

Holistic Care for Patients With Pulmonary Hypertension

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Pulmonary arterial hypertension (PAH) is a rare and often terminal disease. It is often associated with high symptom burden and decreased quality of life, in addition to overall high mortality. Previously, the disease's mortality rate was about 50% over 2.8 years and life expectancy was approximately 4 years from the onset of symptoms.¹ Over the last decade there have been major improvements in the medical management of PAH with the introduction of specific treatments for PAH including prostanoids, phosphodiesterase type 5 (PDE-5) inhibitors, and endothelin receptor antagonists. As a result, disease progression is delayed in some cases. However, as advances in medicine have helped to extend life, patients often struggle with not only the physical progression of disease and uncomfortable side effects of these novel drugs, but also with the psychosocial challenges that come with a chronic illness. Anxiety, depression, difficulty maintaining relationships, difficulty with body image, change in lifestyle, and financial struggles are a few examples.¹ Furthermore, by the time patients are diagnosed with the disease, most have been seen by multiple providers at multiple institutions, which can be emotionally burdensome.² Given the complexities of this disease and the fragility of its treatment, a paradigm shift is emerging in the medical management of the disease toward one of holistic patient-centered care, with the hope of improving patient engagement, compliance, and overall outcomes.³

Part of providing the best holistic care possible is performing a comprehensive psychosocial assessment at the time of diagnosis. This can help to address fears about the disease and its treatment;

examine its impact on work, family life, and finances; and identify patients at a higher risk for anxiety and depression. One international study performed by a committee of PAH specialists revealed that 56% of patients and caregivers felt that PAH resulted in significant impacts on daily life, 85% of patients had concerns about work, and 67% of patients reported an influence on their sex life.⁴ Patients reported concerns regarding the effects of family planning as pregnancy carries a significant risk to both the mother and the fetus, as well as concerns that the disease interfered with the ability to play with children and grandchildren and travel.⁴ Performing a thorough psychosocial evaluation up front can help identify some of these issues and concerns so that they can be appropriately addressed and managed. While we understand that these psychosocial considerations are important, there is a lack of information about what to actually include in that psychosocial evaluation and how to appropriately resolve the issues and provide continued services outside what the medical clinic can offer. Below we share a case study, followed by a sample of questions that can be utilized for a psychosocial evaluation, including suggestions on how one may begin to manage psychosocial distress.

CASE STUDY

Ms. O. is a 33-year-old African-American female with no known past medical history. She has been admitted to the hospital 3 times over the last few months for shortness of breath. During that time, she was treated with antibiotics and inhalers. On this most recent hospitalization, she presented to the hospital

with shortness of breath, lower extremity swelling, and abdominal distension for 2 weeks. In the emergency room, she was noted to have a cough and had an oxygen saturation of 90% on room air. She was started on broad-spectrum antibiotics for possible pneumonia. An echocardiogram was also obtained, which was notable for estimated systolic pulmonary arterial pressure >90 mm Hg, severe right ventricular failure, and dilation of the superior vena cava. At that time, the advanced heart failure team—who specializes in pulmonary hypertension (PH)—was consulted for assistance. She was diuresed with a Lasix infusion for volume overload, and a workup for PH was initiated. She explained that her oldest brother died in his 40s with some lung issue, but that she wasn't sure of the details because they did not have a close relationship. A few days later, following diuresis, she underwent a right heart catheterization that showed her calculated pulmonary vascular resistance was 7 Wood units and transpulmonary gradient was >15. She was diagnosed with PAH, likely familial versus idiopathic. The remaining workup was otherwise negative. The decision was made to start her on intravenous Remodulin, uptitrate to the highest tolerated dose, and discharge home with services and with an outpatient follow-up appointment in a PH clinic.

When the drug was initially started, Ms. O. was in the intensive care unit (ICU) and was undergoing multiple tests and procedures, so she didn't have much time to process her diagnosis. Once she was doing well on the floor and the drug was being slowly uptitrated, she began to express to the nurse her concerns and worries about returning

home. The palliative care team was consulted to assist with managing her anxiety and discussing advanced care planning. On initial assessment, the palliative care social worker learns that Ms. O. is very angry at the medical team for not discovering her PAH earlier. She feels that no one is listening to her and that the team is trying to “rush” her out of the hospital. She is worried about going home and worried about her partner and how her illness will affect their relationship. Ms. O. also has financial concerns, as her partner recently lost his job and she is unsure whether she will be able to return to work. Over the course of a few days, the palliative care team works with Ms. O. to help develop a plan to manage her anxiety at home. The social worker uses reflective statements and summarizing and some motivational interviewing techniques (Table 1) to provide Ms. O. the space to process her illness.⁵ The chaplain works with her on some breathing exercises, and they are able to connect her with a therapist in the community that specializes in chronic illness management. The palliative care team also agrees to follow her in their clinic once a month for advanced care planning.

DISCUSSION

A new diagnosis of PAH can be overwhelming not only physically, but also emotionally and spiritually. It often affects a patient's ability to engage in meaningful activities, leaving them at high risk for psychosocial distress. Validating the multiple losses that come with illness is important to building strong relationships with patients and families.¹ How can we best approach patients holistically to ensure we are screening for psychological problems at diagnosis? Some sample questions are provided in Table 2, which could be useful when completing a holistic psychosocial assessment. During the initial screening, one can utilize some of the questions, and then follow up with more in-depth assessment after initial diagnosis, as it can be difficult for patients to process a lot of information after receiving

Table 1. Reflective Statements

Ms. O.: I am feeling so angry at the doctors; no one could figure out what was wrong with me for months and now I am in this situation. I need to have this new pump and I feel so overwhelmed.
Clinician: It sounds like you have been through a lot the last few months.
Ms. O.: Yes, and I don't know how I can manage all of this at home. It is going to be too much for my family. I can't ask them to help with everything.
Clinician: I hear how difficult this all is for you and how worried you are about how this will impact your family.
Ms. O.: Yes. It's so hard.
Clinician: Is it okay if we talk more about what things might look like at home?
Ms. O.: Yes. That would be helpful. Thank you.

Table 2. Sample Assessment Questions

Questions that can be used at diagnosis and beyond:
What do I need to know about you to give you the best care possible? ⁶
What are you worried about?
Tell me more about your pain experience.
How has your illness affected relationships?
Tell me about a typical day at home.
What brings you joy?
What do I need to know about?
What keeps you going? Where do you get your strength from?
Do you feel you are at peace? ⁷

ing a new diagnosis.⁴ For Ms. O., it was important for her to express her feelings of frustration with the health care team and have a space to process what was happening to her both physically and emotionally. In listening to her concerns, the social worker and chaplain offered her space to process and assistance in determining a plan to help her better manage her illness.

There is little research for PAH and palliative care, but it is important to

involve palliative care early to assist with symptom management and evaluate for psychosocial challenges.¹ In this case, the palliative care team was consulted early and was able to help create a plan to support the management of all aspects of Ms. O.'s illness. Conversations around care planning can begin when a patient is first diagnosed with PH. The palliative care team was able to implement strategies of motivational interviewing and utilization of reflection statements to help the patient process her feelings therapeutically.

CONCLUSION

As management of PH continues in the years to come, a holistic approach by the health care team will be essential, as it will result in more patient engagement and self-care, which will ultimately lead to improved patient outcomes.³ We provide a sampling of questions that can be utilized for a psychosocial assessment and suggest having experts from palliative care involved early in the disease process.

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