

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.

20 December 2021 Edition | Issue #748



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Compiled & Annotated by Barry R. Ashpole

If palliative care is a human right, then its philosophy should be considered in its entirety, with the inclusion of psychosocial care.

'A systematic literature review exploring the psychosocial aspects of palliative care provision for incarcerated persons: A human rights perspective' (p.9), in *International Journal of Prisoner Health*.

Important Notice: The next issue of Media Watch will be published 3 January 2022.

Canada

Promoting a Cree palliative approach in Eeyou Istchee within the Cree Board of Health & Social Services of James Bay

QUÉBEC | McGill University Council of Palliative Care – 7 December 2021 – The Québec policy on palliative care (PC) stated the main issue with PC services is lack of coordination and this characterises the situation at the Cree Board of Health. However, it has a project funded by the Health Care Policy Contribution Program of Health Canada to explore how to adapt services for the Cree by focusing on four activities. With the project as a catalyst, the organisation is now actively planning how to structure and coordinate PC within its services. PC for Cree not only involves the Cree Board of Health but also the three other regions where Cree patients with long-term serious illness are sent out to receive specialized care, including palliative. In the five years ending in 2019-2020, an annual average of about 28 Cree were being diagnosed as palliative and dying in hospitals outside of the region. This was around 40% of annual deaths and is a minimum number. Other people died following long-term serious illnesses but were not necessarily documented as palliative either inside or outside of the region.

Similar to birthing, the process of dying in Eeyou Istchee has become medicalized and often far removed from the comforting, familiar and familial patterns only found within the family, community and language. Cree rites of passage during the process of dying were founded on common understandings and known practices to witness together that person's final transition onto their new journey. Today, people in the communities and those working within health services are ready to support initiatives to adapt services to find a better approach to ease the way of those who are dying and those they are leaving behind. <https://bit.ly/3GLou93>

Specialist Publications

'Part of the solution: A survey of community organisation perspectives on barriers and facilitating actions to advance care planning in British Columbia, Canada' (p.7), in *Health Expectations*.

U.S.A.

Staffing shortage closes Iowa Hospice House

HOSPICE NEWS | Online – 15 December 2021 – An Iowa hospice provider is closing its inpatient hospice house as of 31 December due to the industry-wide staffing shortage. The organization will continue to provide care in patient homes, skilled nursing and assisted living facilities. Worsening workforce shortages have been keeping hospice leaders awake at night for several years running. Rising turnover due to the COVID-19 pandemic has exacerbated the crisis, and some hospice providers and health systems are starting to shut down their programs or sell off their operations because they cannot recruit or retain a sufficient number of employees. The Idaho-based Minidoka Memorial Hospital home health and hospice program was shuttered in September, also due to insufficient staffing. In Oregon, Grande Ronde Hospital & Clinics recently closed

its hospice program due to labor shortages. The organization indicated the COVID-19 pandemic exacerbated industry-wide workforce issues, leading to the decision to close. Hospices face unique recruitment challenges, particularly because medical, nursing, and social work students receive very little exposure to hospice or palliative care during their training. <https://bit.ly/3q0BH7h>

Specialist Publications

'A qualitative study of the role of palliative care during the COVID-19 pandemic: Perceptions and experiences among critical care clinicians, hospital leaders, and spiritual care providers' (p.4), in *American Journal of Hospice & Palliative Medicine*.

Noted in Media Watch 23 August 2021 (#731, p.2):

- *HOSPICE NEWS* | Online – 16 August 2021 – **'Workforce shortage shutting down hospice programs.'** Worsening workforce shortages have been keeping hospice leaders awake at night for several years running. Rising turnover due to the COVID-19 pandemic has exacerbated the crisis, and some hospice providers and health systems are starting to shut down their programs or sell off their operations because they cannot recruit or retain a sufficient number of employees. Healthcare providers have seen staff turnover rise during the pandemic, and hospice is no exception. Slightly more than 20% of healthcare workers have considered leaving the field due to stress brought on by the pandemic, and 30% have considered reducing their hours, according to a recent study...¹ <https://bit.ly/3iTnrec>

1. 'Experiences of a health system's faculty, staff, and trainees' career development, work culture, and childcare needs during the COVID-19 pandemic,' *JAMA Network Open*, 2021;4(4):e213997. **Full text:** <https://bit.ly/3yYc8aD>

Noted in Media Watch 7 June 2021 (#720, p.3):

