



Full Length Article

“Whole life changed” - Experiences of how symptoms derived from acute pulmonary embolism affects life. A qualitative interview study

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ABSTRACT

Introduction: Acute pulmonary embolism (PE) presents itself with a wide range of hemodynamic consequences. Respiratory symptoms as dyspnea and respiratory pain are common. The aim of this study was to explore patients' experiences of how symptoms affected their physical and social activities following the PE.

Materials and methods: Qualitative interviews were conducted with 14 patients, with median time of 7 months (range 3–34 months) since the PE and analysed with qualitative content analysis according to Graneheim and Lundman.

Results: The findings indicated that respiratory symptoms affected many aspects of life, illustrated by an overall theme: “Whole life changed”. Two major categories, on changes of psychological/social nature, and changes of perception towards physical activity, described how the participants experienced changes in themselves and their relations, and that the psychological affection resulted in an existential crisis. All participants experienced changes in their physical activity and that remaining respiratory symptoms hindered them from being active. Fear inhibited physical activity and created a feeling of low self-efficacy concerning activity in general.

Conclusions: To the best of our knowledge, this is the first study to present results on experiences of how the symptoms deriving from PE affected the physical and social activities of the participants during recovery phase. The results indicate that patients with PE need support from the health care system to manage both psychological and physical symptoms in the aftermath of their illness. Further research is needed to find out how optimal rehabilitation for these patients should be designed.

1. Introduction

Acute pulmonary embolism (PE) is the most serious clinical presentation of venous thromboembolism, the other being deep vein thrombosis [1]. PE presents itself with a wide range of hemodynamic consequences, from being asymptomatic to a life-threatening medical emergency [2]. The clinical signs and symptoms of PE are diverse and non-specific, such as dyspnea at rest or with exertion, respiratory pain, syncope and haemoptysis [1]. Symptoms of PE are clearly described in medical guidelines, but not the consequences caused for the patient experiencing the symptoms [3,4]. Previous studies show that symptoms derived from PE can lead to disability and affect patients up to 7 years after the event [5–8]. Furthermore, studies show that patients with PE display significantly lower health related quality of life, predicted by

impaired functional capacity and persistent dyspnea, and that patients with a previous PE suffer from moderate to severe impairment of physical performance and social activities [9–11].

Qualitative research searches for knowledge through exploration of social phenomena and generates data from which hypotheses can be developed through inductive reasoning [12]. There are a few studies using qualitative methods to study long-term psychological consequences of PE and on coping with life after the event, in both adolescents [6] and adults [5,8]. All of the aforementioned studies found that having a PE was a life-changing event and that the consequences are not only connected to physical restrictions [5,6,8].

To the best of our knowledge there are no studies focusing on the experiences of symptoms for patients falling ill with PE or how the symptoms affect physical and social activities during recovery.

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The aim of this study was to explore patients' experiences of the symptoms when falling ill with PE and experiences of how the symptoms affected the patients' physical and social activities following the PE event.

2. Materials and methods

This study consists of interviews analysed with qualitative content analysis according to Graneheim and Lundman [13]. The study was approved by the Ethical Review Board in Gothenburg (Ref number: 476-14). The study is registered in the database FOU i Sverige (R&D Sweden) with registration number: 165821 <https://www.fou.nu/is/sverige/project/165821>.

Inclusion criteria were patients with verified acute PE, 30–65 years of age, able to read and understand Swedish, who suffered from a PE 3 months to 3 years ago at the time for inclusion. The patients should also have persistent dyspnea/respiratory associated pain at rest or with exertion, at 3 months after the PE. Exclusion criteria were previous PE, dementia, pregnancy, an orthopedic condition affecting walking ability and serious psychiatric or physical conditions as described earlier [14]. The inclusion criteria were adjusted nine months into the study to include patients up to 70 years of age, in order to be able to increase the number of eligible patients. Identification of eligible patients for the study was performed partly from a longitudinal observational study [14] and among consecutive patients at revisits, up to one year after suffering from PE, to the medical outpatient ward at Sahlgrenska University Hospital, Gothenburg. Patients eligible for participation at the medical outpatient ward were identified by a research nurse. Fourteen patients were identified as eligible for participation in the study according to the inclusion and exclusion criteria and were asked to participate. Both written and oral information about the study were given, and all who were asked gave their written consent.

