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The lived experience with pulmonary embolism: A qualitative study using focus groups

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1. Introduction

Acute pulmonary embolism (PE) is, together with deep vein thrombosis (DVT), one of the two clinical presentations of venous thromboembolism (VTE). PE is a life-threatening event with a case fatality rate of 7%–11%, and approximately 10% of symptomatic PE cases are fatal within 1 h after symptom onset [1,2]. Moreover, PE is the third most common cardiovascular syndrome after myocardial infarction and stroke [3,4]. Reported incidence estimates range between 0.19 and 0.95 per 1000 persons per year in Europe [3,5–8]. Since the incidence of PE rises with age, it can be expected that a larger number of patients will be diagnosed with PE in the future in the ageing Western societies [9].

The acute treatment of PE is usually inpatient with anticoagulant and possibly thromboembolytic therapy. Catheter-assisted thrombus removal or surgical pulmonary embolectomy are less common. After discharge, treatment with anticoagulants is continued for at least 3 months, but often much longer. Nowadays non-vitamin K-dependent oral anticoagulants (NOACs) are established for the treatment and secondary prevention of acute PE [10]. After primary therapy, patients still have to expect recurrence of the disease in up to 14% of cases [11].

Experiencing PE may be challenging for the patients in many ways. First, the recognition and immediate referral to treatment is of utmost importance but can be hindered by the wide spectrum of acute PE symptoms (e.g. dyspnea, chest pain, and syncope) which considerably

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overlap with other cardiopulmonary disorders [12,13]. It is so far unclear how patients experience both the process of diagnosis and acute treatment, and the long-term health care. Second, acute and long-term treatment with NOACS may be associated with fears regarding possible bleeding complications [14]. However, it is unknown how persons with PE handle those fears and how they cope with the possible risk of recurrence of this life-threatening disease. Mental reactions such as anxiety, depression and symptoms of post-traumatic stress disorder may accompany such a coping process [15]. Patients may experience transient or persisting impairments in mental and physical quality of life. Studies have shown a significant impairment of quality of life of patients with LE compared to the general population [16,17].

Overall, comprehensive knowledge on the lived experience of patients with PE is scarce. A qualitative inquiry seems appropriate to get a deeper insight into the life after PE. Thus, the objective of this study was to explore the lived experience of patients with PE using a qualitative research approach.

2. Methods

We conducted a qualitative study in patients with PE using the focus group methodology. Focus groups were chosen based on studies which indicated superiority of focus groups compared to individual interviews for a comprehensive exploration of the patient perspective and in order to stimulate mutual exchange between the participants [18].

The manuscript considers the Standards for Reporting Qualitative Research (SRQR) [19].

2.1. Research team and reflexivity

The moderator of the focus groups was the first author (IK). IK is senior researcher, female, and has a PhD degree in Medical Psychology and a Master of Science in Public Health degree. She was involved in a number of focus group studies in the past [20]. The second author (SR) is female, has a Bachelor of Science in Nursing degree and a Master of Science in Public Health degree, and has received a training for her role as focus group assistant and second data analyst by IK.

The moderator IK had no contact with the study participants before the focus group session, whereas the assistant SR was involved in the organization of the sessions and had short telephone contact with some participants. Before the start of the focus group discussion, IK and SP introduced themselves as members of the research team from the Chair of Epidemiology, where different studies on PE are being conducted in collaboration with the University Hospital Augsburg.

2.2. Study design

The study was approved by the Ethics Commission of the Ludwig Maximilians Universität, Munich. All study participants provided written informed consent according to the Declaration of Helsinki as revised in 2000.

2.3. Participant selection

Adults who were diagnosed as having a PE at the University Hospital Augsburg, Germany, from September 2018 to May 2019 were contacted by a study nurse and asked to participate. In addition, 110 persons with PE treated in the same hospital between 2011 and 2018 were invited for study participation by mail or telephone.

Patients were recruited according to a maximum variation strategy based on the criteria age group and disease duration. The group size for the focus groups was set at a maximum of six persons to represent different opinions and facilitate interactions. Sample size (number of focus groups) was determined by saturation, i.e. recruitment stopped when no new categories were arising in two consecutive focus groups.

2.4. Setting

The focus group sessions took place at the Chair of Epidemiology. Besides participants and researchers, no other persons were present, except in the last focus group where a member of the study team (SH) was present, but was not actively involved.

2.5. Data collection

An established topic guide with guidelines describing how to prepare and perform the focus group sessions, as well as open-ended questions, was applied. The questions presented to the focus group participants are shown in Table 1.

