

“You’re Killing Your Father:” Overpromising and Underdelivering for the Family of a Dying Patient (C901)

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Objectives

- Describe how the Palliative Care team assumes the role of primary communicators for a patient’s family during a complex hospitalization.
- Describe how the system leads to failures in treatment plans and confusion for a patient’s family.
- Discuss the ethics of offering “everything” and imposing physicians’ values on patients.

Background: In the fast-paced world of subspecialized medicine parsed out among primary teams and consultants, ever-changing treatment plans are distilled to families on daily rounds; frequently services promised by one team are not delivered by another. Frustrated families need help navigating the bewildering hierarchy of providers to ensure that their voices are heard and wishes are honored.

Case Description: A 61 year old man with metastatic head and neck cancer presented to the ED for dyspnea; an emergent tracheotomy was performed despite a DNR order. Palliative care (PC) was consulted to facilitate decision-making regarding PEG placement. As the patient was unable to communicate, the family chose to forgo PEG insertion based on what they believed their father would have wanted. Shortly thereafter, an ICU physician telephoned the patient’s daughter to inform her that she was “starving” her father. The guilt-ridden daughters reversed course. Ten days later, after multiple delays, Gastroenterology deemed PEG placement futile. PC assumed the lead in coordinating a plan respecting the patient’s wishes and transitioned him to comfort care.

Conclusion: Although PC is often viewed as a peripheral, consult service, our interdisciplinary approach focusing on relationship building and frequent communication positioned our service as the primary communicators with family. As the family struggled with missteps and miscommunications, it was the PC team who they most trusted and relied upon for guidance.

Life Saving Interventions for Children with Trisomy 18: Opportunities for Perinatal Palliative Care (C902)

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Objectives

- Describe the prenatal and post-delivery natural history of Trisomy 18.
- Share how the majority of families describe their experiences with their children with T18.
- List the sources of moral distress for health care providers caring for infants with T18.
- Describe how perinatal palliative care teams can assist families with T18 children and their health care providers.

Background: Trisomy 18 (T18) has been characterized historically by health care providers (HCP) as a "lethal" chromosome disorder in which life-saving interventions (LSI) are futile. In actuality, its presentation is heterogeneous with some long term survivors. The recommendations of professional societies have evolved as have attitudes of HCP on offering LSI to these children, but consensus does not exist nationally or even within health care teams. When families request LSI for their children with T18, conflict with and between HCP can result in mistrust and suffering for the family and moral distress for providers.

Case Description: A baby girl with T18 is born to first-time parents. The family switched providers during pregnancy to optimize support for their decision to continue the pregnancy and seek LSI after their daughter's birth. She has complex cardiac disease, feeding issues and apnea, and her parents request surgical therapy as needed. The pediatric palliative care team establishes a relationship with the family and the numerous care teams interacting with this family and her parents. Cardiac surgery providers have varied willingness to offer intervention, but surgery is eventually offered. The parents chose palliative surgery for her heart defect, but she develops respiratory failure and is unable to be weaned from mechanical ventilation. There is provider conflict and distress about offering this child a tracheostomy. The palliative care team, with help from the ethics consultant, coordinates a consensus between HCP regarding a recommendation. The parents are initially uncertain about tracheostomy as well, but decide they want to pursue life-prolonging treatment, recognizing that mechanical ventilation will limit her quality of life. She is discharged home on mechanical ventilation to her caring parents.

Conclusion: Perinatal palliative care and ethics support can help HCP and families negotiate conflict and come together to create supportive, family-centered care plans for children with Trisomy 18.

Serum β -hCG as a Prognostic Marker in a Patient with Pancreatic Neuroendocrine Tumor (PNET) (C903)

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Objectives

- Review the different malignancies that secrete human chorionic gonadotropin (hCG)
- Identify markers in pancreatic neuroendocrine tumors (PNETs)
- Illustrate that elevated hCG may be useful in prognostication of patients with PNETs

Background: Pregnancy is always considered in women of reproductive age who present with abdominal distention, nausea, and vomiting. A urine pregnancy test detects the presence of human chorionic gonadotropin (hCG) and is used to screen for pregnancy. However, some tumors also secrete hCG. Pancreatic neuroendocrine tumors (PNETs), which comprise 1-2% of all pancreatic tumors, may secrete β -hCG and this can provide prognostic value.

Case Description: A 38-year-old female with a five-year history of PNET who had been treated with surgery and chemotherapy, presented with abdominal enlargement and severe nausea and vomiting. Urine pregnancy test was positive but the patient denied any possibility of pregnancy. Quantitative β -hCG level was elevated at 109.9 mU/ml and repeat level the following day was 94.1 mU/ml. Abdominal ultrasound did not confirm pregnancy but showed small to moderate ascites. With pregnancy ruled out, computer tomography of the abdomen and pelvis was done which revealed marked hepatomegaly with extensive liver metastases. Paracentesis was attempted but fluid pockets were not sufficient for drainage. Symptoms were managed with opioids, steroids, and anti-emetics. Goals of care were addressed, she was transitioned to hospice care, and she expired 2 weeks later.

Conclusion: Elevation of serum β -hCG in patients with PNET signals a poor prognosis. Healthcare providers may use this value, along with other clinical information, to aid goals of care discussion in these patients.

Compassionate Release: Advocating for a Terminally Ill Prisoner (C904)

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Objectives

- Describe the process by which seriously ill prisoners might be released from prison to the community on “compassionate release”, or medical parole
- Highlight opportunities for palliative care practitioners to engage in advocating for individual patients and systemic reform in the criminal justice system

Background: State and federal prisons are increasingly charged with caring for older, seriously ill prisoners. “Compassionate release” is a term given to the statutes that allow seriously ill prisoners to petition for early

release before completing their prison sentence. This case exemplifies some of the difficulties with the compassionate release process in New York State and highlights opportunities for palliative care providers to identify patients with limited prognoses, advocate for their release, and help coordinate their post-incarceration care plans.

Case Description: Mr. D. is a middle-aged man with history of hepatocellular carcinoma (HCC) and subsequent liver transplant. A year after transplant he was arrested and sentenced to prison. One year later he was transferred to a non-prison hospital for evaluation of worsening back pain and was found to have recurrent HCC with bony metastases. His prognosis was thought to be 6 months. The palliative care team was consulted to optimize pain management.

After Mr. D's hospital discharge, the palliative care team initiated a post-discharge planning call to his prison clinicians to offer assistance with an application for compassionate release. The team became concerned about the long timeline described for processing of the compassionate release request and partnered with a prisoner advocacy organization to expedite the application review, to secure visiting privileges for the patient's family, and to coordinate prison discharge plans that were consistent with the patient's goals and values. At the time of this submission the outcome of the compassionate release petition and the patient's case is pending.

Conclusion: Compassionate release programs help ailing individuals die in the community rather than in prison, but achieving a timely discharge for a patient with a limited prognosis is a challenge. Palliative care providers can play a more prominent role advocating for reform in how the criminal justice system works with seriously ill inmates.

Autopsy: Person-Centered Care After Death, Enhancing Learning, Reflection and Team Building (C905)

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Objectives

- Recognize autopsy as an opportunity for professional development, person- and family-centered care, and reflection.
- Demonstrate how autopsy provides value to providers and families after death.
- Describe the leadership role of palliative care teams in promoting autopsies.

Background: Autopsies provide valuable information for families and health care providers. Despite their importance, autopsies rates are low.

Case Description: A 79 year old Army veteran with advanced gastric cancer was transferred to our hospital for a second opinion. The family was distressed and lacked consensus on goals of care. The patient was hypotensive and minimally responsive. The diagnosis was confirmed through chart review and physical exam. Death was expected within hours to days. The palliative care team convened a family meeting including oncology, medicine teams. The wife and daughter received information on prognosis and treatment options including inpatient hospice. They requested transfer to inpatient hospice, but the patient died a few hours later with his daughter at bedside.

The next morning the palliative team met the family for bereavement support and discussed autopsy. The family welcomed the invitation and consented. Following the autopsy, the palliative care attending invited the hospitalist and oncology teams to a person-centered autopsy conference. 20 physicians and nurses attended the 30 minute conference in the morgue. The pathologist presented the findings of the major organs including extreme cachexia, extensive tumor spread throughout the stomach to pancreas, and submucosal hemorrhage of the bowel. Most attendees reported no prior autopsy experience and discomfort asking families for autopsy permission. They expressed appreciation for the anatomy review and noted the discordance of gross and radiologic findings. They discussed the importance of advance care planning, family meetings, care of the dying patient, and bereavement care. The hospitalist attending conveyed the results of the autopsy to the family. The palliative team sent a condolence card.

Conclusion: Autopsies are valuable to families, health care providers, and interdisciplinary teams. Person-centered autopsy conferences present a unique and memorable opportunity to improve end-of-life care, communication, inter-professional teamwork, and personal reflection. Palliative teams may be catalysts in requesting autopsies.

The Beat Goes On...Inotropes and Palliative Care for Advanced Heart Failure (C906)

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Objectives

- Describe the role of inotropes in palliative care for advanced heart failure
- Review the procedural and financial guidelines for outpatient inotropic infusion

Background: Inotropes such as milrinone are effective to treat hemodynamic compromise due to low cardiac output. Although commonly prescribed in hospitals for heart failure, outpatient inotrope usage has been infrequent. This case promotes discussion of inotropes for long-term outpatient symptom management and the role of palliative care and hospice teams.

Case Description: A 55-year-old veteran was admitted to the intensive care unit with multi-organ failure and delirium. Medical history included: heart failure hepatitis C liver cirrhosis, pulmonary hypertension, and kidney failure. As part of his intensive care he received continuous milrinone infusion. After several weeks although his delirium persisted, his cardiac, renal and pulmonary function recovered and he was deemed hemodynamically stable for discharge from the intensive care unit. A trial without milrinone led to severe dyspnea and chest pain at rest. The cardiologist recommended continued milrinone and death was expected in days to weeks. The palliative care team coordinated a family meeting and discharge planning. His family and health care team agreed to a care plan promoting comfort (including milrinone) in a Veterans Affairs Community Living Center (VA CLC). The veteran was admitted to a comprehensive inpatient palliative care program. His milrinone dose was maintained by peripheral intravenous line at the same rate as in the ICU, but without telemetry monitoring. His dyspnea and chest pains were treated with opiates and his delirium improved. He enrolled in physical therapy and walked daily. He is alive and “living well” 3 weeks after palliative care unit admission, enjoying the company of his family, caregivers, and veterans.

Conclusion: Palliative care and hospice teams may increasingly care for people with inotrope-responsive heart failure. We will review the evidence for long-term, outpatient inotrope use, risks, benefits, regulatory and financial challenges, and creative person-centered care solutions made possible by palliative care, hospice, and VA.

Ganglion Impar Block as an Analgesic Adjunct for Bowel Movement-Associated Pain in Anorectal Malignancies (C907)

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Objectives

- Identify the role of interventional pain to supplant conventional pain medication regimens for patients with anorectal malignancies
- Identify patients with difficult social support and co-morbidities who would benefit from interventional pain procedures for adjunctive treatment of pain

Background: Anorectal malignancies can exhibit significant physical and psychosocial distress secondary to pain associated with defecation. Whereas most patient's pain with anorectal malignancies can be treated with conventional opioid and non-opioid analgesics in combination with behavior and lifestyle modification, there is still a significant minority of patients who do not achieve adequate pain control leading to further morbidity such as chronic constipation, diarrhea, rectal bleeding and malnourishment. The most widely accepted guideline for the treatment of cancer-related pain has been the World Health Organization (WHO)3-step analgesic ladder. This abstract describes an example of the proposed 4th step, which includes interventional procedures such as nerve blocks, intrathecal drug delivery systems, and surgical interventions. The ganglion impar block represents such an adjunct for bowel-movement associated pain in anorectal malignancies.