To be able to describe the study group, information about age, gender, time since PE, if the participants were living with another adult, if the participants had right ventricular failure at admission, and also calculated percentage of occlusion caused by the PE quantified with the Qanadli index was collected [15]. To calculate the percentage of occlusion each lung was divided into ten segmental arteries as described by Qanadli et al. [15]. An embolus in a segmental artery scored one point, and emboli in the most proximal arterial level scored a value equal to the number of segmental arteries arising distally. The maximal CT obstruction index was forty per patient. The percentage of vascular obstruction was calculated by dividing the patient score by the maximal total score and by multiplying the result by one hundred [16].

The interviews were conducted during 2015–2017 and were performed between 3 months and 3 years after the PE. Interviews with participants recruited from the earlier longitudinal observation study (9) was conducted by one of the authors (LR), and the participants recruited from the medical outpatient ward (5) were interviewed by the other author (JD), this was to prevent the results being affected by an prior relationship as patient and physiotherapist [14]. The authors introduced themselves as occupational therapist (LR) and physiotherapist (JD) at the time for inclusion.

A semi structured interview guide was developed by the authors. This was tested in a pilot interview with a patient with previous PE, and modifications were made to clarify the questions in the interview guide. The open questions in the guide concerned the participants' experiences of symptoms when falling ill in PE, their experiences of symptoms after discharge from hospital, and how the participants physical or social activities have been affected by the symptoms, see Table 1. A single session interview per participant was completed, and only the participant and the author were present during the interview. The time for the interviews varied between 17 and 49 min and an audio recorder were used; the interviews were transcribed verbatim after completion. No field notes were taken during the interviews, and the transcribed interviews became the unit of analysis of the study.

Table 1
Semi-structured interview guide.

Can you tell me about when you fell ill with pulmonary embolism?
What was your experience of symptoms when you came home from the hospital?
Can you tell me about how pulmonary embolism has affected your everyday life and your daily activities?
Can you tell me about how pulmonary embolism has affected your ability perform physical activity?
Have you had to adapt your physical activity after your pulmonary embolism and if so, how?
Is there anything else you want to tell me about what it was like to fall ill with pulmonary embolism?

The initial analysis was performed by the two first authors (JD and LR). Analysis was made first independently and then in collaboration between the authors. The results of the analysis were discussed with the last authors (MFO and KM), both physiotherapists and senior researchers. All researchers involved in the study are female. Initially, the interviews were listened to repeatedly, and the verbatim transcripts were read several times. Meaning units connected to the aim of the study were identified from the unit of analysis, then condensed and coded. The different codes were sorted based on similarities and differences into sub-categories and categories. During the analysis process there was a constant movement between the whole text and parts of the text to keep a sense of the whole material. The authors sought for both manifest and latent content in the unit of analysis. The manifest content being content close to data, and the latent content being more abstract, searching for underlying meanings of the text, all above according to the method of Graneheim and Lundman [13].

3. Results

Six female and eight male participants were included in the study. Nine of the participants were recruited from an earlier study from the research group, out of forty seven patients [14], and five out of twenty screened patients from the medical outpatient ward were included in the study.

The demographic data of the participants are shown in Table 2.

The participants' description of their symptoms when falling ill is presented in Table 3. The table consists of five categories of symptoms presented with quotes by the participants which describes the experiences the participants had of the symptoms.

Experiences of how symptoms affected their physical and social activities after the PE are presented below in text with quotes from the participants.

An overall theme was identified throughout the unit of analysis: "Whole life changed". Within this theme, two major categories were identified: "Pulmonary embolism changed me and my relationships" and "Changes in perception of physical activity". Each major category has sub-categories related to them, as shown in Table 4.

3.1. Whole life changed

This overall theme covers different aspects, described by the participants, of how the symptoms deriving from the PE affected them in the aftermath of falling ill. The results indicate that the lives of the

Table 2
Demographics of included participants, $N = 14$.

Female (n)	6
Male (n)	8
Age, median (range)	60 (47–70)
Months since PE at time for interview, median (range)	7 (3–34)
Living with another adult (n)	7
Qanadli Index %, median (range)	42.5 (5–52.5)
Right ventricular failure at admission (n)	5

PE pulmonary embolism.

Table 3
Experiences of symptoms when falling ill with PE as described by the participants in the study.

