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Full Length Article

Coping with everyday life and physical activity in the aftermath of an acute pulmonary embolism: A qualitative study exploring patients' perceptions and coping strategies



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ABSTRACT

Introduction: There is an increasing awareness that patients with acute pulmonary embolism (APE) suffer long-term consequences like fatigue, anxiety, and reduced physical capacity. However, we lack knowledge on how patients manage everyday life and physical activity following an APE. The study aimed to explore how patients experience and cope with daily life and physical activity in the first year following an APE.

Materials and methods: Semi-structured individual interviews were performed with 16 patients, 6–12 months after a first-time APE event. The methodological framework for the analysis was interpretive description.

Results: Most participants had managed to return to their daily routines at the time of the interview, although some struggled more than others. They experienced their daily life and well-being to be negatively affected by fatigue, anxious thoughts and bodily hypervigilance, and were concerned about themselves, their family, friends and life situation. In many cases, they lacked advice from health professionals. Participants used various strategies for re-engaging in everyday life and physical activities, reflecting their physical and mental resources, contextual support, and different life situation. One central theme was the challenge of coming to terms with a more vulnerable identity, and adjusting this identity to established family and work roles.

Conclusions: Most participants had managed to resume their everyday life 6–12 months after the APE event, but were still limited in their daily activities and found it difficult to sustain a sufficient level of physical activity. They described different barriers and facilitators, which should be addressed in future rehabilitation interventions.

1. Background

Acute pulmonary embolism (APE) is the most serious clinical manifestation of venous thromboembolism (VTE), and a major cause of mortality, morbidity and hospitalization in Europe [1–4]. APE has an estimated 30-day all-cause mortality rate ranging from 9% to 11%, and a 1-year mortality rate as high as 30% [3,5]. The immediate treatment of APE with anticoagulants is considered highly effective [2] and, as a well-treated acute illness, clinicians expect the majority of patients to recover without any sequelae. This has been contradicted by a number of cohort and cross-sectional studies showing that the long-term consequences of an APE event are common in terms of persistent dyspnea, impaired physical capacity and decreased health-related quality of life [3,6–9]. These residual symptoms and deficits, which are present in up

to 50% of patients after an adequately treated APE are currently defined as post-APE syndrome [3,8,9].

The increasing awareness of these long-term sequelae of APE has led to a growing focus on patient-related outcome measures to evaluate the patients' physical and mental well-being. In order to gain a deeper understanding of how people experience and cope with APE, as well as its psychosocial impact, it would be beneficial to acquire in-depth knowledge from a patient perspective. With the help of a specialized librarian a systematic review of the literature was performed using Medline, Cinahl and Embase, and further, screening of reference lists of the identified studies (the search strategy is provided in Supplement 1). Only a few qualitative studies, performed on a mixed population following either APE or deep vein thrombosis, have explored patients' experiences of the impact of a VTE event [10–13]. These studies report

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that some patients felt VTE as a traumatic, life-threatening event, and in particular, fear of recurrence was found to be an important source of psychological distress, leading to behavior modifications [11,13]. We identified one study targeting a population of patients with APE alone [12], exploring the long-term psychological consequences up to 60 months after the event. The patients experienced APE as a life-changing, distressing event, leading to behavior modifications with reduced physical activity and in some cases, signs of post-traumatic stress.

While the above research has provided some insight into the negative long-term aspects of VTE, there is a lack of knowledge about the patients' experiences of the early phase (< 1 year) following an APE, where they may be more vulnerable due to the acuteness of the disease. Equally important, there is a lack of knowledge on what strategies patients use to manage return to daily living and physical activity following an APE. This qualitative study is nested within a randomized controlled trial (RCT) investigating the effects of a rehabilitation intervention, including nurse consultations and a physiotherapist-guided home-based exercise program on a number of outcomes [14].

2. Aim

The aim of this nested qualitative study was to explore how patients with a first-time episode of APE experience and cope with daily life and physical activity during the first year following the APE event.

