Bereavement

The impact of the caregiver-oncologist relationship on caregiver experiences of end-of-life care and bereavement outcomes.
An AW et al.
Support Care Cancer. 2020 Jan 3.
The quality of the relationship between oncologists and cancer patients has been associated with caregiver bereavement outcomes, but no studies have examined whether the perceived quality of the relationship between cancer caregivers and oncologists is associated with caregiver experiences of end-of-life care or psychological adjustment after the patient's death. Caregivers' early experiences with oncologists may affect their experiences of the patient's end-of-life care.

A standardized approach to bereavement risk-screening: a quality improvement project.
Morris SE, et al.
Identifying family members at-risk of poor bereavement outcomes poses a challenge for clinicians, resulting in inconsistent bereavement follow-up. The current quality improvement study tests a method for identification of at-risk family members, and describes follow-up they received from the bereavement service at Dana-Farber Cancer Institute The Bereavement Risk-Screening Tool (BRST) has the potential to help clinicians in health care settings identify those family members who might be considered at heightened risk of a poor bereavement outcome, facilitating early outreach and recommendations for support. The tool was easy to complete and helped streamline the referral process to the bereavement program.

Children

Paediatric palliative care: a systematic review.
Nilsson S, et al.
We review literature relating to evidence, context and facilitation to describe knowledge translation in paediatric palliative care. Paediatric palliative care requires competences including both paediatric specialists as well as services that are developed for this purpose, and there is a need to facilitate paediatric palliative care knowledge translation. Promoting Action on Research Implementation in the Health Services (PARiHS) is a framework for knowledge translation, which highlights the relationships between evidence, context and facilitation. PARiHS
framework has been revised and updated in a new version called i-PARIHS. The results report strategies to achieve knowledge translation of paediatric palliative care, and these can be interpreted as a guideline for how this process can be facilitated.

**Top Ten Tips Palliative Care Clinicians Should Know About Caring for Serious Illness in Pregnancy.**
Buckingham L. et al

Palliative care (PC) teams are increasingly being called upon to provide care earlier and more remote from end of life. Because much of the field has grown out of hospice and geriatric care, most teams have little to no experience caring for pregnant women or their fetuses when serious or life-threatening illness strikes. This article, written by a team of oncologists (gynecologic, medical, and radiation) and PC providers, seeks to demystify the care of seriously ill pregnant women and their fetuses by exploring the diagnostic, treatment, prognostication, symptom management, and communication needs of these patients. Truly comprehensive PC extends throughout the life span, from conception to death, regardless of age. Accordingly, increased knowledge of the unique needs of these vulnerable groups will enhance our ability to provide care across this continuum.

**Is This My Home? A Palliative Care Journey Through Life and Death in the NICU: A Case Report.**
Walters A, Grosse J.

With advancements in neonatology, patients in the neonatal intensive care unit (NICU) are living in the hospital with complex life-limiting illnesses until their first birthday or beyond. As palliative care (PC) becomes a standard of care in neonatology, a level IV NICU developed an interdisciplinary PC team with the mission to ease the physical, mental, and moral distress of the patients, families, and staff. This case report highlights the teamwork and long-term palliative care and ultimately end-of-life care that an infant received by this dedicated NICU palliative care team. The American Academy of Pediatrics and the National Association of Neonatal Nurses both have statements recommending that palliative care be standard of care in NICUs. Establishing a NICU-dedicated interdisciplinary PC team can improve outcomes for infants and families living in the NICU with complex life-limiting illnesses.

**Compassion in pediatric healthcare: a scoping review.**
Sinclair S. et al

Compassion has been described as a central construct or essential feature of quality healthcare and is as important to patients' and families' overall healthcare experience as the health interventions and treatments they receive. However, there is little shared understanding of what constitutes compassion, how it is delivered within a pediatric setting, and pediatric patients' and families perspectives and preferences for receiving it. Future research is required to generate a comprehensive and accurate understanding of the terms 'compassion' and 'compassionate care' when used in the context of pediatric healthcare.

**Hospital or Home? Where Should Children Die and How Do We Make that a Reality?**
Johnston EE, et al
*J Pain Symptom Manage.* 2019 Dec 27. pii: S0885-3924(19)31084-X.

