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SPRING 2019 PULMONARY UPDATES

Advanced Care Planning and Palliative Care **Meena Kalluri, MD**

One of the studies was about the use of a tool called the life conversation tool. So it's available freely to clinicians who would like to use it. And the tool basically has a few domains. And the most important domains are relationships, trying to inquire about patients' hopes, their fears, their priorities, and their values. And the study was a qualitative study. And the investigators basically gave this tool to a group of IPF patients and caregivers to assess whether or not it's acceptable and whether they'll use it or not. And the key takeaways from this study was that this tool was acceptable. The caregivers were actually very grateful for the opportunity to express these concerns and to be able to openly discuss it. The next aspect was that the domains of the tools were very well understood, and they were found to be very relevant for both patients and caregivers. They emphasized that clinicians and the care team members need to maintain a positive focus throughout the conversations at every time point. And finally, they also said that it probably would be beneficial if clinicians were to introduce this before the first clinic visit or at the first clinic visit. And the whole point being once the patients use the tool, they are better informed, better prepared so that when they come and meet their clinicians in the clinic, they're able to discuss this much more effectively and hopefully the clinicians can thereby save time.

There was another study that explored a conceptual framework for advanced care planning. And this study did qualitative review of literature that's published on advanced care planning needs in the IPF population. And they found about 13 studies and the key takeaway from those studies was that IPF patients and their caregivers really want to have an open conversation and honest conversation. They want to have it early in the career pathway. They want to have the caregivers engaged early during their care, as well as these conversations that should happen in the clinics. Patients really want open information, easy to understand information about their disease. They want to hear their clinicians talk to them about symptom management, provide them some action plan, some guidance on how to live with their disease better at home. They also want practical information around end of life planning. These studies also show that patients perceive that there's a huge need for finding resources in the community. So for clinicians to remember these key takeaway points and to find ways of integrating this in care will be very beneficial. Another study described not just one but two palliative care models. One of the models was the one that we practice in our own clinic which is basically using multidisciplinary team of healthcare providers to start providing palliative approach right from the get-go. Meaning when the patients come in and have their diagnosis, we're also assessing symptoms, providing them resources for managing symptoms, connecting them with community resources, and providing dedicated symptom management. So that's an integrated palliative care model. The other model that was described in this study was utilizing what they called a palliative multidisciplinary team meeting. What the model would do is assess patients, identify those that have increasing needs or high needs or changing needs, and they would refer those patients to this team of care providers that included palliative care, nurses, physicians that included ILD physicians, it included psychologists and they would discuss the patient and come up with strategies to address their needs. They would refer them to community resources and provide them additional support. So these were two different models of palliative care that were described and the expected thing in both of those models was that by

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institution of a systematic approach, they were able to start symptom assessment and management earlier on in the course. For example, one model started approximately 23 months before a patient died compared to 12 months before a patient died compared to what happens in reality, which is basically institutional support in the last one month of life. So clearly, using a dedicated palliative care model leads to early symptom assessment; it leads to early advanced care planning conversations, which are really helpful for patients and caregivers to prepare for what lies ahead, and it also reduced healthcare utilization in the end of life because now patients are well prepared and they know what resources to use in the community. And when they have a crisis they know what to do, and hence they're not using acute care. That's the hypothesis.

There was another study which looked at factors that are responsible or factors that facilitate home death in IPF patients. This is another interesting thing for clinicians to take away because most patients when asked regardless of what disease they have, they prefer to pass away at home with comfort in peace and with dignity. So it's very important for clinicians to understand that home that is feasible and what factors might lead patients to such an outcome when they desire that or when they prefer that. So in this study, they looked at patient factors. They looked at caregiver factors and they looked at care delivery factors that might facilitate a patient dying at home when they choose to do so. So the most important factors were patients being involved in these advanced care planning conversations earlier on, presence of a caregiver during clinic visits, presence of a caregiver during these advanced care planning conversations, as well as a caregiver living at home. The other care delivery factors that were really important to facilitate this was really starting symptom management earlier on, using referral to allied health services or home care services so that patients are connected with nurse practitioners or respiratory therapists or physiotherapists in their own local community, use of action plans. So basically, when patients have a crisis at home, whether it's a shortness of breath crisis or any other types of symptom crisis, then patients know what to do or their caregivers know what to do. So having some sort of an action plan, having a resource where patients can call in and seek advice during weekends, during off clinic hours, to find that kind of support, and to be able to have hospice services in the local community were all important factors that facilitated home death in the IPF population.

So there was a very interesting study looking at the impact of participation in support groups on palliative care, referral and mortality. What the authors in this study did was to divide patients into two groups, one group was connected with support services or support group in the community, the other group was not. And when they compared at palliative care referrals between the two groups, there was a statistically significant difference between the two groups, meaning the people who were actually connected with the support group had a higher chance of being referred to palliative care within the last few months of life, and they also compared mortality between the two groups. And surprisingly, the mortality was less than the group that got referred to palliative care and was connected with support group. The authors think that that's because those people were actually living closer, they were younger, and were also followed in the clinic much more frequently. So those might be the reasons why the mortality was better in that group. But nevertheless, it does show that participating in support groups perhaps educates patients and makes them more open to receiving palliative care.

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The other was about providing peer support to patients. Sometimes we have patients living in far flung areas who do not maybe have direct access to support groups in their local area and this Australian study looked at connecting those people living in remote areas through telephone support with matched peers. And when they connected people like that and they interviewed the Dyads, they found that people valued the shared experience, the people who connected with each other, were able to share information and that solved some of their emotional unmet needs. They appreciated the value of it. Lots of information was shared about how to manage adverse effects, but they also shared personal information and their own strategies to live a better life. So the group concluded that providing peer support through telephone services is also doable and can be facilitated through perhaps local lung foundation. So this is something maybe the clinicians can try and access lung foundations or their local lung associations and see if this kind of support can be provided.

So there was a European study published on priorities of patients, caregivers, and other health care providers and other important stakeholders to explore what their priorities would be for palliative care, for advanced care planning, and end of life. Basically, what the authors did was to get all of these participants in one room, they had sessions going on for one whole day, which also included discussions that were facilitated and included a didactic presentation. And at the end of it, there were dialogues of patients and caregivers that are that were interviewed. So one of the most important things or themes that emerged from that interview was that universally these people acknowledge the lack of advice and lack of support on all of these issues. And when asked what specific advice they would need one of the things that they listed was providing more information, education and support about oxygen services. They wanted a referral to occupational services and other allied health in the community so that they can continue to preserve their quality of life. Patients also wanted more psychological support. Patients wanted to learn about lung transplant access. Patients wanted to learn about acute exacerbation management and what their options would be. Patients also wanted to learn about practical things like end of life planning. They also wanted their caregivers to be involved and engaged early in these conversations. And the study also focused on raising awareness about advanced care planning. In addition, patients also requested that workplace support be provided so that they can continue to have good quality of life even at work.