

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

'Palliative care for case managers: Building capacity to extend community-based palliative care to underserved older adults' (p.9) in *Gerontology & Geriatrics Education*.

Canada

Doctor shortage at Quebec City hospital means patients lose access to outpatient palliative care

QUEBEC | CBC News (Montreal) – 23 November 2018 – An exodus of doctors at Quebec City's Hôtel-Dieu has forced the hospital to shut down its palliative care (PC) outpatient unit, leaving almost 100 people without adequate end-of-life care. Dr. Louis Roy, a family doctor and head of PC at the Centre hospitalier universitaire de Québec, which includes Hôtel-Dieu, said the remaining physicians' workload grew to the point that it was no longer possible to keep the unit operational. "The teams of physicians are tired," he said. "We cut vacations, and all the physicians are working longer hours every week, and we just can't keep up like that." He said the doctors are often on call around the clock. The hospital has lost the equivalent of four full-time physicians in the past 14 months, for various reasons: one went to work in another part of the province, while another is now working full-time at Maison Michel-Sarrazin, a Quebec City hospice. Roy said the strain of being so short-staffed forced administrators to decide between outpatient services and in-hospital needs. The outpatient clinic allowed patients to drop by to have their pain medication or other prescriptions adjusted and have other needs met, without having to be admitted to the hospital or kept there overnight. Almost all of the affected patients

have been redirected to family physicians or specialists, and Roy said the hospital is trying to ensure they also have access to nurses or pharmacists who are up to date on their cases. <https://goo.gl/TwGv7h>

Specialist Publications

'Dying in long-term care: Perspectives from sexual and gender minority older adults about their fears and hopes for end of life' (p.14), in *Journal of Social Work in End-of-Life & Palliative Care*.

'Working with clients who choose medical assistance in dying: A new landscape for counsellors' (p.20), in *Canadian Journal of Counselling & Psychotherapy*

'Situating requests for medical aid in dying within the broader context of end-of-life care: Ethical considerations' (p.20), *Journal of Medical Ethics*.

'A Canadian academic hospital's initial medical assistance in dying experience: A healthcare systems review' (p.20), in *Journal of Palliative Care*.

U.S.A.

Critically ill children who received wishes cut their health care costs

OHIO | National Public Radio (Columbus) – 20 November 2018 – Researchers looked back at the cases of nearly 1,000 children with serious illnesses who were treated at Nationwide Children’s Hospital in Columbus, Ohio.¹ Half the children had received wishes and the other half hadn’t. The children granted wishes were substantially less likely to visit the emergency department or to have an unplanned hospital admission within two years as compared with children who hadn’t received wishes. (Researchers matched the children’s personal and disease characteristics.) “My hypothesis is that these kids, when they come back, are more engaged with their families and medical providers, and perhaps they’re more adherent to their treatment plan,” says the study’s lead author Dr. Anup D. Patel, section chief of neurology at Nationwide Children’s Hospital and an associate professor of pediatrics at Ohio State University College of Medicine in Columbus. To qualify for a wish, a child must have a life-threatening, but not necessarily terminal, condition, says Jamie Sandys, a spokesperson at Make-A-Wish Foundation. The foundation has more than 60 U.S.-based chapters and has granted more than 300,000 wishes since 1980. <https://goo.gl/UhqfZf>

1. ‘Impact of make-a-wish experience on healthcare utilization,’ *Pediatric Research*, published online 18 October 2018. **Abstract:** <https://goo.gl/4z2oQ7>

International

Elder care in England

Companies running “inadequate” U.K. care homes make £113 million profit

U.K. (England) | *The Guardian* (London) – 23 November 2018 – Some of the country’s worst care homes are owned by companies that have made a total profit of £113 million despite some of the vulnerable people they are supposed to look after being neglected, it can be revealed. An investigation by *The Guardian* has found that companies owning homes that care for elderly people with dementia, disabled people and those with learning difficulties – and have been rated “inadequate,” the lowest possible rating by the Care Quality Commission¹ – are turning over a healthy profit. The company accounts do not state whether specific failing care homes make a profit, but critics called on the firms to use their wider income to rectify the issues raised by the CQC reports before taking profits that often amounted to millions. An analysis by *The Guardian* of 220 homes rated inadequate by recent inspection reports in England showed that at least 44 – many of which will receive government funding to care for residents – were owned by companies making millions in pre-tax profits. <https://goo.gl/9xFTbd>

Specialist Publications

‘Health professionals perceived concerns and challenges in providing palliative and end-of-life care: A qualitative analysis’ (p.4), in *American Journal of Hospice & Palliative Medicine*.

‘Primary palliative care education programs: Review and characterization’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Multifactorial examination of caregiver burden in a national sample of family and unpaid caregiver’ (p.10), in *Journal of the American Geriatric Society*.

‘Perspectives of health care payer organizations on cancer care delivery redesign: A national study’ (p.11), in *Journal of Oncology Practice*.

‘End-of-life resource for African American caregivers: Reflections on a field education model’ (p.15), in *Journal of Social Work in End-of-Life & Palliative Care*.

‘Bereavement experiences following a death under Oregon’s Death with Dignity Act’ (p.20), in *Death Studies*.

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1. 'State of Care,' Care Quality Commission, 2018. **Download/view at:** <https://goo.gl/QhEP9P>

N.B. No mention is made in the Care Quality Commission report of palliative and end-of-life care.

Noted in Media Watch 21 May 2018 (#564, p.5):

- U.K. (England) | *The Daily Mail* (London) – 14 May 2018 – **'Number of care homes in England falls by more than 700 over two years with potentially "disastrous" effects for the elderly.'** The figures released by ministers come after a financial analysis showed 148 care home businesses became insolvent in the last financial year – nearly double the number in the previous year. The figures from care minister Caroline Dinenage show the number of residential care homes fell from 12,191 at the beginning of 2016 to 11,615 this year. <https://goo.gl/E11j2S>

Noted in Media Watch 21 August 2017 (#526, p.6):

- U.K. (England) | *The Daily Telegraph* (London) – 16 August 2017 – **'More than 70,000 extra care home places needed by 2025.'** More than 70,000 extra care home places will be needed by 2025, with pensioners now spending twice as long living without independence. Women over the age of 65 can now expect to spend the last three years of their lives in a care home, or receiving help several times daily, research shows.¹ Two decades ago they could expect to spend the last 18 months of their lives in need of such help. <https://goo.gl/QnrQUw>

1. 'Forecasting the care needs of the older population in England over the next 20 years: Estimates from the Population Ageing & Care Simulation (PACSim) modelling study,' *The Lancet*, published online 30 August 2018. **Full text:** <https://goo.gl/AoRuXg>

- U.K. (England) | *The Times* (London) – 14 August 2017 – **'Funding crisis leaves thousands of care homes facing collapse.'** One in six care home companies is in danger of insolvency, according to a report warning that successive rises in the living wage have driven up costs to the point where they may bankrupt a large part of the system. About 420,000 people over the age of 65 are being looked after in Britain's 11,000 residential care homes, including 220,000 of the most vulnerable patients, who are in 4,700 nursing homes. <https://goo.gl/vENpPf>

Poorest dying nearly 10 years younger than rich in "deeply worrying" trend, study shows

U.K. (England) | *The Independent* (London) – 22 November 2018 – The poorest groups in society are dying almost a decade earlier than the richest, new research shows, prompting concern that welfare cuts and a rising cost of living are leaving the most vulnerable "out of the collective gain." The study by academics at Imperial College London revealed the life expectancy gap between the most affluent and most deprived sections of society increased from six years in 2001 to eight years in 2016 for women, and from nine to 10 years for men.¹ Women in the most deprived communities in 2016 lived until an average 79 years old, compared with 87 years in the most affluent group, while for men, the life expectancy was 74 years among the poorest, compared with 84 years among the richest. The findings also reveals that the life expectancy of England's poorest women has fallen in the last seven years – having dropped by three months since 2011. Child mortality rates were also considerably higher among deprived communities, with poorer children two-and-a-half times more likely to die before they reach adulthood than their peers from affluent families. People in the poorest sectors died at a higher rate from all illnesses – but that a number of diseases showed a particularly stark difference between rich and poor, notably respiratory diseases, heart disease, lung and digestive cancers and dementias. <https://goo.gl/Sfrtx8>

1. 'Contributions of diseases and injuries to widening life expectancy inequalities in England from 2001 to 2016: A population-based analysis of vital registration data,' *The Lancet Public Health*, published online 22 November 2018. **Full text:** <https://goo.gl/CdHgRM>



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.22.