Case Description: A 62 year old male presented to an urban Veteran's Affairs Medical Center (VAMC) with profound failure to thrive, weight loss and anemia associated with a bleeding anal mass. The anal mass had caused significant pain with bowel movements and subsequent psychological distress causing the patient to be anorexic. The patient's early-onset dementia and limited social support made pain control with traditional opioid-based regimens difficult secondary to lack of adherence and patient understanding of the disease process. The patient underwent palliative radiation and adjunctive ganglion impar neurolysis to reduce nociceptive pain to the rectum and anus. The patient reported no adverse side effects from the procedure and within 1-3 days reported a reduction in pain and less difficulty with bowel movements. The pain reduction was expected to last for weeks to several months.

Conclusion: Ganglion impar block can be an effective adjunctive treatment for the management of bowel-movement associated pain in patients with anorectal malignancies.

“Blink once if you're in pain”: Ventilator Withdrawal in Patients Totally Locked-In with Amyotrophic Lateral Sclerosis (C908)

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Objectives

- Describe a team approach to ventilation withdrawal in patients with ALS incorporating families' input.
- Develop multiple sedation strategies for patients in the TLS.

Background: The totally locked-in state (TLS) complicates ventilator withdrawal in patients with amyotrophic lateral sclerosis (ALS) because patients' paralysis limits our ability to ensure comfort.

Case Description: Mr. A was a 54-year-old motorcycle enthusiast with advanced ALS in a TLS on three years of home mechanical ventilation. He developed recurrent pneumonias, pneumothoraces, and eventually a bronchopleural fistula without permanent treatment options. Our palliative care team was consulted to assist with ventilator withdrawal. Mr. A's ICU team recently cared for another patient with ALS, whom they had struggled to sedate before extubation. We therefore developed a backup sedation plan for Mr. A. Before attempting ventilator wean, Mr. A's wife observed, "He's definitely still awake," despite multiple, large bolus doses of lorazepam and hydromorphone. Mr. A's wife educated the team about his signs of stress and pain. Propofol was started and titrated until Mr. A stopped blinking, his face relaxed, and his wife indicated he was comfortable. The ventilator was quickly weaned, and Mr. A died.

A minority (1-14% varying by treatment center) of the 12,000-15,000 patients living with ALS in the U.S. uses long-term mechanical ventilation^{[2],[3]}, and an unknown number of ventilated patients develop the TLS. Little is known about the best strategies to assure family members and ourselves that we have achieved comfort for patients with ALS in the TLS with ventilation withdrawal. Our case highlights several lessons: 1) ask families to educate clinicians about patients' personal signs of distress and consciousness; 2) have a backup pharmacologic strategy for sedation prepared at the bedside before attempting ventilator withdrawal; 3) achieve agreement between teams and families that patients are deeply sedated before weaning the ventilator.

Conclusion: Palliative care teams can assist in developing a comprehensive sedation plan for ventilator withdrawal in patients with ALS – and perhaps other conditions – in the TLS.

Beyond Pediatrics: Incorporating Children into End of Life Care in the ICU Setting (C909)

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Objectives

- Identify situations in which it is appropriate to include young children in end of life ICU care
- Develop an approach for involving young children related to patients receiving end of life care in the ICU

Background: Death and dying in the ICU are difficult no matter the circumstances, however, allowing children to participate in the end of life care of a parent or guardian can be beneficial for the entire family. Avoidance is often employed with the intent to protect children from knowledge about death and dying. Children may also be excluded due to parental anxiety or discomfort of the ICU staff. Under the appropriate circumstances including children in visitation and end of life care in the ICU can help to alleviate their anxiety, minimize fantasy, and facilitate healthy grieving.

Case Description: A 49 y/o male with end-stage alcoholic cirrhosis was admitted for hepatic encephalopathy and sepsis secondary to community acquired pneumonia. His hospital course was prolonged and complicated by hepatorenal syndrome requiring dialysis, sepsis with presumed fungal peritonitis, cardiac arrest with ROSC, and DIC. Due to the severity of his illness he was removed from the transplant list and Palliative Care was consulted by the transplant surgery team. In addition to addressing goals of care, the palliative care team addressed issues including how patient's wife should discuss prognosis with their children (ages 9 and 12) and counseled both nursing staff and family on how to incorporate children into end of life care. Both children were present for final family meeting and at the time of compassionate extubation and death. In a debriefing session with the nursing staff after the patient's death, palliative care team interventions alleviated staff anxiety regarding children's participation at end of life. Family also expressed appreciation that children were allowed to participate.

Conclusion: This case illustrates an example of how to allow young children to participate in end of life care in the ICU with appropriate counseling to ameliorate staff and parental anxiety.

In Retrospect, That Could Have Gone Better: Goals of Care Conversations in Early Medical Education (C910)

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Objectives

- Recognize the importance of early training in how to conduct goals of care conversations during medical education.
- Identify opportunities to include family meetings as an aspect of medical education in goals-of-care conversations.

Background: In recent years there has been recognition of the importance of training in how to conduct goals of care conversations during medical education. However, much of the time these sessions focus on patient-physician interactions and leave out the family. Medical students are often excluded when these conversations arise in order to protect the patient from an “audience” during difficult moments. Internship is focused on medical facts and patient management, and it may not be until palliative or geriatric electives late in training when a physician-in-training has substantial exposure to these topics. What happens when an intern on call is faced with an unanticipated family meeting?

Case Description: A 33-year-old internal medicine PGY-1 early in the training year is given sign out that a patient should be DNI and “just needs to sign the paperwork”. The patient is a 75-year-old woman with end-stage COPD admitted for pneumonia. The patient is unable to tolerate face mask due to anxiety, desaturates severely when anxiolytics are attempted, and declines intubation. Earlier in the day this decision was discussed with her primary team, but when the on-call intern arrives, several family members are present and furious. The intern has not had any training in conducting a family meeting and is caught flat-footed by the anger. The family, patient, and intern are eventually able to come to understanding, and the DNI is signed. The patient dies the next day, peacefully. Years later as a senior resident, the physician encounters tools for family meetings and retrospectively understands how things may have gone differently.

Conclusion: This case illustrates a situation in which a physician-in-training was left unprepared for a family meeting. We will discuss the importance of early training in goals of care conversations as part of medical education and emphasize inclusion of family discussions in these trainings.

High-Flow Nasal Cannula for Patients with Advanced Lung Disease at the End-of-Life (C911)

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Objectives

- Describe benefits of high-flow nasal cannula (HFNC) for patients with advanced lung disease (ALD).
- Recognize challenges to providing HFNC for patients in the hospice setting.

Background: High-flow nasal cannula oxygen therapy is increasingly being used for adults with ALD. It is comprised of an air/oxygen blender, and delivers humidified oxygen at up to 60 L/min. HFNC offers a non-invasive interface for relieving dyspnea in patients with ALD, and can prevent need for more invasive respiratory support. Unlike face-mask oxygen delivery devices, HFNC allows patients to eat and interact with others, thereby enhancing quality of life. However, many hospice facilities and nursing homes may be unable to provide HFNC due to cost, need for specialized equipment, or lack of staff training. Additionally, clear guidelines on withdrawal of HFNC are lacking, creating uncertainty about how to manage patients on HFNC at end of life. This case highlights benefits and barriers to use of HFNC in terminally ill patients.

Case Description: A 66-year-old male with metastatic lung cancer and severe COPD presented with hypoxic respiratory failure, with oxygen saturation of 70% on room air. CT of the chest demonstrated severe emphysema and pneumonia. He was placed on HFNC at flow of 40L/min and FiO₂ of 70%, with improvement in oxygen saturation and subjective dyspnea. While on HFNC he had meaningful interactions with his family

members. Despite treatment with antibiotics and steroids, HFNC could not be weaned. His goals were comfort-focused, but he wanted to continue HFNC, as he was still very alert, and would have decompensated quickly without the support. After an extensive regional search, social work found an inpatient hospice facility able to provide HFNC, and the patient was transferred for end-of-life care.

Conclusion: Hospice and palliative care clinicians will increasingly encounter HFNC in patients with ALD and should be familiar with its indications and use. While HFNC has palliative and quality of life benefits, there are barriers to its use in patients seeking comfort-focused care.

Brainstem Disconnection Syndrome: How an Extremely Rare Diagnosis Influences the Palliative Care Discussion (C912)

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Objectives

- Describe the rare syndrome of Brainstem Disconnection.
- List elements of a palliative medicine interdisciplinary approach to a patient with Brainstem Disconnection.
- Identify challenges to a palliative medicine team in patients with rare and not well-understood illnesses/condition.
- Identify the strengths of a multidisciplinary approach in palliative care in pediatric patients with rare illnesses.

Background: Brainstem Connection syndrome is an extremely rare condition characterized by hypodevelopment of the cerebellum, pons and brainstem. In addition to underdevelopment there is a paucity of the normal connections between the patient's brainstem and the rest of the brain. To date, only a handful of patients with this disorder have been reported, and prognosis is grim with the majority of patients dying within the first two months of life. However, recent reports have highlighted several children who have lived beyond infancy and even achieved some developmental milestones.

Case Description: A 4-week old female with a diagnosis of Brainstem Disconnection syndrome presents to a children's hospital, born to health parents of Slovakian heritage who have another healthy, 4-year-old child. The patient's mother had an uneventful pregnancy with routine prenatal care, to include a normal 20-week anatomical survey prenatal ultrasound. The patient was delivered with spontaneous vaginal delivery at term and did well initially with micrognathia as her only noted abnormality. However, the infant soon started

experiencing poor feeding and failure to thrive. She was transferred to a children's hospital where nasogastric feedings were initiated and the patient began to gain weight appropriately. An MRI revealed hypo-development of the pons and cerebellum and Brainstem Disconnection was diagnosed. Due to the rarity of the diagnosis and the uncertainty of the patient's prognosis, a palliative care consult was requested.

Conclusion: A palliative medicine consultation with an interdisciplinary team is essential in patients with serious illnesses. However, when a patient is faced with a rare diagnosis that the medical community has little experience with, the uncertainty of the prognosis and path ahead place increased importance of the interdisciplinary team for social and emotional support. This presentation will review the challenges that arise in the face of added uncertainty.

Hastening the End: Suicidal Ideation and Attempt in a Patient with Widely Metastatic Lung Carcinoma (C913)

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Objectives

- Recognize the increased risk of suicidality in patients with metastatic cancer
- Comprehend the factors that increase the risk of suicide in patients with metastatic cancer.

Background: Suicidal ideation is common in cancer, with measured rates of 4-30%, twice that observed in the general population. A premalignant history of psychiatric diagnosis confers a 15-30 fold increased risk of suicidality. Suicide risk may be correlated with depression, anxiety, lower levels of perceived social support, poor performance status, advanced disease stage, increasing age, and substantial pain. Brain metastases and steroid induced psychosis may also contribute. Formal risk assessment and programs to increase psychosocial support of patients with cancer may reduce depression and mitigate suicidal ideation.

