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Update to Quarterly Medical Review - Venous thromboembolic disease: a tribute to Professor Guy Meyer

Patient-reported outcome measures: A key to patient-tailored and outcome-driven care in pulmonary embolism survivors

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ABSTRACT

Almost half of the acute pulmonary embolism (PE) survivors suffer from long-term sequelae that limit quality of life and their reintegration in society. The post-PE syndrome involves a spectrum of complications ranging from life-threatening pulmonary hypertension to deconditioning and psychosocial issues. The follow-up of acute PE has been demonstrated to be rife with challenges including long diagnostic delays, inefficient use of healthcare resources and the ignorance of psychosocial complications such as depression and anxiety. The best way to monitor recovery of PE comprehensively and reproducibly is the application of patient-reported outcome measures (PROMs), including quality of life assessment. PROMs help to identify and guide diagnostic tests and therapeutic interventions as well as to monitor the impact of the latter. In our view, therefore, PROMs should be integrated as a fundamental part of routine PE follow-up.

1. Introduction

Acute pulmonary embolism (PE) can be a life-threatening condition in the acute setting and leads to long-term sequelae in nearly half of the patients [1,2]. These long-term sequelae are captured within the framework of post-PE syndrome (PPES). The diagnosis of PPES applies to patients who experience persistent symptoms and functional limitations following an acute PE despite adequate anticoagulant therapy for at least three months [2,3]. Symptoms include new or persistent dyspnea, exercise intolerance, impaired mental status due to anxiety and post-thrombotic stress syndrome or depression, not attributed to pre-existing comorbidities [2–5]. PPES can manifest in various forms and varying degrees of severity, which can significantly impact survival (in the setting of chronic thromboembolic pulmonary hypertension [CTEPH]) and patients' quality of life (QoL) [6–11].

Routinely used conventional diagnostic tests in post-PE care like echocardiography to assess right ventricle (RV) function or perfusion imaging to assess persistent perfusion defects do not fully represent the patient's experience regarding QoL and symptom burden [12–14]. Consequently, the medical field needs to change towards a more patient-centered and outcome-driven approach to healthcare delivery, facilitated by patient-reported outcomes. Patient-reported outcome measures (PROMs) capture patients' values and needs by assessing self-reported health status, symptoms, functionality and QoL through validated questionnaires [15]. By utilizing PROMs in post-PE care, it is possible to identify patients who may be suffering from PPES and in whom focussed diagnostic tests and therapeutic interventions are indicated [14]. This review will provide an overview of how PROMs can be employed in clinical care to optimize treatment for patients with PPES.

2. Long-term PE outcomes

PPES consists of a heterogeneous spectrum with various presentations (Fig. 1). The most severe presentation is CTEPH. CTEPH is caused by unresolved thrombi in the pulmonary arteries accompanied by widespread vasculopathy. Although not completely understood, it is known that in CTEPH a combination of inflammation of the vessel wall, disturbed fibrinolysis and defective angiogenesis causes fibrotic thrombi and arteries [16,17]. Chronic obstruction changes the hemodynamics in the affected pulmonary arteries, leading to chronic elevated pressure, RV overload and eventually RV dysfunction and heart failure. The dead space ventilation and RV dysfunction impact functionality and cause persistent symptoms [1,18]. CTEPH is confirmed

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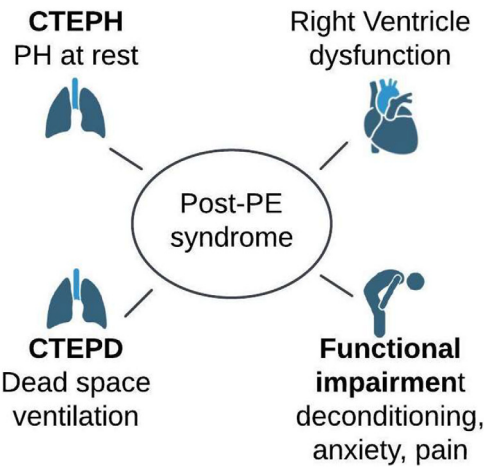

Fig. 1. Spectrum of the post-PE syndrome.
Abbreviations: PE, Pulmonary embolism; CTEPH, Chronic thromboembolic pulmonary hypertension; CTEPD, Chronic thromboembolic pulmonary disease; PH, Pulmonary hypertension.

when right heart catheterization shows an elevated pulmonary artery pressure of ≥ 20 mmHg at rest with normal wedge pressure and increased vascular resistance, combined with ≥ 1 segmental perfusion defect on ventilation/perfusion scintigraphy caused by chronic thrombotic occlusions [19].