Personal Independence Payments: Department “cannot” scrap terminal illness form

U.K. (Northern Ireland) | BBC News (Belfast) – 21 November 2018 – A [government] department has said it cannot scrap a requirement that terminally ill people sign a form stating they have less than six months to live to secure benefits. In June, a review recommended the form for Personal Independence Payments (PIP) be removed. The Department for Communities said it cannot implement this recommendation. More than 100,000 people in Northern Ireland are being reassessed for PIP, which replaces the Disability Living Allowance. Earlier in November a mother-of-two told BBC News that being asked to sign the form was like being “asked to sign her own death warrant.” The review, carried out by Walter Rader, recommended that the clinical judgement of a medical practitioner indicating that the claimant has a terminal illness should be sufficient to secure the benefit payments. Mr. Rader, who sits on the Committee on Standards, recommended that the “six months life expectancy criterion should be removed.” The form ... can be obtained by applicants from their doctor or consultant. PIP benefit ... part of a wider reform of U.K. welfare for people aged between 16 and 64. The payment is made to those who have a disability or long-term illness, with the amount based on how the condition impacts someone’s life. <https://goo.gl/47k5no>

Specialist Publications

‘Addressing the needs of terminally-ill patients in Bosnia-Herzegovina: Patients’ perceptions and expectations’ (p.6), in *BMC Palliative Care*.

‘Better drug use in advanced disease: An international Delphi study’ (p.6), in *BMJ Supportive & Palliative Care*.

‘Place of death and factors associated with hospital death in patients who have died from liver disease in England: A national population-based study’ (p.15), in *The Lancet Gastroenterology & Hepatology*.

‘The Italian law on informed consent and advance directives: Its impact on intensive care units and the European legal framework’ (p.16), in *Minerva Anestesiologica*.

‘Current practices, barriers and enablers for advance care planning among healthcare workers of aged care facilities in western New South Wales, Australia’ (p.18), in *Rural & Remote Health*.

Specialist Publications

Health professionals perceived concerns and challenges in providing palliative and end-of-life care: A qualitative analysis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 November 2018 – The Institute of Medicine identifies that quality palliative/end-of-life (EoL) care should be provided to patients with serious, life-limiting illnesses and their families by competently prepared health professionals.¹ The specific aim [of this study] was to determine thematic concerns in the delivery of palliative/EoL care which emerged from respondents’ impressions of a memorable palliative/EOL patient experience. Interdisciplinary health professionals at a large academic health system in the Midwest were surveyed... Concerns identified by participants emerged around seven themes including: 1) Communication (97%); 2) Decision-making/care planning (75%); 3) Education needs (60%); 4) EoL care (48%); 5) Ethics (24%); 6) Satisfaction with care (9%); and, 7) Spiritual/cultural sensitivity (6%). Challenges exist in the delivery of quality palliative/EOL care in the hospital setting which may be addressed through educational initiatives that focus on recognition of cultural influences on care preferences, improving communication between patients/families and providers, education about the differences between palliative/EoL care, and increased competency of health providers in having EoL/goals-of-care discussions. Health professionals must recognize the benefit of collaborative palliative care in order to meet patient and family needs holistically and comprehensively. **Abstract:** <https://goo.gl/rpEBeg>

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1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** <http://goo.gl/mm4o6W>

Do healthcare professionals really understand the role of occupational therapy in hospice care?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 November 2018 – The distinct value of occupational therapy (OT) in end-of-life (EoL) care is to facilitate quality of life for clients and their caregivers through engagement in occupations during the clients' remaining days. The results of this study revealed that OT's role in hospice care is misunderstood, and OT services are underutilized. Five themes were identified regarding the underutilization of OT services: 1) Lack of reimbursement; 2) Timing of referral; 3) Knowledge of the role of OT; 4) Refusal of services by family members; and, 5) Lack of OT presence in this setting. This study revealed that health-care professionals do believe that OTs are vital members of the hospice care team. However, many recipients of hospice care are not receiving OT. More consistent referrals to OT may better ensure that the terminally ill are able to attain EoL goals and live their lives to the fullest, regardless of life expectancy. **Abstract:** <https://goo.gl/FJveYK>

Noted in Media Watch 28 May 2018 (#565, p.14):

- *PALLIATIVE MEDICINE*, 2018;32(5):960-968. '**Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey.**' This study is the first to examine the provision of occupational therapy in palliative care in Europe. It shows there is a shared core content of occupational therapy services in direct and indirect patient care and that priority is given to clinical care activities over teaching, service development or research. Occupational therapists understand and value their role in making it possible for people facing dying to participate as fully as they wish and are able in their everyday lives ... but do not feel that this role is used to its full potential. **Full text:** <https://goo.gl/E6HiCd>

N.B. Additional articles on the role of occupational therapists in palliative and end-of-life care noted in this issue of Media Watch.

Primary palliative care education programs: Review and characterization

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 November 2018 – Primary palliative care (PPC) education programs have arisen in response to the recognition that all clinicians need to have a basic set of knowledge and skills to provide excellent care to all patients. PPC education programs appear to vary widely, making it difficult for potential learners to find the right program to fit their needs. The authors catalogued and categorized a snapshot of these programs across the U.S. to serve as a resource for those seeking training, and for educators interested in starting or optimizing such programs. There was little overlap between the programs found through medical and commercial search engines (CSEs). Programs found via CSEs varied with respect to intended learners, pedagogy, content, and cost. Among the minority of programs that confer a certification/degree upon completion, there is no consensus as to what these signify. The wide variety of programs is both a challenge to and strength of the field. The authors hope that this report will serve as a call to develop a standard PPC education taxonomy to help define essential components of all PPC programs, while also leaving sufficient room for programs to serve the unique needs of their local learners and patient populations. **Abstract:** <https://goo.gl/BBFERj>

Noted in Media Watch 14 August 2017 (#525, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 August 2017 – '**Primary palliative care education: A pilot survey.**' The demand for palliative services is outpacing the availability of specialist palliative care (PC) clinicians. One strategy to fill this gap is to improve primary PC skills and knowledge of all clinicians who care for seriously ill patients. Previous educational efforts have shown mixed results and one possible explanation is unrecognized discordance of educational goals between those offering education and potential primary PC learners. The results suggest substantial areas of both concordant and discordant opinions with respect to educational topics and learning settings. **Abstract:** <https://goo.gl/tDpuop>

Addressing the needs of terminally-ill patients in Bosnia-Herzegovina: Patients' perceptions and expectations

BMC PALLIATIVE CARE | Online – 20 November 2018 – This study, conducted in a resource limited setting where such issues are barely investigated, emphasised a wide gap between patients' expectations and currently available care and services. While there is a need to improve symptoms management through training of health professionals including capacity building of nurses, better medication and provision of adequate material and devices, this will only tackle the patients' most urgent concerns. Addressing the needs of patients at the end of their life, aiming at maintaining them with the best possible quality of life while providing appropriate support to their relatives, thus remains a much broader challenging task. In order to ensure a comprehensive response to expressed needs, a coordinated inter-professional, inter-institutional and multi-stakeholder approach is required, including appropriate information to the patients and their caregivers about the disease, its stages and its management as well as adequate psychosocial, spiritual, administrative and financial support. The concept of nurse-led navigation/stewardship, that would provide patients with comprehensive services could be explored. A culture of anticipation should be adopted while providing end of life care and support. **Full text:** <https://goo.gl/SCLx8W>

Better drug use in advanced disease: An international Delphi study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 15 November 2018 – Experts in the field of medication management and end-of-life (EoL) care from 13 countries reached a high level of consensus on a number of important recommendations to improve medication management at the EoL. Key issues indicated by the experts concern the central role of the physician in medication management, necessity of awareness on medication management at the EoL [i.e., the last three months of life]; the need for education on medication management for healthcare workers and trainees; and, the importance of communication with the patient and family in the process of medication management. These indications complement the elements provided in the existing tools for medication management. Research is needed to facilitate medication management in EoL care to develop a list of medications inappropriate in EoL care and incorporation of recommendations for EoL medication management in disease-specific guidelines. A best practice for medication management in EoL care including specific guidelines for particular medications and recommendations regarding decision making and communication should be elaborated. **Full text:** <https://goo.gl/BvopDX>

N.B. Selected articles on medications with questionable benefit at EoL noted in 29 October 2018 issue of Media Watch (pp.10-11).