Patient characteristics including age, sex, family status, school education, number of preceeding PE's, date of last PE, antithrombotic medication, history of thrombophilia, diabetes, hypertension, myocardial infarction, heart failure, stroke, cancer, pulmonary hypertension and mental disorders were collected via a short questionnaire.

A pilot focus group was performed in order to test materials and procedures. Based on these experiences, the questions for the participants were slightly modified.

All focus groups were conducted in a non-directive manner according to the focus group guidelines. Prior to the start of the focus groups, the procedure of the session was explained. The open-ended questions were presented in the same order to the participants using a PowerPoint presentation. The assistants documented their observations of the group interaction and the discussion topics using 'field notes'. After each focus group the moderator and the assistant reviewed the course of the session. The focus group sessions were digitally recorded and transcribed verbatim.

2.6. Data analysis

Data analysis was based on the 'Grounded Theory' [21]. The grounded theory approach was chosen because a theory of the effects of PE on the lifes of affected people and their contextual factors which emerges from the life experiences of those people and the processes that the researcher is attempting to understand, is lacking so far. The constant comparative method was used to develop concepts from the data by coding and analyzing the data at the same time [22]. Open coding was applied in a first step, followed by axial coding in order to investigate the relationships between the categories and selective coding to integrate the categories into main themes and an overarching theory [23]. MAXQDA (Release 18.2.0) software was applied to facilitate coding and data analysis.

Transcripts were read several times by the researchers (SR, IK) in order to get an impression of the contents. The first focus group was

Table 1
Focus group questions.

1	How did the PE become noticeable? Which complaints/symptoms did you experience when you were admitted to hospital?
2	Did you experience any complaints/symptoms during the weeks or months before hospital admission which you would now consider initial signs for the pulmonary embolism? Which symptoms did you experience and when did they occur?
3	How has pulmonary embolism affected your physical wellbeing?
4	How has pulmonary embolism affected your mental wellbeing?
5	How has pulmonary embolism affected your daily life?
6	How has pulmonary embolism affected your social life?
7	What were your experiences with the medication for pulmonary embolism treatment?
8	What were your experiences with treatment in hospitals and by office-based physicians or with other health care providers (therapists, health insurance)?
9 ^a	How did you gather information on pulmonary embolism? Which information sources were most helpful, which were less helpful? Did you wish to have additional information sources?

^a Results of this question will not be subject of this paper.

coded by the two researchers independently, codings were compared and discussed and a list of codes was established. The following groups were coded by one researcher by comparing the data with the existing codes and assign them or enlarge the list of codes by adding new codes. The second person reviewed the codings and disagreements were discussed. The researchers used memos to comment on the analysis process. A research diary was established which contains any notes and comments emerging throughout the process of data collection and analysis.

3. Results

Between October 2018 and May 2019, five focus groups with 2–5 participants each (in total $n = 18$) were performed. The focus group sessions took 95 min in average (84–108 min). Table 2 shows the sample characteristics.

Table 3 provides an overview of the identified themes and categories.

3.1. Progressing dyspnea and pain as prodromal and acute symptoms

The most relevant prodromal symptom reported by the patients was progressing dyspnea. Many participants reported that dyspnea often started several weeks before the acute event, was initially recognized when climbing stairs or doing sports but became increasingly more

Table 2
Sample characteristics.

	Median	Range
Age (years)	56	26–82
	<i>n</i>	%
Gender		
Male	9	50
Female	9	50
Age group		
<40 years	3	17
40–49	4	22
50–59	3	17
60–69	4	22
70	4	22
Marital status		
Single	4	22
Married	13	72
Divorced	1	6
School education		
12 years (“Abitur”)	8	44
9 years (“Mittlere Reife”)	3	17
8 years (“Hauptschule”)	7	39
Number of pulmonary embolism events		
1	13	72
>1	5	28
Time between pulmonary embolism and study participation		
3 months	3	17
3 - months to < 1 year	2	11
1 to < 4 years	5	28
4 years	8	44
Ongoing anticoagulative medication	13	72
Type of anticoagulative medication		
Rivaroxaban	7	39
Apixaban	5	28
Edoxaban	1	6
Phenprocoumon	4	22
Tinzaparin	1	6
Concomittant disorders		
Thrombophilia	3	17
Diabetes	2	11
Hypertension	8	44
Myocardial infarction	1	6
Heart failure	1	6
Stroke	0	0
Pulmonary hypertension	1	6
Cancer	2	11
Mental disorders	1	6

Table 3

Overview on major themes and categories derived from the focus groups.

