COVID-19: End-of-Life Care

Provision of palliative care is an ethical imperative for those unlikely to survive, and may have the advantage of diverting dying people away from overburdened hospitals as well as providing the care that people want.


U.S.A.

COVID-19: Hospice providers to receive nearly $1 billion in CARES Act funds

HOSPICE NEWS | Online – 10 April 2020 – The U.S. Centers for Medicare & Medicaid Services has begun distributing the first $30 billion installment of public health funds from the Coronavirus Aid, Relief & Economic Security Act, also called the CARES ACT. An estimated $1 billion is expected to go to hospice and palliative care providers via direct deposit. The CARES Act … will pay for government aid to individuals, families and businesses that were hard hit by the economic turmoil brought on by COVID-19, including healthcare organizations. The law contains a $100 billion Public Health & Social Services Emergency Fund to aid healthcare providers. An additional $70 million in CARES Act public health funds will be available in the coming weeks, though exactly when, and which entities will have access to those funds, remains unknown. The COVID-19 pandemic has hit hospices hard from an operational standpoint as well as financially. https://bit.ly/2xoIaRU

COVID-19: End-of-Life Care


‘The family caregiving crisis meets an actual pandemic’ (p.8), in Journal of Pain & Symptom Management.

‘Rapid de-escalation and triaging patients in community-based palliative care’ (p.8), in Journal of Pain & Symptom Management.

‘Crisis symptom management and patient communication protocols are important tools for all clinicians responding to COVID-19’ (p.8), in Journal of Pain & Symptom Management.
Hospices suspending volunteer activities due to pandemic

HOSPICE NEWS | Online – 8 April 2020 – Hospices nationwide are challenged by the need for social distancing and sheltering in place during the COVID-19 outbreak, and this includes management and recruitment of volunteers, on whom many patients and providers rely for essential support. The U.S. Center for Medicare & Medicaid Services (CMS) in normal circumstances requires that volunteers provide at least 5% of hospice patient care hours. Many hospices also rely on volunteers to organize educational programming, perform back office work, fundraising and to help patients stave off loneliness and social isolation. Due to the pandemic, CMS recently waived several hospice regulations, including the requirement that volunteers provide 5% of patient care. A number of providers have been unable to maintain their volunteer services as the pandemic continues to take its toll. While some hospice volunteer services have proceeded, such as virtual visits with patients, many hospices have canceled volunteer activities and events due to social gathering restrictions nationwide, and as more states enact shelter in place orders. With these limitations, volunteer capacity has diminished in areas such as office support and in-person patient interactions, which can add up to substantial missed volunteer hours for hospices. https://bit.ly/3aWzDo0

COVID-19 outbreak boosting demand for palliative care

HOSPICE NEWS | Online – 7 April 2020 – As healthcare providers across every setting scramble to meet patient needs during the novel Coronavirus pandemic, many are starting to recognize the importance of palliative care (PC) and are seeking more support from those clinicians. The outbreak – and associated morbidity and mortality – has underscored the need for clinicians to navigate difficult, often emotional conversations with patients and families about their goals and wishes for the care they receive, including end-of-life and hospice care. Providers that specialize in hospice and PC excel at navigating these sensitive conversations and undergo specific training to develop those skills. Mount Sinai Hospital in New York City has established a hotline to guide healthcare providers on how to conduct these conversations, particularly for those affected by the novel Coronavirus, The Wall Street Journal reported.1 “The questions poured in: How do I tell someone that mechanical ventilation may not be effective? How do I tell people that they may die?” according to the Journal. “The inquiries reflect the need for clinicians to have empathetic conversations with patients and families about the prospects for survival, the goals of treatment, and how to comfort or say goodbye to loved ones in isolation. Such services are especially vital, some hospital leaders say, because Coronavirus patients are treated away from family or other support systems.” The hospice and PC patient populations are among the most vulnerable to Coronavirus disease (COVID-19) infection. Understanding the risk points can be key for providers to minimize the potential risks of COVID-19 on aging and seriously ill patients. https://bit.ly/2XlyyCk