- *HOSPICE NEWS* | Online – 1 June 2021 – **'Grand Ronde ends hospice program due to workforce shortage.'** Grande Ronde Hospital & Clinics ... indicated that the COVID-19 pandemic exacerbated industry-wide workforce issues, leading to the decision to close. Many hospice providers have seen staff turnover rise during the pandemic... Slightly more than 20% of healthcare workers have considered leaving the field due to stress brought on by the pandemic...¹ More than 35% of hospice leaders surveyed cited staffing shortages as a top concern for their organizations...² Staffing shortages have plagued the hospice industry for years. The U.S. has 13.35 hospice and palliative care specialists for every 100,000 adults 65 and older...³ <https://bit.ly/3g7sBkd>

1. 'Experiences of a health system's faculty, staff, and trainees' career development, work culture, and childcare needs during the COVID-19 pandemic,' *JAMA Network Open*, 2021;4(4):e213997. **Full text:** <https://bit.ly/3yYc8aD>
2. 'Top hospice worries 2021: Accessing facility-bound patients, staffing,' *Hospice News*, published online 8 February 2021. [Noted in Media Watch 15 February 2021 (#704, p.1)] <http://bit.ly/3p78SDs>
3. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 5 February 2018 (#549, p.12)] **Full text:** <http://bit.ly/2CRjxwO>

Hospice stakeholders develop two palliative care quality measures

HOSPICE NEWS | Online – 15 December 2021 – The American Academy Palliative Medicine has unveiled two new patient-reported quality measures for community-based palliative care (PC). These were born as part of the first funding initiatives to develop measures for the U.S. Centers for Medicare & Medicaid Services (CMS) Quality Payment Program, including the Merit-Based Incentive Payment System and alternative payment models. CMS in 2018 awarded \$5.5 million to support a three-year PC project aimed at developing, improving and expanding measures to improve patient outcomes and drive high-quality care. A public-private coalition of seven organizations collaborated on the project. With the recent completion of the Palliative Care Measures Project,¹ these measures became available to hospice, and other providers to implement in their practice. At the project's launch, then CMS Administrator Seema Verma emphasized the importance of collaborating with clinicians, patients and other key stakeholders to identify quality measures that will meaningfully impact patient care. The two new measures fall under the category of "patient-reported outcome performance measures" that specifically assess quality of care using two main indicators: 1) How much patients felt heard and understood; and, 2) If patients got the help they wanted for their pain. <https://bit.ly/3IT09hC>

1. Palliative Care Measures Project, National Coalition For Hospice & Palliative Care: <https://bit.ly/328DmPI>

International

A highly personalised approach to end of life care is needed to help Gypsy, Traveller and Roma communities

U.K. | National Institute for Health Research – 17 December 2021 – Better understanding of the Gypsy, Traveller and Roma communities would help develop healthcare services which are more acceptable to them. New research explored values and beliefs in communities, along with the practical barriers their members face in accessing healthcare.¹ The research team says that these communities need sensitive and highly personalised services. People in Travelling communities are known to struggle to access and engage with standard healthcare services. This research explored the reasons why. It focused on palliative care (which aims to make someone comfortable, rather than to cure them) and end-of-life care. The research described the strong family and community values, distinct health beliefs and practical barriers to healthcare access within Travelling communities. The researchers say that a better understanding of these factors would help healthcare professionals and policymakers take a more sensitive and personalised approach to the care offered to members of these communities. **Full text:** <https://bit.ly/3yFN4p1>

1. 'The palliative and end-of-life care experiences, views and needs of Gypsy, Traveller and Roma communities...', *BMJ Supportive & Palliative Care*, published online 9 February 2021. [Noted in Media Watch 15 February 2021 (#704, p.2)] **Abstract:** <http://bit.ly/36WRaMC>

Breaking the cycle for a better end of life

U.K. (Scotland) | *Holyrood* (Edinburgh) – 13 December 2021 – Preliminary findings from Marie Curie research on poverty at the end of life (EoL) shows that in 2019 in Scotland, over a quarter (27%) of people of a working age (20-64 years old) were in poverty in the their last year of life, as well as 12% of people over 65.¹ The research found that across the U.K. one of the key differences was age; the majority of those dying at working age had experienced poverty at some point in the previous five years and a substantial minority moved below the poverty line in the last two years of life, or experienced movement in and out of poverty. These findings highlight the importance of maximising the income people can receive when terminally ill and approaching the EoL, including ensuring social security benefits reach all terminally ill people and their carers, and are sufficiently high enough to ensure families can at least live above poverty line. We know from existing evidence that terminally ill people affected by this cycle of poverty, deprivation, exclusion

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and wider health inequalities have historically faced multiple barriers in accessing and engaging with palliative care support, from lack of care options and health literacy to barriers because of race, gender, faith, age or sexuality amongst others. Earlier this year in its Programme for Government 2021-2022, the Scottish Government committed to a new National Palliative Care Strategy. This is an opportunity which must be taken to tackle health inequalities for those who are terminally ill and at EoL, working inclusively and collaboratively with those who have lived-experience and all service providers to ensure that services are equipped and empowered to support our most vulnerable in society. <https://bit.ly/3GLUJd7>