Most of the 20,000 US children dying of serious illnesses annually die in the hospital. It is unknown if this hospital death predominance reflects family wishes or systemic issues such as lack of hospice access. Hence, we need to better understand location of death preferences for children and their families. To better understand location of death preferences in North America, we reviewed the literature to examine the evidence for and against home death in seriously ill children (0-18 years). Adequate resources are needed to ensure children can die in their chosen location - be that home, hospital, or free-standing hospice. This review highlights research areas needed to better understand death location preference and programs and policies that will support home death for those that desire it.

**Ethical and legal issues**

**The relationship of palliative care with assisted dying where assisted dying is lawful: A systematic scoping review of the literature.**
Gerson SM et al

A central approach of palliative care has been to provide holistic care for people who are dying, terminally ill or facing life-limiting illnesses while neither hastening nor postponing death. Assisted dying laws allow eligible individuals to receive medically administered or self-administered medication from a health provider to end their life. The implementation of these laws in a growing number of jurisdictions therefore poses certain challenges for palliative care. The studies in this review cast only partial light on challenges faced by palliative care teams.
care when assisted dying is legal. There is pressing need for more research on the involvement of palliative care in the developing practices of assisted dying, across a growing number of jurisdictions.

The Use of Palliative Sedation to Treat Existential Suffering: A Scoping Review on Practices, Ethical Considerations, and Guidelines.
Ciancio, A. L., et al
Though palliative sedation has been recognized as an acceptable practice in Canada for many years now, there is a lack of clinical research and guidelines pertaining to its use as a treatment of existential refractory symptoms in the terminally ill. This scoping review aimed to survey the literature surrounding palliative sedation and existential suffering and to inform research, policy, and practice. Palliative sedation to treat existential refractory symptoms was labelled a controversial practice. A shortage of evidence-based resources limits the current literature’s ability to inform policy and clinical practice. There is a need for both qualitative and quantitative multi-center research so health care professionals and regional-level institutions have firm roots to establish proper policy and practice.

Guidelines
Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement
Piotr Z Sobanski et al
Cardiovascular Research, Volume 116, Issue 1, 1 January 2020, Pages 12–27,
Contrary to common perception, modern palliative care (PC) is applicable to all people with an incurable disease, not only cancer. PC is appropriate at every stage of disease progression, when PC needs emerge. These needs can be of physical, emotional, social, or spiritual nature. This document encourages the use of validated assessment tools to recognize such needs and ascertain efficacy of management. PC interventions should be provided alongside cardiologic management.

Care in the last hours and days of life
Laura Chapman and John Ellershaw
Medicine, Volume 48, Issue 1, 52 - 56
Care in the last hours and days of life is a vital part of medical practice. Ensuring a dignified death for people, with appropriate support for those important to them, is a core activity of all healthcare professionals. Once it has been recognized that a person may be dying, it is important that pain and other symptoms are managed appropriately. All medication that needs to be continued should be converted to a parenteral route, usually subcutaneously when administration via the oral route is no longer possible. As-required medication should be prescribed for the key symptoms that occur in dying people, such as pain, agitation, increased respiratory tract secretions, dyspnoea and nausea and vomiting. The appropriateness of continuing investigations and interventions, including routine observations, antibiotics and blood tests, should be considered. Appropriate communication with the person and those important to them is key, to ensure both that the person’s psychological and spiritual needs are met and that those important to them are aware that the person is dying. Bereavement support can begin before death and is a crucial part of the care offered to the person’s family.

Medicines and Prescribing
Diverting Opioid Diversion: Does It Justify Randomly Screening Palliative Care Patients?
Leah R. Eisenberg
Midazolam: an essential palliative care drug.
Prommer, E.
Palliative Care and Social Practice. January 13, 2020
Midazolam is a commonly used benzodiazepine in palliative care and is considered one of the four essential drugs needed for the promotion of quality care in dying patients. Acting on the benzodiazepine receptor, it promotes the action of gamma-aminobutyric acid. Gamma-aminobutyric acid action promotes sedative, anxiolytic, and anticonvulsant properties. Midazolam has a faster onset and shorter duration of action than other benzodiazepines such as diazepam and lorazepam lending itself to greater flexibility in dosing than other benzodiazepines. The kidneys excrete midazolam and its active metabolite. Metabolism occurs in the liver by the P450 system. This article examines the pharmacology, pharmacodynamics, and clinical uses of midazolam in palliative care.