Topic: Major theme	Categories
Prodromal and acute symptoms: Progressing dyspnea and pain as prodromal and acute symptoms	Prodromal symptoms: Dyspnea under exertion Back pain Pain in the lower extremity Thrombophlebitis Weakness in the feet Dry skin Pressure/pain in the upper body Loss of consciousness Acute symptoms: Dyspnea under exertion Dyspnea at rest Pain in the upper body Unspecific discomfort Sudden weakness Blue-colored leg Sweating Dizziness Nausea High blood pressure High heart rate Low blood oxygen Syncope Hemoptysis Persisting dyspnea Loss of fitness Fatigue Back and rib pain Susceptibility to colds Sensitivity to weather changes Sensitivity to air conditioning Sensitivity to coffee intake Fear of death Anxiety disorder Worries about having a recurrent PE Worries about anticoagulant medication Increased self-observation Depressive mood Sleep disturbance Rumination Loss of drive and interests More sensitive and vulnerable Living more conscious Exhaustion restricts daily activities No time for leisure activities Need to wear thrombosis stockings Travelling Relatives take PE event not serious Increased care from relatives Overprotective behavior Protection against recurrent PE Security Unclear prescription rules Uncertainty about treatment duration Ambivalence regarding medication stop Easy medication use Need to discontinue before surgery Worries about bleedings Frequent hematoma Heavy nosebleeds Heavy menstrual bleedings Hair loss, skin and fingernail problems Stomach pain
Physical well-being: Persisting dyspnea and loss of fitness	
Mental well-being: Depression, fears and threat monitoring	
Daily life: Exhaustion which improves over time	
Social life: Between ignorance and overprotection	
Medication: Anticoagulants as lifesavers and threat	

(continued on next page)

Table 3 (continued)

Topic: Major theme	Categories
Health care: Quick versus delayed diagnosis	Worries about increased risk of osteoporosis
	Early, quick diagnosis
	Misinterpretation of symptoms
	Misdiagnosis
	Delayed acute care
Health care: Left alone by health care providers	Lack of coordination
	Lack of information exchange
	Lack of information
	Lack of empathy
	Not listening to the patient
Health care: Unsupportive healthcare system	Not being taken serious
	Lack of knowledge among physicians
	Lack of holistic view
	Lacking search for disease causes
	Lack of comprehensive after care
	Individual initiative needed

severe:

"... there was a more or less long-lasting shortness of breath. Well, I was not concerned about this, this shortness of breath, it comes up insidious, progressing, not associated with pain. You only notice it when you climb stairs ... And this became increasingly worse." (Female, 62, 2 years post PE)

Patients commonly considered this symptom as unusual and sometimes attributed it to an unspecific loss of physical fitness. However, nobody thought that it would indicate an evolving life-threatening disease such as PE. Most prominent acute symptoms mentioned by the participants were dyspnea and pain. Dyspnea under exertion but also in rest was frequently mentioned as a main acute symptom:

"... finally, in the morning I was only able to walk from the bed to the bathroom, and then it was finished. That was 10 m and then nothing works anymore." (Female, 68, 3 months post PE)

A number of participants reported pain in the upper body, including back pain, rib pain, or shoulder pain. Most participants described the level of pain as severe and mentioned that the pain level was highest in lying position:

"... I had this pain, wasn't able to lie down, so I sat in the armchair smoking one cigarette after the other, and this was for two nights. I wasn't able to move and nothing." (Male, 38, 5 years post PE)

"... an extreme pain there in the rib area which increased over hours. I would say it started in the evening at 6 pm and has increased during one, two hours in a way that one has the feeling that you get a knife strongly stabbed into the ribs." (Female, 62, 2 years post PE)

3.2. Physical well-being: persisting dyspnea and loss of fitness

None of the participants indicated severe and persisting impairments of physical functioning. Participants frequently mentioned that impairments were most severe in the first months after PE and continuously improved. The physical impairments within the first months were unexpected and mentally stressful, because the patients were unsure whether these impairments will persist or improve.

Two major themes emerged, namely persisting dyspnea and a general loss of physical fitness. Firstly, patients mentioned that they still experience a shortness of breath in various situations e.g. when doing sports but also in daily life:

"What bothers me at work sometimes is, also if I talk quickly, I'm lacking air. And the others always think that I got upset, but actually I'm just breathless." (Female, 37, 3 years post PE)

Secondly, the patients complained that they haven't reached their level of fitness before the PE, even after years:

"... and I think even now, after almost 10 years, I cannot reach that 100 percent so easily. I would say 95 percent." (Male, 55, 10 years post PE)

3.3. Mental well-being: depression, fears and threat monitoring

"This has affected also my mind. As I said, for two months I was physically and mentally – yes - finished." (Female, 45, 9 months post PE)

Compared to impairments of physical health, mental health impairments were much more emphasized by the participants. Several times the verbal explanations were accompanied by emotional expressions such as crying, particularly in patients who participated early after their PE.

