BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (http://bmjopen.bmj.com).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open: first published as 10.1136/bmjopen-2018-024805 on 5 February 2019. Downloaded from http://bmjopen.bmj.com/ on June 13, 2025 at Universite Paris Est Creteil .
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

BMJ Open

Long-term psychosocial impact of venous thromboembolism: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-024805
Article Type:	Research
Date Submitted by the Author:	15-Jun-2018
Complete List of Authors:	Hunter, Rachel; Swansea University, Psychology Noble, Simon; Cardiff University, Palliative Medicine Lewis, Sarah; Aneurin Bevan University Health Board, Haematology Bennett, Paul; Swansea University, Clinical Psychology
Keywords:	venous thromboembolism (VTE), QUALITATIVE RESEARCH, HAEMATOLOGY, interviews, psychological morbidity

Long-term psychosocial impact of venous thromboembolism: a qualitative study

Hunter, R.,[1]*, Noble, S.,[3] Lewis, S., & [2] Bennett, P.[1],

[1]Department of Psychology, Swansea University, Wales, UK

[2]Aneurin Bevan University Health Board, Wales, UK

[3]School of Medicine, Cardiff University, Wales, UK

corresponding author: Dr R. Hunter, Psychology Dept., College of Human and Health Science, Swansea University, Singleton Park, Swansea, UK, SA2 8PP, r.hunter@swansea.ac.uk, 01792 295714

Word count: 3913, excluding title page, abstract, references, figures and tables

Abstract

***Objectives**:* Venous thromboembolism is a serious, potentially traumatic, life-threatening condition and a major cause of mortality and morbidity. The aim of this study was to obtain detailed understandings of the impact of VTE and examine individual's experiences over the first year since a first time VTE.

Design: A longitudinal qualitative interview study using inductive thematic analysis. This study presents follow-up data for eleven participants, first interviewed six months following a first-time VTE.

Setting: Outpatients recruited a community haematology clinic in a one UK District General Hospital.

Intervention: Audio-recorded semi-structured interviews with a sample of eleven participants who experienced a first-time DVT or PE within the previous year and completed similar interviews three months previously. Interviews were transcribed and analysed using inductive thematic analysis.

Results: Four over-arching themes were identified: life changing and forever changed, the trauma of care, 'thrombo-neuroses' and through adversity comes growth. Theme content varied according to age and developmental stage, presence of VTE symptoms and the experience of diagnosis.

Conclusions: The data demonstrates the psychosocial impact of VTE and its diagnosis as physically and psychologically challenging, and individuals reported being forever changed by the experience. Participants' reported continued high levels of trauma and anxiety symptoms, triggered by physical (e.g. symptoms) and psychological (e.g. health anxiety, negative emotions) reminders of VTE. Wider primary care service issues including misdiagnosis maintained negative emotions and health anxiety with implications for relationships with professionals. Targeted clinical interventions to better identify and support individuals at risk of distress and enhance psychological well-being and reduce distress are discussed.

Keywords: venous-thromboembolism (VTE), haematology, qualitative, interview, psychological morbidity,

Article summary

- This is the first longitudinal study of psychosocial impact of venous thromboembolism (VTE).
- The study had sequential entry so is as representative as possible of people early in patient career.
- The patients were recruited from a single site.
- While appropriate in numbers for thematic analysis, the numbers of participants are relatively low so there must be caution in generalisation of findings.
- This paper gives patients a voice and highlights unmet clinical needs.

Introduction

Venous thromboembolism (VTE), comprising deep vein thrombosis (DVT) and pulmonary embolism (PE), has an incidence rate of 1-2 per 1000 persons in Western populations[1].Mortality rates are high[2], and around 25 per cent of those affected experience further events over the subsequent five years[3]. Post-thrombotic syndrome is a complicating factor in 25 to 50 percent of DVT cases[4], presenting a considerable burden for services and the individual.

Despite substantial research into its medical consequences, the emotional and psychological implications of VTE have received less attention. Studies[5-7] have highlighted impaired quality of life across physical, social and psychological domains in the early months following the event. However, no study has examined the evolving emotional and coping experiences in a representative sample of VTE patients over time.

The present study addresses this gap. It follows up eleven participants, first interviewed six months following a first-time VTE. At this time, themes from inductive thematic analysis included VTE as a life changing and traumatic experience; living with uncertainty and fear of reoccurrence; feeling let down by health services, and positive changes and outcomes. Thematic content varied according to participants' age and experiences of diagnosis and treatment, and highlighted a dual process of trauma and growth and a vicious circle of symptom-related panic. To better understand the longitudinal impact of this experience, participants were re-interviewed approximately three months after their first interview.

Methods

Participants

Participants were a consecutive series of patients recruited from an out-patient haematology clinic in a UK District General Hospital[8].They were over 18 years of age, had experienced a first-time VTE in the six months prior to a first interview, and consented to being re-interviewed three months subsequently. Eleven of twelve participants participated in this second interview: seven women and four men aged 18 to 69 (mean = 53.4) years, and all white British. Participant characteristics are summarised in table 1.

Procedure

The study was approved by an NHS Research Ethics Committee (ref: 14/WA/0019). Following written consent, participants took part in a semi-structured interview, lasting between 30 and 80 minutes. A semi-structured interview template allowed exploration of participants' responses whilst ensuring particular topics were discussed (see table 2 for interview schedule).

Patient involvement

Patient representatives were consulted in the development of the interview topics guide and interview questions.

Analysis

Participants' verbatim transcripts were analysed individually by RH, an experienced clinical psychologist, using inductive thematic analysis[9]. This approach was best suited to elucidating the nature of a group's conceptualisation of the phenomenon under study. It has a growing body of literature examining a wide variety of health topics[9]. Audio recordings were listened to repeatedly to ensure accuracy and enable the identification and generation of relevant initial codes and textual units for features and patterns in the data. Extracts and phrases were used to identify potential themes, with relevant data (‘quotes’) gathered within identified themes. The data were systematically reviewed to ensure that a name, definition, and exhaustive set of data were identified to support each category. The same unit of text could be included in more than one category. Themes and sub-themes emerged from the data and findings were checked and validated by PB; any differences were resolved through discussion.

Results

Thematic analysis revealed four major themes and nine sub-themes. Major themes were; life changing and forever changed, the trauma of care, ‘thrombo-neuroses’ and through adversity comes growth.

Theme: life changing and forever changed

A different life

Continuing from time one, participants reflected on how their life had been forever changed by VTE. Participants reported active attempts to integrate their experience, resulting in a new, post-VTE identity. Those taking warfarin increasingly identified as a ‘warfarin patient’: “*others probably don’t take warfarin so they probably don’t know” (Kerry),* as did those around them:

> *[My husband] bought me a bracelet with warfarin on for my birthday… He got it from New York for me actually. [He] said I should have it tattooed across my head [laughs] (Rebecca)*

Their emerging self was also shaped by the suddenness and life-threatening nature of the condition. It triggered reappraisal of the life lived, and their future. Many reported increased spontaneity and living 'in the moment' because of the uncertainty surrounding their future health:

> *You really don't know what's coming next so I think it's a good to do what makes you happy in that moment... It's changed me like that, so I'm more 'alright let's go!' (Kerry)*

By contrast, for some, their care needs subverted the normal order of parenting, as a result of their children caring for them, or them being unable to care for their children. These experiences highlighted a loss of autonomy and purpose:

> *My daughter, who I frightened when I collapsed, she hovers around me… She's there every time I turn around (Eleanor)*

> *And in the night my son would be crying and my partner...he'd be up all hours rocking him back and forth and I was just sat there watching, 'cos I couldn't do it. Physically couldn't do it. And it was really hard (Fiona)*

Illness and treatment resulted in a different experience of growing up for some younger participants, differentiating them from their peer group as well as older VTE patients, leaving them isolated and highlighting the restrictions VTE and its treatment created for them:

> *I'm different to my friends now (Fiona)*

> *And when it all adds up, it's like, I can't really DO anything!!...Like tattoos. I probably wouldn't ever have a tattoo but it would be nice to have the option to have it (Kerry)*

Changing expectations

Participants coping responses were shaped by their changing expectations of themselves and life post-VTE. Age and life stage, in particular, played an important role in this participants' adaptation. Younger participant felt it had "*bought independence a lot sooner" (Kerry, age 18y)* while older participants noted an increased in dependence.

