Palliative Care and Idiopathic Pulmonary Fibrosis

Jessica McCannon, MD

Director of Critical Care

Mount Auburn Hospital

Outline & goals

- What is palliative care?
- Why should it interest my family and me? How can it help?
- What is the difference between palliative care and hospice?
- How does palliative care apply specifically to IPF?
- How can I learn more?

The first question...

Would you accept a palliative care consultation right now?

What about this?

Would you accept a therapy that would help you and your loved ones cope with your disease, improve your sense of well-being, enhance your quality of life, make you feel better, and perhaps help you live longer?

Palliative care: what is it?

- From the Latin *palliare* to cloak
- Specialized medical care for those with serious or chronic illnesses
- Provides pain and symptom control, communication/coordination, emotional support, family/caregiver support
- At any stage of illness, in parallel with curative therapies
- Goal: Wellness, improved quality of life



Palliative care: a team-based approach

- Physicians
- Nurses
- Social workers
- Massage therapists
- Physical and occupational therapists
- Pharmacists
- Nutritionists
- Chaplains



Are you surprised?

Palliative care does not equal End of Life care!

What's the difference between palliative care and hospice?

- Hospice is a palliative care approach at the end of life
- Focus on managing pain and other symptoms
- Attending to medical, social, psychological and spiritual needs of patients and families at the end of life
- Again, a team-based approach
- Important: Hospice is not a place (but a way of life!)
 - Care can be provided at home, in the hospital, in long-term care facilities and in hospice houses.
- Criteria = life-limiting progressive illness with 6 months or less to live

How does palliative care apply to IPF?

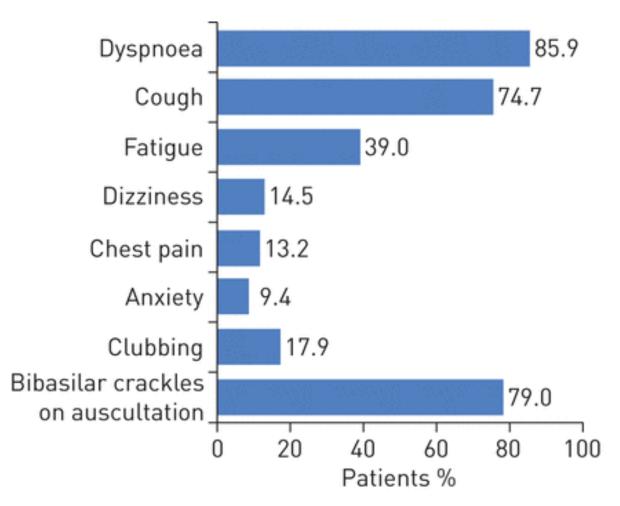


Table 2 Reported symptoms and symptom relieving medication during the last 7 days of life

Symptoms	Number (%)
Breathlessness	39 (66 %)
Pain	18 (31 %)
Delirium	11 (19 %)
Anxiety/depression	10 (17 %)
Cough	9 (15 %)
Nausea	4 (7 %)
Constipation	1 (2 %)
Medication	
Opioids	42 (71 %)
Anxiolytics	26 (44 %)

How does palliative care apply to IPF?

- Management of cough
- Management of shortness of breath
- Treating side effects of therapies
- Help with decision-making about
 - Life-prolonging interventions (intubation, cardiac resuscitation)
 - Matching goals and values with medical care
 - Hospitalizations
- Preparing for death

Cough

- Frequent, chronic, and debilitating
- No benefit from anti-tussives
- Treatment options
 - Prednisone
 - Opiates
 - Gabapentin
 - Thalidomide
- Other conditions contributing?
 - Airways disease Albuterol, etc.
 - Reflux/heartburn PPI
 - Sinus disease intranasal steroids



Shortness of breath

- Oxygen
- Pulmonary rehabilitation
- Steroids
- Opiates
- Treat other diseases (i.e. asthma, COPD)
- Cold air/fan on face

Resuscitation (CPR, intubation)

- A personal decision
- Majority of patients who are on ventilator in ICU did not have palliative care services previously

Prolonged quality (and quantity)

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

Resources

https://getpalliativecare.org/

Advocate!

PERSPECTIVES

Inadequate Palliative Care in Chronic Lung Disease An Issue of Health Care Inequality

Crystal E. Brown¹, Nancy S. Jecker², and J. Randall Curtis¹

- Palliative care services mostly utilized in patients with cancer
- However, chronic lung disease patients have
 - Increased burden of symptoms
 - Decreased quality of life
 - Increased social isolation
- Large proportion of patients with advanced lung disease do not receive advanced care planning or palliative care

Advocate!

ORIGINAL RESEARCH

Symptom Burden of Chronic Lung Disease Compared with Lung Cancer at Time of Referral for Palliative Care Consultation

Nicholas G. Wysham^{1,2,3}, Christopher E. Cox^{1,3}, Steven P. Wolf^{2,4}, and Arif H. Kamal^{2,5}

¹Division of Pulmonary and Critical Care Medicine and ⁵Division of Medical Oncology, Department of Medicine, ³Duke Program to Support People and Enhance Recovery (ProSPER), and ⁴Department of Biostatistics and Bioinformatics, Duke University, Durham, North Carolina; and ²Center for Learning Healthcare, Duke Clinical Research Institute, Durham, North Carolina

ORCID ID: 0000-0003-1302-6296 (N.G.W.).

Talk about it!

- Reflect on what is most important to you.
- Talk to your family and loved ones about it.
- Talk to your pulmonologist about symptom management.
- Teach them about what's most important to you (not just symptoms, PFTs and CT scans).
- Request a palliative care consultation.





Take home points

- Palliative care is not the same as end-of-life or hospice care
- Multidisciplinary approach, benefits patients, families
- At any stage of disease, for any patient
- Focus on quality of life
- The earlier the better

Questions?