1. 'The Better End of Life Report 2021: Dying, Death & Bereavement During COVID-19 Research Report,' Marie Curie, April 2021. [Noted in Media Watch 12 April 2021 (#712, p.4)] **Download at:** <https://bit.ly/3mrvbNWP>

Noted in Media Watch 20 September 2021 (#735, p.10):

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 12 September 2021 – '**The impact of poverty and deprivation at the end of life: A critical review.**' This review interrogates what we know about how poverty and deprivation impact people at the end of life (EoL) and what more we need to uncover. While we know that people in economically resource-rich countries who experience poverty and deprivation over the life course are likely to die younger, with increased co-morbidities, palliative care researchers are beginning to establish a full picture of the disproportionate impact of poverty on how, when and where we die. The authors use a critical social science lens to investigate an eclectic range of literature addressing health inequities and is focused on poverty and deprivation at the EoL. **Full text:** <https://bit.ly/3Aa3E02>

N.B. Search back issues of Media Watch for additional articles on palliative and end-of-life care in "Scotland" at: <http://bit.ly/2ThijkC>

[Specialist Publications](#)

A qualitative study of the role of palliative care during the COVID-19 pandemic: Perceptions and experiences among critical care clinicians, hospital leaders, and spiritual care providers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 December 2021 – Palliative care (PC) offers a unique skill set in response to challenges posed by the COVID-19 pandemic, with expertise in advance care planning, symptom management, family communication, end-of-life care, and bereavement. However, few studies have explored PC's role during the pandemic and changes in perceptions and utilization of the specialty among health and spiritual care providers and hospital leaders. The authors conducted the study at a tertiary academic medical center in Boston, Massachusetts, U.S. Between August and October 2020, they interviewed 25 participants from three informant groups: 1) Critical care physicians; 2) Hospital leaders; and, 3) Spiritual care providers. Respondents recognized that PC's role increased in importance during the pandemic. PC served as a bridge between providers, patients, and families; supported provider well-being; and, contributed to hospital efficiency. The pandemic reinforced participants' positive perceptions of PC, increased their understanding of the scope of the specialty's practice, and inspired physicians to engage more with PC. Respondents indicated the need for more PC providers and advocated for their role in bereavement support and future pandemic response. Findings highlight evolving and increased utilization of PC during the pandemic, suggesting a need for greater investment in PC programs and for PC involvement in public health emergency preparedness and response. **Abstract (w. references):** <https://bit.ly/3GBNj7l>

Noted in Media Watch 13 December 2021 (#747, p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 December 2021 – '**Hospital-based palliative and end-of-life care in the COVID-19 pandemic: A scoping review.**' This review highlights the increased awareness and knowledge of palliative and end-of-life care provided in hospitals. The COVID-19 pandemic and subsequent increased admission to hospitals has led to increased referral rates to these services, which in turn has the potential to improve patients and family care and assist with greater interaction and consultation with specialist palliative care (PC) in the future. The review also highlights the rapid response of hospital-based PC teams to an evolving crisis, within the context of developed health systems under sustained and overwhelming pressure. **Full text:** <https://bit.ly/3lYs3AH>

Qualitative insights into the palliative care experience of a hospice-based sensory room

ARTS & HEALTH | Online – 7 December 2021 – The use of multi-sensory rooms as a form of engagement with art in palliative care is largely unexplored. This practice-based report discusses a qualitative study exploring the experiences of hospice-based inpatients receiving end-of-life (EoL) care and their carers who immersed themselves into a multi-sensory room. Findings demonstrate that the room provided a safe space for reflection and reconnection that counteracted challenging times during their EoL. It fostered healing and wellbeing by alleviated suffering through respite and sharing of treasured memories with loved ones. Key considerations for future iterations are also discussed. **Abstract:** <https://bit.ly/3pTvV7m>

N.B. Video of the Kwop Wirrin Human Room, the hospice-based sensory room, at the Albany Community Hospice, Albany, Western Australia: <https://bit.ly/31VGtdU>

Palliative and end-of-life Care in undergraduate medical education: A survey of New Zealand medical schools

BMC MEDICAL EDUCATION | Inprint – 8 December 2021 – In New Zealand, 34% of deaths occur in the hospital setting where junior doctors are at the frontline of patient care. The death rate in New Zealand is expected to double by 2068 due to the aging population, but many studies report that graduates feel unprepared to care for people near the end of life (EoL) and find this to be one of the most stressful parts of their work. International guidelines recommend that palliative and EoL care should be a mandatory component of undergraduate medical education, yet teaching varies widely and remains optional in many countries. Little is known about how medical students in New Zealand learn about this important area of clinical practice. This article reports the findings of the first national survey of formal teaching, assessment and clinical learning opportunities in palliative and EoL care in undergraduate medical education in New Zealand. There has been significant progress towards integrating this content into the curriculum, although further development is needed to address barriers and maximise learning opportunities to ensure graduates are as well prepared as possible. **Full text:** <https://bit.ly/31WfRJR>

