Media Watch...

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

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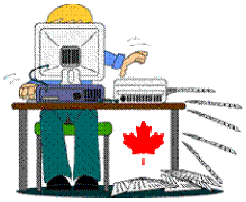

Compiled & Annotated by Barry R. Ashpole

Transitions at the end of life: Scroll down to Specialist Publications and 'Risk factors for hospitalization of home hospice enrollees: Development and validation of a predictive tool' (p.5), in *American Journal of Hospice & Palliative Medicine*.

Canada

Fixing care for seniors will help Canada's entire health system

SASKATCHEWAN | *The Regina Leader-Post* – 18 July 2016 – Health care now consumes half of provincial revenues because we are getting older. Statistics Canada reported last fall that there are more Canadians over the age of 65 than kids under 15. Some 16.1% of us make up that age group; by 2051, it will be one in four. How is our health care system coping? Our hospitals are now filled with more and more seniors not requiring acute care, but because Canada doesn't have enough long-term care (LTC) facilities or home-care services for aging baby boomers requiring chronic care, they have nowhere else to go. Hospitals are not supposed to be in the housing business. Yet 16% of hospital beds – at a cost of more than $800 per day – are tied up with seniors waiting for someplace to go. The Canadian Medical Association believes that $2.3 billion-a-year price tag could be better spent if seniors got the care they needed in LTC or through home and community care. The federal government's plans to have a new health accord by the end of the year are most opportune. http://goo.gl/nvdedE

Extract from *The Regina Leader-Post* article

As federal Health Minister Jane Philpott has noted, proper home care must include palliative and end-of-life care.

Specialist Publications

'Dying and death within the culture of long-term care facilities in Canada' (p.8), in *International Journal of Older People Nursing.*

N.B. Additional articles on the need for a new health accord between the federal and the provincial and territorial governments are noted in Media Watch, 11 July 2016, #470 (p.2), and 4 July 2016, #469 (p.1). And, selected articles on meeting the present and future needs in long term care in Canada are noted in Media Watch, 18 July 2016, #471 (p.2).

Cont.

Related

- ONTARIO | CTV News (Toronto) – 19 July 2016 – **'Ontario provides $100 million for homecare clients and their caregivers.'** Health Minister Eric Hoskins says $80 million will help provide 350,000 hours of additional nursing care in the home for patients and 1.3 million additional hours of personal support. The other $20 million will be used to provide another 600,000 hours of respite services for caregivers and another 100,000 hours of rehabilitation. http://goo.gl/L4qFjd

- ONTARIO | *The Toronto Star* – 18 July 2016 – **'Immigrant seniors face unequal access to home care: Report.'** Immigrant seniors are less likely than their Canadian counterparts to receive government-funded home care and must count on family, friends and neighbours for help, a new study finds.[1] Access to these services ... also varies drastically among newcomer communities, with visible minority groups least likely to be served, says the report. https://goo.gl/VxurHw

    1. 'Ensuring Healthy Aging for All: Home Care Access for Diverse Senior Populations in the Greater Toronto Area,' The Wellesley Institute, July 2016. http://goo.gl/29nKtZ

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- TORSTAR NEWS SERVICE | Online – 17 July 2016 – **'Provinces vary on ensuring access to assisted dying.'** Some provinces have neglected or been slow to adopt a recommended measure to ensure patients wanting an assisted death can get it and that doctors who offer it are sheltered from professional stigma and physical threats, a review by Torstar News Service has found. One month after the controversial law was adopted, only a few jurisdictions – Alberta, Ontario, Manitoba, New Brunswick and Northwest Territories – have such a centralized service in place. Some, including Saskatchewan and Prince Edward Island, are compiling lists of doctors who would be willing to administer a deadly drug cocktail upon request from a terminally ill patient who meets the legal requirements. In Quebec, where doctor-assisted death has been legal since December, it is the responsibility of doctors who refuse to perform the procedure to refer their patient to another physician. The Quebec and Nova Scotia health ministries confirmed they have no central referral service. Without coordination agencies, health officials fear a scenario in which terminally ill patients and their families have to shop around for a physician willing to fulfill their wishes. http://goo.gl/uF0NlR

U.S.A.