Coping resources were also influenced by their life experience and developmental stage. Younger participants reported less empathy and support from peers because they felt who did not understand VTE and its implications:

> *If I was older they would understand…well they might understand. But because of my age the people I socialise with don't get it, they don't get it. And they don't understand (Kerry)*

By contrast, older participants acknowledged their life experiences helped them accept and integrate the experience more easily, with one commenting; "*Had I been younger, it might have affected me more (Jenny).*

The anxieties relating to VTE related symptoms reported at time one developed, for many, into a growing awareness that symptoms and treatment may be life-long. For younger patients, this realisation presented a significant physical and emotional burden and resulted in them taking increasing control over their treatment and developing a sophisticated understanding of their condition; although this often went unacknowledged:

> *I have my INR done weekly. They [practice nurses] don't like it. But I've read evidence that weekly INR's reduce your risk by death by 46%! They keep you in therapeutic range 90% of the time as oppose to 55% of the time when you go every 6 weeks (Fiona).*

Theme: The trauma of 'care'

Lack of care in primary care

Consistent with the findings reported at time one, the lack of information in relation to VTE and its treatment remained a source of frustration, and resulted in several participants seeking unregulated advice on the internet. Participants reported a perceived lack of care and support in community and primary care services with negative interactions with primary care physicians and office staff triggering and maintaining feelings of abandonment, and anxiety:

> *The doctors don't say to you,' if you don't feel better come back in a couple of days'. They just give you a prescription if you've got to have one and then through the door! I've got nobody to turn to (Alice)*

> *I think it would be better if the doctors in the surgery were more equipped to deal with the results themselves. And if they gave you the results themselves rather than the receptionist… the reception desk is right in front of where everyone is sitting! (Kerry)*

Such negative experiences were most frequently reported by, but not limited to, participants who had experienced missed diagnosis and/or who were experiencing on-going PTS. They were anxious about symptom recurrence and believed their concerns were sometimes dismissed as inappropriate:

> *[I said] 'What if it's the same in 3 days? You going to refer me then?' But it was getting to the point where I was getting into a sort of argument with the doctor. And in the end I said 'don't worry, I'll ring my consultant' (Fiona).*

Trust: lost, broken & regained

Participants who experienced repeated misdiagnoses reported a range of negative emotions, including blame attributed to the health professionals involved, and a lack of trust in medical opinion:

> *It's no good going to your GP. That's one thing I'm…I'm a bit sceptical about. I think, come on! Telling me it's muscular! Twice!? (Joe)*

> *That's the only reason I got this [PTS] is because the damage got so big. And it frustrates me cos they did that to me! (Fiona)*

These negative outcomes could be challenged and reversed. Rebecca, for example, described how her primary care physician made efforts to 'repair' their relationship following missed diagnosis, enabling them to rebuild trust. This contributed to a more positive experience of recovery, and facilitated emotional adjustment:

> *[The doctor] said 'I really want to speak to you'. … And I said, 'basically I know we're all human. I said, we all make mistakes, but I'd been telling you for a very long time that I don't feel right… And I was really nice to her cos she's a lovely, lovely woman… And I've gone back to seeing her again. And even my husband said 'you should see someone else' and I said [to him] I'm happy with her. I said, because I know I can talk to her (Rebecca).*

Theme: Thrombo-neuroses

"Post-thrombotic panic"

Participants reported hyper-vigilance and panic related to fear of illness recurrence that endured over time and could be triggered by sensations associated with the experience of VTE. Some described this as living with a "*paranoia [the clots] are going to come back" (Rebecca).* These anxieties formed a chronic burden, impacting on day-to-day life by contributing to episodes involving a vicious cycle of '*post-thrombotic panic'* as described by one VTE patient[8] (see figure 1):

> *Oh if I get an ache, my one leg if I get a bit of an ache in that it's like 'oh my god, there's something happening there again' (Sally)*

Anxieties were further escalated by difficulties differentiating between VTE symptoms and those of panic. Bodily sensations of breathlessness, leg pain, or tightness in the chest led participants to balance the risks of attributing these sensations to panic or VTE recurrence, and whether to seek medical help:

> *Because it's so similar to the symptoms... as a PE that's the problem. Chest pains, can't breathe, heart racing. I don't think I will ever not be frightened of them cos no matter how much I read into them you could always have that [PE].There's a very small chance it could happen and you should never ignore you know (Kerry)*

The 'matrix' of anxiety and uncertainty

Participants frequently described long term worries and rumination focusing on the cause of their VTE and its related symptoms, including PTS:

> *There has to be something that's made me have this! But they can't answer that! I mean, the doctors have told me they can tell me what I haven't got, but they can't tell me what I've had (Rebecca)*

Future worries related to symptom deterioration, quality of life and mortality, and reflected existential concerns about how VTE would affect participants' wider wellbeing as they age:

> *I always think about what will it be like as I get older?! As you get older you get a bit, you know, not so [healthy] as when you're younger. It does give me those thoughts then. It's like oh my god, what's my leg going to be like? And with post-thrombotic syndrome it can progress. It can get worse. It can stay the same, or it can get worse. (Fiona)*

Indeed, adjusting to the permanence of post-thrombotic syndrome was a chronic source of concern for many participants. Participants were aware that VTE-related anxiety impacted on their day to day lives as well as their wider psychological wellbeing:

> *It's the thought that I might have to live with this. If you think you're going to get better then you just put up with it. But I suppose in the back of my mind I'm concerned that it won't improve (Eleanor)*
>
> *It definitely has [affected me] but … if I think about it too much, if I start dwelling on it I start to get depressed (Fiona)*

Many found the implications of anticoagulant treatment restrictive and complex. The regular testing, monitoring, and dosage adjustments required in warfarin treatment repeatedly triggered anxieties and memories. Some made attempts to better understand the risks and benefits of treatment, which led to further anxieties:

> *It's not just black and white. It is kind of…that's one thing, but there's about twelve branches off it that could happen. And then that's another thing that has… It's a bit like the Matrix, you take one pill or the other pill and the whichever one you take…[shrugs](Kerry)*

A private struggle with emotion

Most participants reported being reluctant to share their worries with health professionals; unwilling to appear ungrateful to the health care system. They were also concerned about burdening family and friends, felt unable to fully articulate their concerns, or believed they would not be fully understood:

> *I'm not saying he's said he [husband] doesn't want to hear it but I wouldn't expect him to sit through. He couldn't sit there and listen to me talking about it (Sally)*

Participants commented that "*nobody talked about the psychological side of things" (Eleanor)* and so the struggle with emotions remained hidden, exacerbating anxieties, and preventing access to appropriate support. These private worries were separate from the more acute cycle of hypervigilance and panic and were chronic, repetitive, and involved a dual awareness and avoidance of worries:

> *There's probably an underlying worry about will it happen again, and all that nonsense. But I try to put right at the back of my mind (Michael)*

> *I don't think a great deal about it. It will always be in the back of your head (Ralph)*

By contrast, most participants felt that being able to discuss their fears, and engage with fellow patients could have been of benefit. The likely extent of these various emotion difficulties may be determined from, as yet, unpublished data from the larger longitudinal study from which participants were recruited, in which 36% reported high levels of post-trauma symptomology (score of 24 or more on the Impact of Events scale-revised[10], 22% met the criteria for 'probable diagnosis of PTSD', and 39% had "severe" psychological morbidity as assessed by the Hospital Anxiety and Depression Scale[11].

