



Swansea University
Prifysgol Abertawe



Cronfa - Swansea University Open Access Repository

This is an author produced version of a paper published in:
British Journal of Health Psychology

Cronfa URL for this paper:
<http://cronfa.swan.ac.uk/Record/cronfa30100>

Paper:

Hunter, R., Lewis, S., Noble, S., Rance, J. & Bennett, P. (2016). "Post-thrombotic panic syndrome": A thematic analysis of the experience of venous thromboembolism. *British Journal of Health Psychology*
<http://dx.doi.org/10.1111/bjhp.12213>

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence. Copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder.

Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

<http://www.swansea.ac.uk/library/researchsupport/ris-support/>

“Post-Thrombotic Panic Syndrome”: A thematic analysis of the experience of Venous-
Thromboembolism

Hunter, R.,^{1*} Lewis, S.,² Noble, S.,³ Rance, J.,¹ & Bennett, P. D.¹

¹Department of Psychology, Swansea University, Wales, UK

²Aneurin Bevan University Health Board, Wales, UK

³School of Medicine, Cardiff University, Wales, UK

**Correspondence should be addressed to Dr Rachael Hunter, Department of Psychology,
Swansea University, Singleton Park, Swansea SA2 8PP (email 130333@swansea.ac.uk)*

Abstract

Objectives: Venous thromboembolism (VTE, including deep vein thrombosis (DVT) and pulmonary embolism (PE) is a serious, potentially traumatic, life-threatening condition and a major cause of mortality and morbidity. The aim of this study was to explore patients' experiences of VTE and its psychosocial impact.

Methods: Audio-recorded semi-structured interviews with a purposive sample of 12 participants who had experienced a first-time DVT or PE within the previous 6 months. Interviews were transcribed and thematically analysed.

Results: Four key themes with 10 sub-themes were identified. The major themes were: VTE as life changing and traumatic; living with uncertainty and fear of reoccurrence; feeling let down by health services; positive changes and outcomes. The content of themes varied according to age at time of VTE and participants' experiences of diagnosis and treatment.

Conclusions: The data demonstrates the psychosocial impact of VTE as life-changing, encompassing a dynamic duality of trauma and growth. The findings highlight a potential role for health professionals in identifying and supporting individuals at risk of post-traumatic stress, and targeted interventions to enhance psychological well-being and recovery, and reduce distress.

Venous thromboembolism (VTE) is a clot in the venous system, most often occurring in the leg as a deep vein thrombosis (DVT) which can travel to the lungs, causing a pulmonary embolism (PE). It has an incidence rate of 1-2 per 1000 persons in Western populations (Beckman, Hooper, Critchley, & Ortel, 2010) and mortality rates after first-time DVT and PE of 6 and 12 per cent respectively (White, 2003). Around 25 per cent of those affected will experience further events over the subsequent five years (Heit et al, 2000). Between 20-25 per cent of those affected will go on to develop post-thrombotic syndrome (PTS) (Yamaki et al, 2011); up to 4 per cent will experience chronic thromboembolic pulmonary hypertension. Risk for conditions, and fatality, increases with subsequent VTE. These complications confer considerable life-long burden for the individual and health care services, and may require surgery (Vedantham, 2009).

The psychological consequences of VTE may be significant. Its onset is frequently life threatening and traumatic with the potential for long-term health anxiety and post-traumatic stress disorder (PTSD) (Ozer, Best, Lipsey, & Weiss, 2003). In addition, those affected may have to live with on-going symptoms, the risk of bleeding associated with anti-coagulant treatment, and knowledge of future risk of recurrence. Despite this, those studies that have been conducted have focussed largely on health related quality of life (e.g. Kahn et al., 2005; van Es et al., 2013; Ziegler, Schillinger, Maca, & Minar, 2001) or understandings of the disorder and symptom control (Moore, Norman, Harris, & Makris, 2008). Few studies have explored the nature, causes, and associated coping strategies of any emotional difficulties individuals may experience, and these have been in unrepresentative samples of individuals who experienced a VTE between two and seven years previously (Bennett, Patterson & Noble, 2014; Noble, Lewis, Whithers, Lewis, & Bennett, 2014).

The present study involved a thematic analysis (see Braun & Clarke, 2006) of the experience of people who had experienced a VTE within the previous six months. The aim was

to obtain detailed understandings of their experiences and the inter-relations between participant's understanding of the nature of the condition and its treatment, its emotional consequences, and the coping efforts they used in response to them. It provides the first study of these phenomena in a representative sample relatively close to the VTE event, and may inform wider understandings of how people understand and cope with the acute onset of what may become a long-term condition.

Method

Design

This was a qualitative study using semi-structured interviews to explore the experience of VTE and its psychosocial impact on participant's lives.

Participants

Participants were a consecutive series of patients recruited from an out-patient haematology clinic in a UK District General Hospital. They were over 18 years of age, could read and speak English fluently, and had experienced a first-time VTE in the previous six months. Seven women and five men volunteered to participate (see Table 1 for participant details) and ages ranged from 18 to 69 years (mean = 51.17; SD = 18.70). All participants were white British; one participant had a co-morbid diagnosis of Parkinson's disease and one was being treated for breast cancer.

Insert table 1 about here

Materials

The semi-structured interview schedule (see Appendix 1) was developed in consultation with Thrombosis UK (a national thrombosis charity) and comprised seven open-ended questions

exploring participant's experience of their VTE and their subsequent life. Interviews lasted between 45 and 90 minutes, with most lasting around 60 minutes. They utilised open questions (e.g. can you tell me what happened when you became unwell?) followed by more specific questions (e.g. "How have you coped since the VTE?"). Topics addressed included: (i) the emotional impact of the VTE; (ii) any changes to their view of life that occurred as a consequence of the VTE; (iii) the impact of anti-coagulant treatment; (iv) worries and difficulties as a result of VTE and how they had coped with them.

Procedure

Approval was granted by the relevant NHS Regional Ethics Committee. Participants meeting the study criteria were given written information during an outpatient haematology clinic of a District Hospital in the UK by a consultant haematologist who discussed the research with them. The participant had time to read a Patient Information Sheet before giving verbal and written consent to participation, and to the interviews being recorded and transcribed anonymously. Sixty seven per cent of those approached consented to take part. Interviews were conducted at a time convenient for the participant and all participants opted to be interviewed in their own home. All participants were offered a debrief session should they feel it was required. All data collected in the study were stored anonymously with identifying details removed and for the purpose of anonymous reporting participants have been given pseudonyms.

