

Journal of Health Psychology I-9 © The Author(s) 2014 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/1359105314540965 hpq.sagepub.com



# Paul Bennett<sup>1</sup>, Katie Patterson<sup>1</sup> and Simon Noble<sup>2</sup>

#### Abstract

This research identified psychosocial factors associated with post-traumatic stress and health anxiety following a venous thrombotic embolism. In all, 158 participants, largely registered with a venous thrombotic embolism information website (*Lifeblood: The Thrombosis Charity*), completed an online survey. Post-traumatic symptom scores were linked to health threat, and not moderated by perceived control over risk for further venous thrombotic embolism. Health anxiety was associated with continuing symptoms and a negative emotional response to the venous thrombotic embolism. There is a need to intervene to reduce both short- and long-term distress in this population, ideally using a stepped-care model.

#### **Keywords**

beliefs, event threat, health anxiety, illness, post-traumatic stress, venous thromboembolism

#### Introduction

Venous thrombotic embolism (VTE) affects 1 in 1000 people per year. The experience of a VTE differs from a relatively innocuous deep vein thrombosis (DVT) to a pulmonary embolism (PE) which is acute, severe and lifethreatening. Clinician and patient reports, and the experience of relevant support organisations such as Lifeblood: The Thrombosis Charity, indicate the potential for significant psychosocial problems following VTE. However, we are aware of only three small empirical studies that have examined this issue. Both Moore et al. (2008) and Etchegary et al. (2008) conducted qualitative studies with a limited number of patients following VTE and found modest psychosocial impacts. In the quantitative arm of Moore's study (Moore et al., 2006), they found

levels of distress greater than those associated with myocardial infarction 1 month following a VTE, and that mastery, self-esteem and optimism were associated with positive emotional outcomes.

The experience of a VTE, and particularly a PE, may be highly traumatic and has the potential to provoke long-term fear of recurrence or trauma memories. This distress may be added to by two important factors. First, the experience

**Corresponding author:** 

<sup>&</sup>lt;sup>1</sup>Swansea University, UK <sup>2</sup>Cardiff University, UK

Paul Bennett, Department of Psychology, Swansea University, Singleton Park, Swansea SA2 8PP, UK. Email: p.d.bennett@swansea.ac.uk

of one VTE indicates increased risk for further VTEs either as a consequence of genetic or other clotting factors. The individual is necessarily aware of their risk of experiencing a second potentially traumatic or fatal VTE. Second, treatment of VTE generally involves long-term treatment with medication that increases risk of spontaneous bleeds. As one participant noted in a qualitative arm of the study, the individual is 'involved in a tightrope between experiencing a clot or a bleed'. Reducing the risk of a bleed may also involve behavioural changes, including lower levels of engagement in activities likely to result in vascular damage such as sports or exercise. This may significantly impact on the quality of life they experience.

From a theoretical perspective, the degree of post-traumatic stress disorder (PTSD) symptoms or health anxiety experienced is likely to be influenced by a number of factors. According to Joseph et al.'s (1997) model of post-traumatic stress, these include (1) peri-traumatic factors, including immediate threat cognitions, the experience of fear and dissociation at the time of the event and (2) subsequent appraisal of ongoing health threat and reappraisal of the threat experienced at the time of the VTE. These appraisals may involve re-consideration of the experience ('It was more/less serious than I originally thought'), relevant illness beliefs and the perceived costs and benefits of treatment, particularly in relation to minimising risk for further VTE. Interestingly, although not explored here, they may also be predicted by a number of physiological parameters (Cremeans-Smith et al., 2013). According to Salkovskis and Warwick (2001), health anxiety is also likely to be influenced by cognitive errors, including exaggerated fears of risk to health.

The present cross-sectional study explored these issues in a sample of people who had experienced a VTE, as a DVT, PE or both. Participants were largely registered users of a website of a VTE charity: *Lifeblood: The Thrombosis Charity*. They therefore cannot be considered representative of all patients who have experienced a VTE. For this reason, although we report scores of measures of PTSD

symptoms (Weiss and Marmar, 1997) and health anxiety (Salkovskis et al., 2002), the key focus of this article is to assess the relationship between PTSD symptoms, health anxiety and a number of psychosocial variables suggested by Joseph et al.'s theory of post-traumatic stress and Salkovskis' model of health anxiety. In particular, it explored the relationship between measures of PTSD symptoms and health anxiety, illness and treatment beliefs, threat appraisal at the time of the VTE and its subsequent reappraisal, and dissociation at the time of the VTE. It was hypothesised that high levels of threat and dissociation at the time of the event, negative event reappraisals and more negative illness and treatment beliefs would be associated with higher scores on measures of both PTSD symptoms and health anxiety.