Noted in Media Watch 15 November 2021 (#743, p.3):

- NEW ZEALAND | Maxim Institute (Auckland) – 2 November 2021 – ‘**Ending well: The urgent case for accessible palliative care.**’ In spite of the care, expertise, and knowledge now available, bad deaths are unfortunately all too common for many New Zealanders. Palliative care (PC) is an important ingredient for good end-of-life care – even when the person has complex medical issues or has struggled with significant pain. It is an approach that “prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.” This paper identifies five key areas where policy changes could improve access to PC services for New Zealanders. **Download at:** <https://bit.ly/3oiACXA>



[Barry R. Ashpole](#)

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

The little things are big: Evaluation of a compassionate community approach for promoting the health of vulnerable persons

BMC PUBLIC HEALTH | Online – 11 December 2021 – This study is important as it adds to the growing international evidence about the positive impacts of compassionate communities (CC) on individual and community health. The majority of the evidence is published in the palliative and end-of-life care literature. This is the first study to evaluate a CC approach within a targeted vulnerable care sector. The results demonstrate that health and social care sectors can be mobilized by a CC approach to holistically address the big and little needs of society's most vulnerable and invisible persons. The qualitative findings suggest the "little things" often had the biggest impact on client well-being and on care management. The "big and little things" characterize the vulnerable persons intervention, and they were addressed through the processes of taking time, advocacy and empowerment. In this study, these processes appear to address vulnerabilities, such as housing security, physical and mental disabilities, and social isolation. They also meaningfully address the holistic concerns that were most pressing and important to program clients, with social isolation being a significant concern. Recruiting and re-

taining volunteers is the most key opportunity for improvement and sustainability of the program. The Canadian healthcare system and those of other countries remain entrenched in approaches that are largely siloed and not coordinated to meaningfully address the things that are most valued by people and that contribute to their quality of life. **Full text:** <https://bit.ly/3oMeoyv>

The compassionate community movement

CCs are spreading worldwide, but are relatively new in Canada. The CC movement is a population-based theory of practice that calls on society to intentionally contribute to caring for its citizens, especially those experiencing indicators of vulnerability. In this model, citizens are purposefully mobilized as volunteers with health and social care institutions to help people in need identify their own person-centred goals for living well. People are then connected with community resources and empowered to act on their goals and needs. With collective engagement, a CC becomes an interplay of caring actions with and among a community, its citizens, and health/social care organizations.

Noted in Media Watch 1 November 2021 (#741, p.10):

- *PALLIATIVE MEDICINE* | Online – 22 October 2021 – '**Compassionate community structure and function...**' Compassionate communities (CC) are essential to those who wish to die at home by helping to avoid carer stress and burnout associated with physical and emotional labour when a person is at the end of life (EoL). However, compassionate community models are top-down in nature as they focus on public policy, missing a domestic-scale, standardised design applicable when someone wishes to die at home. Research with EoL doulas in four countries demonstrates the importance of CC for death literacy and support for a person at EoL and their networks, and that all practitioners were using *ad hoc*, variable approaches to compassionate community formation and maintenance. **Full text:** <https://bit.ly/3bd4FK3>

Noted in Media Watch 27 September 2021 (#736, p.7):

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 22 September 2021 – '**Centering sexual and gender diversity within compassionate communities...**' The compassionate communities movement emphasizes the importance of illness, disability, dying, caregiving, and grief across the lifespan and highlights the communal responsibility of caring for one another. There is a need to recognize and incorporate the needs of diverse communities within this movement and research on dying, caregiving and grief. The authors' findings [as part of the Healthy End of Life Project Ottawa] emphasize the importance of incorporating the voices of diverse sexual and gender identities and promoting health equity within compassionate community initiatives. **Full text:** <https://bit.ly/39y7mFi>

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Noted in Media Watch 23 March 2020 (#658, p.7):

- *DEATH STUDIES* | Online – 19 March 2020 – ‘**Grief literacy: A call to action for compassionate communities.**’ The compassionate communities (CC) movement challenges the notion that death and dying should be housed within clinical and institutional contexts, and works to normalize conversations about death and dying by promoting death literacy and dialogue in public spaces. Community-based practices and conversations about grief remain marginal in this agenda. The authors theorize how grief could be better conceptualized and operationalized within the CC movement. They develop the concept of *grief literacy* and present vignettes to illustrate a grief literate society. Grief literacy augments the concept of death literacy... **Abstract:** <http://bit.ly/2vyvsiN>

