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Thrombophilia ad dies vitae

Cohn, D.M.

Publication date
2010

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Citation for published version (APA):

Cohn, D. M. (2010). *Thrombophilia ad dies vitae*. [Thesis, fully internal, Universiteit van Amsterdam].

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Chapter 5

Quality of life after pulmonary embolism:
the development of the Pulmonary Embolism
Quality of Life questionnaire (PEmb-QoL)

Cohn DM, Nelis EA, Busweiler LA, Kaptein AA, Middeldorp S. Quality of life after pulmonary embolism: the development of the PEmb-QoL questionnaire. J Thromb Haemost 2009 Jun;7(6):1044-6.

Pulmonary Embolism (PE) is a rather common disease, with an annual incidence of approximately 0.5 in 1000 persons in Western countries.¹ As PE shares many features with deep vein thrombosis (DVT), both diseases are considered to be different manifestations of the same entity: venous thromboembolism (VTE).² PE and DVT share the same risk factors such as thrombophilia, pregnancy, cancer, surgery, immobilisation, and oral contraceptive use. Furthermore, both manifestations occur in venous blood and coincide frequently.³⁻⁵ Accordingly, treatment recommendations are similar.²

PE is a leading cause of mortality and morbidity: death occurs in about 15% of the cases within 6 months of its presentation.⁶ In addition, VTE often can be considered a chronic disorder: recurrence is common with an incidence of approximately 30% within 10 years.^{7,8} Moreover, residual complaints (known as post thrombotic syndrome) are reported in 30% of patients with DVT within 2 years after the initial event, despite the use of compression stockings.⁹ The most important long-term complication of PE is chronic pulmonary hypertension (which may manifest as fatigue, limited exercise tolerance or shortness of breath) which was shown to affect 3.8% of PE patients within 2 years following the initial event in one study.¹⁰

Quality of life is conceptualized increasingly as the central outcome of health care. "Perceived health, health-related quality of life, and health-state utilities bring health assessment progressively closer to the patient's perspective", is a conclusion in a paper by Sullivan on taking the patient's point of view on health care and health into account.¹¹ To illustrate the gained interest in quality of life, we performed a broad-brush search in Medline with the MeSH term "quality of life". This yielded 7143 articles published in 2007, compared to 4923 in 2002. Surprisingly, a more sophisticated search without any restriction yielded not a single publication on quality of life after PE (neither by a disease generic questionnaire, nor by a disease specific questionnaire). In contrast, quality of life following DVT has been subject of investigation and several DVT specific questionnaires have been developed over the past decade.¹²⁻¹⁶

We aimed to develop a disease specific questionnaire to assess quality of life after PE using the principles of grounded theory. We performed qualitative, semi-structured interviews in 10 outpatients (4 males / 6 females) whom we selected for the gravity of their complaints following PE. These patients did not have other cardiopulmonary diseases that might have resembled PE related complaints. Two investigators (LB and EN) visited the subjects at their homes and structured the interviews into social functioning, physical complaints and emotional disturbances. The interviews were tape-recorded with consent and transcribed

later. Characteristics of the interviewed patients are listed in Table 1. The most remarkable complaints were shortness of breath/difficulty in breathing, fatigue, fear of recurrence after discontinuing anticoagulant treatment, more readily emotionally disturbed (which bothered a subgroup of the patients) and more social isolation than prior to the PE. The authors (of whom 2 are experienced clinicians with a specific interest in patients with VTE) remodelled the outcomes of the interviews into the draft questionnaire.

The original version was developed in Dutch. For the creation of the English version, the Dutch version was independently translated by two native English speakers and subsequently back-translated by a third native English speaker. The structure of the questionnaire, which we named PEmb-QoL (Pulmonary Embolism Quality of Life), was modelled in line with the existing generic SF-36 (short form 36) questionnaire and the disease specific VEINES-QOL/Sym questionnaire, which has been developed for DVT. The PEmb-QoL currently contains 10 questions (40 items) covering 6 dimensions: Frequency of complaints (8 items), Activities of Daily Living (ADL) limitations (13 items), Work related problems (4 items), Social limitations (1 item), Intensity of complaints (2 items) and Emotional complaints (10 items). Two questions provide descriptive information. The PEmb-QoL is a self administered questionnaire, in line with the SF-36 and Veines-QOL/Sym questionnaires.

Our future aims are to further validate this questionnaire. We are currently distributing the PEmb-QoL questionnaire amongst patients with a recent PE to assess construct validity. The PEmb-QoL questionnaire will be distributed together with the disease generic SF-36 questionnaire to measure criterion validity. A subgroup of patients with PE will receive the PEmb-QoL a second time for analysis of the test-retest reliability.

Quality of life after pulmonary embolism: development of the PEmb-QoL questionnaire

Table 1. Characteristics of interviewed patients

	gender, age (years), marital status	PE event	main functional complaints	main psychological complaints	main social limitations
1	female, 37, married	7 months prior to interview. Massive PE, resuscitated	fatigue, muscle weakness	anxiety: more readily emotional; fear of recurrent PE; worried to stop anticoagulant treatment	afraid to be a burden of relatives and friends, afraid of being alone
2	male, 31, unknown	6 years prior to interview first PE; 2 recurrences (22 months and 7 months respectively)	pain behind the shoulder blades, pain in the chest, tiredness, difficulty in breathing	fear of recurrent PE, more readily emotional (experienced as annoying), depressed	not able to work, limited in social contacts
3	female, 84, widow	1 year ago	fatigue, not able to exert herself	depressed (at times)	becomes easily weary after having a visit from friends/relatives
4	female, 43, married	13 months and 5 months prior to the interview	pain in the back and fatigue	fear of recurrence, depressed feeling, more readily emotional	avoids visits to friends and shopping in the centre of the city, which is too exhausting
5	female, 73, widow	4 years prior to the interview	breathlessness, sensation of pressure, fatigue	fear of recurrence	more socially isolated, limited in taking a trip
6	female, 32, single	14 months prior to PE	difficulty in breathing, pain at the back and between shoulder blades	anxious of recurrence, worried to stop anticoagulant treatment	no complaints
7	male, 34, married	4 months prior to interview	difficulty in breathing, fatigue, shortness of breath, pain behind shoulder blades, chest pain	fear of recurrence, more readily emotional (which bothers the patient)	feeling of lack of attention to his children, not able to work, not able to have visitors too often (too exhausting)
8	male, 63, married	13 months prior to interview	shortness of breath, tired, difficulty in breathing	much more emotional disturbed	not able to perform as much as he intends
9	female, 79, widow	first PE 7 years prior to interview, recurrent PE 6 years ago	difficulty in climbing stairs and fatigue, shortness of breath	no typical complaints	no typical complaints
10	male, 55, married	18 months prior to interview	more easily tired, difficulty in breathing following exercise, chest pain	afraid of a recurrent PE, worried of stopping anticoagulant treatment	prefers staying at home

PE=pulmonary embolism

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