Coronavirus is changing the rituals of death for many religions

NATIONAL PUBLIC RADIO | Online – 7 April 2020 – For centuries, Hindus gathered to burn corpses on funeral pyres along the Ganges River. Jews received condolences at home during a seven-day mourning period. Muslims huddled together to wash the corpses of loved ones in Iraq and across the Arab world. But global burial rituals are being dramatically changed by the Coronavirus pandemic. The World Health Organization in its … guidance on burials of COVID-19 victims says dead bodies are generally not infectious.1 But its recommendations that relatives not touch or kiss the body and government rules on social distancing to prevent the spread of disease have upended important funeral and death rituals in virtually all of the world’s faiths. Just as the U.S. now restricts gatherings for funerals, so do countries and religious authorities around the world. Here, some of National Public Radio’s foreign correspondents share details of how COVID-19 has changed traditions in the countries they cover. https://n.pr/2Xrg2Zj

Hospices redesign bereavement care due to social distancing

HOSPICE NEWS | Online – 6 April 2020 – Hospice providers nationwide are reassessing how they provide bereavement care due to the need for social distancing during the ongoing pandemic. With few other options, many are turning to telehealth systems to support grieving families. Hospices have had to cancel in-person counseling sessions, meetings with families as well as support groups and other services to avoid spreading the COVID-19 virus. These necessary restrictions come at a time in which many families in addition to their grief are coping with increased anxiety, depression, loneliness and isolation as the outbreak continues. Hospices around the country are working to reduce risk of exposure to the Coronavirus among their vulnerable patient populations. Increased use of telemedicine is one of the various tactics that providers are employing, and hospices have had to move quickly to move services online. The U.S. Centers for Medicare & Medicaid Services (CMS) recently expanded Medicare coverage to enable beneficiaries to receive an expanded range of telehealth services for the duration of the pandemic, though questions remain as to how (or if) hospices will be reimbursed by CMS for services rendered online. Increasing the use of telehealth does come with a price tag. Hospices nationwide are buying more electronic equipment, software licenses, training materials and other telehealth necessities. Many hospices … open their bereavement care services to anyone in the community, regardless of whether they are the family of one of their deceased patients. https://bit.ly/2UPijeP

International

Sue Ryder warns it may be forced to close hospices

U.K. | Civil Society News – 7 April 2020 – One of the U.K.’s largest hospice charities has warned that it is on “the brink of closure” as a result of the Coronavirus crisis. Sue Ryder, which provides end-of-life care for 5,000 people each year, says that it faces a £12 million financial black hole over the next three months. It has launched an emergency appeal for public donations and called for urgent funds from the government. Without that support, the charity warns that it may be forced to close its hospices and end its services helping terminally ill people in their own homes. The charity says that its investment fund has lost £2 million since the crisis began, as a result of falling stock market values. This is in addition to losing £440,000 in monthly retail profits, and a further £200,000 in potential fundraising after the cancellation of the London Marathon. If its services close, Sue Ryder warns that patients in its care will have to turn to the National Health Service for help instead. https://bit.ly/3e0gTWx

N.B. The government announced 9 April 2020 quarterly funding of up to £200 million to support the hospice sector in response to the Coronavirus pandemic.
Sick children without COVID-19 dying at home as parents told not to take them to hospital

U.K. | The Daily Express – 6 April 2020 – Sick children without COVID-19 are dying because parents are scared to take them to hospital, health specialists have warned. Some parents say they have been told to keep their children at home by National Health Service (NHS) 111 [a phone service locally-commissioned to a national NHS standard], which follows government advice not to attend medical centres if you have Coronavirus symptoms. Others have been unable to get through to the hotline and many are too frightened to go to Accident & Emergency in case they or their youngsters pick up Coronavirus. Last week senior child specialists issued an urgent warning to managers at NHS 111 and the Department of Health asking them to revise its current guidance. They said the issue has affected children with existing chronic illnesses such as cystic fibrosis, liver disease and sickle cell disease as well as youngsters who develop fatal blood poisoning, sepsis. They say this led to the deaths of at least 10 children last week. Others have been placed in intensive care which could have been prevented by earlier intervention. The British Medical Journal is currently reviewing an article on the problem written by Dr. Joe Brierley, a leading child specialist in intensive care at Great Ormond Street Hospital. https://bit.ly/2UPYSTd

Specialist Publications

Trauma to transformation: The lived experience of bereaved parents of children with chronic life-threatening illnesses in Singapore