Theme: Through adversity comes growth

Cumulative adversity: the hero's journey

By the present interviews, the realisation that VTE-related physical difficulties may endure or worsen over time had become more evident to participants over time. Recovery presented enduring physical and psychological challenges, and coping with or overcoming them enabled participants to grow in confidence, and contributed to a search for meaning:

> *So that's been the benefits of having a pulmonary embolism, so to speak [laughs]. It's focussed my mind to lose weight and just think about healthy lifestyles. In a way I probably wasn't beforehand. Wake-up call that's what you call it (Peter)*

Their experiences focused participants on their strengths, which began to define their emerging post-VTE identity and enabled a view of their illness experience through the lens of a survivor who had overcome adversity:

> *I think I could deal with anything now really! Throw the book at me! [laughs] (Rebecca)*

> *I think I'll do things more. I know that sounds silly. Because it's stopped me from doing a lot of things (Kerry)*

The parental role, in particular, highlighted a duality of negative and positive impacts of the VTE experience. Parenting provided a reason greater than oneself for which to overcome the challenges faced post-VTE:

> *Like my partner said "there's no chance of the boys [sons] ever having anything wrong with them because you'll make sure they won't!"[laughs]. And yeah, that's good. And I help everybody who's in my life (Fiona)*

The duality was also reflected in descriptions of benefits and growth as being inter-related. The impact of living with VTE-related uncertainty led participants to search for meaning in their experience and this in turn in turn enabled them to find positives:

> *You know, in some ways it has been difficult. It's a whole 'pull you up' incredibly sharp and think about your life. But emerging out of that there's been the value of taking health more seriously and so forth (Peter)*

> *You'd almost say it's done me good (Michael*

"Enlightenment"

Even more evident than in time one interviews, many participants described aspects of the VTE and their response as an existential experience that "*really opened my eyes (Michael)*. Participants likened this to "*enlightenment*" and described how things "*just sort of clicked*" *(Kerry)* and the *"mist clears" (Rebecca)* in a way that facilitated adjustment:

> *Well things just seem to fall into place. The slightest thing. I can't really explain it. It's like an enlightenment. It's like, ping! Something goes off in your brain and you think, 'oh god it's really not as bad as that!' (Sally)*

They reported a new, post-VTE, outlook which they valued highly and which one participant was fearful of losing:

> *It's interesting in relation to the stuff to do with [work] that has concerned me. That it could be a return to a sort of, eyes down, dogged life as it were if we're not very careful. And that has concerned me these last couple of weeks (Peter)*

Participants reflected on their life in general and engaged in reprioritisation leading to active changes in their life, such as weight loss, spending savings and changing personal relationships. Central to that was the life-threatening nature of VTE which served as both catalyst and maintaining factor for these post-VTE alterations:

> *Oh yeah. You're out to enjoy your life now and get what you can out of it. It's something you don't really think about – death (Ralph)*

> *Life's short, live it to the full as much as you can afford to do so. And have time to do so. That's been drummed into me for god knows how long but I'm only now beginning to realise (Michael)*

Discussion

This study followed up eleven participants, previously interviewed within the first six months of a first time VTE, about its psychosocial impact[8] over the subsequent three months. This time frame was considered significant as participants had now moved beyond initial illness and diagnosis and many decisions had been made about their longer-term management of care; in particular, whether they would remain on anticoagulation treatment. Some issues remained constant. As at time one, participants reported significant levels of anxiety with many experiencing ongoing symptoms of trauma including intrusive thoughts, flashbacks and hypervigilance. The previously reported cycle of *'post-thrombotic panic'* remained, and participants continued to experience a vicious circle of panic and hypervigilance maintained by VTE-related symptoms (see Figure 1). The hyper-vigilance to bodily symptoms, common following illness[12], reflected the difficulties participants faced in avoiding internal sensations and reminders of the VTE *and* differentiating between symptoms of anxiety and VTE (e.g. shortness of breath, leg pain, tightness in chest); with implications for over-use of health care resources as well as individual distress.

(*insert figure 1 about here)*

Negative emotions such as anger and sadness, experienced because of missed diagnosis and chronic VTE related symptoms (including post-thrombotic syndrome, pain etc.) notably remained a concern for participants. They precipitated and perpetuated intrusive memories and anxieties. Furthermore, these emotions negatively impacted on relationships with professionals and influenced the use of health care resources. Anticoagulant treatment with warfarin necessitates regular monitoring and this provided frequent reminders of the VTE, treatment restrictions and future health risk; all of which contributed to low mood and anxiety. Participants also continued to experience wider, more diffuse fears of VTE recurrence, causal searching and concerns about future health alongside worries and restrictions about anticoagulation treatment. These may be understood as wider 'thrombo-neuroses'.

This study also highlights other potential sub-groups of VTE patients that may require additional support. Younger VTE patients seem most at risk of illness related isolation and health related anxiety due to their greater levels of uncertainty when contemplating their future, and they may be further disadvantaged by a lack the life experience and resources upon which older people can draw[13]. As such it is important to consider that VTE may impact a young person's development, with consequences for their emerging sense of identity.

Finally, the findings highlight the continuation of a dual process of trauma and growth in the aftermath of VTE, which may be best understood as post-trauma growth and benefit finding[14] both of which have been reported following a range of physical health disorders[15]. More definitive evidence of these processes in VTE could usefully be determined by larger, quantitative, studies.

In considering the limitations of this research, it is important to acknowledge the relatively small number of participants in the study, and the potential bias as a consequence of self-selection which limits interpretation and generalisability of the findings. More studies, with larger populations are clearly required. Nevertheless, the study provides the first longitudinal in-depth study of the experience of this group of patients. The findings support those reported in unrepresentative samples which suggest peri-traumatic factors seem to play a key role in the development and maintenance of post-traumatic responses[5]. Furthermore, it seems that through coping with such adversities individuals are able to experience growth, lending weight to the suggestion that the consequence of a traumatic illness onset are multi-dimensional; encompassing both negative and positive aspects[14-15]. In particular, it supports the notion that self-perceived posttraumatic growth is both a coping effort and a consequence of coping[16].

Future research may usefully compare the relationship between anxiety, health concerns, and warfarin treatment and its frequent engagement with health professionals, with the newer DOAC treatments which require lower levels of monitoring. The dynamic between the reassurance of drug levels being closely monitored at the cost of frequent reminders of patients' condition, and lower levels of monitoring, with less potentially reassuring data is important from a clinical perspective. As a cautionary note, since completing the study we have been made aware of 'warfarin envy'; a state in which individuals taking DOACs prefer the constant monitoring of warfarin levels to their absence. Given these psychological responses to differing treatment approaches, it would be of value to determine what type of medication regimen suits which individuals. Relatedly, it would be beneficial to understand how younger VTE patients and those affected by missed diagnosis are disadvantaged compared to older VTE patients and those with a clearer diagnostic pathway. Finally, it is important to consider how targeted support can help patients to manage their recovery[17] in such a way as to facilitate growth[8]. Cognitive behaviour therapy protocols for anxiety disorders have traditionally aimed to modify faulty threat appraisals and their value can be questioned in a population for whom health risks are a real threat. However, cognitive acceptance and mindfulness-based interventions may clearly be of benefit[18 19].

Table 1: Participant characteristics

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	N/A	27	PE	*opted out of time two interview
11	Alice	69	DVT & PE	Receiving chemotherapy Missed diagnosis
12	Joe	68	DVT	Missed diagnosis

Table 2: Interview schedule

Interview Schedule

Q1. How have things been since last time we met?

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

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?

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

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

Q6. Can you tell me about how you have coped since the PE/DVT?

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

Author contributions

Contributors: SN, PB, SL, RH conceived the study. RH undertook the interviews. RH and PB undertook analysis of data. All authors contributed to the final version of the manuscript.

Funding: The research was completed as part of a PhD funded by Thrombosis Research in Advanced Disease.

Competing interests: None

Ethics approval: Ethical approval was obtained through the National Health Service (NHS) South Wales Ethics Committee.