Patients with persistent symptoms attributable to persistent thrombotic occlusions of the pulmonary artery tree but in whom pulmonary hypertension (PH) is ruled out, are diagnosed with chronic thromboembolic pulmonary disease (CTEPD) [3,8,19]. In CTEPD the residual perfusion defects are smaller compared to CTEPH, and the distal arteriopathy is absent [20]. Therefore, the hemodynamic changes are less severe, resulting in the absence of PH at rest. However dead space ventilation, which can be diagnosed by cardiopulmonary exercise testing and exercise-induced PH contributes to experienced exercise intolerance [21,22].

A third category involves patients with persistent abnormal RV function, which is referred to as post-PE cardiac impairment. The International Society of Thrombosis and Hemostasis (ISTH) defined post-PE cardiac impairment as presence of intermediate/high echocardiographic probability of PH according to the European Society of Cardiology criteria, RV dilatation or hypokinesia, along with exertional dyspnea, NYHA II-IV [23]. This correlates to a higher symptom burden too. Post-PE cardiac impairment may be caused by RV fibrosis, but the pathophysiological mechanism is not fully understood [12,24–27].

The majority of patients with PPES however present with post-PE functional impairment. Patients with post-PE functional impairment can present with symptoms as persistent dyspnea, exercise intolerance, and/or diminished functional status after an acute PE without the abovementioned hemodynamic characteristics and no apparent non-PE-related alternative explanation [23]. Deconditioning is the most frequent reason for functional limitations in post-PE functional impairment [28]. Due to pain, dyspnea and other symptoms in the acute setting, patients are often immobilized for a certain time, leading to loss of condition. Using cardiopulmonary exercise testing, the differentiation between deconditioning (reduced VO_2 max with low anaerobic threshold and normal cardiovascular response) or underlying (cardiopulmonary) comorbidities can be made [21]. Patients with functional limitations due to deconditioning may benefit from cardiopulmonary rehabilitation or physical training. Several exercise training programs have shown to be safe and cohort studies have shown that these training programs have a positive effect on training intensity, functional status, dyspnea and QoL [29–31].

Apart from physical limitations and symptoms, an acute PE can also have a psychosocial impact. Survivors from acute PE can suffer from psychological symptoms, including depression, anxiety, and post-traumatic stress disorder (PTSD). These patients experience acute PE as a traumatic and life-changing event [32]. Symptoms of anxiety and depression are common after a PE, with a reported prevalence of up to 25 to 50% three months after the PE diagnosis [33–35].

3. Diagnosing PPES in PE survivors

CTEPH is a rare complication of acute PE, with a reported incidence of 2.7% [36]. However, as it is a life-threatening disease if not adequately treated, early diagnosis is associated with better survival and substantial gain in quality-adjusted life years (QALYs) [37–40]. Due to the nonspecific character of the symptoms of PPES, it can be difficult to identify CTEPH patients at an early stage. For this reason, CTEPH is usually diagnosed after considerable diagnostic delay and inefficient use of healthcare resources [41,42]. Several algorithms have been proposed for the early diagnosis of CTEPH in the course of acute PE, where identifying symptoms suggestive for CTEPH is one of the first steps. PROMs can, if applied in a structured way, be used to identify the patient's suggestive symptoms early and guide which patients need further diagnostic tests. Such symptom-based algorithms have been demonstrated to reduce diagnostic delay at acceptable costs [43–47].

If CTEPH is ruled out, the next step is to explore the manifestations of PPES by classifying symptoms and limitations. The different forms of PPES necessitate distinct treatment strategies, making a structured approach to capture these outcomes essential. The routine implementation of PROMs in clinical care is an effective tool for identifying the impact of PPES on the patient, as recognized in a position paper by the European Society of Cardiology and endorsed by the European Respiratory Society [48].

Given the broad spectrum of PPES, it is crucial to identify which outcomes need to be captured and which matter the most to patients. To address these fundamental questions, the International Consortium for Health Outcome Measurement (ICHOM) identified core outcomes to capture the full spectrum of venous thromboembolism (VTE), including long-term consequences. Using a modified Delphi voting procedure, a group consisting of VTE-experts and patient representatives identified the most important aspects of VTE care. Ultimately, a set of PROMs was composed, covering functional limitations, pain, dyspnoea, treatment satisfaction, psychosocial well-being (e.g., post-thrombotic panic syndrome, anxiety and depression), generic and disease-specific QoL, and changes in life perspective [15]. This set can serve as a guide for implementing PROMs in clinical practice.