Analysis

Participants' verbatim transcripts were analysed individually using inductive Thematic Analysis procedure described by Braun and Clarke (2006). This technique was chosen because it offers a flexible method to gain a rich and detailed account of data and is a useful research

tool in exploring quality of life in health conditions (Nicolson & Anderson, 2001). During the analytical process, initial thoughts and ideas were noted down and transcribed data were repeatedly read and the recordings were also listened to several times to ensure the accuracy & ‘data immersion’ (Braun & Clarke, 2006). The next stage of analysis involved identifying and generating initial codes and textual units for interesting features and patterns in the data relating to the research topic. Analysis then refocused at the broader level of themes, and different codes were used to label potential themes, with relevant data extracts (“quotes”) gathered within the identified themes. The same unit of text could be included in more than one category. The data were systematically reviewed to ensure that a name, definition, and an exhaustive set of data to support each category were identified. Gradually overarching themes and sub-themes emerged, and these were then validated by PB to ensure rigour of analysis, and any differences resolved through discussion.

Results

Thematic analysis of interview transcripts revealed four major themes and 10 sub-themes viewed as essential to determine the experience of all the participants (see Table 2). The content of each major theme and sub-theme are described below and illustrated using quotes from participants (numbers following the pseudonym indicate the page and line numbers where the quote can be found within the transcript). Major themes were: a) VTE as life changing and traumatic, b) feeling let down by services, c) living with uncertainty and fear of reoccurrence and d) positive changes and outcomes.

Insert table 2 about here

VTE as life changing and traumatic: *‘It’s as though it happened yesterday’.*

Living with post-traumatic stress

Participants reported experiencing intrusive traumatic memories and thoughts relating to the VTE; 'I just had visions of being in the house with my kids and dropping dead on the floor' (Fiona, 12; 21-2). The impact of these intrusions became an organizing principle around which they lived in the aftermath, and was reflected in descriptions of the event as being ever-present:

I can feel that feeling as though it was yesterday. Especially that bit when I was on the floor and everything was pitch black and I just wanted to shout out or move and I just couldn't. I couldn't [tearful]. Awful. But that to me is still like it is. Now I'm talking about it now, it's like it happened yesterday. (Sally, 16; 19-22)

Participants described hyper-vigilance and a sense of imminent danger, triggered and maintained by the intrusive thoughts and images of the VTE as well as their ruminations on what might have happened. Many reported significant levels of anxiety; some had experienced panic attacks:

And every time I had them [panic attacks] I kept thinking it was a PE so I was having a panic attack. All the time! Every day! I was...it was just ridiculous. And I just felt like it was a big dark cloud. [Starts to cry]. (Fiona, 6; 16-21)

Fears that the thrombosis may return were reinforced by internal and external reminders of the VTE, reinforcing participant's health anxiety. Triggers included visual or physical reminders such as a scar from treatment that one participant described as 'a little reminder', hearing sirens or taking anticoagulant medication. Peter was so aware of his health anxieties and the vicious circle of anxiety and feelings of panic he gave it a diagnostic label, describing it to his GP as 'post-thrombotic panic syndrome':

I was anxious then; very anxious. And I managed to get in to see the doctor who said ‘don’t worry about it. It’s just a varicose vein’. So that was an anxious moment thinking, was that another manifestation of this? I actually joked with the doctor that I think I’m suffering from post-thrombotic panic syndrome! (Peter, 21; 2-11)

These intrusions, flashbacks, hypervigilance, depression or anxieties were rarely disclosed to anyone. Most participants coped alone, despite good social support: ‘I don’t really talk to him [partner] about the dark deep feeling inside me, because I don’t want to put that on him’ (Rebecca, 16; 8-9). This resulted in psychological distress going unreported, missed opportunities for intervention and difficulties becoming more chronic over time.

VTE as life changing

Participants recalled their VTE as a defining moment that was both traumatic and life changing. On-going symptoms and treatment brought this into their consciousness daily. Participants felt *they* were changed by the VTE and were left with future focussed concerns as a consequence:

This little, little clot which has apparently come from nowhere, and no-one can find out where it’s come from or why it’s come! And it can change everything! Literally change everything. Potentially if I have kids. Everything. And when I think of it that way, it’s... [struggles for words] (Rob, 16; 18-21).

Symptoms and the physical impact of VTE resulted in restrictions and frustrations that had both practical and emotional implications, and that reinforced negative beliefs about the VTE. Managing physical symptoms and treatments also provided daily reminders, triggering negative thoughts about their illness and future:

But the emotional side of it as well. I wanted to have three children. But I'm happy with two and I can accept two. But this has stopped me from having another child. (Fiona, 37; 11 -12)

It's terrible. You know, I feel like a disabled person. It's ridiculous! (Rebecca, 11; 19)

Coping with life after VTE marked a new chapter of the participant's life which acknowledged the loss of an old self (see Charmaz; 1983) and the start of a new, post-VTE self that integrated their experience along with new restrictions, fears and uncertainties.

Everybody thinks I'm still the same person I was before. Cos I put on a front. (Rebecca; 14, 15)

It does change you, and your outlook is different. You've still got at the back of your mind, the fear of 'that. (Joe; 21; 9-10).

Life after VTE was defined by efforts to cope with the physical impact, health anxieties, and hyper-vigilance. For many, this led to high levels of stress in this early phase and affected their lives significantly. The most anxious participants engaged in avoidance behaviours; withdrawing and isolating themselves to avoid triggers or situations in which they felt vulnerable:

It's easier just to stay in these four walls, in my little bit of comfort. And wherever I go I take my phone just in case anything does happen you know. But no I try to... [pause]. I isolate myself basically. (Rebecca, 17; 10-12).

Others found it hard to reflect on how they were coping. Michael described VTE and the treatment as: 'a blooming nuisance; but sod it. Get on with it' (Michael, 6; 18-1); reflecting different coping styles, avoidance or previous life experiences.

Feeling let down by services: ‘It’s a clot on your lung. Did no-one tell you?’