Data sharing statement: No additional data are available

References

---

[1]Beckman, V. I. G., Hooper,W. C., Critchley, S.E., & Ortel, T. L. (2010). Venous-thromboembolism: A public health concern. *American Journal of Preventive Medicine*, *38*,S495–S501.doi:10.1016/ j.amepre.2009.12.017

[2] White, R. H. (2003). The epidemiology of venous thromboembolism. *Circulation, 107,* 14 – 18. doi:10.1161/01.CIR.0000078468.11849.66

[3] Heit,J. A., Mohr, D. N., Silverstein, M. D., Petterson, T. M., O'Fallon,W. M., & Melton, L. J.III (2000). Predictors of recurrence after deep vein thrombosis and pulmonary embolism: A population based cohort study. *Archives of Internal Medicine, 160,* 761–768. doi:10.1001/ archinte.160.6.761

[4] 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,* 126–133. doi:10.1016/j.ejvs.2010.09.018

[5] Bennett, P., Patterson, K., & Noble, S. (2016). Predicting post-traumatic stress and health anxiety following a venous thrombotic embolism. *Journal of Health Psychology, 21,* 863–871.

[6] Kahn, S., Ducruet, T., Lamping, D., Arsenault, L., Mironm, M., Roussin, A., ...Shrier, I. (2005). Prospective evaluation of health related quality of life in patients with deep vein thrombosis. *Archives of Internal Medicine, 165*, 1173–1178. doi:10.1001/archinte.165.10.1173

[7] van Es, J., den Exter, P. L., Kaptein, A. A., Andela, C. D., Erkens, P. M., Klok, F. A., ... & Huisman, M. V. (2013). Quality of life after pulmonary embolism as assessed with SF-36 and PEmb-QoL. *Thrombosis research*, *132*(5), 500-505 doi.org/10.1016/j.thromres.2013.06.016

[8] Hunter, R., Lewis, S., Noble, S., Rance, J., & Bennett, P. D. (2016). "Post-thrombotic panic syndrome": A thematic analysis of the experience of venous thromboembolism. *British Journal of Health Psychology*, DOI:10.1111/bjhp.12213

[9] Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.

---

[10] Weiss, D. S. (2007). The impact of event scale: revised. In *Cross-cultural assessment of psychological trauma and PTSD* (pp. 219-238). Springer, Boston, MA.

[11] Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370.

[12] Tyrer, P., Cooper, S., Crawford, M., Dupont, S., Green, J., Murphy, D., ... & Keeling, M. (2011). Prevalence of health anxiety problems in medical clinics. *Journal of Psychosomatic Research*, *71*(6), 392-394.

[13] Corbeil, A., Laizner, A. M., Hunter, P., & Hutchison, N. (2009). The experience of uncertainty in young adults with cancer. *Cancer nursing*, *32*(5), E17-E27.

[14] Joseph, S. (2011). *what doesn't kill us: The new psychology of post-traumatic growth. Basic Books, New York.*

[15] Hefferon, K., Grealy, M., & Mutrie, N. (2009). Post□traumatic growth and life threatening physical illness: A systematic review of the qualitative literature. *British Journal of Health Psychology*, *14*(2), 343-378.

[16] Maercker, A., & Zoellner, T. (2004). The Janus face of self-perceived growth: Toward a

---

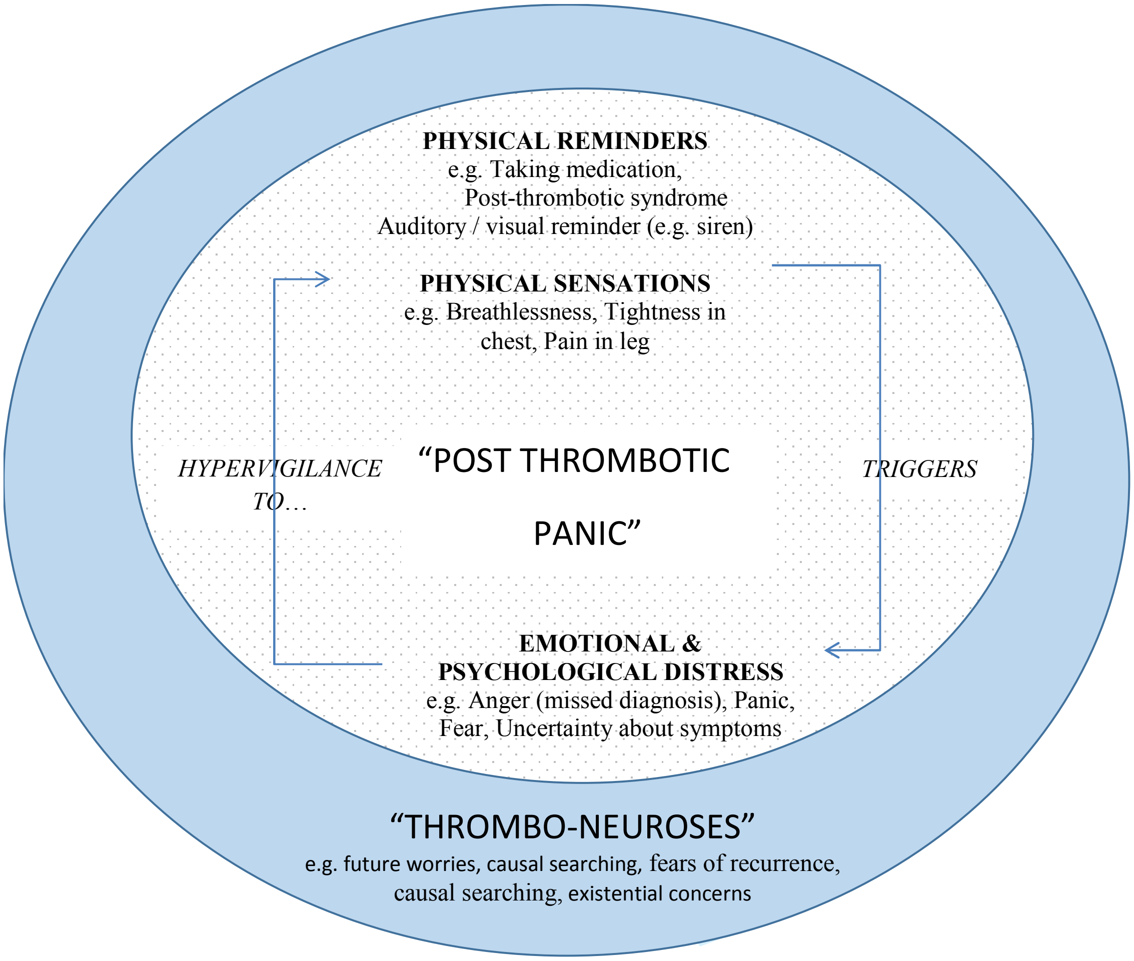
two-component model of posttraumatic growth. *Psychological Inquiry*, *15*(1), 41-48.

[17] 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*(4), e004561.

[18] Lundgren, T., Dahl, J., & Hayes, S. C. (2008). Evaluation of mediators of change in the treatment of epilepsy with acceptance and commitment therapy. *Journal of behavioural medicine*, *31*(3), 225-235.

[19] Montgomery, K. L., Kim, J. S., & Franklin, C. (2011). Acceptance and commitment therapy for psychological and physiological illnesses: A systematic review for social workers. *Health & Social Work*, *36*(3), 169-181.

Figure 1: psychological responses to VTE including "post-thrombotic panic" and more diffuse concerns about health and recurrence ('thrombo-neuroses').