BMC PALLIATIVE CARE | Online – 6 April 2020 – This is the first known Asian study to critically examine the lived experience of parents bereaved by their child’s death due to a chronic life-threatening illness. The sample comprises Singapore-based middle-aged parents whose children suffered from a wide variety of conditions ranging from cancer to congenital conditions, with the caregiving period lasting between 5 months to 31 years. The narratives obtained from this demographically diverse sample provides invaluable insight into the major milestones that formed the parental bereavement trajectory, and the rituals parents adopted to confront the challenges that life presented. The findings also reinforce the need to upgrade the health-and-social-care system within which participants’ experiences were rooted, while offering recommendations for enhancing global pediatric palliative services in general, and pediatric palliative services for Asian populations in particular. Additionally, the multicultural composition of Singapore society which is dominated by the major Asian racial and religious groups implies that findings from this Singapore-based study have moderatum generalization to other Asian societies as well. Full text: https://bit.ly/2XiwsS

N.B. Peer review reports of the BMC Palliative Care article: https://bit.ly/3e1W3WP

The value of implementation science in bridging the evidence gap in bereavement care

DEATH STUDIES | Online – 6 April 2020 – There is a gap in the use of evidence in bereavement care. Implementation science is a field focused on moving evidence into practice and therefore may help close the gap. Implementation science advances the design, relevance, and dissemination of research and the adoption, implementation, and maintenance of evidence-based practices. The authors provide an overview of implementation science, describe five implementation frameworks – 1) Knowledge to action; 2) Behavior change wheel; 3) Exploration preparation implementation sustainment; 4) Interactive systems framework; and, 5) Reach, adoption, implementation, maintenance – and illustrate their application in bereavement care. These advancements will promote high-quality bereavement care that improves the lives of bereaved people. Abstract: https://bit.ly/2wmMqRF

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Integrating social services and health

HEALTH AFFAIRS, 2020;39(4):551. Despite growing understanding within the health sector that social factors play a critical role in people’s health, the programs and systems that help people meet their social needs remain largely isolated from those designed to meet their healthcare needs. This issue of Health Affairs examines the integration of social services and health. Contents page: https://bit.ly/2yF353u

A national, palliative care competency framework for undergraduate medical curricula

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH, 2020;17(7):2396. As nearly all doctors deal with patients requiring palliative care (PC), it is imperative that PC education starts early. This study aimed to validate a national, PC competency framework for undergraduate medical curricula. They conducted a Delphi study with five groups of stakeholders (PC experts, physicians, nurses, curriculum coordinators, and junior doctors), inviting them to rate a competency list. The list was organized around six key competencies. For each competency, participants indicated the level to which students should have mastered the skill at the end of undergraduate training. Stability was reached after two rating rounds. The results showed high levels of agreement within and between stakeholder groups. Participants agreed that theoretical knowledge is not enough. Students must practice PC competencies, albeit to varying degrees. Overall, communication and personal development and well-being scored the highest. Junior doctors should be able to perform these in the workplace under close supervision. Advance care planning scored the lowest, indicating performance in a simulated setting. A wide range of stakeholders validated a PC competency framework for undergraduate medical curricula. Full text: https://bit.ly/2JFH1rU

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 case for focused palliative care education in oncology training

JOURNAL OF CLINICAL ONCOLOGY | Online – 9 April 2020 – In oncology, we often do not consider the importance of person-centered care in our daily clinical practice and how it relates to our training. Every day, in every oncology clinic, we make innumerable decisions on how to deliver bad news. Like most oncologists, we struggle with the words we choose. Do we begin by validating emotions, or asking how the patient and caregiver are coping? Is it necessary to ask permission: “Would you like to discuss what this means?” Is this the appropriate visit to discuss prognosis? Do we focus on the progression of the tumor or investigate for new symptoms? How long do we stay silent when our patients cry? Some of these difficulties are a consequence of our limited education in palliative care during oncology fellowship. In the scenario described, the subsequent words we choose will have a great impact on both the patient and his caregivers and how they process information and make decisions. Does the training of oncologists reflect the gravity of these clinical situations? Full text: https://bit.ly/2RoWjoX

Building an interdisciplinary pain medicine and palliative care program in Ethiopia

