Assessing quality of life after pulmonary embolism: Comparing results from the PEmb-QoL with semistructured interviews

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Abstract

Background: The Pulmonary Embolism Quality of Life questionnaire (PEmb-QoL) assesses quality of life (QoL) in patients with previous pulmonary embolism (PE).

Objective: Our aim was to assess the agreement between the PEmb-QoL and interviews and to explore other QoL concerns in patients diagnosed with PE.

Methods: This mixed-method study included interviews with 21 patients about QoL after PE, followed by the PEmb-QoL questionnaire. In interviews, patients were asked about their lived experiences and impact of PE. Our analysis identified the frequency and severity of decreased QoL in qualitative interviews and compared with the PEmb-QoL score. Excerpts that described the effect of PE on QoL in interview transcripts were transcoded to match the answers corresponding to the 1 to 6 numeric values for each question from the PEmb-QoL using a predetermined matrix (eg, “constant” and “daily” = all of the time = value 1) and directly compared with responses on the PEmb-QoL in the areas of emotional complaints and activities of daily living/social limitations.

Results: Interviews showed more functional impairment than predicted by PEmb-QoL. For fear of recurrence, 86% of participants had disagreements between PEmb-QoL scores and transcoded interview scores. We found 42% disagreement between reported descriptions of the inability to do or enjoy hobbies in interviews and the PEmb-QoL score.

Conclusion: Patient interviews showed discordances compared with a validated psychometric tool. To capture a more detailed and accurate picture of the effect of PE on QoL, providers and researchers should consider the addition of qualitative methods to assess outcomes.

KEYWORDS
fear of recurrence, hobbies, interviews, pulmonary embolism, qualitative research, quality of life
1 | INTRODUCTION

In both clinical trial research and clinical care, patient-reported quality of life (QoL), is an important outcome. QoL captures patients’ lived experiences of the impact of disease and treatment on patients’ physical, psychological, and social functioning and well-being.1-4 QoL can be assessed by general QoL instruments that score standardized responses to standardized questions (eg, the Short Form 36 [SF-36]).5-7 These general instruments are designed to sample a broad spectrum of function, disability, and distress that is relevant to QoL. QoL can also be assessed by disease-specific instruments, which may have higher content validity for detecting and quantifying changes in QoL with a specific disease.8-10

Patient-reported outcomes are becoming an increasingly important metric of success in therapeutic clinical trials for pulmonary embolism (PE).14 Over the past 2 decades, researchers have relied on the Pulmonary Embolism Quality of Life questionnaire (PEmb-QoL) as a primary method to assess quality of life in patients with diagnosis of PE.15-18 The PEmb-QoL consists of nine questions with a total of 40 items covering six categories: frequency of complaints (8 items), activities of daily living limitations (13 items), work-related problems (4 items), social limitations (1 item), intensity of complaints (2 items), and emotional complaints (10 items).19 The PEmb-QoL has been used in multiple cohorts and languages.20-22

While the PEmb-QoL is often considered to be validated, it is not clear how completely it captures a patient’s lived experience of PE. The PEmb-QoL may not capture all thoughts, fears, and perceived deprivations that degrade QoL after PE. We hypothesized that patients may disclose these additional QoL concerns in a conversation. Therefore, we aimed to assess the alignment of patient responses on the PEmb-QoL with their responses to QoL questions during an in-depth interview. We compare the severity, frequency, and domain of QoL concerns between the PEmb-QoL and interview transcripts.

2 | METHODS

2.1 | Design

This mixed-methods design collected qualitative and quantitative data sequentially. More detailed methodology was previously described in a separate publication.23 First, qualitative, in-depth individual interviews were done to allow for richly detailed data about the lived experiences of patients diagnosed with PE and the impact on QoL after the diagnosis of PE. Immediately after the interview, participants were asked to complete the English version of the quantitative PEmb-QoL. Combining the qualitative and quantitative data had several purposes, including cross-validating responses and identifying information in the qualitative data that was not obtained by the quantitative survey. The methodology is described in more detail in a separate publication.23 The study was approved by a local institutional review board (IRB) and was conducted in compliance with the ethical standards of the responsible institution on human subjects and with the Helsinki Declaration. A waiver for recruitment was obtained from the IRB, and the participants were contacted by phone to participate in the study. All participants signed an informed consent before the interviews.

