Anticipatory Grief in the Sister of a Boy with a Brain Tumor (TH322A)

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Objectives
• identify age-specific understanding of death among children and adolescents
• Describe common grief reactions among children of various ages
• Recognize behaviors that suggest pathological grief
• Provide resources for siblings of children with life-limiting illness

Background: Life-limiting illness in a pediatric patient affects the global environment of the child. Siblings in particular may perceive a sense of invisibility and exhibit signs of grief that begin at the time of diagnosis. These are developmentally specific and may be anticipated in order to sharpen awareness and promote healing.

Case Description: The patient is a 6 year-old boy with diffuse intrinsic pontine glioma diagnosed in March 2016. He received radiation (XRT) and chemotherapy (CT) followed by a second regimen of CT when the tumor progressed. He was enrolled in hospice 4 months after progression. Following Phase I therapy and palliative XRT, he remains at home with a focus on comfort-directed therapies and the support of home hospice.

The patient's 4 year-old sister has developed anxiety, hyper-vigilance, loss of boundaries (getting into things that are not hers), and mimicking existential ideations expressed by her brother while creating religious symbolic objects similar to his. The sister is now increasingly bonding with a family friend and two cats as her mother's attachment to the dying child intensifies. Books dealing with loss of a sibling have been provided, as well as ongoing input from the nurse, chaplain, and social worker on the interdisciplinary team to assist the child and her family with the manifestations of bereavement.

Conclusion: Expression of grief in siblings is age-specific and may be expressed through non-verbal behaviors that affect the dynamics of the family. Early recognition and management of grief in siblings may improve coping and adaptation to loss.
Pediatric Home Visit Death: His Story, Our Lessons (TH322B)
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Objectives
• Describe medico-legal variables around pediatric in-home death logistics.
• Describe interpersonal counseling principles to develop resiliency of providers and family after an experience of death.

Background: Some pediatric patients will not have DNR orders at the time of death, even when enrolled in hospice services and dying at home. A death at home which engages EMS and law enforcement may cause significant distress to patients, families, community members, and providers. Therefore, it is important providers understand medico-legal variables and psycho-social-emotional maneuvers to ensure best patient, provider, and family care.

Case Description: A palliative physician and chaplain –both in their fellowships-- arrive at the home of a well-known patient for a routinely scheduled home visit. The patient is a 17 year old boy with renal medullary carcinoma recently enrolled in hospice; he does not have documentation to limit scope of treatment. The home visit goals are to address the patient’s fears, to set mom’s expectations, and to complete a POST (Physician Order for Scope of Treatment). Upon arrival, EMS and police are at the scene; CPR has been in progress for 20 minutes. The patient’s mother is on the front porch in tearful duress. Emergency personnel are eager for orders from the physician. A crowd of apartment dwellers, family, and the patient’s school friends are gathering across the parking lot. The physician and chaplain are faced with addressing the medical care of the patient, emotional support of several groups, and working within the bounds of EMS staff and law enforcement.

Conclusion: Death at home is the goal for many patients but is complicated by several legal considerations as well as need to re-define the interdisciplinary team. Balancing medical management and attending to the psycho-social-emotional needs of several disparate groups at the scene is a rewarding challenge.
Palliative Extubation of the Awake and Interactive Patient Electing to be Liberated from the Ventilator: Interdisciplinary Strategies for Helping Providers Cope (TH322C)
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Objectives
- Identify factors that contribute to clinicians’ moral distress associated with awake and interactive patients who elect to cease therapies that could reasonably prolong their lives.
- Discuss the value of interdisciplinary perspectives in resolving our confusion and struggle as providers, and refocusing care on the patient’s dignity and comfort.
- Describe how structured debriefing can help clinicians process moral distress and provide patient centered, goal-oriented care.

Background: Palliative extubation of the awake and interactive patient is often fraught with moral distress and concern by clinicians. The complexities of the patient-doctor relationship play a large role in this struggle.

Case Description: The Palliative Care consult team was consulted by the MICU to consider transferring patient MB to the Palliative Care unit (PCU) for palliative extubation. MB, a 58yo mother, grandmother and wife, suffered from Swyer-James syndrome, a rare post-infectious respiratory condition that in general boasts a favorable prognosis; however, a devastating pneumonia left MB with debilitating tracheomalacia requiring tracheostomy and nursing home residence one year ago. Despite being intermittently ventilator dependent, MB stayed active through the support of her family and her Catholic faith. Bleeding from the trach site brought her into the hospital one week prior to our involvement. Our ENT team obtained a custom tracheostomy to maximize her respiratory status and minimize her need to return to the hospital; however, due to the extent of her tracheomalacia, this new tracheostomy needed frequent cuff re-inflation by the MICU team, without which the patient could not take adequate tidal volumes, resulting in air hunger and shortness of breath. The patient expressed desire to be liberated from the ventilator, thus our team was called. Upon meeting MB, we struggled to simply follow her wishes without feeling ethical reticence. At first glance, she lacked the typical features of a chronically ill patient near the end of life. With the help of structured interdisciplinary debriefing, our team transitioned the patient from MICU to PCU, where she was liberated from the ventilator, and died peacefully with her family singing at her bedside.

Conclusion: Structured interdisciplinary debriefing guides clinicians in overcoming countertransference and personal bias to confidently provide patient-centered and goal-oriented palliative care.
Defining Due Diligence: How to Locate Long-Lost Family, and Why It Matters (TH322D)
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Objectives
• Describe a systematic approach to identify and locate potential surrogate decision makers when a patient is unable to communicate.
• Discuss the impact of an exhaustive search and family reunification on a patient’s end-of-life experience and family’s risk for complicated bereavement.

Background: Despite living in a time when technology connects persons across the world, some patients enter the medical system estranged from family or friends. This case explores the legal and ethical obligations to search for surrogate decision makers, describes a systematic approach to conducting an exhaustive search, and demonstrates the emotional impact a palliative care team can have by reconnecting a patient with family.

Case Description: A 56-year-old undomiciled man with alcoholic cirrhosis was admitted to the hospital with spontaneous bacterial peritonitis complicated by renal failure and encephalopathy. The palliative care team was consulted and the patient asked for assistance contacting family, whom he had not seen in several years. He was unable to provide contact information. We employed a search strategy that incorporated social media, online databases, court records, and voter registration rolls. While this search was ongoing, the patient was intubated for respiratory arrest. The medical team recommended a transition to comfort care, a plan of care that depended upon an exhaustive, diligent search. We were able to locate the patient’s son and contacted him using certified mail. We discovered he had been actively searching for the patient for three years. Several family members came to the hospital, and their participation resulted in the medical team offering therapies such as dialysis they had previously considered inappropriate. His family achieved a consensus that he would not desire prolonged life support and he died surrounded by those who loved him.

Conclusion: For patients who are incapacitated, many states have a legal requirement to perform a due diligence search for potential surrogate decision; likewise there is an ethical imperative. This case exemplifies a comprehensive strategy for conducting such a search and demonstrates how this process can reunite families, mitigate bereavement risk, and be emotionally rewarding for the interdisciplinary team.
Mindful Journeys: An Innovative Approach to Helping Parents Facing or Dealing with Loss of a Child (TH342A)
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Objectives
- Attendees will be able to list at least 3 methods of achieving mindfulness for self-calming or to discover new insights to make decisions for their children
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Background: Mindfulness-based techniques focus one’s attention on the moment, acknowledging feelings, thoughts, and sensations. Meditation, deep prayer, guided imagery create an inner space where new wisdom may be gained. Indigenous shamans journey to gain information about illness or life on behalf of patients. Integrative medicine practices can also lead people to a similar inner state. These mind-body approaches share a common thread of achieving a tranquil inner state in which new insights may ‘appear’ to patients, parents, or caregivers. A priest, rabbi, chaplain, shaman, or healer can guide people to a mindful state. This state can aid patients in making difficult decisions regarding healthcare, especially in those world cultures which do not easily embrace Western cognitive behavioral therapies. The process of journeying into one's inner self is facilitated through the use of a sonic drive such as a rattle or drum to focus the attention and achieve a tranquil inner state. In this state, one becomes open to new insights, visions, understandings, epiphanies, and information that may not be accessible in our usual state of awareness and inner talking.

Case Description: We conducted mindful journeying with 14 patients in the last 3 years. Families report new insights and achieve new clarity about decisions they feel they need to make. There were no negative psychological repercussions. Several patients were critically ill, terminally ill or legally brain dead. Families found the experience comforting, reassuring, and largely successful in achieving insights they were not able to achieve with conventional Western approaches. The work was featured nationally on PBS Healing Quest. Workshop attendees will be given an opportunity to experience this process to understand how it may benefit their patients.