3. Methods

3.1. Methodological approach

The methodological framework of this study was interpretive description (ID) [15,16]. An ID study is a smaller scale qualitative investigation of a clinical phenomenon for the purpose of capturing themes and patterns within subjective perceptions. The intention is to generate an interpretive description to inform clinical practice around complex clinical questions [15,16]. The qualitative method used was semi-structured individual interviews. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [17].

3.2. Study setting

The setting for the study included three regional hospitals and one university hospital in Denmark. Health care services in Denmark are primarily free of charge and independent of the individual's income and insurance.

3.3. Study participants

The participants in were a selected sample of participants included in a multi-center RCT investigating the effect of an eight-week home-based exercise program compared to a control group receiving only nurse consultations [14]. The inclusion of participants in study was initiated half way through the RCT (15th of August 2017), and thus only the last 70 patients included in the RCT were eligible for participation in the present study. A purposive sampling method was used and participants were recruited from all four hospitals participating in the RCT, giving consideration to variety in type and cause of APE and in demographic characteristics to facilitate maximum information and sufficient data richness [15]. The included participants were required to have experienced a first-time episode, objectively verified APE, received anticoagulation treatment, been between 18 and 80 years of age, and been capable of speaking and understanding Danish. The exclusion criteria were: severe comorbidities, not being able to perform a shuttle-walk test, other diseases being the primary diagnosis, and cognitive impairments [14].

Physiotherapists screened participants for eligibility, according to purposive sampling techniques, when attending their final physical test in the RCT study 6–7 months after their APE event. Participants were informed about the purpose and methods of the qualitative study after completion of their final test in the RCT study. If they gave an initial consent they were contacted by telephone by one of the researchers (NR, BB) within a week, and the information and the details of the study were repeated. In cases of acceptance, the interview took place at one of the hospitals or at the participant's home, depending on their preference.

3.4. Data collection

Data were gathered using individual, semi-structured interviews [18]. The interview guide was designed using information obtained from a literature review and on knowledge-based experience with the patient population (see Supplement 2). NR and BB, both of female gender, PhDs and experienced physiotherapists within the specialty, performed the 16 interviews from September 2017 to May 2018. Six of the participants chose to have a spouse present at the interview. Seven of the participants had no other co-morbidity besides the APE, whereas the remaining reported cardiovascular disease as the most common co-morbidity (e.g. previous DVT, heart failure, myocardial infarction). The majority of participants (thirteen) were vocationally educated or had held jobs as unskilled workers. The last three participants had higher level education. See Table 1 for further participant characteristics. Two pilot interviews were performed; but since only minor changes were subsequently made to the interview guide, both interviews were included in the data. Four people, one being the first author, transcribed the interviews in accordance with an explicated transcription guide [18]. The first author checked all transcriptions for quality. The interviews were audio-taped and transcribed verbatim shortly afterwards, as the analysis was a continuous on-going process [15]. The duration of the interviews was between 45 and 90 min.

3.5. Data analysis

The analysis was a dynamic process using a step-by-step approach, and the authors went back and forth in the analytical process to question, define, decide, and conclude as recommended by the ID approach [15]. Initial readings of the transcriptions were performed to get a sense of the overall material. The first analytical interpretations were open and broad preliminary categories derived from data using a comparative approach from parts to the whole and vice versa [15]. All three authors analyzed the meanings, experiences and thoughts from each

Table 1
Participant characteristics.

| Participant pseudonym | Gender | Age | Months since APE | Marital status | Job status | Treatment group in RCT |
|-----------------------|--------|-----|------------------|----------------|------------|------------------------|
| Dorit | Female | 67 | 12 | Married | Retired | Usual care |
| Laurits | Male | 34 | 8 | Married | Employed | Intervention |
| Jutta | Female | 64 | 6 | Alone | Retired | Intervention |
| Axel | Male | 63 | 6 | Married | Retired | Usual care |
| Ludvig | Male | 78 | 9 | Alone | Retired | Usual care |
| Nikolaj | Male | 64 | 7 | Married | Retired | Usual care |
| Inger | Female | 62 | 9 | Alone | Employed | Intervention |
| Kresten | Male | 68 | 7 | Married | Retired | Usual care |
| Peter | Male | 77 | 8 | Married | Retired | Intervention |
| Helene | Female | 70 | 7 | Married | Retired | Usual care |
| Jan | Male | 68 | 9 | Married | Retired | Usual care |
| Eskild | Male | 74 | 9 | Married | Retired | Usual care |
| Bonnie | Female | 53 | 8 | Married | Employed | Usual care |
| Valther | Male | 47 | 7 | Married | Employed | Intervention |
| Christina | Female | 70 | 8 | Married | Retired | Intervention |
| Mikkel | Male | 55 | 7 | Married | Employed | Intervention |