Noted in Media Watch 4 February 2019 (#600, p.10):

- *HEALTHCARE* | Online – 28 January 2019 – ‘**Last Aid course. An education for all citizens and an ingredient of compassionate communities.**’ Knowledge in palliative care (PC) is very limited or totally absent in most communities, and information about the effects of educational procedures in teaching non-professionals in basic PC is sparse. In the Last Aid courses, the public knowledge approach and the initial experiences from the implementation process are described in this article. In addition, a review of the literature on educational efforts regarding PC for non-professionals and the existing literature on courses is provided. An international working group has established a curriculum for Last Aid courses based on four teaching hours (45 minutes each). **Full text:** <http://bit.ly/2Bem43h>

Part of the solution: A survey of community organisation perspectives on barriers and facilitating actions to advance care planning in British Columbia, Canada

HEALTH EXPECTATIONS | Online – 14 December 2021 – This study identifies numerous opportunities to increase and improve advance care planning (ACP) according to non-profits engaging in ACP education in British Columbia. It offers new insights into ACP from both a British Columbian and a community lens, and encourages, among other things, greater collaboration with and inclusion of community organisations in the ACP landscape in British Columbia. Findings from this study should be used to inform existing and future ACP policies across the province, and may be used to provide guidance on working with community groups and ACP on a national and international level. Research into ACP barriers and facilitating actions has largely limited itself to the clinician–patient dichotomy. Further inquiry into the needs of non-profits, as the “middle men” in ACP education, will be necessary to fully incorporate them into ACP processes. The inclusion of these “new” voices can continue to offer novel and effective ways to increase and improve ACP in British Columbia and beyond. **Full text:** <https://bit.ly/3p5Cbd7>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.13.



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Palliative Care Network
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Knowledge & Technology
<http://bit.ly/2DANDFB>

Implementation of evidence-based guidance for dementia palliative care using participatory action research: Examining implementation through the Consolidated Framework for Implementation Research

IMPLEMENTATION SCIENCE COMMUNICATION | Online – 11 December 2021 – The Consolidated Framework for Implementation Research (CFIR) provided a useful framework for analysing the implementation context and informed the strategy for implementing dementia palliative care (PC) guidance. The participatory action research approach involving work-based learning groups (WBLGs), tailored to the context of each setting, was identified as a key factor that facilitated the implementation of the guidance. Post-implementation, CFIR helped identify factors influencing implementation including features of the guidance, the inner setting of the long-term care facility, and the process of engaging with stakeholders. Recommendations for practice include greater organisational investment and involvement of all key stakeholders in the implementation process. Valued components of the participatory action research process were the engagement of staff of different backgrounds who have a role in change, a practical focus with action plans, and opportunities to observe the impact of the guidance and share this with other staff. This suggests that putting a mechanism in place to continue the WBLGs may help to sustain the shift to reflection and the use of evidence-based guidance in practice. However, it is important to ensure equitable access to WBLGs for all staff involved in change. This will involve early engagement with higher-level management, to enable staff to attend. Factors identified as potential barriers to implementation of guidance for dementia PC were limited staff time and support for

the implementation from other healthcare professionals. This emphasises the importance of organisational factors and managerial support in facilitating the implementation process. In the future implementation of guidance in PC, the authors recommend the use of the CFIR to identify context-specific factors affecting the implementation that can be targeted in a participatory approach.

Full text: <https://bit.ly/3oPexBr>

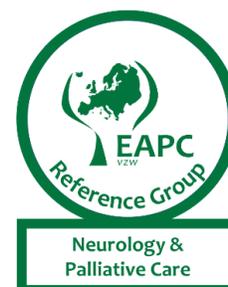
The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog

– 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample

of journal articles on the subject published during the past year or so. Included are articles on Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, motor neurone disease, Huntington's disease, **dementia**, epilepsy and neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers' perspective, and advance care planning (including advance directives and goals-of-care). <https://bit.ly/3cdwyIS>

N.B. This posting is part of a series on neuro-palliative care developed in partnership with the EAPC Neurology Reference Group: <https://bit.ly/3rqe50A>



The meaning of comfort measures only order sets for hospital-based palliative care providers

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELLBEING | Online – 14 December 2021 – The authors' findings clearly indicated that palliative care (PC) specialists and acute care providers held diverging concepts of comfort. An understanding of what patients, as well as family members, regard as important to comfort would be helpful in future studies. Coelho and colleagues employed a phenomenological approach to examine how PC patients defined comfort and its precursors and to generate a preliminary model for the concept, inclusive of relational and spiritual concerns.¹ This study adds to an understanding of the historical and cultural barriers to changing care practices. Arising from a grass-roots movement in home-based care at the end of life (EoL), PC has now moved into acute care settings where the challenges of effecting EoL culture change are more complex. The "notion of home" as a goal of PC could open a crucial dialogue in understanding the patient's and family's goals and interacting as being-