Conclusion: Mindful journeying can provide patients access to information that can help them understand their illness and facilitate decision making and life closure.
Non-Beneficial CPR in Pediatrics – When to Compress? (TH342B)
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Objectives
- Describe professional guidelines for responding to requests for potentially non-beneficial intensive medical therapy.
- Analyze the ethical issues and pros and cons of unilateral do not attempt resuscitation orders in pediatric populations.
- Evaluate the contextual features and medical decision-making in the presented cases that resulted in different outcomes at the end of life.

Background: Although parents may request medical treatments, clinicians are not required to provide interventions that are not medically-indicated, particularly if associated with a low likelihood of benefit and risk of potential harms. These disagreements between family and the medical team can be particularly distressing as a child with terminal illness approaches the end of life. In rare circumstances, providers are placed in the difficult position of enacting a do not attempt resuscitation order against the wishes of the patient’s family (unilateral DNAR) or providing cardiopulmonary resuscitation (CPR) that is expected to be non-beneficial. These cases raise ethical questions and are often associated with moral distress. Some in the field argue that unilateral DNAR is never appropriate. Because neither option is ideal, an examination of individual case circumstances may guide clinician decision-making.

Case Description: Sara was a 9-year-old girl with progressive, incurable leukemia admitted to the hospital with worsening respiratory distress and multi-system organ failure. Her family continued to request “everything be done,” however the medical team universally agreed that CPR would be non-beneficial and potentially harmful. Ultimately a unilateral DNAR order was placed on the chart and Sara died uneventfully without efforts at resuscitation. One week later Diamond, a 12-year-old with incurable osteosarcoma, was admitted with an identical clinical picture. Although the team felt CPR was not indicated her family demanded resuscitation and Diamond died after 3 rounds of chest compressions with epinephrine.

Conclusion: In the cases above, clinicians recognized that these children were actively dying from complications of progressive cancer and CPR would only prolong inevitable death and potentially result in physical harms. In both cases, despite quality palliative care involvement, the family continued to demand full escalation of treatment to include CPR. We will examine the contextual features that guided clinician-decision-making and resulted in different outcomes at the end of each child’s life.
Fostering Trust with a Homeless Young Man Experiencing Advanced Cancer (TH342C)

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Objectives
- Understand the considerations of building trust with patients experiencing homelessness, for whom “safety” is not a daily reality.
- Integrate skills for fostering trust from an interdisciplinary perspective, including chaplaincy, social work, medicine, nursing, and advanced practice nursing.

Background: Patients experiencing homelessness are inherently vulnerable. In the context of advanced serious illness, myriad dimensions of pain may be exacerbated by unstable living conditions, poor or absent caregiving supports, a history or risk of substance abuse, complexities associated with what it means to survive, and no home for safe discharge. Building trust when the world has been untrustworthy from a patient’s perspective is a foundational task.

Case Description: KL is a 24-year old male, well-spoken, groomed, and polite despite difficult circumstances. He was severely abused then abandoned as a child, living in multiple foster homes until 18. With no caring adult figure, he predictably fell into a chaotic life style, had three children by multiple mothers and became homeless in New York City. He presented with newly diagnosed renal cell carcinoma metastatic to lung, lymph nodes, and bone. Spine and pelvic involvement resulted in paralyzing somatic pain preventing KL from performing the activities of daily living essential for his survival on the streets. High symptom burden and needs in safekeeping of opioids made a care plan challenging for a young, homeless, and truly isolated man. The inpatient and outpatient interdisciplinary team members partnering with KL each earned his trust with time. A “safe place” opened hearts on both sides, and led to a plan acceptable to the patient.

Conclusion: This case examines the complexities of providing care for the homeless patient with advanced cancer, and the effect on the multidisciplinary providers of an endearing patient with no visitors or loved ones, and no home to discharge to.
The Heart and the Storm: A Challenging Case of Treating Paroxysmal Sympathetic Hyperactivity in a Teenager with Brain Injury and Hypertrophic Cardiomyopathy (TH342D)
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Objectives
- Recognize the signs and symptoms of paroxysmal sympathetic storm in children with neurologic injury.
- Differentiate between sympathetic storm and potentially overlapping conditions.
- Know the pharmacological treatment of sympathetic storm.

Background: Paroxysmal sympathetic hyperactivity (PSH), or “storm”, is a recognized, poorly-understood sequela of neurologic injury. A trigger causes a multi-system array of signs and symptoms, including tachycardia, hypertension, and sweating. Patients may have fever, urinary retention, posturing, and rhabdomyolysis. With underlying cognitive impairment, there is increased risk of harm to self and others. PSH is a diagnosis of exclusion, overlapping with life-threatening conditions including sepsis, seizures, and delirium. Treatment focuses on sympathetic antagonism, and opioids, benzodiazepines, and antipyretics are also used. PSH episodes may begin early, and can persist for months or years. The symptom burden is high for patients and their caregivers.

Case Description: A 14-year-old healthy male experienced cardiac arrest while playing basketball. He received compressions for 7-10 minutes prior to defibrillation and intubation. He was diagnosed with hypertrophic cardiomyopathy, at high risk for ventricular fibrillation and sudden death. Brain MRI showed ischemic injury to the basal ganglia and hypothalamus. Early on, he began to “storm,” with tachycardia, fever, sweating, and hypertension, requiring continuous, high-dose infusions of beta blockers. Cardiology was concerned about frequent tachycardia. The patient’s mother was distressed by her son’s condition and prognosis. He responded well to morphine, and the pediatric palliative care team (PPC) considered methadone, but the effect of QT prolongation precluded its use. A team of PPC, pediatric cardiology and critical care decided on high-dose morphine, propranolol, diltiazem, and clonidine, with melatonin for circadian disruption. The frequency and severity of his episodes decreased, and, with signs of returning cognition, the patient was referred for inpatient rehabilitation.

Conclusion: Sympathetic “storm” is a life-threatening condition for children with neurologic injury. A multidisciplinary approach is instrumental for symptom control. This case highlights the specialized involvement of a PPC team in a patient for whom a single episode could lead to sudden death.
It Takes a Village: Incorporating Intravenous Ketamine into a Comprehensive Wound Care Plan (TH372A)
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Objectives
- Recognize the critical role of wound care and its impact on patients’ quality of life at the end-of-life
- Describe ketamine’s mechanism of action and its potential to treat opioid hyperalgesia and address wound care-related pain
- Identify challenges related to ketamine administration in the setting of daily wound care

Background: Ketamine is effective in preventing pain caused by dressing changes in burn patients. Palliative care patients can have similarly painful skin wounds and dressing changes, which can be a significant source of distress at the end-of-life. However, the palliative care literature does not describe the use of intravenous ketamine in these patients.

Case Description: TL was a 20 yr old morbidly obese female (BMI = 56) admitted to the Inpatient Palliative Care Unit from home hospice with worsening sacral decubitus ulcers, bilateral lower extremity edema, large ruptured bullae (6 x 5 cm) on her lower legs, along with cellulitis due to complications of metastatic intrahepatic cholangiocarcinoma. Due to body habitus, she required the synchronized care of six nurses to complete the daily wound care recommended by the wound management team. Her complex pain regimen, consisting of topical lidocaine, morphine inrasite gel, IV dexamethasone, continuous methadone, and hydromorphone infusion and boluses, was unable to control the pain associated with skin lesions and dressing changes, and led to hyperalgesia and myoclonus. Addition of IV bolus ketamine concurrent with dressing changes, administered by an anesthesiologist on the inpatient chronic pain team, and subsequent ketamine infusion reduced hyperalgesia and myoclonus and provided her with adequate pain relief.

Conclusion: High quality wound care complimented by a robust pharmacological intervention can be achieved by the coordination and dedication of many members of the palliative care interdisciplinary team, and was critical to this patient’s care. We will discuss the mechanism of action of ketamine, and the challenges and benefits of administering intravenous ketamine when wound care-related pain is refractory to typical management. Palliative care clinicians can identify patients in whom ketamine can play a key role in wound care, and develop a comprehensive palliative approach to wound care to reduce end-of-life suffering.
The Use of Pharmacogenomics to Determine a Pain Management Plan in the Case of Extreme Opioid Tolerance  (TH372B)
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Objectives
- Describe pharmacokinetics as a potential mechanism of opioid tolerance
- Demonstrate pharmacogenomic analysis as a means to assess patients with opioid tolerance and individualize a pain management care plan.
- Describe interdisciplinary assessment in forming a care plan for a case of significant opioid tolerance

Background: Pain management in patients with opioid tolerance can be challenging, especially when mutations in mu and/or kappa receptors, CYP enzymes, and glucuronidation alter pharmacodynamics and pharmacokinetics. In cases of significant opioid tolerance, high levels of daily oral morphine equivalents (OMEs) leads to difficulty in caring for a patient and discomfort with providing necessary doses to maintain pain control. Interdisciplinary collaboration with pharmacists can assist in using pharmacogenomics to evaluate potential mechanisms for tolerance.