#### Method

Ethical approval for the study was granted by the Swansea University Department of Psychology Ethics Committee. Potential participants were all those registered with the *Lifeblood: The Thrombosis Charity* website, who were tweeted a link to an online questionnaire. Notice of the study was also placed on the website itself, as it was regularly visited by nonregistered individuals.

#### Participants

Participants were 158 individuals registered with the Lifeblood website or visitors to their website, and all had experienced some form of VTE. Of these, 47 (30%) had experienced a DVT only, 68 (43%) had experienced a PE only and 43 (27%) had experienced both. In all, 23 were men, and 130 were women. Their average 40.5 years age was (standard deviation (SD)=12.26 years), and the average time since VTE was 25.6 months (SD=33.78 months). The number of people visiting the site independently of the registered Lifeblood members during the period of the study cannot be calculated. However, there were 224 registered members of the website who were informed about the study

via Twitter. An estimated 'best' response rate for the questionnaire was therefore 70.5 per cent, although the actual response rate may, clearly, have been lower.

#### Questionnaires

The online measure included the following: brief demographic details: age, gender and time since their VTE (or if they had experienced more than one, the time since the most recent VTE). In addition, the following psychometric measures were used:

Subjective Threat Scale. This comprised items from two previously reported scales. The first was a five-item measure of acute health threat (Marke and Bennett, 2013), measuring perceived vulnerability, severity of symptoms, concern, the ability to 'handle' the symptoms and confusion at the time of the VTE. A second scale, comprising three items from Initial Subjective Reaction (ISR) sub-scale of the Potential Stressful Events Interview (Resnick et al., 1996), measured (memories of) fear at the time of the event: 'I think I was close to death, I feel vulnerable, I think I could have been seriously injured or killed'. The two scales were highly correlated (r=.95) and were therefore combined into a single measure of 'subjective threat' (Cronbach's  $\alpha = .87$ ).

Threat reappraisal. The reappraisal measure involved all relevant items of the Subjective Threat Scale (STS) (n=7), and asked participants to consider the items 'looking back at events and how you feel now'.

Dissociation. The five dissociation items of the ISR (Cronbach's  $\alpha = .73$ ) were used to measure dissociation at the time of the VTE (Falsetti et al., 1994).

The Brief Illness Perceptions Questionnaire (BIPQ). This comprised eight, 11-point, singleitem Likert scales (Broadbent et al., 2006). Each item corresponded with one illness dimension of the Illness Perceptions Questionnaire (IPQ) – Revised (Moss-Morris et al., 2002): consequences, timeline, personal control, treatment control, identity, patient concern, illness comprehension and affective response. Items related to participants' 'risk of having another blood clot'. Scores for each dimension are reported separately.

Revised Impact of Event Scale. This comprised a 22-item questionnaire measuring the frequency of intrusive thoughts (n=8: Cronbach's  $\alpha=.92$ ), avoidance of intrusive thoughts (n=8: Cronbach's  $\alpha = .87$ ) and general arousal associated with PTSD (n=6; Cronbach's  $\alpha=.88$ ; Weiss and Marmar, 1997). The scale originators state the mean item response in each scale should be reported, so scale scores vary between 0 and 4, and the total score varies between 0 and 12. They did not recommend a cut-off score to indicate a likely diagnosis of PTSD. Other authors (e.g. Creamer et al., 2002) have reported total sub- and full-scale scores and suggested a cutoff score of 33 as indicative of a likely diagnosis of PTSD. Both scores are reported here to allow comparisons with other studies.

Health Anxiety Inventory. The Health Anxiety Inventory (HAI) was used to measure levels of health-related anxiety (see below) during the previous week using a 14-item scale (Cronbach's  $\alpha$ =.88; Salkovskis et al., 2002). Each item comprises four sentences describing increasingly anxious responses to various aspects of health anxiety, including frequency of worry, attention given to aches and pains, being afraid of having a serious illness and difficulties in taking one's mind off worries about health. A cut-off score of 18 is indicative of a likely diagnosis of what is now termed illness anxiety disorder (American Psychiatric Association, 2013)<sup>1</sup>.