Misdiagnosis and its implications

One third of participants reported that their VTE had been repeatedly misdiagnosed. Fiona for example, saw seven doctors before being diagnosed and treated, and several participants had concerns they may have a blood clot repeatedly dismissed. These participants were angry that significant risk factors, such as chemotherapy, swollen legs and painful calves, had been disregarded:

I said [to nurse] ‘well I’ve had swollen ankles and terrible pain in the back of my calves. Now she should have known then there was something up, as I think back now. They say in those booklets if you’ve got pain in the back of your calves and swollen ankles. But she said ‘oh it will be fine’. So then I went for my second chemo’ a fortnight after and I said ‘my ankles are swollen’, so she had a look at them and she said ‘they’re not that bad. Have your second chemo’, and it was two days later that I had that [PE]. (Alice, 8; 29-6)

The experience of missed diagnosis had both physical and psychological implications. Alice’s untreated DVT, for example, developed into a life threatening PE, and Fiona’s untreated DVT caused significant damage to her veins and chronic problems with post-thrombotic syndrome:

If they’d treated me that Friday when I went in and I stayed in hospital, that clot wouldn’t have got as big. My symptoms weren’t anything compared to what they were on the Tuesday. It wasn’t swollen [down] to my foot. It was discoloured and painful but it was ten times better than it was three days later. They could have

stopped that. They could have stopped from having what I have now – post-thrombotic syndrome. (Fiona, 25; 5-10)

Furthermore, some participants were left with unresolved anger and frustration towards services making integration of their VTE experience problematic and impacting on relationships with health professionals. Many lost trust in doctors and felt that going to see them was a ‘waste of time’ (Joe, 1; 31). The onset of physical symptoms of post-thrombotic syndrome reinforced one participant’s belief that services had let them down or were responsible for on-going symptoms:

I’m really angry! ‘Cos now I’ve got to live with this [post-thrombotic syndrome] and they go home at the end of the day, you know when they finish their shift, with their families and they forget about me. But I will never forget what they done to me. (Fiona, 25; 20-22)

Feeling alone and abandoned

A perceived lack of acknowledgement or support from health care services deepened participants’ anxiety and reinforced their beliefs that the world was unsafe and unpredictable. None of the participants interviewed had been offered professional emotional support, supporting their view that they had been ‘abandoned’ by health professionals on discharge:

Oh it wiped me out. Cos you are left to work it out for yourself and you’re left to worry about it on your own. And you’re left to panic. (Rob, 24; 7-8)

I had nothing. I was just, you know, it was me...On my own. Trying to deal with things. (Rebecca, 22; 4)

Some participants responded to this apparent abandonment by increasing their use of GP and primary care resources, seeking reassurance about symptoms and neutralization of anxiety:

Sometimes I was ringing the GP saying ‘Phone me back!’ to the receptionist ‘get him to phone me back. I was like a nutter! Ringing the GP! And he’d ring me back and be like ‘what’s the matter?’ and I’d say ‘I’m having one’ and he’d ask ‘what are you frightened of?’ (Fiona, 21; 7-10).

Lack of information and poor communication

The reported lack of information about the nature of VTE and the treatment perpetuated beliefs that they had been “let down” and poor communication enhanced concerns. Participants believed professionals did not adequately explain details of their condition and treatment, resulting in a sense of being a bystander in their own care, with little control:

It took about a week and half to tell me that it was a PE in my lung! I didn’t know until then. So in fairness the doctor, the GP was useless. I don’t mean to speak out of turn but he was useless. (Rob, 4; 18-20)

I went in [to hospital] and after a few days they sort of said ‘oh your blood. It’s a blood clot’. And then a week and a half later I went back and the GP said ‘oh, it’s a clot on your lung. Did no-one tell you? And I said, ‘well, no’. (Rebecca, 14; 27-29)

Lack of information and confusion was particularly prevalent at discharge from hospital which participants identified as a critical time for information and support. This caused participants significant anxiety and left some telephoning hospitals to chase prescriptions or seek appointment dates escalating anxiety further. They felt they had been given inadequate guidance on when to return to work/education, strengthening beliefs about their lack of control over their condition and reinforcing uncertainty. At times this lack of guidance placed participants at further physical risk because they were unclear how much to physically exert themselves:

[The doctor] just said ‘go back as soon as you want, so I thought brilliant, back to normality. But it wasn’t at all. (Kerry, 21; 17-18)

I went back to school about 2 or 3 weeks after coming out of hospital. Had my first day and was ‘phew! That was a bit tiring, but it’ll be alright’. The second day then, I nearly collapsed. (Kerry, 21; 8-11)

Seeking reassurance and filling this void of information led all participants to seek out alternative and less regulated sources on the internet, which for some provided sources of support but for all raised new anxieties. For some, however, the frustrations and feeling of disempowerment and abandonment by services had a paradoxical effect over time, driving them to be more self-sufficient, to educate themselves about VTE and take control of their recovery.

Living with uncertainty and fears of reoccurrence: *‘It’s like a big dark cloud hanging over me’.*

Living under the ‘cloud’ of uncertainty

Participants described overarching fears of reoccurrence, bringing a constant feeling of uncertainty and threat to their life post-VTE. This was described metaphorically as like living with a ‘big dark cloud’ (Fiona, 6; 17), or an invasive, germ that was ready to attack. Most were troubled by the uncertainty of whether the blood clots were still there:

I worry that the clots are still there. You know like little things. You get rid of something, and then they start collecting again. Like germs things like that and I’m thinking they could be travelling round my body and thinking [the clots thinking] ‘right, lets hit there again now’ (Sally, 14; 17-19)

For the majority of participants, the VTE was categorised as ‘unprovoked’ and the absence of any medical explanation further reinforced anxiety and hyper-vigilance, causing a preoccupation with re-occurrence and for some, causal searching. It was these uncertainties that participants believed differentiated VTE from other illnesses or medical experiences and added another difficulty to their recovery; managing and living with unknown threat:

It was just everything. It was physical, emotional. It was the uncertainty. I was out of work. There were no answers, there was no feedback and I was just... [Struggles to find word. Becomes emotional]. (Rob, 21; 7-8)

Living with these uncertainties was reported as being the hardest part of coping with life after VTE, and it was the aspect in which participants reported the least support.

Awareness of own mortality

Participant’s uncertainties and fears of reoccurrence were influenced in part by retrospective reflections on the threat to life when more information was available to them. As Rebecca described; ‘I’m thinking, well you know, I could actually have died! But it wasn’t the realisation then, what I know now’ (Rebecca, 12; 12-13). This proximity to death and risk to life was reinforced by ongoing intrusive memories and it began to influence how participants appraised their life and their VTE. It led some to make preparations for their death and to reflect on their own mortality:

I came home and I was in the bedroom and I was just sorting old paperwork out. Files. And filed things. Put passports safe. Put building society books safe. Put direct debits safe. Marked them all in books. So if anything happened like that again they’d know everything was there. (Sally, 26; 17-20)

When I came home that night after the initial DVT I thought, you know, it's the end of the road. What am I going to do? (Joe, 3; 8-10)

For participants who were particularly low in mood, fears of death became a preoccupation that influenced their mental health, reinforcing isolation and restricting opportunities to access support: 'I'm afraid of dying. And I don't see me getting out of this black hole any time soon... Do you know, I haven't even told my partner [becomes tearful]. (Rebecca, 15; 9-12).

