PE Looks Like Me: A New Initiative From The National PERT Consortium™

Bridging the gap between providers and patients to raise awareness of PE and open the discussion on prevention of PE on a broader level.

By Brent Keeling, MD; Amy Ranier, MPM; and Scott Kaatz, DO, MSc, FACP, SFHM

To physicians, the complexities and broad reach of pulmonary embolism (PE) are not new. The medical community is accustomed to the insidious and potentially fatal presentation of PE, and providers are trained to look for its symptoms. But, unlike conditions and events that can easily be recognized by nonclinicians (heart attacks, fractures, etc), PE can affect anyone of any ethnicity, gender, or age and with varying degrees of health and wellness. Although the understanding of the need for PERTs (PE response teams) is still growing across the medical community, patients and families are even further removed from how to spot the symptoms of a PE (when they present at all) and how to understand treatment options. Barnes et al stated that "optimal care of patients with venous thromboembolism (VTE) requires the input of patient preferences into clinical decision-making. However, the availability and impact of decision aids to facilitate shared decision-making in care of VTE is not well known."[1] In addition to low patient awareness and understanding of PE, the investigators conclude that "despite numerous calls to increase use of shared decision-making, a paucity of data exists to help patients engage in the treatment decisions for VTE. Future studies of additional VTE clinical decisions with longer-term clinical outcomes appear necessary." Although PE may lack the flashiness and celebrity spokespersons of other conditions, the need to educate patients and families on recognizing symptoms is both clear and urgent. By leveraging the focused but meaningful efforts already undertaken by colleagues to broaden understanding of PE and help patients and families be active partners in treatment options, we can bring a new level of awareness to clinicians and patients—and save many lives.

THE NEED FOR INCREASED AWARENESS OF AND EDUCATION FOR PE

Unknown True Incidence

The presentation of PE can be insidious, and this fact makes true demographic data difficult to ascertain. PE is estimated to occur in 60 to 70 patients per 100,000 of the general population.[2] However, much of these data were generated from autopsy studies and rates of VTE, which again cloud the true incidence of PE. What is known is that approximately 10% of patients with PE present with sudden death. This falls in line with the fact that PE is likely the leading cause of in-hospital death for patients in the United States. Septuagenarians have the highest rates of PE, but diagnosis is often difficult in these patients given other comorbid conditions that may mask or mimic PE symptoms. All of these data are sobering and reflect the significant challenges that PE presents to both patients and providers.

Variable and Nonspecific Risk Factors

Risk factors for PE are varied and often not specific to one certain population. Certain causes of PE are not preventable and include prior family history of PE or the need for surgery. Others, such as obesity and relative inactivity, fall into a category best labeled as modifiable. Regardless of whether a risk factor for PE is modifiable or not, PE can affect patients from all backgrounds and all ages. As an example, 2% of patients with PE in the RIETE registry were aged 10 to 24 years.[3] Younger patients with PE tend to be female, but males develop more risk factors for PE beyond age 60 years, including malignancy and heart failure.[4]

The ubiquity of PE is undeniable, as any patient at any age can potentially be affected. However, there are special subpopulations of patients at higher risk for PE throughout their lifetimes. Patients with heritable thrombophilias represent a nonmodifiable risk factor for the potential development of PE, the most common of which is factor V Leiden deficiency, affecting 3% to 8% of people of European ancestry.[5] Although common, this genetic mutation does not increase VTE risk as much as other genetic mutations like protein C or protein S deficiency, which may increase VTE risk 10-fold. Malignancy is another potential nonmodifiable risk factor for VTE and PE. Certain

PE IN SPECIAL POPULATIONS: GUIDELINE-RECOMMENDED TREATMENT IN BRIEF

By Scott Kaatz, DO, MSc, FACP, SFHM

CANCER

Malignancy has a well-known association with VTE, and the type of cancer, chemotherapy, presence of metastatic disease, age of the patient, and need for surgery effect the risk. The American Society of Hematology (ASH) guideline recommends either low-molecular-weight heparin (LMWH) or a direct oral anticoagulant (DOAC) in the first week of acute VTE treatment, but suggest DOAC over LMWH for the initial 3 to 6 months of treatment. The guideline also recommends long-term (> 6 months) treatment with a preference for DOACs.[1] For extended treatment, it is vital that bleeding risk is continuously evaluated because many cancer patients are at high risk.

PREGNANCY

ASH guidelines recommend treatment with LMWH for VTE during pregnancy and, although not explicitly stated in guideline statement, they allude that treatment is similar to nonpregnant patients, with a minimum of 3 months of treatment. There was general agreement among panel members that treatment should extend to 6 weeks postpartum.[2] The panel suggests against systemic thrombolytic therapy for PE, with evidence of right ventricular dysfunction, unless there is hemodynamic instability. On the other side of the spectrum of the disease, they suggest outpatient therapy for low-risk VTE.

The guideline panel suggests a scheduled delivery with discontinuation of LMWH and muse about transitioning LMWH to unfractionated heparin if there was a recent proximal deep vein thrombosis or PE to shorten the interruption of anticoagulation. Additional considerations in pregnancy include a suggestion not to perform routine anti–factor Xa monitoring and recommends against the use of DOACs while breastfeeding.