Case Description: A 45 year old female diagnosed with a C7 lytic lesion and fracture presented for uncontrolled neck/arm pain. Four years earlier, she had been diagnosed with metastatic colon adenocarcinoma, and developed chronic pain after multiple surgeries, chemotherapy, and radiation. Her home pain regimen included fentanyl, oxycodone and intrathecal hydromorphone with a daily OME of 12,520mg. While inpatient, she required a hydromorphone drip which peaked at a rate of 255mg/hour. Including her drip and PRN medications, she was receiving 136,495mg daily OMEs. During this time, she was neurologically intact and ambulatory. An interdisciplinary team consisting of providers from critical care, oncology, and palliative care, and critical care pharmacists collaborated to simplify her pain regimen with the addition of methadone 20mg Q8H. At discharge, her daily OME was 8,195mg.

It was initially postulated the patient had ultra-rapid opioid metabolism, however pharmacogenomics demonstrated reduced/intermediate function of phase I enzymes that are involved in various opioid metabolism, which would not explain her high opioid tolerance. There was speculation of hyperalgesia, however she never experienced side effects from her high opioid dosing. These results indicate possible mu receptor dysregulation or mutation, which cannot be tested. Her appropriate response to methadone may be related to the NMDA component of methadone.
Conclusion: Interdisciplinary collaboration with pharmacy and pharmacogenomic analysis may provide assistance in developing a pain management care plan in cases of extreme opioid tolerance.
Opioid-Induced Chorea: an Atypical Presentation of Opioid Neurotoxicity (TH372C)
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Objectives
- Identify chorea as a potential side effect of opioids.
- Describe the clinical presentation and management of opioid-induced neurotoxicity.
- Recognize the involuntary movements associated with hyperkinetic movement disorders in opioid-induced neurotoxicity.

Background: The pathophysiology of drug-induced movement disorders is poorly understood. While opioid-induced myoclonus is well described in the palliative care literature, there are few case reports of opioid-induced chorea. Here we present a case of new myoclonus and chorea in the setting of opioid neurotoxicity. Notably, the patient’s hyperkinesia worsened during periods of sleep and deep relaxation; a phenomenon not well described in the literature.

Case Description: A 20 year-old woman presented with fever and rash and was subsequently diagnosed with primary cutaneous lymphoma. During her admission she underwent surgical wound debridement with an initial post-operative pain regimen consisting of oral and intravenous morphine. On post-operative day three she developed generalized spontaneous positive myoclonus in the setting of normal renal function. Morphine was replaced with fentanyl with resolution of myoclonus within 48 hours. The following week hydromorphone was added to her pain regimen; within seven days she had recurrence of myoclonus in addition to visual hallucinations, delusions, and irregular, purposeless, flowing movements of her bilateral extremities consistent with chorea. Her choreic movements were most prominent during sleep and while in a state of deep relaxation during inpatient Reiki therapy. She had no personal or family history of central, peripheral, or autonomic nervous system disorders and was not taking any medications typically associated with drug-induced chorea. The remainder of her neurologic examination was unremarkable. No etiology was found on neuroimaging or laboratory workup. Hydromorphone was discontinued and her myoclonus, delusions, hallucinations, and chorea resolved within 72 hours.

Conclusion: A subset of patients may have a unique sensitivity to opioids and/or their metabolites, predisposing them to abnormal movement disorders, including chorea. Hypnic modulation of the neural pathways involved in drug-induced hyperkinesia may, in certain patients, result in more pronounced symptoms during sleep.
Narcan or Narcan’t? (TH372D)
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Objectives
• Improve knowledge of naloxone prescribing regulations
• Improve knowledge of potential barriers to assess to opioid pain medications

Background: Patient safety is a priority, and palliative providers must be experts not only in safe opioid prescribing, but in the laws, guidelines, and evidence related to that prescribing.

Case Description: Mr. P is a 39-year-old with metastatic renal cell carcinoma whose pain was controlled with methadone 10mg BID and PRN oxycodone 10mg. At a routine pharmacy visit, the patient was informed by his pharmacist that his opioids would not be filled without an accompanying naloxone prescription. When the prescribing physician called to discuss current Virginia laws negating the mandatory naloxone prescription for cancer patients, the pharmacist still refused to refill the prescriptions. The patient went to a different pharmacy within the same retail chain and was similarly denied his opioids. Three days later, he finally received his medications after going to a different pharmacy chain.

According to Virginia law, a naloxone prescription was not required for our patient given his active cancer and negative history of opioid abuse. Furthermore, he went to a national pharmacy that provides standing naloxone orders, thus bypassing the need for a prescription. The pharmacy refusal to fill the prescription raises important questions about the future of opioid prescribing. Amid the opioid epidemic, caution is necessary, but what happens when caution leads to potential adverse outcomes? Mr. P was required to make multiple phone calls, and pharmacy visits, and even risked opioid withdrawal as he was forced to wait the weekend for his medications. Furthermore, no evidence exists that co-prescribing naloxone for cancer patients reduces overdose risk.

Conclusion: Cancer patients have a myriad of psychosocial issues that can decrease quality of life, and the emotional impact of an unnecessary ordeal such as this cannot be ignored. We must advocate for our vulnerable patient population during the current medical and political climate of the opioid crisis.
The Role of an Outpatient Kidney Palliative Care Program: A Patient's Story (FR421A)
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Objectives
- To demonstrate the impact of an ambulatory kidney palliative care service on establishing realistic goals that meet a patient’s needs and match the natural disease trajectory of kidney disease.
- To demonstrate how physical symptoms of kidney disease can be assessed and managed in the outpatient non-dialysis setting.
- To demonstrate how emotional symptoms of kidney disease can be assessed and managed in the outpatient non-dialysis setting.

Background: Patients with advanced kidney disease have limited exposure to palliative care. Nephrologists’ perception of palliative care as only end-of-life care can partially explain this. In contrary, early palliative care that follows patients throughout their disease trajectory can improve quality of life and allow people to live life better.

Case Description: Mr. AB is a 67 year old male with hypertension and diabetic chronic kidney disease stage V. He was referred to our ambulatory kidney palliative care (KPC) clinical program for goals of care. The KPC clinic is embedded in the nephrology group practice and consists of a palliative care psychologist and a nephrology/palliative care doctor.
Mr. AB’s initial visit involved a discussion of the risks and benefits of dialysis versus conservative management of kidney disease. The decision was made to start dialysis, but quality of life goals for treatments, such as interacting with family and traveling were established. His next visit was three months later, after he had initiated dialysis. Advance care planning, a review of his expectations of dialysis, and his experience with the treatments was discussed.
In his next three visits, his neuropathic pain and nausea were managed. He engaged in cognitive behavioral therapy with the psychologist for anxiety treatment. With improved symptom control, he was able to go on a family cruise for his grand-daughter’s birthday.
Mr. AB eventually completed a Medical Order for Life Sustaining Treatment form documenting his limitations on disease directed therapy and his end-of-life wishes. He now has hope for the future and is pursuing transplant evaluation.

Conclusion: Mr. AB demonstrates that upstream interdisciplinary palliative care for patients with advanced kidney disease, and throughout its trajectory, can facilitate patients’ emotional and physical strength to the point where life extending procedures such as a transplant can be pursued. This example can help disseminate palliative care within nephrology.
Skills2Care™/Palliative Care for the Alzheimer’s and Dementia Communities (FR421B)
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Objectives
• Understand the Skills2Care™ program and how it is utilized under a palliative care model design.
• Recognize the value of the palliative care model for the AD and dementia communities.
• Explain the role of OT among the interdisciplinary team for patients diagnosed with AD or dementia.

Background: Palliative care is more commonly discussed in relation to cancer, however, the philosophies of palliative care are applicable for all persons facing a long-term illness that cannot be cured such as Alzheimer’s disease (AD) or dementia. Skills2Care™ is a caregiver education and training program that is provided by an occupational therapist for caregivers providing care for a loved one with AD or dementia. These skilled services delivered under a palliative care model design can help patients diagnosed with Alzheimer’s disease (AD) and their caregivers’ identify and address target problems and challenging behaviors that are negatively impacting their quality of life.

Case Description: A 73 year old female is referred to palliative care for end stage AD symptom management. Her primary caregiver is her husband who was newly diagnosed with limb-girdle muscular dystrophy. The patient is a 7A on the Functional Assessment Scale (FAST). Through administration of the Caregiver Assessment and Management of Problems (CAMP) the caregiver identified the following daily care challenges: managing incontinence, poor eating/nutrition, lack of engagement in leisure, crying episodes, bathing/dressing, medication management, and functional transfers. The caregiver had also noted that at times the patient was tremoring. It was later determined through further assessment and observation that patient was experiencing episodic seizures.