Worries and uncertainties about anticoagulant treatment

Anti-coagulant medication provided all participants with a further source of anxiety: largely due to uncertainties about treatment duration and the risks associated with bleeding. Joe likened this risk to living with the 'Sword of Damocles' hanging over you and for many 'the treatment has made a bigger impact' (Kerry, 12; 18-19) than the VTE itself. This was especially true for active or younger participants, who may have experienced greater losses and life restrictions as a result of anti-coagulation than others:

I got a worry now cos obviously I'm on warfarin for life I'm looking into now the long term effects of it, when I get old and things. Like if I need operations, that's obviously gonna be a risk to me. I'm sort of going through a point now, where I got to accept that. That I've got to be on it. I want to be, obviously but in the long term it does frighten you sometimes (Fiona, 28; 15-21).

Where warfarin is prescribed as an anti-coagulant, treatment is taken daily and may require initial daily and then weekly visits to a clinic or GP over a period of months to assess risk for bleeds or clots. For many, this formed a daily reminder, reinforcing beliefs that VTE was life changing, that treatment was problematic and which prevented them from putting the VTE behind them:

‘It’s just you want to say, that’s happened. It’s fine. It’s done. But you can’t. You can’t just go and move on. It’s just you’re constantly reminded’ (Kerry, 12; 26-28).

Positive changes & outcomes: ‘*On the whole it’s affected me for the better rather than for the worse*’.

Acknowledging the positive impact of VTE

Even in this initial six month period, many participants described both negative and positive changes and benefits from the VTE. Fiona, for example, felt the VTE ‘in some ways, has ruined my life’ (Fiona, 7; 1) but simultaneously chose to take positives from her experience in a way that enabled her to grow and be in control:

As horrible as it is, I’ve changed it for the positive now. I’ve had to take positives from it. For every negative there’s a positive. I’m a true believer in that. And I’ve just had to say right, that’s the case whatever it is, it’s not worth worrying about because I can spend another ten years worrying about it or ten years living. (Fiona, 23; 2-7)

VTE was described by most as a ‘wake-up call’ event that came at the right time: ‘I can’t think more of how to express it. It just seemed to come along at a time of my life that, you know, I can cope’ (Jenny, 11; 21-22). It triggered re-prioritisation in their life, as well as active behavioural changes such as weight loss, or even changes in career. All participants independently reported positives and benefits from the experience:

Because even though it did happen, it’s had more positive impact on me, in the sense I’ve changed. Not changed my life, but changed what I’m planning on doing and what I’m going to do and what I want to do. (Kerry, 31; 8-12)

It's made me stop and think about my health. It's been a wake-up call in terms of that and I think generally making the most out of life. And enjoying life. (Peter, 34; 1-3)

It was notable that all participants spontaneously described themselves as 'lucky' not just to survive the VTE, but because the VTE had enriched their life in some way:

To be honest I still feel I've got good health. I'm reasonably fit and fairly active so yeah. I feel lucky. (Michael, 17; 17-18)

So in some aspects I'm lucky it's happened, 'cos it has made me change my outlook on life. (Kerry, 20; 20-21)

Acknowledging the positive outcomes from the VTE did not appear to reflect any denial or avoidance of the negative aspects; rather, it suggested a process of post-traumatic growth (Tedeschi & Calhoun, 1995). Fiona, for example described her experience as an interaction of the 'worst thing I've ever been through' from which she takes 'positives' and that had 'put my life in perspective'.

VTE as catalyst for fundamental changes in self

Participants reported fundamental changes to their outlook on life and sense of self, particularly younger VTE patients like Kerry, who was seventeen at the time of her PE:

I think it's affected me massively because I think it's made me more of who I am. It's brought out aspects of me that were always there that I...not hid, but the side of me that stands there and [says] 'No! This isn't okay anymore (Kerry, 26; 1-6)

Participants' reported they were changed by the VTE and were 'more tolerant', 'more patient', 'more appreciative', and notably 'more empathic' towards others. They described a process of personal growth, as is evident in the language used to describe their experience:

And I was thinking what if anything happened to me here now and I couldn't get to the phone? But I grew out of that bit, that didn't bother me then after a while. (Sally, 29; 17-19).

I am, a lot more [confident]. And I think I'm a lot more...I've educated myself a lot more now. Like I read all case studies. I read about things. I go on Google Scholar now whereas before I would never have understood all that, but now I do (Fiona, 28; 5-7).

The dynamic process of trauma and growth could be seen in the ambivalence participants demonstrated when considering their future, and how they expected to integrate their VTE experience:

It is a massive shock. I don't think I'll ever get over it. I don't! Maybe time...? Maybe time will...? [Searches for words. Appears distracted] (Sally, 5; 12)

I'm not sure. I don't think it will ever go away completely. But I think it will. (Eleanor, 18; 2-3)

Interestingly, participants understood their positive re-appraisals and subsequent reprioritisations as being a direct response to the trauma itself and the significant threat to life they experienced, and they wondered if they would sustain them over time or in the face of recovery or further challenge.

Discussion

This study examined the experience of people in the months immediately following a VTE, and the impact it had on them and their life. Its findings support those of earlier studies in less representative samples (Noble et al., 2014; Bennett et al., 2015) which found high levels of trauma, health anxiety, and PTSD symptoms within this patient population. Key themes

identified suggested the experience of VTE, its treatment and uncertain future each contributed to a life-changing experience, risk for high levels of distress, and the paradoxical experience of post-traumatic growth and more positive life benefits.

The unexpected and life threatening nature of VTE left a majority of participants coping with intrusive thoughts and memories, attempts to avoid them, hyper-vigilance to symptoms, and significant fears of recurrence: all symptoms associated with a diagnosis of PTSD. Findings were consistent with Joseph, Williams & Yule's (1997) model of PTSD aetiology, with both peri-traumatic and longer term perceptions of threat to life and health uncertainty being associated with the presence of PTSD symptoms. While high levels of anxiety and hyper-vigilance is common after sudden illness, particularly after discharge (Davies, 2000), participants' described a 'vicious circle', labelled by one as a "*post-thrombotic panic syndrome*". Participants described the onset of panic symptoms which were initially difficult to discriminate from those of a PE, causing further distress and reinforcing appraisals of threat and future risk. Over time, this 'vicious circle' exacerbated negative beliefs about illness severity, duration and treatment, and escalated fears of reoccurrence (see Salkovskis & Warwick, 2001).

Insert Figure 1 here

The theme of uncertainty over VTE cause, future health and treatment risks was reported as defining characteristics of participants' VTE experience. These appraisals, central to Leventhal's self-regulation model (e.g. Leventhal et al., 1997), occupied a constant space in patients working memory, escalating anxieties and fears of re-occurrence and decreasing quality of life (Simard & Savard, 2009; Van den Beuken-van Everdingen et al., 2008). Participants appeared to respond to this increased anxiety by seeking reassurance, focussing on physical symptoms or engaging in avoidant coping, which subsequently increased isolation. While potentially beneficial in the short-term, in the longer term this prevents the activation of

the fear network necessary for the cognitive work that leads to resolution (see Wells, 2013), maintaining emotional distress and delaying adjustment (Moser, 2007). Lack of information from health professionals also reinforced uncertainties further and led to increased use of primary health care resources; often as a means of both information provision and reassurance. These features of post-VTE anxiety may contribute to the high levels of psychological distress reported here and in early studies (Bennett, Paterson & Noble, 2014; Bennett et al, 2015).