Dyspnea/shortness of breath	Respiratory associated pain	Fatigue
I did not get any air There wasn't enough air Like breathing through a straw It's like you can't get any oxygen Breathing was heavy I had to force myself to breathe to get any air	It was crazy painful I was in terrible pain It was a severe pain It was a heavy pain I had severe pain	I was completely exhausted I just got more and more tired An unnatural physical fatigue Very tired
Other symptoms	Diffuse symptoms	
High pulse Cough Palpitations Cold sweating Sweating	Something was not right I felt generally low (emotionally) Something was not right in my body I did not feel well at all in my whole body I felt really weird and freezing cold	

Table 4
Theme and categories with associated sub-categories.

Overall theme	
Whole life changed	
Category	Sub-category
Pulmonary embolism changed me and my relationships	Ending up in an existential crisis Redefinition of how to live my life Altered social relationships Strategies for moving forward in life
Changes in perception of physical activity	Symptoms affect and hinder physical activity Physical activity as a strategy to manage life Physical recovery takes time

participants had been affected in different ways. The PE and its symptoms affected them and led to changes in both themselves and in their relationships with others, as well as changes in perception of their physical abilities. This led to the participants trying to cope and reorientate in their new life after PE. As a participant said:

“My life has changed since that day, I can definitely say that...it's changed.”

Participant 3

3.2. Pulmonary embolism changed me and my relationships

This category contains descriptions of experiences of PE changing both the participants themselves, and furthermore their relationships with other people and comprises the sub-categories: “Ending up in an existential crisis”, “Redefinition of how to live my life”, “Altered social relationships” and “Strategies for moving forward in life”.

3.2.1. Ending up in an existential crisis

The event of falling ill with PE caused several of the participants to experience a fear of death and fear of recurrence that took a lot of energy in their daily lives.

Other feelings experienced were fragility, sudden awareness of their mortality, anxiety, and shock. Also feelings of self-blame were experienced concerning why they suffered a PE, and some of the participants felt a need for psychological support to overcome these unpleasant feelings about their new situation.

“A lot of things like that... which are worries... how will it be... things like that... then of course this was based on my fear of dying...”

Participant 6

“I want to go to a psychologist to learn how to deal with these feelings, because it has really left deep, deep wounds.”

Participant 12

3.2.2. Redefinition of how to live my life

The participants experienced feelings of frustration that their whole lives were affected, from work life to personal life. They experienced not having the energy and capacity to work full time, to travel for work, or even work at all. This led to changes in the way the participants looked at themselves. Another more positive aspect of change was experienced through redefining life. Various everyday moments received a new value in the context of the changes in the participants' lives, giving them the possibility of experiencing new things and seeing ordinary things with completely new eyes. This could be because the participants were not working as much as they used to under a period of time after the PE and having a near death experience which could lead to feelings of gratitude towards life.

“I still tried to keep going, doing what I was doing, but it was a double-edged sword...you want to live the life you lived before, but I didn't really have the energy to do that.”

Participant 2

“I value the small things, going out during the week...going out into nature and listening to birds and stuff like that, there's a clear...that that kind of experience, in nature, has been elevated on the 'worth scale'.”

Participant 14

3.2.3. Altered social relationships

The participants experienced that their whole family were affected by them falling ill with PE. Some of the participants tried to protect their family and friends by covering up facts about the severity of their disease as a way to relieve them and not to put more strain on them if they had other problems to attend to. On the other hand, the participants described experiences of family and friends that started to protect and guard the participants more after PE. At the same time some participants had concerns about what would happen to their family if they had died. For some of the participants it came as a shock that their family reacted with fear and worry and that it was a tough experience to carry one's family's fear when you yourself were in crisis. Many participants experienced that their relatives and friends became even more important as a social support network around them after having a PE. However, several participants experienced that the demands of being social became an obstacle to overcome and a burden instead. Also, some participants had guilty conscience when they had a loss of energy around domestic work and instead let their spouse do the work at home. On the other hand, one

participant described that changes in traditional gender roles came about in his family after the PE event.

“I did not understand how much it affected my son because I myself was so much in the process, you get so busy with this, how to fix it... but when I discover his fear... his terrible fear, there was no safety net for it.”

Participant 2

“You do not have to do everything as you, all the manly stuff, you can distribute your family commitments in a different way. Settle into it well.”