Thinking about dying, even when the doctor has no time for it

MASSACHUSETTS | WBUR-FM (Boston) – 20 July 2016 – I care deeply about learning what my patients want, but sometimes there just isn't time. This is an everyday failure in health care – one that can have tragic consequences. The vast majority of patients haven't told their doctor what kind of care they want at the end of life, which means some could be put on a breathing machine even if they might not have wanted it. Still other patients could receive care that's less aggressive than they want. A recent survey suggests why: 66% of primary physicians and specialists in California said they didn't have enough time to talk about end-of-life decision-making in their hospitals and clinics.[1] Organized efforts ... encourage patients to express and document their final wishes. But none of this changes the fact that American doctors struggle to order the right tests, prescribe the right medicines, and give the right shots and still have time left to talk with patients about their end-of-life wishes. http://goo.gl/NovjTF

Specialist Publications

'Beyond "rationing" and "death panels": The potential "escape fire" of palliative care' (p.8), in *Critical Care Medicine*.

1. 'Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?' John A. Hartford Foundation, California Health Care Foundation & Cambia Health Foundation, April 2016. [Noted in Media Watch, 18 April 2016, #458 (p.3)] http://goo.gl/NTzOpZ

International

Analgesic "road map" gives hope for better palliative care in Russia

RUSSIA | *Russia Beyond the Headlines* – 22 July 2016 – The Russian government has adopted a "road map" for increasing accessibility to drugs and psychotropic substances for providing patients with painkillers. Experts believe that this is a strategically important step for constructing a system of palliative care in Russia. http://goo.gl/JPVyIF

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

- *БЮЛЛЕТЕНЬ МЕДИЦИНСКИХ ИНТЕРНЕТ-КОНФЕРЕНЦИЙ* | Online – 10 September 2014 – **'Palliative medicine: Overview and statistics.'** Palliative care developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. http://goo.gl/oiFF5E

  N.B. Russian language article.

End-of-life care in England

Charity calls for radical changes in support for end-of-life care

U.K. (England) | National Council for Palliative Care (NCPC) – 19 July 2016 – The Council is calling for radical changes in the way that communities support bereaved and dying people. The call follows the evaluation of earlier work by eight "pathfinder" groups aiming to develop compassionate communities.[1] The evaluation was published in conjunction with new guidance supporting community development in end-of-life care (EOLC).[2] This contains practical advice for community development in EOLC with case studies and practical ideas for working with hospices, hospitals, Health & Wellbeing Boards, Clinical Commissioning Groups in rolling out community development in EOLC. Simon Chapman, Director of Policy & External Affairs for the NCPC, said "taken together these two documents point us towards radical changes in community support for bereaved and dying people. We need to recognise dying, death and bereavement as being much more than just medical happenings, and re-imagine the role we all have to support each other as we go through these experiences, which are an inevitable part of life. The pathfinder projects have shown how relevant and supported local initiatives can make a difference to their areas. Although each had both good and bad experiences, overall we see there is a real need for these activities, and that the only limitation is the resources available. At the same time, the guidance on Ambition 6 adds further practical advice." http://goo.gl/hrGVoj

Specialist Publications

'End-of-life planning with frail patients attending general practice: An exploratory prospective cross-sectional study' (p.7), in *British Journal of General Practice*.

'Embracing inherent uncertainty in advanced illness' (p.7), in *The British Medical Journal*.