4. Implementation in clinical care

In our view, PROMs can and should be a fundamental part of routine clinical VTE care to identify patients' needs and provide guidance on what to focus on during treatment. To create the biggest impact, PROMs should be implemented at multiple time points along the care pathway (Fig. 2) [15,49]. PROMs should be used to evaluate the baseline situation at the PE diagnosis. Next, following the first three months of adequate anticoagulant therapy, patients should be asked to complete the ICHOM-VTE PROMs set. This enables the treating physician to evaluate limitations and symptom burden, and to make the distinction between patients with no limitations, who do not require further diagnostics, and patients with psychical or psychosocial limitations, early in the treatment process. Patients with psychosocial limitations can be referred for counselling while patients with physical limitations are referred for CTEPH screening. After CTEPH screening and cardiopulmonary exercise testing, patients can be classified into different categories; CTEPH, CTEPD, post-PE cardiac impairment, post-PE functional limitations and limitations due to

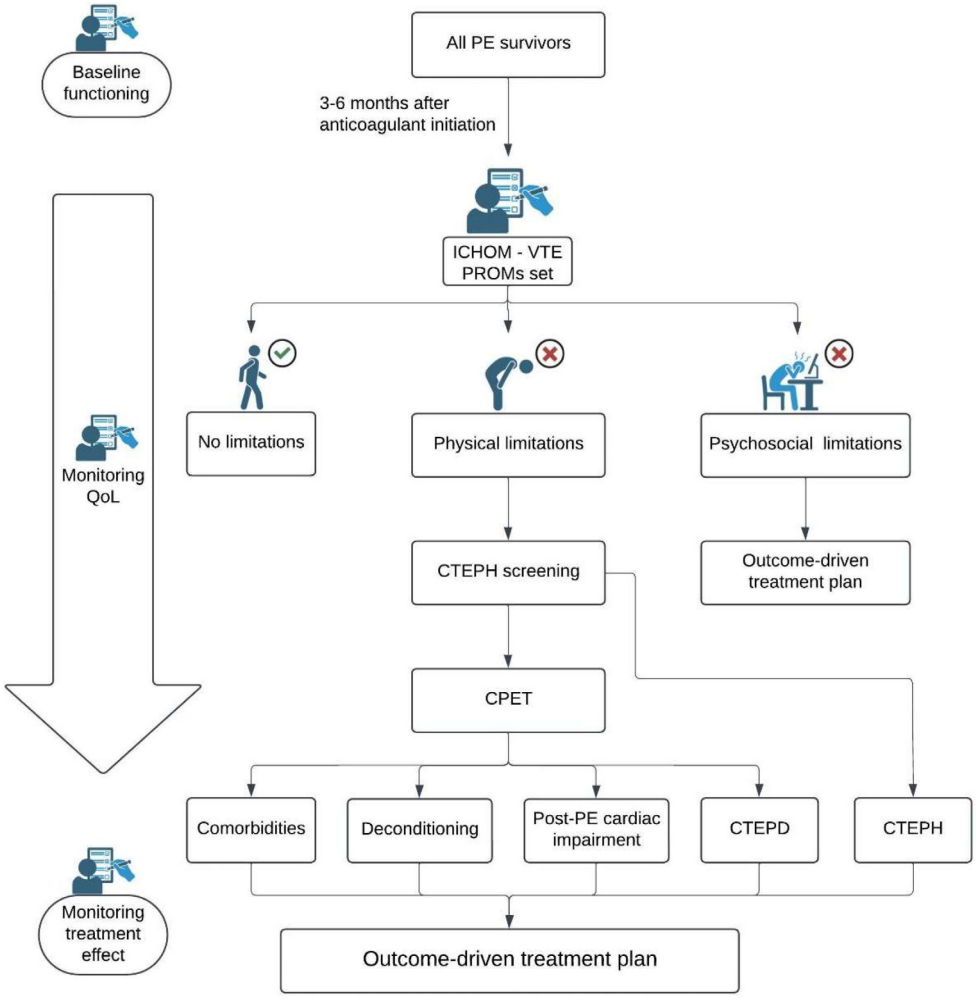

Fig. 2. Proposed application of PROMs in post-PE follow-up.