Participant 14

3.2.4. Strategies for moving forward in life

Both physical and psychological strategies that led the participants to being able look forward, to a life after PE. The participants coped with life through different strategies that were used to be able perform the activities in their everyday life. They described prioritization between activities, postponing activities or letting other people do their chores for them to avoid the strain the activities would place on them. Another strategy for the participants to be able to look forward in life and to reduce fear and worry was to build a social security net around themselves to use if a new PE event were to occur. For example, by always having the telephone near so that they could call for help if something happened or by including relatives or friends in a system that created a sense of security. Several of the strategies that the participants described were about mental focus, focusing on something else other than the PE. It could be focusing on the good effects of their anticoagulation medicine or engaging in a mindfulness group to learn to focus on the present. Trying to change their mindset about life was another strategy. Some participants described trying to adapt to the status of their current abilities instead of stressing recovery.

“I prioritize, and do the things I... I do not stress, I get to do whatever it is on Monday instead.”

Participant 7

“So I told my son that now you can call me once a day... if I do not answer you should come here...”

Participant 6

3.3. Changes in perception of physical activity

This category contains descriptions of different changes experienced of how physical activity has been affected due to the symptoms deriving from PE and comprises the sub-categories: “Symptoms affect and hinder physical activity”, “Physical activity as a strategy to manage life” “Physical recovery takes time”.

3.3.1. Symptoms affect and hinder physical activity

The participants described that they knowingly or unknowingly chose to avoid or decrease their physical activity due to not wanting to experience physical symptoms such as dyspnea, respiratory pain or extensive sweating. Different ways for achieving this were described, for example by avoiding taking stairs or taking the bus instead of walking or riding a bike. Another way of not triggering symptoms was to reduce the intensity of the activity performed, for example, when engaging in everyday activities like as walking the dog or taking regular walks. The participants also experienced that by avoiding symptoms, they increased their sedentary behaviour. The symptoms also led to the participants slowing down their activities with the consequence that every task at home took longer time to perform. Trying to pretend that everything was like it was before the PE was not at strategy that worked since the symptoms came regardless.

The symptoms triggered fear of death and inhibited physical activity and created a feeling of uncertainty concerning activity in general. This led to some participants choosing not to perform any physical activities even though they would like to. Others found that their body was functional, however, their fears held them back from fully participating in physical activity because of anxiety and worry. One way of trying to deal with the fear, as described by many participants, was to perform an activity, but at a lower intensity. Another way to choose activity was after the feeling of what felt safe and secure, like to choose slow walks instead of running. However, even though making these adjustments, physical activity still did not feel safe for all participants. Some participants described that even if you were a person used to engage in tough physical exercise before PE, you still chose to not do it anymore due to fear of what could happen if you have too much strain on the body.

“It is probably more the knowledge that I get so short of breath, that it feels difficult to breathe, that is, what should I say... inhibits you in a way so that you do not do it... you avoid it rather than trying.”

Participant 8

“There's a gnawing little suspicion, that you're a little cautious so that's probably what is holding me back a little, that has made me a little more cautious now to expose myself to exercise.”

Participant 11

3.3.2. Physical activity as a strategy to manage life

After the acute phase with experiences of extensive, mainly respiratory symptoms such as dyspnea and respiratory pain, the participants used physical activity in different ways to manage life after PE. One participant experienced that physical activity could be used as a way to survive after PE. The support of a leader, for example in a yoga group, strengthened the participant's sense of security in performing physical activity. Physical activity became a way to reduce stress and was also used for relaxation. Several participants described that falling ill with PE gave them a reason to make a lifestyle change in the direction of more physical activity and less sedentary behaviour after the acute phase. They described that they prioritised physical activity several times a week and that the physical activity led to them feeling better. Being able to affect their own recovery was seen as positive, instead of only sitting and waiting to get better. Some participants focused on everyday activities through work, for example by standing more while working at their desk, or by getting a dog to maintain physical activity in their life and to prevent recurrence of PE.

“I did what I was keen on, but hadn't done for a long time, I joined a yoga group. I also joined Weight Watchers, I was so incredibly focused on surviving, it was a theme.”

Participant 1

“We got a new little dog, so I've got [the dog] to go out with in the evenings and take a few little extra walks, in the morning and late in the evening, I've been able to increase [my physical activity] that way and it's good for my circulation too.”