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in-the-world versus the curative view that reduces being to a corporeal body. In this study what was revealed is the common philosophical perspective of corporeal body versus lived-body, which uncovers the taken for granted meaning of curative healthcare in today's hospital systems. The underlying focus on the medical regimen and care of the body, serves to limit the person's perspective of their being and existence focusing on the patient as a passive object with limited sense of agency and being with others. **Full text:** <https://bit.ly/3s8pa48>

1. 'Comfort experience in palliative care: A phenomenological study,' *BMC Palliative Care*, published online 2 August 2021. [Noted in Media Watch 8 August 2016 (#474, p.7)]. **Full text:** <https://bit.ly/3oWetje>

A systematic literature review exploring the psychosocial aspects of palliative care provision for incarcerated persons: A human rights perspective

INTERNATIONAL JOURNAL OF PRISONER HEALTH | Online – 15 December 2021 – The results from 26 articles revealed multiple models of care, with the U.S. prison hospice program depicted as optimal, because of the use of trained incarcerated caregivers, working as aides to the interprofessional team. The bereavement needs of caregivers were highlighted. The barriers to adequate psychosocial care were negative public discourse, prison processes and resources, provider attitudes and the incarcerated person's level of knowledge and trust. Identified facilitators were related to incarcerated persons' caregiving programs, a sense of purpose and visitation leniency. Human rights principles were identified in studies that featured compassionate release and advance care planning. There is inconsistency in the literature regarding what constitutes psychosocial care, which meant that the authors needed to draw on multiple literature sources to formulate a definition. Additionally, the review only included studies written in English, meaning some high-quality studies could have been missed. The articles that conducted interviews with incarcerated individuals were undertaken in male prisons only and not female prisons. Understanding the importance of psychosocial care for incarcerated persons with a life-limiting illness requires a shift in negative public discourse and the need for a stronger human rights focus. Some countries, such as the U.S. and U.K., are achieving effective outcomes... **Abstract:** <https://bit.ly/3dQSbsM>



**Prison Hospice: Backgrounder
Updated 1 November 2021**

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 can be downloaded from the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

Related

- *CRIMINOLOGY & CRIMINAL JUSTICE*, 2022;22(1):150-170. **“It was like an animal in pain”: Institutional thoughtlessness and experiences of bereavement in prison.** This article examines a range of issues embedded within daily prison life which have a detrimental effect upon the lives of those bereaved during a prison sentence. The article explores how individual and institutional goals compete, compounding bereavement experiences and the management of grief. This article illuminates the need for far greater understanding of bereavement in the prison population and explores how a universal life experience can be particularly debilitating within the prison setting with the potential to exacerbate what is often cumulative loss among prisoners. **Abstract (w. references):** <https://bit.ly/30jrQ3z>

Consensus Guideline For The Standard Of Care Of Adults With Duchenne Muscular Dystrophy

JOURNAL OF NEUROMUSCULAR DISEASES, 2021;8(6):899-926. There are growing numbers of adults with Duchenne muscular dystrophy (DMD) living well into their fourth decade. These patients have complex medical needs that to date have not been addressed in the international standards of care. The authors sought to create a consensus based standard of care through a series of multi-disciplinary workshops with specialists from a wide range of clinical areas: neurology, cardiology, respiratory medicine, gastroenterology, endocrinology, palliative care medicine, rehabilitation, renal, anaesthetics and clinical psychology. Detailed reports of evidence reviewed and the consensus building process were produced following each workshop and condensed into this final document which was approved by all members of the Adult North Star Network including service users. The aim of this document

is to provide a framework to improve clinical services and multi-disciplinary care for adults living with DMD. **Full text:** <https://bit.ly/3DYfaww>

Extract from *Journal of Neuromuscular Diseases* article

This is a new group of patients for palliative care (PC) and the trajectory of their condition is not as clear cut as patients with other life-limiting diseases such as cancer for example. However, it does fit with the change in the PC ethos with an emphasis on patients with non-malignant conditions rather than cancer and an emphasis on symptom control as well as end-of-life care. Any chronic condition, particularly when life-limiting, can lead to psychological adjustments and the fear of dying and how that process will happen.