THROMBOPHILIA

ASH has also published a guideline to address thrombophilia testing. For patients with unprovoked VTE, the guideline panel recommends against testing because other guidelines suggest indefinite treatment for these patients.[3] For surgically provoked VTE, the panel suggests not testing because treatment is usually limited to 3 months. When a patient is in the gray zone between VTE that is clearly provoked (surgery) and unprovoked (eg, hospitalized for medical reason < 3 days, confined to bed for > 3 days, out of hospital with an acute illness, or leg injury with decreased mobility > 3 days), caused by pregnancy or postpartum, or estrogen-associated VTE, the panel suggests testing for hereditary and acquired thrombophilia to guide the duration of treatment beyond 3 months.

PEDIATRICS

Many of the recommendations and suggestions for pediatric patients with VTE are extrapolated from literature in adults given the relative paucity of strong evidence in the pediatric population. The panel recommends treatment of symptomatic VTE but recommends anticoagulation or no anticoagulation in asymptomatic disease (such as incidental findings on imaging) and suggests against thrombolysis in submassive PE unless there is hemodynamic compromise.[4] Warfarin or LMWH are the suggested anticoagulants in pediatric patients, with a duration of ≤ 3 months for provoked VTE. For unprovoked VTE in children, the suggested duration is 6 to 12 months versus a longer duration (as is suggested for adults), as the burden of treatment and bleeding risk is considered to be higher in this young population.

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2. Bates SM, Rajasekhar A, Middeldorp S, et al. American Society of Hematology 2018 guidelines for management of venous thromboembolism: venous thromboembolism in the context of pregnancy. Blood Adv. 2018;2:3317-3359. doi: 10.1182/bloodadvances.2018024802
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4. Monagle P, Cuello CA, Augustine C, et al. American Society of Hematology 2018 guidelines for management of venous thromboembolism: treatment of pediatric venous thromboembolism. Blood Adv. 2018;2:3292-3316. doi: 10.1182/bloodadvances.2018024786

cancers, such as lung cancer, can be associated with VTE rates of 17% to 43%.[6] Special attention should be paid to symptoms in patients with known risk factors for PE.

Pregnancy is another common risk factor for PE and can affect many unsuspecting mothers and mothers-to-be. Pregnancy increases the risk of VTE by four- to 4.5-fold when adjusted for age.[7] Moreover, PE during or after pregnancy accounts for just over 9% of all maternal mortalities. Indeed, 60% of maternal mortalities related to PE occur within 42 days after delivery. Pregnancy is an extremely common medical condition, and slightly over 50% of the United States population may be pregnant during their lifetimes. Although a good deal of effort and patient education has gone into the recognition of certain risk factors for PE such as thrombophilias and cancer, less has been mentioned about pregnant patients and PE. The National Pulmonary Embolism Response Team (PERT) Consortium™ aims to change that.

THE "PE LOOKS LIKE ME" CAMPAIGN

This article serves to highlight that PE can and does occur to a wide variety of patients, some of whom have known risk factors but many of whom have common medical conditions that predispose to PE. The National PERT Consortium™ is proud to announce a new campaign called "PE Looks Like Me," and hopefully, through this article and indeed through this entire supplement to *Endovascular Today*, the point has been reinforced that PE is a ubiquitous yet underrecognized disease. PE can afflict the young and the old, the seemingly healthy and the seemingly ill, and patients of all races.

"PE Looks Like Me" seeks to bridge the gap between care providers and patients to raise awareness of the diagnosis of PE in all patients and discuss prevention of PE on a broader level. The National PERT Consortium™ is uniquely positioned to accomplish these goals given the pioneering, team-based approach to the treatment of PE and the many treating specialties involved in The Consortium. The reach of The Consortium is far, but in partnering with our patients, we can further improve PE care. With our patients as partners in this endeavor, "PE Looks Like Me" will broaden the scope of knowledge of PE and save lives through increased prevention and awareness. ■

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Brent Keeling, MD
Associate Professor of Surgery
Division of Cardiothoracic Surgery,
Department of Surgery
Emory University School of Medicine
Atlanta, Georgia
brent.keeling@emory.edu
Disclosures: Consultant to AngioDynamics, Penumbra, Inc., and Viz.ai.

Amy Ranier, MPM
Board Member, The National PERT Consortium™
Vice President, Marketing and Communications Strategy
Beth Israel Lahey Health
Boston, Massachusetts
Disclosures: None.

Scott Kaatz, DO, MSc, FACP, SFHM
Clinical Professor of Medicine, Michigan State University – College of Human Medicine
Clinical Professor of Medicine, Wayne State University – School of Medicine
Senior Staff Hospitalist
Medical Director for Professional Development and Research
Division of Hospital Medicine
Co-Director, Anticoagulation Clinics
Henry Ford Hospital
Detroit, Michigan
Disclosures: Consultant to Janssen, Pfizer, Bristol Myers Squibb, AstraZeneca, Gilead, Phase Bio, Boston Scientific; research funding from Janssen, Bristol Myers Squibb, Osmosis Research, NIH; board member for Anticoagulation Forum, National Blood Clot Alliance; scientific advisory board for The PERT Consortium™.