participant under each category and the overall findings within each category were described in prose and illustrated by quotations, to support essential findings associated with the theme. The findings were critically analyzed and the final analysis resulted in five themes.

3.6. Ethics

The Regional Ethics Committee of Central Denmark Region approved the study (reference no. 1-10-72-243-15). Participants received written and oral information about the study and informed written consent was obtained prior to participation. Participants were informed that any quotations used in the documentation of the findings (here displayed in italics to clearly differentiate them from the rest of the text) would be anonymized and pseudonyms used, although the participants themselves might recognize their own quotations. Further, they were informed that withdrawal of consent could be done at any time without consequences for present or future treatment.

4. Results

The overall theme was named “Everyday life after an acute pulmonary embolism”, and the other four themes were closely related to, and influenced, the overall theme in complex and dynamic ways as shown in Fig. 1.

The four interrelated themes consisted of factors, experiences and emotions affecting how participants managed to resume their everyday life following the APE event. Each theme included subthemes, as displayed in Table 2. Within each theme a spectrum of responses was seen, meaning that elements that affected and frustrated some participants might not be an issue for others.

4.1. Theme 1: everyday life after acute pulmonary embolism

Most participants expressed that their everyday life had been negatively influenced by the APE event and its consequences. The way the APE had emerged, and how the health care system had handled their situation in the acute phase, greatly influenced the participants' trajectory and well-being afterwards. Some were worried at not being able to notice symptoms of a recurrent APE in time, whereas others feared that the health care system might not take their symptoms seriously in case of recurrence. By the time of the interview, the participants still experienced their daily life to be affected by fatigue, and daily chores were occasionally interrupted by anxious thoughts. The participants tried to cope with their situations using a variety of strategies, with the

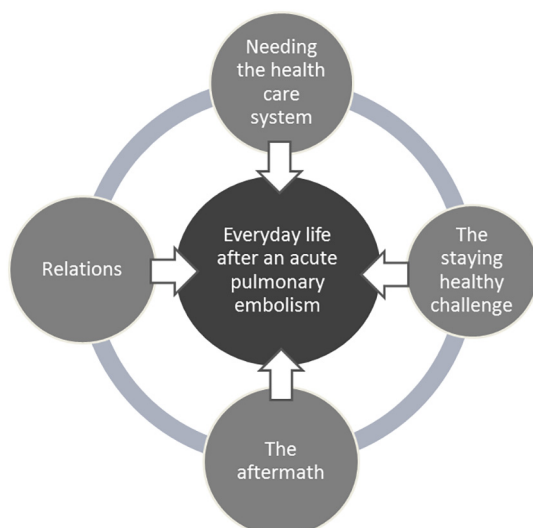


Fig. 1. The themes and their relationships.

Table 2

Overview of themes and subthemes.

| Major theme | Sub themes |
|--|---|
| Theme 1. Everyday life after an acute pulmonary embolism | <ul style="list-style-type: none"> • What's wrong with me? • I changed identity |
| Theme 2. Needing the health care system | <ul style="list-style-type: none"> • Going through the mill • Medication as a lifesaver |
| Theme 3. The aftermath | <ul style="list-style-type: none"> • My strength was depleted • Anxiety and distress • Being alert to bodily signals |
| Theme 4. The staying healthy challenge | <ul style="list-style-type: none"> • Coping with the aftermath • Taking health for granted |
| Theme 5. Relations | <ul style="list-style-type: none"> • Handling physical activity • Involving next of kin • Family and work roles |

aim to resume a normal everyday life.