2.2 | Patient selection

We used purposive sampling to recruit patients representing varying degrees of PE severity, from multiple venues.23 These included an anticoagulation clinic, an outpatient ED follow-up clinic, and a registry of patients treated by a PE response team.

Participants were contacted by phone and compensated with a Visa card at the end of the interview. More detailed information about sampling, transferability, and recruitment has been previously published.23

2.3 | Interviews

The interviews included opened-ended questions covering areas including participant experiences at the time of diagnosis (eg, reaction to diagnosis), knowledge about the disease, life-changing aspects after the diagnosis, concerns (eg, fear of recurrence) since diagnosis, attitudes, coping mechanisms, and need of support after diagnosis (see Appendix S1). The interviewees were encouraged to tell their story about being diagnosed with PE in their own words. For instance, participants were asked to give their thoughts about the possibility of having another clot, then the interviewer, depending on the answer, could follow up with probing questions such as "Tell me about your fears of recurrence. What triggers those fears? How often does this happen?" to elicit a more detailed response.
Twenty-one interviews were completed. Fifteen interviews were conducted face to face. After Indiana’s COVID-19 public health “stay at home” orders, the remaining six interviews were switched to a web conferencing platform (Zoom; Zoom Video Communication, San Jose, CA, USA). The structure, format, and verbal instructions of the face-to-face interviews were adapted to the video interviews.

The duration of the interview remained identical (60-90 minutes) after transition from face-to-face interviews to a web conferencing platform (Zoom). The interviews were audio-recorded and transcribed verbatim. The interviewer was an internal medicine physician with prior venous thromboembolism (VTE) and qualitative research experience and no prior clinical relationship with the participants.

### 2.4 | Questionnaire

The PEmb-QoL was administered immediately after the interview. The PEmb-QoL is a disease-specific questionnaire that assesses QoL after PE. It was developed in 2009 using the principles of grounded theory. To allow comparison with present results, it is necessary to briefly review the PEmb-Qol derivation and content. The questionnaire was drafted by two experienced clinicians with interest in patients with VTE based on symptoms as reported by the interview of 10 participants (4 men/6 women) selected for the gravity of their complaints following their PEs. Of these, 3 had experienced a recurrence and only 1 was described as a massive PE. Their ages were between 31 and 84 years old and the time since first PE diagnosis was between 4 months and 6 years. The main participants’ complaints were shortness of breath/difficulty in breathing, fatigue, fear of recurrences after discontinuing treatment, more readily emotionally disturbed, and more social isolation than before the PE. The structure of the questionnaire was modeled in line with the existing generic SF-36 questionnaire and the disease-specific Venous Insufficiency Epidemiological and Economic Study—Quality of Life/Symptoms questionnaire, which was developed for deep vein thrombosis.

| Numeric value | Description | Description |
|---------------|-------------|-------------|
| 1             | All of the time | Back of my mind/constant/daily |
| 2             | Most of the time | Aware/Hypervigilance |
| 3             | A good bit of the time | 3 times per week |
| 4             | Some of the time | Once per week |
| 5             | A little of the time | Once in a while |
| 6             | None of the time | None |

Abbreviations: PEmb-QoL, Pulmonary Embolism Quality of Life questionnaire.

### 3 | ANALYSIS

Qualitative content analysis was used to identify patterns and common topics in the qualitative data. A more detailed qualitative analysis has been previously published. Initially, deductive codes such as the concerns for recurrence were drawn from a review of the literature. We used existing literature, such as that focused on the development of the PEmb-QoL measure, to identify a preliminary set of codes. Examples of deductive codes include fear of recurrence, life-changing aspects, and family communication. We additionally developed codes through an inductive approach, allowing the emergence of new codes that represented the reality of the participants’ experiences. Examples of inductive codes include health care provider communication, concerns of death, and medicine as lifesaving treatment. As additional data were analyzed, codes were further refined. Broad codes were subdivided into more specific codes. Similar codes were grouped together. Patterns were identified and organized into tentative models.