Case Description: Ms. B was a 33 year old woman with a history of depression and stage 4 non-small cell lung carcinoma metastatic to brain treated with chemotherapy and radiation. Patient was referred to palliative care for management of pain, depression, and psychosocial distress. Nociceptive and neuropathic pain were managed with hydromorphone and gabapentin, depression was treated with escitalopram, and she received dexamethasone 4mg PO twice daily. Shortly after the palliative care referral, Ms. B attempted suicide by jumping out of a window. This prompted hospitalization for treatment of both suicidality and worsening pain. She responded well to opiate titration, addition of haloperidol and benzodiazepine, and reduction in the dexamethasone dose. She was ultimately discharged to hospice care in her mother's home, with aggressive pain management, psychiatric oversight, and vigorous social work and clergy support prior to her death.

Conclusion: Cancer increases the risk of suicide. In this case, the patient's premorbid mental health history, pain, lack of social support, use of steroids and advanced disease stage contributed to this risk. Screening for risk factors that may predispose patients to suicidal ideation is a critical part of the Hospice and Palliative Care skillset. Early screening facilitates referral to an interdisciplinary team to both lessen this risk and increase comfort at end of life.

The Long Journey Home: Travelling with Advanced Terminal Illness (C914)

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Objectives

- Explore the barriers to quality palliative care in the international traveler with advanced terminal illness.
- Recognize the importance of honest, effective communication with terminally ill patients who wish to travel
- Explore the role of the palliative care team in advocating for patients traveling with advanced disease to minimize the potential risks associated with travelling.

Background: Obtaining quality healthcare internationally may pose a challenge to patients diagnosed with advanced chronic illnesses. As the receiving hospital for a major NYC International airport, encounters with the ill traveler are common and pose unique challenges to our health care system. Patients with advanced cancers seeking expensive, radical treatment in hopes of a cure are common scenarios for our palliative care service.

Case Description: WS is a 73 year old American male living in the Philippines who was diagnosed with a large obstructing bladder mass with subsequent renal failure. He began dialysis in the Philippines, but was unable to obtain a biopsy of the bladder mass due to financial constraints. WS arranged a flight home for himself and his wife from the Philippines to China, China to New York and New York to North Carolina for further health care. During his flight from China to New York, the patient became confused and lethargic. Upon arrival to NY, WS was brought to our hospital. On admission, WS was noted to have altered mental status, end stage renal disease, sepsis due to a urinary tract infection, and a large obstructing mass with bilateral hydronephrosis, and lymphadenopathy on CT. WS's son travelled to NY with goal of returning his father to North Carolina for further diagnosis and treatment. WS and his family faced many barriers to travelling including finding an accepting ICU physician in North Carolina and an \$8000 bill for ambulance transport. Our

Palliative care team met with the pt and son and helped them navigate through this complex process and obtain the necessary requirements to facilitate the safe transfer of WS home.

Conclusion: Providing Palliative care to the international traveler with advanced terminal illness requires open, honest discussions regarding patient's medical condition, appropriate forward planning and proactive management of potential medical crisis.

Continuing Care After Betrayal (C915)

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Objectives

- How to identify patient dishonesty that compromises care
- Identify the motives behind falsification of truth between patient and staff
- Explore the explanations as to why palliative care team may be more susceptible to patient lies.

Background: A 2004 survey found that 38% of patients lied about following their doctor's orders, 16% lied about their intake of alcohol, and 12% lied about recreational drug use. The experience of being deceived is often associated with complex emotions. Lying also has a negative effect on the liar including feelings of guilt and loss of credibility.

Case Description: 45-year-old AA M (DP) presented to our hospital 07/2014 with acute abdominal pain from a recently diagnosed unresectable pancreatic tumor. Our palliative care team was consulted in 03/2015 for uncontrolled pain. DP gave a history of PTSD after his tour in Afghanistan, where he had lost his left leg and was the victim of a propelled grenade to his stomach. DP opted to forgo aggressive treatment, and agreed for inpatient hospice care for pain control. During hospitalization, he had fluctuating mental status and DP's mother was contacted. She informed the team that DP had acquired his abdominal injury and leg amputation after being shot in a drug raid while buying illegal drugs. When confronted, DP became depressed and withdrawn. A psychiatric evaluation described DP to have symptoms of "pseudologia fantastica". His pain medication was then readjusted and pain was controlled. DP was discharged home and returned 1 week later for diarrhea and vomiting. At this time patient was put on a continuous dilaudid drip and died comfortably on 4/13/2015.

Conclusion: Honest communication between patient and medical staff is important because fabrication of information can lead to ineffective clinical care. With growing federal regulations on opioid prescriptions, physicians may be reluctant to prescribe opioids to those in pain struggling with drug abuse, especially once a

deception has been revealed. Maintaining a nonjudgmental perception of patients who lie, despite feelings of betrayal is pertinent to providing quality end of life care.

Breaking "Good" News: Communication about Hospice Discharge When the Prognosis is Longer than Anticipated (C916)

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Objectives

- Describe the emotional, psychosocial and practical complexities associated with live hospice discharge.
- Recognize the concept of "breaking good news" as a distinct palliative care communication skill.

Background: Approximately 200,000 living patients are discharged from hospice annually. The majority of these patients are discharged because they no longer meet criteria for hospice due to medical stabilization. Live hospice discharge has been associated with significant distress for patients and families and thus requires careful communication.

Case Description: An 83-year-old man had a syncopal event in which he struck his head and suffered a large subdural hematoma. Despite evacuation of the hematoma, he remained minimally responsive, with an estimated prognosis of days to weeks. During discussions with his family, the goal of his care was transitioned to comfort. He was transferred to the inpatient hospice unit. Shortly thereafter, he became more responsive and started to eat and drink. During meetings held to discuss this improvement, his family endorsed feelings of mistrust toward providers and concern regarding his future care needs. The goal of care shifted towards rehabilitation and life prolongation. He was discharged from hospice to a rehabilitation center, then to a nursing home for long-term care. He is now cognitively impaired, wheelchair-bound and requires supervision with activities of daily living. His prognosis is significantly longer than originally estimated, however his quality of life is different.

Conclusion: Discussions surrounding improvement in estimated prognosis and impending discharge from hospice are inherently associated with mixed emotions, uncertainty, a sense of abandonment and, in this case, a lack of trust that can impact medical decision-making. The interdisciplinary hospice team may address many of these issues during the discharge process. Just as we carefully and thoughtfully break bad news, we must carefully and thoughtfully break good news.

The Pitfalls of Withdrawing Life-Sustaining Treatment from an Awake and Decisional Patient: an Increasingly Common Challenge with Advances in Life-prolonging Therapies (C917)

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Objectives

- Illustrate the distress of alert and decisional patients receiving continuous life-sustaining treatment who are considering discontinuation of treatment and how to support them through the process.
- Recognize provider distress while caring for alert and decisional patients facing the decision to discontinue life-sustaining treatment and strategies to reduce distress and prevent it from interfering with patient care.
- Identify system based practice factors that influence the care of alert and decisional patients receiving life-sustaining treatment.

Background: Advances in life prolonging therapies in the hospital are allowing more patients to live longer in an inpatient setting while remaining alert and decisional. Because many of these therapies do not change the progressive nature of the underlying illness, many of these patients are burdened with deciding when to stop life prolonging treatments that may result in a rapid decline to death once discontinued. There is a paucity of medical literature to guide clinicians in these case scenarios.

Case Description: A 70-year-old female with pulmonary hypertension was admitted with hypoxia. Through her hospital course she developed hyperammonemia with encephalopathy and became dependent on CVVH to clear the ammonia and prevent recurrent encephalopathy. In addition, right heart failure led her to become dependent on vasopressor support and high flow nasal cannula. As it became medically apparent that there was no hope for recovery or weaning from these life prolonging agents, she was presented with the opportunity to tell providers when she would have the life-sustaining treatment stopped. Unfortunately, the discontinuation of the life prolonging therapies would likely lead to abrupt mental status decline with progression to death in hours to days. For several weeks she experienced significant psychological distress upon repeated questioning about the timing of treatment discontinuation. After nearly a month in an ICU, she decided to stop all life prolonging care and died in the hospital one day later.

Conclusion: The decision to withdraw life-sustaining treatment when a patient is alert and decisional may be influenced not only by ethical, legal, religious, cultural, and financial factors, but by system-based practice factors to expedite the decision-making process. Providers must be mindful of how they guide the patient's

decision-making and ensure they are not compounding patient and caregiver distress when facing such decisions.

How Do We Provide Optimal Palliative Care for Patients with Developmental Disabilities (DD)? Opportunities and Challenges (C918)

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Objectives

- Review current protocol to implement patient and families wishes in patients with Developmental Delay (DD).
- Discuss the complexities in establishing goals of care for patients with developmental delay, who often have multiple stake holders

Background: Advocating medically appropriate care at the end of life for developmental delay (DD) patients can be challenging. There are strict legal regulations to protect the rights of DD patients, given historical misconduct, such as the Willowbrook case (1987). When DD patients are at the end of life, such regulations may do more harm and prolong suffering.

Case Description: A 52 year old male, nursing home resident with profound mental retardation (MR), presented to emergency department after displacing his PEG. He was bedbound, nonverbal, contracted and without capacity. Over the last 6 months he had progressive dysphagia and stopped eating. A PEG was placed, which he pulled out repeatedly. There was concern about the consequences of replacing the PEG, including displacement, discomfort, treatment burden and restraints. Eventually an aunt was contacted, who agreed for comfort care and to withhold the PEG. Despite having a decision maker, legal and risk management consultation was necessary.

The Health Care Decisions Act for Persons with Mental Retardation states decisions regarding life-sustaining treatment (LST) can be withheld, if the patient will die within a short time. This usually applies in a case of imminent death, and becomes complicated when an individual is hemodynamically stable.

Existing state protocol for stopping LST in patients with DD include several criteria: capacity assessment; medical condition; benefits and burdens.¹ We used a collaborative model to provide medically appropriate care with input from medicine, legal, family, ethics, and state designee. All parties agreed to comfort care and withholding further PEG placement. Patient died peacefully.

Conclusion: Medically appropriate end of life care for individuals with DD can be achieved when there is collaboration among key stakeholders and the state guidelines are followed.

Reference

1. OPWDD: NYS Office for people with Developmental disabilities: Putting people first. Feb 2012

Case Report: *The role of Palliative care in Fatal Familial Insomnia (C919)*

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Objectives

- Consider early testing for any patient with family history of terminal disease.
- Broaden knowledge base of prion diseases and other neurodegenerative diseases, and their diverse clinical presentations.

Background: Fatal Familial Insomnia (FFI) is an extremely rare inherited prion disorder. Testing is limited to genetic tests, with mutations of D178N PRNP gene often implicated. Unfortunately, clinical presentation varies making diagnosis difficult.

Case Description: A 60 year old male with a history of many family members with FFI presented with fatigue, daytime somnolence and hot flashes. Despite a rigorous sleep hygiene regimen, he noted no improvement over the subsequent four months. He was admitted with an acute respiratory decompensation, diagnosed as COPD despite no prior history of pulmonary disease. Despite aggressive treatment, he continued to suffer from persistent dyspnea, hypoxia, confusion, myoclonus, dysarthria and ataxic gait. The patient had refused genetic testing, desiring comfort care at home. Advanced care planning was strongly encouraged when the patient expressed a desire for no life sustaining treatments to his PCP. Ultimately, his family convinced him to get tested for his daughter's future healthcare considerations. Home Hospice was consulted; however, the patient experienced a sudden decline with respiratory failure, renal failure with gross hematuria and delirium. He was admitted to the ICU on mechanical ventilation at his wife's insistence. Results were not available for at least a month and both the family and treatment team struggled with appropriate goals of care without a clear diagnosis. Clinical deterioration continued and the patient was transitioned to comfort care. Six weeks after his death genetic testing confirmed the diagnosis of FFI.