JOURNAL OF GLOBAL HEALTH, 2020;10(1):0103017. Cancer is beginning to eclipse infectious disease as a major cause of mortality in low-to-middle income countries like those in sub-Saharan Africa. In Ethiopia, people with cancer who reach a hospital are diagnosed with advanced disease for which there is little treatment available and practically nothing to stem their unbearable disease-related pain. The Ethiopian government has made cancer treatment a health priority and is investing in new treatment centers and clinical services not previously available, such as radiation oncology. Pain management for cancer patients remains a challenge, as opioid analgesics are hard to come by and clinicians lack the experience to use them. A pain and palliative care training pilot program at the Ayder Specialty Hospital in Mekelle, Ethiopia, is helping meet the urgent need for pain management expertise. Physicians in several medical disciplines are enrolled in the two-year demonstration project to produce Ethiopian physicians who are experts in pain medicine as well as palliative and hospice care. Part of their training emphasizes the establishment of barriers to avoid the opioid abuse crisis unfolding in developed countries. This group of physicians will serve patients and educate the next generation of medical professionals in the important role of pain management. Full text: https://bit.ly/2JLyF21

Noted in Media Watch 6 February 2017 (#498, p.9):

- INTERNATIONAL NURSING REVIEW | Online – 2 February 2017 – ‘An ethnography of managing emotions when talking about life-threatening illness.’ Ethiopia, as a developing country, had few resources for caring for those requiring end-of-life care. However, palliative care (PC) was supported by local champions and by the Federal Ministry of Health. This ethnographic study was concerned with how dying patients, PC staff and family caregivers communicate about terminal illness and dying, ultimately they deferred to family wishes about significant news disclosures, in order to avoid upset. Abstract: https://bit.ly/2xclDGu

Prison Hospice: Backgrounder

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/viewed on the Palliative Care Network website at: http://bit.ly/2RdegnL

Photo: Lori Waselchuk. Philadelphia, PA
The role and response of palliative care and hospice services in epidemics and pandemics: A rapid review to inform practice during the COVID-19 pandemic

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 April 2020 – This study aimed to synthesise evidence for the role and response of palliative care (PC) and hospice teams to viral epi/pandemics, to inform the COVID-19 pandemic response. The authors conducted a rapid systematic review according to PRISMA guidelines in five databases. Of 3,094 papers identified, ten were included in this narrative synthesis. Included studies were from West Africa, Taiwan, Hong Kong, Singapore, the U.S. and Italy. All had an observational design. Findings were synthesised using a previously proposed framework according to “systems” (policies, training and protocols, communication and coordination, data), “staff” (deployment, skill mix, resilience), “space” (community provision, use of technology) and “stuff” (medicines and equipment, personal protective equipment). The authors conclude that hospice and PC services have an essential role in the response to COVID-19 by: 1) Responding rapidly and flexibly; 2) Ensuring protocols for symptom management are available, and training non-specialists in their use; 3) Being involved in triage; 4) Considering shifting resources into the community; 5) Considering redeploying volunteers to provide psychosocial and bereavement care; 6) Facilitating camaraderie among staff and adopt measures to deal with stress; 7) Using technology to communicate with patients and carers; and, 8) Adopting standardised data collection systems to inform operational changes and improve care. Full text: https://bit.ly/2UXFJz0

COVID-19 – what countries must do now (extract)

THE LANCET, 2020;395(10230):P1100. Palliative care (PC) services must be scaled up. The only certainty is that deaths will accumulate. PC’s goal is to alleviate serious health-related suffering. That suffering will take place in the coming weeks in the community as well as the hospital. The Lancet's 2018 Commission on Palliative Care & Pain Relief defined an essential package of PC services that can be provided at all levels of the health system, in all countries, and by multiple categories of health workers. Those services, together with the people needed to deliver those services, need to be identified urgently. Full text: https://bit.ly/3c7kLmG


Related:

- BRITISH MEDICAL JOURNAL | Online – 6 April 2020 – ‘COVID-19: Don’t apply advance care plans to groups of people, doctors’ leaders warn.’ Medical leaders have said it is “unacceptable” for advance care plans – with or without a completed ‘Do not attempt to resuscitate’ form – to be applied in a blanket manner to whole groups of people during the COVID-19 pandemic. The joint statement from the Royal College of General Practitioners, British Medical Association, Care Provider Alliance, and Care Quality Commission comes amid concern that GPs are feeling under pressure not to admit their older vulnerable patients to hospital if they contract COVID-19 because of restrictions on acute care capacity. Full text: https://bit.ly/34iGBRz

- JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 8 April 2020 – ‘American Geriatrics Society policy brief: COVID-19 and nursing homes.’ This policy brief sets forth American Geriatrics Society (AGS) recommendations to guide federal, state, and local governments when making decisions about care for patients with COVID-19 in nursing homes (NHs) and other long-term care facilities (LTCFs). The AGS continues to review guidance set forth in peer-reviewed articles and editorials, as well as ongoing and updated guidance from the Centers for Medicare & Medicaid Services, the Centers for Disease Control & Prevention, and other key agencies. This brief is based on the situation and any federal guidance/actions as of 4 April 2020. Abstract: https://bit.ly/39UvoYH

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pg. 7
JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 April 2020 – ‘Rapid implementation of inpatient telepalliative medicine consultations during COVID-19 pandemic.’ Telepalliative medicine has been used to great effect in outpatient and home-based palliative care (PC), but has had fewer applications in the inpatient setting. As we plan for decreased provider availability due to quarantine and redeployment and seek to reach increasingly isolated hospitalized patients in the face of COVID-19, the need for telepalliative medicine in the inpatient setting is now clear. The authors describe a rapid and ongoing implementation of telepalliative medicine consultation for inpatient PC teams and discuss lessons learned... Full text: https://bit.ly/39ZXHoA

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 April 2020 – ‘The family caregiving crisis meets an actual pandemic.’ The unprecedented growth in numbers and needs of older adults with serious illness has already necessitated widespread changes in the healthcare system to support caregiving families. The COVID-19 pandemic brings to light how reliant we are on families to support each other during illness. The multi-tasking, uncertainty, and strain that many feel now is emblematic of the pre-existing situation that many caregivers have faced for years. As we share in the public health urgency to contain COVID-19 and care for the most vulnerable, at-risk populations, we must not forget the frontline family caregivers. Full text: https://bit.ly/2y5B0lO

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2020 – ‘Rapid de-escalation and triaging patients in community-based palliative care.’ The following are recommendations by the Palo Alto Medical Foundation Palliative Care & Support Services team to help triage and coordinate for timely, safe, and effective palliative care in the community and outpatient setting during the ongoing COVID-19 pandemic. Patients are initially triaged based on location followed by acuity. Interdisciplinary care is implemented using strict infection control guidelines in the setting of limited personal protective equipment resources. Thorough screening for COVID-19 symptoms is implemented at multiple levels before a patient is seen by a designated provider. Full text: https://bit.ly/2RIFoUs

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2020 – ‘Conservative management of COVID-19 patients – emergency palliative care in action.’ Most patients with COVID-19 need palliative care input due to the large symptom burden and need for clear and open communication with patients and their families. However, due to the potential for rapid deterioration, decisions need to be made quickly, and treatment plans need to be clear and simple to follow for the generalist staff caring for them. Care of patients with COVID-19 results in huge ethical dilemmas and a toll on the healthcare teams caring for them, not least from shortages in resources, both staffing and pharmaceutical. Full text: https://bit.ly/3e5tRCn

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2020 – ‘Crisis symptom management and patient communication protocols are important tools for all clinicians responding to COVID-19.’ Palliative care (PC) teams must strategically deploy scarce resources where they can provide the most benefit in the form of relief of suffering for patients and families. The role of PC teams is thus twofold: 1) To provide direct consultation to colleagues when they need help caring for those patients whose needs are most acute; and, 2) To enable all clinicians to provide PC services, by connecting non-PC colleagues to crisis-appropriate resources for symptom management and patient and family communication. Full text: https://bit.ly/2VdFyhS

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2020 – ‘Palliative care in the time of COVID-19: Reflections from the frontline.’ When our palliative care (PC) unit was closed to make room for COVID-19 patients, we were prepared. At the initial stages, Singapore … was the country with the most confirmed COVID-19 cases outside of China. We are part of a large general hospital of 1,800 beds with a 13-Bed acute PC unit and a busy inpatient referral and outpatient service. We are also situated next to the National Centre of Infectious Diseases where the majority of COVID-19 positive or suspected patients were housed. Consequently, clinicians from our PC team were deployed to help “fight” in this nation-wide healthcare crisis. Full text: https://bit.ly/3e86eJg