1. 'Dying Well Community Charter Pathfinder Project,' National Council for Palliative Care, July 2016. http://goo.gl/bdgG9S
2. 'Each Community is Prepared to Help: Community Development in End-of-Life Care: Guidance on Ambition Six,' National Council for Palliative Care, Hospice UK & Public Health Palliative Care UK, July 2016. http://goo.gl/GhoC2q

N.B. Public health palliative care and community development approaches were recommended in Ambition 6, 'Every Community is Prepared to Help' of 'Ambitions for Palliative & End-of-Life Care: A National Framework for Local Action 2015-2020,' National Palliative & End-of-Life Care Partnership, September 2015. [Noted in Media Watch, 14 September 2015, #427 (p.14)] http://goo.gl/1cXKFe

Countries start to act on non-communicable diseases but need to speed up efforts to meet global commitments, report

WORLD HEALTH ORGANIZATION (WHO) | Online – 18 July 2016 – A new WHO report highlights the need to intensify national action to meet the global targets governments have agreed to protect people from heart disease, cancers, diabetes, and lung diseases. Globally, these non-communicable diseases (NCDs) represent the largest cause of death in people aged under 70 years, posing a major threat to sustainable development. The global survey ... shows that some countries are making remarkable progress. A number of countries have put in place measures to protect people from exposure to tobacco use, harmful use of alcohol, unhealthy diet and physical inactivity. Some have created new financing opportunities to build strong public health systems by taxing tobacco products. "Countries, including some of the poorest, are showing it is feasible to make progress and reduce premature deaths from NCDs. But that progress, particularly in low and middle-income countries, is insufficient and uneven," says Dr. Oleg Chestnov, Assistant Director-General at WHO. "If countries continue on this trajectory, there is no way they will all meet the 2030 Sustainable Development Goals target of reducing, by one-third, premature mortality from NCDs." The report tracks progress on four time-bound commitments agreed in 2014 to strengthen countries' abilities to tackle NCDs. These are to set national NCD reduction targets, develop national multi-sectoral policies and plans to achieve these national targets, reduce exposure to factors that put people at risk of NCDs, and strengthen health systems to address NCDs. To date, 60% countries have set national time-bound targets for NCDs indicators and 92% have integrated NCDs in national health plans. http://goo.gl/wrTTJu

World Health Organization

Extract from WHO report: Palliative care

The European Region reported the highest availability of PC with 73% of countries in primary health care, and 69% in community or home-based care. The region with the second highest levels of PC, was the Western Pacific Region with 48% of countries offering PC in a primary health care setting, and 44% in a community or home-based care setting. Among the remaining four regions, PC in a primary healthcare setting was generally available in 10-29% of countries, and in a community or home-based care setting in 9-26% of countries.

N.B. Click on 'Report of 2015 NVD global survey' (left-hand column of web page) to access 'Assessing national capacity for the prevention and control of non-communicable diseases,' WHO, July 2016.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MALTA | *The Malta Independent* (St. Julian's) – 18 July 2016 – Alternattiva Demokratika (AD) has called for a "real discussion" on the possibility of being able to draw up a "biological will" – a form drawn up while a person is mentally healthy to outline the medical intervention the person in question deems acceptable should there condition worsen. AD [the green political party in Malta] considers that the current discussion on euthanasia is premature... http://goo.gl/imhpa0

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

Specialist Publications

Risk factors for hospitalization of home hospice enrollees: Development and validation of a predictive tool

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 22 July 2016 – Over 10% of hospice patients experience at least 1 care transition 6 months prior to death. Transitions at the end of life, particularly from hospice to hospital, result in burdensome and fragmented care for patients and families. Little is known about factors that predict hospitalization in this population. Reasons for hospitalization among home hospice patients [i.e., the patient population studied] are complex. Patients who are younger, belong to a minority group, and have a greater number of chronic conditions are at increased odds of hospitalization. The authors newly developed predictive tool identifies patients at risk for hospitalization and can serve as a benchmark for future model development. http://goo.gl/cnxnHB

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 July 2016 – **'Interventions for reducing hospital readmission rates: The role of hospice and palliative care.'** Previous research has not examined exactly how hospitals may promote the appropriate use of hospice and palliative care (PC) for their discharged patients. The authors found that a positive effect for hospitals participating in the State Action on Avoidable Readmissions initiative was enhanced engagement in efforts to promote greater use of hospice and PC as a possible method of reducing unplanned readmissions... http://goo.gl/nwpwsE

N.B. Additional articles on the avoidability of hospital readmissions in the context of end-of-life care are noted in Media Watch 18 July 2016, #471 (p.14) and 14 March 2016, #455 (p.12).