BMJ Open

Long-term psychosocial impact of venous thromboembolism: a qualitative study in the community

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-024805.R1
Article Type:	Research
Date Submitted by the Author:	10-Dec-2018
Complete List of Authors:	Hunter, Rachael; Swansea University, Psychology Noble, Simon; Cardiff University, Palliative Medicine Lewis, Sarah; Aneurin Bevan University Health Board, Haematology Bennett, Paul; Swansea University, Clinical Psychology
Primary Subject Heading:	Haematology (incl blood transfusion)
Secondary Subject Heading:	Qualitative research
Keywords:	venous thromboembolism (VTE), QUALITATIVE RESEARCH, HAEMATOLOGY, interviews, psychological morbidity, interview

Long-term psychosocial impact of venous thromboembolism: a qualitative study in the community

Hunter, R.[1]*, Noble, S.,[3] Lewis, S., & [2] Bennett, P.[1],

[1]Department of Psychology, Swansea University, Wales, UK

[2]Aneurin Bevan University Health Board, Wales, UK

[3]School of Medicine, Cardiff University, Wales, UK

*corresponding author: Dr R. Hunter, Psychology Dept., College of Human and Health Science, Swansea University, Singleton Park, Swansea, UK, SA2 8PP, r.hunter@swansea.ac.uk, 01792 295714

Word count: 3894, excluding title page, abstract, references, figures and tables

Abstract

Objectives: Venous thromboembolism is a serious, potentially traumatic, life-threatening condition and a major cause of mortality and morbidity. The aim of this study was to obtain detailed understandings of the impact of VTE and examine individual's experiences over the first year since a first time VTE.

Design: A longitudinal qualitative interview study using inductive thematic analysis. This study presents follow-up data for eleven participants, first interviewed six months following a first-time VTE.

Setting: Outpatients recruited from a community haematology clinic in a UK District General Hospital.

Participants: Eleven participants (seven female and four male) recruited from a community haematology clinic. Participants had experienced a first time VTE and participated in qualitative interviews three months previously.

Intervention: Audio-recorded semi-structured interviews with a sample of eleven participants who experienced a first-time DVT or PE within the previous year. Interviews were transcribed and analysed using inductive thematic analysis.

Results: Four over-arching themes were identified: life changing and forever changed, the trauma of care, 'thrombo-neuroses' and through adversity comes growth. Theme content varied according to age and developmental stage, presence of VTE symptoms and the experience of diagnosis.

Conclusions: The data demonstrates the psychosocial impact of VTE and its diagnosis as physically and psychologically challenging, and individuals reported being forever changed by the experience. Participants' reported continued high levels of trauma and anxiety symptoms, triggered by physical (e.g. symptoms) and psychological (e.g. health anxiety, negative emotions) reminders of VTE. Wider primary care service issues including misdiagnosis maintained negative emotions and health anxiety with implications for relationships with professionals. Targeted clinical interventions to better identify and support individuals at risk of distress and enhance psychological well-being and reduce distress are discussed.

Keywords: venous-thromboembolism (VTE), haematology, qualitative, interview, psychological morbidity,

Strengths and limitations of this study

- This is the first longitudinal study of psychosocial impact of venous thromboembolism (VTE).
- The study had sequential entry so is as representative as possible of people early in their patient career.
- The patients were recruited from a single site.
- This paper gives patients a voice and highlights unmet clinical needs.
- While appropriate in numbers for thematic analysis, the numbers of participants are relatively low so there must be caution in generalisation of findings.

Introduction

Venous thromboembolism (VTE), comprising deep vein thrombosis (DVT) and pulmonary embolism (PE), has an incidence rate of 1-2 per 1000 persons in Western populations[1].Mortality rates are high[2], and around 25 per cent of those affected experience further events over the subsequent five years[3]. Post-thrombotic syndrome is a complicating factor in 25 to 50 percent of DVT cases[4], presenting a considerable burden for services and the individual.

Despite substantial research into its medical consequences, the emotional and psychological implications of VTE have received less attention. Studies[5-7] have highlighted impaired quality of life across physical, social and psychological domains in the early months following the event. However, no study has examined the evolving emotional and coping experiences in a representative sample of VTE patients over time. This is despite evidence that psychological distress among the chronically is associated with a range of adverse consequence, including reduced adherence treatment, increased symptom burden, and elevated levels of disability and death.[8]

The present study addresses this gap. It follows up eleven participants, first interviewed during the first six months following a first-time VTE. At this time, themes from inductive thematic analysis included VTE as a life changing and traumatic experience; living with uncertainty and fear of reoccurrence; feeling let down by health services, and positive changes and outcomes. Thematic content varied according to participants' age and experiences of diagnosis and treatment and highlighted a dual process of trauma and growth and a vicious circle of symptom-related panic. To better understand the longitudinal impact of this experience, participants were re-interviewed approximately three months after their first interview

Methods

Participants

Participants were a consecutive series of patients recruited from an out-patient haematology clinic in a UK District General Hospital[9].They were over 18 years of age, had experienced a first-time VTE in the six months prior to a first interview, and consented to being re-interviewed three months subsequently. Eleven of twelve participants participated in this second interview: seven women and four men aged 18 to 69 (mean = 53.4) years, and all white British. Participant characteristics are summarised in table 1.

Procedure

The study was approved by an NHS Research Ethics Committee (ref: 14/WA/0019). Following written consent, participants took part in a semi-structured interview, lasting between 30 and 80 minutes. A semi-structured interview template allowed exploration of participants' responses whilst ensuring particular topics were discussed (see table 2 for interview schedule). An open and flexible interview process enabled the participants' perspectives to be accessed; allowing them to speak freely and ensuring rigor and trust worthiness of data.

Patient involvement

Patient representatives were consulted in the development of the interview topics guide and interview questions. The findings of this study will be disseminated to participants who requested this.

Analysis

Participant interviews were recorded and transcribed verbatim. Transcripts were analysed individually by RH, an experienced clinical psychologist, using inductive thematic analysis[10]. This exploratory approach was best suited to elucidating the nature of a group's conceptualisation of the phenomenon under study. It has a growing body of literature examining a wide variety of health and is considered a useful method for examining different perspectives and generating novel topics insights[10]. Audio recordings were listened to repeatedly to ensure accuracy and enable the identification and generation of relevant initial codes and textual units for features and patterns in the data. Extracts and phrases were used to identify potential themes, with relevant data ('quotes') gathered within identified themes. The data were systematically reviewed to ensure that a name, definition, and exhaustive set of data were identified to support each category. The same unit of text could be included in more than one category. To ensure rigour and trustworthiness of recruitment, data collection and analysis, the process of saturation was adhered to[11]. Themes and sub-themes derived from the data and findings were checked and validated by PB; any differences were resolved through discussion.

Results

Thematic analysis revealed four major themes and nine sub-themes. Major themes were; life changing and forever changed, the trauma of care, 'thrombo-neuroses' and through adversity comes growth.

Theme: life changing and forever changed

A different life

Continuing from Time One, all participants reflected on how their life had been changed by VTE and its treatment. Participants reported active attempts to integrate their experience, resulting in a new, post-VTE identity. Those taking warfarin increasingly identified as a 'warfarin patient': "*others probably don't take warfarin so they probably don't know" (Kerry),* as did those around them. Their life and emerging self post-VTE were also shaped by the suddenness and life-threatening nature of the condition. It triggered reappraisal of the life lived, and their future. Many reported increased spontaneity and living 'in the moment' because of the uncertainty surrounding their future health:

> *You really don't know what's coming next, so I think it's a good idea to do what makes you happy in that moment... It's changed me like that, so I'm more 'alright let's go!' (Kerry)*

By contrast, for some, their care needs subverted the normal order of parenting, as a result of their children caring for them, or them being unable to care for their children. These experiences highlighted a loss of autonomy and purpose:

> *My daughter, who I frightened when I collapsed, she hovers around me… She's there every time I turn around (Eleanor)*

> *And in the night my son would be crying and my partner…he'd be up all hours rocking him back and forth and I was just sat there watching, 'cos I couldn't do it. Physically couldn't do it. And it was really hard (Fiona)*

Illness and treatment resulted in a different experience of growing up for some younger participants, differentiating them from their peer group as well as older VTE patients, leaving them isolated and highlighting the restrictions VTE and its treatment created for them:

> *And when it all adds up, it's like, I can't really DO anything!!...Like tattoos. I probably wouldn't ever have a tattoo but it would be nice to have the option to have it (Kerry)*

Changing expectations

Participants coping responses were shaped by their changing expectations of themselves and life post-VTE. Age and life stage played an important role in this participants' adaptation. Younger participants felt it had "*brought independence a lot sooner" (Kerry, age 18y)* while older participants noted an increase in dependence.