Conclusion: Treatment of FFI is primarily palliative. Due to the rapid decline experienced by patients with FFI, support is often limited, although some options for symptom management are available. Patients and

families benefit from early diagnoses and sufficient time to evaluate goals. This patient died within six months of his presenting symptoms of FFI and prior to receiving results of genetic testing, thus dramatically impacting everyone's decision-making ability.

Transfusions for Uncontrollable Bleeding at the End of Life; When Should We Stop and Who Decides? (C920)

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Objectives

- Name the ethical principles involved when weighing the use of scarce medical resources near the end of life
- Discuss the intersection of societal justice, beneficence, patient autonomy and medical futility
- Explain the limitations of the term “medical futility”
- Discuss the ethical need for national guidelines on integrating societal considerations of resource allocation into decisions on the use of scarce resources near the end of life

Background: Sometimes patients or their families request treatments near the end of life which health care providers feel are futile, but which may achieve important patient and/or family goals. Medical futility refers to interventions that are unable to produce benefit. However, only a minority of cases are irrefutably biologically futile, limiting the use of this concept in biomedical ethical discourse. Ethical analysis reveals that the principles of patient autonomy, beneficence and societal justice are germane to these cases.

Case Description: An 85-year-old man was admitted with gastrointestinal bleeding and was diagnosed with gastric cancer. He elected to forgo surgical intervention and requested a DNR/DNI order. He continued to have profuse rectal bleeding requiring up to four transfusions of packed red cells daily to control symptoms of agitation and altered mental status. After transfusion, his mental status would return to baseline briefly. After four days, the medical team proposed discontinuation of the transfusions. The patient deferred decision-making to his doctors and family. His family believed blood transfusions allowed him to have more quality time with them and requested continuation. Three days later, the patient's wife assented to have transfusions stopped, and the patient was transferred to a hospice residence and died several days later.

Conclusion: Currently, it falls to the individual physician or medical team to weigh benefit to the patient against societal cost. Such bedside decisions carry the risk of being subjective and idiosyncratic and can undermine the physician's role as the patient advocate. It may be necessary to limit the use of scarce resources

for dying patients; however, a mechanism outside the scope of the individual physician-patient relationship, such as national guidelines proposed by experts, should be used. Such guidelines must be based on the best available data, consistent across institutions, and subject to public scrutiny.

Aneurysm Repair in a Frail Surgical Patient (C921)

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T Johelen Carleton, MD, Banner University Medical Center, Phoenix, AZ

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Objectives

- Demonstrate the value of preoperative palliative care involvement for a frail surgical patient.
- Recognize that palliative care and surgical care are not mutually exclusive.
- Demonstrate how collaboration between surgical and palliative care teams can improve quality of life and care satisfaction.

Background: Evidence has shown that early palliative care increases survival and improves quality of life in patients with metastatic non-small cell lung cancer (NEJM 2010). Recent literature suggests preoperative palliative consultation decreases mortality in frail surgical patients (JAMA Surg 2014). As a quality improvement measure, our institution is implementing frailty screening and encouraging preoperative palliative consultation for frail patients.

Case Description: Elderly patient with a 5.8 cm abdominal aortic aneurysm was referred to Palliative Care clinic by Vascular Surgery for goals of care discussion and advance care planning prior to elective endovascular repair. He was able to perform the majority of his activities of daily living, and used a scooter for mobility. Possible postoperative complications including respiratory failure, kidney failure, enteral feeding, and prolonged rehabilitation were discussed in detail. Interestingly, patient was unaware that he was considered moderate-to-high risk for complications, and that his DNR status would need to be rescinded perioperatively. After the discussion, he felt more informed and confident in his decision to rescind his DNR and pursue surgery. He experienced no postoperative complications, and was discharged home after 9 days.

Conclusion: Preliminary data indicates that frailty screening identifies at-risk surgical patients and reduces mortality for those who undergo timely preoperative palliative care consultation. Early palliative care consultation empowers patients with the knowledge of potential complications associated with surgical procedures. With this knowledge, they can make informed decisions and document their wishes regarding advance care planning.

All They Needed Was a Smile: Developmental Milestones, Quality of Life, and Decision Making in a Medically Complex Infant (C922)

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Objectives

- Understand that parents of infants with medical complexity are continually reassessing quality of life for their child as information about their development and prognosis is learned.
- Recognize that the uncertain prognosis in extremely rare conditions provides a challenge for medical providers in counseling parents regarding decision-making as it relates to quality of life.
- Understand that families may use specific developmental milestones in infants to determine if quality of life, as they define it, can be achieved.

Background: Parents of infants with complex medical conditions may have an evolving definition of quality of life for their child as information about their condition is learned and developmental delays emerge. When medical providers cannot offer a clear prognosis in rare conditions, decisions about care may rely more heavily on parental definitions of quality of life. This case examines one family's process identifying their own values regarding quality of life for their infant, and how it impacted decision-making.

Case Description: "Baby Boy D" was a full term infant from an uncomplicated pregnancy who, from birth, had near constant movements of his body and eyes that were eventually diagnosed as myoclonus. He also had worsening episodes of central apnea and hypoventilation, requiring escalation of respiratory support, and eventually ventilator dependence. After an exhaustive diagnostic work-up he was diagnosed by whole exome sequencing with a rare neurological disorder that had never been seen before in a child. Without a well-described diagnosis his parents had no clear prognosis to inform their decision about tracheostomy and home ventilation. At the time of diagnosis, Baby Boy D was about 2 months old and had yet to develop a social smile. His parents decided that quality of life for them meant the ability to engage in the world and with family. Absence of this developmental milestone was an early indicator that this might not be possible. His parents decided to wait until he was 3 months old to allow for a delayed smile to emerge, but none came. His parents discontinued life-sustaining therapy, and he died shortly thereafter.

Conclusion: Parents definition of quality of live evolve for children with rare and severe medical conditions. Parents may use known developmental milestones to determine if an acceptable quality of life can be obtained.

Sickle Cell Disease and Palliative Care: A Match Made in DBT Heaven (C923)

Objectives

- To identify three advantages of palliative care in patients with sickle cell disease.
- To describe the prevalence of depression, anxiety and borderline personality disorder in patients with sickle cell disease.
- To illustrate the use of psychotherapy-based behavior modification techniques with sickle cell patients.

Background: The management of symptoms related to sickle cell disease is multifaceted. In addition to physical symptoms, this population sometimes has concomitant socioeconomic challenges and mental illness. Similar to other chronic diseases, it is difficult to determine the proper time to consult palliative care. Given that these individuals with recurrent hospital admissions for pain crises have a higher risk of mortality, they may benefit from earlier involvement of palliative care.

Case Description: LC is a 25 year old man with sickle cell disease complicated by priapism, acute chest syndrome and avascular necrosis. He was well known for multiple pain crisis admissions and disruptive behavior which led to suboptimal care. Palliative care was consulted for pain and behavior management. The patient was enrolled in a Sickle Cell Palliative Care Clinic. The treatment plan was modeled after dialectical behavior therapy (DBT). The weekly appointments included opiate prescriptions and urine drug screens. He kept a pain journal in which he documented his pain score, physical activity, and opiate use. Between visits he was given assignments such as going to a job assistance agency and play dates with his child. If he had an acute crisis he could call and reach the clinic physician for guidance. If the patient was admitted to the hospital he was seen by the same physician. After six months the patient's behavior improved and his admission rate reduced by 50%. He started a job training program and became involved in a sickle cell support group.

Conclusion: Studies have shown the benefit of cognitive behavioral therapy (CBT) in sickle cell patients. More research is needed to explore the use of DBT in challenging sickle cell patients. There may also be a need for CBT and DBT training for palliative care professionals to aid in the management of challenging patients.

Do Opioids Offer Life-Sustaining and Legacy-Building Potential? A Case Series and Discussion (C924)

Objectives

- Upon completion of the presentation, the learner will be able to describe the pathophysiologic effect of opioids on the respiratory system, as well as cite the well-described literature in support of the assertion that opioids do not hasten death.
- Upon completion of the presentation, the learner will be able to recognize scenarios in which rapid escalation of opioid therapy is warranted, as well as to consider the potential for opioids to provide not only increased comfort and quality of life, but also increased survival with further opportunities for legacy-building at EOL.
- Upon completion of the presentation, the learner will be able to identify opportunities for further research regarding use of opioids at EOL.

Background: Palliative Care (PC) centers on the holistic management of patients with serious illness and their families through the provision of physical, psychological, social, and spiritual care. Both adult and pediatric literature strongly support the impact of PC in improving the quality of care for patients and families at the end of life (EOL), with recent data suggesting that PC involvement may, in fact, prolong patient survival. Opiate therapy is a cornerstone of PC management for pain and dyspnea, with robust data to support its efficacy in symptom control at the EOL. Nevertheless, clinician concerns regarding opiate-induced respiratory depression continue to result in cautious prescription patterns in EOL patients, particularly in the pediatric population.

Case Description: In our pediatric palliative care (PPC) practice, we have encountered a series of cases in which experienced clinicians predicted that critically ill patients in severe extremis would live only minutes to hours, yet subsequent aggressive escalation of opioids at EOL resulted in unexpected prolongation of life. We will discuss a diverse series of cases in which this phenomenon occurred, including a 4 month old girl with hydrancephaly, a 13 year old boy with Batten's disease, and a 5 year old girl with spinal muscular atrophy type I. In each of these cases, the patient experienced an unexpected increase in survival without receiving any other significant changes in their medical management, subsequently resulting in increased quality time with family for legacy-building prior to death.

Conclusion: In this case series, PPC patients at the EOL who received aggressive opioids for symptomatic control experienced unexpected life prolongation without evidence of additional morbidity, as well as

improvement in quality of life and legacy-building opportunities. Future studies are needed to better understand the impact of opioid administration on life prolongation for PPC patients at the EOL.

The Crossroads Between Child Abuse and Palliative Care (C925)

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Objectives

- Describe the relationship between child abuse and neglect using specific case examples.
- Describe specific case examples of palliative care patients who are also victims of child abuse, child neglect, or misclassification.

Background: Child abuse and neglect are tragic occurrences that most pediatric providers encounter at some point during practice. In 2013, approximately 679,000 children nationally were estimated to be victims of abuse or neglect, with 3.5 million referrals made to state Child Protective Services.¹ These referrals occur across a range of children, from healthy children to children with complex health care needs. These can be particularly ethically-challenging cases, especially when decision-making regarding goals of care is required. Palliative Care providers may be asked to assist in medical decision-making, advanced care planning, goals of care discussions, and symptom management for suspected or known victims of abuse and/or neglect. The result of these care decisions may lead to legal ramifications and may require surrogate decision-makers to be involved. Little is known about the role Palliative Care teams play in these cases.

Case Description: This is a retrospective case series in which all Pediatric Palliative Care consultation patient charts were searched for mention of child abuse and neglect or synonyms, or “3200.” A series of illustrative cases was then abstracted which met the criteria. Illustrative case examples were selected to describe predominant themes.

Chart review included 918 patients followed by the Palliative Care Team aged newborn through 18 years. Twelve patients (1.3%) also had billing diagnosis of child abuse or neglect, and significantly more had a referral to Children’s Protective Services. Individual cases included suspected physical abuse, neglect, improper medication administration, and diversion. Case examples are described in each of these subclasses.

Conclusions: This study describes one institution’s experience with patients who receive palliative care services in the setting of suspected child maltreatment. This population is highlighted to provide additional background on the psychosocial, ethical, and medical issues needing assessment and management in these cases.