Noted in Media Watch 8 April 2019 (#609, p.11):

- *SAGE OPEN MEDICINE* | Online – 27 March 2019 – ‘**Palliative care services in families of males with muscular dystrophy...**’ This study presents data from a population-based sample of young men with Duchenne and Becker muscular dystrophy (DBMD) and their families regarding their use of palliative care (PC) services. Although overall use of PC is high among families of males with DBMD, use of individual PC services is extremely variable. All but one of the individual PC services were used by less than 50% of families and 9 of the 14 services were used by 37% or less families. Use of PC services is associated with fewer predisposing and enabling characteristics such as primary caregiver’s education and family income than it is with the needs of affected males. **Full text:** <http://bit.ly/2FIEpXP>

Noted in Media Watch 18 September 2017 (#530, p.11):

- *CURRENT OPINION IN NEUROLOGY* | Online – 13 September 2017 – ‘**Palliative care in neuromuscular diseases.**’ There is sparse literature on palliative care (PC) in neuromuscular disorders (NMDs) such as Duchenne muscular dystrophy, spinal muscular atrophy, muscular dystrophies, some congenital myopathies, Pompe’s disease and myotonic dystrophy type. These NMDs are often associated with imminent respiratory insufficiency and/or heart failure leading to a reduced life expectancy. Reasons for underutilization may include misconceptions about PC amongst patients, family carers and healthcare professionals or lack of awareness of the usefulness of this approach in these severely affected patients and the possibilities of integration of palliative principles into their care. **Abstract:** <https://bit.ly/3DWDcbA>

Enhancing paediatric palliative care: A rapid review to inform continued development of care for children with life-limiting conditions

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 14 December 2021 – A rapid review using thematic synthesis was conducted to synthesise existing information about improving paediatric palliative care (PC). Information was extracted in relation to key areas for investment and change: quality, access, advance care planning (ACP), skills, research, collaboration and community awareness. A total of 2,228 literature sources were screened, with 369 included. Synthesised information identified clear ways to improve quality of care, access to care, ACP, and research and data collection. The synthesis identified knowledge gaps in understanding how to improve skills in paediatric PC, collaboration across Australian jurisdictions and community awareness. The findings of this review bring together information from a vast range of sources to provide action-oriented information to target investment and change in paediatric PC over the coming decades. **Abstract:** <https://bit.ly/3ysQUBG>

Cont.

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 December 2021 – ‘**Primary palliative care integrated model in paediatric ICU: An international cross-sectional study.**’ The authors of this study found universal though heterogeneous and overall insufficient fulfilment of Initiative for Paediatric Palliative Care (IPPC) recommendations. Healthcare providers complete numerous palliative care (PC) tasks in pediatric ICUs worldwide, although inconsistently and imperfectly. In general, high-income country units exhibited better adherence to the delivery of primary PC than units in lower income groups. In addition, units with shorter shift lengths had higher overall IPPC scores than units with longer shift lengths. All units surveyed had opportunities for considerable improvement. **Full text:** <https://bit.ly/3E3diTr>
- *ILLNESS, CRISIS & LOSS* | Online – 16 December 2021 – ‘**Attending patient funerals as a follow-up practice of pediatric oncologists.**’ Many professionals endorsed some level of agreement that funeral attendance respects professional boundaries. Nearly all pediatric oncology professionals surveyed (89.2%) reported attending a patient funeral at least once, a rate significantly higher than estimates in other specialties. Attitudes and rates of attendance were slightly higher in older physicians. While periodic funeral attendance may have been somewhat normative in this sample, further reflection and research is needed to ensure the risks and benefits of involvement in funerals and other family rituals and practices are better understood. **Abstract (w. references):** <https://bit.ly/3IQ7sbP>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 17 December 2021 – ‘**Synthesis of health promotion concepts in children’s palliative care.**’ 55 policies and guidelines were reviewed. Eight themes were generated: 1) Health promoting children’s palliative care (PC) policy and guidelines; 2) Planning ahead; 3) Creating a supportive environment; 4) Enabling coping and independence; 5) Re-orienting children’s PC sectors; 6) The lengthening trajectory of need for support; 7) Strengthening community engagement in children’s PC; and, 8) Quality of life and value-based ideologies. The best fit framework synthesis confirmed a conceptual relationship between children’s PC and health promotion. This is captured in a new model that will extend professionals’ understanding. **Abstract:** <https://bit.ly/3p6nS7M>
- *JOURNAL OF PALLIATIVE CARE* | Online – 13 December 2021 – ‘**Challenges in the provision of pediatric palliative care in Mexico: A cross-sectional web-based survey.**’ An enormous need for pediatric palliative care (PC) has been reported, especially in low- and middle-income countries. However, the access to pediatric PC is limited. This study identifies the current challenges and their severity from the perspective of healthcare professionals. The three most severe barriers reported were: 1) Few teams and/or networks of out-of-hospital/domestic support; 2) Absence of training centres and continuing medical/paramedical education in pediatric PC; and, 3) Lack of legal, labor, and economic protection for parents who must stop working to be with their children. **Full text:** <https://bit.ly/3DVvspY>