Related

- *SOCIOLOGY OF HEALTH & ILLNESS* | Online – 20 November 2018 – **“Treat them into the grave”: Cancer physicians' attitudes towards the use of high-cost cancer medicines at the end of life.** The authors explore the factors perceived by cancer physicians to be driving the use of high-cost cancer medicines at the end of life (EoL). Drawing on semi-structured interviews with 16 Australian oncologists and haematologists, they demonstrate that these physicians believe that the use of high-cost medicines at the EoL is driven by multiple factors, including individual, interpersonal, socio-cultural and public policy influences. **Abstract:** <https://goo.gl/5u5Pwp>

[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>



Barriers to specialist palliative care in interstitial lung disease: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 November 2018 – Current guidelines recommend palliative care (PC) based on individual needs for patients with idiopathic pulmonary fibrosis. However, patients with interstitial lung disease (ILD) are less likely to receive specialist PC services compared with patients with malignant disease. Ten studies with a total of 4,073 people with ILD, 27 caregivers and 18 healthcare professionals were selected and analysed. Frequency of PC referrals ranged from 0% to 38%. Delay in PC referrals and end-of-life decisions, patients' fear of talking about the future, prognostic uncertainty and confusion about the roles of PC were identified as barriers to accessing PC services. Further research should concentrate on the early identification of patients who need specialist PC possibly with establishment of criteria to trigger referral ensuring that referrals are also based on patient's needs. **Abstract:** <https://goo.gl/RN5GB1>

Noted in Media Watch 23 October 2017 (#535, p.11):

- *THE LANCET: RESPIRATORY DISEASE* | Online – 12 October 2017 – ‘**Palliative care in interstitial lung disease: Living well.**’ Progressive fibrotic interstitial lung diseases (ILDs) are characterised by major reductions in quality of life and survival, and have similarities to certain malignancies. However, palliative care (PC) expertise is conspicuously inaccessible to many patients with ILD. The incorrect perception that PC is synonymous with end-of-life care, with no role earlier in the course of ILD, has created a culture of neglect. **Full text:** <https://goo.gl/yBaK5G>

Palliative care in England

Community palliative medicine out-of-hours needs and the 7-day week: A service evaluation

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 November 2018 – Palliative care makes up 11.4% of the total out-of-hours of GP home visits [in the County of Shropshire] ... 56% of which are for patients who are expected to die within 48 hours, with 80% of the symptoms being agitation, secretions, and pain. Overall, 5.7% of out-of-hours GP palliative home visits resulted in hospital admission; however, this decreased to 0.6% adjusting for the last 48-hour prognosis. GPs deal with a wide variety of scenarios in a heterogeneous population. The greatest demand is from 17:00 to 00:00 (65% of the total shift) on weekdays, and from 09:00 to 00:00 on weekends (82% of the shift). These data begin to quantify the role being performed by out-of-hours GPs, have implications for service provision, and support for a 7-day work week. **Abstract:** <https://goo.gl/Tnggdc>

Noted in Media Watch 3 October 2016 (#482, p.11):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):244-245. ‘**End-of-life care at home out-of-hours: Think 3 a.m.**’ The “in-hours” period is only between 9 a.m. and 5 p.m., or thereabouts, while the out-of-hours period represents all the rest; that is, approximately two thirds of the time. The same number of people die every hour, whether this is during the day or at night, during the week or at the weekend. Therefore, out of all people who die, two thirds die during the out-of-hours period. **Access to this article via journal website:** <https://goo.gl/tN4Ra6>

Follow the trail: Using insights from the growth of palliative care to propose a roadmap for cancer rehabilitation

CA: A CANCER JOURNAL FOR CLINICIANS | Online – 20 November 2018 – Despite research explicating the benefits of cancer rehabilitation interventions to optimize physical, social, emotional, and vocational functioning, many reports document low rates of referral to and uptake of rehabilitation in oncology. Cancer rehabilitation clinicians, researchers, and policy makers could learn from the multidisciplinary specialty of palliative care (PC), which has benefited from a growth strategy and has garnered national recognition as an important and necessary aspect of oncology care. The purpose of this article is to explore the actions that have increased the uptake and integration of PC to yield insights and multimodal strat-

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egies for the development and growth of cancer rehabilitation. After examining the history of PC and its growth, the authors highlight 5 key strategies that may benefit the field of cancer rehabilitation: 1) Stimulating the science in specific gap areas; 2) Creating clinical practice guidelines; 3) Building clinical capacity; 4) Ascertaining and responding to public opinion; and, 5) Advocating for public policy change. Coordinated and simultaneous advances on these 5 strategies may catalyze the growth, utilization, and effectiveness of patient screening, timely referrals, and delivery of appropriate cancer rehabilitation care that reduces disability and improves quality of life for cancer survivors who need these services. **Full text:** <https://goo.gl/R3DXuy>

Implementation of a competency-based, interdisciplinary pediatric palliative care curriculum using content and format preferred by pediatric residents

CHILDREN | Online – 22 November 2018 – A one-hour monthly palliative care (PC) curriculum was designed and implemented in a participatory manner with 20 pediatric residents at a free-standing Midwestern children's hospital [in the U.S.]. Outcome measures included pediatric residents' personal attitude and perceived training environment receptivity before and after implementation of a PC competency-based curriculum. An 18-item survey utilizing Social Cognitive Theory Constructs was administered at baseline and after PC curriculum implementation (2017-2018 curricular year). Pediatric residents prioritized real case discussions in group format over other learning formats. Topics of highest interest at baseline were: discussing prognosis and delivering bad news, pain control, goals of care to include code status, and integrative therapies. Summary of ordinal responses revealed improvement in self-assessment of personal attitude toward PC and training environment receptivity to PC domains after year-long curriculum implementation. Curricular approach which is attentive to pediatric residents' preferred learning format and self-assessment of their behaviors within their care setting environment may be beneficial in competency-based primary palliative training. **Full text:** <https://goo.gl/dXSX8a>

Related

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 November 2018 – 'Practice concepts and innovations for pediatric end-of-life care by the interdisciplinary care team.' In recent years, clinical approaches to anticipatory grief and inclusivity amongst the medical team and family members have grown. In thinking about the end-of-life concerns within the pediatric care setting, practice concepts, and innovations inform how physicians and members of the interdisciplinary care team choose to approach conversations with parents and family members, as well as the particular level of involvement parents should have in decisions regarding the end of their child's life. **Abstract:** <https://goo.gl/Yi1MSC>

Technology and grieving: A relationship

ETHICS & MEDICINE: AN INTERNATIONAL JOURNAL OF BIOETHICS, 2018;34(3):177-192. Since the 1940s, both end-of-life (EoL) care and advancements in medical technologies have expanded exponentially. This article explores advancements in medical technologies and how these have altered the way Western society grieves death. With the capabilities to prolong life, the family, the patient, and the medical team all grieve the EoL in different ways. Using a literature review and interviews with clinicians, this article provides a chronological analysis of palliative care, hospice care, and various medical advancements. These changes in medicine are then paralleled with alterations in the bereavement process. The authors explore historical and anecdotal narratives of Western society's transformation of grief through the lens of medical advancements. They consider the implications of these findings for the Christian community, especially the local church. **Abstract (via EBSCO):** <https://goo.gl/ncDDWg>

Palliative care for case managers: Building capacity to extend community-based palliative care to underserved older adults

GERONTOLOGY & GERIATRICS EDUCATION | Online – 15 November 2018 – Despite increasing availability, there are significant disparities in access to and utilization of palliative care (PC), particularly among diverse, low-income, and community-dwelling older adults with chronic illness. Training frontline service providers is a novel approach to expanding access to PC among underserved elders. This article presents a process and outcome evaluation of a PC curriculum that was developed and piloted for geriatric case managers in a large urban area. The authors describe the background, planning, design, implementation, and preliminary outcomes associated with a pilot implementation of the curriculum. They conclude with implications for replicating efforts to enhance frontline providers' knowledge, skills, and self-efficacy in extending PC to communities that lack access to critical supports for their burdensome symptoms. **Abstract:** <https://goo.gl/3XXqjs>

Noted in Media Watch 5 October 2015 (#430, p.13):