Conclusion: Occupational therapy/Skills2Care™ therapy services offered under a palliative care model design positively impacts the quality of life of those diagnosed with and those caring for someone diagnosed with AD or dementia. The interdisciplinary care among the OT, physician, social workers, chaplain, and NP staff can provide care along the way to help better manage the chronic and progressive nature of AD and dementia.
Challenges and Lessons Learned in Supporting a Patient’s Choice to Voluntarily Stop Eating and Drinking (VSED) (FR421C)
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Objectives
- After the case presentation, audience members will be able to define Voluntary Stopping of Eating and Drinking (VSED).
- After the case presentation, audience members will be able to describe management of common symptoms during VSED.
- After the case presentation, audience members will be able to identify possible pitfalls during VSED.

Background: VSED is an option for patients who feel their quality of life is poor and who are not eligible for, do not have access to, or do not choose Physician Assisted Death. Most case series of VSED involve elderly patients with serious medical illnesses with a 7 day median time to death.

Case Description: 33 year old woman with EDS diagnosed 8 years prior on TPN due to severe gastroparesis who did not tolerate enteral feeding. She was referred to palliative care clinic for discussion of discontinuing TPN and minimizing oral intake. SN hoped to minimize oral intake and thirst once TPN and IVF were discontinued. She discontinued TPN and had thirst in spite of ice chips. Morphine PCA was started for severe muscle pain. 6 weeks after discontinuing ANH, she was taking ice chips and sips of liquid and continued to have ongoing nausea/vomiting. She developed painful parotits treated with IV antibiotics which contributed to nausea. Haloperidol and scopolamine were ineffective. She had multiple antiemetic allergies. Parenteral versed was initiated with some relief of nausea and ongoing anxiety. Her IV medications constituted 210 mL of fluid/day. SN liberalized her oral intake and had continued nausea, even off IV antibiotics. Atropine ophthalmic drops were used orally for nausea but caused dry mouth. Two months after discontinuing TPN, SN developed delirium and died the next day.

Conclusion: Most cases of VSED involve older patients whose intake has been reduced prior to stopping oral intake completely. Our patient was young and had good nutritional stores. This patient had more enteral absorption of liquid than expected and was receiving fluids via IV medications. Patients may take more orally than they had planned. This case was emotionally and medically complicated for the patient, family and team.
Synsepalum Dulcificum: Help for Patients with Alterations in Taste from Chemotherapy (FR421D)
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Objectives
- Describe alterations in the sense of taste secondary to chemotherapy
- Discuss current integrative strategies for palliating alterations in taste
- Identify new therapies with potential for positive impact on patient’s QOL including Synsepalum dulcificum

Background: Taste changes are common during chemotherapy. The exact reason for taste changes is unclear, although it is thought to be a result of the damage to the cells in the oral cavity, which are especially sensitive to chemotherapy. Studies have shown that up to 60 - 80% of palliative care patients experience alterations in smell and taste. However, there are limited resources in the palliative care literature regarding the assessment of alterations in taste, its impact on QOL, and specific therapies to palliate it.

Case Description: A 50 year old female with metastatic colon cancer was admitted to the hospital for intractable pain to her lower extremities. Her course was complicated by multiple infections, hydrenephrosis, and cholangitis. She had multiple complaints including alterations in taste secondary to her cancer therapies. Patient was hesitant to eat or take oral medications due to dry mouth and alterations in taste. Palliative care was asked to assist with symptom management. A Palliative/Integrative Medicine approach was used to relieve her symptoms which included both pharmacologic and non-pharmacologic therapies. Given her resistance to oral medications, symptom management was challenging. Patient tried M Berry (Synsepalum dulcificum) 30 minutes prior to meals. She reported immediate improvement in her sense of taste and was able to eat and take her oral medications.

Conclusion: A literature review was done to identify new and innovative ways to provide management for patients suffering with alterations in taste. Treatments will be ranked according to scientific evidence of efficacy, as well as anecdotal “Pearls of Wisdom” from experts working in palliative care. Use of Synsepalum dulcificum, and salivary stimulants will be discussed. We will summarize some of these new therapies and make recommendations for clinical practice including the potential for impact on palliative care patients.
My Husband is a Stranger and my Home is not my Home: Capgras Syndrome and Reduplicative Paramnesia in a Young Breast Cancer Patient (FR422A)
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Objectives
- Describe two forms of delusional misidentification syndrome: Capgras syndrome and reduplicative paramnesia
- Depict the challenges in symptom management for a patient with Capgras syndrome and reduplicative paramnesia associated with early onset dementia secondary to progression and subsequent treatment of metastatic breast cancer

Background: With Capgras syndrome (CS) a patient believes that someone, usually a close relative, has been replaced by an imposter. In Reduplicative Paramnesia (RP) a patient believes that a place has been duplicated, existing in at least two geographically distant locations simultaneously. We present a young breast cancer patient who manifest simultaneous and refractory expression of these two delusional syndromes which compromised her independence.

Case Description: A 33 year old female was diagnosed with breast cancer in 2007 and treated with lumpectomy and subsequent chemotherapy, radiation, and hormonal therapy. In 2012 metastatic disease to midline cerebellum was found, resected and treated with gamma knife radiation. In 2013 leptomeningeal involvement was treated with whole brain radiation, chemotherapy and hormonal treatment. During this time, the patient developed agitation, confabulation, memory loss and hallucinations. She was diagnosed with early onset dementia and subclinical seizures and treated with levetiracetam. Recurrent metastatic disease was found in early 2017, treated again with gamma knife radiation therapy. Her mental status declined and she transitioned to home hospice care. She then developed a fixed delusion that her devoted husband of 21 years had been replaced by a stranger and that she was living in a duplicate of her house located several blocks from her true home. She started sleeping with a pair of scissors for protection and would often wander away from home. She was admitted to inpatient hospice in attempts to improve these symptoms with trials of antipsychotics, antidepressants, and valproic acid for mood stabilization, possible subclinical seizures, and delusions. Unfortunately her symptoms proved refractory and she was unable to return home as previously hoped.

Conclusion: The combination of CS and RP in the palliative care setting can be extremely difficult to manage leading to immense barriers in keeping a dying patient safe at home.
Co-Modal Art Therapy: Interdisciplinary Collaboration to Create a Personalized Tool for the Emotional Assessment Toolbox (FR422B)
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Objectives
- Describe the role of art therapy in a palliative context
- Identify patients for whom collaborative art therapy might be appropriate based on specific vulnerabilities and aesthetic affinities
  - Describe how a clinical assessment tool can be collaboratively augmented with an expressive therapy intervention
- Apply a co-modal assessment tool in clinical practice to help identify thresholds for medical intervention and enhance patient care

Background: Art therapy is an extremely valuable component of the palliative care interdisciplinary team approach. Not only is the creative process itself therapeutic, but the creative output that is generated has important potential to augment clinical assessment and enhance patient care.

Case Description: A 61-year-old man with metastatic renal cell carcinoma was referred to palliative care for management of psychological symptoms after multiple medical and surgical complications, and a prolonged hospital course. The patient suffered significant emotional and existential distress generated by feelings of disconnectedness and worry about his 21-year-old son, who had struggled to cope for many years with his father's illness. Because of the importance of music to both the patient and his son, art therapy was initiated to help heal their strained relationship. The palliative physician and the art therapist collaborated with the patient during several concurrent visits, exploring media suitable for a legacy project. The patient's disease progressed to his vocal cords, threatening his voice as a means of expression, and heralding the end of life. The patient's anxiety and depressive symptoms worsened, but he chose to manage his symptoms nonpharmacologically. Working with collage inspired by one of his preferred genres, psychedelic rock, the patient created a striking visual representation of his emotional spectrum, fears, and goals. This creative work subsequently served as an adjunct to clinical assessment tools such as the Patient Health Questionnaire-9 (PHQ-9) to help guide the management of his psychological symptoms over subsequent sessions.

Conclusion: In this co-modal treatment model, the palliative physician and art therapist worked concurrently with the patient. By carefully tailoring the intervention to patient-specific vulnerabilities and aesthetic affinities, this process yielded a creative work that was not only grounded in the patient's subjective experience, but also became a tool for tracking patient symptoms and response to therapy over time.
Hospice as a “Holding Environment”: Recognizing the Therapeutic Benefit of Hospice for Patients with Trauma Histories (FR422C)
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Objectives
• To recognize pathology associated with trauma history
• To describe features of a “holding environment”
• To appreciate the benefit of hospice for a patient with trauma history

Background: Although hospice is usually understood as a binary decision, for many patients and families, the philosophical shift from cure to comfort does not coincide with signing consents. Patients with trauma histories, often distrustful of caregivers, may have an exaggerated response to this ambivalence. Pediatrician and psychoanalyst DW Winnicott understood this response to be partly due to early environmental deficits. He described psychotherapy as a “holding environment,” which provides the missing stability and empathy necessary for healthy psychological development. This case illustrates how hospice provides such an environment for one patient.