Coping resources were also influenced by their life experience and developmental stage. Younger participants reported less empathy and support from peers because they felt who did not understand VTE and its implications:

> *If I was older they would understand…well they might understand. But because of my age the people I socialise with don't get it, they don't get it. And they don't understand (Kerry)*

By contrast, older participants acknowledged their life experiences helped them accept and integrate the experience more easily, with one commenting; "*Had I been younger, it might have affected me more (Jenny).*

The anxieties relating to VTE related symptoms reported at Time One developed, for many, into a growing awareness that symptoms and treatment may be life-long. For younger patients, this realisation presented a significant physical and emotional burden and resulted in them taking increasing control over their treatment and developing a sophisticated understanding of their condition; although this often went unacknowledged:

> *I have my INR done weekly. They [practice nurses] don't like it. But I've read evidence that weekly INR's reduce your risk by death by 46%! They keep you in therapeutic range 90% of the time as oppose to 55% of the time when you go every 6 weeks (Fiona).*

Theme: The trauma of 'care'

Lack of care in primary care

Consistent with the findings reported at Time One, the lack of information in relation to VTE and its treatment remained a source of frustration and resulted in several participants seeking unregulated advice on the internet. Participants reported a perceived lack of care and support in community and primary care services with negative interactions with primary care physicians and office staff triggering and maintaining feelings of abandonment, and anxiety:

> *The doctors don't say to you,' if you don't feel better come back in a couple of days'. They just give you a prescription if you've got to have one and then through the door! I've got nobody to turn to (Alice)*

> *I think it would be better if the doctors in the surgery were more equipped to deal with the results themselves. And if they gave you the results themselves rather than the receptionist… the reception desk is right in front of where everyone is sitting! (Kerry)*

Such negative experiences were most frequently reported by, but not limited to, participants who had experienced missed diagnosis and/or who were experiencing on-going PTS. They were anxious about symptom recurrence and believed their concerns were sometimes dismissed as inappropriate:

> *[I said] ‘What if it’s the same in 3 days? You going to refer me then?’ But it was getting to the point where I was getting into a sort of argument with the doctor. And in the end I said ‘don’t worry, I’ll ring my consultant’ (Fiona).*

Trust: lost, broken & regained

Participants who experienced repeated misdiagnoses reported a range of negative emotions, including blame attributed to the health professionals involved, and a lack of trust in medical opinion:

> *It’s no good going to your GP. That’s one thing I’m…I’m a bit sceptical about. I think, come on! Telling me it’s muscular! Twice!? (Joe)*

These negative outcomes could be challenged and reversed. Rebecca, for example, described how her primary care physician made efforts to ‘repair’ their relationship following missed diagnosis, enabling them to rebuild trust. This contributed to a more positive experience of recovery, and facilitated emotional adjustment:

> *[The doctor] said ‘I really want to speak to you’. … And I said, ‘basically I know we’re all human. I said, we all make mistakes, but I’d been telling you for a very long time that I don’t feel right… And I was really nice to her cos she’s a lovely, lovely woman… And I’ve gone back to seeing her again. And even my husband said, ‘you should see someone else’ and I said [to him] I’m happy with her. I said, because I know I can talk to her (Rebecca).*

Theme: Thrombo-neuroses

“Post-thrombotic panic”

Participants reported hyper-vigilance and panic related to fear of illness recurrence that endured over time and could be triggered by sensations associated with the experience of VTE. Some described this as living with a "*paranoia [the clots] are going to come back" (Rebecca)*. These anxieties formed a chronic burden, impacting on day-to-day life by contributing to episodes involving a vicious cycle of '*post-thrombotic panic'* as described by one VTE patient[8] (see figure 1):

> *Oh, if I get an ache, my one leg if I get a bit of an ache in that it's like 'oh my god, there's something happening there again' (Sally)*

Anxieties were further escalated by difficulties differentiating between VTE symptoms and those of panic. Bodily sensations of breathlessness, leg pain, or tightness in the chest led participants to balance the risks of attributing these sensations to panic or VTE recurrence, and whether to seek medical help:

> *Because it's so similar to the symptoms... as a PE that's the problem. Chest pains, can't breathe, heart racing. I don't think I will ever not be frightened of them cos no matter how much I read into them you could always have that [PE]. There's a very small chance it could happen and you should never ignore (Kerry)*

The 'matrix' of anxiety and uncertainty

Participants frequently described long term worries and rumination focusing on the cause of their VTE and its related symptoms, including PTS:

> *There has to be something that's made me have this! But they can't answer that! I mean, the doctors have told me they can tell me what I haven't got, but they can't tell me what I've had (Rebecca)*

Future worries related to symptom deterioration, quality of life and mortality, and reflected existential concerns about how VTE would affect participants' wider wellbeing as they age:

> *I always think about what will it be like as I get older?! As you get older you get a bit, you know, not so [healthy] as when you're younger. It does give me those thoughts then. It's like oh my god, what's my leg going to be like? And with post-thrombotic syndrome it can progress. It can get worse. It can stay the same, or it can get worse. (Fiona)*

Indeed, adjusting to the permanence of post-thrombotic syndrome was a chronic source of concern for many participants. Participants were aware that VTE-related anxiety impacted on their day to day lives as well as their wider psychological wellbeing:

> *It's the thought that I might have to live with this. If you think you're going to get better then you just put up with it. But I suppose in the back of my mind I'm concerned that it won't improve (Eleanor)*

Many found the implications of anticoagulant treatment restrictive and complex. The regular testing, monitoring, and dosage adjustments required in warfarin treatment repeatedly triggered anxieties and memories. Some made attempts to better understand the bleeding risks and benefits of treatment, which led to further anxieties:

> *It's not just black and white. It is kind of…that's one thing, but there's about twelve branches off it that could happen. And then that's another thing that has… It's a bit like the Matrix, you take one pill or the other pill and the whichever one you take… [shrugs](Kerry)*

A private struggle with emotion

Most participants reported being reluctant to share their worries with health professionals; unwilling to appear ungrateful to the health care system. They were also concerned about burdening family and friends, felt unable to fully articulate their concerns, or believed they would not be fully understood:

> *I'm not saying he's said he [husband] doesn't want to hear it but I wouldn't expect him to sit through. He couldn't sit there and listen to me talking about it (Sally)*

Participants commented that "*nobody talked about the psychological side of things" (Eleanor)* and so the struggle with emotions remained hidden, exacerbating anxieties, and preventing access to appropriate support. These private worries were separate from the more acute cycle of hypervigilance and panic and were chronic, repetitive, and involved a dual awareness and avoidance of worries:

> *There's probably an underlying worry about will it happen again, and all that nonsense. But I try to put right at the back of my mind (Michael)*

> *I don't think a great deal about it. It will always be in the back of your head (Ralph)*

By contrast, most participants felt that being able to discuss their fears and engage with fellow patients could have been of benefit. The likely extent of these various emotion difficulties may be determined from, as yet, unpublished data from the larger longitudinal study from which participants were recruited, in which 36% reported high levels of post-trauma symptomology (score of 24 or more on the Impact of Events scale-revised[8], 22% met the criteria for 'probable diagnosis of PTSD', and 39% had "severe" psychological morbidity as assessed by the Hospital Anxiety and Depression Scale12[9].