- *JOURNAL OF ADVANCED NURSING* | Online – 28 September 2015 – ‘**Appraisal of cooperation with a palliative care case manager by general practitioners and community nurses: A cross-sectional questionnaire study.**’ GPs and community nurses are moderately positive about support from the case manager (CM). Of GPs, 46% rated the CM as helpful in realizing care appropriate for the patient; for community nurses this was 49%. The CM did not hinder the process of care and had added value for patients, according to the GPs and community nurses. **Abstract:** <https://goo.gl/ANwtQy>
- *PLOS ONE* | Online – 24 July 2015 – ‘**Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients: A mortality follow-back study in primary care.**’ The GP is more likely to know preferred place of death, the place of death is more likely to be at the home, and less likely to be the hospital, and there are fewer hospitalisations in the last 30 days of life, when cancer patients receive additional support from a case manager compared with patients receiving standard GP care. **Full text:** <https://goo.gl/n6jeRz>

Softening our approach to discussing prognosis

JAMA INTERNAL MEDICINE | Online – 19 November 2018 – We tend to cringe when we hear “So, how much time do I have, doc?” Yet prognostic discussions are a core skill of being a compassionate physician, preparing patients and families to live with serious illnesses, and enabling informed medical and personal decisions. The first challenge of prognostic communication is the inherent and unavoidable uncertainty, that the exact trajectory of health (or illness) is unknowable. Thus, clinicians are inaccurate prognosticators, overestimating by up to a factor of 5. We have difficulty making accurate short-term time-based prognostic estimates for common diseases, such as congestive heart failure, and can be off by as much as 1 to 2 years. Compounding this uncertainty, we worry about upsetting our patients with too much or unwanted information. On one hand, patients say that they want to know their prognosis and report that it is one of their highest priorities. On the other hand, patients also say that they are unsure about how much they want to know and give mixed messages about how much they want to talk about it. As one patient said, “I ask the question, and then I don’t want to know the answer. But the question is out there, and then I am devastated.” Uncertain about the information and not wanting to cause emotional harm, we hesitate to talk with patients about their futures. We watch colleagues hesitate with statements such as “Well, I don’t have a crystal ball” or “You know I can’t tell you that,” or “Only God knows,” or “We are very bad at predicting this sort of thing.” But we also worry that our patients do not have the prognostic information that they need, however imprecise. And perhaps worse, we worry that patients perceive that we cannot handle the tough discussions they need from us. **Introductory paragraph:** <https://goo.gl/LrtzxX>



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Noted in Media Watch 24 September 2018 (#582, p.6):

- *AMERICAN JOURNAL OF BIOETHICS* | Online – 20 September 2018 – **“I know I’m going to beat this”: When patients and doctors disagree about prognosis.** As palliative care physicians who frequently discuss goals of care with seriously ill patients and their families, we often get called because the patient/family is in “denial.” In a common scenario, we are consulted by a medical team where team members want us to make sure the family “gets it” and then makes the “appropriate” decision for a do not resuscitate order or for hospice care. Too often, from the consulting service perspective, the term “denial” is a substitute for “the patient won’t do what we think they should be doing.” **First page review:** <https://goo.gl/zKZ834>

N.B. Selected articles on prognosis noted in 18 June 2018 issue of Media Watch (#568, pp.5-6).

Contours of “here”: Phenomenology of space for assisted living residents approaching end of life

JOURNAL OF AGING, 2018;47(12):72-83. This study investigates how assisted living residents who are approaching end of life (EoL) navigate and experience space. Since its development, environmental gerontology has moved beyond the concept of person-environment fit to encompass aspects of place attachment and place integration, processes by which inhabited impersonal space becomes a place of individual personal meaning and this person-place relationship evolves with changing needs. Findings show that participants experience a neutral theme of shrinking space, negative themes of confinement and vulnerability, and positive themes of safety and intimacy. Findings have implications for interventions to improve place integration in assisted living and enhance residents’ quality of life at EoL, including developing strategies to promote small meaningful journeys within context of shrinking life space. **Abstract:** <https://goo.gl/Kcb4ZM>

Noted in Media Watch 7 April 2014 (#352, p.10):

- *JOURNAL OF AGING STUDIES*, 2014;30(4):1-13. **“This is our last stop.”: Negotiating end-of-life transitions in assisted living.** The authors present a model for how end-of-life (EoL) care transitions are negotiated in assisted living (AL) that depicts the range of multi-level intersecting factors that shape EoL processes and events in AL. These vary across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EoL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EoL processes and events (including how deaths were communicated and formally acknowledged), and the impact of death and dying on the residents and staff. **Abstract:** <https://goo.gl/a3hzYj>

Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 19 November 2018 – An estimated 14.9 million caregivers [in the U.S.] assisted 7.6 million care recipients. More than half of caregivers reported burden related to caregiving. In a multivariable regression model, caregivers who assisted with more activities of daily living and instrumental activities of daily living, health management tasks, and health system logistics were more likely to experience burden, as were female caregivers, adult child caregivers, caregivers in poor health, caregivers with anxiety symptoms, and those using respite care. Dementia was the only care recipient characteristic associated with burden. Caregiver characteristics and provision of caregiving tasks determine caregiver burden more than care recipient characteristics. Absence of an association between type of a care recipient’s chronic conditions and burden, except for dementia, suggests that the tasks that caregivers who assist older adults with a variety of health conditions undertake shape the experience of caregiving. **Abstract:** <https://goo.gl/hvqvEV>

“Magic happens here”: Environmental serenity in residential hospice care

JOURNAL OF HOUSING FOR THE ELDERLY | Online – 17 November 2018 – The purpose of this study was to explore the unique interaction between the care that is provided in and the environmental features of hospice residences. Interviews with 40 professionals from eight hospice residences focused on elements of care. Visual content analysis was conducted with 187 photographs of internal and external environments. Three themes illuminated residential care as: 1) Patient-family-centered; 2) Flexible; and, 3) Comfort-focused. Six environmental features are described as: 1) Site and context; 2) Nature connectivity; 3) Arrival spaces; 4) Communal spaces; 5) Private spaces; and, 6) Transitional spaces. The interaction between residential care and the environmental features creates environmental serenity. **Abstract:** <https://goo.gl/y1a8XS>

Perspectives of health care payer organizations on cancer care delivery redesign: A national study

JOURNAL OF ONCOLOGY PRACTICE | Online – 16 November 2018 – Despite advancements in cancer care, persistent gaps remain in the delivery of high-value end-of-life (EoL) cancer care. Participants endorsed strategies to redesign EoL cancer care delivery to improve EoL care. Participants supported the use of non-professionals to deliver some cancer services through alternative formats (e.g., telephone, Internet) and delivery of services in non-clinical settings. Participants reported that using non-professional providers to offer some services, such as goals-of-care discussions and symptom assessments, via telephone in community-based settings or in patients’ homes, may be more effective and efficient ways to deliver high-value cancer care services. Participants described challenges to redesign, including coordination with and acceptance by oncology providers and payment models required to financially support clinical changes. Some participants suggested solutions, including providing funding and logistic support to encourage implementation of care delivery innovations and to financially reward practices for delivery of high-value EoL cancer care services. **Abstract:** <https://goo.gl/8ivkDk>

Death, dying, and end-of-life experiences among refugees: A scoping review

JOURNAL OF PALLIATIVE CARE | Online – 21 November 2018 – The objective of this scoping review is to identify and map the global literature on death, dying, and end-of-life (EoL) experiences among refugees. The study aims at identifying gaps in the literature produced on the topic and informs areas for future research in the field. The authors included articles that met the following inclusion criteria: 1) Population (refugees and/or internally or externally displaced individuals due to wars, conflicts, non-natural disasters, or emergencies); 2) Setting (EoL phase, dying, and death that took place following the refuge or displacement and reported after the year 1980); and, 3) Study Design (all types of studies including but not limited to primary studies, narrative reviews, systematic reviews, news, editorials, commentaries, opinion pieces, technical reports, and policy briefs). Seven articles met the authors’ inclusion criteria. All articles were co-authored by scholars in universities/research institutes in high-income countries and, except for one, all were conducted in the country of the final settlement of refugees. One article adopted a qualitative approach, another article adopted a mixed-methods approach, one was a narrative review, and four articles were reviews of the literature. Three articles discussed access to medical/palliative care (PC) among older refugees, and three others addressed bereavement and death arrangements. Moreover, one article examined how transmigration and previous experiences from two cultural settings in home countries affect the contemplation of death and dying. Research on EoL experiences among refugees is sorely lacking. This study raises awareness of the need for empirical data on EoL challenges and PC among refugees, thus equipping humanitarian agencies with a more explicit and culturally sensitive lens targeting those with life-limiting conditions. **Abstract:** <https://goo.gl/jB84nS>



Noted in Media Watch 20 August 2018 (#577, p.12):