Fear of recurrence of PE is assessed in the PEmb-QoL and has been identified as an important cause for emotional and psychological distress after PE diagnosis. The PEmb-QoL assesses fear of recurrence by asking: “These questions are about how you feel and how things have been with you during the past 4 weeks as a result of your lung symptoms. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks did you worry that you may have another pulmonary embolism?” In the in-depth interviews we asked: (1) Do you currently have fears of the blood clot happening again? (2) How often do you think about having another clot?

### 3.1 | Transcoding procedure

To allow a quantitative comparison between interviews and the results of the PEmb-QoL, two authors used the consensus method to convert theme-coded phrases into numbers that they believed to match the intensity, frequency, or severity represented by the
numeric answers from the PEmb-QoL (see Table 1). For example, in the case of fear of recurrence, the patients’ words “always on my mind,” “constant,” and “daily” were deemed equivalent to the response “all the time,” which provides 1 point in the PEmb-QoL.

4 | RESULTS

4.1 | Participants

Twenty-one participants were enrolled. Participants were between the ages of 18 and 70 years old and had experienced a symptomatic PE at least 6 months before enrollment. At the time of the interview, 38% of participants had a recurrence and 71% of participants had the first diagnosis of PE >2 years prior. The exclusion criteria were diagnosis of active cancer or known history of mental illness other than anxiety or depression before the PE. Patient characteristics are shown in Table 2. More than half of patients (70%) had an unprovoked PE and were on lifetime anticoagulation. Five participants (24%) received thrombolysis within 24 hours of diagnosis, and 2 (10%) participants were discharged from the emergency department at the time of diagnosis. One (5%) participant had some high school education, 5 (24%) completed high school, 7 (33%) had 1 to 3 years of college education, 5 (24%) completed 4 years of college, and 3 (14%) completed a master’s degree; 42% had hypertension, 10% had asthma, and 10% had a known thrombophilia.

| TABLE 2 Demographics |
|-----------------------|
| Female (n = 13) | Male (n = 8) | Total (N = 21) |
|-------------------|-----------|---------------|
| **Age, y, n (%)** |
| <50 | 5 (24) | 3 (14) | 8 (38) |
| >50 | 8 (38) | 5 (24) | 13 (62) |
| **Race, n (%)** |
| Black | 4 (19) | 2 (9.5) | 6 (28.5) |
| White | 9 (43) | 6 (28.5) | 15 (71.5) |
| **Marital status, n (%)** |
| Married | 6 (28.5) | 6 (28.5) | 12 (57) |
| Single | 3 (14) | 1 (5) | 4 (19) |
| Divorced | 2 (9.5) | 1 (5) | 3 (14.5) |
| In relationship/not married | 2 (9.5) | 0 (0) | 2 (9.5) |
| **Time since VTE diagnosis, y, n (%)** |
| <2 | 4 (19) | 5 (24) | 9 (43) |
| >2 | 9 (43) | 3 (14) | 12 (57) |
| **Received thrombolysis, n (%)** |
| Yes | 2 (9.5) | 3 (14) | 5 (23.5) |
| No | 11 (52.5) | 5 (24) | 16 (76.5) |
| **Lifetime anticoagulation, n (%)** |
| Yes | 8 (38) | 6 (28.5) | 14 (66.5) |
| No | 5 (24) | 2 (9.5) | 7 (33.5) |
| **Type of VTE, n (%)** |
| PE | 7 (33.5) | 5 (24) | 12 (57.5) |
| Both (PE/DVT) | 6 (28.5) | 3 (14) | 9 (42.5) |

Abbreviations: DVT, deep vein thrombosis; PE, pulmonary embolism; VTE, venous thromboembolism.

