

Emotional and psychological coping after venous thromboembolism

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Emotions run high after informing a patient and family of the new diagnosis of acute deep venous thrombosis (DVT) or pulmonary embolism (PE). Often, the prevailing sentiment is anger at physicians and other healthcare professionals for perceived delay of diagnosis and, often, initial misdiagnosis. The "cellulitis" of the legs may not have improved with a course of antibiotics. This unexpected result might raise the question of whether unsuspected DVT caused the leg discomfort. And asthma or congestive heart failure may not have improved with standard care, thus leading to an expanded differential diagnosis that includes PE. It may require weeks of patient education for anger to abate. Eventually, most patients and families come to realise that venous thromboembolism (VTE) remains a challenging diagnosis because of its non-specific symptoms and signs (1).

The next phase for patients dealing with the new diagnosis of VTE focuses on how this illness will affect survival (2). Will it shorten their life span? Is it associated with other cardiovascular illnesses that will surface over the ensuing years? These are difficult questions to answer. But for patients without underlying illness, the responses can be encouraging. And for those with concomitant disease, the additional diagnosis of acute VTE provides a special opportunity for intervention.

Treatment of DVT and PE requires far more than anticoagulation. Detailed attention to lifestyle is essential. Is the patient exercising daily? Is the nutritional plan well balanced? Has the patient achieved ideal body weight? If overweight, has a weight reduction program, focusing on exercise and diet, been initiated? Are blood pressure, blood sugar, and lipid profiles well controlled?

Frustration with the illness of VTE will persist even if anticoagulation control is excellent and a heart-healthy lifestyle is achieved. There will often be a major imbalance between how a patient looks (healthy) and how the patient feels (fragile, vulnerable, and unwell). The patient with VTE might complain that others do not realise and cannot understand the inner emotional turmoil caused by DVT or PE. What will be the duration of anti-

coagulation? What are the overall odds of recurrent VTE (3) after anticoagulation is discontinued? Patients are inevitably surprised and discouraged to learn that, overall, there is a 30% recurrence rate during the first 10 years after anticoagulation is discontinued. Yet indefinite duration anticoagulation means foregoing activities such as downhill skiing or competitive horseback riding where a fall or a collision could be fatal. Perhaps more importantly, it means redrawing one's body image and perception as unwell, or at least hindered by a chronic thrombotic illness.

As healthcare professionals, we have rightly emphasised prevention, early detection, and rapid risk stratification and treatment (4, 5). But, in general, we have paid little attention to the emotional ramifications and burden of VTE. We have focused on the physical aftermath of chronic venous insufficiency, post-thrombotic syndrome, and chronic thromboembolic pulmonary hypertension. But we have not explored the psychological aftermath and imprint of VTE with the requisite depth, sensitivity, and rigorous methodology.

Paul Lukas, MD and his colleagues from Berne, Switzerland are to be congratulated for examining and analysing fatigue and psychological distress among patients with confirmed VTE. Lukas forged collaboration between internal medicine, clinical psychology, and psychotherapy to administer three separate tests to assess psychological well-being and both mental and physical quality of life. These aspects of VTE care have been overlooked for far too long.

In this issue of *Thrombosis and Haemostasis*, Lukas et al. report on 205 consecutively enrolled outpatients who had DVT or PE (6). They were young, with an average age of only 47 years. By the time of this study, they had lived with their illness of VTE for an average of 1.5 years. Both increased fatigue and increased psychological distress were correlated with decreased mental quality of life. Even though physical quality of life improved over time, mental quality of life, when adversely affected, did not improve over a one-year period. This observation suggests the

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need to identify quickly those with adverse emotional responses to VTE so that early intervention programs can be placed into motion.

It is unclear what the next steps should be. At Brigham and Women's Hospital, my nurse and I have run a PE Support Group on a monthly basis for more than 15 years (7). We meet on a weekday night for about 75 minutes. Although there are occasional guest speakers and specialised topics, most of the time the

meetings are unscripted, and patients ask questions and explain to each other how they are feeling. Peer-to-peer support is emphasised. Though patients "feel good" about these meetings, we have not attempted to test or quantify our results.

In summary, Lukas et al. are to be congratulated for their groundbreaking work. Their findings are descriptive and serve as necessary first steps in our efforts to improve the quality of life of our patients stricken by PE or DVT.

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