4.1.1. What's wrong with me?

The participants reported very different experiences with respect to the severity and acuteness of symptoms and the course of events prior to diagnosis. Symptoms of increasing breathlessness, fatigue, and pain in the chest, back or leg, were described by most as the initial signs of APE. For several participants, their symptom complaints did not initially result in the correct diagnosis, but instead, they were told to wait and see, or they underwent differential diagnostic examinations, delaying correct diagnosis and treatment. This journey through the healthcare system resulted in confusion, uncertainty, and distrust of in the care provided. Some chose to change their GP following this experience.

“My neighbor said we should go see the doctor. I said no, I had this problem with trusting them; I thought, I don't want go to the doctor with breathlessness, and hear them say once more to go home and wait.”

(Inger)

The participants suffering only vague symptoms like mild breathlessness or fatigue were shocked by the need for instant hospitalization and treatment when APE was finally diagnosed, because they had not felt critically ill.

“And then in the evening they called me from the hospital, they were looking at my pictures, and they could see bloodclots in both my lungs. I was told to drive to the hospital straight away, and they had already been notified of my imminent arrival. And I hadn't felt a thing! So that was quite a shock.”

(Kresten)

4.1.2. A changed identity

For several participants, it was their first acquaintance with a serious and potentially life-threatening disease, and this negatively impacted their self-image. At one end of the spectrum was Axel, a widowed senior citizen, who felt the bloodclots had not changed his life one bit, whereas others found it difficult to adapt to a more vulnerable self-image. Resuming the daily routines following the APE event seemed to have importance for re-establishing one's identity.

“Before I got these bloodclots, I never got tired. I was like a Duracell battery; I could just keep on going all the time. And I can't now, still [...] And the others, they can see it, they can see it in my eyes, they say. And I feel like, no, that's not me. But I have to accept it.”

(Dorit)

Overall, participants had re-established their daily routines by the time the interviews occurred. This seemed to be a way of finding comfort and feeling more secure, trying to normalize everyday life again. However, once in a while, the troubling thoughts and worries of the APE would surface.

“You can sometimes be tired of the daily humdrum – but there is also something comforting in the fact that things can go on. Because all of a sudden, you can see that you can be fragile, right? From one day to the next, you are kind of left out. Can you handle your job and things like that.”

(Mikkel)

4.2. Theme 2: needing the health care system

The participants expressed a need to be met by health care professionals who had knowledge about their situation and took charge of their course of treatment. Due to the diverse ways the APE event entered the participants' lives, some participants felt confused and insecure during and after their interaction with the health care system (GP and/or hospital), whereas others had experienced an efficient health care system, where the right actions were taken at the right time. Factors like being taken seriously by the staff, the timing of health care interventions, and consistent information about their condition seemed to be of utmost importance for a reassuring journey through the health care system.

4.2.1. Going through the mill

Although participants expressed feeling safe at the hospital with health care professionals who knew everything about their condition, at the same time they compared their experience to going through a mill or a machine. A number of medical examinations were performed and lots of information was given over just a few days of hospitalization, which for some participants induced feelings of frustration and insecurity.

“I went through an enormous number of examinations that evening and night, you know...they checked everything, cardiogram and everything, right? And it was just like I was inside a running mill (laughs). With oxygen and examinations and medication and...”

(Inger)

Receiving the right level of information about their condition, and at the right time, seemed important for the participants to be able to subsequently cope with their new situation. Having the opportunity to talk to a specialized nurse after discharge was perceived as valuable and reassuring.

“Well, it was because there was so much information right after it happened, and I have to say, it was...it was too much for you. Way too much!”

(Wife of Nikolaj)

“The nurse was actually the first person to provide kind of an overview of what all this was about. I didn't get that at the hospital. No, I didn't really. And I was so grateful that I had that lifeline I could call, and I knew they [the nurses] were there, right?”

(Inger)

The lack of a concluding dialogue with the doctor, to get closure on the course of the disease, was emphasized. Some also requested a new scan to make sure the APE was gone when terminating medical treatment, but were told that this was irrelevant.