The feasibility of creating partnerships between palliative care volunteers and healthcare providers to support rural frail older adults and their families: An integrative review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 July 2016 – Volunteers are important in the support of frail older adults requiring palliative care, especially in rural areas. However, there are challenges associated with volunteer supports related to training, management and capacity to work in partnership with healthcare providers (HCP). Studies were drawn from international sources to understand how volunteer roles vary by culture and organization; the majority of studies were conducted in North America. Studies varied in methodology, including quantitative, qualitative and educational commentary. Identified factors that were crucial to the feasibility of volunteer-HCP partnerships in rural areas included volunteer training dynamics, relationships between volunteers and HCP, and rural environmental factors. Preliminary evidence indicates that a volunteer-HCP palliative partnership is feasible. However, training policies/procedures, volunteer-HCP relationships, and rural specific designs impact the feasibility of this partnership. Additional research is needed to further establish the feasibility of implementing these partnerships in rural settings. http://goo.gl/zqRrl6

Improving the quality of life of palliative and chronic disease patients and carers in remote Australia with the establishment of a day respite facility

BMC PALLIATIVE CARE | Online – 18 July 2016 – It seems clear from this evaluation that the establishment of the respite service has met an important unmet need in the Alice Springs region. The qualitative findings and case studies clearly indicate that the establishment of the respite service has resulted in marked improvements in daily living for respite patients and their carers. Establishing the respite service improved case management of chronic and complex patients. Over time, the service became a "hub" for chronic and complex patients. http://goo.gl/7TBokA

Worth Repeating

'Boundary issues for hospice palliative care volunteers: When to say "yes" and when to say "no,"' (p.11), in *American Journal of Hospice & Palliative Medicine.*

Cont.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 July 2016 – **'Hospice palliative care volunteers as program and patient/family advocates.'** The majority of the volunteers surveyed consider themselves advocates for their programs and many of those, who have not already done so, would be willing to promote their program (e.g., give a community presentation, talk to local media) if asked. Half of the volunteers were aware of unmet needs of the patients/families they supported, and just over one-third wanted to advocate on behalf of their patients/families but did not know what to do or where to go. Recommendations for training are made. http://goo.gl/Lpk4Ep

N.B. Additional articles on hospice and palliative care volunteers are noted in the issues of Media Watch, 18 January 2016, #445 (p.6), 27 July 2015, #420 (p.13), and 16 February 2015, #397 (pp.8-9).

Physicians in postgraduate training characteristics and support of palliative sedation for existential distress

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 July 2016 – Palliative sedation for refractory existential distress (PS-ED) is ethically troubling, but potentially critical to quality end-of-life care (EOLC). Physicians' in postgraduate training support toward PS-ED is unknown nor is it known how empathy, hope, optimism, or intrinsic religious motivation (IRM) affect their support. These knowledge gaps hinder efforts to support physicians who struggle with patients' EOLC preferences. Only 22.7% of residents [i.e., study participants] were very supportive of PS-ED, and 82.0% were very supportive of PS for refractory physical pain (PS-PP). Support for PS-PP or PS-ED did not correlate with levels of empathy, hope, optimism, or IRM; however, for residents with lower IRM, greater optimism was associated with greater PS-ED support. In contrast, among residents with higher IRM, optimism was not associated with PS-ED support. Comparing current results to published surveys, a similar proportion of residents and practicing physicians support PS-ED and PS-PP. In contrast to practicing physicians, however, IRM does not directly influence residents' supportiveness. http://goo.gl/a6Xghr

