, bereavement services benefit loved ones. The authors conclude that the inclusion of PC within the regular clinical framework for people with heart failure results in a substantial improvement in quality of life as well as comfort and dignity whilst dying. Abstract: http://bit.ly/30UYOSz

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

Noted in Media Watch 29 July 2019 (#624, p.7):

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 July 2019 – ‘Clinician barriers and facilitators to heart failure advance care plans: A systematic literature review and qualitative evidence synthesis.’ The main barriers were lack of disease-specific knowledge about palliative care in heart failure, high emotional impact on clinicians when undertaking advance care planning (ACP), and lack of multidisciplinary collaboration between healthcare professionals to reach consensus on when ACP is indicated. The main facilitators were being competent to provide holistic care when using ACP in heart failure, a patient taking the initiative of having an ACP conversation, and having the resources to deliver ACP at a time and place appropriate for the patient. Abstract: http://bit.ly/30UYOSz

Noted in Media Watch 22 July 2019 (#623, p.13):

- PALLIATIVE MEDICINE | Online – 15 July 2019 – ‘Multi-disciplinary palliative care is effective in people with symptomatic heart failure: A systematic review and narrative synthesis.’ Overall, the results of this review support the use of multi-disciplinary palliative care in people with advanced heart failure, but trials do not identify who would benefit most from specialist palliative referral. There are no sufficiently robust multi-centre evaluation phase trials to provide generalisable findings. Use of common population, intervention and outcomes in future research would allow meta-analysis. Abstract: http://bit.ly/2GdC5i

N.B. Additional articles on palliative care for patients living with heart failure noted in 27 May 2019 issue of Media Watch (#615, pp.9-10).

Trends and racial disparities of palliative care use among hospitalized patients with end-stage kidney disease on dialysis

JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY | Online – Accessed 7 August 2019 – Studies have shown significant racial and ethnic disparities in the end-of-life care received by dialysis patients with end-stage kidney disease in the U.S., but little is known about disparity in the palliative care (PC) services received by such patients in the inpatient setting. This retrospective cohort study of 5,230,865 hospitalizations of patients on dialysis found that, despite a significant increase in use of PC services from 2006 through 2014, such services remained underused. Black and Hispanic patients were less likely than white patients to receive PC services in the hospital, disparities that persisted in all hospital sub-types, including hospitals with a high proportion of minority patients. These results complement previous findings and highlight the importance of further investigation of systemic issues contributing to barriers and racial disparities in PC use. Abstract: http://bit.ly/2GT8oO1

N.B. Additional articles on palliative and end-of-life care for people living with chronic kidney disease noted in 18 February 2019 issue of Media Watch (#602, p.15). Additional articles on ethnic and racial disparities in the provision and delivery of PC in the U.S. noted in 8 July 2019 issue of Media Watch (#621, p.7).
Quality of spiritual care at the end of life: What the family expects for their loved one

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 5 August 2019 – Spiritual care at the end of life (EoL) is a “keystone” investment at any Regional Tertiary Acute Care Hospital. Spiritual Care Departments need to demonstrate quality indicators in the provision of spiritual care at an EoL not only for their patients, but to satisfy family expectations of that care for their loved one. A fixed choice survey instrument using a structured interview via telephone was utilized for 202 criterion families who had lost a loved one. Three domains surfaced: 1) Families retained traditional chaplain role expectations of priestly/liturgical (78.6%) and pastoral/shepherd (67.5%); 2) Expectations of an expanded chaplain role after the EoL (50%); and, 3) Traditional spiritual care services regardless of one’s religion or spirituality: Comfort and care, emotional support (96%); active listening (96.5%); the Chaplain as a reminder of God’s presence (93.6%); prayer (96%); scripture reading (69.3%); and ritual/sacramental anointing of the sick (71.3%).


N.B. Scroll down to ‘Media Watch: Spiritual Care.’

Noted in Media Watch 24 June 2019 (#619, p.10):

- PATIENT EDUCATION & COUNSELING | Online – 19 June 2019 – ‘How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt list?’ Palliative care (PC) patients were randomised to either receive a question prompt list (QPL) prior to a consultation or not, to see whether its provision influenced patients'/caregivers’ questions and discussion of topics relevant to end-of-life care during consultations with a PC physician. Spirituality was discussed in half the consultations. Patients receiving a QPL discussed spirituality 1.38 times more than controls. Abstract: http://bit.ly/2Ku6JSr

N.B. Additional articles on spirituality in the context of PC noted in this issue of Media Watch.