4.2 | Fear of recurrence

We observed low consistency in reports of fear of recurrence when we compared PEmb-QoL (worry that you may have another pulmonary embolism) with transcoded interview scores (Figure 1). PEmb-QoL scores indicated relatively better QoL (higher numbers), thus underestimating fears of recurrence; 86% had at least a 1-point difference, and 57% of scores differed by more than 3 points. In interviews, participants often described a higher frequency and severity of fears than would be predicted by that individual’s PEmb-QoL score. Of the 21 participants, only 3 (14%) demonstrated consistency between the PEmb-QoL and their interview descriptions of fears of recurrence. Half of the participants (52%) reported in the PEmb-QoL that “none of the time” they were worried about having another PE; however, the same participants responded that their thoughts of, or fears about, having another clot were “in their back of their mind” or were “constant,” with two participants responding that those fears and thoughts were present daily (Table 3).

Deeper qualitative analysis of the interviews provided potential explanations for thought processes underlying the differences in the scores. For example, female participants described the forced choice to avoid pregnancy.

P: I’m one and done. Absolutely no other children are coming out of my body. If we want to add any more, we’ll need to adopt or borrow or something.  
I: This is just solely because the blood clots?  
P: Yeah, I’m not, I don’t want to risk it for myself. I don’t want to risk it for the baby. (Patient 7)

Others described fear of stopping anticoagulation when the cause of their blood clots was never identified or they feared breaking a bone or traveling due to the increased risk of having a new clot.

But I’m afraid to stop the Xarelto for fear that since they could never identify the reason I have blood clots, it could happen again. (Patient 9)

Our in-depth interviews revealed that the lung symptoms were not the only trigger that made participants worry about recurrence. Participants also indicated that they associated fear of recurrence with immobility, chest pain, palpitations, dizziness, or missing medications. Some participants viewed taking medication as a constant reminder that they may have another clot. Another noteworthy finding during the in-depth interview was that participants who had unprovoked PE
or had a recurrence were more likely to worry about recurrence and commonly described their fear of recurrence as "constant" because, other than taking the medications, they do not know how to prevent the "next one."

4.3 | Social restrictions and hobbies—A previously unmeasured concern

We also saw low consistency in reports of self-imposed social restrictions between PEmb-QoL and qualitative interview descriptions, with participants reporting higher frequency and severity of limitations/restictions in interviews. Nearly half of the participants described their sadness/frustration about the inability to do or enjoy activities like woodworking, riding a motorcycle, or walking the dog. The PEmb-QoL has two questions that assess the impact of PE on social activities that were close enough to cross-validate responses: (1) Do your lung symptoms now limit you in these activities? If so, how much? Social activities (traveling, going to movies, parties, shopping); and (2) During the past 4 weeks, to what extent have your lung symptoms interfered with your normal social activities with family, friends, or neighbors.

In qualitative interviews, participants described more frequent and severe limitations on social activities as a result of their PE. Participants described restrictions such as avoiding skating, riding a bike, walking the dog, or working in the yard.

When we compared interviews to PEmb-QoL answers, we again found higher rates of impairment in interviews compared with reports on the PEmb-QoL surveys. Despite the fact that we considered two questions from the PEmb-QoL, the agreement with the coded answers from the transcripts of the in-depth interviews assessed the same day was only 56%. Table 4 shows examples of participants who reported low social limitations on PEmb-QoL but qualitatively described significant limitations.

The participants reported sadness/frustration over the inability to do activities/hobbies that they used to enjoy. Similar to the question about fear of recurrence, we found in our interviews that asking participants if their social activities are limited due to lung symptoms undervalues many other factors that patients considered to stop doing activities that they enjoy. For instance, patients reported that they avoid activities that may place them at risk to get another PE such as becoming immobile due to fractures. Another significant reason was abstention of activities that will place them at significant risk of bleeding, such as woodworking or falling from a motorcycle while taking anticoagulants.

5 | DISCUSSION

This study was done to examine the extent to which respondents’ answers to the PEmb-QoL are consistent with those given in-depth interviews and to determine if detailed interviews could yield data to improve QoL assessments in individuals experiencing PE. In the emotional category of the PEmb-QoL, our study identified a high rate of discordance (=86%) in the PEmb-QoL reported fear of recurrence when compared with answers to in-depth interviews completed immediately before the PEmb-QoL. We found a similarly high level (42%) of discordance in participants’ descriptions on avoiding activities that they enjoy with much higher reports of social limitations in the in-depth interviews compared with the PEmb-QoL.