Noted in Media Watch, 6 June 2016, #465 (p.9):

- *BRITISH COLUMBIA MEDICAL JOURNAL*, 2016;58(5):268-273. **'Addressing existential suffering.'** Through a brief exploration of the foundations of existentialism and existential psychotherapy, this article aims to demystify existentialism and provide practical tips for addressing existential suffering, even in parents and children with terminal illness. With the aid of a physician who addresses existential suffering, it is possible for patients to transition from feeling hopeless to feeling more alive than ever. http://goo.gl/NrmH2e

Experiences of interpreters in supporting the transition from oncology to palliative care: A qualitative study

ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY | Online – 20 July 2016 – Medical consultations focused on managing the transition to palliative care (PC) are interpersonally challenging and require high levels of communicative competence. In the context of non-English speaking patients, communication challenges are further complicated due to the requirement of interpreting; a process with the potential to add intense layers of complexity in the clinical encounter, such as misunderstanding, misrepresentation and power imbalances. The aim of the study was to explore the experiences and perspectives of professional interpreters in supporting the transition of culturally and linguistically diverse patients to specialist PC. Four key themes emerged: 1) The challenges of translating the meaning of "palliative care"; 2) Managing interpreting in the presence of family care-givers; 3) Communicating and expressing sensitivity while remaining professional and interpreters' own emotional burden of difficult clinic encounters between doctor; and, 4) Patient negotiations. The results suggest that interpreters face a range of often concealed interpersonal and interprofessional challenges and recognition of such dynamics will help provide necessary support for these key stakeholders in the transition to PC. http://goo.gl/pkwQlh

N.B. Selected articles on patients with limited English proficiency in the context of end-of-life care are noted in Media Watch, 20 June 2016, #467 (p.15).

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

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

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 19 July 2016 – The British Medical Association and the National Health Service acknowledge the benefits of identifying patients approaching the end of life (EOL), to address their care needs and the needs of their families. There is much policy in this area, across many health systems. In the current study, the Supportive & Palliative Care Indicators Tool was helpful in prompting GPs to raise EOL issues systematically.[1] Given the known inaccuracies of healthcare professionals in predicting death, and in recognising the clear risks of misinterpreting patients' wishes if they are not provided with the opportunity to express their preferences, the approach used in this exploratory study may be useful in further studies. The majority of participants completed all or some of Think Ahead [a tool developed in 2011 by the Forum on End-of-Life Care in Ireland].[2] Despite known concerns of GPs about raising EOL preferences, most participants were not upset by Think Ahead, while many found it useful and indicated that the tool should be distributed more widely. Results from this exploratory study ... provide direction on how further progress might be made, in what remains a challenging but important area for patients and GPs. http://goo.gl/xlb0oO

1. Supportive & Palliative Care Indicators Tool: http://goo.gl/R6rItR
2. Think Ahead: http://goo.gl/pVaH9Y

Related

- *JOURNAL OF INTERPROFESSIONAL CARE* | Online – 19 July 2016 – '**An exploratory study of interprofessional collaboration in end-of-life decision-making beyond palliative care settings.**' The authors recommend an interprofessional team approach to facilitate end-of-life (EOL) decision-making across care settings and before death becomes imminent. Increasing educational initiatives and developing tools that focus on interprofessional collaboration may help health care professionals to understand each other's roles and perspectives, so that they can work together to provide a more coherent and coordinated approach to EOL decision-making. http://goo.gl/eykkZ0