Case Description: A 55 year-old woman with history of COPD, CHF, substance abuse, and physical and sexual trauma presented to the emergency department (ED) with respiratory distress for the fourth time this year, despite being in hospice. Each time she called hospice first, but when a nurse could not arrive “fast enough,” she called 911. After stabilization, the primary medical team consulted the palliative care team, partly in frustration with her repetitive behavior that seemed inconsistent with hospice. She adamantly stated that she did not want treatment for COPD or CHF, understood her limited prognosis, and was ready to die; therefore hospice fit her conscious goals. Yet she continued returning to the ED, oscillating between “comfort and horror” (Emanuel 2017) while facing her death. In her interactions with medical providers, she struggled with trust, control, and delays, suggesting early developmental arrests. However, when these were recognized, hospice provided a reliable, empathic environment, tolerant of her oscillation, such that she was empowered to trust and ask her hospice team to take her back at discharge.

Conclusion: This case demonstrates that, for patients who do not have and cannot form the intimate relationships necessary for psychological growth, hospice can provide a holding environment that facilitates healing, even during the final developmental crisis of facing death.
Interpreting Difficult Conversations: When the “Invisible Team Member” Needs to be Seen (FR422D)
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Objectives
- Describe the unique challenges faced by interpreters during palliative care encounters.
- Recognize the emotional burden experienced by interpreters during and after palliative care encounters, and be aware of the current lack of available support for them.
- Describe an initiative to prepare interpreters for, and to help emotionally process, palliative care encounters.

Background: Palliative medicine providers rely on language interpreters to communicate effectively with patients and families who have limited English proficiency. Interdisciplinary palliative care providers receive extensive education in effective communication strategies, but interpreters typically aren’t offered specialized palliative care training, making palliative care encounters more stressful. Additionally, palliative care conversations can be emotionally challenging. While palliative medicine providers offer each other emotional support, there is no similar support for interpreters, who often feel like “invisible team members.”

Case Description: A Bengali-speaking man with esophageal adenocarcinoma developed an esophageal perforation and empyema. He was intubated and palliative care consulted to help establish goals of care. In an interdisciplinary meeting, the family and team agreed to make the patient DNR/DNI and transfer him to the PCU for palliative extubation. A pre-extubation meeting was planned before the procedure, with a Bengali interpreter present for the meeting as well as the extubation. During the meeting, the interpreter turned to the palliative care fellow and stated, “This is my fourth family meeting today. This is very difficult for me.” She was distressed and tearful, but continued interpreting for the remainder of the meeting. Afterward, the fellow offered emotional support to the interpreter, who expressed gratitude and confirmed that end-of-life conversations were more stressful and emotionally difficult than other encounters. The fellow subsequently attempted to contact the interpreter to explore this case, but was told that that the interpreter’s agency would discourage this type of follow-up.

Conclusion: The hospital’s Interpreter Coordinator recognized the need for palliative-care specific training and emotional support resources for interpreters. A quality improvement collaboration between palliative care physicians and interpreters is currently underway. Objectives of the project are to: 1) Improve interpreters’ skills and confidence in palliative care encounters; 2) Develop structured ways to provide emotional support to interpreters before, during, and after palliative care encounters.
Perinatal Palliative Care for Families with Fetal Critical Congenital Heart Disease: How to Develop and Implement a Family-Centered and Multi-Disciplinary Birth Care Plan (FR442A)

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Objectives
- Identify the role of the palliative care team in developing a family-centered multi-disciplinary birth plan
- Identify the members of the multi-disciplinary team necessary to form a birth plan for a fetus with critical congenital heart disease
- Develop a birth plan with a multi-disciplinary approach that removes barriers, reduces angst, prepares for comfort, and focuses on the family

Background: Approximately 4,800 babies are born annually with a diagnosis of fetal critical congenital heart disease. Up to 40% of parents when offered palliative care services in pregnancies with life-limiting fetal diagnoses choose to continue the pregnancy and mostly report positive feedback about their experience. The perinatal palliative care/hospice team provides the opportunity to pursue family-centered care, encourages family bonding, and helps alleviate distress. Developing a family-centered birth plan is a key step in improving family experiences.

Case Description: A 34 year old Gravida2 Para1001 presents to palliative care at 34 weeks in the setting of diagnosed left hypoplastic heart syndrome. The family had met with cardiology/surgery who felt palliative staged surgeries were not in the infant's best interest. The patient and her husband hoped to “have a normal birth experience and then let nature take its course.” They worried about “unnecessary medical care” that would “prevent spending as much as time as possible” with their newborn. They also valued “having a baptism” and "keeping their newborn comfortable." We helped implement a birth plan in conjunction with obstetrics/midwifery, neonatology, pediatric cardiology, pediatrics, anesthesiology, spiritual care/clergy, nursing, and hospice. The plan focused on forgoing “routine” medical interventions as well as having medications readily available for comfort to allow family bonding and to allow discharge as soon as possible to home with hospice. After an uneventful delivery, mother and baby were not separated, which allowed bonding and helped keep the baby comfortable. They were discharged within 8 hours of delivery to home with hospice.

Conclusion: Identifying and planning with the multiple teams involved in the perinatal period is crucial in developing a successful family-centered birth plan for families with fetal critical congenital heart disease. Collaboration and teamwork can lead to an improved experience that maximizes time for family bonding, time for rituals, and time at home.
A Bridge to Family Healing: The Case of an Infant with Critical Congenital Heart Disease and Pontocerebellar Hypoplasia (FR442B)

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Objectives
- Identify some pros and cons of continuing mechanical ventilation and prostaglandin infusion in a child who is no longer a surgical candidate
- Emphasize the importance of being sensitive to past family experience of child loss during goals of care and end-of-life discussions
- Explore different palliative options that can be offered to families of infants with heart disease that cannot be surgically corrected and who are expected to die

Background: Cardiac surgery is the intervention of choice for newborns with critical congenital heart disease. Prostaglandin infusion serves as a “bridge” to keep infants hemodynamically stable until surgery. When additional anomalies are discovered that shift the benefit-burden against surgery, difficult decisions must be made regarding the continuation of this life-sustaining treatment (LST). This case presents the challenges of using mechanical ventilation and prostaglandin infusion in an infant with critical congenital cardiac disease for whom surgery was not an option due to comorbid pontocerebellar hypoplasia (PCH).

Case Description: A 5-week-old boy with ductal-dependent critical congenital heart disease (Tetralogy of Fallot variant) on prostaglandin infusion, a familial Xp21.2 deletion of unknown significance, multiple congenital anomalies, and respiratory failure requiring intubation and mechanical ventilation was awaiting cardiac surgery. MRI done as part of the genetic work-up revealed PCH, prompting a reversal in the surgical plan due to poor prognosis. When the PICU and palliative care teams met with the patient’s mother to discuss this new information, she reported grief from prior losses: 2 fetal losses and death of a son at 5 weeks of age. Mother agreed to a “Do Not Resuscitate” (DNR) order but declined discontinuing LST. Meaningful family activities took place (including baby’s baptism and visit from older sister) as LST continued. When the baby became persistently hypoxic (with SpO2 around 50-60) despite prostaglandin infusion, high ventilator settings, and 100% oxygen, his parents were told that he was dying despite maximum medical therapy. They agreed to extubation. He died peacefully with his parents by his side.

Conclusion: Prostaglandin infusion is considered a “bridge to surgery” for newborns with critical congenital heart disease. What should clinicians do when surgery is no longer an option? In this case, the prostaglandin infusion served as a "bridge to healing" for the family, allowing for precious time with their son.
When the ICU is Home: Indefinite Non-Invasive Positive Pressure Ventilation in Pediatric Patients (FR442C)
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Objectives
- Describe the current “state of the art” of NIPPV use in pediatric patients, and how the use of this technology has expanded to a variety of pediatric populations, including those patients with terminal conditions and limits to escalation of care.
- Discuss the ethical principles of beneficence, nonmaleficence, and distributive justice, and how this extreme clinical example may inform a larger discussion of just resource allocation.

Background: Non-invasive positive pressure ventilation (NIPPV) is a useful and commonly utilized method of supporting pediatric patients through acute respiratory events. It can allow patients to avoid intubation or act as a temporizing intervention to allow more time for evaluation of need for intubation. However, for some patients with chronic, life-limiting conditions for which intubation, mechanical ventilation, and tracheostomy placement are not aligned with overall goals of care, NIPPV may become chronic, life-sustaining therapy with no obvious end point. This can lead to indefinite care in an intensive care unit (ICU) setting, provider and family distress, and ethical dilemmas surrounding resource allocation.