These findings raise concerns that the current syntax or framing of the PEmb-QoL may not comprehensively assess fear of recurrence. The PEmb-QoL assesses fear of recurrence by asking if patients are worried about having another blood clot due to lung symptoms. However, as noted above, fear of recurrence can be triggered by a myriad of symptoms and experiences ranging from palpitations and dizziness to missing medication doses.

The recently developed Post-VTE Functional Status (PVFS) may be a partial solution to shortcomings identified in the PEmb-QoL. Specifically, PVFS adds anxiety as a contributing factor affecting the functional status after VTE. However, the PVFS has not been independently validated and does not contain a method to indirectly assess anxiety. We believe an indirect approach may be important, as differences between men and women has been reported in their willingness to recognize, discuss, report, and manifest their anxiety.

Also of concern is that the disagreement between the PEmb-QoL and the coded interviews regarding the impact on social activities was close to 50%. Again, social limitations were often not associated with lung symptoms, but instead the limitations were perceived as a
**TABLE 3** Comparison of interview responses with the PEmb-QoL for fear of recurrence

| PEmb-QoL                                                                 | In-depth interview                                                                                                                                                                                                 |
|------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| How you feel and how things have been with you during the past 4 weeks as a result of your lung symptoms. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks do you worry you may have another pulmonary embolism? | Do you currently have fears of the blood clot happening again? How often do you think about the possibility of developing another clot?                                                                                                       |
| A little of the time                                                   | Patient 17                                                                                                                                                                                                           |
|                                                                        | I’d say daily I think about it, but it doesn’t paralyze me. It’s on my mind that I need to think about it. That’s why I’m so careful to take my medicine and to do the things that I know to do, so I purposely, I daily think about it probably. |
| A little of the time                                                   | Patient 7                                                                                                                                                                                                            |
|                                                                        | It’s always in the back of my mind, but I don’t necessarily let it focus or control my life.                                                                                                                       |
| A little of the time                                                   | Patient 8                                                                                                                                                                                                            |
|                                                                        | Yes. I figured it hasn’t gone away. They don’t know if it will go. If it goes to my lungs it could kill me, you know? So, yeah, that’s the constant worry. Because of the blood clot, because it really slows you down, the pain, and you do have pain. You just have to watch what you’re doing. You think you’re gonna get it again. Is it going to come back? More blood clots in your body, that’s scary. That’s what I mainly worry about now, if I’m gonna get another blood clot, because more can come. That’s my main problem. |
| None of the time                                                       | Patient 10                                                                                                                                                                                                            |
|                                                                        | Because I am on the blood thinner. I’m doing everything I can to control my heart rate, which is the biggest risk factor for me. And I think most of the time I manage it pretty well. So I think it’s the kind of thing, it’s in the back of my head. |
| None of the time                                                       | Patient 1                                                                                                                                                                                                            |
|                                                                        | Oh, I guess in the back of my mind somewhere there is a fear that it could, I mean it happened, it happened 7 years ago. The only difference now is I take medicine for it every single day. But if for whatever reason those pills wouldn’t work or my blood decides to change as I get older somehow. Yeah, that could be a recurrence. |
| A little of the time                                                   | Patient 12                                                                                                                                                                                                            |
|                                                                        | Oh, yeah, that’s always in the back of my mind.                                                                                                                                                                      |
| A little of the time                                                   | Patient 16                                                                                                                                                                                                            |
|                                                                        | It’s just something that’s in the back of my mind that I have learned to live with that I don’t have answers for.                                                                                                                                 |
| A little of the time                                                   | Patient 18                                                                                                                                                                                                            |
|                                                                        | How often do you think about it?                                                                                                                                                                                        |
|                                                                        | F: Quite a bit, and it’s mainly at nighttime, when I go to lay down.                                                                                                                                                   |
|                                                                        | I: How many times a week do you think about it?                                                                                                                                                                        |
|                                                                        | F: Probably four times a week.                                                                                                                                                                                          |
|                                                                        | I: About the possibility of a clot happening again?                                                                                                                                                                     |
|                                                                        | F: Yes.                                                                                                                                                                                                                |
| None of the time                                                       | Patient 15                                                                                                                                                                                                            |
|                                                                        | You get small trigger every morning when I take the pills. I think well, I need to do this. And because I have a tendency for this to happen.                                                                             |
| None of the time                                                       | Patient 25                                                                                                                                                                                                            |
|                                                                        | You’re paranoid about, immediately, am I going to have a blood clot in 2 weeks? You know, that kind of stuff. And you still think about it all the time. Every day you take a pill.                                                |