VTE Treatment Beliefs (VTE-TB). A three-item, 10-point scale, questionnaire was used to measure three salient treatment beliefs: How effective is your treatment likely to be in reducing your risk of another blood clot? How likely is your treatment to increase your risk of bleeding following an injury? and How likely is your treatment to cause other unwanted side effects? In scaling the measure, scores of the first question were reversed such that high-item scores reflect worse outcomes. The scale achieved a Cronbach's  $\alpha$  of .82.

### Analysis

Two types of analyses are reported. First, oneway analysis of variance (ANOVA) was used to compare mean scores of each of the key measures. A PE is often acutely life-threatening, with symptoms in its severe form involving acute shortness of breath, coughing up blood, chest pain, feeling faint and even collapse. Presentation of a DVT is less threatening and problematic in the short-term. Accordingly, it was hypothesised that participants who experienced a PE would have higher PTSD symptoms and health anxiety and less positive IPQ scores than those with a DVT alone. Power analysis, assuming an effect size of 0.25, an error probability of 5 per cent, and a power of 0.80 indicated a required sample size of 159. The second set of analyses explored the relationship between PTSD symptoms, health anxiety and each of the potential predictor variables. These were first explored using correlations (Pearson's r or Spearman's rho as appropriate). The independent contribution of the independent variables was then examined through linear regression. The full Revised Impact of Event Scale (R-IES) and R-IES scale scores and HAI scores formed the dependent variables.

## Findings

Mean scores across the three groups for the study variables are reported in Table 1. The mean scores of only two variables differed significantly across the groups: age (F(2, 154)=7.00, p < .001) and threat reappraisal (F(2, 154)=4.76, p < .01). Post hoc analyses using Tukey's method showed the DVT-alone group to be younger than either of the other condition groups, and to be experiencing lower levels of threat reappraisal. Other findings of

note were that the mean scores of both the R-IES were above the cut-off scores for likely PTSD (33; Creamer et al., 2002) and illness anxiety disorder (18; Salkovskis et al., 2002). The mean time following the most recent VTE was also substantial, averaging 2 years and 3 months, with a wide range (1 month to 9 years 6 months).

Of note also was that participants generally reported their condition to have a chronic timeline and still to be evoking concern and a negative emotional reaction. Belief in their ability to control whether they experienced a further VTE was relatively low. Finally, there was consistent evidence of women reporting significantly higher trauma and health anxiety scores than men (total R-IES, women x=53.68 (20.43), men=40.87 (18.53), t(151)=2.79, p < .01; total HAI, women x=22.28 (6.11), men=18.56 (5.53), *t*(151)=2.72, *p* < .01). Participants also reported a range of causes of their VTE. They were asked to write up to three causes of their condition in a text box. In order of frequency of reporting, causes were considered a result of genetic factors (36% of participants), the contraceptive pill/pregnancy (32%), immobility including medical care and long-haul flights (28%), sedentary lifestyle/overweight (25%), trauma (21%), unknown/luck (16%), medical condition (6%), medical procedure (6%), smoking (5%), dehydration (5%) and stress (2%). Although participants were not asked to link causes, many did so linking, for example, a combination of genetic risk and taking the contraceptive pill.

Correlational analyses are reported in Table 2. Key findings were largely insignificant negative associations between time since participants' last VTE and both the R-IES and HAI scales. By contrast, strong and consistent findings between measures of threat and dissociation at the time of the event were found with both the HAI and R-IES scales. R-IES scores were also significantly correlated with reappraisal of threat, continuing symptoms and contemporaneous measures of the perceived impact of the VTE, a lack of control over risk of future VTEs, concern over risk for further VTE and a