“Well, I think it's a little strange just from one day to the next, to just stop [medication]. Without any sort of control. [...] Because they just assume, then, that my bloodclot is gone, right? They don't check and see if it's there anymore, do they?”

(Axel)

4.2.2. Medication as a lifesaver

The participants expressed a feeling of being on safe ground as long as they were on anticoagulant medication, because in that period, they

felt they were unlikely to experience a new APE. They perceived side-effects as insignificant and unimportant with respect to their ability to resume daily activities. When stopping medication, the participants were distressed and worried due to fear of developing a new APE, and they lacked information from the doctors regarding the rationale for stopping the medication.

“The doctor wanted to take away my Marevan, but then I said “I really wouldn't be happy about that!” [...] Imagine if I got one more, and that's what I told him. He said, well, then we'll just start all over again. And I replied, “Yeah right, if I'm alive!”.”

(Dorit)

A few participants received a letter from the hospital concerning the termination of their anticoagulant medication, which contradicted the previously received information at the hospital. This caused confusion and left the participants feeling insecure about who had control of their treatment.

4.3. Theme 3: the aftermath

Lack of energy and fatigue were expressed as the most common conditions in the aftermath of the APE event, and also mental well-being was conveyed as being negatively affected in several ways. Although the symptoms of dyspnea and pain experienced at the time of the APE event had mostly diminished or disappeared at the time of the interviews, an increased alertness to bodily signals indicating a new APE was still voiced by participants. Laurits, a father of two small children, still experienced dyspnea and weekly attacks of severe chest pain in addition to the increased alertness; he felt it was difficult for him and his family to resume everyday life.

4.3.1. My strength was depleted

Lack of energy and fatigue were experienced in different ways by the participants; some described it as a bodily exhaustion forcing them to rest during the day, some felt an increased need for sleep, while others, primarily men, described it as lacking strength when performing physically demanding tasks or sports. This caused frustration and sadness because it was a daily reminder of the APE event and a sign that they were still not back to normal, impacting their self-image and identity.

“[...] you can reproach yourself for not getting the things you want done. Sometimes, you can get a bit annoyed [...] You can say to yourself in the morning, now you are going to do this and that today. But I never get around to it.”

(Peter)

4.3.2. Being alert to bodily signals of an APE

Almost all the participants had an increased alertness of bodily signals that could indicate a new event. If signals emerged, they would get anxious, being reminded of “the little black ghost”, as Eskild, one of the participants described it. Most participants managed to cope with the bodily signals using a watch-and-wait strategy, or using distraction by engaging themselves in an activity to get their minds off the symptoms. Shortness of breath during exercise or physical activity was however not considered a signal of a new APE, as participants found this to be distinguishable from the breathlessness experienced at the time of the APE event. However, only a few participants actually engaged in high-intensity physical activity on a regular basis at the time of the interviews, and they were those who had been the most worried about exerting themselves when resuming their sports.

“I have been alert to this! Could anything happen, if I put stress on myself? Could a new embolism suddenly emerge, which would be fatal? If it's fatal I don't have many minutes to react. So I've had the thought.”

(Mikkel)

4.3.3. Anxiety and distress

The participants' mental well-being was compromised in different ways by the APE event. Some described feelings of being more fragile or sensitive, and found themselves worrying and ruminating.

“Well, I'm not usually one to cry easily, but I can just feel so sorry for myself all of a sudden. [...] So I definitely think my mental state has taken a blow.”

(Dorit)

Some participants described how anxious thoughts disturbed their sleep. Others complained about changed sleeping patterns, but primarily attributed this to the fatigue described previously, forcing them to sleep during the day.

“Then, suddenly, one night it can take two or three hours before you can sleep. And you can also wake up. Like one night I woke up at 5 a.m., I think. Then I got up, walked around and drank some water, and I couldn't get back to sleep after that. Then you ruminate about all kinds of things.”

(Nikolaj)

The influence of the APE on mental health affected not only the participants' quality of life, but also had a negative effect on their social life and their surroundings. For instance, travelling abroad, even with a partner, was perceived as unsafe by several participants, while others felt that participating in social events was not as manageable as before.