Worries and anxiety were most prominent problems which presented in different facets and at different time points after PE. For instance, one patient experienced very disturbing fear of death in the acute situation. In the focus group session she was still heavily emotionally affected and started crying when talking about her fears.

Furthermore, many participants worried about having a recurrent PE, particularly in the first months after the acute event, but several participants reported that these worries persisted:

"... but when I go to bed in the evening, the pulmonary embolism is permanently present And I think, hopefully, this will not happen to you again tomorrow in the morning." [participant starts crying] (Female, 70, 5 years post PE)

Persisting worries seemed to be driven by the potentially fatal nature of PE and the uncertainty of the causes of PE especially when patients had no obvious risk factors

"And I was also mentally burdened, because I was unsure whether it will recur, because nobody was able to tell me what the causes were." (Female, 26, 2 years post PE)

The use of anticoagulant medication was often named as a source of worries, either the fear of having an increased risk of recurrent PE if medication intake was missed or the fear of bleeding complications.

"I tend to get slight panic if I go away without the stuff [the medication]. This has become a routine, just as the key. The medication box, plus key, plus wallet, then we can leave." (Female, 62, 2 years post PE)

Increased self-observation and threat monitoring emerged as an important theme. Participants reported that they tended to become overly cautious if they noticed any bodily symptoms.

"Then you had this symptom again and you were cracking up again and you went to the doctor at once, really because of minor symptoms and in the past I never consulted a doctor (...). And since then, as soon as you notice something or so, you think ... My wife calls me a hypochondriac. Okay, not always, but (.). Then I also think, are you going crazy now? Since then I'm simply overcautious and this is ..., I don't know." (Male, 38, 5 years post PE)

Further mental problems were depressive mood and symptoms related with a depressive syndrome such as sleep disturbance, rumination, and loss of energy, drive and interests:

"I wasn't in the mood anymore to talk or to do anything else. I was completely lacking drive. I was offered a number of activities by my family. But I preferred just to sit there". (Female, 72, 5 years post PE)

Patients also reported that the experience of PE made them more sensitive and vulnerable and they tended to respond to common incidents in a more emotional manner:

„I really became more sensitive, much more sensitive and more emotional in everything. Sometimes I think this is not appropriate, my husband has to cope with this ((laughing)). But I hope this will improve, it has already improved, I'm resolving to do this. But I have to conclude that I actually became more sensitive, yes.” (Female, 69, 6 months post PE)

On the other hand, many patients mentioned a positive consequence of the PE experience, namely that they started leading a more conscious life keeping in mind that life may end unexpectedly.

„Right, it's the same for me. You live more conscious, more intensive ... From one moment to the other it may be finished.” (Female, 68, 3 months post PE)

3.4. Daily life: exhaustion which improves over time

Overall, a broad range of impairment levels of daily life activities after PE were found. A few participants reported that they are no longer able to lead a normal life, e.g. have no time for leisure activities due to frequent doctors' visits. Some participants mentioned, that their daily activities including domestic work and job became more exhausting or took more time and they had to adapt their own level of aspiration. A third group of patients found no changes compared to the situation prior to PE. Again, it became clear that impairments of daily life were strongest in the first months after PE and tend to improve over time:

„Everything is going slower.” (Female, 72, 1.5 years post PE)

„As I said, but the first two, three, yes four months I was (.). The first two months it was bad for me, and afterwards a little bit. But then it is back to normal, the daily life.” (Female, 45, 9 months post PE)

The most common theme was the need to wear thrombosis stockings. While a number of patients did not feel any discomfort and said that it has become part of daily routine, other patients found it terrible to wear the stockings, especially in hot weather periods:

„Right, they are driving me crazy. Especially, if it's 40 degrees outside.” (Male, 54, 5 years post PE)

3.5. Social life: between ignorance and overprotection

Reported responses of closely related persons, mainly partner and family, to the life after PE can be placed on a continuum ranging from ignorance over tender care to overprotection and control. Firstly, a few participants reported that people took the PE event and the consequences not serious, mainly because they were lacking appropriate information about it:

„In my family nobody took that serious. Well, you had pulmonary embolism, but only a few persons ever knew what it is ... Just blather, you are fine and everything is okay. And in contrast I'm taking Marcumar (Phenprocoumon) and I'm worrying about everything.” (Male, 38, 5 years post PE)

