

- Understand the potential of machine learning technology.

Accurate prognostication of survival is needed to facilitate complex clinical decision making, especially when patients are approaching the end-of-life. Many important decisions regarding investigations, treatments, and personal care plans are dependent on how long a patient is expected to live. Traditionally, clinicians rely on their clinical judgement to formulate a prognosis, which is subjective by nature and often overly optimistic. This presentation will focus on two main technological advances that may enhance clinicians' accuracy of prognostication and decision making: (1) web-based prognostic tools and (2) machine learning algorithms. We will discuss the multiple prognostic models that have been developed for patients with advanced diseases, such as the Palliative Prognostic Score (PaP) and Palliative Prognostic Index (PPI) for patients with advanced cancer, the Integrated Prognostic Model for patients on hemodialysis, the Acute Physiology and Chronic Health Evaluation (APACHE) for critically ill patients, and the Model for End-Stage Liver Disease (MELD) for individuals with hepatic failure. Many of these prognostic models have been validated in multiple settings and are available as web-based tools. Studies have found that these tools are more accurate than clinician intuition alone and may help to reduce serious prognostic errors. However, they are often not used by palliative care clinicians because of lack of familiarity, lack of time, cumbersome data entry and difficulties with interpretation. By the end of this session, participants should feel more comfortable applying these prognostic tools in practice. The widespread use of electronic health records has also paved the way for machine learning algorithms to take advantage of big data to further improve the accuracy of prognostication. We shall discuss the potential of machine learning technology to augment prognostication and clinical decision making. The last 15 minutes of this session will be open to the audience for discussions.

### ***Caring for the Complex Congenital Heart—Should It Be Palliative from the Start? (FR457)***



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#### ***Objectives***

- Identify the current state of congenital heart disease (CHD) and its impact on quality of life for patients and families.

- Describe the role of early palliative care in supportive pediatric patients and families facing CHD.
- Discuss the perspective of primary cardiology teams on early integration of palliative care in the treatment of CHD patients.

In 2010, data extrapolated to the US population estimated that approximately 2 million people of all ages were living with CHD. It is now estimated 85-90% of all patients born with CHD in the past two decades are estimated to live survive to age 18. Although research suggests an increasing prevalence of palliative care from the time of diagnosis, the role of palliative care remains unclear. Families of children born with CHD face complex decisions and unpredictable outcomes from the start. Still, palliative care consultation is not routinely offered at the time of diagnosis, perhaps in part because of concerns about the message it may convey to families. Many families choose "palliative procedures", however, and CHD patients may survive well into adulthood, continuing to confront the challenges of limited treatment options and an uncertain prognosis. Strong collaboration between cardiology teams and palliative care teams is essential for promoting optimal quality of life for CHD patients and their families.

Using didactics, case studies, and discussion, this session will provide an overview of CHD and the distinct role of early palliative care for this patient population. It will also explore the crucial intersection of cardiac care and palliative care, as well as highlighting the unique challenges of adult patients with CHD. Topics will include:

1. Review of existing literature about benefits of early palliative care for assistance with decision-making and goal setting. Case studies highlighting both pediatric and adult patients living with CHD will be included.
2. A cardiologist's viewpoint on presenting palliative options to families, as well as tips on what PC teams need to know when partnering with cardiology.
3. Exploration of the long-term outcomes of CHD, including medical comorbidities as well as the emotional and social consequences of living into adulthood.

### ***Circle of Trust: How Psychodynamic Themes Such as the 'Holding Environment' Optimize Coping with Serious Illness (FR458)***



Keri Brenner, MD MPA, Stanford University, Palo Alto, CA. Vicki Jackson, MD MPH FAAHPM, Massachusetts General Hospital, Boston, MA. Linda Emanuel, MD PhD, Northwestern Medicine, Chicago, IL.

#### ***Objectives***

- Describe the essential aspects of holding presence, holding environment and containment as

they relate to psychological integration and improved prognostic awareness.