A second, health care system related factor, was the detrimental impact of missed diagnosis, both physical and psychological. In particular, the relationship between missed diagnosis and negative emotional responses, including blame and anger. Treatment regimes and on-going physical symptoms associated with post-thrombotic syndrome served as daily reminders and contributed to feelings of depression, anxiety and fear of illness recurrence (see Anagnostopoulous, & Spa Nea, 2005; Moss-Morris et al., 2002). Despite late or missed diagnosis in VTE being commonly reported there is a scarcity of research exploring the physical or psychological impact.

It is of particular note that there appeared little difference in the distress experience of participants who had experienced a PE or DVT, despite the latter, from an objective perspective, being less traumatic and immediately life threatening. However, this finding was not unique and has also been reported by Bennett, Paterson & Noble (2014), albeit in a more biased sample of people accessing a VTE internet support website (Thrombosis UK).

Younger people reported a greater impact of VTE on their life than older participants, reporting high levels of anxiety, panic and post-traumatic stress symptomology. These emotional responses reflect the significant challenges younger patients may face in integrating their experience of VTE and the “biographical disruption” (Bury, 1982) of an illness that occurs “off-time” (Neugarten, 1979) or out of developmental context. Such individuals are likely to experience more disruption to routine life events such as occupation, pregnancy, travel,

planning for the future, and even engagement in sport and other physical pastimes. They may also experience the lack of peer support (Buchalz et al, 2014) described here, and have more limited life experiences/resources on which to draw to facilitate their recovery. As a result younger VTE patients may require greater levels of support to help them cope with and adjust to treatment regimes, uncertainties and loss.

In contrast to the negative impact of VTE so far outlined, the experience had a positive impact on individuals' views of self and others as well as future plans. In particular, participants planned significant positive life changes in the wake of VTE, and considered it to be both a 'wake-up call' and a positive event from which they drew meaning. The search to understand why a traumatic event happened can shatter people's assumptions about themselves and the world, triggering a new found appreciation of life, while also reflecting their distress and awareness of personal vulnerability (see Janoff-Bulman & Frantz, 1997). Coping with such an experience appears to be a 'dynamic, interactional process' (Somerfield, 1997) through which the distress triggers for some a 'new post-trauma sense of identity' (Joseph, 2011; p132; Calhoun & Tedeschi, 2006; Park et al, 2009) that many participants described. As such, coping with illness may present opportunities for the post-traumatic growth reported in other patient groups (Danoff-Burg & Revenson, 2005; Katz, Flasher, Cacciapaglia & Nelson, 2001; Cordova et al, 2001) but reported here for the first time in VTE patients. Such experiences require further exploration and understanding if we are to promote coping and positive adjustment following traumatic onset conditions such as VTE.

The present study provides only a snapshot in time of the experience of VTE and has limitations. A subsequent study will report participants' changing experience over a period of nine months. Participation bias is always a risk in research of this nature, regardless of the methodology and it is difficult to know if the high uptake of the study reflected a higher level of distress particular to this group or if psychological morbidity is generally higher in VTE

patients. Nevertheless, these findings are consistent with the high levels of psychometrically measured trauma previously reported (Bennett et al, 2014) and are methodologically consistent with the need to achieve both “vertical” and “horizontal” generalization in research of novel issues (see Yardley, 2000).

In summary, this study demonstrates that the psychosocial impact of VTE can be traumatic and life-changing. Longitudinal research is required to better understand the processes at work in long-term recovery after VTE. Based on these data, subsequent studies could focus on a range of issues, including: (i) how the post-traumatic growth and benefit finding reported here relate to models of PTSD; (ii) whether these benefits are maintained over time, particularly in the face of further VTE and challenge (for example, ongoing physical symptoms including post-thrombotic syndrome); (iii) the role of other peri-traumatic risk factors, particularly missed or late diagnosis, in psychological morbidity and adjustment after VTE, and; (iv) factors such as personality, coping styles, or previous trauma experiences that may moderate individuals’ responses to VTE.

The data reported here also clearly suggest that people who have experienced a VTE would benefit from some form of psychosocial intervention, perhaps utilising a triage approach ranging from psycho-education to post-traumatic counselling. Identifying and supporting individuals at risk of post-traumatic stress or significant psychological distress could enable early intervention, the development of targeted interventions to enhance psychological wellbeing, promote adjustment and growth, and reduce distress. Providing such intervention could in turn, improve patient’s wider emotional and physical health outcomes. There is a strong case to provide specific support to younger VTE patients for whom the psychosocial impact of VTE seems particularly significant.

References

- Anagnostopoulos, F., & Spanea, E. (2005). Assessing illness representations of breast cancer: A comparison of patients with healthy and benign controls. *Journal of Psychosomatic Research, 58*, 327-334
- Andrykowski, M. A., Brady, M. J., & Hunt, J. W. (1993). Positive psychosocial adjustment in potential bone marrow transplant recipients: Cancer as a psychosocial transition. *Psycho-oncology, 2*, 261-276
- Andrykowski, M. A., Curran, S. L., Studts, J., Cunningham, I., Carpenter, J. S., McGrath, P. C., Sloan, D. A., & Kenady, D. E. (1996). Psychosocial adjustment and quality of life in women with breast cancer and benign breast problems: A controlled comparison. *Journal of Clinical Epidemiology, 49*, 827-8346.
- Astin, F., Jones, K., & Thompson, D. R. (2005). Prevalence and patterns of anxiety and depression in patients undergoing elective percutaneous transluminal coronary angioplasty. *Heart and Lung, 34*, 393–401.
- Beckman, V. I. G, Hooper, W. C., Critchley, S. E., & Ortel, T. L. (2010). Venous thromboembolism: A public health concern. *American Journal of Preventative Medicine, 38*, S495-501 <http://dx.doi.org/10.1016/j.amepre.2009.12.017>
- Beyth, R. J. (2003) Oral anticoagulant therapy: quality-of-life issues. *Seminars in Vascular Medicine. 3*(3), 239-42.
- Beyth, R. J., Cohen, A. M., & Landefeld, S. C. (1995). Long-term outcomes of venous thrombosis. *Archives of Internal Medicine, 155*, 1031–1037.
<http://dx.doi.org/10.1001/archinte.1995.00430100053006>
- Bennett, P., Patterson, K., & Noble, S. (2014). Predicting post-traumatic stress and illness anxiety following a venous thrombotic embolism. *Journal of Health Psychology, doi:1359105314540965*.