A high level of worry over a recurrent PE among the family led to behaviors which were considerably more often reported by the participants than ignorance, namely tender care and overprotection. Tender care of relatives was considered as positive on the one hand, because it entails a feeling of security and trustworthiness. On the other hand, if the level of care converted into overprotection, the participants felt controlled. Participants reported that this overprotective behavior caused considerable distress within couples, especially during the first months after PE:

„I rather feel like my family pays more attention to how I am ... Sometimes I have less worries compared with my husband or my daughter, who

then ask: are you fine? So you recognize that it [the disease] has also affected the family a little bit.” (Female, 62, 2 years post PE)

„What beat everything, my husband gave me a whistle. For my living room. Because if my husband is further away or downstairs in the house, to better hear me. Because I wasn't able to shout loud enough. This was not possible. If I don't feel fine I just can use the whistle.” (Female, 72, 1.5 years post PE)

3.6. Medication: anticoagulants as lifesavers and threat

Anticoagulation treatment was discussed extensively by the participants. All of them were treated with anticoagulants and 13 out of 18 participants had ongoing treatment.

The first important point was the question, why people received different medication classes namely, Vitamin K antagonists or NOACs. Patients reported that it was not clear for them why some participants were prescribed Vitamin K antagonists instead of NOACs and had the impression that the prescription may be mainly influenced by the physicians' preferences. Indeed, none of the participants was able to explain why he/she was using Vitamin K antagonists instead of NOAC:

„There are now two persons, who utilize injections. And on the other hand there is Marcumar (Phenprocoumon) and Xarelto (Rivaroxaban). But I have not understood so far, why we were prescribed different medications.” (Male, 48, 3 years post PE)

Some patients mentioned that initially they regarded anticoagulants as “dangerous blood-thinners” which imply the risk of bleeding to death.

„At the beginning it was a bit strange, blood-thinning medication. Everybody said: ‚Oh, you have to take blood thinners‘ - that was somehow considered as very bad or very terrible.” (Female, 69, 6 months post PE)

This negative preconception, however, changed with increasing information and own experiences with the medication. Overall, anticoagulants were viewed as a major advantage for the protection of a recurrent PE and generated a sense of security in the patients.

„Marcumar (Phenprocoumon) gives me the feeling that no bad things can happen in the future. You have the blood thinning now, if you take care that it works, no bad things will happen in terms of the lung.” (Female, 70, 5 years post PE)

An extensively discussed issue was the duration of NOAC intake. It turned out that the participants received different advices regarding the appropriate duration of NOAC treatment. Moreover, patients reported that they also received conflicting proposals from different physicians or even the same physician and no explanation of the risk increase or decrease associated with a deviation from the suggested duration:

„But I don't know, how it is decided, what are the criteria.” (Female, 49, 5 years post PE)

„That was really strange, because they first said my problems are so severe that I need a lifelong blood thinning ... And suddenly they said: ‚Oh no, actually you may stop that‘. And I said: ‚Okay, basically no problem, but you told me first I shall take it lifelong or unlimited, and now you simply say I can stop it.‘” (Male, 48, 3 years post PE)

Patients reported a major ambivalence regarding a potential medication stop. On the one hand, they felt relieved that they no longer require such a “dangerous” medication. On the other hand, a great uncertainty remains whether the risk for a recurrent PE will increase:

„For instance my doctor says, yes you have to take it for one year. The others say, what for? But I'm afraid. If I stop that, will it [the disease] recur? That's the fear I have.” (Female, 45, 9 months post PE)

Daily medication intake was considered as easy and comfortable by

the NOAC users. Some users of Vitamin K antagonists reported that they regarded self-assessment of INR as an advantage compared to frequent doctors' visits while others – older aged persons – preferred measurement by the doctor since these visits raise the feeling of having a closer health monitoring:

„But that's also an advantage, you are checked every four weeks. I have doctors' visits in four weeks intervals because of the Marcumar (Phenprocoumon).“ (Male, 82, 4 years post PE)

One aspect of medication management was the need to discontinue medication before a planned surgery or visit at the dentist.

A major theme were worries about bleeding. Many patients confirmed that initially they had the idea to bleed to death when cutting themselves slightly.

„At the beginning, I was also concerned because I thought now I'm a bleeder, in quotation marks. And I really thought if I have an accident or if I cut myself ... I actually thought that in theory I may bleed to death, if I cut myself accidentally.“ (Male, 48, 3 years post PE)

Over time they developed a more realistic view of the potential danger of bleeding. Some reported that bleedings were stronger or took longer, but these events were not accompanied by any worries.