Case Description: A 2-month-old male infant with severe osteogenesis imperfecta type III (OI) was admitted to the pediatric ICU with hypoxic respiratory failure due to bronchiolitis in the setting of restrictive lung disease due to OI. He was unable to be weaned from NIPPV support, and after conversations with parents regarding overall goals of care, the decision was made to forego intubation or tracheostomy placement in the event of clinical decline. The patient has now been hospitalized for nearly 300 days, requiring ongoing NIPPV support without the ability to be transferred out of the ICU setting. Parents perceive quality of life to be acceptable; the child is reaching developmental milestones, feeding as able, and is tolerating NIPPV equipment without discomfort. This prolonged ICU stay led to Ethics consultation questioning appropriate resource allocation in the ICU.

Conclusion: Indefinite management of respiratory failure with NIPPV illustrates the complex ethical, medical, and logistical challenges that arise when a temporary solution becomes a permanent one. As NIPPV becomes more common there will likely be more cases such as this. Understanding the complexities of decision making in these cases and working to develop an institutional strategy can potentially avoid or mitigate prolonged ICU stays for these therapies.
“We Didn’t Come All This Way for You”: The Challenges of Providing Palliative Care for Children Who Travel to America Seeking a Cure (FR442D)
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Objectives
- Attendees will understand that children’s hospitals are increasingly providing care to international patients with aggressive and curative goals
- Participants will be able to identify common barriers to palliative care for international pediatric patients
- Attendees will be able to problem solve strategies for providing palliative care despite these barriers

Background: Children’s hospitals are increasingly recruiting international patients with life-threatening and complex medical conditions. Many of these patients are private pay, either individually or through their governments, and travel to American children’s hospitals seeking therapies not available in their home countries. These children have conditions such as metastatic cancer, may be candidates for bone marrow or solid organ transplant, or desire complex surgeries and medical technology.

Case Description: We will describe a case series of patients from the Middle East and Asia who came to America seeking aggressive care, and the challenges faced by a pediatric palliative care team to provide symptom management, psychosocial support, and end of life care. We will discuss common barriers to connecting with these families and providing care for their children and strategies to navigate these difficult encounters.

Cultural norms and values impact international families’ expectations for their care in America in ways that may be unclear to American providers, at times creating conflict within the framework of our healthcare system. In addition, many families have made great sacrifices to travel to a foreign country, with a language they do not speak and where they lack social support, seeking the best chance for a cure for their child. Therefore, they may desire more aggressive therapies and expect every life sustaining treatment option for their child. Providers may feel pressure from families to provide care that they view as futile. It can be particularly difficult to provide palliative care in this setting, and lead to moral distress among staff.

Conclusion: Despite the difficulty providing palliative care for international families, we have successfully navigated these cases. Increased awareness and understanding of common religious, medical and psychosocial barriers can lead to strategies to overcome the complexity in caring for these patients and families.
Neuroaxial Analgesia as a Key Treatment to Achieve Staying Home for Cancer Patient with Pain from Malignant Psoas Syndrome (FR462A)
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Objectives
• Understand the refractory nature of pain from malignant psoas syndrome.
• Recognize effectiveness of neuroaxial analgesia in managing pain from malignant psoas syndrome.

Background: Malignant psoas syndrome (MPS) is a rare but distressing pain syndrome observed in advanced cancer patients. Pain due to MPS is often refractory to multi-modal analgesic treatment, including systemic opioid analgesics.

Case Description: A 68-year-old female with recurrent squamous cell carcinoma (SCC) of the skin presented with left thigh pain. Eight months before presentation, she was found to have recurrence with left common iliac lymph node metastasis. She gradually developed left anterior thigh pain (maximal intensity 8/10 on the numerical rating scale [NRS]) which made walking difficult. Physical examination found the left psoas stretch test exacerbating the patient’s left anterolateral thigh pain without any sensory or motor abnormalities. Abdominal computed tomography showed a bulky metastatic lesion in the left ilio-psoas muscle, and we diagnosed her pain as MPS. Oral oxycodone was initiated and titrated to 60 mg/day in addition to loxoprofen and pregabalin; however, the patient developed intractable somnolence with persistent severe pain which disturbed her walking. We then switched the opioid administration route to epidural catheter introduced at the L3/4 level, and fentanyl (3.4 mcg/ml) combined with ropivacaine (2.3 mg/ml) was infused at 4 ml/h. Subsequently, her resting pain completely resolved and her maximal pain intensity on exertion decreased to 3/10. She became able to extend her left hip joint and walk with a walking aid. Her palliative performance scale (PPS) improved from 40 to 60, and her Functional Independent Measure (FIM) score improved from 84 to 89. She was discharged 2 weeks later and passed away with no pain exacerbation at home 2 weeks after being discharged.

Conclusion: Neuraxial analgesia may contribute to achievement of staying home and the best possible quality of life in cases of severe pain from MPS which is refractory to systemic multi-modal analgesic treatment.
A Mind Numbing Tale of Two Tails: A Re-Emergence of Lidocaine Infusions for Refractory Neuropathic Pain Syndromes and Opioid Induced Hyperalgesia (FR462B)
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Objectives
- Recognize cancer related neuropathic pain crises and opioid induced hyperalgesia in oncology patients where lidocaine infusions can be beneficial and impact quality of life.
- Identify risks, benefits, and side effects of lidocaine infusions for palliative care patients.
- Utilize lidocaine infusions to lower pain scores and oral morphine equivalents in a safe manner by following current practice guidelines to initiate, monitor, and titrate infusion rates.

Background: Cancer patients experiencing severe neuropathic pain often require high doses of opioids and multiple neuropathic adjuvants with increased risk of side effects, including sedation and respiratory depression, which greatly reduce quality of life. Despite aggressive multi-agent therapy, pain often remains poorly controlled. In appropriate patients, short term administration of intravenous lidocaine can produce rapid pain relief and reduce total opioid use, thereby reducing side effects and improving quality of life.

Case Description: Patient 1 is a 37 year old male with metastatic urothelial cell carcinoma with a large sacral mass who presents with intractable neuropathic pain despite high opioids requirements of 1220 mg per day. Pain worsened with IV opiates raising concern for opioid induced hyperalgesia. Methadone was prescribed but slow to act, therefore, lidocaine infusion was prescribed. Patient experienced a 50% reduction in pain scores and opioid requirements within 24 hours. Patient 2 is a 65 yo lady with metastatic breast cancer to the spine who was admitted for intractable back pain with lumbar radiculopathy despite opioid regimen of 90 mg per day and gabapentin. She experienced sedation and respiratory depression with titration of opioids. Patient initiated on a lidocaine infusion and within 24 hours, experienced marked improvement in pain relief and total 24 hour OME was cut in half. Both patients experienced intractable neuropathic pain syndromes due to metastatic disease to the spinal cord and lidocaine infusions proved to be a safe option for fast pain relief.

Conclusion: Despite its benefits, lidocaine utilization is uncommon in palliative care patients. Many providers feel uncomfortable with prescribing lidocaine infusions, which may be due to unfamiliarity with indications and contraindications, or how to properly initiate, titrate, and monitor infusions. We present two cases which include neuropathic pain crisis and opioid induced hyperalgesia in which lidocaine infusions provided significant relief without side effects.
Sublingual Buprenorphine for Oral Mucositis Related to Cancer Therapy (FR462C)
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Objectives
- Understanding the burden of oral mucositis in cancer patients
- Understanding the existing data and guidelines for management of pain from oral mucositis due to cancer therapy
- Determine the effectiveness of current standard treatments for oral mucositis from cancer therapy
- Describe the rationale for choosing sublingual buprenorphine as a frontline analgesic when treating oral mucositis due to cancer therapy
- Outline a successful method for obtaining approvals from insurance companies for outpatient use of sublingual buprenorphine

Background: Oral mucositis from chemotherapy and radiation is debilitating, painful and causes malnutrition, often leading to hospital admissions and feeding tubes. Guidelines provided by the Multinational Association of Supportive Care in Cancer and International Society of Oral Oncology for treating mucositis from cancer therapy recommend transdermal fentanyl and 0.2% morphine mouthwash for pain, with weak evidence. However, we frequently encounter patients in clinical practice who do not respond effectively to common potent opioids.

Case Description: Ms. P is a 48-year-old female with high-grade tonsillar mucoepidermoid carcinoma. She underwent bilateral tonsillectomy and radical left neck dissection after which she received post-operative radiation with weekly cisplatin. Soon after starting treatment she developed painful mucositis. Despite magic mouthwash, gabapentin, nortriptyline and multiple opioids, the mucositis progressed to grade 3, resulting in admission for dehydration, orthostatic hypotension and uncontrolled pain. She had lost 24 pounds. Palliative care recommended she start on sublingual buprenorphine 1mg, three times a day. Ms. P reported dramatic improvement in her pain within four hours. She was able to finish a meal for the first time in weeks. Her pain continued to improve over the next two days after which she was discharged home.