- Bucholz, E.M., Kelly, M., Strait, MS, Dreyer, R. P., Geda, M., Spatz, E. S., Bueno, H., Lichtman, J. H., D'Onofrio, G., Spertus, J. A., & Krumholz, H. (2014). Effect of low perceived social support on health outcomes in young patients with acute myocardial infarction: results from the VIRGO (Variation in Recovery: Role of Gender on Outcomes of Young AMI Patients) study. *Journal of the American Heart Association*, 3(5): e001252. doi: 10.1161/JAHA.114.001252
- Bury M. Chronic illness as biographical disruption. (1982). *Sociology of Health Illness*, 4, 167—82. <http://dx.doi.org/10.1111/1467-9566.ep11339939>
- Calhoun, L. G., & Tedeschi, R. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks, CA. Sage.
- Calhoun, L. G., & Tedeschi, R. G. (Eds.). (2006). *Handbook of posttraumatic growth: Research and practice*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Charmaz K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195
- Cordova, M. J., Cunnigham, L. C. C., Carlson, C. R., & Andrykowski, M. A. (2001) Posttraumatic growth following breast cancer: a controlled comparison study. *Health Psychology*, 20(3), 176-185
- Coyne, J. C. (1997). Commentaries on the utility of systems models of stress and coping for applied research: The case of cancer adaptation by Mark R. Somerfield. *Journal of Health Psychology*, 2(2), 153-172
- Danoff-Burg, S., & Revenson, T. A. (2005). Benefit finding among patients with rheumatoid arthritis: positive effects on interpersonal relationships. *Journal of Behavioural Medicine*, 28, 91-103 <http://dx.doi.org/10.1007/s10865-005-2720-3>

- Davies, N. (2000), Patients' and carers' perceptions of factors influencing recovery after cardiac surgery. *Journal of Advanced Nursing*, 32(2), 318–326
- Doukatis, J. D., Gu, C. S., Schulman, S., Ghirarduzzi, A., Pengo, V., & Prandoni, P. (2007). The risk for fatal pulmonary embolism after discontinuing anticoagulant therapy for venous thromboembolism. *Annals Internal Medicine*, 147, 766-774
<http://dx.doi.org/10.7326/0003-4819-147-11-200712040-00007>
- Etchegary H., Wilson B., Brehaut J., Lott A, Langlois N., & Wells P.S. (2008). Psychosocial aspects of venous thromboembolic disease: an exploratory study. *Thrombosis Research*, 122: 491-500.
- Hayes, N. (2000). *Doing psychological research: gathering and analysing data*. Buckingham/Philadelphia: Open University Press
- Henman, M. J., Butow, P. N., Brown, R., Boyle, F., & Tattersall, M. H. (2002). Lay constructions of decision-making in cancer. *Psych-oncology*, 11: 295-306
- Heit, J. A., Mohr, D. N., Silverstein, M. D., Petterson, T. M., O'Fallon, W. M., & Melton III, L. J. (2000). Predictors of recurrence after deep vein thrombosis and pulmonary embolism: A population based cohort study. *Archives Internal Medicine*, 160, 761-768 <http://dx.doi.org/10.1001/archinte.160.6.761>
- Janoff-Bulman, R., & Frantz, C., M. (1997). The impact of trauma on meaning: From meaningless world to meaningful life. In M. Power, & C. R. Brewin (Eds). *The transformation of meaning in psychological therapies* (pp. 91-106). New York: Wiley.
- Janoff-Bulman, R., & Berger, A. R., (2000). The other side of trauma: Towards a psychology of appreciation. In J. H. Harvey, & E. D. Miller (Eds), *Loss and trauma: General and close relationship perspectives* (pp. 29-44). Philadelphia: Taylor and Francis

- Joseph, S. (2011). *What doesn't kill us: The new psychology of post-traumatic growth*. Basic Books.
- Kahn, S., Ducruet, T., Lamping, D., Arsenaault, L., Mironm M., Roussin, A., Desmarais, S., Joyal, F., Kassis, J., Solymoss, S., Desjardins, L., Johri, M., & Shrier, I. (2005). Prospective evaluation of health related quality of life in patients with deep vein thrombosis. *Archives Intern Med*, 165: 1173-8.
<http://dx.doi.org/10.1001/archinte.165.10.1173>
- Katz, R. C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: A cross validation study that extends the generality of benefit-finding in patients with chronic disease. *Journal of Behavioral Medicine*, 24, 561- 571
<http://dx.doi.org/10.1023/A:1012939310459>
- Lane, D., Carrol, D., Ring, D., Beevers, D. G., & Lip, Y. H. G. (2001). Predictors of attendance at cardiac rehabilitation after MI. *Journal of Psychosomatic Research*, 51(3); 497-501
- Lazarus, R. S., & Launier, R. (1978). Stress-related transactions between person and environment. *Perspectives in interactional psychology*. Springer US. p287-327.
- Leung, Y. W., Gravely-Witte, S., Macpherson, A., Irvine, J., Stewart, D. E., & Grace, S. L. (2010). Post-traumatic Growth among Cardiac Outpatients Degree Comparison with Other Chronic Illness Samples and Correlates. *Journal of Health Psychology*, 15(7): 1049-1063 doi: 10.1177/1359105309360577
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: theoretical foundations. *Perceptions of health and illness*, 2, 19-46.

- Moore, T., Norman, P., Harris, P.R., & Makris, M. (2008). An interpretative phenomenological analysis of adaptation to recurrent venous thrombosis and heritable thrombophilia. The importance of multi-causal models and perceptions of primary and secondary control. *Journal of Health Psychology, 13*: 776-784
doi.org/10.1177/1359105308093861
- Moser, D. K. (2007). "The rust of life": Impact of anxiety on cardiac patients. *American Journal of Critical Care, 16*(4), 361-9.
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health, 17*(1), 1-16. doi: 10.1080/08870440290001494
- Neugarten, B. (1979). Time, age and the life cycle. *American Journal of Psychiatry, 136*, 887-894
- Noble, S., Lewis, R., Whithers, J., Lewis, S., & Bennett, P. (2014). Long-term psychological consequences of symptomatic pulmonary embolism: a qualitative study. *BMJ Open; 4*: e004561. doi:10.1136/bmjopen-2013-004561
- Ozer E.J, Best, S. R., Lipsey, T. L., & Weiss, D. S. (2003). Predictors of posttraumatic stress disorder and symptoms in adults: A meta-analysis. *Psychological Bulletin, 129*(1): 52-73. doi.org/10.1037/0033-2909.129.1.52
- Park, C. L., Lechner, S. C., Antoni, M. H., & Stanton, A. L. (Eds.) (2009). *Medical illness and positive life change: can crisis lead to personal transformation?* Washington, DC: American Psychological Association
- Pesavento, R., Bernardi, E., Concolato, A., Dalla Valle, F., Pagnan, A., & Prandoni, P. (2006). Post-thrombotic Syndrome. *Seminars in Thrombosis & Hemostasis, Oct*;

32(7):744-51. *International Journal of Community Based Nursing & Midwifery*.
2(2): 60-8. doi.org/10.1055/s-2006-951460

Salkovskis, P. M., & Warwick, H. (2001). *Meaning, misinterpretations, and medicine: a cognitive-behavioural approach to understanding health anxiety and hypochondriasis*. p202-222.