„In general I had no problems with strong bleedings. It was stronger than usual, but not extremely bad.“ (Female, 26, 2 years post PE)

However, worries on the risk of unstoppable internal bleeding after a severe traumatic accident remained in some patients.

„I think the most critical thing would be such internal bleedings, if anything like that would occur. I'm worried about this sometimes.“ (Male, 48, 3 years post PE)

The most common side effect of the anticoagulants reported by the participants were frequent hematoma.

„But indeed (.) I'm getting bruises rather easily, I notice this frequently, if I bang into something, large bruises.“ (Female, 49, 4 Jahre post PE)

3.7. Health care

3.7.1. Quick versus delayed diagnosis

Patients' experiences regarding diagnosis and acute care can be divided into two groups. The first group consisted of persons with an early and quick diagnosis and referral to the hospital. In contrast, participants from the second group reported an often incredible sequence of misinterpretation of PE symptoms, misdiagnosis and delayed initiation of acute care:

Patient: „I was sleeping and suddenly I woke up, ...and then I could not breathe and had terrible back pain. I was told that I'm stressed and that's the reason for having back pain, yes. And I had asthma and that's why I had dyspnea.“

Interviewer: „That means you were at the general practitioner first?“

Patient: „I was at the general practitioner first, but someday I had such severe pain that I went to the emergency unit. (...) I got injections for the back pain mostly, and this extended for a longer time and in 2014 the time has come that I wasn't able to do anything. In the meantime, I had this again, for one and a half years, repeatedly back pain and shortness of breath.“ (Female, 34, 3 years post PE)

Overall, it became clear that initial symptoms of PE can be very unspecific and are often misinterpreted by the patients themselves but also by physicians. This can lead to a delay of referral to treatment.

Moreover, patients often noted a lack of coordination and information exchange within the hospital staff, which increases feelings of

helplessness or being left alone:

„Nobody knew, what will happen with me ... “ (Female, 34, 3 years post PE)

3.7.2. Left alone by health care providers

A large number of themes came up, addressing the relationship and communication between patients and physicians or nurses. Especially during the hospital stay, patients noted lacking information about their own health situation and about the disease. They developed the feeling of being left alone:

„... I was at the ward and lying in bed and I did not know whether I'm allowed to stand up. There were 40 degrees outside, I had nothing to drink and nobody was able to tell me whether I may move or remain lying, because I was just now coughing blood. Also the person I have called wasn't able to advise me and that's why I just turned out sometime.“ (Female, 34, 3 years post PE)

„I also think that I have received far too little information about pulmonary embolism. Even later, what they told me that was almost nothing. You'll get Marcumar (Phenprocoumon) and return to work and that's it.“ (Male, 38, 5 years post PE)

Moreover, communication deficits such as missing empathy or not listening to the patients, emerged:

„When I came to the intensive care unit, the first doctor had no idea. Right, what means no idea. I mean she was not able to listen to me, actually she didn't notice, what I said.“ (Male, 61, 6 years post PE)

Patients also reported that they were not taken serious by physicians when presenting with symptoms that may indicate a recurrent PE:

„And then the doctor said, okay, maybe have heard about this celebrity yesterday who died of pulmonary embolism. And I said, yes, but I already had a first pulmonary embolism and I know how it feels like. And now it feels exactly the same. And he said, no, he doesn't believe it's the same, it can be something different.“ (Male, 48, 3 years post PE)

3.7.3. Unsupportive healthcare system

The participants identified some aspects of the healthcare system which were not helpful for them. Overall, patients reported on a lack of knowledge on PE among physicians:

„... but specifically the office-based physicians, you sometimes get the impression that this [pulmonary embolism] is a very unfamiliar field. For instance a general practitioner seems to lack knowledge, partly.“ (Male, 43, 3 months post PE)

Another point was the specialization among the physicians and the lack of a holistic view:

„Well, a specialist for lung diseases is just specialized on the lung, this means he takes care that the pulmonary embolism passes quickly and doesn't recur, and that's why he's prescribing blood thinners, but of course he is not looking for the causes. Actually he isn't a specialist for blood coagulation. He also openly admits that he can just take care of the symptoms and its recurrence.“ (Male, 57, 5 years post PE)

In addition, many of them were missing comprehensive care after being discharged from the hospital. Some of them were offered in-patient or out-patient cardiac rehabilitation, some agreed and found it very helpful for their recovery. The participants' reports indicated that they require a high level of individual initiative to manage post acute care, for instance to receive additional diagnostic tests or treatments:

„You have to organize this yourself. It is your own business to get in contact with other experts who are going to make an additional examination.” (Female, 62, 2 years post PE)

The core theory which emerged from the study highlights the importance of mental well-being after PE. As shown in Fig. 1, mental well-being, which is often impaired by symptoms of depression, anxiety and threat monitoring is related with aspects of physical function, daily and social life post PE but also strongly affected by contextual factors. Characteristics of provided health care have a considerable influence on mental well-being. Moreover, anticoagulant medication plays an important role for the life after PE, and specifically affects mental well-being.