Embracing inherent uncertainty in advanced illness

THE BRITISH MEDICAL JOURNAL | Online – 18 July 2016 – Everyone dies, but uncertainty about how and when that will happen is inevitable. Uncertainty can be seen as an "enemy" to be constrained by medical science. Work continues on tools that try to provide a reliable prognosis for people with advanced health conditions as far as six or 12 months ahead on the grounds that meaningful choices require robust evidence of risk of death. However, such tools are not reliable when applied to individuals. Uncertainty also drives fears about future debility, loss of control, and either inadequate or excessive healthcare. The authors question the perception that uncertainty is a barrier to appropriate person centred care towards the end of life. Uncertainty may in fact be more friend than foe. An unpredictable but evident risk of deteriorating and dying should be a trigger for planning care with all people who have an advanced illness and in all care settings. It offers a prime opportunity to accept and manage the inherent uncertainties of living and dying well with progressive, advanced conditions. http://goo.gl/zGMGIT

N.B. Selected articles on managing uncertainty in advance illness are noted in Media Watch, 2 May 2016, #460 (pp.11-12).

Updated 07.20.2016

Prison Hospice Backgrounder

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: http://goo.gl/qgd4hp

Beyond “rationing” and “death panels”: The potential “escape fire” of palliative care

CRITICAL CARE MEDICINE, 2016;44(8):1605-1606. A recent article by Cassel *et al* quoted the speech of Dr. Don Berwick that an “escape fire,” or revolutionary innovation, for the U.S. Health care system would need to “make sense in the world of science and professionalism, in the world of the patient and family, in the world of the business and finance of health care, and in the world of the good, kind people who do the work of caring” and that “the toughest part of this may be in terms of the business and financing of care.”[1] Discussions on the “business” of medicine can be readily twisted by critics to imply “the ‘R word’” or “proverbial third rail in politics” – rationing, and consequently, the finances of different medical practices are frequently under-discussed and under-researched. As a case example, the founding legislation for the Patient-Centered Outcomes Institute (PCORI) explicitly prohibits funding of cost-effectiveness research; PCORI can finance whether a treatment improves a patient’s health-related quality of life or reduces a caregiver’s burden, but not whether that treatment is actually more cost-effective to the healthcare system itself. This phenomena holds doubly true in palliative care. Indeed, it is but a short jump from discussions about the “business” of medicine to someone suggesting “rationing” to someone else resurrecting the feared spectres of Sarah Palin’s “death panels.” http://goo.gl/6uxH5v

1. ‘The business case for palliative care: Translating research into program development in the U.S.,’ *Journal of Pain & Symptom & Pain Management,* 19 August 2015. [Noted in Media Watch, 24 August 2015, #424 (p.15)] http://goo.gl/uX0q7h

Dying and death within the culture of long-term care facilities in Canada

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 19 July 2016 – This ethnographic study was undertaken to identify the cultural factors within long-term care (LTC) facilities that explain why residents are often not understood to be dying until within a few hours or days before death despite often lengthy trajectories of decline related to progressive chronic conditions and advanced old age. One contextual factor and three beliefs were uncovered: 1) The mismatch of care demands in LTC facilities and the resources that are available to meet those demands; 2) The belief that LTC facilities are for living; 3) The belief that no one should die in pain; and 5) The belief that no one should die alone. The belief that LTC facilities are for living, within a context that separates living and dying, contributed to the delay of a palliative approach to care. The beliefs that residents must not die in pain or alone were highly positive as they lead to the initiation of palliative measures when death was considered to be certain and within the very short term. The earlier initiation of a palliative approach to care to ensure that psychosocial and spiritual needs, as well as pain and other symptoms, are more often met will require changes in the culture of LTC, not just improvements in palliative care expertise and staffing. It would be very helpful for staff, residents and their families, and general society to understand that those who are needful of LTC support are living and dying simultaneously. http://goo.gl/7hYXQZ

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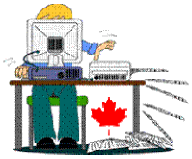

Barry R. Ashpole

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.[1] In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://goo.gl/5CHoAG

1. Ashpole BR. ‘Communications with the Public, Politicians, and the News Media,’ *Oxford Textbook of Palliative Medicine*, 5th Edition (pp.357-359), Oxford University Press, 2015. https://goo.gl/Vi07RS.