4.3.4. Coping with the aftermath

The participants used different strategies to cope with the aftermath of the APE in everyday life. In addition to strategies for maintaining a healthy lifestyle, it was also a matter of strategies related to living with the underlying presence of “the little black ghost”, accepting their new, more fragile self-image, and handling feelings of anxiety in stressful situations. Some of the typical coping strategies were keeping it at a distance, being defiant, and using humor.

“I have quite a good sense of humor, and I can use that a lot. And I have a couple of girlfriends where we kind of, well we don't exactly make fun of the situation, laugh at the disease, but we can sort of turn it around. And if you don't have a little dark humor when you're in the hospital, then... (laughs)”

(Christina)

Similarly, participants who felt their daily routines were impeded by the APE due to worries or fatigue, described different kinds of strategies to manage practical tasks. One strategy was doing less than planned, or doing a task in smaller steps. Another strategy was using the mind to overcome the anxiety, as described by Bonnie, who experienced panic-attacks the first time she went grocery shopping on her own:

“My disease will not stop me from doing things. I've used that one mentally sometimes. My disease doesn't care about whether or not I just dropped that shopping trolley. But I do. My disease shall not take over my life.”

(Bonnie)

4.4. Theme 4: the staying healthy challenge

Following the APE event, the majority of participants had reflected upon their lifestyle and how their food and exercise habits could influence future risk of disease. Different strategies were attempted to adopt a healthier lifestyle, but most found this difficult to maintain. Previous routines and a social network seemed important to sustain an active lifestyle following the APE.

4.4.1. Taking health for granted

Participants described an increased awareness of the importance of

a healthy lifestyle after the APE event, and some felt they had been taking their health for granted. This caused some to reflect and in some instances to blame themselves, whereas others were already paying attention to their diet due to e.g. diabetes, or chronic illness of a spouse. Many expressed an extra attention towards limiting alcohol intake due to the anticoagulant medication.

“I was a smoker once, a heavy smoker. I've also..., I haven't been an alcoholic, but damn, we've had a party. One could blame... I could blame myself for all that smoking.”

(Peter)

Their new situation in combination with insight into their illness became an eye-opener for some participants regarding their level of physical activity.

“Because I can see now that it is important in a completely different way to maintain my physical fitness, for the good of my health, too. And I never saw that before.”

(Inger)

4.4.2. Handling physical activity

The different strategies used to resume physical activity reflected the various life settings, conditions and motivational factors of the participants. Those with years of solid exercise routines or who engaged in physical activity with friends, family or a sports club seemed to be those who found it the easiest to overcome barriers to being physically active.

“Well, it's good [being in a sports club]. You get out and socialize, right? You walk with others and talk, and we walk fast. There are a couple of us who say, “Let's get the heart rate up”, when we're walking.”

(Axel)

Some of the participants who were anxious about exercising alone, or who were generally not familiar with exercise routines, were not very physically active after the APE. Others found their own strategies to keep up an active lifestyle:

“I can honestly say, I don't walk away from the road. I don't go into the woods for a walk, unless someone is with me.”

(Peter)

4.5. Theme 5: relations

The APE did not only affect the participants, but also influenced their surroundings to various degrees. The participants felt that their family and friends had to make an extra effort to maintain daily routines and social life because the participants themselves were challenged by fatigue and anxiety. Just as importantly, family and friends were also negatively influenced because they were often just as worried and anxious as the participants were themselves. The different reactions of family and friends affected the participants' ability to manage their life situation, identity and family roles after the APE, both in negative and positive ways.

4.5.1. Involving next of kin

Spouses or close relatives were involved in the course of the disease to different extents. Some spouses were very involved and supportive, some couples handled the disease like a team, whereas others chose to protect their spouses and go to the consultations with their doctor alone, to shield their spouses from emotional distress.

“No, my wife hasn't been very involved. I go [to the hospital] by myself, I haven't wanted her there. I just tell her about what has happened and stuff like that...I think she will get too emotional, right?”