Abbreviation: PEmb-QoL, Pulmonary Embolism Quality of Life questionnaire.
Bold text is supposed to reflect the emphasis given by the patient.
| PEemb-QoL | PEemb-QoL | In-depth interviews |
|-----------|-----------|---------------------|
| Do your lung symptoms now limit you in these activities? If so, how much? | During the past 4 weeks, to what extent have your lung symptoms interfered with your normal social activities with family, friends, neighbors, or groups? | How has having a clot affected your life? |
| Social activities (traveling, going to movies, parties, shopping) | | |
| No, not limited at all | Not at all | Patient 15 I don’t do nearly as many. I used to do woodworking and I used to work around the house more. And I do much less of those things. Well, yes, taking blood thinners is … again, I don’t do things that would expose me to a lot of risk to being cut. |
| No, not limited at all | Not at all | Patient 17 My husband and I used to ride. He still rides motorcycles, and since my episode I do not ride with him anymore. That saddens me because I always enjoyed to ride motorcycles. We always wore our gear. We always wore a helmet, but just more of the fear of falling and hurting myself or bleeding out or having a concussion, or having a hemorrhage to my brain is real to me, and so I don’t ride motorcycles with him anymore. |
| No, not limited at all | Not at all | Patient 19 My husband made a comment about going skiing, and I’m like, “I’ll never go skiing because I’m too worried that I’ll break something and that I’ll get another clot.” I guess there’s things like that. There’s risks that I won’t take any more out of fear. |
| No, not limited at all | Not at all | Patient 7 Again, I don’t take anything hormone related. I don’t take birth control. I’m not having another kid. I don’t run out and do crazy things like I used to. I used to ride all the crazy rides at all the fairs. I’ve been skydiving, all that’s past. I don’t want to risk breaking a leg. |
| No, not limited at all | Not at all | Patient 8 I used to go skating and go do activities. It makes me worry about the activities that you can do. And so I don’t really do all that stuff anymore |
| No, not limited at all | Not at all | Patient 3 Do I really need to be pushing it? Why don’t I just enjoy, go down to the lodge or whatever. But yeah, I would be much less aggressive on the slopes. So I look at that as preventative. I guess my comment would be before you would be aggressive and you go do the black diamonds. Now I’d probably be the greens and the blues. So I would be cautious. |
| Yes, limited a little | Moderately | Patient 9 And to this day, 4 years later, I can’t walk the dog. And it bothers me a lot. I’m going to cry. I’ve always been a large woman, but I’ve always been really healthy because I rode my bike, I walked the dog, I worked in the yard, I mowed our yard. I can’t do any of that anymore |

Abbreviation: PEemb-QoL, Pulmonary Embolism Quality of Life questionnaire. Bold text is supposed to reflect the emphasis given by the patient.
result of avoiding activities that they feared might increase the risk of recurrence or put them at risk of bleeding. These findings show the need for in-depth interview to disclose ongoing threat perceptions that may not be revealed by a questionnaire. These findings raise the question of whether the directive nature of the statement “due to your lung symptoms” causes patients to underestimate the full impact of PE because they do not associate perceived threats with ongoing lung symptoms. The patient perspectives detailed in our interviews clearly provide different and new information about the lived experience of PE as it pertains to fear of recurrence and social limitations. These findings suggest the need to modify the PEmb-QoL or add patient interviews to better reflect the patient experience.