Reference

1. <http://www.acf.hhs.gov/sites/default/files/cb/cm2013.pdf>

***“I Want To Trust You, But I Don’t Even Know You”:* Challenges and Strategies in Providing After-hours Telephone-based Palliative Care (C926)**

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Objectives

- Recognize the communication challenges inherent to after-hours telephone-based palliative care
- Identify strategies that may enhance trust between providers and patients or family members calling after-hours

Background: Access to palliative care services 24 hours-a-day is now a preferred practice within our field. As such, palliative care clinicians may increasingly be providing guidance and support after-hours via telephone. Establishing trust with individuals facing serious illness is fundamental to palliative care. However, this may be more challenging in after-hours telephone-based encounters.

Case Description: A 68 year old woman with advanced endometrial carcinoma with pulmonary metastases was admitted with dyspnea secondary to disease progression. Following a goals-of-care discussion on hospital day five, her care was transitioned to focus on intensive comfort, with the palliative care service becoming her primary inpatient treatment team. The next evening, the patient’s daughter contacted the on-call palliative care provider, distressed that her mother’s intravenous fluids had been stopped. She tearfully expressed her concern that her mother would die sooner and less comfortably without fluids. During the subsequent 40-minute phone conversation, the daughter expressed multiple times, “But you don’t really know my mother’s case... you’re just the person on-call.” The provider worked to gain trust and provide reassurance by listening, reflecting back empathic statements, making reference to palliative care team members known to the family, and establishing a clear follow-up plan. Both parties agreed not to restart fluids overnight, and to meet the next morning to discuss the issue further.

Conclusion: Key challenges in communicating with patients and families after-hours by telephone can include the absence of nonverbal cues, the lack of a prior relationship between the caller and provider, and the potentially heightened emotions of both parties dealing with a distressing issue after-hours. This case discussion will highlight such communication challenges, review the limited literature on after-hours telephone-based palliative care, and suggest strategies to help clinicians establish trust and provide reassurance.

L-Acetyl-Carnitine (ALC): A Potential Solution to the Difficult Challenge of Chemotherapy induced Neuropathy (CIN) (C927)

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Objectives

- The attendee will be able to describe the difficulties in treating CIN
- The attendee will be able to discuss various approaches to the management of CIN and highlight a potentially effective yet relatively unknown therapy for CIN

Background: Neurotoxicity, a common side effect of platinum based chemotherapy, can lead to chronic painful paresthesias (1) that significantly limit the quality of survivorship, post treatment. Many of the drugs currently used to treat neuropathic pain have not proven beneficial in the treatment of CIN (2). Experimental models have shown that using Acetyl-L-Carnitine (ALC) concurrently or post chemotherapy can improve peripheral nerve function as well as relieve neuropathic pain (3). While clinical data is limited, small trials have shown ALC to be effective for the treatment of CIN (4).

Case Description: The patient is a 54 year-old male with rectal adenocarcinoma s/p neoadjuvant chemoradiation with 5FU followed by abdominoperineal resection. A year prior to presentation, he was started on adjuvant FOLFOX, but soon developed neurotoxicity, described as constant, burning, sharp, and stabbing pain in his lower extremities, rated 7/10. He reported decreased sensation, confirmed on exam. He required dose reduction of Oxaliplatin on cycle 3 and was discontinued three months later due to debilitating neuropathy, non-responsive to traditional pain therapies of gabapentin and Lortab 10/325. He was referred to the Palliative Care Clinic for symptom management one year after cessation of chemotherapy He was started on 1000mg TID of ALC, based on literature review showing success at this dose (4). Initial follow up shows promise for improvement in his symptoms and increased patient satisfaction.

Conclusion: Although there are few studies to support its use, ALC should be considered for the treatment of CIN. The pros are low cost and low side effect profile. The cons are lack of awareness by many Palliative Care providers that this agent exists. We anticipate that additional case reports will highlight its utility in the management of this very debilitating and difficult to treat side effect of chemotherapy.

Innovation Through Inter-professional Collaboration: Improving Caregiver Confidence and Reducing Unscheduled RN Visits (C928)

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Objectives

- Identify factors contributing to unscheduled RN visits in a community hospice setting.
- Describe the inter-professional collaboration intended to reduce caregiver stress and increase caregiver confidence in managing patients' symptoms at home.
- Discuss the innovative patient care tool used in supporting non-professional caregivers at home to improve patient care quality.

Background: Central to the mission of hospice is providing high-quality end-of-life care for patients and caregivers. In a home hospice setting, caregivers are heavily involved in providing daily care to patients. However, non-professional caregivers often lack confidence in managing patient symptoms and seek additional support through unscheduled after-hours and weekend RN visits. Although most hospice agencies provide 24-hour patient care support, unscheduled RN visits can result in delays in meeting urgent patient care needs, which can create a sense of crisis, contribute to poor patient and caregiver satisfaction, and may result in unnecessary hospital admissions.

Case Description: To increase caregiver confidence and reduce unscheduled RN visits, a team of two RNs, two nurse's aides, one social worker, and one chaplain collaborated on a quality improvement project. The team met weekly for three months and reviewed after-hours and weekend calls that resulted in unscheduled RN visits. During these case reviews, each team member identified issues presented by each case. The most common reason for the after-hours and weekend calls was difficulty in managing patient symptoms. Specifically, exacerbation of anxiety, shortness of breath, pain, and sudden decline of patient condition were the most common reasons for the calls. The innovation team identified lack of caregiver education as a major factor contributing to the calls and developed a disease-specific script for each disease type to provide additional caregiver education on disease trajectory and symptom management.

Conclusion: Interprofessional team collaboration is an effective way to improve patient care quality in hospice. By understanding unique perspective each discipline, the interprofessional team was able to develop innovating caregiver support tools to increase caregiver confidence in symptom management. Further evaluation is necessary to assess the impact of the caregiver educational tools in reducing the number of unscheduled RN visits.

Palliative Consultation for the Adult ECMO Patient: Navigating the Changing Landscape (C929)

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Objectives

- Understand the unique characteristics of ECMO
- Identify ethical considerations that are unique to ECMO
- Identify unique psychosocial needs associated with ECMO
- Recognize potential efforts to address the needs of ECMO programs in one's community
- Objectives #1, #2, #3 and #4

Background: Extracorporeal membrane oxygenation (ECMO) is increasingly being used to aid in resuscitation of patients with cardiac or respiratory failure. This use of extracorporeal cardiopulmonary resuscitation (E-CPR) is based on small studies showing improved survival compared with conventional resuscitation in patients <75 years old with potentially correctable conditions. Nonetheless, mortality remains high in patients who are resuscitated using ECMO and, due to clinical urgency, these patients often have limited opportunity for informed consent. The American College of Cardiology recommends a comprehensive team approach to ECMO use, including the participation of Palliative Medicine. We present a patient who was resuscitated using ECMO in our large community hospital where an ECMO program is rapidly developing.

Case description: The patient was a 66 year old male without significant past medical history who was hospitalized emergently in the setting of acute myocardial infarction. He underwent emergent intubation and cardiac catheterization with subsequent cardiogenic shock. He was then placed on ECMO due to refractory shock. Five days later, the patient had impaired cortical brain function and persistent poor cardiac function. Palliative care consultation was requested to aid in transition to comfort measures. We will discuss the unique characteristics of navigating ECMO at end of life compared to other life prolonging measures, including ethical considerations, symptom management, psychosocial support and the role of Palliative Medicine in an ECMO program.

Conclusion: ECMO presents a novel challenge to Palliative Medicine teams and is expected to be utilized with increasing frequency, necessitating education and preparation.

Dexmedetomidine Infusion for Palliation in a Pediatric Patient Transitioning to Home Hospice (C930)

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Patricia Keefer, MD, University of Michigan, Ann Arbor, MI

Objectives

- Recognize cases where an atypical plan of care, such as continuous infusion of dexmedetomidine for a medically complicated infant, may indeed be the best plan of care for end-of-life.
- Appreciate how attending to goals and needs of parents of medically complicated, critically ill infants may provide lasting meaning and closure for grieving families.

Background: Dexmedetomidine has been widely used in the realm of anesthesia for years. More recently its value with post-op neuropathic pain, intractable cancer pain and delirium have been described. Its pharmacokinetics are ideal in that it promotes analgesia without respiratory depression or strong sedation. This case describes a novel, palliative use of dexmedetomidine infusion to allow an infant with a prognosis of days to transition to home hospice in a comfortable and timely fashion.

Case Description: Baby A is an 8 1/2 month old infant girl who has spent all but 6 weeks of her life in the hospital due to CHARGE syndrome and associated, severe cardiac defects. Her heart disease contributed to poor tolerance of feeds, which in turn limited the growth needed to continue with step-wise surgical correction of her cardiac anomalies. Over the many months it took to determine that she would not be a surgical candidate, dexmedetomidine infusion had become a key manager of her evolving neuroirritability. Parents were clear and resolute in their hope of getting Baby A home with hospice, at least briefly, when surgery was no longer an option. Attempts to wean dexmedetomidine and transition to other agents were ineffective, while her prognosis continued to shorten. As such, the Palliative Care team worked with a local hospice agency to discharge her home with dexmedetomidine infusion to support her comfort at the end-of-life.

Conclusion: Dexmedetomidine infusion is not a typical pediatric home hospice agent. However, in this case it was the only option for managing neuroirritability and getting a critically ill infant with a prognosis down to days out of the hospital. Having Baby A home, even briefly, was incredibly important to and meaningful for parents who had otherwise had little control or experience of family over their daughter's short life, supporting the atypical use of this drug.

Palliative and Ethical Considerations in a Patient with Persistent Vegetative State (C931)

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Objectives

- Define the persistent vegetative state (PVS) and its implications for ongoing patient care.
- Recognize challenges in providing adequate pain management for patients with PVS.

- Recognize the role and importance of Ethics and Palliative Care consultation for patients with PVS.

Background: Providing care for patients who have sustained traumatic brain and spinal cord injuries presents numerous challenges for the palliative care provider. Non-verbal communication and objective diagnostic testing becomes increasingly important when the patient is no longer able to report symptoms or express his/her wishes for ongoing care. This case examines the medical and ethical dilemmas that are often faced in caring for these patients.

Case Description: Mr. DD is 33-year-old man with history of a gunshot wound to the neck that resulted in complete C1-2 spinal cord transection as well as diffuse ischemic/anoxic brain injury after being down for more than 10 minutes in the field. At the request of his family, he received aggressive care including tracheostomy for ongoing mechanical ventilation and PEG tube placement for enteral nutrition. After more than 1 month, his neurologic exam showed no significant improvement and he was determined to meet criteria for PVS. His hospital course was complicated by ventilator-associated pneumonia, abdominal compartment syndrome requiring laparotomy, and multiple non-healing decubitus wounds. Members of the medical team held differing opinions as to the patient's experience of pain, the need for pain medications, and the ethical considerations in providing ongoing care to Mr. DD. The Ethics and Palliative Care teams were consulted for assistance with pain management and goals of care. He was subsequently assessed using the Nociception Coma Scale and received opiate analgesia appropriately. Interdisciplinary meetings involving the patient's family led to establishment of limitations to care and to improved communication.

Conclusion: A multidisciplinary approach, including early consultation from Palliative Care and Ethics, can help to improve quality of care for patients with PVS.

Integrated Outpatient Palliative Care in Amyotrophic Lateral Sclerosis: A New Model (C932)

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John Mulder, MD FAAHPM HMDC, Trillium Institute, Holland Home, Grand Rapids, MI

Objectives

- After the presentation, participants will be able to describe a novel model for integration of palliative medicine into an ALS clinic.
- After the presentation, participants will be able to list the advantages of early palliative intervention in neurologic diseases.