Comparing Methadone Rotation to Consensus Opinion.
Smith MA et al
A process evaluation study was conducted. This paper reports on the results of this process evaluation, of which the programme has been implemented in 37 LTCFs in 7 European countries. Alongside an effective educational and development intervention for staff to improve palliative care in long-term care facilities (LTCFs). In a cluster randomized controlled trial, this intervention was associated with better patient outcomes.

A Systematic Review of the Effectiveness of Oral Baclofen in the Management of Hiccups in Adult Palliative Care Patients.
Hiccup is a recognised symptom amongst the palliative care population. It can be debilitating, with significant impact on quality of life. The pathophysiology is poorly understood and the list of aetiological factors is extensive. The current treatment recommendations are based on a small body of evidence and there remains uncertainty regarding optimal management. The aim of this study was to systematically review the evidence for oral baclofen in the management of hiccups in adult palliative care patients. While baclofen is an option in the management of hiccups, it is difficult to make recommendations based on the body of evidence presented in this systematic review. There is a lack of RCTs in this field and further research is warranted.

Deprescribing in Older People Approaching End of Life: A Randomized Controlled Trial Using STOPPFrail Criteria
Denis Curtin et al
Journal of the American Geriatrics Society 23 December 2019
Older people approaching end of life are commonly prescribed multiple medications, many of which may be inappropriate or futile. Our objective was to examine the effect of applying the STOPPFrail, a recently developed deprescribing tool, to the medication regimens of older patients with advanced frailty. STOPPFrail-guided deprescribing significantly reduced polypharmacy and medication costs in frail older people. No significant differences between groups were observed with regard to falls, hospital presentations, quality of life, and mortality, although the trial was likely underpowered to detect differences in these outcomes.

What is the evidence for mirtazapine in treating cancer-related symptomatology? A systematic review.
Economos G et al
Cancer patients often experience multiple distressing symptoms which are challenging to manage. It would therefore be helpful to find a treatment that alleviates more than one symptom, to avoid polypharmacy: mirtazapine has been used in several studies for this purpose. The objective of this study was to assess the effectiveness and safety of mirtazapine in alleviating one or more frequently encountered cancer-related symptoms. Study design and small sample sizes limit the ability to interpret results. Trials to assess the impact of mirtazapine or other medicines in alleviating multiple symptoms would be valuable.

3-month versus 6-month adjuvant chemotherapy for patients with high-risk stage II and III colorectal cancer: 3-year follow-up of the SCOT non-inferiority RCT
Iveson T, et al
National Institute for Health Research 19 December 2019
Oxaliplatin and fluoropyrimidine chemotherapy administered over 6 months is the standard adjuvant regimen for patients with high-risk stage II or III colorectal cancer. However, the regimen is associated with cumulative toxicity, characterised by chronic and often irreversible neuropathy. The study achieved its primary end point, showing that 3-month oxaliplatin-containing adjuvant chemotherapy is non-inferior to 6 months of the same regimen; 3-month treatment showed a better safety profile and cost less. For future work, further follow-up will refine long-term estimates of the duration effect on disease-free survival and overall survival. The health economic analysis will be updated to include long-term extrapolation for subgroups. We expect these analyses to be available in 2019–20. The Short Course Oncology Therapy (SCOT) study translational samples may allow the identification of patients who would benefit from longer treatment based on the molecular characteristics of their disease.

Place of care
Evaluating the implementation of the PACE Steps to Success Programme in long-term care facilities in seven countries according to the RE-AIM framework
Oosterveld-Vlug, Mariska et al
Implementation Science 14, Article number: 107 (2019)
The PACE ‘Steps to Success’ programme is a complex educational and development intervention for staff to improve palliative care in long-term care facilities (LTCFs). In a cluster randomized controlled trial, this programme has been implemented in 37 LTCFs in 7 European countries. Alongside an effectiveness study, a process evaluation study was conducted. This paper reports on the results of this process evaluation, of which
the aim was to provide a more detailed understanding of the implementation of the PACE Programme across and within countries. The implementation of the PACE Programme was feasible but leaves room for improvement. Our analysis helps to better understand the optimal levels of training and facilitation and provides recommendations to improve implementation in the LTC setting. The results of the process evaluation will be used to further adapt and improve the PACE Programme prior to its further dissemination.

