



**2018 CONFERENCE**  
*PHinding Your Hope*

## Defining Palliative Care and Why It's Misunderstood

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### Session Description

Coordination of care and time restraints can make it difficult for people with a chronic disease to express their concerns and goals for treatment, as well as to ask for support with emotional distress and/or side effect management. Palliative care is a branch of medicine that focuses on alleviating symptom discomfort and the emotional stress of living with a chronic illness, for anyone living with a chronic illness, at any point in his or her diagnosis. Panelists will define palliative care, discuss the myths and misconceptions that palliative care is the same as hospice care, and delve into how palliative care can benefit PH patients, their caregivers and their PH care team.

### Speakers

Stephen Mathai, M.D., M.H.S., FCCP, The John Hopkins University; Fran Rogers, M.S.N., CRNP, Temple University Hospital; Namita Sood, M.D., FCCP, The University of Texas Health Science Center at Houston

### Objectives

Attendees will be able to:

- Define and describe the goals of palliative care
  - Palliative Care: An approach that improves the quality of life of patients and their families facing the problems associated with a chronic disease, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
  - Palliative care focuses on:
    - Relieving symptoms (e.g., fatigue, shortness of breath), pain and stress of a serious illness
    - Being an extra layer of support for all patients with a serious illness
    - Defining and discussing goals of care, advance directives and honoring your wishes
    - Affirmation of life by working toward the best quality of life for patients and their families
- Understand some of the common myths and misconceptions of palliative care
  - Myth: Palliative care just like hospice
    - Palliative care begins with the symptoms of an incurable disease
    - Hospice care is a specific type of palliative care that occurs when a patient is terminally ill (less than six months to live)
  - Myth: Palliative care is only for people dying of cancer
    - Palliative care is appropriate at any stage in a serious illness, and can be provided together with curative treatment
  - Myth: Introducing palliative care means my doctor has given up hope
    - Palliative care is designed to supplement the care you receive with your PH doctor; studies in other diseases have shown that incorporating palliative care into the “standard” care for some other diseases improved patients’ ability to describe their goals of treatment, improved their quality of life, reduced the burden of symptoms and reduced hospitalization; studies still need to be completed in PH to understand the specific potential impact for PH patients
  - Myth: Palliative care is only for people in a hospital setting
    - Though many patients do see a palliative medicine doctor in the hospital, it is increasingly available outside the hospital; some patients see a palliative care specialist in the hospital, in the

outpatient setting or at home; your PH care team can help you find services available in your area

- Myth: I must choose between palliative care and aggressive care
  - Palliative care can be provided while receiving aggressive care
- Understand the holistic benefits of palliative care for the PH patient, caregiver and their PH care team
  - New standard: Early integration of palliative care has seen effects in PH patients
    - Ability to express goals of therapy to health care providers
    - Improvements in mood
    - Improvement in quality of life
    - Increased satisfaction with care
    - Decreased physical symptom severity
    - Decreased hospital length of stay
    - Less chemotherapy at end of life
  - Studies have shown that early palliative care also improves the health of caregivers, with fewer reported symptoms of depression and anxiety

#### **Take away messages**

- Palliative care is an extra layer of support for patients and caregivers
- Palliative care is: excellent, evidence-based treatment; care of pain and symptoms throughout illness, any age, any stage; care that patients want at the same time as efforts to cure/prolong life
- Palliative care is not: giving up on a patient; in place of curative or life-prolonging care; the same as hospice or comfort care
- Palliative care has a focus on planning and planning is a team effort
- PH care teams realize that patient preferences change over time; open and honest discussions need to occur among the team so that the patient's voice is heard