Noted in Media Watch, 3 February 2014, #343 (p.9):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 24 January 2014 – **'Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers.'** Study participants had a relatively positive attitude toward more than one-half of selected aspects of interdisciplinary practice and end-of-life palliative care for long-term residents. Overall, however, there are significant differences between upper-level professionals and managers (registered nurses, physicians, rehabilitation staff, and clinical managers) versus the hands-on caregivers (nursing assistants, patient assistants and volunteers) with regard to some aspects of the care of the dying. http://goo.gl/B5rwp1

N.B. Additional articles on issues specific to long-term care in Canada are noted in Media Watch, 18 July 2016, #471 (p.2).

Witnessing a body in decline: Men's and women's perceptions of an altered physical appearance

JOURNAL OF WOMEN & AGING | Online – 19 July 2016 – There has been a tendency within the literature to ignore how men and women who are very ill and at the end of life perceive and experience their visibly altered bodies. This article aims to provide new insights about this matter. In-depth interviews were conducted with 10 hospice patients, 20 family members, and 20 members of hospice staff. Findings reveal that because of masculine and feminine norms, physical appearance is more a matter of concern to women than to men who are close to death. This contradicts theories that suggest that patients experience a disinvestment on their sense of masculinity and femininity alongside the process of bodily deterioration and decay prior impending potential death. http://goo.gl/mHkTU5

End-of-life care in Germany

Integrating palliative care into Comprehensive Cancer Centers: Consensus-based development of best practice recommendations

THE ONCOLOGIST | Online – 20 July 2016 – A total of 38 experts from 15 Comprehensive Cancer Centres (CCCs) performed all three Delphi rounds. Consensus was achieved for 29 of 30 recommendations. High agreement related to having an organizationally and spatially independent palliative care unit, a mobile multi-professional specialized palliative care (SPC) team, and cooperation with community-based SPC. Until round 3, an ongoing discussion was registered on hospice volunteers, a chair of palliative care, education in SPC among staff in emergency departments, and integration of SPC in decision-making processes such as tumor boards or consultation hours. General and specialized palliative care (SPC) is an integral part of comprehensive cancer care. However, significant diversity concerning the design of SPC in the German Comprehensive Cancer Center (CCC) Network led to the establishment of consensual best practice recommendations for integration of SPC into the clinical structures, processes, research, and education throughout the CCC network. http://goo.gl/I63bFe

Media Watch: Searching Back Issues

GLOBAL PALLIATIVE CARE NEWS ARCHIVE

MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE

Please feel free to share this weekly report with your colleagues.
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MW 467: Compromised autonomy: When families pressure patients to change their wishes

Download the complete issue (PDF 300 KB)

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 15 June 2016 | Living with a life-threatening illness is extraordinarily challenging. This challenge intensifies when patients struggle to weigh personal and familial interests when facing difficult medical decisions. When patients are unduly pressured by their families to make medical decisions that are not in line with previously held values, beliefs, or perspectives, autonomy is compromised. **read more...**

Media Watch Archives

- 2015, Jan - Dec
- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
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Back issues of the weekly report can be downloaded at http://goo.gl/frPgZ5. Enter keyword/s in the search box. Links to back issues of Media Watch that include mention of the subject or topic of interest (among other links to information/resources on the IPCRC website) will be displayed.

End-of-life care in Sweden

Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams

PALLIATIVE & SUPPORTIVE CARE | Online – 22 July 2016 – Those who are seriously ill and facing death are often living with physical, emotional, social, and spiritual suffering. Teamwork is considered to be necessary to holistically meet the diverse needs of patients in palliative care (PC). Reviews of studies regarding PC team outcomes have concluded that teams provide benefits, especially regarding pain and symptom management. Much of the research concerning PC teams has been performed from the perspective of the service providers and has less often focused on patients' and families' experiences of care. Two themes were constructed through thematic analysis: 1) Security ("They are always available," "I get the help I need quickly"); and, 2) Continuity of care ("They know me/us, our whole situation and they really care"). Patients' and family members' descriptions of the work of specialized palliative home care teams are conceptualized through experiences of security and continuity of care. Experiences of security are fostered through the 24/7 availability of the team, sensitivity and flexibility in meeting patients' and families' needs, and practical adjustments to enable care at home. Experiences of continuity of care are fostered through the team's collective approach, where the individual team member knows the patients and family members, including their whole situation, and cares about the little things in life as well as caring for the family unit. http://goo.gl/UwaBrh