Siegel, K., & Scrimshaw, E. W. (2000). Perceiving benefits in adversity: Stress related growth in women living with HIV/AIDS. *Social Science and Medicine*, 51, 1543-1554. [http://dx.doi.org/10.1016/S0277-9536\(00\)00144-1](http://dx.doi.org/10.1016/S0277-9536(00)00144-1)

Somerfield, M. R. (1997). The utility of systems model of stress and coping for applied research: The case of cancer adaptation. *Journal of Health Psychology*, 2, 133-151

Turpie, A. G. G., Chin, B. S. P., & Lip, G. Y. H. (2002). ABC of antithrombotic therapy: Venous thromboembolism: Pathophysiology, clinical features and prevention. *British Medical Journal*, 325, 887–890. doi:10.1016/j.socscimed.2006.06.014

Van Es, J., den Exter, P. L., Kaptein, A. A., Andela, C. D., Erkens, P. M. G., Klok, F. A., Douma, R. A., Mos, I. C. M., Cohn, D. M., Kamphuisen, P. W., Huisman, M. V., & Middeldorp, S. (2013). Quality of life after pulmonary embolism as assessed with SF-36 and PEmb-QoL. *Thrombosis Research*, 132, 500-505
<http://dx.doi.org/10.1016/j.thromres.2013.06.016>

Van den Beuken-van Everdingen, M., Peters, M., Rijke, J., Schouten, H., van Kleef, M., & Patijn, J. (2008). Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psycho-Oncology*, 17, 1137-1145.
doi: 10.1002/pon.1340

- Vedantham S. (2009). Valvular dysfunction and venous obstruction in the post-thrombotic syndrome. *Thrombosis Research*; 123 (Suppl 4):S62–5.
[http://dx.doi.org/10.1016/S0049-3848\(09\)70146-X](http://dx.doi.org/10.1016/S0049-3848(09)70146-X)
- Von Känel, R., Margani, A., Stauber, S., Meyer, A. F., Biastiutti, D. F., Vokt, F., Wissman, T., Lämmle, B., & Lukasm, P. (2015). Depressive Symptoms as a Novel Risk Factor for Recurrent Venous Thromboembolism: A Longitudinal Observational Study in Patients Referred for Thrombophilia Investigation. *PlosOne*, doi10.1371/journal.pone.0125858
- Wells, A. (2013). Cognitive therapy of anxiety disorders: A practice manual and conceptual guide. John Wiley & Sons
- White, R. H. (2003). The epidemiology of venous thromboembolism. *Circulation*, 107, 14–18. <http://dx.doi.org/10.1161/01.CIR.0000078468.11849.66>
- Yardley, L. (2003). Demonstrating validity in qualitative psychology. In, J. A. Smith (Eds.) *Qualitative Psychology: A Practical Guide to Research Methods*. Sage Publications; London.
- Yamaki, T., Hamahata, A., Soejima, K., Kono, T., Nozaki, M., H. Sakurai, H. (2011) Factors predicting development of post-thrombotic syndrome in patients with a first episode of deep vein thrombosis: preliminary report. *European Journal of Vascular & Endovascular Surgery*. 41:126–33. <http://dx.doi.org/10.1016/j.ejvs.2010.09.018>
- Ziegler, S., Schillinger, M., Maca, T. H., & Minar, E. (2001). Post-thrombotic syndrome after primary event of deep venous thrombosis 10–20 years ago. *Thrombosis Research*, 101, 23–33. [http://dx.doi.org/10.1016/S0049-3848\(00\)00370-4](http://dx.doi.org/10.1016/S0049-3848(00)00370-4)

Appendix 1. Interview Schedule:

Q1. Can you tell me exactly what happened when you became unwell with the VTE?

Prompts: can you tell me a bit more about that? What was that like? Can you remember anything else? What sticks in your mind? What happened then/next?

Q2. How would you say that the PE/DVT has affected you and your life?

Can you say a bit more about that? How exactly do you mean? Can you give me an example? How about socially? And your relationships? Do you think you are different to before? What are the main differences? Can you describe how you feel different? What are the main differences from before?

Q3. Do you have to take any regular medication, like an anti-coagulant? Could you tell me what that's like / how you find that?

Prompts: how does it affect you / your life? What does that mean / involve? Do you stick to the regime / take it when you are supposed to? What does that involved day-to-day? How does it affect you? How do you feel about that? What's that like?

Q4. What do your family and friends think about how the VTE has affected you?

What do you think they would say if they were here? Can you say more about that? What makes you think that? Do you know that for sure? How does that make you feel? What's that like for you?

Q5. Do you have particular worries or difficulties as a result of your VTE? These might be about physical, emotional or social?

Prompts: can you give me an example? How exactly does it worry you? What concerns you most? ...about that? Do you worry about that a lot? Does it ever change? Is that difficult?

Q6. Can you tell me about how you have coped since the VTE?

Prompts: what has helped? How exactly has that been helpful? What other sources of support have you had? How have you managed to do that? Why / how do you think that

*helped you? Is that something you would have done before? Was that easy / hard to do?
What else has made a difference?*

Q7. Finally, if you could sum up your overall experience of the VTE and how it has affected you and your life, what would you say?

Prompts: anything else? Anything else that's important to mention? Could you say a bit more about what you mean? What has been the most important thing? What has been the biggest challenge?

Table 1. Participant information

Pt. No	Pseudonym	Age	VTE event	Relevant information
1	Fiona	24	DVT	Missed diagnosis
2	Kerry	18	DVT & PE	n/a
3	Peter	56	DVT & PE	Family history of DVT
4	Michael	68	PE	Family history of PE
5	Sally	48	DVT & PE	Family history of VTE
6	Rebecca	45	PE	Missed diagnosis
7	Jenny	63	DVT	Speedy diagnosis
8	Ralph	63	DVT & PE	Family history of VTE
9	Eleanor	65	PE	Parkinson's diagnosis
10	Rob	27	PE	n/a
11	Alice	69	DVT & PE	Receiving chemotherapy Missed diagnosis
12	Joe	68	DVT	Missed diagnosis

VTE = venous thromboembolism

DVT = deep vein thrombosis

PE = pulmonary embolism

Table 2. Table of themes and sub themes: number of the transcript this appears within is presented after each subtheme.