Background: The value of palliative medicine has become recognized in the inpatient setting. More recently, interest in the practice of outpatient palliative medicine has developed, including cardiology and oncology, which have adapted models for integrating palliative medicine into their clinics. In neurology, the presence of palliative medicine is also beginning to emerge. These clinics are typically structured to provide all supportive services (social work and physical, occupational, and speech therapy) in a single visit. Patients with amyotrophic lateral sclerosis (ALS) in particular can benefit from comprehensive, integrated palliative services.

Case Description: In our model, patients with a new diagnosis of ALS are scheduled with a palliative physician early in their care. Patients are educated in prognosis and course of the disease, as well as introduced to advanced care planning issues. DNR orders, advanced directives, potential symptom issues and options for nutritional, respiratory and communication support are addressed early in the diagnosis, allowing for ongoing conversations about these choices. While patients are scheduled with each of the supportive providers at each visit, physician visits alternate between the neurologist and the palliativist. Many of these patients are also followed up with a home visit by a member of the palliative team.

Conclusion: Integration of a palliative physician into this ALS team has resulted in the development of effective planning strategies for patients, families and the ALS team. It has been well accepted, and has enhanced the opportunities for the patients to engage in sophisticated values-based decision making.

Revisiting Medical Decision-Making Capacity of a Patient Admitted for Attempted Suicide (C933)

Michael Pottash, MD, North Shore LIJ University Hospital, New York, NY

Objectives

- Recognize the difficulty in assessing the capacity of a patient with a psychiatric illness.
- Appreciate the difference between advance directive planning and assisting suicide in a patient diagnosed with depression.

Background: Determining medical decision-making capacity in the hospital can be complicated, time consuming and often incorrectly assumed to be the purview of a psychiatrist. Additionally, psychiatric illness, especially suicidality, is mistakenly assumed to preclude patients from having capacity for medical decision-making and establishing an advance directive. Capacity is determined at the outset of hospitalization, acts as a blanket disqualifier for all decisions and is often never revisited.

Case Description: A 65 year old female with a history of major depression was admitted after an attempted suicide. Her injuries included a skull fracture and subdural hematoma. On exam she was alert but functionally

quadriplegic. The neurologist believed that the clinical findings were due to “brainstem shear” noted on MRI. Initially the patient refused tests and later a feeding tube when it was discovered that she was aspirating. The psychiatrist determined that she was still suicidal and had no capacity for medical decision-making. Her son was identified as a health surrogate and, with his consent, the patient received a feeding tube.

After several weeks of psychiatric care her depression was resolving. Palliative care met the patient at this time and determined that the patient had regained capacity for medical decision-making. She expressed the desire to eat by mouth and have the feeding tube removed as a quality of life measure. She also wished to avoid future resuscitation and artificial ventilation. She demonstrated understanding and reasoning of the risks and benefits of her decisions. Despite the circumstances of her hospitalization, her team of physicians and her family acted to honor her autonomy. They did not misinterpret her preference for quality of life and wish to set advance directives as assisting in suicide.

Conclusion: This case emphasizes the difficulty of protecting medical autonomy in a patient with psychiatric illness, especially after attempted suicide.

High Flow Oxygen Therapy for Patients at the End of Life: is it a good option? (C934)

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Objectives

- Session participants will become aware of the lack of clinical consensus about the use of high flow oxygen therapy (HFOT) as a treatment for palliative care patients.
- Session participants will be able to identify multiple challenges experienced by an interdisciplinary team caring for palliative care patients on HFOT.

Background: Dyspnea is a very common and distressing symptom at the end of life. Although High Flow Oxygen Therapy (HFOT) does not serve as a bridge to restoration of lung function for terminally ill patients, it has been suggested at a previous study that HFOT may increase comfort and reduce breathlessness for patients with a Do Not Intubate order. Patients and families usually accept HFOT when it is offered as a non-invasive treatment for breathlessness. Many patients who transfer to our palliative care unit at a large tertiary care teaching hospital arrive on HFOT for dyspnea management.

Case Description: Of 9 patients transferred to our PCU on HFOT, all had a poor prognosis, with goals of care focused on symptom management; five were on hospice. HFOT was typically discontinued because of delirium, the noise of the equipment and the discomfort it causes for the patient, or because opioids and alternate support modalities proved more effective for symptom relief. HFOT also delayed discharge because of

transportation difficulties, inadequate insurance coverage, and shortage of facilities that would accept these patients. In addition, the complex equipment and need for supervision by trained providers ruled out receiving care at home under hospice.

Conclusion: In view of the lack of clinical benefit and challenges encountered, our team does not recommend HFOT for treatment of dyspnea at the end of life. For patients with irreversible loss of lung function, HFOT doesn't serve as a bridge to recovery, doesn't effectively manage dyspnea, but does cause multiple discharge barriers. In addition, other treatment modalities are available to increase patient comfort and provide effective symptom management. We suggest further review of the current hospice and palliative medicine guidelines for treatment of dyspnea evaluating the role of HFOT as part of a comprehensive symptom management of patients near the end of life.

Dying with Dignity: How to Maintain Dignity when Suicide is not an Option (C935)

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Objectives

- Discuss current interdisciplinary support available for hospice patients with high suicide risk.
- Identify challenges related to designing a safe plan of care for a hospice patient after a suicidal attempt when discharged home.

Background: Suicide is a growing topic for hospice care providers. Current hospice care practices don't support suicide and struggle to find safe options to support these patients. In an attempt to preserve autonomy and dignity we present the case of Mr. S. who attempted suicide to avoid suffering.

Case Description: He is an 80 year old former avid traveler with extensive cardiovascular disease with functional decline, dependence on activities of daily living and increase in symptom burden over the course of a year. He was admitted to Beth Israel Hospital after a suicide attempt. He had clearly expressed to his wife his discontent with a life of dependence and confinement.

Patient had attempted suicide on two prior occasions for similar reasons. On his first attempt, he was resuscitated despite having a DNR order. Prior to his third attempt in September, he was enrolled in hospice. Psychiatric care through hospice was involved and treatment for depression was initiated. On his third attempt, his wife contacted the hospice team, which instructed her to call 911. This decision shocked her as she agreed with hospice enrollment for emotional and symptoms support. He was transferred to the emergency department despite her acceptance. He was kept on a regular medical floor with psychiatric surveillance until he was

cleared. Hospice agreed for transition planning and further care in our inpatient palliative care unit. His discharge plan included a safety box with proof of purchased to prevent another suicide attempt. Despite her frustration for not been able to support her husband's wishes, his wife agreed with the care plan and accepted continuation of hospice care.

Conclusion: We attempted to highlight the complexity of caring for a hospice patient with suicide risk. Hospice care practices attend terminal patients and caregiver's needs; nonetheless suicide remains a non-supported dying choice.

Rethinking Cultural Competence: When Norms Mask Individual Truths (C936)

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Objectives

- Recognize the importance of eliciting individual preferences while providing culturally competent care.
- Identify situations where inferences may be incorrectly made about best practice based on cultural norms.

Background: Culture plays an integral role in the way families frame decisions surrounding end of life care. Cultural competence is the ability to understand, appreciate and interact with persons from cultures and/or belief systems other than one's own. While efforts are made to remain culturally competent, assumptions are made based on generalizations.

Case Description: CJ is a 7 year-old male from Saudi Arabia with a history of combined immunodeficiency admitted for ongoing fevers, ultimately diagnosed with hemophagocytic lymphohistiocytosis. During his hospitalization his clinical picture acutely worsened and he developed multi-system organ dysfunction.

The pediatric palliative care (PPC) team was consulted. During the initial consult CJ's parents expressed hope that he would fully recover. The family shared they were of Muslim faith and found comfort and support in prayer.

The team was aware that families of Muslim faith often choose to pursue all medical interventions for life sustaining treatment (LST). There was hesitation to discuss advance care planning in order to spare the family from a difficult conversation. Similarly the Arabic interpreter was averse to participating in the conversation about LST. Recognizing the critical nature of CJ's illness and the high likelihood of an acute life-threatening event, the PPC team felt adamant about discussing the plan of care in conjunction with the family's wishes. In

speaking with the family and allowing for open discussion, they expressed their primary goal of maximizing CJ's comfort and sparing him from treatments likely to cause suffering. To the teams' surprise, the family chose to limit cardiac resuscitative efforts. CJ died peacefully surrounded by his family.

Conclusion: Cultural awareness is a crucial aspect of practicing PPC in a globalized society. In pursuing efforts to be culturally competent, providers must be mindful of balancing sensitivity to cultural norms with awareness of individual practices and beliefs.

Use of the "Malignant Bowel Obstruction Cocktail" in the Treatment of Severe Constipation after Failure of Conventional Therapy (C937)

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Objectives

- Describe a case where opioids, corticosteroids, octreotide, anticholinergics and antiemetics reversed a very prevalent cause of morbidity at the end of life; refractory constipation.
- Understand the mechanism of action of each of these drugs.

Background: Current published guidelines recommend the use of opioids, corticosteroids, and octreotide for the treatment of malignant bowel obstruction. Some patients, however, present with non-malignant bowel obstructions and treatment preferences vary.

Case Description: 88 year old male with a history of multiple abdominal surgeries. He presented with a three day history of abdominal pain, constipation, nausea, vomiting, though he had flatus. Of note he had been on hydromorphone 2 mg PO q6h around the clock for years due to chronic pain and was not compliant with his bowel regimen. Initial imaging including a CT scan and barium enema radiographic imaging showed severe fecal impaction but no point of obstruction was identified. Patient was hospitalized for 21 days during which he received several trials of pro motility agents, stool softeners, enemas, NGT, and a trial of methylnaltrexone. On the 14th day of his admission, palliative care team held an extensive family meeting with the patient, his family and the primary team. His options were discussed, patient declined any further invasive tests or procedures and after discussing the option of attempting a treatment that involved a cocktail of octreotide, antiemetics, corticosteroids and opiates, it was agreed upon that this treatment would be attempted given its potential for benefit and low side-effect profile. Three days after he was started on the IV octreotide 100 mg IV TID, Reglan 10 mg IV q4h, Decadron 8 mg IV Am and Mid-day and his dilaudid 2 mg IV q4h was continued, patient had a bowel movement, NGT was discontinued and he was able to tolerate a soft diet.

Conclusion: There is well established data on the use of this cocktail in relieving symptoms of malignant bowel obstruction, our case report warrants expanding future studies to include a broader group of patients with limited prognosis who present with refractory constipation.

Radiation Enteritis: A Challenge to Diagnose and Treat (C938)

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Objectives

- Consider etiologies of diarrhea in advanced cancer patients receiving disease-directed treatment.
- Examine pathophysiology of radiation enteritis
- Discuss treatment options for radiation enteritis.

Background: Diarrhea is a common, debilitating symptom experienced by cancer patients receiving chemotherapy and/or radiation. It has varied etiologies including, but not limited to, infection, gut neuropathy and radiation enteritis. A patient with diarrhea requires a thorough history and physical as well as diagnostic workup to differentiate among these potential causes. Patients receiving radiation and chemotherapy are at increased risk for radiation enteritis. Evidenced based guidelines for treatment of radiation enteritis are limited.