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Expanding the interdisciplinary palliative medicine workforce: A longitudinal education and mentoring program for practicing clinicians

**JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 7 April 2020 – The disparity between gaps in workforce and availability of palliative care (PC) services is an increasing issue in healthcare. To meet the demand, team-based PC requires additional educational training for all clinicians caring for persons with serious illness. From 2015-2017, twenty-six social workers, chaplains, physicians, nurses and advanced practice providers representing 22 health systems completed a two-year training program. The curriculum was comprised of bi-annual interdisciplinary conferences, individualized mentoring and clinical shadowing, self-directed e-learning, and profession-focused seminar series for social workers and chaplains. Site-specific practice improvement projects were developed to address gaps in PC at participating sites. PC and program development skills were self-assessed pre and post training. Among 12 skills common to all disciplines, trainees reported significant increases in confidence across all 12, and significant increases in frequency of performing 11 of 12 skills. Qualitative evaluation identified a myriad of program strengths and challenges regarding the educational format, mentoring, and networking across disciplines. Teaching PC and program development knowledge and skills to an interdisciplinary, regional cohort of practicing clinicians yielded improvements in clinical skills, implementation of practice change projects, and a sense of belonging to a supportive professional network. **Abstract** (w. link to references): [https://bit.ly/2JOSEqb](https://bit.ly/2JOSEqb)

Noted in Media Watch 9 March 2020 (#656, p.4):

- **HOSPICE NEWS** | Online – 2 March 2020 – ‘Staffing a barrier to palliative care growth.’ While the number of hospices and other organizations providing palliative care (PC) continues to expand nationwide, staffing shortages represent a barrier that threatens to slow this growth. The U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older, according to a 2018 study.¹ The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Hospice and PC providers also experience shortages in non-physician disciplines, including chaplains, nurses, and social workers. Widespread reform in medical and nursing education may be necessary to fully address this issue. [http://bit.ly/2Pl0AmC](http://bit.ly/2Pl0AmC)


**N.B.** Additional articles on the status of the PC workforce noted in past issues of Media Watch: 17 February 2020 and 10 June 2019 (#653, p.13, and #617, p.1, respectively).
Depression, anxiety, delirium and desire to die in palliative care: Recommendations of the S3 guideline on palliative care for patients with incurable cancer

DER NERVENARZT | Online – 3 April 2020 – This article presents the recommendations of the S3 guideline on palliative care (PC) for patients with incurable cancer with regard to psychotherapeutic and psychiatric contents. The guideline was developed under the leadership of the German Society for Palliative Medicine within the methodological framework of the German Guideline Program in Oncology. Systematic literature reviews were carried out to identify relevant publications... Based on the publications included and clinical experience, representatives of 61 professional associations developed and agreed on evidence-based and consensus-based recommendations. Out of the total of 15 chapters in the guidelines, four have a special reference to psychiatry or psychotherapy; they cover the topics depression, anxiety, delirium in the dying phase and dealing with the desire to die. These chapters contain a total of 71 recommendations, almost one third of which are evidence-based. In view of the regularly undetected psychological symptoms in patients with incurable cancer, an early assessment is recommended. Optimal control of physical symptoms and support in social and existential matters are general measures that should be provided in addition to non-pharmacological and pharmacological procedures. The guideline on PC deals with important mental issues that should be considered by all disciplines and professions. The need for research in PC remains high. Abstract (w. list of references): https://bit.ly/3dZOG25

N.B. German language article. The ‘S3-level’ refers to the German classification scale of guidelines. The highest ‘S3-level’ means that the guideline is evidenced and consensus-based and has been developed according to strict methodological criteria: systematical search of evidence, representative guideline-group, and structured process of consensus. Additional articles on patient desire to die noted in 9 March 2020 issue of Media Watch (#656, p.9).