Patient’s perspectives on the notion of a good death: A systematic review of the literature

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 August 2019 – There is no clear definition of what constitutes a good death or its features. Patients, caregivers, physicians and relatives have different notions of a good death. Discussions have been driven by academic perspectives, with little research available on the patients’ perspectives. 2,652 titles were identified; after elimination of duplicates, screening and final selection, 29 relevant publications remained for analysis. Sample populations included patients with terminal diseases (AIDS, cardiovascular disease, and cancer). Core elements for a “good death” included control of pain and symptoms, clear decision-making, feeling of closure, being seen and perceived as a person, preparation for death, and being still able to give something to others; while other factors such as culture, financial issues, religion, disease, age, and life circumstances were found to shape the concept across groups. Studies agree on the individuality of death and dying while revealing a diverse set of preferences, regarding not only particular attributes but also specific ways in which they contribute to a good death. Although sharing common core elements, patient’s notions of good death are individual, unique and different. They are dynamic in nature, fluctuating within particular groups and during the actual process of dying. Abstract (w. link to references): http://bit.ly/2Kp3DxS
Agreement of nursing home staff with palliative care principles: A PACE cross-sectional study among nurses and care assistants in five European countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 31 July 2019 – Given the rise of chronic diseases and complex care needs among nursing home residents, optimal palliative care (PC) in this setting is essential. To be able to provide high-quality PC to a growing number of nursing home residents, nursing home staff need to possess at least a basic level of understanding of PC. This study shows that the extent of agreement of nursing home staff with the basic principles of PC differs between countries, with room for improvement in all. For that reason, PC needs to become an integral part of all nursing school curricula and healthcare trainings, as well as of continuing education programme offerings. Also, a cultural shift regarding PC in nursing homes is needed. Most staff in all countries agreed that PC involves more than pain treatment (58% Poland to 82% Belgium) and includes spiritual care (62% Italy to 76% Belgium) and care for family or relatives (56% Italy to 92% Belgium). Between 51% (Netherlands) and 64% (Belgium) correctly disagreed that PC should start in the last week of life and 24% (Belgium) to 53% (Poland) agreed that PC and intensive life-prolonging treatment can be combined. The overall agreement score ranged between 1.82 (Italy) and 3.36 (England). Older staff, nurses, and staff who had undertaken PC training scored higher. Full text: http://bit.ly/2GHHdWf

Noted in Media Watch 9 July 2018 (#571, p.14):

- PALLIATIVE MEDICINE | Online – 4 July 2018 – ‘The palliative care knowledge of nursing home staff: The European Union FP7 PACE cross-sectional survey in 322 nursing homes in six European countries.’ Although the authors found that many problematic issues are the same across countries, huge heterogeneity persists even after adjusting for confounders. Knowledge about basic palliative care (PC) issues is generally poor among nurses and care assistants in all countries, but particularly so in Poland and in Italy. A White Paper of the European Association for Palliative Care on PC education identifies nursing homes as a setting in which the staff, irrespective of their discipline, need to know the basic principles of PC.¹ Full text: http://bit.ly/2NjCKif


TeamTalk: Interprofessional team development and communication skills training

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 August 2019 – The purpose of this article is to report on the development, exploratory outcomes, and lessons learned from a pilot project, ‘TeamTalk,’ which adapted VitalTalk methodology for interprofessional learners. TeamTalk included a series of interactive workshops led by an interprofessional faculty team at a health sciences university. Teaching methods were small group discussion, reflection, and high-fidelity simulated patient/family encounters, using a “Skills and Capacities” handout. Sixty-one learners participated in TeamTalk over two academic years. Attitudes toward interprofessional collaboration improved from pre- to post-test … with no difference among the professional groups. Self-confidence for interprofessional communication improved in “eliciting the contributions of colleagues, including those from other disciplines” … for all learners during year two; chaplains improved in the greatest number of areas (15/19), followed by nurses (7/19) and physicians (4/19). Learners expressed appreciation for the opportunity to explore their professional roles together with other professions. Preliminary findings indicate that TeamTalk improved attitudes toward interprofessional collaboration and self-confidence for participating on an interprofessional team. The lessons derived from creating and implementing this course may be applicable to interprofessional education in serious illness management. Abstract: http://bit.ly/2yDrjYO