Case Description: This patient is a 59-year-old woman with a history of metastatic colon cancer receiving chemotherapy and radiation after multiple abdominal surgeries that resulted in extensive small bowel and colon resection. She presented with a chief complaint of diarrhea/high ostomy output of over eight liters per day following a course of radiation for tumor burden surrounding her right iliac vessels. The patient was initially treated with scheduled loperamide and diphenoxylate-atropine without improvement in her symptoms. Octreotide was then added and increased without resolution of her diarrhea. Additional symptom management medications with the additional benefit of decreasing gut motility were added including scheduled opioids, ondansetron and tincture of opium. However, she continued to have high ostomy output for two and a half weeks. During that time her diagnostic workup was negative for infectious or anatomical causes. A MRCP revealed bowel wall edema consistent with enterocolitis. She was diagnosed with radiation enteritis and started on budesonide 3 mg daily that resulted in complete resolution of her symptoms in five days.

Conclusion: Treatment for radiation enteritis is limited and not well supported. A general approach should consist of supportive measures, including IV fluids and bowel rest, and a thorough diagnostic workup to rule out other causes and identify the appropriate targeted therapy. In this case an anti-inflammatory agent, like budesonide, played an important role in treatment of radiation enteritis.

Botox Injections for Refractory Sialorrhea (C939)

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Objectives

- Recognize indications and side effects of botulinum toxin injections in the management of refractory sialorrhea in children and adults with neurologic disorders.
- Promote awareness and improve understanding of alternative options for management of secretions/sialorrhea among physicians and palliative providers.

Background: Sialorrhea is a common problem that creates major hygienic and psychosocial problems. Many methods have been used to treat sialorrhea, including oral motor therapy, intraoral devices, medications, surgery and radiotherapy. Recently Botox injections have been used in children and adults with neurodegenerative diseases to treat sialorrhea. We report a unique case of a child with Miller-Dieker syndrome who presented with recurrent aspiration pneumonia and refractory sialorrhea and was treated with Botox injections.

Case Description: A 4 year-old child with history of Miller-Dieker syndrome, global developmental delay, seizures, chronic respiratory failure presented with recurrent aspiration pneumonia. She was treated with intravenous antibiotics but still had copious amounts of thick oral secretions that required frequent suctioning. Anticholinergic medications were trialed but made the secretions thicker. The child was being maintained on BiPAP but the parents goals were to minimize invasive procedures, including intubation or tracheostomy. Because the symptoms were so severe and refractory, ultrasound directed Botox injection was administered into bilateral parotid and submandibular glands by neurology. Post procedural ultrasound was normal and she had no complications.

Conclusion: Many children and adults with neurological diseases such as Amyotrophic Lateral Sclerosis are unable to swallow their secretions. Targeted Botox injections into the salivary glands blocks acetylcholine release reducing production of saliva and usually last 3-6 months. Adverse effects reported include dysphagia, dry mouth and chewing difficulties. Low doses are recommended under ultrasound guidance to minimize side effects and spread to surrounding tissues. Administration of Botox is a minimally invasive procedure that may significantly improve quality of life for these patients. It is important to consider all options to palliate oral secretions after reviewing risks and benefits with the patients' and promote awareness among all physicians about alternatives such as Botox injections.

Pseudobulbar Affect or Depression in Dementia? (C940)

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Objectives

- Describe the signs and symptoms of pseudobulbar affect (PBA) and how to differentiate between depression and PBA
- Review the pathophysiology of PBA
- Review current pharmacologic options for treatment

Background: Pseudobulbar affect is a stereotyped emotional display with characteristically uncontrollable, involuntary outbursts of laughing or crying disproportionate or unrelated to mood. Recognition of PBA is challenging as physicians may be unaware of the criteria for diagnosing PBA, the patient's emotional response is noted as disproportionate and therefore, overlooked as poor coping or depression, or changes are attributed to the patient's baseline neurocognitive disease. The pathophysiology remains unclear, but serotonin and glutamine appear to play a significant role. Dextromethorphan/quinidine is the only FDA approved pharmaceutical for PBA, however other medications (SSRIs, TCAs) have been successfully used to treat PBA as well.

Case Description: A 92 year old woman enrolled in hospice for Alzheimer's was evaluated for episodic crying. Crying episodes started 3 months ago, occurring a few times a day, with the woman randomly shouting out "help me", lasted 10-20 minutes and she would stop crying abruptly without any intervention. Numerous medications were tried, often worsening her symptoms. Her current performance status met FAST Score 7D. She had urinary and bowel incontinence, no meaningful communication skill, was able to sit with assistance but was bedridden most of the time. Her vital signs were unremarkable. She had a non-tender stage II pressure ulcer in left hip and buttock area. She had shallow, unlabored breathing. Abdomen was soft, non-tender, with hypoactive bowel sounds. She was alert, blinking both eyes occasionally. Pupils were equally round, 3mm, reactive to light reflex appropriately. She had symmetrical face and moved all four extremities without difficulty. Further neurologic exam including psychiatric evaluation was not available with her poor cooperation. PBA was diagnosed and the patient was started on sertraline with a fantastic response.

Conclusion: PBA is a relatively common neurologic disease often present in the hospice population. Diagnosis followed by pharmacologic intervention can lead to rapid amelioration of symptoms.

When New Technology Leads to New Ethical Concerns: Supporting a Family with a Genetic Diagnosis (C941)

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Objectives

- Discuss the ethical issues surrounding prenatal and preimplantation genetic diagnosis.
- Describe the methods used by a Palliative care team to support the whole family when a genetic diagnosis is made.
- Identify how involvement of the Palliative Care team improved quality of life for the patient directly.

Background: Advancements in genetic testing have allowed the identification of new mutations and syndromes, often before a patient is born. As a result, parents may find themselves facing complex ethical issues surrounding prenatal and preimplantation genetic screening. Pediatric Palliative Care teams are in a unique position to help families understand these genetic diagnoses and navigate the decision-making process involved in these situations.

Case Description: A 4-month-old male was diagnosed with intractable seizures and developmental delay one month ago. Patient was the product of an IVF pregnancy and the first child for both parents. There is a maternal family history of multiple male family members with similar symptoms spanning three generations, but no diagnosis has ever been made. Our patient is the first member of this family to undergo comprehensive genetic testing. The inheritance pattern in this family was strongly suggestive of an X-linked disorder, so sequencing of the X chromosome was pursued. This revealed a rare mutation in the PIGA gene, which has been associated with disorders in other families characterized by neonatal hypotonia, early-onset intractable epilepsy leading to encephalopathy, developmental regression, severe intellectual disability, and variable congenital anomalies. Parents were grateful for a definitive diagnosis, but there was still no treatment available for the patient. In addition, parents had 7 viable embryos that remained cryopreserved and were facing ethical decisions about whether or not to implant these embryos in the future.

Conclusion: An interdisciplinary team approach to Pediatric Palliative Care provides the most comprehensive support for families facing prenatal or preimplantation genetic diagnoses. This case demonstrates how each member of our team was used to identify the various needs, values and goals of this family that influenced their understanding of a complex diagnosis. This information was used to help the parents make the best decisions for their family.

Brief Mindfulness Meditation as a Non-pharmacologic Adjuvant for Anxiety at End of Life Treatment (C942)

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Objectives

- Recognize patients who would benefit from mindfulness meditation techniques.
- Understand the components of mindfulness meditation.
- Initiate mindfulness meditation at the bedside.
- Understand the benefits of mindfulness meditation

Background: Mindfulness meditation is a type of meditation during which one focuses on the present moment nonjudgmentally. It has been shown to increase parasympathetic nervous system response, resulting in relaxation. Mindfulness based stress reduction programs uses mindfulness meditation as a treatment modality for depression and anxiety as well as for stress relief. The courses are widely available, easily accessible, fairly cheap, and have no undesirable side effects.

Case Description: Our patient is a 57 year old woman with a history of advanced metastatic pancreatic cancer and debilitating anxiety, who was admitted to the inpatient hospice unit with functional decline, uncontrolled abdominal pain and nausea. She was very nervous about her trajectory and worried she would not be able to achieve her goal of dying at home. Anxiety significantly interfered with treatment of nausea and pain. Anxiolytics caused intolerable somnolence and impairment in function. She underwent a guided mindfulness meditation session, during which she was asked to bring her attention to her breath. Her anxiety and fears improved after a single session. Her regimen was then able to be adjusted to allow her to return home for her final days.

Conclusion: Although mindfulness meditation is a course taught over days to weeks by qualified teachers, it can be implemented at the bedside by anyone able to perform it or through apps. In our case, the patient's husband did continue to guide the patient once he was taught the technique. Its effects are immediate, there are no undesirable side effects and it can be performed anywhere at almost no cost. It is worthwhile to consider adding mindfulness meditation as a non-pharmacological modality during end of life care.

When A Child Suffers: A Case for a Palliative Care Specialist in a Children's Hospital (C943)

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Objectives

- Identify the need for a pediatric palliative care specialist in children's hospitals
- Define the role of the anesthesiologist on pediatric palliative care teams

Background: Many children's hospitals in the United States lack a dedicated palliative care service led by a palliative care specialist, and therefore rely on palliative care consultants for end-of-life care and decision making. These consultants often specialize in oncology, psychiatry, or pain management, but lack comprehensive formal training in palliative care. These consultants also lack a palliative care interdisciplinary team, which provides additional expertise and coordination across domains of need. This fragmented model of care often results in substandard care for children with serious illnesses who endure unwanted treatments and prolonged hospital stays.

Case Description: A 19-year-old young man with recurrent metastatic Ewing's sarcoma was admitted to the pediatric hematology-oncology service with intractable pain. The primary service asked the anesthesiologist on the acute pain service to serve as the palliative care consultant until the oncologist who handled palliative care consults returned from vacation. The anesthesiologist adjusted medications but encouraged the primary service to address goals of care and the psychiatrist to address psychological symptoms. The patient expressed frustration over the endless carousel of consultants and refused to see the anesthesiologist and the psychiatrist. A projected one-week stay for pain medication titration turned into a one-month course. As the patient and his family wavered between inpatient and home hospice options, the patient's disease and symptoms rapidly progressed. In informal discussions, the patient expressed a desire to leave the hospital and to spend time with his dog and his father in his remaining days. He eventually went home with hospice and passed away shortly following his discharge.

Conclusion: This case highlights the need for a dedicated pediatric palliative care service. Without access to care coordination and expertise in critical domains, patients may experience avoidable burdens. End-stage cancer patients, particularly children and young adults, would benefit from the care of a palliative care specialist and team.

Ethical Decision-Making in Geriatric Trauma: An Interdisciplinary Team Approach (C944)

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Objectives

- Identify 4 core ethical issues faced in geriatric trauma

- Apply 4 key ethical issues in geriatric trauma to a clinical scenario

Background: Trauma presents as an abrupt and often life threatening event fraught with physical and emotional challenges for both patients and families. Geriatric trauma, specifically, presents unique challenges for families as well as for providers and is expected to increase dramatically over the next 2 decades given demographic trends. Palliative care consultation is increasingly being recognized for facilitating ethical decision-making. A case from a community-based hospital highlights the process by which core ethical issues can be identified and applied to guide ethical decision-making by the interdisciplinary team.

Case Description: A 70 year old female with a history of metastatic breast cancer suffers a fall and CT of the brain shows large subdural hematoma. She has no advanced directives and her mental status declines and is intubated in the emergency room. The patient's two daughters demand that "everything be done". Although the neurosurgeon paints an extremely poor picture of the situation, her daughters want her to remain a full code and proceed with surgery, while her husband wants to continue medical care but wants her to be DNR. Inter-family conflict is evident and providers feel conflicted. Palliative care and Ethics Committee consults are called the next morning to address the "family dynamics" and "futility" of care. Palliative care team not only identified conflict among family members but also addressed the conflict within the interdisciplinary team and ethics committee involvement was avoided.