(Jan)

Talking to family and friends about the APE event and the reactions

and experiences following the event seemed to be helpful in terms of processing the experience, and getting on top of things again. Some engaged with their spouse to discuss worries; others used their friends or exercise companions.

4.5.2. Family and work roles

Often the participants perceived their families as more anxious and worried than themselves, and this could sometimes be an obstacle for the participants in re-establishing everyday life and their usual family roles.

“My family and our friends are very worried. And that irritates me, because I’m not that old. Don’t worry about me! Like last year, we were supposed to go see starling magic in the autumn, but no-one would go because I’d had these bloodclots. That annoyed me.”

(Dorit)

Some participants who had previously been those in charge at home were suddenly vulnerable and in need of support.

“Well, Jan has been the rock in our family. He’s never ill. I’ve had diabetes since I was 20 years old, and now suddenly it’s the other way round.”

(Wife of Jan)

Similarly, work roles could change for those who were still in the labor market, like Inger, who found herself deprived of her usual responsibilities and tasks when resuming her job after a period of sick leave. Different strategies were used by the participant’s family, friends and colleagues to help the participant return to usual roles, like taking over daily chores for a period, or being supportive during exercise, or providing a flexible return to work.

“It’s been fine, it’s been great to get going again. Also, that it’s been possible to increase [work tasks] gradually. [...] Just to put your mind to something else other than the disease. I think you recover by going to work.”

(Laurits)

5. Discussion

The aim of this qualitative study, embedded within a larger RCT, was to investigate and describe thoughts, feelings and experiences of patients in the early recovery phase following an APE event, with special attention to strategies for resuming everyday life and physical activity. The participants experienced the perception that the health care system encouraged them to cease care-seeking quite quickly which caused worries, especially anxiety associated with a recurrence which emerged periodically, and they lacked the opportunity to communicate and interact with a specialist in APE when terminating their medical treatment. Most participants had managed to return to their everyday lives and daily routines at the time of the interview, 6 to 12 months after the APE event. Still, they experienced their daily life and well-being to be negatively affected by fatigue, anxious thoughts and bodily alertness, and they were concerned about themselves, their family and friends and their life situations.

Participants used a variety of strategies for re-engaging in everyday life activities, sports and social life, reflecting their physical and mental resources, contextual support, and different life situations. Seeking support from family or friends, resuming work and exercise routines quickly after the event, and adopting an attitude of distraction, defiance or humor, were all strategies used for managing everyday life, in order to cope with the presence of “the little black ghost” lying just beneath the surface. These are universal human strategies, commonly described in the literature for coping with chronic illness [19].

At the time of the interview, the awareness of the risk of recurrence seemed to have lessened, and rather, participants described the risk of disease as becoming more salient during specific time periods (e.g. at

night time) or with specific events (e.g. when travelling abroad). A similar pattern was described in the study by Etchegary et al. [10], but it differed from the findings of Hojen et al. [13], where adolescents, having experienced an APE, described a permanent awareness as “it is always lying in wait”, even 5 years after the event. The reasons for this discrepancy may be due to the older population in our study (approximately 50–75 years of age). Several of our participants had previous experience with critical illness, either themselves or next of kin, and thus might already have developed strategies for coping with critical illness. This is consistent with the literature exploring the consequences of VTEs [10,11].

One central theme, underlying many of the thoughts and feelings described across subthemes, was the more existential challenge of coming to terms with a new and more vulnerable identity, and adjusting this identity to established family and work roles. This is a well-known phenomenon within the field of chronic illness, described by Bury et al. as ‘biographical disruption’ [20]. The participants’ efforts to achieve transition back to everyday life and re-establishment of self-identity are central to the construction of an alternative reality, where the illness is incorporated into everyday life [20,21]. Despite the participants’ intentions of returning to normal life and routines, the existential anxiety was present to various degrees in their lives, also when being physically active. This finding has also been reported in studies where patients have had diseases related to essential body organs [22] indicating that this is an important element in treatment and involvement.