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 beginning on p.16.
Global survey of the roles, satisfaction, and barriers of home healthcare nurses on the provision of palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 August 2019 – The World Health Assembly urges members to build palliative care (PC) capacity as an ethical imperative. Nurses provide PC services in a variety of settings, including the home and may be the only healthcare professional able to access some disparate populations. Identifying current nursing services, resources, and satisfaction and barriers to nursing practice are essential to build global PC capacity. Five hundred thirty-two home healthcare nurses in 29 countries participated in a survey. Nurses from developing countries performed more duties compared with those from high-income countries, suggesting a lack of resources in developing countries. Significant barriers to providing home care exist: personnel shortages, lack of funding and policies, poor access to end-of-life or hospice services, and decreased community awareness of services provided. Respondents identified lack of time, funding, and coverages as primary educational barriers. In-person local meetings and online courses were suggested as strategies to promote learning. It is imperative that home healthcare nurses have adequate resources to build PC capacity globally, which is so desperately needed. Nurses must be up to date on current evidence and practice within an evidence-based PC framework. Healthcare policy to increase necessary resources and the development of a multi-faceted intervention to facilitate education about PC is indicated to build global capacity. **Abstract:**  

Related

- **ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING, 2019;6(4):389-396.** ‘Visiting nurses’ perspectives on practices to achieve end-of-life cancer patients’ wishes for death at home: A qualitative study.’ This study found that the participants advocated for the patient’s views about continuing homecare until death while coordinating views between the patient and their family; they further supported the patient’s daily life while helping them prepare for death to achieve their wish for death at home. In addition, authors study uncovered the visiting nurses’ unconscious practical wisdom of using humorous responses to death-related work to alleviate the patients’ feelings of hopelessness. To develop practical wisdom for using humor effectively in end-of-life care, nurses need to verbalize unconscious practices, and accumulate empirical knowledge about nursing interventions using humor, including cultural attitudes, through case study analysis. **Full text:** http://bit.ly/2Kjx04F

- **MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 5 August 2019 – ‘A gap between the philosophy and the practice of palliative healthcare: Sociological perspectives on the practice of nurses in specialised palliative homecare.’** Palliative care philosophy is based on a holistic approach to patients, but research shows that possibilities for living up to this philosophy seem limited by historical and administrative structures. From the nurse perspective, this article explore nursing practice in specialised palliative homecare, and how it is influenced by organisational and cultural structures. The findings show that nurses consolidate the doxa of medicine, including medical-professional values that configure a control-oriented, positivistic approach, supported by the organising policy for clinical practice. **Full text:** http://bit.ly/2MJ1AX3

An analysis of Charlie’s Law and Alfie’s Law

MEDICAL LAW REVIEW | Online – 4 August 2019 – The Charlie Gard and Alfie Evans cases were high-profile cases involving disagreements between the parents of young infants and medical practitioners, which have given impetus to pre-existing calls for law reform that have been rebranded as ‘Charlie’s Law’ and ‘Alfie’s Law.’ The author argues against the proposal to replace the best interest test, which is currently determinative in such contentious cases, with a significant harm test, as it would render U.K. law divergent from international law. He also employs critical theory to rebut the notion that parents are the best decision makers and refute criticisms of clinicians (who reflexively acknowledged the limits of medicine). The author utilises theories of distributive justice to demonstrate that legal reform may exacerbate unfairness, and case law to show that it may be unworkable. Nonetheless, he applies critical and Fou-
cauldian theory to critique the lack of patient and public empowerment within the National Health Service (NHS) and endorses the proposal to ensure that mediation is offered in contentious cases, as this may empower patients and their carers. The author also avers that the best interests test should be informed by clearer criteria regarding the allocation of finite resources, which the public should influence via the democratisation of the NHS. **Abstract:** [http://bit.ly/2KpGqdK](http://bit.ly/2KpGqdK)