Theme: Through adversity comes growth

Cumulative adversity: the hero's journey

By the present interviews, the realisation that VTE-related physical difficulties may endure or worsen over time had become more evident to participants over time. Recovery presented enduring physical and psychological challenges, and coping with or overcoming them enabled participants to grow in confidence, and contributed to a search for meaning:

> *So that's been the benefits of having a pulmonary embolism, so to speak [laughs]. It's focussed my mind to lose weight and just think about healthy lifestyles. In a way I probably wasn't beforehand. Wake-up call that's what you call it (Peter)*

Their experiences focused participants on their strengths, which began to define their emerging post-VTE identity and enabled a view of their illness experience through the lens of a survivor who had overcome adversity:

> *I think I could deal with anything now really! Throw the book at me! [laughs] (Rebecca)*

> *I think I'll do things more. I know that sounds silly. Because it's stopped me from doing a lot of things (Kerry)*

The parental role in particular, highlighted a duality of negative and positive impacts of the VTE experience. Parenting provided a reason greater than oneself for which to overcome the challenges faced post-VTE:

> *Like my partner said, "there's no chance of the boys [sons] ever having anything wrong with them because you'll make sure they won't!" [laughs]. And yeah, that's good. And I help everybody who's in my life (Fiona)*

The duality was also reflected in descriptions of benefits and growth as being inter-related. The impact of living with VTE-related uncertainty led participants to search for meaning in their experience and this in turn in turn enabled them to find positives:

> *You know, in some ways it has been difficult. It's a whole 'pull you up' incredibly sharp and think about your life. But emerging out of that there's been the value of taking health more seriously (Peter)*

> *You'd almost say it's done me good (Michael)*

"Enlightenment"

Even more evident than in Time One interviews, many participants described aspects of the VTE and their response as an existential experience that "*really opened my eyes (Michael)*. Participants likened this to "*enlightenment*" and described how things "*just sort of clicked*" *(Kerry)* and the *"mist clears" (Rebecca)* in a way that facilitated adjustment:

> *Well things just seem to fall into place. The slightest thing. I can't really explain it. It's like an enlightenment. It's like, ping! Something goes off in your brain and you think, 'oh god it's really not as bad as that!' (Sally)*

Participants reflected on their life in general and engaged in reprioritisation leading to active changes in their life, such as weight loss, spending savings and changing personal relationships. Central to that was the life-threatening nature of VTE which served as both catalyst and maintaining factor for these post-VTE alterations:

> *Oh yeah. You're out to enjoy your life now and get what you can out of it. It's something you don't really think about – death (Ralph)*

> *Life's short, live it to the full as much as you can afford to do so. And have time to do so. That's been drummed into me for god knows how long but I'm only now beginning to realise (Michael)*

Discussion

This study followed up eleven participants, previously interviewed within the first six months of a first time VTE, about its psychosocial impact[9] over the subsequent three months. This time frame was considered significant as participants had now moved beyond initial illness and diagnosis and many decisions had been made about their longer-term management of care; in particular whether they would remain on anticoagulation treatment. Some issues remained constant. As at Time One, participants reported significant levels of anxiety with many experiencing ongoing symptoms of trauma including intrusive thoughts, flashbacks and hypervigilance. The previously reported cycle of *'post-thrombotic panic'* remained, and participants continued to experience a vicious circle of panic and hypervigilance maintained by VTE-related symptoms (see Figure 1). The hyper-vigilance to bodily symptoms, common following illness[12], reflected the difficulties participants faced in avoiding internal sensations and reminders of the VTE *and* differentiating between symptoms of anxiety and VTE (e.g. shortness of breath, leg pain, tightness in chest); with implications for over-use of health care resources as well as individual distress.

(insert figure 1 about here)

Negative emotions such as anger and sadness, experienced because of missed diagnosis and chronic VTE related symptoms (including post-thrombotic syndrome, pain etc.) notably remained a concern for participants. They precipitated and perpetuated intrusive memories and anxieties. Furthermore, these emotions negatively impacted on relationships with professionals and influenced the use of health care resources. Anticoagulant treatment with warfarin necessitates regular monitoring to manage risk of haemorrhage and this provided frequent reminders of the VTE, treatment restrictions and future health risk; all of which contributed to low mood and anxiety. Participants also continued to experience wider, more diffuse fears of VTE recurrence, causal searching and concerns about future health alongside worries and restrictions about anticoagulation treatment. These anxieties may be understood as wider 'thrombo-neuroses' and weighed heavily on participants; described metaphorically as "*the sword of Damocles" or "a dark cloud" with which they must learn to live.*

This study also highlights other potential sub-groups of VTE patients that may require additional support. Younger VTE patients may be most at risk of illness related isolation and health related anxiety due to greater levels of uncertainty when contemplating their future, and they may be further disadvantaged by a lack the life experience and resources upon which older people can draw[13]. As such it is important to consider that VTE may impact a young person's development, with consequences for their emerging sense of identity. Finally, the findings highlight the continuation of a dual process of trauma and growth in the aftermath of VTE, which may be best understood as post-trauma growth and benefit finding[14] both of which have been reported following a range of physical health disorders[15]. More definitive evidence of these processes in VTE could usefully be determined by larger, quantitative, studies.

In considering the limitations of this research, it is important to acknowledge the relatively small number of participants in the study, and the potential bias as a consequence of self-selection which limits interpretation and generalisability of the findings. More studies, with larger populations are clearly required. Nevertheless, the study provides the first longitudinal in-depth study of the experience of this group of patients. The findings support those reported in unrepresentative samples which suggest peri-traumatic factors seem to play a key role in the development and maintenance of post-traumatic responses[5]. Furthermore, it seems that through coping with such adversities individuals are able to experience growth, lending weight to the suggestion that the consequence of a traumatic illness onset is multi-dimensional; encompassing both negative and positive aspects[14-15]. In particular, it supports the notion that self-perceived posttraumatic growth is both a coping effort and a consequence of coping[16].

Future research may usefully compare the relationship between anxiety, health concerns, and warfarin treatment and its frequent engagement with health professionals, with the newer DOAC treatments which require lower levels of monitoring. The dynamic between the reassurance of drug levels being closely monitored at the cost of frequent reminders of patients' condition, and lower levels of monitoring, with less potentially reassuring data is important from a clinical perspective. As a cautionary note, since completing the study we have been made aware of 'warfarin envy'; a state in which individuals taking DOACs prefer the constant monitoring of warfarin levels to their absence. Given these psychological responses to differing treatment approaches, it would be of value to determine what type of medication regimen suits which individuals. Relatedly, it would be beneficial to understand how younger VTE patients and those affected by missed diagnosis are disadvantaged compared to older VTE patients and those with a clearer diagnostic pathway. Finally, it is important to consider how targeted support can help patients to manage their recovery[17] in such a way as to facilitate growth[9]. Cognitive behaviour therapy protocols for anxiety disorders have traditionally aimed to modify faulty threat appraisals and their value can be questioned in a population for whom health risks are a real threat. However, cognitive acceptance and mindfulness-based interventions may clearly be of benefit[18 -19].

Table 1: Participant characteristics

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	N/A	27	PE	*opted out of time two interview
11	Alice	69	DVT & PE	Receiving chemotherapy Missed diagnosis
12	Joe	68	DVT	Missed diagnosis

*no details were forthcoming about the participant’s decision to opt out of follow-up interview

Table 2: Interview schedule

Interview Schedule

Q1. **How have things been since last time we met?**

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

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?**

Q4. **What do your family and friends think about how the PE/DVT has affected you?**

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

Q6. **Can you tell me about how you have coped since the PE/DVT?**

Q7. **Finally, if you could sum up your overall experience of the DVT/PE and how it has changed or affected you and your life, what would you say?**

Author contributions

Contributors: SN, PB, SL, RH conceived the study. RH undertook the interviews. RH and PB undertook analysis of data. All authors contributed to the final version of the manuscript.

Funding: The research was completed as part of a PhD funded by Thrombosis Research in Advanced Disease.

Competing interests: None

Ethics approval: Ethical approval was obtained through the National Health Service (NHS) South Wales Ethics Committee.