A child’s right to receive pediatric palliative care at prenatal stage

OBSTETRICS, GYNECOLOGY & REPRODUCTION, 2020;14(1):80-88. The authors aim at outlining the essence, nature as well as range of child’s guarantees for receiving pediatric palliative care (PC) at prenatal stage including common scope of the rights for such patients. It is emphasized that a child at prenatal stage (starting from certain age) is able to feel pain sensation and suffer from it, thereby underlying its right for PC. It is underscored as to why a child’s right at prenatal stage for pediatric PC (if necessary) is subject to legal recognition and legal protection. Full text (click on pdf icon): https://bit.ly/2UQ9yS0

Noted in Media Watch 10 August 2015 (#422, p.8):

- AMERICAN JOURNAL OF MATERNAL CHILD NURSING, 2015;40(1):44-50. ‘Clinician perspectives of barriers in perinatal palliative care.’ Physicians and nurses [i.e., study participants] differ significantly in the barriers they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Members of both disciplines express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about perinatal palliative care. Abstract: https://bit.ly/3e3Gpu4

Current issues with implementing a palliative approach in long-term care: Where do we go from here?

PALLIATIVE MEDICINE | Online – 10 April 2020 – Given the aging population and its demands on healthcare systems worldwide, the long-term care (LTC) sector is being particularly challenged. Most countries are witnessing a changing profile of LTC residents, with residents entering LTC very frail with multiple comorbidities, resulting in more complex care for staff to manage. Moreover, the length of stay for residents are shorter than ever before, and LTC homes are becoming more hospice-like; but unlike hos-
pices, they are heavily regulated with little flexibility to provide person-centered care. Even more troubling is the fact that capacity within LTC homes has not progressed at the same pace to meet the acuity level of this growing population, nor are they equipped to implement a palliative approach to care, which is evidenced by numerous reports of poor outcomes and costly reliance on hospitals to manage care for residents at end of life. Fortunately, both researchers and national funding agencies are beginning to recognize and respond to this emerging “crisis” within healthcare systems across countries with some large initiatives being implemented and evaluated… Full text: https://bit.ly/3a0xXbC

Noted in Media Watch 2 March 2020 (#655, p.10):
- JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE | Online – 27 February 2020 – ‘Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper.’ This is the first study the authors are aware of that has formulated recommendations on strategies for implementation of palliative care (PC) interventions in long-term care facilities (LTCFs) based on international research with experts. The recommendations aim to guide how PC can be introduced, embedded and sustained in LTCFs. The authors offer a framework of recommendations at each level in which strategies can be implemented and outlines the processes involved, although the authors acknowledge that change is unlikely to be linear. Full text: http://bit.ly/2wicpcg

N.B. Additional articles on end-of-life and PC in LTCFs noted in this issue of Media Watch.

Healthcare professionals’ awareness of a child’s impending death

QUALITY HEALTH RESEARCH | Online – 4 April 2020 – Healthcare professionals’ (HCPs) experiences during early pediatric end-of-life care (EoLC) were explored using a theory-building case study approach. Multiple data collection methods including observation, electronic medical record review, and semi-structured interviews were collected with 15 interdisciplinary HCPs across four cases. Within- and across-case analyses resulted in an emerging theory. HCPs’ initial awareness of a child’s impending death is fluid, ongoing, and informed through both relational and internal dimensions. Initial cognitive awareness is followed by a deeper focus on the child through time-oriented attention to the past, present, and future. HCPs engage in a “delicate dance of figuring out” key issues. Awareness was exemplified through four themes: 1) Professional responsibility; 2) Staying connected; 3) Grounded uncertainty; and, 4) Holding in. The emerging theoretical model provides a framework for HCPs to assess their ongoing awareness, identify personal assumptions, and inform gaps in understanding when facilitating early EoLC discussions with families. Abstract (w. list of references): https://bit.ly/2UOg9ft

Media Watch: Editorial Practice

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

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Access on Online

International

[Scroll down to ‘Media Watch: Updates’]
[Scroll down to ‘Media Watch by Barry Ashpole’; also ‘Media Watch: Behind the Scenes’ at: http://bit.ly/2MwRRAU ]

Australia

PALLIATIVE CARE RESEARCH NETWORK: http://bit.ly/2E1e6LX
[Click on e-News (November 2019); scroll down to ‘Useful Resources in Palliative Care Research’]

Canada

[Scroll down to ‘Are you aware of Media Watch?’]
ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): http://bit.ly/2TboKFX

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): HTTP://BIT.LY/300WMRT
HUNGARY | Magyar Hospice Alapítvány: http://bit.ly/2RgTvYr

U.K. | Omega, the National Association for End-of-Life Care: http://bit.ly/2MxVir1

South America


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