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. **Abstract:** [http://bit.ly/2T4Zwd6](http://bit.ly/2T4Zwd6)

Noted in Media Watch 11 February 2019 (#601, p.10):

- **JOURNAL OF MEDICAL LAW & ETHICS, 2018;6(1):41-53.** ‘Can “medical futility” conflicts be mediated?’ Mr. Justice Francis ended his judgment in *Great Ormond Street Hospital v Yates, Gard and Gard* with the recommendation that “mediation should be attempted in all cases such as this one.” Although this gave the impression that mediation would be unquestionably beneficial in the Gard case and other “medical futility” cases where the patient is incompetent, the author contends this is not as straightforward as it might at first appear. With the general absence of a middle ground and with the law in such cases frequently on doctors’ side, mediation’s potential for a satisfactory resolution of medical futility conflicts is arguably limited. **Abstract:** [http://bit.ly/2Dpp50W](http://bit.ly/2Dpp50W)

**N.B.** Selected articles on the Charlie Gard case noted in 3 December 2018 issue of Media Watch (#592, pp.12-13).

**Going home to die from critical care: A case study**

*NURSING IN CRITICAL CARE,* 2019;24(4):235-240. Much of the activity in critical care is complex but repetitive. In order to standardize care and maintain safety, delivery of care is often directed by protocols and care bundles. This case study will reflect on an instance where care transcended the standard protocol-directed path to be more individualized, creative and compassionate. Acts like these can be unique for the practitioners involved and require an element of positive risk taking, which happened here. It will look at the decision-making, planning and risk involved in preparing for a terminally ill patient, who was inotrope and high-flow oxygen dependent, to go home to have treatment withdrawn there instead of in the hospital. This was to fulfill his wish to die at home. In unpicking the circumstances where this positive risk taking led to the desired outcome and the relationship between safety, uncertainty and risk, three themes arose. These were the journey to safe uncertainty; decision-making with uncertain outcomes; and the importance of robust human factors, particularly effective communication and inter-professional teamwork. If positive risk taking can result in enhanced outcomes for the patient, then the question of how this behaviour can be fostered and encouraged must be addressed. **Abstract:** [http://bit.ly/2YKvpwL](http://bit.ly/2YKvpwL)

Special issue on bereavement care

Related

- DEATH STUDIES | Online – 7 August 2019 – ‘How do family members experience drug death bereavement? A systematic review of the literature.’ Despite high rates of drug-related deaths (DRDs), drug-related bereavement has been sparsely investigated. Three themes emerged from the thematic analysis – 1) Emotional roller coaster; 2) Lack of understanding by the social world; and, 3) Meaning making – describing an emotional and existential overload, stigmatization and lack of understanding and help from support systems. The results also shed light on life after the loss. Directions for further research were subsequently outlined. Abstract: http://bit.ly/2GSC5Pa

- JOURNAL OF LOSS & TRAUMA | Online – 5 August 2019 – ‘The psychosocial variations in grieving parental and spousal death.’ The existing literature on grief, bereavement, and mourning lacks analyses on the differences in grief caused by parental and spousal deaths. This study intended to measure the same by involving 546 purposively selected participants. Section 5 of the Grief Evaluation Measure was used to gather data. No significant differences were found in grieving parental and spousal deaths. The study also analyzed the differences in grieving on the bases of gender, age, religiosity, social interaction, and occupation, and found significant variations in grieving. Abstract: http://bit.ly/2YGmJHX

The medicalisation of the dying self: The search for life extension in advanced cancer

NURSING INQUIRY | Online – 9 August 2019 – Although many studies have previously examined medicalisation, the authors add a new dimension to the concept as they explore how contemporary oncological medicine shapes the dying self as predominantly medical. Through an analysis of multiple case studies collected within a comprehensive cancer centre in Ontario, Canada, the authors examine how people with late-stage cancer and their healthcare providers enacted the process of medicalisation through engaging in the search for oncological treatments, such as experimental drug trials, despite the incurability of their disease. They propose that searching for life extension enact medicalisation by shaping the dying person afflicted with terminal cancer into new medical subjectivities that are knowledgeable, active, entrepreneurial and curative. Participants initially took up medical thinking from the formal oncology system, but then began to apply and internalise medical rationalities to alter their personhood, thereby generating new curative possibilities for themselves. For people seeking life extension, the embodied and day-to-day experiences of suffering and being close to death became expressed and moderated in fundamentally medicalised terms. Abstract: http://bit.ly/2yRB1p7