**Quality of Health Care**

**Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners**

Julia Tapsfield et al

*BMJ Supportive & Palliative Care* 2019;9:e28.

Key Information Summaries (KIS) were introduced throughout Scotland in 2013 so that anticipatory care plans written by general practitioners (GPs) could be routinely shared electronically and updated in real time, between GPs and providers of unscheduled and secondary care. We aimed to describe the current reach of anticipatory and palliative care, and to explore GPs’ views on using KIS. GPs are identifying patients for anticipatory and palliative care more equitably across the different disease trajectories and earlier in the disease process than they were previously identifying patients specifically for palliative care. However, many patients still lack care planning, particularly those dying with organ failure.

**Economic evaluations of palliative care models: A systematic review.**

Matthew C. et al


Palliative care aims to improve quality of life by relieving physical, emotional, and spiritual suffering. Health system planning can be informed by evaluating cost and effectiveness of health care delivery, including palliative care. Applicability and generalizability of evidence is uncertain due to small sample sizes, short duration, and limited modeling of costs and effects. Further economic evaluations with larger sample sizes are needed, inclusive of the diversity and complexity of palliative care populations and using patient-centered outcomes.

**Spiritual and psychological care**

**Research literature on the intersection of dementia, spirituality, and palliative care: A scoping review.**

Palmer JA, et al


Dementia marks an increasingly prevalent terminal illness for which palliative care, including spiritual care, could improve quality of life. Research gaps exist in understanding the intersection of dementia, spirituality, and palliative care. Research across dementia, spirituality, and palliative care needs to examine distinct stages of dementia, settings beyond long-term care, and formal spiritual care interventions plus utilize rigorous study designs (e.g., randomized clinical trials). Such research could advance practice and policy that enhance quality of life for tens of millions of persons with dementia and their family members worldwide.

**Signal: Holistic services in advanced lung disease can help people cope better with breathlessness**

NIHR Dissemination Centre 19 December 2019

Services providing holistic health care can improve the psychological well-being of people who are living with breathlessness associated with chronic or advanced lung disease, such as lung cancer or chronic obstructive pulmonary disease. Breathlessness is a distressing symptom in which feelings of fear and helplessness, social isolation, high levels of anxiety and significant carer burden are common experiences. Drugs can have limited effectiveness in advanced disease and do not address the underlying psychosocial problems that can worsen symptoms. Holistic breathlessness services can help patients manage breathlessness more effectively through patient-centred approaches addressing breathing training, relaxation techniques and psychological support. This NIHR-funded UK based study provides a reliable basis for the development of holistic breathlessness services to improve the quality of life for people with chronic or advanced lung disease.

**An EAPC white paper on multi-disciplinary education for spiritual care in palliative care.**

Best M et al


The EAPC White Paper addresses the issue of spiritual care education for all palliative care professionals. It is to guide health care professionals involved in teaching or training of palliative care and spiritual care; stakeholders, leaders and decision makers responsible for training and education; as well as national and local curricula development groups.

**Symptoms**

**Constipation and malignant bowel obstruction in palliative care**

Boland, Jason W. et al.
Constipation affects about half of patients with advanced illness and nearly all terminally ill patients receiving opioids. Constipation can be very distressing, leading to abdominal pain/distension, anorexia, nausea/vomiting, faecal impaction, intestinal obstruction, urinary retention and incontinence; reducing quality of life. A thorough assessment is critical to diagnose it, assess its severity, impact and associated symptoms, and find the cause. Management includes explanations to the patient/family, treating reversible causes (where appropriate) and optimizing non-pharmacological treatments and drugs.

**Delirium: non-pharmacological and pharmacological management**
Boland JW, Lawlor PG, Bush SH
*BMJ Supportive & Palliative Care* 2019;9:482-484.