- *PALLIATIVE MEDICINE* | Online – 16 August 2018 – ‘How do expatriate health workers cope with needs to provide palliative care in humanitarian emergency assistance? A qualitative study with in-depth interviews.’ Fifteen expatriate health workers took part in individual in-depth interviews after their assignment with the organisation Médecins sans Frontières. Clinical situations requiring advanced pain control or palliative care do occur during assignments. **Abstract:** <https://goo.gl/aHsnJh>

Noted in Media Watch 14 May 2018 (#563, p.6):

- *HUMANITARIAN HEALTH DIGEST* | Online – Accessed 11 May 2018 – ‘It’s about time for palliative care in humanitarian emergencies.’ The Syrian crisis has shed light on a myriad of complex issues and gaps, many relating to the protracted nature of conflict and displacement outside of camp settings in middle-income countries. The importance of palliative care in such contexts is critical, but rarely discussed, never mind addressed.¹ **Full text:** <https://goo.gl/DZUKxX>

1. ‘The role of palliative care in addressing the health needs of Syrian refugees in Jordan,’ *Medicine, Conflict & Survival*, 2018;34(1):19-38. **Abstract (w. link to references):** <https://goo.gl/uHNYML>

N.B. Additional articles on the provision of PC during humanitarian crises or natural disasters noted in 7 May 2018 issue of Media Watch (#562, p.11).

Developing a research agenda for adult palliative care: A modified Delphi study

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 November 2018 – Little is known about research priorities in adult palliative care (PC). Identifying research priorities will help in increasing research quality and translation. PC researchers and clinicians in Australia were invited to participate. A total of 25 panelists completed round 1, 14 completed round 2, and 13 completed round 3. Round 1 resulted in 90 research priorities in 13 categories. Round 2 showed consensus agreement on 19/90 research priorities. Round 3 resulted in the top 10 research priorities of the 19 achieving consensus in round 2. Panelists agreed that research is needed on the transition to PC; improving communication about prognosis; increasing access to PC for indigenous communities, people who wish to remain at home, and people in aged care; addressing family caregivers’ needs; promoting patients’ and families’ decision making; improving cross-cultural aspects of PC; determining the effects of assisted dying legislation; and, improving bereavement care in rural, remote, and Aboriginal populations. These identified research priorities are the most urgent topics requiring attention to increase the quality of life of patients requiring PC and their family members. **Abstract:** <https://goo.gl/8g7UE5>

Noted in Media Watch 2 July 2018 (#570, p.7):

- *BMJ EVIDENCE BASED MEDICINE* | Online – 25 June 2018 – ‘Barriers and facilitators to knowledge transfer and exchange in palliative care research.’ Limited evidence exists as to how palliative care (PC) researchers use existing models to support their practice and to what extent they are perceived as effective. Ten themes were identified and categorised as either barriers or facilitators to knowledge transfer and exchange (KTE). Perceived barriers included inadequate time and funding, limited institutional capacity, competing priorities, weak communication channels and negative perceptions of PC. Perceived facilitators included dedicated time and resources, aligned priorities, strong professional networks, multipronged approach and KTE experience. **Abstract:** <https://goo.gl/hvPDor>

N.B. Additional articles on PC research noted in 19 February 2018 issue of Media Watch (#551, pp.11-12).

Spiritual and religious coping of medical decision makers for hospitalized older adult patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2018 – Critically ill adult patients who face medical decisions often delegate others to make important decisions. Those who are authorized to make such decisions are typically family members, friends, or legally authorized representatives, often referred to as surrogates. Making medical decisions on behalf of others produces emotional distress.

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Spirituality and/or religion provide significant assistance to cope with this distress. The majority (67%) of surrogates [i.e., study participants] endorsed belief in God and a personal practice of religion. Five themes emerged in this study: 1) Personal prayer was demonstrated as the most important coping resource among surrogates who were religious, 2) Trusting in God to be in charge or to provide guidance was also commonly expressed; 3) Supportive relationships from family, friends, and co-workers emerged as a coping resource for all surrogates; 4) Religious and non-religious surrogates endorsed coping strategies such as painting, coloring, silent reflection, music, recreation, and reading; and, 5) Some surrogates also shared personal experiences that were transformative as they cared for their ill patients. The coping resources identified in this study may guide professional chaplains and other care providers to design a patient-based and outcome-oriented intervention to reduce surrogate stress, improve communication, increase patient and surrogate satisfaction, and increase surrogate integration in patient care. **Abstract:** <https://goo.gl/uUuKjK>

Noted in Media Watch 27 August 2018 (#578, p.13):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 24 August 2018 – ‘**Cultural and religious diversity in hospice and palliative care: A qualitative cross-country comparative analysis of the challenges of healthcare professionals.**’ Research has demonstrated a strong relationship between culture, religion and the experiences of death, dying and bereavement. Consequently, cultural competence and a religiously sensitive practice have become highly relevant to social policies and professional practice. However, current knowledge of culturally competent and religiously sensitive end-of-life care is primarily context specific, with little space for generalizability. **Abstract:** <https://goo.gl/XmihGd>

N.B. Selected articles on spirituality in the context of palliative and end-of-life care noted in 30 April and 18 June 2018 issues of Media Watch (#561, p.14 and #568, pp.7-8, respectively).

An audit of end-of-life care in persons with intellectual disabilities and dementia

JOURNAL OF POLICY & PRACTICE IN INTELLECTUAL DISABILITIES | Online – 15 November 2018 – With a rise in the life expectancy of people with intellectual disabilities in recent decades, there has been a related increase in rates of dementia. As a chronic, progressive condition dementia presents opportunities for provision of pre-planned end-of-life care (EoLC). This audit focussed on the level of compliance with pre-defined EoLC standards for a group of patients with intellectual disabilities and severe dementia. Compliance with pre-defined EoLC standards was found to be highly variable. Areas of high compliance included all 32 patients [i.e., patient population studied] having access to their primary care physician, 84% having regular review by their psychiatrist and 94% having had a review of their medication regime. In contrast, there was only clear evidence of patient involvement in advance planning for 25% of patients, with similarly few patients having agreement on the use of CPR, a plan for supporting their carers and/or family or a documented preferred place of death. Possible reasons for variable compliance include limited awareness of EoLC standards among intellectual disabilities professionals and carers, difficulties in discerning when patients are approaching the end of their lives and limited involvement of both the patient and palliative care professionals in decision-making approaches. **Abstract:** <https://goo.gl/1tcBMM>

Related

- *LEARNING DISABILITY PRACTICE*, 2018;21(5). ‘**Helping young people who have learning disabilities and their families to plan end of life care: the ADVANCE toolkit.**’ This article introduces the ADVANCE toolkit featuring a values-based framework that aims to help caregivers who work with young people who have learning disabilities, including nurses, social workers and care assistants, develop their confidence and skills in end-of-life care (EoLC) planning. The toolkit enables insight in knowing how, when and with whom to discuss the sensitive topic of planning for EoLC. Six activities are included for readers to complete with a view to enabling engagement with the material presented. **Abstract:** <https://goo.gl/hZicVA>

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Noted in Media Watch 9 July 2018 (#571, p.11):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 1 July 2018 – ‘**Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI).**’ The authors developed a screening tool for deteriorating health, indicative of a limited life expectancy. They describe development of PALLI and explore its applicability. The authors used a five-stage mixed-methods procedure to develop PALLI based on knowledge from practice. **Abstract:** <https://goo.gl/Qev4Mj>

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in 23 April 2018 issue of Media Watch (#560, p.12).

Dying in long-term care: Perspectives from sexual and gender minority older adults about their fears and hopes for end of life

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 20 November 2018 – As lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities age, many individuals expect a need to enter the long-term care (LTC) system toward the end of life (EoL). Not unlike most aging Canadians, this anticipation is met with concern and fear. However, previous research suggests that older LGBTQ+ individuals have unique fears often related to personal safety and discrimination. This qualitative study examined the hopes and fears of older LGBTQ+ adults considering LTC as they face EoL. Specific and frequent reference to fear of entering LTC homes was common across all focus groups, as participants anticipated: social isolation, decreased independence and capacity for decision-making, increased vulnerability to LGBTQ+-related stigma as well as exposure to unsafe social and physical environments. The results from this study, therefore, emphasize the need for palliative care specialists and LTC home staff to address the unique health needs of older LGBTQ+ adults nearing the EoL in order to work toward allaying fears and creating supportive and inclusive LTC environments. **Abstract:** <https://goo.gl/LtYEjZ>

Noted in Media Watch 20 August 2018 (#577, p.13):

- *JOURNAL OF GERONTOLOGICAL SOCIAL WORK* | Online – 13 August 2018 – “**Fear runs deep”: The anticipated needs of LGBT older adults in long-term care.**’ This study adds to the existing literature about the worries of older lesbian, gay, bisexual, and transgender (LGBT) adults as they anticipate long-term care. The results suggest that they seek LGBT-inclusive residential care settings that encompass two distinct yet related aspects of LGBT-affirmative care: the procedural (e.g., culturally competent skills and knowledge of practitioners) and the implicit (e.g., the values and mission of the organization). This paper identifies implications for practice, policy, and training. **Abstract (w. link to references):** <https://goo.gl/pbBf7r>

N.B. Selected articles on palliative and end-of-life care for LGBTQ persons noted in this issue of Media Watch.