Participant 5

3.3.3. Physical recovery takes time

Several participants shared experiences about the time of physical recovery. The range of time since falling ill among the participants was wide, giving a broad range of experiences on the matter of time to recover. Some experienced that they felt like they were still not the same as they were before the PE physically even though some time had passed. Others, with a longer time since falling ill, experienced that it

was a long process to get back to earlier physical status but that their physical status had clearly improved over time.

“Normally, I’m a sporty person on the verge of an elite exerciser... I like to be active... I have had an awakening to, it’s been more than three months since this happened, I’m still not restored in terms of fitness.”

Participant 14

“But it has taken time to come back again... to somewhere I was when I got sick in terms of fitness.”

Participant 2

4. Discussion

The findings of this qualitative study indicate that patients who suffer from acute PE are affected in many aspects of their life due to the consequences the symptoms cause, and this resulted in an overall theme of the study: “Whole life changed”. Moreover, two major categories, one focusing on changes of psychological and social nature as consequences of the symptoms of PE, and the other focusing on changes of perception connected to physical activity were identified in the unit of analysis, see [Table 4](#).

The results include descriptions of the different symptoms patients suffer from the onset of a PE event, and how these symptoms are experienced by the participants. To the best of our knowledge, this is the first study to present results on experiences of symptoms when falling ill with PE, and also the first time an extensive description on how the symptoms affect the physical and social activities of the participants during the recovery phase of a PE event are presented.

All participants experienced that suffering from PE changed them and their relationships. Several participants experienced that the psychological affection resulted in an existential crisis. Fear of death, feelings of fragility, sudden awareness of mortality, anxiety, shock, difficulties concentrating, and mental fatigue were described by the participants. This is consistent with the results Hunter et al. [17] found, that the psychosocial impact of PE is physically and psychologically challenging. High levels of anxiety that could be triggered by both physical and psychological factors, such as health anxiety and negative emotions, were found and the participants in the study reported being forever changed by the experience. Bennett et al. [18] found that the levels of health anxiety was unrelated to the clot burden, and this is confirmed by the results of the present study since the range of clot burden was vast (as measured with the Qanadli index, see [Table 2](#)) but the experiences of existential crisis among the patients were similar. Management of the emotional effect of PE, including increased knowledge of the disease, intervention focused on increased self-efficacy, for example regarding physical activity, discussion on expectations of recovery, health goals, perceived facilitators as described by Bandura [19] could be of use in the recovery phase to minimize the effect of existential crisis in PE.

The participants described that suffering from PE had changed them both mentally and physically and this led to changes in their self-image. Different strategies on how to cope with changes in life were described. Many participants experienced a need for protecting those close to them by not giving them all information on the PE disease. The strategy of omitting information has been previously described in literature and it is important to capture it when talking to patients who suffered from PE [8]. Not talking or sharing thoughts and worries about the disease could mean that the struggle with psychological distress is missed and opportunities for intervention are lost [8]. Some strategies that were described focused on practicalities to make everyday life work and on creating safety nets in life. Others were more focused on adaptation and coping both physically and mentally to be able to reorientate in this new life after PE. The results of the present study are consistent with the ones

found by Haynes et al. [20] in their study on strategies that plays key roles in ability to handle illness. They found that different coping patterns, support systems and to focus on other aspects of life rather than disease, helps redefining life after illness [20]. The participants of the present study found their different strategies by themselves, however, the health care system needs to identify the needs of the individual in the aftermath of PE, to be able to support the patient in their recovery process in the best way.

All participants experienced changes in their physical activity after PE. Persistent respiratory symptoms hindered the participants from being active, this since the symptoms were present at both housework and leisure time activity. Also, fear inhibited physical activity and created a feeling of low self-efficacy around activity in general. Fear of movement is a term used in patients with heart disease, both in the acute phase and during rehabilitation [21,22]. Fear of movement has been shown to be connected with lower training session attendance and lower muscle endurance in test situations [21,23]. An earlier longitudinal study on patients with PE, showed that patients chose to decrease their physical activity after the event due to fear of different symptoms such as: respiratory pain, dyspnea at exertion, and loss of energy [14]. Health care providers need to acknowledge the patients fears and thoughts on physical activity being harmful after PE. Support for how to manage any fear of movement should be offered in the recovery phase to avoid future sedentary behaviour and risks connected to a sedentary lifestyle.

