PANEL DISCUSSION

PE After the Algorithm: Ensuring Optimal Aftercare

Nuances of follow-up care, surveillance and office visit protocols after an acute PE, lessons learned to improve patient education and communication, and exploring optimal follow-up in future studies.

With Vivian L. Bishay, MD, and Steven Pugliese, MD

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What are some of the underappreciated nuances of the follow-up needs you've encountered with pulmonary embolism (PE) patients posttreatment?

Dr. Bishay: Patients need close follow-up in the short and medium term after a PE event. There is a lot of communication that needs to occur to make this happen between providers and the patient before they leave the hospital. Patients need to understand and adhere to an anticoagulation plan, follow-up on pending tests, and monitor for residual or new symptoms. Important and I think underappreciated are the psychosocial factors that impact PE patients related to cost and adherence to medication(s) and debilitation from a hospital admission that may have included an intensive care unit stay as well as potentially related to the PE itself. There are also emotional impacts that we are still learning about. This is why it is so important that PE response teams (PERTs) have established outpatient protocols for following PE patients after the initial event.

Dr. Pugliese: Current guidelines and recommendations focus on screening patients for chronic thromboembolic pulmonary hypertension (CTEPH) at 3 to 6 months,[1] so many subspeciality clinics follow patients after an acute PE with this time frame in mind. The reality is that although persistent symptoms following acute PE are common, only a small percentage of patients will go on to develop CTEPH. A much more common scenario that patients encounter within the first 3 months after their PE before they get to a post-PE follow-up clinic is the inability to afford anticoagulation after their initial 30-day supply or not being able to find a physician willing to refill the medication. This means patients show up to the 3-month PE clinic having been off anticoagulation for 8 weeks. Additionally, patients can have bleeding or ongoing symptoms that lead to repeat

emergency room visits. We've found that seeing patients within 30 days of their hospital stay provides appropriate guardrails for patient safety and goes a long way to help answer questions and mitigate the stress and anxiety associated with their PE diagnosis.

What schedule does your group follow for surveillance imaging, office visits, and other check-ins, and who is responsible for each step?

Dr. Pugliese: We offer every post-PE patient a visit at 30 and 90 days. At the 30-day visit, we ensure the anticoagulation has refills and is affordable for the patient. We provide education and expectations, and we review the patient's history and all the imaging. If the history or imaging are suggestive of preexisting chronic thromboembolic disease/CTEPH, we will order follow-up testing at the 90-day appointment, typically an echocardiogram and a nuclear medicine lung perfusion scan. Otherwise, we will see the patient at the 90-day time point and only order testing if the patient has ongoing symptoms. We typically follow patients for at least 1 year after the acute PE.

Dr. Bishay: We try to have patients return to see their primary care doctor within 1 to 2 weeks after discharge. If they don't have a primary doctor, then a provider from the PERT is identified to take responsibility for following up with the patient in the short term. This is a critical step in patient care, as we well know from PERT registry data that many PE patients are lost to follow-up after hospital discharge. This first appointment is necessary to address any anticoagulation adherence issues, monitor for complications, and ensure that patients understand their follow-up care plan.

Patients are seen in a dedicated venous thromboembolism (VTE) clinic 4 to 8 weeks after discharge depending on the severity of the initial event and whether there were associated high-risk features such as elevated pulmonary artery systolic pressure. Patients with intermediate- or high-risk PE undergo echocardiography to assess for resolution of right ventricular dysfunction. For patients who have persistent symptoms of dyspnea or abnormalities on echocardiography beyond 3 months, further workup is initiated per European Society of Cardiology guidelines. These patients are typically followed by pulmonary critical care or vascular medicine physicians.

Patients who were enrolled in a PE trial and/or underwent an intervention see the interventionalist who treated them to assess for procedure-related complications and comply with study follow-up. Often, this follow-up involves additional assessment of symptoms of post-PE syndrome (PPES), functional capacity with a 6-minute walk test, and use of validated quality-of-life assessment tools. If an inferior vena cava filter was placed at the time of PE or if concomitant deep vein thrombosis was present, these issues can be further addressed by the interventionalist.

WHAT ARE THREE KEYS TO ENSURING OPTIMAL AFTERCARE FOR PE PATIENTS?

1. Clear and direct patient communication
2. Developing a pragmatic outpatient follow-up plan that works for your health system and maximizes patient retention and satisfaction
3. Ensuring a short follow-up period after the patient's hospital stay with a provider experienced in caring for patients with acute PE

How has your center's approach to follow-up evolved in the past few years?