Walking in two worlds: Hmong end-of-life beliefs and rituals

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 20 November 2018 – For over 40 years, the Hmong have sought refuge in the U.S.; however, many Hmong elders continue to honor healthcare and end-of-life (EoL) beliefs and rituals that they practiced in their home country. With little knowledge by the general public and healthcare systems about these beliefs and rituals, healthcare professionals may struggle to provide the Hmong community with culturally-sensitive care. This study sought to address this gap by conducting in-depth face-to-face interviews with 12 Animist and 8 Christian Hmong elders born in Southeast Asia, who now reside in the U.S. Results provided insights regarding the heterogeneity among these Hmong elders concerning their EoL beliefs and rituals. Both Animist and Christian respondents believed family should provide care at EoL. Animist Hmong elders reported the importance of Shamanistic rituals such as soul calling or spiritual offering while Christian Hmong elders believed in the power of prayers. Healthcare providers need to assess Hmong elders’ preferences for care at EoL, be open to the inclusion of traditional healers in their care and/or decision-making, and understand preferences of family and community members’ involvement in care at the EoL. **Abstract:** <https://goo.gl/Nz5foT>

End-of-life resource for African American caregivers: Reflections on a field education model

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 20 November 2018 – Research into end-of-life care issues has grown exponentially over the past decade, while the science undergirding direct practice remains underdeveloped. Several national consensus panels – National Consensus Project for Quality Palliative Care (2009), National Hospice & Palliative Care Organization (2016) – have included strategic initiatives to advance patient-centered practices and confirmed the need for research into the experiences of individuals, families and extended support systems of for for the dying. Many social work students, in the program that generated this report, have expressed that one of the most important issues to address is racial disparity in hospice & palliative care. **First page view:** <https://goo.gl/jqjYYP>

N.B. Selected articles on racial disparities in the provision and delivery of end-of-life care in the U.S. noted in 16 July and 5 November 2018 issues of Media Watch (#572, p.5 and #588, p.8, respectively).

Place of death and factors associated with hospital death in patients who have died from liver disease in England: A national population-based study

THE LANCET GASTROENTEROLOGY & HEPATOLOGY | Online – 21 November 2018 – Liver disease is a major cause of mortality, with high numbers of hospital deaths, and disproportionately affects people younger than 65 years. 135,953 decedents were included in this national population based study, of whom 56,065 (41.2%) died from alcohol-related liver disease. Annual deaths from liver disease increased from 7,811 in 2001, to 11,017 in 2014. Hospitals were the main place of death ... for patients who died from liver disease. The proportion of hospital deaths reduced from 71.5% in 2001 to 60.0% in 2014. After adjusting for socio-demographic factors, patients who died from alcohol-related liver disease had the highest chance of hospital death; people who died from liver cancer were less likely to die in hospital than people with alcohol-related liver disease... People with four or more contributory causes of death were more likely to die in hospital than those with no contributory causes... Patients with sepsis, hepatorenal syndrome, and peritonitis had higher chances of hospital death than those without these respective contributory causes, and those with alcohol-related disorders had lower chances of hospital death. The high risk of hospital death in patients with sepsis, hepatorenal syndrome, or peritonitis warrants further investigation, and the low chance of hospital death in patients with alcohol-related disorders also needs to be explored. Prevention strategies and end-of-life care services are urgently needed to prevent and tackle harms from liver disease. **Abstract (inc. list of references):** <https://goo.gl/wHAQQE>

Related

- *THE LANCET GASTROENTEROLOGY & HEPATOLOGY* | Online – 21 November 2018 – ‘**Unmet needs in end-of-life care for chronic liver disease.**’ Despite improvements in other chronic diseases, liver disease mortality increased by 400% in the U.K. between 1970 and 2010, resulting in rising pressures on acute hospital services, and an increasing need for end-of-life care. Alcohol-related liver disease has been responsible for at least two in every five deaths due to liver disease over the past two decades. Corresponding to increased rates of obesity, the proportion of chronic liver disease-related deaths due to non-alcoholic fatty liver disease has doubled over the past decade. Together with other aetiologies such as chronic viral hepatitis, these key drivers of hepatic mortality represent opportunities to reduce premature mortality and improve quality of life, especially in symptomatic end-stage liver disease. **Abstract (w. list of references):** <https://goo.gl/Z5njXD>



Closing the Gap Between Knowledge & Technology
<http://goo.gl/OTpc8I>

The Italian law on informed consent and advance directives: Its impact on intensive care units and the European legal framework

MINERVA ANESTESIOLOGICA | Online – 21 November 2018 – The Italian parliament has recently approved a law on informed consent, advance directives and advance care planning. The law also deals with health care proxy and health care decisions for minors and adults who are not able to give consent. The Italian law arrived quite late in comparison with other European countries. After several years of debate on the need to approve such a law, the focus has now shifted to the assessment of the legislative provisions and their impact on clinical practice. In this article, the authors firstly offer an overview of the findings from the empirical research regarding the use of the different legal tools in the field of intensive care medicine; secondly, they present the tools now provided by law no. 219/2017 particularly with regard to the decision-making processes in the intensive care unit; thirdly, the authors offer a comparison between the new Italian law and other European legal orders, with special reference to France, Spain, Germany and England. The aim of the article is to assess the degree of innovation of the law *vis-à-vis* the previous framework. **Abstract:** <https://goo.gl/Rkn81B>

Exploring the concept of *Ubuntu* in relation to dying with dignity in palliative and hospice care

OBITER, 2018;39(2):384-398. The [South African] Supreme Court of Appeal in *Minister of Justice & Correctional Services v Estate Stransham-Ford* raised more questions than the answers it provided. However, of note is the enquiry it made regarding the implications of palliative care (PC) in relation to whether the criminality of physician-assisted suicide and physician-administered euthanasia infringes a person's dignity. In response, the author aims to reconstruct – through the lens of *Ubuntu* – our understanding of human dignity and draw links with how the values of compassion and survival, which underpin *Ubuntu*, enjoin us as a re-affirmation of human dignity, to strive towards making hospice and PC readily available. Ultimately, this is done for the benefit of providing constitutionally sound reasons for why greater emphasis should be placed on hospice and PC when it comes to dying with dignity. To this effect, a conceptual framework of human dignity that is based on *Ubuntu* is summarised. This is done for the purpose of properly aligning the understanding of the right to dignity to one that represents our constitutional dispensation and ethos. Flowing from this is an extract of the values of compassion and survival that underpin *Ubuntu*. These values are then used to gain a lucid perspective, as to why – in our pursuit of providing a dignified death for terminally ill patients – greater emphasis should be placed on hospice and PC. **Abstract:** <https://goo.gl/TiVrv6>



N.B. *Ubuntu* is a Nguni Bantu term meaning “humanity.” It is often translated as “I am because we are,” and also “humanity towards others,” but is often used in a more philosophical sense to mean “the belief in a universal bond of sharing that connects all humanity. In Southern Africa, it has come to be used as a term for a kind of humanist philosophy, ethic, or ideology, also known as Ubuntuism (source: Wikipedia).