The participants’ experiences of the encounter with the health care system revealed a number of problematic issues. Several participants distrusted their GP after the APE event, due to a delay in achieving the correct diagnosis and timely initiation of treatment. This finding corresponds to the findings of Hunter et al., where participants similarly felt alone and let down by services, and developed distrust in their doctors due to a delayed diagnosis [11]. Additionally, our findings on the need for timely and comprehensible information, having a lifeline and someone taking charge, and being treated respectfully and as a human being by the health care system, are similarly described in the studies by Noble et al. [12] and Hunter et al. [11].

5.1. What does this study add

Our study specifically aimed to explore the strategies used by the participants to resume everyday life and physical activity. The focus on physical activity is important, as this will hopefully provide health professionals with an in-depth understanding of the human processes underlying the challenge of maintaining or initiating a healthier and more resilient lifestyle after the initial APE.

The participants described coping strategies similar to those reported for other patients with critical illness (e.g. cardiac disease or cancer), like using humor, distracting oneself with activities or an attitude of defiance. In terms of returning to physical activities, it seemed that having the support of family and friends or being in a sports club facilitated regular participation in physical activities. The role and importance of social relations in influencing health behavior is established [23], so both the individual and their families/communities should reflect upon how to support the participant’s process of becoming ‘normal’ again. Although most participants did not perceive themselves as being afraid of exerting themselves following the APE, several expressed that performing physical activity with others, or where others could see them (e.g. walking by the road instead of in the woods), was also a way of feeling safe. These findings indicate that although the participants generally had returned to physical activities to some extent, the fear of being struck by a new APE event during exercise was present at some level.

5.2. Strengths and limitations

This study has several strengths. First, to our knowledge, it is the only study of its kind to provide a qualitative, in-depth description of the experiences, thoughts and feelings of people in the early phase following an APE event, and explore the strategies used to resume everyday life and physical activities. This knowledge is important considering the need to improve future practice for this population. When designing rehabilitation programs, we need to know the needs, challenges, strategies and motivational factors influencing the lives of those affected and thereby include these elements in a rehabilitation program to ensure patient involvement and relevance. We included a relatively large sample size of 16 participants with varied backgrounds regarding age, gender and social circumstances (work and marital status), and symptom severity, achieved by both convenience and purposeful sampling [15]. Although this is a strength, it should be emphasized that the population was a sub-sample of patients volunteering for participation in an RCT including a home-based exercise intervention. These are typically patients with surplus energy, social resources (e.g. spouse), and a desire to exercise, which could limit the transferability of our results. It should further be noticed that the included patients had a closer follow-up and more interaction with the health care system due to the RCT design, than patients not enrolled in the study. This may have affected their experiences and concerns, as they have received more education about their condition than usually provided. Nevertheless, our findings were very similar to those of other studies in this field, and as discussed above, we believe our results reflect the general challenges experienced by a broader population of patients.

5.3. Perspectives and implications for research and practice

National and international guidelines primarily focus on the biomedical treatment of APE, and no recommendations of physical or psychological rehabilitation are provided [2]. The findings of our study strongly indicate that rehabilitation focusing on physical and mental health is important and necessary, as many continue to suffer physically and mentally and therefore, also experience social consequences similar to those seen in patients with other chronic diseases [24–26]. In those populations, biopsychosocial rehabilitation has been part of the treatment guidelines for several years, and we therefore recommend that this should be initiated for the APE population as well. Our findings are supported by the findings of both qualitative studies and cohort studies in the field [3,7,9,10,12,27]. Two of the authors (NR and BB) are currently running a multicenter RCT testing a rehabilitation intervention comprising a nurse consultation and a home-based exercise program, the results of which will be published in the near future [14]. In addition to this, a qualitative study of the stakeholders' perspectives of the intervention (patients and health care professionals) will also soon be published. We believe that this study, together with the results of the RCT and the stakeholders' perspectives, will shed light on how we can provide optimal integrative rehabilitation for this group of patients.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.thromres.2019.06.007>.

Contributions

All authors designed the study; NR and BCB performed the interviews; all authors analyzed and interpreted the data; NR and BCB drafted the manuscript and all authors critically revised it.

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