4. Discussion

During the focus group sessions, progressing dyspnea was identified as the major prodromal symptom, and dyspnea and pain as most important acute symptoms. Worries and depressive symptoms emerged as major impairments after PE. Persisting dyspnea and a general loss of physical fitness were named as major impairments in the physical area. Activities of daily living were mainly influenced by exhaustion. Overprotection by partners/family members was a major theme in terms of social consequences. However, all negative consequences of the PE regarding physical and mental well-being as well as daily and social life, improved over time. Anticoagulants were regarded as life-saving but were also associated with significant fears of bleeding complications and worries regarding treatment discontinuation. A major topic regarding health care was delayed diagnosis due to unspecific symptoms and potentially lacking knowledge of physicians. In addition, deficits in the communication between patients and health care professionals emerged.

The results confirmed that dyspnea and pain are most common symptoms in the prodromal and acute phase of PE. More importantly, symptoms were not recognized as indicators of a potentially life-limiting disease by the patients and in a number of cases also not by the doctors. This finding is consistent with the results from Rolving et al. [24] and

Hunter et al. [25].

The finding that symptoms of depression and anxiety were experienced as major problems of patients with PE is a most relevant result of the present study. Evidence of mental health problems in patients with PE is still scarce and many available studies also included patients with DVT who had no PE [25–28]. However, available qualitative studies consistently reported symptoms of anxiety, depression, or even symptoms of a post traumatic stress disorder [15,24,25,28]. Chuang et al. [29] showed that about 50% of 1399 patients with PE were slightly to extremely depressed and/or anxious after the acute event and 12 months later this rate decreased to about 35%. The results from Bennett et al. [27] suggest that mental problems may also be long-term and stable over time. In 158 individuals with some form of VTE and an average time since VTE of 26 months, they found that the mean questionnaire scores were above the cut-off scores for likely illness anxiety disorder and posttraumatic stress disorder.

Patients who reported emotional problems after PE noted that they have received no information on the potential psychological consequences of experiencing this traumatic disease or support by the health care system. Bennett et al. [27] therefore suggests a stepped-care intervention with information, self-help literature and cognitive-behavioral treatment for those with significant and continuing emotional problems.

In accordance with Rolving [24] the present study found that anticoagulant medication was regarded as lifesaver by the patients and that medication discontinuation produced distress regarding a possible recurrent PE. Of interest, the participants from Rolving's study also were lacking information about the rationale for stopping medication and similarly received contradictory information by the physicians. Contrary to the present study, side-effects of anticoagulants were perceived as insignificant, while patients in the present study reported considerable worries in terms of potential bleeding complications. Unrealistic worries, however, might be reduced by timely provision of information.

The patients' experiences with the health care system revealed further problematic issues. Delayed diagnosis of PE was common and associated with a high level of distress in the affected individuals. In fact, PE was found to be one of the most frequently reported missed diagnoses