Quality indicators for palliative day services: A modified Delphi study

PALLIATIVE MEDICINE | Online – 19 November 2018 – Currently, there are no published quality indicators for palliative day services (PDS). A panel of experts independently reviewed evidence summaries for 182 candidate indicators and provided ratings on appropriateness, followed by a panel discussion and further independent ratings of appropriateness, feasibility and necessity. This exercise resulted in the identification of thirty indicators which were used in practice testing. The final indicator set comprised seven structural indicators, twenty-one process indicators and two outcome indicators. The indicators fulfil a previously unmet need among PDS providers by delivering an appropriate and feasible means to assess, review, and communicate the quality of care, and to identify areas for quality improvement. **Abstract:** <https://goo.gl/tygV66>

Information provision as evaluated by people with cancer and bereaved relatives: A cross-sectional survey of 34 specialist palliative care teams

PATIENT EDUCATION & COUNSELING | Online – 19 November 2018 – A cross-sectional survey was conducted within four multidisciplinary palliative homecare teams, 17 hospital-based palliative care units (PCUs) and 13 hospital-based mobile palliative support teams (PSTs) in Belgium. During four measurement periods, structured questionnaires were administered to people being guided by specialist palliative care services (PCSs) and relatives of patients who had died while under the care of PCSs. Compared with those receiving care within a PCU, those being supported by a PST were more likely to report sub-optimal information provision and decision-making. Relatives of those who had died while under the guidance of a PST were also more likely to report suboptimal information provision than their PCU counterparts. Although information provision to cancer patients and relatives being supported by PCSs is generally evaluated positively, evaluations depend on the type of service. Information provided within PCUs offering highly personalised, continuous care appears to both groups more satisfactory than that provided by palliative care teams mainly supporting care staff. **Abstract:** <https://goo.gl/71AxRY>

Related

- *ANNALS OF ONCOLOGY*, 2018;29(10):2033-2036. ‘**Training in communication of oncology clinicians: A position paper based on the third consensus meeting among European experts in 2018.**’ Since there is sound evidence that communication skills training programs modify communication behavior of oncology clinicians, they have been widely implemented over the last decades. However, more recently, certain aspects of this training have been criticized. The expanded recommendations recall the guiding principles of communication in cancer care, underline the important role of clinician’s self-awareness, and of relational and contextual factors in clinical communication, and provide direction for the further development of communication training. **Abstract:** <https://goo.gl/s35EK6>

Guiding practitioners through end-of-life care for people with dementia: The use of heuristics

PLOS ONE | Online – 14 November 2018 – End of life (EoL) care for people with dementia can present a multitude of challenges and difficult decisions for practitioners. These challenges may include assessment and management of difficulties with eating and swallowing, responding to agitation, treating pain, and managing recurrent infections. Practitioners sometimes lack both confidence in making EoL decisions and guidance. This study developed an alternative to lengthy guidelines, in the form of heuristics which were tested in clinical settings. Four heuristics were developed covering: 1) Eating and swallowing difficulties; 2) Agitation and restlessness; 3) Reviewing treatment and interventions at the EoL; and, 4) Providing routine care. Five clinical or care settings sites reported that the heuristics were simple and easy to use, comprehensive, and made implicit, tacit knowledge explicit. Four themes emerged from the qualitative evaluation: 1) Authority and permission; 2) Synthesis of best practice; 3) Providing a structure and breaking down complexity; and, 4) Reassurance and instilling confidence. Use of heuristics is a novel approach to EoL decision making in dementia which can be useful to both experienced and junior members of staff making decisions. Heuristics are a practical tool which could overcome a lack of care pathways and direct guidance in EoL care for people with dementia. **Full text:** <https://goo.gl/zDLYNa>

Related

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 November 2018 – ‘**Welcoming death: Exploring pre-death grief experiences of caregivers of older adults with dementia.**’ This qualitative study explored the end-of-life experiences for 36 bereaved family caregivers of older adults with dementia, focusing on understanding their experiences with pre-death grief. These caregivers shared experiences with the phenomenon of “welcoming death” and findings highlighted the primary reasons they anticipated, accepted, or wished for the death of their family member with dementia. With the overarching goal of improving bereavement outcomes and reducing feeling of guilt, inclusion of pre-death grief support services throughout the caregiving process are recommended. **Abstract:** <https://goo.gl/Sh9UT1>

N.B. Selected articles on palliative care for people living with Alzheimer’s and other forms of dementia noted in 1 & 22 October 2018 issues of Media Watch (#583, p.10 and #586, p.12, respectively).

Current practices, barriers and enablers for advance care planning among healthcare workers of aged care facilities in western New South Wales, Australia

RURAL & REMOTE HEALTH, 2018;18(4):4714. Advance care planning plays a critical role in aged care and end-of-life care, and several factors influence its implementation into residential aged care facilities in western New South Wales. There is a consensus that advance care directives (ACDs) are important and will only become increasingly so given Australia's ageing population. Healthcare workers find that ACDs provide a large benefit in optimising care for their patients. The present research also shows that, within the central west and Orana regions, ACDs are approached in a multidisciplinary fashion with responsibility shared among multiple practitioners, and that a patient's ability to communicate effectively is conducive to the facilitation of an ACD. Current healthcare workers are desirous of more training, but acknowledge that on-the-ground experience may be more beneficial. **Full text:** <https://goo.gl/huoNqT>

Revisiting “awareness contexts” in the 21st century hospital: How fragmented and specialized care shape patients’ awareness of dying

SOCIAL SCIENCE & MEDICINE, 2019;220(1):212-218. Glaser and Strauss offered the concept of “awareness contexts” to explain what patients in hospitals do or don't know about their death trajectories.¹ Awareness ranges from closed (where patients are completely unaware and family and providers protect “the secret”) to open (where all parties communicate openly and honestly). While closed awareness was the norm in 1960s, open awareness is now considered standard practice in the U.S., a reflection of mounting evidence that patients, families, and providers benefit from clear and honest communication at end of life... Despite the known benefits of open awareness, many terminal patients remain unaware or confused about their prognoses. This paper asks why, in an era of open awareness, are patients and families uncertain about dying? To answer this question, the authors focus on an aspect of Glaser and Strauss's theory that remains relatively understudied by researchers, namely the role of institutional and organizational realities in shaping awareness contexts. Based on interviews with 43 family members of deceased patients who died at General Hospital in the Midwestern U.S., the authors argue that two related conditions in hospitals – the increased specialization of medical professionals and the fragmentation of patient care – serve as important context for the death awareness of patients and families. **Full text:** <https://goo.gl/zqFGCE>

1. 'Awareness contexts and social interaction,' *American Sociological Review*, 1964;29(5):669-679. **Pre-view:** <https://goo.gl/KXuJYg>

End-of-life care in prison

SOCIAL WORK TODAY, 2018;18(6):16. For many of the individuals incarcerated across the U.S., dying is more than a possibility or passing thought. Given their sentences, their age, and, often, their health, dying in prison is inevitable. The circumstances of the death vary based not only on the person but the facility as well. For some, dying in their cell with their cellmate nearby is the best of terrible options. “They die in their ‘homes,’ where their cellmates are, their friends are,” says Marvin Mutch, associate of the Humane Prison Hospice Project and director of advocacy at the Prisoner Reentry Network.^{1,2} Mutch was imprisoned for 41 years after a wrongful conviction in 1975 and was released in 2016. Dying in one's cell, however, is difficult, not only for the prisoner but also for their cellmate, Mutch says. “In San Quentin [State Prison],” where Mutch was, “there were many times when guys died on their cell floor. If you die in your cell, your cellmate goes to segregation until the autopsy is completed. Most of these guys have lived together as lifers for years, [and] now their grief process must start in total isolation.” In other circumstances, when the individual goes to the infirmary and end-of-life services are not available, the prisoner is often faced with dying completely alone. Documentary filmmaker Edgar Barends (‘Prison Terminal: The Last Days of Private Jack Hall’), whose film ‘Angola Prison Hospice: Opening the Door’ has been used as a training tool for prisoners, concurs with Mutch.^{3,4} “Most people either die alone in their cells, in the

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prison infirmary, or they get sent off to a state or university hospital where they are shackled to the bed. If there's a nurse in there when you're dying, you're lucky," he says. Fortunately, individuals, such as Mutch and Barends, and organizations throughout the country, are working to implement hospice services in prisons. In doing so, the prisoners – the people – are able to die with dignity and compassion. **Full text:** <https://goo.gl/uogd8R>

1. Humane Prison Hospice Project website: <https://goo.gl/HZmEJX>
2. Prisoner Reentry Network website: <https://goo.gl/JGiiGm>
3. 'Prison Terminal: The Last Days of Private Jack Hall' website: <https://goo.gl/Nr1APX>
4. 'Angola Prison Hospice: Opening the Door,' Open Society Foundations: <https://goo.gl/ypF72Q>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report [last updated 1 November 2018] can be downloaded/viewed on the Palliative Care Network website at: <https://goo.gl/dqwNBA>