Conclusion: Sublingual buprenorphine not only provided long-lasting analgesia, but also had a more immediate analgesia due to accumulation in oral mucosa and buccal fat. It has so far not been studied for mucositis. We believe sublingual buprenorphine may be used as a frontline analgesic because it is 1) uniquely locally sequestered, 2) useful with oropharyngeal dysphagia as it does not require swallowing, 3) very lipophilic and able to penetrate deeper into tissues unlike morphine and 4) longer acting than fentanyl which is also lipophilic. These properties will be reviewed in more detail. We will also include a successful method we have used to obtain approvals from insurance companies for outpatient buprenorphine.
Tincture of Time: Consideration of a Time-limited Trial -- It’s Not Always about Death and Dying! (FR462D)
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Objectives

- Understanding that aggressive measures can be recommended when prognosis is unclear
- When recommending a time limited trial, setting a clear time frame for follow up is crucial, as is continued presence and support to the family during this time trial

Background: Palliative providers are often asked to facilitate goals of care discussions for critically ill patients in the intensive care unit. In this age of technology, it is often assumed that our role is to dissuade families from continuing aggressive measures such as ventilator support/tracheostomies. What is our role then when prognosis is unclear and it is families who want to move forward with terminal extubation while the primary team suggests tracheostomy/PEG?

Case Description: RP is a 32 year old male, previously healthy, who collapsed while playing volleyball. He received bystander CPR and was also defibrillated and intubated. Initial brain imaging findings suggested hypoxic brain injury. Clinically, he had significant agitation which the family attributed to severe hypoxic brain injury. Neurological exams could not be performed as he became immensely agitated when sedating medications were decreased. His family was very distressed by his agitation and his mom, a clinical nurse, requested a terminal extubation. However the neuroICU team suggested a trachestomy/PEG. We met with the family, along with the attending neurointensivist, bedside side nurse and neurology team. We reframed the trachestomy as a time-limited trial to see if the agitation was in part due to the presence of the endotracheal tube. We assured family that the tracheostomy was reversible-- we could make the decision to stop ventilator support if his mental status did not improve. We also set a date/time for a follow up meeting. Post tracheostomy, he was eventually weaned off sedating meds, liberated from the ventilator and at time to discharge to rehab, was walking and communicating with his family.

Conclusion: Aggressive measures such as tracheostomies can be framed as a time-limited trial, especially when prognosis is unclear. Giving the family a clear time frame for follow up is crucial, along with continued presence and support.
When Emotional Expression is Blunted: Navigating Goals of Care Discussions in Patients with Autism Spectrum Disorders (SA509A)

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Objectives
- Recognize barriers to emotional awareness and communication in a patient with Autism Spectrum Disorder
- Identify approaches to meeting the communication needs of individuals with Autism Spectrum Disorders when faced with challenging medical situations

Background: Autism Spectrum Disorder is associated with Alexithymia, difficulty with emotional awareness and verbal expression. Imaging reveals blunted activation of the amygdala. Decision-making situations can result in mental freezing with increased anxiety.

Case Description: A 27 year old woman with Asperger’s Syndrome and ovarian adenocarcinoma was admitted to our hospital. She previously underwent extensive surgical interventions and chemotherapy. Her parents were involved in all aspects of her healthcare, but described that their daughter made her own decisions. The Palliative Medicine team was consulted given serial admissions with no further curative options available. She answered simple questions but was unable to discuss her hopes, fears, and burdens. Her mother’s words: “It is almost a blessing, the Asperger’s Syndrome. She doesn’t feel the emotion that anyone else in her place would feel.” As we discussed her prognosis, she further withdrew from us. It became increasingly clear that asking open-ended questions and trying to identify emotional cues were causing her to disengage further. We asked what would be most helpful for further communication. The patient did not answer, but her parents said it would help if they could talk to her privately and asked that we proceed slowly with further discussions. A discharge and re-admission later, with slowly progressing conversations spanning over weeks, she elected to enroll in hospice and died soon after.

Conclusion: Alexithymia makes it challenging to respond to the open-ended questions and empathic responses that are often used in goals of care discussions. A tailored approach to communication is necessary. Asking the patient what is the most helpful way to communicate is an effective first step. Strategies that may help include small concrete information chunks over longer periods of time, closed direct questioning, avoidance of ambiguity, recognizing subtle behavioral changes indicating increased stress levels and allowing extra time for processing of emotions.
Happy 18th Birthday – Navigating Emerging Decisional Competence in an Intellectually Disabled Young Adult (SA509B)
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Objectives
- Learners will be able to describe typical young adult decision-making patterns.
- Participants will be able to identify methods for assessing capacity for decision-making, focusing on young adults with mild intellectual disability.
- Participants will be able to describe strategies to support young adults with intellectual disabilities in decision-making.

Background: A core responsibility of palliative care providers is to assist patients and families who are faced with difficult healthcare decisions. Caring for adolescents and young adults with serious illness presents a unique challenge, as this is the age when the decision-making focus shifts from parent to patient. This case discusses the additional challenge of supporting a young adult with intellectual disability.

Case Description: Joey is an 18-year-old male with a newly diagnosed metastatic hepatocellular carcinoma. He celebrated his eighteenth birthday during a prolonged hospital stay, necessitating a switch from parent consent/patient assent to patient consent. This shift became a source of dignity for Joey. However, the team continued to request parental assent, as providers remained doubtful of his understanding of illness severity, treatment options and impact of decision-making. By utilizing a “teach back” approach to carefully assess his understanding and adapting communication strategies with consideration of his learning limitations, the Palliative Care team helped to navigate this delicate situation.

Conclusion: Attention to this patient’s individualized learning needs and family dynamics allowed the palliative care team to support and empower decision making in this emerging young adult despite intellectual disability. This is necessary for all chronically ill teens as they transition from pediatric to adult care.
Care Planning Challenges and Recommendations for Patients with Communication Impairment (SA509C)
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Objectives
- Identify barriers to care planning for patients with communication impairment
- Appropriately involve communication partners and speech language pathologists in conversations with patients having communication impairment

Background: Best practice for determining patients’ goals and values is to ask open-ended questions. In patients with communication limited to head or eye movements, clinicians change their approach dramatically (Scott 2004). Speech language pathologists help patients use word boards and eye-gaze communication, which facilitate conversations. Communication partners (family, caregivers) have expertise in interpreting small movements and may provide narrative and context to the conversation. However, using caregivers as mediators in these conversations can introduce bias and increase caregiver distress, just as using an ad hoc interpreter can result in misunderstanding and distress (Flores 2003, Ngo-Metzger 2003).

Case Description: A 77-year-old man with atypical Parkinson’s disease was admitted for hypoxia attributed to aspiration. He was quadriplegic and anarthric, communicating by nodding. A video swallow study showed severe oropharyngeal dysphagia. A family meeting was convened to determine if artificial nutrition via a gastrostomy tube was consistent with his goals. The situation was further complicated by his health care proxy only participating by phone, unable to see his head nods. Clinicians struggled to simplify the complex situation into yes and no questions. His speech language pathologist facilitated communication by asking clarifying yes or no questions. Ultimately, he chose to forgo a feeding tube and eat for pleasure, assuming the risk of aspiration, and was discharged home with nursing support.

Conclusion: When patients have intact cognition and impaired communication, discerning a goal-concordant clinical course is challenging. Conversing is laborious, exhausting, and time-consuming. We will discuss the role of caregivers and speech language pathologists as team members to facilitate optimal communication. We will review augmentive and alternative communication devices (such as microphones, letterboards, eye-gaze systems and text to voice software) and explain why a line of yes-no questioning--despite its limitations--may be the best way to ensure that the patient’s voice is heard.
When Cancer is Not the Biggest Source of Suffering: Palliative Care for a Transgender Male with a Gynecologic Malignancy (SA509D)
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Objectives
- To recognize the necessity for further research into how best to provide palliative care to transgender patients with cancer.
- To identify the psychosocial implications of a gynecologic malignancy in a transgender male.
- To recognize how palliative care practices need to be tailored to accommodate transgender patients.

Background: Palliative care improves quality of life when embedded into standard oncologic care. Yet, within the LGBT community, a sexual minority with a high risk of cancer, evidence regarding delivery of palliative care remains sparse (Farmer et. al 2015). It is an underserved population with a unique sense of community and usually poor social support (Barrett 2015). When a transgender male is diagnosed with a gynecologic malignancy it conjures past struggles with sexual identity and becomes essential for providers to understand the cultural context of his transition to provide effective palliative care.

