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Editorial

Addressing emotional and physical distress after pulmonary embolism

Researchers have spent many years developing improved medical treatments for pulmonary embolism (PE), such as development of the direct oral anticoagulants, outpatient management of PE and optimization of treatments for cancer-associated PE. Much of this research has focused on reducing venous thrombotic recurrence and reducing bleeding complications, with success measured in terms of absolute risk reduction. Evidence-based medicine assumes that reduction in a measurable untoward outcome translates into improved patient-centered care. However, we seldom ask patients how they feel, nor do we study the effects of these interventions on patient satisfaction [1].

Psychological distress following the diagnosis of PE is not unusual, nor is it a new phenomenon. Dr. Edgar Allen first published details of a new syndrome which he labelled ‘neurosis of the extremities’ in 1931 [2]. Thirty years later, Dr. Irwin Schatz published an analysis of 65 patients diagnosed with ‘postphlebitic psychoneurosis’ [3], where he described excessive anxiety provoked by symptoms reminiscent of symptoms experienced with the thrombotic episode, and the wrongly founded preoccupation that a blood clot could ‘go to the heart’. This 1962 paper recommends ensuring proper patient education and understanding, along with reassurance that the condition is treatable and easily managed.

Recent studies have demonstrated a reduced mental and physical quality of life after venous thromboembolism [4,5], and wide variation in patient estimated quality adjusted life years [6,7]. Qualitative research is a powerful technique to understand the reasons behind the negative impact on quality of life after PE, but has been little used. The few qualitative studies to date have verified that the same symptoms of distress, fear, anxiety and heightened symptom awareness described in 1931 are common in patients today [8–11]. This is despite many practice-changing research advances in the management of PE. There is a lack of research addressing prevention or management of this psychological distress, and on whether such interventions would translate into improved quality of life after PE.

In this issue, Rolving et al. report on the negative experience of coping with daily life and exercise after a first episode of PE. The group gathered data from 16 in-depth interviews in patients aged 34 to 78, six months after diagnosis. Most patients reported that their everyday life had been negatively affected. They report four themes relating to and influencing everyday life after pulmonary embolism: 1). Needing the healthcare system (including receiving the right level of information at the right time, and relying on their anticoagulation), 2). The aftermath (fatigue, alertness to symptoms and anxiety), 3). The staying healthy challenge (lifestyle and exercise) and 4) Relations (physical and psychological support from and impact on family and friends). The authors summarize that patients lack advice from health professionals regarding their PE and no rehabilitation intervention is offered.

This study by Rolving et al. echoes the findings of Schatz et al. in 1962, that to improve the patient experience of PE we should identify and treat emotional, physical and social distress. If we continue to focus solely on clinical outcomes such as venous thrombosis recurrence and bleeding, we will likely fail to improve patient quality of life after PE.

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Kerstin de Wit
Department of Medicine, McMaster University, Hamilton, Canada
E-mail address: dewitk@mcmaster.ca.

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