Abbreviations: PE, Pulmonary embolism; ICHOM, International Consortium for Health Outcomes Measurement; VTE, Venous thromboembolism; PROMs, Patient-reported outcome measures; CTEPH, Chronic thromboembolic pulmonary hypertension; CPET, Cardiopulmonary exercise test; CTEPD, Chronic thromboembolic pulmonary disease; QoL, Quality of life.

other comorbidities. This approach can guide an outcome-driven treatment plan focused on the patient's needs. After initiation of specific therapy, PROMs can be used to measure whether therapy has the desired treatment effect. By integrating PROMs into clinical care, early recognition of patient's needs leads to an individualised and outcome-driven treatment plan with targeted and efficient use of the resources.

5. Quality of life

During the development of the ICHOM-VTE set, QoL was identified as one of the outcomes that matter most to patients [15]. This highlights the crucial role that QoL plays in capturing health outcomes. However, measuring QoL can be challenging, as it encompasses a wide range of factors, making it difficult to put in the correct perspective if the context of other PROMs is unavailable. Typically, a combination of PROMs is needed to effectively capture the nuances of QoL. The most used questionnaire for the disease-specific QoL is the Pulmonary Embolism QoL questionnaire (PEmb-QoL), which is included in the ICHOM-VTE set [50]. This instrument focuses on 6 distinct dimensions, being frequency and intensity of complaints, social limitations, limitations in activities of daily living, work-related problems, and emotional complaints. External validation has been done in several cohorts with different geographic backgrounds, proving its reliability [6,51–57]. By implementing the PEmb-QoL and other PROMs at several points in the PE care pathway, it is possible to focus treatment on improving the QoL (Fig. 2).

Of note, one of the difficulties of QoL questionnaire interpretation relates to the fact that the results of QoL instruments are scores. Higher or lower scores do not necessarily indicate a clinically relevant difference and considerable changes in different domains could in theory lead to a comparable overall score, in contrast to for instance an ordinal scale where every change in scale grades indicates a relevant difference [58–61]. Even so, QoL remains a must-have outcome, both in clinical practice as well as in clinical trials.

6. Challenges

As promising as PROMs are, certain challenges complicate implementing these in daily care, as has been communicated by the ISTH [49]. The first challenge is how to collect and interpret the PROMs data efficiently. Completing the questionnaires by the patients and interpreting the results of the PROMs by the treating physician takes considerable time. The ICHOM-VTE PROMs set consists of 8 PROMs with a significant total of 79 core and 44 cascade questions, which will appear dependent on the presence of particular symptoms [15]. To achieve a higher response rate, it might be necessary to create a shorter set of PROMs. In the current ICHOM-VTE set there is some overlap between the different PROMs. Furthermore, understanding of the PROMs by the patient requires a certain language level and the

questionnaires are only available in select languages, hindering large-scale usage and introducing health disparities. Ideally, the collected data is either directly integrated in a dashboard embedded into the electronic health record system of the health facility, or incorporated in a patient health platform which can send the information to the electronic health record system [62]. Unfortunately, such technical support is expensive.

Secondly, the PROMs must be incorporated in routine clinical care, making them easily accessible. The ISTH suggested that this can be achieved by acquiring the PROMs results before consultation to allow the treating physician to prepare well and focus on the patients' needs during the consult [49]. Asking patients about their symptoms and functionality not only creates awareness for the treating physician: it will also result in better prepared patients. This will greatly enhance the patients' involvement and supports shared decision making by giving patients more control and say in their treatment, leading to higher patient satisfaction [14,63,64].

Despite the challenges that need to be tackled, studies that assessed the implementation of ICHOM PROMs sets have shown its feasibility [65–67]. Future studies should focus on the effect of implementation of the ICHOM PROMs set.

7. Conclusion

Implementation of PROMs can help identifying patients with long-term sequalae of acute PE in a standardized and reproducible way by quantifying symptom burden, as well as help measuring the impact of therapeutic interventions. Therefore, in our view, PROMs should be integrated as a fundamental part of routine PE care. Future research should focus on creating shorter PROMs without overlap, and the structural implementation in clinical care.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Sophie N.M. ter Haar: Conceptualization, Investigation, Visualization, Writing – original draft. **Cindy M.M. de Jong:** Writing – review & editing. **Francis Couturaud:** Writing – review & editing. **Thijs E. van Mens:** Writing – review & editing. **Frederikus A. Klok:** Conceptualization, Investigation, Supervision, Writing – original draft.

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