There were limitations in our study design. Our sample size was limited and, although the numbers are appropriate for such qualitative methodology, a larger study is clearly needed to identify the true difference. We did not ask the same questions as the PEmb-QoL. The need for lifetime anticoagulation and experiencing an unprovoked VTE may play a role in ongoing reminders of their illness and their responses. Our study, however, provides helpful material to reflect on the assessment of QoL.

In conclusion, we believe that the results of our in-depth interviews show their methodological value to assess QoL after PE and offer an opportunity to improve the syntax of the PEmb-QoL to better reflect the patient’s perceptions of the fear of recurrence and disruption of hobby activities.

AUTHOR CONTRIBUTIONS
JH-N: concept and design, analysis and/or interpretation of data, critical writing or revising the intellectual content, and final approval of the version to be published. MT: analysis and/or interpretation of data, critical writing or revising the intellectual content, and final approval of the version to be published. ABA: critical writing or revising the intellectual content, and final approval of the version to be published. JAK: concept and design, analysis and/or interpretation of data, critical writing or revising the intellectual content, and final approval of the version to be published.

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REFERENCES
1. Fletcher AE, Bulpitt CJ. Measurement of quality of life in clinical trials of therapy. Cardiology. 1988;75(suppl 1):41-52.
2. Unger JM, Vaidya R, Gore JL. Key design and analysis principles for quality of life and patient-reported outcomes in clinical trials. Urol Oncol. 2019;37(5):324-330.
3. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA. 1995;273(1):59-65.
4. van Es J, den Exter PL, Kaptein AA, et al. Quality of life after pulmonary embolism as assessed with SF-36 and PEmb-QoL. Thorbm Res. 2013;13(5):500-505.
5. Patel AA, Donegan D, Albert T. The 36-item short form. J Am Acad Orthop Surg. 2007;15(2):126-134.
6. Lins L, Carvalho FM. SF-36 total score as a single measure of health-related quality of life: scope of review. SAGE Open Med. 2016;4:2050312116671725.
7. Brazier JE, Harper R, Jones NM, et al. Validating the SF-36 health survey questionnaire: new outcome measure for primary care. BMJ. 1992;305(6846):160-164.
8. Busija L, Pausenberger E, Haines TP, Haymes S, Buchbinder R, Osborne RH. Adult measures of general health and health-related quality of life: medical outcomes study Short Form 36-Item (SF-36) and Short Form 12-Item (SF-12) health surveys, Nottingham Health Profile (NHP), Sickness Impact Profile (SIP), Medical Outcomes Study Short Form 6D (SF-6D), Health Utilities Index Mark 3 (HUI3), Quality of Well-Being Scale (QWB), and Assessment of Quality of Life (AQoL). Arthritis Care Res (Hoboken). 2011;63(suppl 11):S383-412.
9. Finkelstein FO, van Nooten F, Wiklund I, Trundell D, Celladra D. Measurement properties of the Short Form-36 (SF-36) and the Functional Assessment of Cancer Therapy - Anemia (FACT-An) in patients with anemia associated with chronic kidney disease. Health Qual Life Outcomes. 2018;16(1):111.
10. Bunevicius A. Reliability and validity of the SF-36 health survey questionnaire in patients with brain tumors: a cross-sectional study. Health Qual Life Outcomes. 2017;15(1):92.
11. de Vries M, Uwoudijk R, Karlsson AG, et al. Comparison of generic and disease-specific questionnaires for the assessment of quality of life in patients with peripheral arterial disease. J Vasc Surg. 2005;41(2):261-268.
12. Arribas F, Olmaetxe JM, Peinado R, Ramírez P, Badía X. Validation of the AF-QoL, a disease-specific quality of life questionnaire for patients with atrial fibrillation. Europace. 2010;12(3):346-370.