Data sharing statement: Additional data is available upon reasonable request from the corresponding author

References

---

[1] Beckman, V. I. G., Hooper, W. C., Critchley, S.E., & Ortel, T. L. (2010). Venous-thromboembolism: A public health concern. *American Journal of Preventive Medicine*, *38*,S495–S501.doi:10.1016/ j.amepre.2009.12.017

[2] White, R. H. (2003). The epidemiology of venous thromboembolism. *Circulation, 107,* 14 – 18. doi:10.1161/01.CIR.0000078468.11849.66

[3] Heit,J. A., Mohr, D. N., Silverstein, M. D., Petterson, T. M., O'Fallon,W. M., & Melton, L. J.III (2000). Predictors of recurrence after deep vein thrombosis and pulmonary embolism: A population based cohort study. *Archives of Internal Medicine, 160,* 761–768. doi:10.1001/ archinte.160.6.761

[4] 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,* 126–133. doi:10.1016/j.ejvs.2010.09.018

[5] Bennett, P., Patterson, K., & Noble, S. (2016). Predicting post-traumatic stress and health anxiety following a venous thrombotic embolism. *Journal of Health Psychology, 21,* 863–871.

---

[6] Kahn, S., Ducruet, T., Lamping, D., Arsenault, L., Mironm, M., Roussin, A., ...Shrier, I. (2005). Prospective evaluation of health related quality of life in patients with deep vein thrombosis. *Archives of Internal Medicine, 165*, 1173–1178. doi:10.1001/archinte.165.10.1173

[7] van Es, J., den Exter, P. L., Kaptein, A. A., Andela, C. D., Erkens, P. M., Klok, F. A., ... & Huisman, M. V. (2013). Quality of life after pulmonary embolism as assessed with SF-36 and PEmb-QoL. *Thrombosis research*, *132*(5), 500-505 doi.org/10.1016/j.thromres.2013.06.016

[8] Katon, W., Lin, E. H., & Kroenke, K. (2007). The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *General hospital psychiatry*, *29*(2), 147-155.

[9] Hunter, R., Lewis, S., Noble, S., Rance, J., & Bennett, P. D. (2017). “Post-thrombotic panic syndrome”: A thematic analysis of the experience of venous thromboembolism. *British journal of health psychology*, *22*(1), 8-25.

[10] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

[11] O’Reilly M, Parker N. “Unsatisfactory Saturation”: a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*. 2012;13:190- 197. doi:10.1177/1468794112446106.

---

[12] Weiss, D. S. (2007). The impact of event scale: revised. In *Cross-cultural assessment of psychological trauma and PTSD* (pp. 219-238). Springer, Boston, MA.

[13] Corbeil, A., Laizner, A. M., Hunter, P., & Hutchison, N. (2009). The experience of uncertainty in young adults with cancer. *Cancer Nursing*, *32*(5), E17-E27

[14] Joseph, S. (2011). *What doesn't kill us: The new psychology of post-traumatic growth. Basic Books, New York.*

[15] Hefferon, K., Grealy, M., & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: A systematic review of the qualitative literature. *British Journal of Health Psychology*, *14*(2), 343-378.

[16] Maercker, A., & Zoellner, T. (2004). The Janus face of self-perceived growth: Toward a two-component model of posttraumatic growth. *Psychological Inquiry*, *15*(1), 41-48

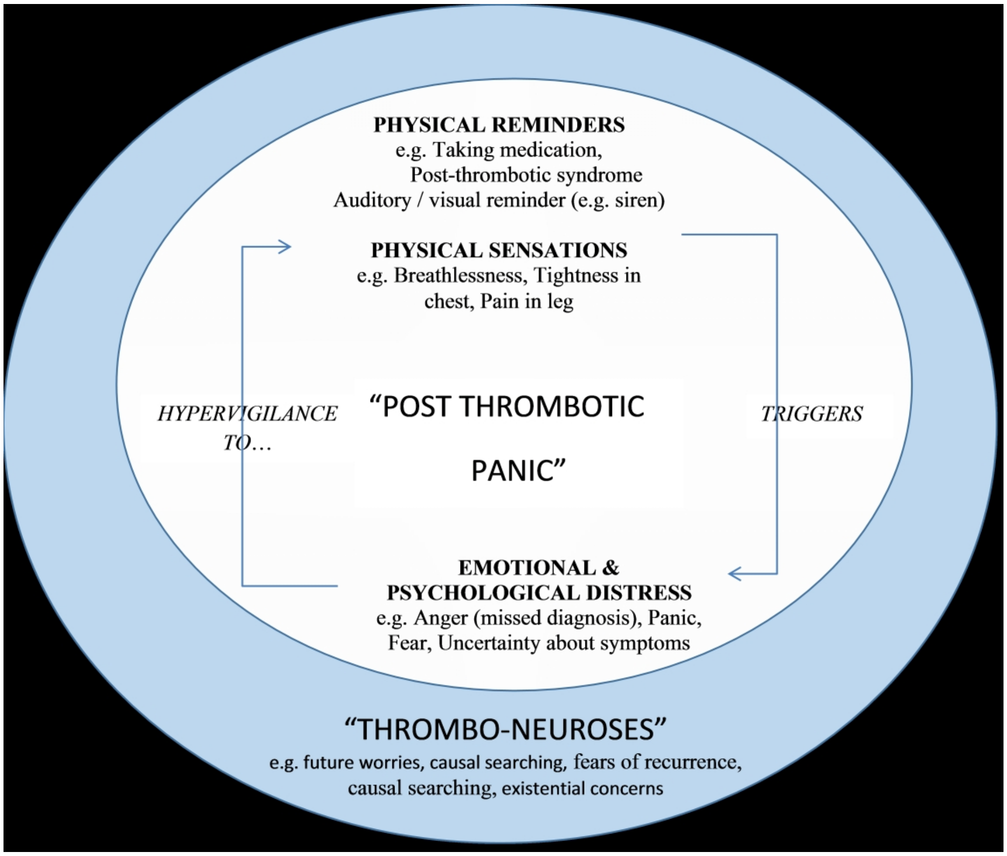
[17] Noble, S., Lewis, R., Whithers, J., Lewis, S., & Bennett, P. (2014). Long-term psychological consequences of symptomatic pulmonary embolism: a qualitative study. *British Medical Journal Open*, *4*(4), e004561.

[18] Lundgren, T., Dahl, J., & Hayes, S. C. (2008). Evaluation of mediators of change in the treatment of epilepsy with acceptance and commitment therapy. *Journal of Behavioural Medicine*, *31*(3), 225-235.

---

[19] Montgomery, K. L., Kim, J. S., & Franklin, C. (2011). Acceptance and commitment therapy for psychological and physiological illnesses: A systematic review for social workers. *Health & Social Work*, *36*(3), 169-181.

Figure 1: psychological responses to VTE including "post-thrombotic panic" and more diffuse concerns about health and recurrence ('thrombo-neuroses').



387x328mm (300 x 300 DPI)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1, line 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2-3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 4, line 1-15
Purpose or research question - Purpose of the study and specific objectives or questions	Page 4, 12-18 Page 4, 23-24

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 2 line 6-7 Page 6, line 1-6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 6, line 2
Context - Setting/site and salient contextual factors; rationale**	Page 5, line 3-6
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 3, line 13-14, Page 6, line 9-12
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 5, line 11-12.
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 5, line 12-16, Page 5, line 24-25, Page 6, line 1-12

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 5, line 19-20, Page 20, line 24-25, Page 20 (interview schedule)
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 19, (table of patient characteristics), Page 5, line 12-13
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 5, line 24-25, Page 5, line 4-12
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 5, line 25, Page 6, line 1-12
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 6, line 4-9, Page 6, line 10-12

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 6, line 14 until Page 16, line 3.
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 6, line 14 until Page 16, line 3.

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 16, line 4 onwards
Limitations - Trustworthiness and limitations of findings	Page 17, 19-22

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 20, line 6
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 20, line 4-5

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388