Case Description: 69 year old transgender male with hypertension, combined variable immunodeficiency s/p hysterectomy referred to the palliative care clinic after diagnosis with metastatic ovarian cancer. While a cancer diagnosis is devastating for any patient, a gynecologic malignancy in a transgender male has specific psychosocial implications. It is unavoidable to address the suffering associated with his gynecologic malignancy without simultaneously recounting the opposition he received during his transition from female to male. Opposition from his family and isolation from his friends dwarfed the life altering diagnosis of cancer. He viewed cancer and chemotherapy as “normal,” a path traveled by many and socially acceptable which starkly contrasted his previous journey in gender identity. His transition also left him with no social supports as he underwent chemotherapy; no one to assign as a health care agent. In regards to medical treatment, he was initiated on standard chemotherapy, but subtleties in how we delivered care were tailored. For example, chemotherapy was rescheduled with the general oncology patients to avoid the discomfort of being the only male in the chemotherapy suite with other gynecologic oncology patients.

Conclusion: This case examines the psychosocial factors which must be addressed in order for the provider to successfully deliver comprehensive palliative care to a transgender male with a gynecologic malignancy.
Tell-Tale Heart: Special Considerations for Total Artificial Heart (SA519A)

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Objectives

- Describe the roles of PC providers, social works, and MCS coordinators in patients receiving a TAH and review the multidisciplinary approach to advance care planning before device implantation.
- Explain the challenges faced by palliative care providers and the multidisciplinary team when caring for patients with a TAH at the end of life.
- List the unique considerations that need to be made when preparing patients, families, and providers for device discontinuation.
- Describe how to terminally discontinue a TAH and the medications used to ensure a comfortable dying process.

Background: A total artificial heart (TAH) is an available treatment option for carefully selected patients with advanced heart failure as a bridge to transplant. A TAH is a unique mechanical circulatory support (MCS) device in that it completely replaces a patient’s native failing heart. Regardless of the functionality of the patient’s other organs, a TAH will continue to function and provide pulsatile flow, unless it is shut off, or the patient has a severe loss of volume causing the TAH to malfunction. A TAH changes the way an individual lives and potentially changes the way they die.

Case Description: Mr. A was a 27 year old male with a past medical history of congenital heart disease, leading to heart failure, status post orthotopic heart transplant in adulthood. A few years after his transplant, he developed antibody mediated rejection, unresponsive to conservative management. He eventually underwent TAH implantation as a bridge to transplant. His post implantation course was complicated by multiple hospitalizations, infections, and hemorrhagic strokes that resulted in neurological devastation. Unfortunately, the patient never regained his ability to communicate and remained unresponsive until his death. At the time of device discontinuation, special considerations were made when preparing family and medical staff and when pre-medicating the patient in order to ensure comfort. These specialized preparations were necessary, given that death is immediate upon the sudden cessation of circulation that occurs once a TAH is discontinued.

Conclusion: This case addresses the complexities of the TAH population and describes key challenges faced by PC providers and MCS teams while caring for these patients, especially at the end of life. It also highlights the importance of advance care planning before device implantation and the importance of a multidisciplinary approach during withdrawal of a TAH.
Rest for the Restless: Intermittent Respite Sedation In a Case of Progressive Chorea (SA519B)
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Kristin Meade, MD, Duke Palliative Care, Durham, NC
Laura Patel, MD, Transitions LifeCare, Raleigh, NC

Objectives
- Recognize the role of intermittent respite sedation as an alternative to continuous sedation in situations of intractable or distressing symptoms.
- Describe a technique by which intermittent sedation can serve as a route for meeting patient and family goals while still providing episodic symptom relief
- Identify ways in which direct communication between family, hospital-based teams, and hospice can ensure smooth transitions across the continuum of care.

Background: Palliative Sedation is a method of last resort for relief of intractable suffering when other methods have been exhausted.1 However, continuous sedation until death may be incongruent with family or patient goals. Intermittent respite sedation provides relief of distressing symptoms at predetermined intervals and has been used as a technique for managing pain, existential distress, and uncontrolled delirium.2,3 This case describes use of intermittent sedation for palliation of rapidly progressive choreoathetosis.

Case Description: A 66 year-old woman with metastatic non-small cell lung cancer developed progressive choreiform movements 2 months after initiating immunotherapy. Evaluation revealed progressive damage to the basal ganglia on MRI presumed to be accelerated by her immunotherapy. Aggressive attempts to reverse the basal ganglia damage, including steroids, IVIG, and plasmapheresis, as well as numerous pharmacologic trials to manage her movements were ineffective. Her condition progressed to ceaseless generalized choreoathetoid movements as well as worsening speech and dysphagia. Despite these distressing symptoms, she and family valued maintaining alertness and oral intake. As such, continuous palliative sedation was incongruent with family goals. After extensive discussion between hospital interdisciplinary team, hospice team, and family, a plan of intermittent respite sedation was formed. Using continuous infusion of IV benzodiazepines, the patient was sedated nightly, offering relief from her constant disordered movements with reduction in sedation for daytime wakening to allow interaction, oral intake, and verification of ongoing need for sedation. After transition to inpatient hospice, her mental status and oral intake further deteriorated and she died comfortably with eventual conversion to uninterrupted sedation in the last hours of life.

Conclusion: This case highlights the utility of intermittent respite sedation as an alternative to continuous sedation until death for management of refractory symptoms. This presentation will review a framework for use of intermittent sedation as a means of providing symptom relief while honoring family goals.
**Bending the End Trajectory: The Illusion and Disillusion of Euthanasia in Hospice (SA519C)**

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**Objectives**

- Better understanding the true perceptual dynamic of this issue, the attendee will be equipped to educate both the lay public, and referring healthcare professionals, in the correct comfort measure goal of both hospice, and the inpatient facility.

- Better appreciating the need for a highly individualized treatment regimen for each patient, and the hazard of digressing into a "one-size-fits-all" mindset, the attendee will be incentivized to both personally and organizationally fine-tune medication strategies.

**Background:** Legalization of physician-assisted suicide in a handful of US states has prompted an ongoing dialogue among Hospice & Palliative medicine professionals on the broader topic of euthanasia. Little discussion has centered on the belief by some members of the public that a form of euthanasia is a feature of inpatient hospice facilities. This case study addresses this topic.

**Case Description:** Consider three responses from family members of patients nearing end of life:

“**My father came to this hospice house to die. All of us said our goodbyes, and believed that he would pass within 48 hours of his arrival. That is what you do here in a hospice house, right? You give patients who are ready to die Morphine and Ativan and say goodbye. The process is over quickly. Yes, Dad is comfortable, but he’s been here 5 days; the family is exhausted, and sleep deprived. This is not what we bargained for, and it isn’t right. You are keeping my father alive against his will.”**  
  [daughter, occupational therapist]

“**Under no circumstance will my mother enter hospice. I enrolled my father, and they simply anesthetized him with Morphine and Ativan, and hastened his death. She deserves better”**.
  [daughter, head nurse, emergency room]

“I had to plead with the hospice house physician to curtail the scheduled Morphine and Ativan; simply placing the Foley catheter relieved the major cause of my father’s agitation. By the next day, Dad had awakened, and was both comfortable and conversant. He remained interactive until 3 days prior to his passing.”
  [son, practicing neurosurgeon]

**Conclusion:** Public perception that death is often expedited in an inpatient hospice facility is a worrisome concern, and warrants both enhanced education of the lay community, and internal review by hospice organizations to guarantee methodical, standard-of-care symptom management for all patients.
Islamophobia in Medicine: How Cultural Insensitivities Can Lead to Complicated EOL care (SA519D)

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Objectives

- Understand Muslim religious doctrine in regards to end of life care.
- Identify effective strategies for communication at the end of life for Muslim patients and their families.

Background: Palliative care providers often meet patients of diverse cultural backgrounds. Unfortunately, poor cultural understanding regarding end of life care can often lead to poor outcomes. Of interest, the Muslim faith is often misunderstood. Below is a case that highlights these concerns and identifies an area for improvement for palliative care providers.

Case Description: A 72 year old Muslim Egyptian man with widely metastatic pancreatic cancer was admitted to our facility with abdominal pain and dyspnea. Palliative care was consulted for symptom management as well as a goals of care discussion following oncology recommendations for palliation and best supportive care. Unfortunately, during a code status discussion prior to consultation, the primary team discussed goals of care with the family and recommended against resuscitation. The family opted for full resuscitative measures and he was subsequently intubated and transferred to the medical ICU. Following several days of intubation, a family meeting was called and recommendations were made to transition to comfort care. The family expressed understanding of this but were confused about why resuscitation was offered as an option if we did not believe it would ultimately help him and he would die anyway. They also shared that they were unable to remove him from life support, citing religious discussions with their Imam. The patient died 8 days later on the ventilator.

Conclusion: Palliative care teams are often responsible for providing communication with a diverse patient population at the end of life. However, many providers are uncomfortable and have a poor understanding of religious doctrine and its influence in end of life medical decision making. This presentation will review multiple areas of end of life care and how it intersects with the Muslim community. Our goal is to help shine light on this issue and provide an opportunity for further education and awareness.