Delirium is an acute onset, fluctuant, confusional state with cognitive, emotional, perceptual, psychomotor and sleep–wake cycle disturbances. It is often worse in the evening and at night, particularly with underlying dementia. Delirium is often not diagnosed due to fluctuating signs and symptoms. The most common clinical subtype in palliative care is hypoactive delirium, with reduced psychomotor activity. Delirium is especially common in palliative care, almost ubiquitous towards the end of life; up to 88% of patients develop delirium in the last weeks to hours of life. Older age and dementia are major risk factors. Current and projected demographic changes, with an increased elderly population, signal a need for physicians to have a better awareness of delirium diagnosis and assessment. A high level of suspicion and multidisciplinary team involvement is needed in diagnosis and management.

**The Role of Ketamine in Depression**
April Christensen and Jennifer Pruskowski
*Journal of Palliative Medicine* Vol. 23, No. 1

This Fast Fact aims to provide a concise review of the role of ketamine to treat TRD in adults for experienced palliative care clinicians.

**Naloxegol for opioid-induced sphincter of Oddi spasm/dysfunction**
Andrew Neil Davies and Charlotte Leach
*BMJ Supportive & Palliative Care* 2019;9:365-366.

The paper describes a case report of a patient with a significant history of opioid-induced dysfunction of the sphincter of Oddi, who required morphine sulfate to manage oral mucositis pain, and who was successfully treated with concomitant oral naloxegol.

**Management of bleeding in palliative care patients in the general internal medicine ward: a systematic review**
R.Sood et al
*Annals of Medicine and Surgery* Volume 50, February 2020, Pages 14-23

Palliative care patients, those suffering from at least one chronic lifelong medical condition and hospice care patients, those with a life expectancy less than 6 months, are regularly hospitalised in general internal medicine wards. By means of a clinical case, this review aims to equip the internist with an approach to bleeding in this population. Firstly, practical advice on platelet transfusions will be provided. Secondly, the management of bleeding in site-specific situations will be addressed (from the ENT/pulmonary sphere, gastrointestinal - urogenital tract and cutaneous ulcers). Finally, an algorithm pertaining to the management of catastrophic bleeding is proposed. Literature is lacking regarding management of bleeding in the palliative care population hospitalised in an acute medical setting. Recommendations are of limited quality, the majority based on case reports or expert opinion. Further studies, exploring for example the impact on patient quality of life, are desirable to improve the management of this frequently encountered complication.

**Conformity in Prescription and Administration of Respiratory Distress Protocols in a Tertiary Care Hospital in the Province of Quebec: RELIEVE Study.**
Dufort-Rouleau, C et al

Respiratory distress protocols (RDPs) are protocolized prescriptions comprised of 3 medications (a benzodiazepine, an opioid, and an anticholinergic) administered simultaneously as an emergency treatment for respiratory distress in palliative care patients in the province of Quebec, Canada. However, data on appropriate use that justifies the combination of all 3 components is scarce and based on individual pharmacodynamic properties along with expert consensus. This study highlights important gaps in the use of RDPs in our institution. Health-care provider training appears necessary in order to ensure adequate conformity and allow for further evaluation of RDP effectiveness.

**A rapid positive influence of S-ketamine on the anxiety of patients in palliative care: a retrospective pilot study**
Eduard Falk et al
Patients in palliative care need rapid-acting pharmacological options for psychological distress. N-methyl-D-aspartate antagonist ketamine is known to have a fast onset of anti-depressant and anxiolytic action. Its S-enantiomer S-ketamine (or esketamine) is an analgesic used as a routine treatment for refractory pain as an intravenous infusion (0.25 mg/kg over 45 min). This study investigates whether S-ketamine pain therapy has a positive impact on psychological distress caused by anxiety and depression in palliative care. Our findings show that psychological distress of patients in palliative care may improve after a single administration of S-ketamine, which mainly alleviates anxiety in those patients. Limitations of this study arise from non-randomization, retrospective analysis and low sample size. Therefore, further prospective and ideally randomized studies are necessary.