Habermasian communication pathologies in do-not-resuscitate discussions at the end of life: Manipulation as an unintended consequence of an ideology of patient autonomy

SOCIOLOGY OF HEALTH & ILLNESS | Online – 20 November 2018 – The focus on patient autonomy in American and increasingly British medicine highlights the importance of choice. However, to truly honour patient autonomy, there must be both understanding and non-control. [In this study] at hospitals where autonomy was prioritised, trainees equated autonomy with giving a menu of choices and felt uncomfortable giving a recommendation based on clinical knowledge as they worried that that would infringe upon patient autonomy. Employing Habermas's 'Theory of Communicative Action,' this article explores how physician trainees' communication practices of using purposefully graphic descriptions of resuscitation to discourage that choice prevent greater understanding and compromise non-control. Central to this problem are also issues of colonisation of the life-world by the system. Physicians are fully inculcated in their respect for autonomy but unintentionally resort to strategic forms of communication that prevent patients from adequately understanding their situation because trainees feel constrained against making recommendations. However, if the ideal of autonomy is to be realised, physicians might have to move towards practices that embrace a more authentic autonomy that fosters open communication that allows for co-creation of consensus between doctors and patients. **Abstract:** <https://goo.gl/NVYicx>

N.B. In sociology, communicative action is cooperative action undertaken by individuals based upon mutual deliberation and argumentation. The term was developed by German philosopher-sociologist Jürgen Habermas in his work 'The Theory of Communicative Action' (source: Wikipedia).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 November 2018 – '**Conscientious objection and physician-assisted suicide: A viable option in the U.K.?**' Conscience objection is a proposed way of ensuring that medical practitioners who object to physician-assisted suicide may avoid having to be involved in such a procedure if this is legalised. This right on the part of healthcare professionals already exists in certain circumstances. This paper examines the ethical and legal grounds for conscientious objection for medical professionals and shows how it is heavily criticised in circumstances where it is already used. The authors come to the conclusion that as the grounds and application of conscience objection are no longer as widely accepted, its future application in any legislation can be called into question. **Abstract:** <https://goo.gl/cZWN3i>

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- *CANADIAN JOURNAL OF COUNSELLING & PSYCHOTHERAPY*, 2018;52(45). ‘**Working with clients who choose medical assistance in dying: A new landscape for counsellors.**’ The passing of Bill C-14 legalized medical assistance in dying (MAiD) in Canada in June 2016. As of October 2017, more than 2,000 Canadians had successfully utilized MAiD. Currently, it remains unclear how to best serve the psychological needs of these individuals. The extant literature is reviewed to offer awareness and understanding about who chooses MAiD. The rationale for this decision, the impact on family members, and changes in attitudes and experiences of death and dying are provided. Counsellor recommendations are discussed along with future research directions. A call is made to examine existing theories of death and dying to expand and reflect this new experience of dying. **Abstract:** <https://goo.gl/Y7N1Xx>
- *DEATH STUDIES* | Online – 21 November 2018 – ‘**Bereavement experiences following a death under Oregon’s Death with Dignity Act.**’ This qualitative study explores bereavement experiences with an assisted death. Thematic analysis of data from interviews with 22 people who had a family member die under Oregon’s Death with Dignity Act revealed the following themes: 1) General grief reactions; 2) Anticipating the death; 3) Sense of control; 4) Level of agreement with assisted death; and, 5) Grief expression and stigma. Grief from an assisted death is a varied experience, including aspects that are unique to this mode of death, and aspects that can both ease and bring challenges to the grieving process. **Abstract:** <https://goo.gl/KxGbQF>
- *JOURNAL OF MEDICAL ETHICS* | Online – 21 November 2018 – ‘**Situating requests for medical aid in dying within the broader context of end-of-life care: Ethical considerations.**’ Medical aid in dying (MAiD) was introduced in Quebec in 2015. Quebec clinical guidelines recommend that MAiD be approached as a last resort when other care options are insufficient; however, the law sets no such requirement. To date, little is known about when and how requests for MAiD are situated in the broader context of decision-making in end-of-life (EoL) care; the timing of MAiD raises potential ethical issues. A retrospective chart review of all MAiD requests between December 2015 and June 2017 at two Quebec hospitals and one long-term care centre was conducted to explore the relationship between routine EoL care practices and the timing of MAiD requests. Of 80 patients requesting MAiD, 54% (43) received the intervention. The median number of days between the request for MAiD and the patient’s death was 6 days. The majority of palliative care consults (32%) came less than 7 days prior to the MAiD request and in another 25% of cases occurred the day of or after MAiD was requested. 35% of patients had no level of intervention form, or it was documented as 1 or 2 (prolongation of life remains a priority) at the time of the MAiD request and 19% were receiving life-prolonging interventions. Whether or not MAiD is conceptualised as morally distinct from other EoL options is likely to influence clinicians’ approach to requests for MAiD as well as the ethical importance of the authors’ findings. The authors suggest that in the wake of the 2015 legislation, requests for MAiD have not always appeared to come after an exploration of other options as professional practice guidelines recommend. **Abstract:** <https://goo.gl/1SjstG>
- *JOURNAL OF MEDICAL ETHICS* | Online – 21 November 2018 – ‘**Drawing the line on physician-assisted death.**’ Drawing the line on physician assistance in physician-assisted death (PAD) continues to be a contentious issue in many legal jurisdictions across the U.S., Canada and Europe. As more legal jurisdictions establish PAD for at least some class of patients, the question of the proper scope of this practice has become pressing. This paper presents an argument for restricting PAD to the terminally ill that can be accepted by defenders as well as critics of PAD for the terminally ill. The argument appeals to fairness-based paternalism and the social meaning of medical practice. These two considerations interact in various ways... The right way to think about the social meaning of medical practice bears on fair paternalism as it relates to PAD and *vice versa*. The paper contends that these considerations have substantial force when directed against proposals to extend PAD to non-terminally ill patients, but considerably less force when directed against PAD for the terminally ill. The paper pays special attention to the case of non-terminally ill patients who suffer from treatment-resistant depression, as these patients present a potentially strong case for extending PAD beyond the terminally ill. **Abstract:** <https://goo.gl/NDjivS>
- *JOURNAL OF PALLIATIVE CARE* | Online – 21 November 2018 – ‘**A Canadian academic hospital’s initial medical assistance in dying experience: A healthcare systems review.**’ The authors describe the manner in which London Health Sciences Center (LHSC) has approached local and regional requests for medical assistance in dying (MAiD, including the administration, ethics, privacy, and clinical-

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cal process. Between 6 June 2016 and 30 May 2018, the LHSC's MAiD Internal Resource Committee triaged and referred 260 cases. Ninety-six received the requisite assessments were deemed eligible for and received MAiD. The procedure was completed in hospital 59 (61%) times, and 37 (39%) times in the community (either private residence or long-term care facility). Nineteen patients did not meet MAiD criteria and 63 patients died while awaiting the procedure. The median wait time between first request and referral was one day. The median time between referral and the procedure was 12.0 days. The ratio of referrals its completed cases is 96 of 260 (or 37% conversion rate). The LHSC's MAiD processes, including committee structure, referral triage process, and physical site have all undergone extensive review and improvement cycles ... with the aim of ensuring this procedure is managed in a respectful, confidential, safe, efficient, and patient-centered manner. **Abstract:** <https://goo.gl/dJQZ8W>

Publishing Matters

Why researchers decide to publish papers in questionable journals: Awareness and motivation

LEARNED PUBLISHING | Inprint – Accessed 23 November 2018 – Peer review is a cornerstone of scientific publication and consequently, predatory journals are feared to be a threat to the credibility of science as they perform no or low-quality peer review. The question of why researchers decide to publish in a questionable journal remains relatively unexplored. This paper provides an overview of the existing literature on why researchers decide to publish papers in questionable journals, specifically whether or not they search for a low-barrier way to getting published, while being aware that the chosen journal probably does not adhere to acceptable academic standards. The choice of a publication outlet can be seen as a submission tree which consist of various incentives, and explaining why authors publish in deceptive journals may thus consist of a combination of awareness and motivational factors. Awareness as well as motivation of diligent authors is far from those of unethical authors. Unethical authors may use lack of awareness to excuse their actions, but they do indeed search for a low-barrier way to getting published. There are different types of authors who publish in deceptive journals, and we thus need different approaches to solve the problem. **Abstract:** <https://goo.gl/kzeZZd>

Media Watch: Editorial Practice

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Something Missed or Overlooked?

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

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International



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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

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

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

Europe

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

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

South America



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

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