Some participants used physical activity as a way to gain control of their lives, as stress reduction and for relaxation in the aftermath of PE. Considering the event as a reason to make positive lifestyle changes including increased physical activity levels were also addressed. Rolving et al. [7] found the same results in their study on coping with life in the aftermath of an acute PE. This indicates that if lifestyle changes can be discussed at discharge from hospital and/or at follow ups with health care providers, patients with PE could be encouraged to consider a lifestyle where higher levels of physical activity are present. This could give the patients with PE health benefits in the long term after an event.

Offering patients with PE rehabilitation covering both physical and psychological support is in line with the recommendations from the 2019 ESC Guidelines for diagnostics and management of acute pulmonary embolism that states: “The aims of an efficient follow-up strategy after PE should be to: provide appropriate care (exercise rehabilitation, treatment of comorbidity, behavioral education, and modification of risk factors) to patients with persisting symptoms.” [3]. How this follow-up should be structured is not yet established, however, according to results of earlier studies and confirmed by the present study it is important to give patients with PE tools to manage their respiratory symptoms and to offer psychological support before discharge. Also, a discussion about physical activity and exercise should take place before discharge with possibilities of follow-up [7,14,24,25].

The results concerning symptoms give us a new understanding of the experience of falling ill with PE, beyond the actual meaning of words as dyspnea, respiratory pain and fatigue. The participants described the experience of the symptoms at onset with their own words and described well known symptoms. However, fatigue and diffuse symptoms of “something not being quite right in my body” were also described. Fatigue was experienced by the participants both before falling ill, but also during recovery. Fatigue has been found as a symptom in one earlier qualitative study on PE and it is also known as a symptom in other cardiovascular diseases [7,26,27]. Fatigue has been studied in PE after clinical observations reported that patients treated with rivaroxaban had higher levels of fatigue than patients with other anticoagulation, however, no connection between fatigue and certain anticoagulantia were detected [28]. Fatigue has been found by O’Connell et al. [29] to be an important predictor to detect unsuspected PE in patients with cancer. The results of the present study among with earlier studies support that questions on fatigue are important when diagnosing PE. Fatigue is not mentioned as a symptom in existing guidelines [3,4].

In existing guidelines symptoms of PE are described but do not

include the impact the symptom has on the patient experiencing the symptom. It is important to acknowledge the patients' experiences of symptoms, it gives health care providers an opportunity to give information on how to manage their experienced symptoms.

In qualitative research, trustworthiness of the results is an important matter to raise. The terms credibility, dependability and transferability are used to describe the trustworthiness of the research process and the results achieved [13,30,31]. The credibility of the result of the present study is enhanced by the participants being a heterogeneous group with regards to age, gender, time since the PE and burden of the disease measured with the Qanadli-score, which contributes with a richer variation of experience. The analysis of the material being done by four researchers, that reached agreement on the results through the whole analysis process, also contributes to the credibility of the study. In addition, the categories cover the material well and an over-all theme could be formed. The use of a semi-structured interview guide enhanced the dependability of the results since all participants were asked the same questions. The issue of transferability of the results of this study to other PE populations has to be judged by the readers. However, by the context of this study being well described on matters of participants, settings of the study, the analysis process, and the use of quotes in the result section, could increase transferability to other similar PE populations.

A limitation of this study is that nine out of fourteen participants were recruited from an earlier longitudinal observational study on respiratory symptoms and physical activity in PE. This participation might have had impact on these participants thoughts on physical activity, however, this connection is not established in the study. Another limitation is that the participants were recruited from an earlier study and not consecutively from the hospital which could affect the sample and be less generalizable to other PE populations. All participants were recruited from the same university hospital, and this could be considered as both a strength and a limitation. A strength since the participants all received the same care, however, a limitation since not including patients from smaller hospitals could have a negative impact on the generalizability. The use of the method of content analysis by Graneheim and Lundman [13], and following their recommendations for the method, enhanced the credibility and dependability of this study.

5. Conclusion

To the best of our knowledge, this is the first study to present results on experiences of symptoms when falling ill with PE, and also the first time an extensive description on how the symptoms affect the physical and social activities of the participants during the recovery phase. The study contributes new knowledge on the experiences that patients with PE go through during their journey of illness and recovery. The results indicate that patients with PE need support from the health care system to manage both physical and psychological symptoms in the aftermath of their illness. Further research is needed to find out how the optimal rehabilitation for these patients should be designed.

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.

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