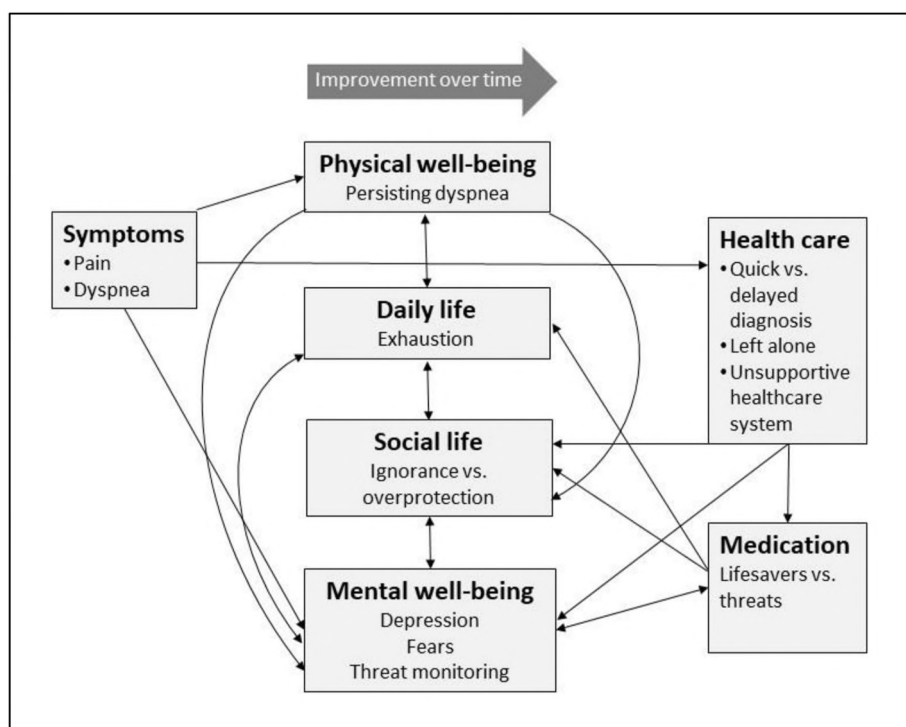


Fig. 1. Associations between the main themes which emerged from the focus group discussions.

in primary care [30] and in a French study family physicians did not apply diagnostic rules although diagnostic tools such as the Wells score or the D-dimer test were proven safe and efficient for the exclusion of a PE diagnosis in primary care [31,32]. In the present study, many patients had the impression that physicians in general are lacking knowledge on PE.

Aspects of the doctor-patient communication, such as lack of information, lack of empathy and not being taken seriously, resulting in a feeling of being left alone, are similarly described in other qualitative studies [15,24,25,28]. In addition, the present study revealed further negative issues which are rooted in the structures of the existing health care system, e.g. the high degree of specialization among the physicians which results in a lacking holistic view of the patient. The patients identified a frequently addressed problem in the structure of the German health care system, namely the gap of care between hospital discharge and out-patient care. Rolving [24] reported that it was perceived as valuable by patients to talk to a specialized nurse after discharge. The German health care system, however, is lacking such an opportunity for patients with PE. Of interest, the recent update of the guidelines on diagnoses and management of acute PE from the European Society of Cardiology includes a Level-I recommendation on the implementation of an integrated model of care after acute PE in order to ensure optimal transition from hospital to ambulatory care [33].

4.1. Strength and limitations

To our knowledge this study is the first qualitative study exploring PE from the patient perspective which included solely patients with first time or recurrent PE and a wide range of disease durations. Insights in the patients' experiences are an important basis to improve the health care in this patient group in the future.

In qualitative research, sample sizes typically remain small because intensive data analysis is required [34]. A small sample size with a diverse range of participants was used to obtain the required level of rich and meaningful data. However, we cannot exclude that selection bias has influenced the study results. For instance, individuals who participate in a focus group study may have a higher burden of disease (specifically more emotional problems) than persons who refused to participate. The trustworthiness of the data was ensured by measures to improve credibility (e.g. investigator triangulation and persistent observation) and reflexivity (e.g. research diary) [35]. However, since the sample consists only of German participants, the results – specifically those regarding the health care system – may not be entirely transferable to patients with PE from other countries.

4.2. Implications for research and practice

The lack of a sufficiently evidence-based rationale for stopping or continuing anticoagulants may be one reason that physicians are not able to discuss this issue with the patients or involve them in the decision process. The recent update of the guidelines on diagnoses and management of acute PE from the European Society of Cardiology now provides clearer recommendations on the discontinuation of anticoagulants than before [33]. These guidelines also mention the importance of involving the patient into the decision process, as these recommendations are based on only very few randomised clinical trials. Hopefully, this will help physicians in decision-making and stimulate communication with the patient in the future.

Guidelines, however, do not at all mention emotional problems which may occur after PE. Indeed, scientific evidence on the extent of mental health problems after PE is still scarce. This highlights the need for larger sample, quantitative data collection in consecutively recruited PE patients. For instance, the “Lungenembolie Augsburg (LEA)” study includes measures of depression, anxiety and health-related quality of life and will provide prospective long-term data on these patient-oriented outcomes in the future [36].

Based on results from larger studies, interventions which may improve the situation of patients with PE can be developed. These may include the provision of comprehensive health information material for the patients, additional physical and psychological rehabilitation or stepped care models which close the existing gap between in-hospital treatment and out-patient 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

Inge Kirchberger: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft. **Sarah Ruile:** Methodology, Formal analysis, Investigation, Writing - review & editing. **Jakob Linseisen:** Conceptualization, Resources, Supervision, Writing - review & editing. **Sabine Haberl:** Investigation, Project administration, Writing - review & editing. **Christine Meisinger:** Conceptualization, Resources, Supervision, Writing - review & editing. **Thomas M. Berghaus:** Conceptualization, Resources, Supervision, Writing - review & editing.

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