Palliative care physicians’ motivations for models of practicing in the community: A qualitative descriptive study

PALLIATIVE MEDICINE | Online – 17 December 2021 – The authors found palliative care (PC) physicians have varying underlying personal motivators that influence their practice model, which are associated with different challenges and rewards. In the takeover model, PC physicians were primarily motivated by their relationships with patients. In the consultation model, PC physicians were primarily motivated by their relationships with primary care, specifically with respect to mentorship and capacity building. The different practice model also influenced the day-to-day processes and overall outcomes of their care, including differences in sources of job satisfaction, challenges, and systems advocacy. The findings of this study about the role of personal motivations in influencing the practice of PC physicians have implications for healthcare system planners. It is noteworthy that PC physicians who worked in the takeover model perceived that family physicians preferred not to be involved in PC. If health systems aspire to encourage the development of generalist PC, they will need to expose medical trainees to such models during undergraduate and post-graduate training. Participants who described taking over care from family physicians also recognized a current lack of confidence to provide PC amongst family physicians. A study of primary care physicians in 10 countries found that over half indicated that they felt uncomfortable providing PC.¹ To address this, regulatory bodies will need to advocate for more salaried positions for PC specialists that include explicit deliverables for primary care mentorship and capacity building, not just for direct patient care. **Full text:** <https://bit.ly/3e5FZVm>

Cont.

1. 'Primary care physicians in ten countries report challenges caring for patients with complex health needs., *Health Affairs*, published online 7 December 2021. [Noted in Media Watch 14 December 2015 (#440, p.8)] Full text: <https://bit.ly/3yDyJcx>

Service change and innovation in community end-of-life care during the COVID-19 pandemic: Qualitative analysis of a nationwide primary care survey

PALLIATIVE MEDICINE | Online – 17 December 2021 – This study provides insights from primary healthcare teams into the individual efforts and service changes that were perceived to be beneficial through the first phase of the COVID-19 pandemic. The pivotal role of primary care in ensuring the global ambition of universal palliative care (PC) requires much more attention in future research, service design and policy. As international healthcare systems move to a period of restoration following the first phases of the COVID-19 pandemic, there is a need to ensure learning from rapidly implemented service changes. A once in a generation opportunity has arisen to incorporate cross-boundary service changes and innovations, implemented rapidly at the time of crisis into future service delivery. These include the use of technology, to facilitate more collaborative working, improved access to specialist PC and provision of PC in primary care settings. Future research should focus on which service changes and innovations provide the most benefits, who for, and how, within the context of increased patient need and complexity in the community. Full text: <https://bit.ly/3FcVOWg>

“It felt like a black hole, great uncertainty, but we have to take care for our patients”: Qualitative findings on the effects of the COVID-19 pandemic on specialist palliative home care

PLOS ONE | Online – 15 December 2021 – The COVID-19 pandemic has impacted specialist palliative home care (SPHC) in various ways. Due to their unique and heterogeneous structure, teams were often overseen by health authorities. Critically ill COVID-19 patients are in some cases not admitted to hospitals because of their personal preferences, but also because of limited resources in hospitals. SPHC teams could be the key provider to ensure good care for these patients, at home or in nursing homes. Additionally, SPHC patients are highly vulnerable, and especially impacted by the pandemic measures, because contact restrictions and fear of infection severely limit their ability to be with loved ones during their remaining time. Although visits to a dying person were officially excluded from contact restrictions in Germany, this was not always adequately communicated and put into practice. Specialist palliative care (PC), including home care, should receive more attention and be involved in planning and regulating healthcare during a pandemic. The PallPan [i.e., National Strategy for Palliative Care in Pandemic Times] project has developed a national strategy for PC of severely ill and dying people and their relatives in pandemics, which contains recommendations for general and specialist care providers. Full text: <https://bit.ly/3mdN2Q1>

N.B. Additional information on PallPan at: <https://bit.ly/32ez8Gb>

Noted in Media Watch 24 May 2021 (#718, p.8):

- *ONKOLOGE* | Online – 12 May 2021 – ‘**General palliative care during the pandemic.**’ The German healthcare system is facing unprecedented challenges due to the COVID-19 pandemic. Palliative care (PC) for critically ill patients and their families was also severely compromised, especially during the first wave of the pandemic, in both inpatient and outpatient settings. This article is based on the authors’ experience in routine inpatient PC and partial results of a study conducted as part of the collaborative project, National Strategy for Palliative Care in Pandemic Times (PallPan). Based on their experience from the inpatient care of patients suffering from severe or life-limiting disease, best-practice examples for improving or maintaining care in the on-going pandemic are described. Full text: <https://bit.ly/3eOrJ4g>

N.B. German language article.

Media Watch: Editorial Practice

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IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Media Watch: Access on Online

International



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[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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