<p>Theme: VTE as life changing an traumatic</p> <p><u>Subthemes:</u></p> <p>-Living with Post-traumatic stress: 1, 2, 3, 5, 6, 8, 9, 10, 11, 1.</p> <p>-VTE as life changing: 1, 2, 3, 4, 5, 6, 8, 9, 10, 12)</p> <p>-Living under the cloud of uncertainty**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12</p> <p>-VTE as a catalyst for fundamental changes in self**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 12,</p>	<p>Theme: Feeling let down by services</p> <p><u>Subthemes:</u></p> <p>-Misdiagnosis and its implications: 1, 6, 11, 12</p> <p>-Feeling alone and abandoned: 1, 5, 6, 8, 10, 12</p> <p>-Lack of information and communication: 1, 2, 4, 5, 6, 8, 9, 10, 11, 12,</p> <p>-Worries and uncertainties about treatment**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12</p>
<p>Theme: Living with uncertainty & fears of reoccurrence</p> <p><u>Subthemes:</u></p> <p>-Living under the ‘cloud’ of uncertainty**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12</p> <p>-Awareness of own mortality: 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12</p>	<p>Theme: Positive outcomes and changes</p> <p><u>Subthemes:</u></p> <p>-Acknowledging the positive impact of VTE: 1, 2, 3, 4, 5 6, 8, 10, 12</p> <p>-VTE as a catalyst for fundamental changes in self**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 12,</p>

<p>-Worries and uncertainties about treatment**: 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12</p>	
---	--

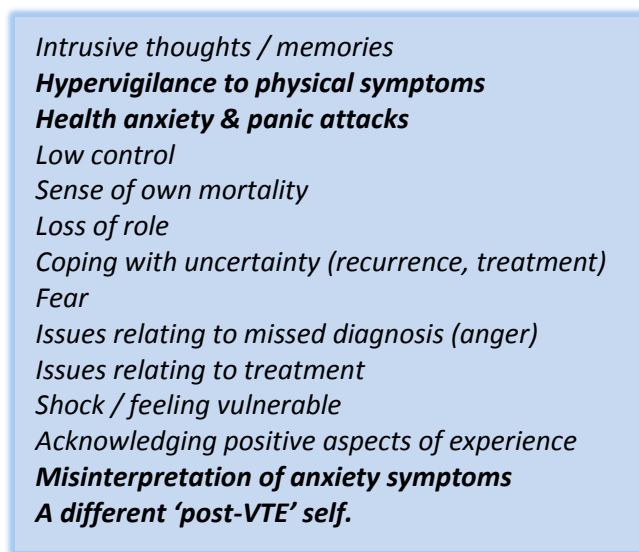
VTE = venous thrombo-embolism

**appears in more than one theme

DVT = deep vein thrombosis

PE = pulmonary embolism

Figure. 1: A model of participants' experience of VTE (OR see below)



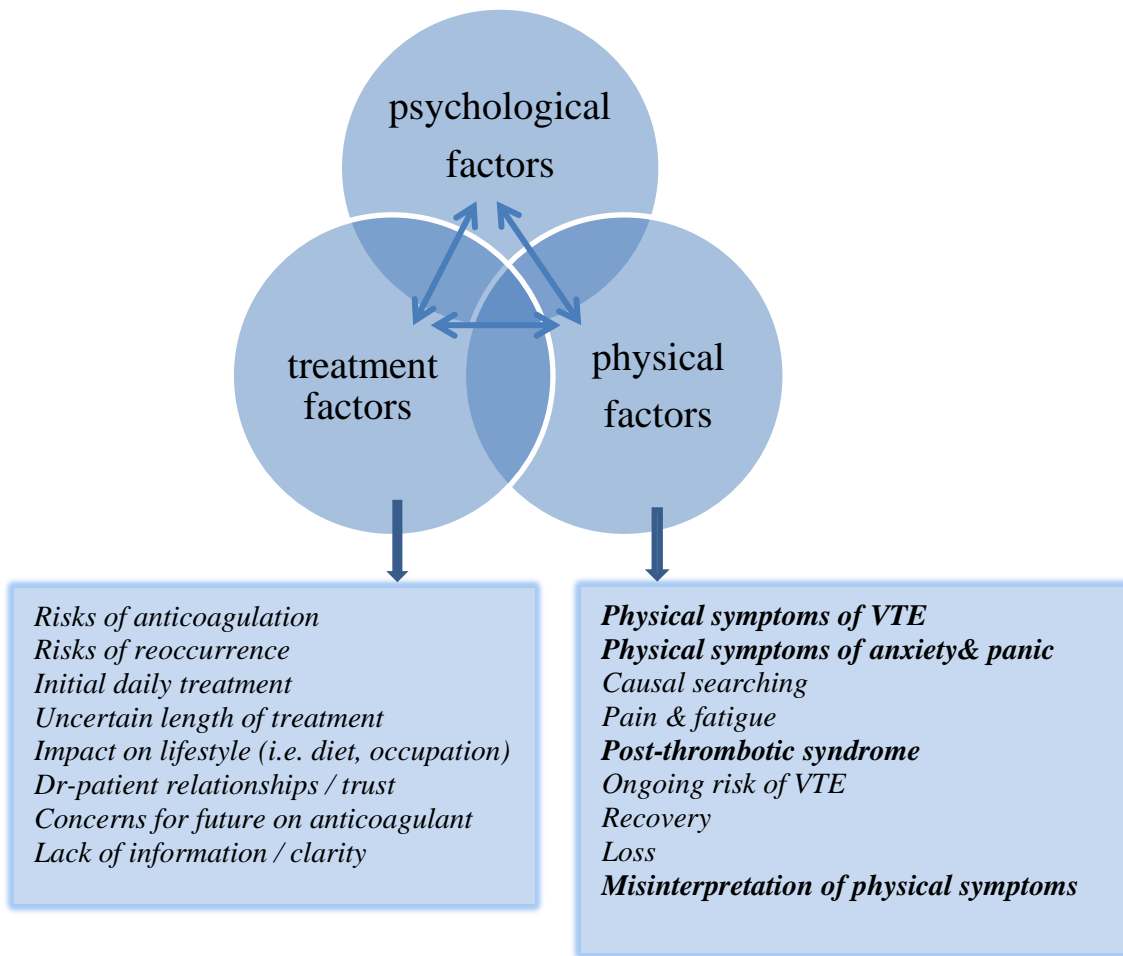


Figure 2: 'Post-thrombotic panic syndrome': the process described by participants

