Palliative Care for Patients with IPF

Sapana Panday: Hi. We’re here at the last day of the Chest annual conference in Toronto and I’m here with Dr. Meena Kalluri. I understand that you actually been talking a lot on the IPF and Palliative care here. Can you tell us a little bit about it for folks who miss the conference?

Dr. Meena Kalluri: Well thank you for the questions Sapana and I’m really excited to be here and talking about IPF and palliative care. Before I get into that question, I’m actually very excited about two other things. One was a dedicated palliative care session at this Chest conference this time around. I think it’s probably one of the first times that palliative care has been given its due attention, particularly in IPF. I’m very excited about that. Of course my own session, we had the opportunity to talk about the care gaps in IPF. In particular, about palliation and to discuss our care module, which is a newer approach on how to integrate care.

So briefly, if I were to summarize, I would probably say that most people are aware IPF is a fatal disease. It’s one of the most commonest idiopathic ILDs. There’s no cure. There are new antifibrotic therapies available, but the studies don’t show a significant or a huge impact on quality of life or symptoms in general. As a result, symptoms that don’t get attended to lead to a very poor quality of life and creates a tremendous burden, not just for the patients, but also for the caregivers. This is what they struggle with constantly in and out throughout their disease course.

The other thing it leads to is a constant in and out of emergencies and hospitalizations because patients are struggling with symptoms. They have to go in and out because these are not being addressed effectively in clinic. So I think it’s not just the patients and the caregivers, it’s also a tremendous strand to the system, the healthcare system as well. What’s being recognized is that there is a need to integrate Palliative care alone with disease specific therapies and ATS guideline says so. However, if you look in reality, in clinical practice, it’s not implemented widely.

The frustrations that patients and caregivers express is that care in clinics stands to be very disease-centric. What they would like the care-providers to do is to provide a more patient-centric approach to care. The healthcare providers seem to be quite frustrated, because they don’t know how to integrate palliative care with disease management. I think there is a tremendous need to (A) come up
with care models that can do both, and (B) how to operationalize this. The purpose of my talk was really to explain our approach into a team-based approach on how to live and die with IPF. The second part of the talk explains in further detail our approach on symptom management, as well as advanced care planning limited to IPF.

(A) a care model has been in practice for about five years, we've been implementing it so it feasible to do that. (B) we just published a paper in the Journal of Pain and Symptom Management, which has demonstrated that this application of this care model can have an impact on symptom management, it can reduce health care burden and it can improve patient and caregiver satisfaction.

My hope from this talk is that people walk away with new ideas, people walk away with the hope that it is possible to integrate palliative care with disease management, and that they can now take these ideas and use what's available to them locally, and be able to come up with their own innovative solutions to improve care delivery for patients and caregivers with IPF, because I very strongly feel that the status quo can not be tolerated any longer. Thank you.