Conclusion: Palliative care teams can facilitate decision-making regarding key ethical issues facing the geriatric trauma population. Early communication and a platform for exploration of emotional and family issues can impact shared decision-making among families as well as among interdisciplinary team members. Limitations exist, but benefits far outweigh limitations and can provide more meaningful, patient-centered care than the alternative of having cases referred to ethics committees.

A Communication Tool to Assist Frail Older Adults Facing Acute Surgical Decisions (C945)

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Objectives

- Describe current problems with treatment decision-making including traditional informed consent.
- Consider new strategies for high-stakes treatment decisions that describe uncertainty and the impact of treatment on overall health status.

- Recognize how the use of the "best case/worst case" communication tool can promote preference sensitive decisions for older adults with acute surgical problems near the end of life.

Background: Twenty-five percent of Americans 65 and older will have a surgical procedure within the last three months of life. Surgery can start a patient along a care trajectory that may be inconsistent with end-of-life goals. A critical barrier to reducing unwanted treatment is the existing framework for surgeon-patient communication. Our interdisciplinary team (surgery, palliative care, nursing) developed a novel tool to structure decision-making conversations using narrative and a graphic aid to engage patients in a discussion about treatment preferences. We performed a pilot study to evaluate use of the “best case/worst case” communication tool with frail older patients with acute surgical problems.

Case Description: An 87 year-old woman with diabetes and atrial fibrillation presented to our hospital with sepsis. Although she was living at home, her health was failing precipitously; she had frequent falls and weight loss. She was evaluated by the surgical service for massive colonic dilation and chronic constipation that failed to respond to aggressive medical management. The consulting surgeon used the best case/worst case framework to describe both surgery and a palliative strategy. This framework promoted dialogue about treatment options, allowed patient and family to express preferences about outcomes and enabled the surgeon to recommend treatment concordant with her preferences, *“This is what I know about her ...that she didn’t want a lot of these interventions...and we’re gonna do a maximum amount of those things if we decide to go for surgery ...so my general thought is that, surgery where she ends up in a nursing home, with complications from surgery, is not something that she ever wanted.”*

Conclusion: Use of the best case/worst case tool for in-the-moment surgical decisions allows surgeons to engage patients and families in a discussion about goals and options near the end of life and make preference sensitive treatment recommendations.

When Fear of Poor Outcomes is Confused with Futile Care: Renal Replacement Therapy in Cardio-Renal Syndrome (C946)

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Objectives

- Discuss medical futility
- Explore the efficacy of renal replacement therapy in cardio-renal syndrome

Background: Hippocrates declared that physicians should “refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless.” When and how does a physician make that determination? There are no specific criteria to define medical futility, simply a “virtual certainty that the action will fail.” Some view renal replacement therapy (RRT) as medically futile when acute heart failure (HF) results in renal dysfunction (cardio-renal syndrome, CRS). In-hospital mortality for CRS requiring RRT is as high as 62%. If patients do survive, many experience multiple morbidities: ambulation problems, pain, mood disturbances, and decreased quality of life. RRT is not seen as an effective therapy in CRS as it does not improve survival.

Case Description: Ms. W is a 55 year-old female with severe HF (ejection fraction of 15-20%) who is not a transplant or ventricular assist device candidate. She presented with acute on chronic renal failure due to decompensated HF associated with hyperkalemia and confusion. During a recent admission Renal consultants concluded “dialysis would not prolong her life and only inflict more suffering.” She was discharged with hospice care, which she subsequently revoked. This admission, RRT was considered due to her hyperkalemia. RRT was initiated to allow her to participate in goals of care discussions. Her nausea and confusion resolved on RRT. She and her family viewed RRT as a means to keep her comfortable, and therefore wished to pursue it indefinitely. After much consideration, she was trialed on intermittent hemodialysis (HD) and tolerated it well. She remains on HD two months after discharge.

Conclusion: The evidence suggests RRT in CRS is non-beneficial therapy. However, some patients with CRS are able to live longer with an acceptable quality of life on RRT. A time-limited trial of RRT may inform patients and providers of its feasibility and utility.

Schizophrenia, Diminished Capacity, and the Ethics of Forced Medical Treatment: A Case Study (C947)

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Objectives

- To recognize common issues encountered when determining decision-making capacity in patients with serious mental illness.
- To understand basic bioethical principles involved in court-ordered medical treatment in a patient with serious mental illness.

Background: Decision-making in life-threatening illnesses is especially difficult when the patient has a serious mental illness and limited ability to participate in treatment decisions. Palliative care is uniquely situated to assist both psychiatry and medical teams with goals-of-care.

Case Description: Mary, a 75-year-old woman with schizophrenia, was hospitalized on a psychiatric unit after she stopped her antipsychotic medication and became delusional and paranoid. The psychiatry team restarted Mary's medication and subsequently discovered she had been diagnosed with advanced neuroendocrine lung carcinoma one year earlier, but had declined treatment because she did not believe she had cancer. The team consulted oncology for treatment recommendations.

Mary refused all tests and was found to lack decision-making capacity. She had no family or friends to act as healthcare proxies, and so, as is common in inpatient psychiatry, the psychiatry team and the court became her decision-makers. A court-ordered CT scan showed significant disease progression. Oncology then requested a surgical biopsy for staging purposes, which Mary also refused. Because of the increasingly invasive medical procedures required and the fact that Mary would have to be court-ordered to undergo them against her will, psychiatry consulted palliative care to help with treatment decisions.

The interdisciplinary palliative care team met with Mary several times to talk about what quality of life (QOL) meant to her. They also met with oncology and psychiatry to better understand the treatment options as well as the particular burden they might have on a patient with schizophrenia. They helped frame the goals-of-care discussion in the context of Mary's QOL. Eventually, the psychiatry team decided to take a palliative approach and opted not to pursue aggressive treatment.

Conclusion: Court-ordered medical treatment is burdensome, and warrants careful consideration of risks and benefits. The palliative care team is crucial in helping to elicit patient goals-of-care in such situations.

Considering Quality of Life in the Treatment of Refractory Ascites in the End of Life: A Case Study (C948)

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Objectives

- Assess and weigh the benefits and harms from interventions designed to relieve the distressing symptoms of ascites
- Identify future areas of research needed to guide clinical decision making with regards to choosing the optimal intervention to relieve a patients' symptoms from ascites.

Background: In patients with refractory symptomatic ascites with rapid re-accumulation of fluid following paracentesis, placement of an indwelling peritoneal catheter (IPC) can result in improved quality of life (QOL), but may also result in complications with significant morbidity at the end of life.

Case Description: A 59-year-old gentleman with decompensated liver cirrhosis complicated by recurrent ascites refractory to diuretics was admitted for a therapeutic large-volume paracentesis (LVP). Since this was his third admission in the past month for LVP, with weeks to live, the primary palliative care (PC) team suggested interventional radiology (IR) place an IPC to decrease the frequency of his hospitalizations, allowing him to spend more time at home with his family, and giving him more control over draining his ascites with the assistance of home hospice nurses.

IR asked PC to consult hepatology to 1) weigh the QOL benefits from IPC considering potential morbidity from infection and technical complications from placement, and 2) compare IPC with other modalities like transjugular intrahepatic portosystemic shunting (TIPS). Hepatology did not endorse TIPS because it would likely worsen the patient's existing encephalopathy. Hepatology believed that the patient would not benefit from IPC because he was not "imminently dying" and the procedure carried a high risk of infection. PC believed the patient was not actively dying, and the benefit of him staying home at the end of life outweighed the 4-5% risk of peritonitis. Given the reframing of the patient's situation to emphasize QOL instead of the relatively low risk of infection, ultimately the IR team felt comfortable with placing an IPC.

Conclusion: This case exemplifies the complexity of decision-making regarding optimal therapeutic options for patients with refractory symptomatic ascites at the end of life, and highlights the contribution of palliative care teams in illuminating QOL as an endpoint for clinical decision-making.

When Opioids Hurt (C949)

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Objectives

- Recognize opioid-induced hyperalgesia (OIH) as a cause of inappropriate opioid dose escalation.
- Identify diagnostic signs of OIH versus opioid tolerance
- Discuss management strategies for OIH

Background: Adverse effects are associated with long-term opioid use. Opioid-induced hyperalgesia (OIH) is an uncommon side-effect described as a paradoxical pain increase in response to an escalating opioid dose. It is theorized that neural changes induced by mu-opioid agonists lead to OIH. OIH is managed by rotating opioids and utilizing adjunctive therapies to manage pain.

Case Description: A 55 year-old woman with stage IIIA breast cancer was admitted with severe mucositis following chemotherapy. She had a history of chronic pain from osteoarthritis controlled by hydrocodone-acetaminophen 325/10mg every 4-6 hours, and no history of alcohol or substance abuse. On admission, she was placed on morphine PCA 1.5mg every 10 minutes with an hourly clinician bolus of 4mg as well as topical anesthesia with lidocaine mouthwash. Initially, she had an intravenous Morphine Equivalent Daily Dose (MEDD) of 70mg and a pain score of 4/10. Over next 48 hours, she reported worsening pain and scores documented as 9/10 with intravenous MEDD escalated to 200mg. She was at baseline cognition with no features of delirium. Worsening pain related to increased opioid doses suggested strongly suggested OIH rather than tolerance. She was then rotated to a hydromorphone PCA and given topical cocaine for further symptomatic relief. Pain score improved to 4/10, allowing return to oral intake and oral hydromorphone with MEDD of 120mg. On discharge she was able to continue her home dose of acetaminophen-hydrocodone 325/10mg every 4 hours.

Conclusion: Causes of increased pain expression such as delirium, chemical coping or under-treatment, were not consistent with the patient's clinical presentation. Recognizing OIH allowed us to discontinue the offending opioid and provide rapid, effective pain relief with opioid rotation.

Hospice in the Eyes of a Korean Family: The Culture Barriers in Providing Palliative Care to Geriatric Asian Patients (C950)

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Objectives

- Recognize the challenges in caring for a terminally ill geriatric Korean patient
- Examine the culture barriers in providing palliative care to Asian geriatric patients

Background: With baby boomers advancing in age, providing quality palliative care has become increasingly important. Another level of complexity is added when the patients are of an ethnic group whose beliefs and practices are less known. In a metropolitan city such as New York, palliative care physicians need to be

culturally sensitive and competent to better help different groups of patients, who may also have limited access to health care due to language and socioeconomic barriers.

Many Asians take pride in caring for their elders, as it's the presumed filial responsibility. Palliative care, especially hospice is often mistakenly viewed as a form of abandonment.

Case Description: Mr. H was an 85-year-old with history of multiple strokes rendering him severely disabled. This time he became comatose after another CVA. Mr. H's daughter and surrogate decision maker Miss. H was initially reserved when approached by the palliative team. Later she expressed dissatisfaction with her father's care stemming from what she considered a "lack of respect" from the ICU team. The offensive acts included the staff not greeting her with smiles, residents openly discussing a poor prognosis, and attendings planning to downgrade him from ICU to stroke unit. Eventually Miss. H elected hospice care at another institute solely with the goal of transferring him there and revoking hospice.

Being of Chinese decent herself, this encounter raised the fellow's curiosity regarding how palliative care is perceived in her own culture. Through search and interviews with hospice staff who cared for other Asian patients, the fellow learned more about the culture barriers in providing palliative care to this group of patients.

Conclusion: This case examines the challenges of providing palliative care to a terminally ill Korean geriatric patient. It raised self-awareness for the fellow's own culture and examines the barriers to providing palliative care to Asian geriatric patient.