Medical University of Vienna study

Pushing boundaries – culture sensitive care in oncology and palliative care: A qualitative study

PSYCHO-ONCOLOGY | Online – 18 July 2016 – In increasingly globalized societies patient-centred cancer care requires culture-sensitive approaches in order to ensure patients wellbeing. While migrant patients' needs are frequently reported in the literature, staff members' perception of work with migrant patients, associated challenges or individual work approaches are largely unknown. This study aims to understand staff experience of the impact of culture on cancer care. This study was conducted at the Medical University Vienna, including staff from different settings of oncology and palliative care, in different professional positions and with a range of individual migration backgrounds. Interviews revealed four key topics: 1) Culture-specific differences; 2) Assumed reasons for differences; 3) Consequences of multicultural care; and, 4) Tools for culture-sensitive care. Concrete suggestions for improvement include measures on an organizational level, team level, and personal tools. The suggested measures are applicable to improve work satisfaction and culture-sensitive care not only cancer care, but also in other areas of medicine. http://goo.gl/0P0OiW

Advance care planning in South Korea: Social work perspective

SOCIAL WORK IN HEALTH CARE, 2016;57(7):545-558. As ethical issues arise concerning the continuation of futile medical treatment for dying patients in Korean society, advance directive planning (ACP) initiatives have been put into place to guide practice. Seventy-three percent of the [survey] participants reported no knowledge of advance directives. Social workers who emphasized self-determination as a professional value, professed a preference for hospice care, and who were comfortable discussing death were more likely to have a positive attitudes toward ACP. http://goo.gl/rJTFZY

Noted in Media Watch, 20 June 2016, #467 (p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. '**Hospice palliative care in South Korea: Past, present, and future.**' Hospice palliative care (HPC) in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. http://goo.gl/Aa6FL3

Worth Repeating

Boundary issues for hospice palliative care volunteers: When to say "yes" and when to say "no"

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 February 2011 – A total of 79 hospice palliative care volunteers from two community-based hospice programs responded to a 27-item Boundary Issues Questionnaire developed for this study. They were asked to indicate whether or not they considered each item (e.g., "lend personal belongings to a patient or family," "agree to be a patient's power of attorney," "attend/go into a patient's medical appointment") to be something they should not do and to indicate whether or not they have ever done it. On the basis of the responses, the authors distinguished between "definite boundary issues" (things volunteers should never do, for example, "accept money from a patient or family"), "potential boundary issues" (things volunteers should stop and think twice about doing, for example, "accept a gift from a patient or family"), and "questionable boundary issues" (things volunteers should be aware of doing, for example, "give your home phone number to a patient or family"). The implications of these findings for training volunteers are discussed and the need for clear and unambiguous organizational policies and procedures to preserve boundaries is stressed. Without clear policies, etc., community-based hospice programs may be putting themselves at legal risk. [Noted in Media Watch, 14 February 2011, #446 (p.6)] http://goo.gl/OvGR3V

> **N.B.** A version of this article (i.e., the full-text) can be downloaded at the Canadian Virtual Hospice website: http://goo.gl/RZ7QyR.

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: Online

International

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

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK COMMUNITY: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://GOO.GL/JNHVMB

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://goo.gl/XrhYCH

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): http://goo.gl/AhlqvD

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://goo.gl/o7kN3W [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://goo.gl/5d1l9K

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

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