- Demonstrate practical techniques and communication strategies to cultivate a holding presence for patients and families.
- Identify key insights from psychodynamic theory that provide a useful framework for optimal psychological coping.

One of the most challenging aspects of hospice and palliative care is encountering a patient's fear of the dying process, including the common existential worries of dying alone and the losses of physical decline. How does a patient have the psychological strength to go from the security of their previous healthy life to the many phases of loss and uncertainty with life-limiting illness? Recent literature reveals that many patients mitigate these fears by proactively creating a tightknit circle of trusted people "on the inside." This "inner circle" generally consists of reliable family, loved ones and clinicians who are emotionally available to the patient, but not overly invasive or intrusive.

The "holding presence" of this inner circle allows patients to better tolerate the possibility of dying by facilitating an environment where patients can smoothly vacillate between comfort and fear as well as more and less realistic hopes. This swinging between such extremes is most successful when a patient has secure attachments to this inner circle of relationships that can witness this back and forth. Moreover, this containing presence allows patients to better communicate their values and goals amidst intense affective experiences. Thus, such a holding environment can facilitate improved prognostic awareness and advance care planning.

In this interdisciplinary concurrent session, three experts in psychodynamic theory and palliative care will highlight how the "holding presence" of an inner circle creates a containing environment for patients to better cope with life-limiting illness. One expert is a psychoanalyst and will reveal how contributions from thinkers such as Winnicott, Bion, Bowlby and Buber illuminate these relational dynamics at the end of life. Presenters will draw upon clinical case material to demonstrate practical techniques utilizing these insights when caring for patients and families.

***“God Is Able”: Miracles and Hope in Our African-American Patients: Challenges, Historical Perspective and the Way Forward (FR459)***



Ronit Elk, PhD, University of South Carolina, Columbia, SC. Kimberly Johnson, MD MHS, Duke University Medical Center, Durham, NC. Alvin Reaves, MD FACP FAAHPM, MedStar Southern Maryland Hospital, Clinton, MD. Gloria White-Hammond, MD,

Harvard Divinity School, Cambridge, MA. Shellie Williams, MD, University of Chicago, Chicago, IL. Leigh Vaughan, MD, Medical University of South Carolina, Charleston, SC.

***Objectives***

- Recognize potential pitfalls and missed opportunities in responding to family members' communication about their belief that God will perform a miracle and heal their loved one despite medical team's belief that patient is at the end of life. Gain understanding of both sides of an interaction in which the clinician encounters a terminally ill African-American patient and family who are expecting a miracle; the clinician who feels frustrated and manipulated by the patient/family who are not facing the reality of impending death; the patient and family who feel their beliefs and culture are being entirely disregarded.
- Describe the ongoing challenges and historical context which inform a belief in miracles and emphasis on hope for African Americans across the lifespan, including at the end of life. Gain insight into the concept of "hope and miracles" in the African-American community, from (1) A historical and cultural context and (2) In terms of how it plays out in serious illness.
- Describe communication strategies which demonstrate respect, build trust, and reduce conflict in responding to family's expression of a belief in miracles in the face of a patient's poor prognosis. Gain insight into a communication method in which the patient and family's values of hope and a miracle are respected by the clinician; and the resulting feelings of (a) the patient/family and (b) the clinician.

End of life care in the U.S. has been rooted in values that represent the cultural and religious values of the white middle class. Yet what is perceived and promoted as beneficial for one group may not hold the same value for another groups, with a different frame of reference, value system and life experience. Lack of understanding of, and respect for, the cultural values of others often results in negative consequences for the patient and family. Patients and families whose beliefs and values are not understood or addressed, understandably feel disrespected and devalued, and have to make additional efforts to ensure that the goals of care they wish for themselves/ their loved ones, are followed. Palliative care clinicians often feel frustration when they see a terminally ill patient undergoing "needless" interventions/treatments. In the African-American community the importance of faith, spiritual beliefs and church are key components in understanding and coping with illness, and provide a framework within which treatment decisions are