Dr. Bishay: Everyone recognizes the need for ongoing excellent posthospital care for these patients, and many centers have sought to address this need by establishing post-PE clinics and streamlining the discharge plan to include their follow-up in a VTE clinic. This process starts well before discharge and involves communication among providers, the patient, and social workers. Importantly, there is often a knowledge gap with patients regarding the acute emergent PE event and the short-, medium-, or long-term effects they might feel after leaving the hospital. This gap can lead to missed appointments or medication nonadherence, so using plain language when explaining events to patients and communicating the plan after discharge is critical. At our center, we have formalized the follow-up care plan for intermediate- and high-risk PE patients as soon as the PERT is activated so that their follow-up care with primary care and specialty providers is set up before they are discharged.

Dr. Pugliese: As mentioned, we added the 30-day follow-up period, which was a big ask on our clinic, as patient wait time is a huge issue for the health system; however, we've found this to be invaluable for patients.

Another issue we've encountered is a high no-show rate in our patients who are following up after a hospitalization. There are several reasons for this, including that the acute PE itself is overwhelming for patients and remembering all the appointments they have can be difficult. Secondly, health literacy and overall access to care is a problem for many patients as well. Like many big health systems, it can be complicated to been seen at the right clinic in our health system. To help with this, we have a single scheduler who does all the PE clinic scheduling. All appointments are scheduled via a phone call to the patient and not a letter, text, or message in the portal, which can be unreliable. Our scheduler asks the patient about their anticoagulation medication and if they need a refill issued by a physician before the follow-up visit. Lastly, we've adapted to having the inpatient teams coordinate directly with our scheduler via the electronic medical record instead of having the patient call a phone number after follow-up.

What has been learned in recent years about the emotional needs of post-PE patients, and how can provider communications improve to help meet them?

Dr. Pugliese: We know that anxiety, depression, and symptoms of posttraumatic stress disorder are common following an acute PE. Due to the stressful nature of the hospital stay and the size of inpatient hospital teams with varying levels of communication, most patients retain very little from their inpatient stay. We've found that our PE clinic visits are key to answer patients' questions and provide expectations. Anecdotally, I've found seeing patients sooner goes a long way to help with anxiety and helping them get back to normal.

Dr. Bishay: To reiterate, I think that often in the acute setting, the severity and time course of events can be lost on patients despite the fact that they are going through them. We've all had patients who continue to be symptomatic after the initial PE event who require further workup and care. They can often be surprised as to the degree of disability after their admission, and this can take a significant emotional toll. Helping patients understand the disease process, anticoagulation plan, and any further workup they might need goes a long way in ameliorating their worries and helps with plan adherence. This is only a small part of the puzzle though. There is an established association between acute PE and mental health issues in the aftermath that includes anxiety and depression, but certainly more research is needed to understand the relationship between PE and mental health. Awareness as a first step is important for both the patient and provider and utilizing a screening tool to help identify issues early is key.

How can optimal follow-up be more comprehensively explored in future PE studies? What most needs to be better understood?

Dr. Bishay: This work is already underway in trials like PE-TRACT, which highlight the need for longer-term follow-up in the PE trial world. Early identification of patients with symptoms due to PPES is a natural byproduct of following these patients more closely with established follow-up protocols, but we need to know whether interventions that improve anticoagulation adherence or that target thrombus reduction during the acute PE event can impact the degree of and incidence of PPES. We may also want to know whether certain follow-up protocols (frequency and when further workup is initiated) leads to better treatment adherence and improved long-term outcomes for these patients.

Dr. Pugliese: Right now, much of the data being produced in the PE space revolves around the acute diagnosis and treatment of PE. There are fewer studies on when and how patients should be optimally followed after PE. Additionally, the current data focus more on utilizing follow-up as a means to screen for long-term complications of PE and perhaps less focus on how to optimize follow-up from a patient perspective. I'd like to see studies on strategies to improve the number of patients seen in PE clinics and how we can improve patient-reported outcomes and adherence to guideline-based care around anticoagulation and appropriate follow-up testing. ■

1. Humbert M, Kovacs G, Hoeper MM, et al. 2022 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension. Eur Respir J. 2023;61:2200879. doi: 10.1183/13993003.00879-2022

Disclosures
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