Unusual case of transdermal fentanyl in cachexia
Deborah Lam et al

BMJ Supportive & Palliative Care 2019;9:363-364.
Fentanyl has a low molecular weight and is lipophilic making it suitable for transdermal administration. However, multiple factors appear to lead to interindividual variation in absorption via this route. Here we describe an unusual case where a patient was found to have twelve 100 μg/hour fentanyl patches in situ which she was using as background analgesia.

Family and healthcare staff’s perception of delirium
Enrico Mossello

European Geriatric Medicine pp 1–9 2020
We review the available literature regarding delirium experiences of family caregivers and healthcare staff, to discuss how caregivers and staff perception can increase delirium detection and to summarize how to address the needs of family caregivers and healthcare providers in delirium care. Delirium is a stressful event not only for patients but also for family caregivers and healthcare staff, especially nurses. Recording the observations of family members and healthcare staff can help in delirium detection. Staff education is crucial to reduce the burden of professional and family caregivers.

Symptom relief and palliative care in gynecologic oncology
Roy, Mohana; et al

Current Opinion in Obstetrics and Gynecology: February 2020 - Volume 32 - Issue 1 - p 65–75
Patients with gynecologic malignancies experience varied and often difficult-to-manage symptoms through their disease course, along with decisions surrounding preferences for advance care planning. This review focuses on evidence-based symptom management for these patients and offers a framework for conversations regarding goals of therapy. Integration of early palliative care and focus on symptom management is an important and multidisciplinary approach to help patients with gynecologic malignancies.

Interventional management of pain in cancer and palliative care.
Bhaskar AK, Simpson KH.

A significant number of cancer patients suffer from pain caused by the disease or its treatment. The World Health Organization analgesic ladder promotes the use of oral opioids and adjuncts, and reserves interventional procedures as the ‘fourth’ step in the ladder. Although this can to an extent be justified as most patients achieve reasonable analgesia with minimal adverse with oral analgesia, 10% of patients continue to have severe pain and/or experience poor quality of life from drug adverse effects. These patients could benefit from appropriate interventions including nerve blocks and central neuraxial blockade, and more specialized treatment options such as neurolytic blocks, intrathecal drug delivery systems, neuromodulation and percutaneous cordotomy. They should be assessed and referred in a timely manner for specialist pain management rather than reserving such interventions for a last resort. Delay in referral can make it too late to deliver the quality of care that is expected by both patients and clinicians.

An in-hospital clinical care pathway with integrated decision support for cancer pain management reduced pain intensity and needs for hospital stay.
Lohre ET, Thronaes M, Brunelli C, Kaasa S, Klepstad P.
A clinical care pathway for pain management in a palliative care unit was studied with outcomes related to patients, physicians, and health care service. Mandatory use of patient-reported outcome measures (PROMs) and physician-directed decision support (DS) were integrated parts of the pathway. The interventions were implemented according to the intentions and PI was reduced as hypothesized. For evaluation of generalizability, the interventions should be studied in other settings and with a controlled design.
NIHR Signal: Longer duration of urinary catheter placement associated with an increase in urinary infection
NIHR Dissemination Centre 19 December 2019
The risk of urinary infection appears low with very short-term use but increases with the time that a patient has a catheter. Women and patients with paraplegia or cerebrovascular disease are at increased risk. The overall infection rate was 1.64 infections per 1,000 catheter days, and about 2.7% of patients developed an infection if the catheter was in place at ten days. Reviewing their need for catheterisation is important where possible.

Clinical Evidence for Association of Acupuncture and Acupressure With Improved Cancer Pain
Yihan He, et al
JAMA Oncology 19 December 2019
Is the use of acupuncture and acupressure associated with improved cancer pain management compared with sham intervention and/or analgesic therapy alone? We evaluate the existing randomized clinical trials (RCTs) for evidence of the association of acupuncture and acupressure with reduction in cancer pain. This systematic review and meta-analysis found that acupuncture and/or acupressure was significantly associated with reduced cancer pain and decreased use of analgesics, although the evidence level was moderate. This finding suggests that more rigorous trials are needed to identify the association of acupuncture and acupressure with specific types of cancer pain and to integrate such evidence into clinical care to reduce opioid use.

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