13. Ware JE Jr, Gandek B, Guyer R, Deng N. Standardizing disease-specific quality of life measures across multiple chronic conditions: development and initial evaluation of the QOL Disease Impact Scale (QDIS®). Health Qual Life Outcomes. 2016;14:84.
14. Kline JA, Hernandez-Nino J. Quality of Life 3 and 12 months after acute pulmonary embolism: analysis from a prospective multicenter cohort study (new hope for outcomes envy). Chest. 2021;159(6):2153-2155.
15. Piazza G, Sterling KM, Tapson VF, et al. One-year echocardiographic, functional, and quality of life outcomes after ultrasound-facilitated catheter-based fibrinolysis for pulmonary embolism. Circ Cardiovasc Interv. 2020;13(8):e009012.
16. Duffett L, Castelucci LA, Forgie MA. Pulmonary embolism: update on management and controversies. BMJ. 2020;370:m2177.
17. Keller K, Tesche C, Gerhold-Ay A, et al. Quality of life and functional limitations after pulmonary embolism and its prognostic relevance. *J Thromb Haemost*. 2019;17(11):1923-1934.
18. Barco S, Schmidtmann I, Ageno W, et al. Survival and quality of life after early discharge in low-risk pulmonary embolism. *Eur Respir J*. 2021;57(2):2002368.
19. 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;7(6):1044-1046.
20. Tavoly M, Jelsness-Jørgensen LP, Wik HS, Roaldsnes C, Sandset PM, Ghanima W. Quality of life after pulmonary embolism: first cross-cultural evaluation of the pulmonary embolism quality-of-life (PEmb-QoL) questionnaire in a Norwegian cohort. *Qual Life Res*. 2015;24(2):417-425.
21. Frey PM, Méan M, Limacher A, et al. Quality of life after pulmonary embolism: prospective validation of the German version of the PEmb-QoL questionnaire. *Thromb Res*. 2015;135(6):1087-1092.
22. Sun X, Li J, Shi J. Validating the Chinese version of the PEmb-QoL questionnaire: a measure for quality of life assessment after pulmonary embolism. *Thromb Res*. 2018;166:86-91.
23. Hernandez-Nino J, Thomas M, Alexander AB, Ott MA, Kline JA. The use of qualitative methods in venous thromboembolism research. *Res Pract Thromb Haemost*. 2021;5(6):e12593.
24. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-115.
25. Noble S, Lewis R, Whithers J, Lewis S, Bennett P. Long-term psychological consequences of symptomatic pulmonary embolism: a qualitative study. *BMJ Open*. 2014;4(4):e004561.
26. Hojen AA, Sorensen EE, Dreyer PS, Sogaard M, Larsen TB. Long-term mental wellbeing of adolescents and young adults diagnosed with venous thromboembolism: results from a multistage mixed methods study. *J Thromb Haemost*. 2017;15(12):2333-2343.
27. Hunter R, Lewis S, Noble S, Rance J, Bennett PD. "Post-thrombotic panic syndrome": a thematic analysis of the experience of venous thromboembolism. *Br J Health Psychol*. 2017;22(1):8-25.
28. Bennett P, Patterson K, Noble S. Predicting post-traumatic stress and health anxiety following a venous thrombotic embolism. *J Health Psychol*. 2014;21(5):863-871.
29. Tran A, Redley M, de Wit K. The psychological impact of pulmonary embolism: a mixed-methods study. *Res Pract Thromb Haemost*. 2021;5(2):301-307.
30. Boon G, Barco S, Bertoletti L, et al. Measuring functional limitations after venous thromboembolism: optimization of the Post-VTE Functional Status (PVFS) scale. *Thromb Res*. 2020;190:45-51.
31. Giorgianni SJ, Brott A. Conference summary: behavioral health aspects of depression and anxiety in the American male, an expert panel report from men’s health network. 2019. Accessed February 7, 2022. https://www.menshealthnetwork.org/library/depression-anxiety-males-report.pdf
32. Smith DT, Mouzon DM, Elliott M. Reviewing the assumptions about men’s mental health: an exploration of the gender binary. *Am J Mens Health*. 2018;12(1):78-89.
33. Galdas PM, Cheater F, Marshall P. Men and health help-seeking behaviour: literature review. *J Adv Nurs*. 2005;49(6):616-623.

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Additional supporting information may be found in the online version of the article at the publisher’s website.

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