Attitudes towards the dying and death anxiety in acute care nurses – can a workshop make any difference? A mixed-methods evaluation

PALLIATIVE & SUPPORTIVE CARE | Online – 6 August 2019 – In Singapore, the core curriculum for end-of-life (EoL) care used in nurse training courses is limited. Only 45% of nurses indicated familiarity with inpatient palliative care (PC). Nurses who lack skills in PC may develop anxiety and negative attitudes towards caring for dying patients. Forty-five nurses participated in a two-day workshop. Six weeks post-workshop, in-depth interviews were conducted. There was a significant improvement in nurses' knowledge score and reduction in their death anxiety score. Fear of death and death avoidance subscores decreased significantly. However, domains such as neutral acceptance, approach acceptance, and escape acceptance did not show any significant difference, although escape acceptance showed a trend towards a reduced score. After the workshop, more nurses adopted the neutral acceptance stance (76.2%), and none of them fell into the fear of death sub-domain. Most nurses interviewed reported a positive change in their knowledge, attitudes, and practice even after the workshop. The positive change in nurses’ attitudes and practices were noted to be sustained for at least six weeks after the intervention. Abstract (w. list of references): http://bit.ly/2yJzlR

Would this article be of interest to a colleague?
Palliative care in the U.S.

Palliative care: Special issue

PRIMARY CARE: CLINICS IN OFFICE PRACTICE, 2019;46(3). The nation’s population is aging, and the cultural and social diversity in our country is steadily increasing. More and more people are suffering with multiple chronic complex illnesses. In addition to this, we have increasing numbers of people who are suffering from functional decline, frailty, debility, and dementia. The complexities of caring for our elderly put an increasing strain on our healthcare system, and much of this burden is placed on our primary care providers. The need to educate our providers on the care of these individuals is paramount to ensuring the quality of care that our elderly require and deserve for a fulfilling life. It is essential that our primary care providers maintain the continuity of care relationship with the patient and their families. This will ensure that the best possible care is given and that the wishes of our patients are met as they approach the end of life. The scope and practices of the field of hospice and palliative care medicine are well suited to the work of our primary care providers. Essential skills, such as basic pain and symptom management, communication, prognostication, and advance care planning, are core competencies for all of our primary care clinicians.


Noted in Media Watch 1 April 2019 (#608, p.12):

- JOURNAL OF PALLIATIVE MEDICINE | Online – 29 March 2019 – ‘Predicting those who are at risk of dying within six to twelve months in primary care: A retrospective case-control general practice chart analysis.’ The most predictive patient characteristics of a risk of death within 6 to 12 months were: deteriorating performance status, weight loss, persistent symptoms, request for palliative care or treatment withdrawal, impaired activities of daily living, falls ± fractured hip, neurological deterioration, advanced lung disease, and estimated glomerular filtration rate with deteriorating health. The Supportive & Palliative Care Indicators Tool demonstrated a sensitivity and specificity of 67% and 87%, respectively, with a predictive accuracy of 78%. Abstract: http://bit.ly/2uBWC4a

Noted in Media Watch 11 March 2019 (#605, p.6):

- BMC FAMILY PRACTICE | Online – 5 March 2019 – ‘Recruiting general practitioners for palliative care research in primary care: Real-life barriers explained.’ Recruitment in primary palliative care research is difficult for many reasons. This study shows a high level of interest from the GPs to be involved, but also produced high GP dropout rates and low data completion. Suggestions for future recruitment and quality improvement efforts in this field are formulated. The key is to offer a well-defined intervention which clearly benefits the GPs and/or the patients and a well-designed research protocol which takes the research burden as much as possible away from GPs and patients. Full text: http://bit.ly/2H61nLE

Assisted (or facilitated) death

Representative sample of recent journal articles:

- BMJ SUPPORTIVE & PALLIATIVE CARE – 7 August 2019 – ‘Restricting conversations about voluntary assisted dying: implications for clinical practice.’ On 19 June 2019, assisted dying became lawful in Victoria, the second most populous state in Australia. Section 8 of the Voluntary Assisted Dying Act is a legislative safeguard that is designed to ensure a patient’s request for assistance to die is voluntary. This section prohibits health practitioners from initiating a conversation about assisted dying with the patient. This article explores the potential implications of this prohibition for effective communication between doctors and their patients, and the ability of doctors to provide high quality end-of-life (EoL) care in some cases. Contemporary literature suggests that open and honest communication between doctor and patient including the provision of information about all EoL options when sought by
the patient represents good practice and will lead to optimal EoL care. The provision of such information also reflects professional, ethical and legal norms. Despite (arguably) promoting an appropriate policy objective, the legislative prohibition on health professionals initiating conversations about voluntary assisted dying may, in cases where patients seek information about all EoL options, lead to less optimal patient outcomes. Abstract: http://bit.ly/2YV5DBZ

- **DEATH STUDIES** | Online — 7 August 2019 — ‘Determinants of unbearable suffering in hospice patients who died due to euthanasia: A retrospective cohort study.’ The four dimensions of suffering (physical, psychological, social, and existential) were used as a framework. Twenty-eight patients (5% of all admitted patients in nine years) were included. Most indicated 3-5 determinants, predominantly a combination of physical (96% of patients) and existential determinants (89%). Fatigue, anorexia, and dry mouth were the most prevalent and severe symptoms. Psychological (21%) and social determinants (4%) were much less often described. The results of this study may be used to assess determinants playing a role in euthanasia requests. Full text: http://bit.ly/2TpRs77

- **INTERNETOWY PRZEGŁAD PRAWNICZY,** 2019;46(2):89-96. ‘Physician-assisted suicide: Reflections on the possibility of legalization on the basis of the Polish legal system.’ Physician-assisted suicide is one of the current moral dilemmas around which a debate in contemporary countries is conducted. This debate, with increasing intensity, also takes place in Poland. The article in the first part focuses on explaining the concepts relevant to the debate, proper understanding of which is necessary for further consideration. Then the article makes an attempt to present and evaluate arguments raised by supporters and opponents of legalization of this procedure. The text also touches upon the issue of Polish legal regulations focused on this subject as well as problems and difficulties, which are necessary in the context of Polish debate on medically assisted suicide and is a prerequisite for further consideration of possibility of legalization of this procedure in the Polish legal system. Abstract: http://bit.ly/337pNh

N.B. Click on ‘Open/View’ to access full text in English.

**Publishing Matters**

Predatory journals: A potential threat to nursing practice and science

**CRITICAL CARE NURSING,** 2019;39(4):9-11. Even experienced authors are challenged by the volume and questionable legitimacy of emails from predatory journals. First, it is important to recognize that these emails are automated, similar to robocalls and texts. Automated web crawlers locate authors’ email addresses by trolling a variety of websites to obtain author information. Second, publication ethics do not permit a duplicate article on the same topic, also known as redundant publication. If the results and discussion sections look the same in 2 articles, they have too much similarity and cannot be published again in another journal. Unless you are an experienced author with a program of research or clinical expertise, emails that look too exciting to be true, probably are. Most predatory journals appear to be more interested in profit than in the quality of scientific dissemination. They often do not comply with typical editing and publishing standards. No formal peer-review and/or editing process may exist, which lowers the quality of the publications. In a study of 358 randomly selected articles from predatory nursing journals, investigators found that fewer than 4% were considered to be excellent quality. Forero et al also questioned whether inadequate peer review may lead to published findings that are potentially harmful to patients. Full text: http://bit.ly/2GLOS6c


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

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing … and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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Something Missed or Overlooked?

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

Media Watch: Access on Online

International


[Scroll down to ‘Media Watch: Spiritual Care’]


Cont.
World Hospice & Palliative Care Day 12 October 2019

The theme ‘My Care, My Right’ aims to communicate that palliative care (PC) can be demanded by the public – and that, together, every person impacted by a life limiting illness can influence their policy makers to prioritize PC financing under universal health coverage. http://bit.ly/2RMImQK

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