	DVT alone	PE alone	DVT + PE
Time since VTE	28.10 (37.42)	23.99 (29.59)	27.61 (34.16)
Age	34.04 (13.9)	42.10 (11.58)	41.98 (11.29)***
Threat appraisal	25.63 (8.35)	26.97 (6.32)	25.91 (5.02)
Dissociation	13.95 (3.17)	14.08 (3.57)	13.59 (3.28)
Threat reappraisal	18.62 (5.94)	20.91 (4.43)	21.28 (2.67)**
IES – intrusion	2.43 (1.19)	2.54 (1.08)	2.32 (1.12)
IES – avoidance	2.17 (1.08)	2.31 (0.98)	2.00 (0.87)
IES – arousal	2.15 (1.12)	2.45 (1.09)	2.06 (1.14)
IES – total (based on item means)	6.79 (3.07)	7.31 (2.88)	6.42 (2.96)
IES – total (based on item sum)	49.68 (32.41)	53.46 (20.97)	46.98 (21.55)
HAI	32.53 (7.76)	33.90 (6.61)	32.26 (5.97)
IPQ – impact	6.77 (2.83)	6.78 (2.48)	6.77 (2.62)
IPQ – timeline	8.27 (3.03)	8.34 (2.34)	8.91 (2.52)
IPQ – personal control	4.15 (2.68)	5.18 (2.71)	5.19 (2.47)
IPQ – medical control	5.77 (2.70)	7.04 (2.24)	6.81 (2.18)
IPQ – concern	7.40 (3.25)	7.84 (2.54)	7.49 (2.24)
IPQ – understand	6.81 (3.20)	7.46 (2.72)	6.91 (2.97)
IPQ – emotion	6.96 (3.28)	7.09 (2.79)	6.58 (2.94)
Treatment – reduce risk	5.78 (3.07)	6.84 (2.54)	6.81 (2.80)
Treatment – risk of bleed	6.82 (3.96)	7.27 (3.38)	7.65 (3.46)
Treatment – side effects	5.65 (3.59)	6.25 (2.78)	5.60 (3.07)

Table I.	Mean (S	SD) scores	on each	study variable,	by	participant group.
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SD: standard deviation; DVT: deep vein thrombosis; PE: pulmonary embolism; VTE: venous thrombotic embolism; IES: Impact of Event Scale; HAI: Health Anxiety Inventory; IPQ: Illness Perceptions Questionnaire. \*\*\*p < .001; \*\*p < .01.

	R-IES – intrude	R-IES – avoid	R-IES – arousal	R-IES total	HAI total
Time since VTE	169*	091	113	138	150
Age	089	.008	.025	027	.057
Event scores					
Threat + fear	.547**	.483**	.509**	.558**	.387**
Dissociation	.517**	.542**	.504**	.571**	.378**
Diagnostic 'severity'	-041	095	075	.084	062
Present problems					
Reappraisal threat	.521**	.412**	.501**	.521**	.559**
Ongoing symptoms	.463***	.284**	.490**	.486**	.445**
Illness beliefs					
Impact	.505**	.350**	.505**	.493**	.579**
Time	.138	.165*	.143	.158*	.172*
Personal control	<b>292</b> **	<b>−.26</b> I**	243**	<b>299</b> **	146
Medical control	111	040	088	093	050
Concern	.452**	.391**	.418**	.453**	.403**
Coherence	117	060	064	088	.021
Emotional	.615**	.464**	.520***	.577**	.568**
Treatment beliefs	.112	.143	.190*	.161*	.225**

 Table 2. Correlations between predictor variables and measures of PTSD (Revised IES) and illness anxiety (HAI).

PTSD: post-traumatic stress disorder; IES: Impact of Event Scale; HAI: Health Anxiety Inventory; VTE: venous thrombotic embolism.

\*\*\*p < .001; \*\*p <.01.

	Total IES scale scores			Total HA	Total HAI scores			
	Beta	t value	þ value	Beta	t value	p value		
	Adjusted $R^2$ = .494, $F(11, 145) = 9.544$ , p < 0.001			Adjusted R <sup>2</sup> =.400, F(11,145)=8.182 p < 0.001				
Age	019	-282	.779	013	212	.832		
Gender	.156	2.382	.019	.192	3.059	.003		
Threat reappraisal	.156	2.118	.036	.089	1.159	.249		
Time	.148	2.019	.045	.101	1.327	.187		
Personal control	163	-2.070	.040	.059	.727	.468		
Medical control	.124	1.631	.105	055	698	.486		
Impact	.029	.298	.776	.316	3.143	.002		
Coherence	152	-2.181	.031	-004	049	.961		
Emotional	.275	2.426	.017	.226	1.924	.056		
Total symptoms	.237	3.271	.001	.089	1.159	.249		
Time since VTE	057	86 I	.391	118	-1.712	.089		
Treatment beliefs	-026	398	.691	021	-306	.760		

Table 3. Multiple regression analyses, with total IES and HAI scales as dependent variables.

IES: Impact of Event Scale; HAI: Health Anxiety Inventory; VTE: venous thrombotic embolism.

strong emotional reaction to the VTE. Beliefs about the risks and benefits of treatment were less consistently associated with R-IES scores, but were significantly associated with HAI scores.

Reports of threat and dissociation at the time of the VTE were clearly retrospective and open to significant bias. Accordingly, while reported here for completeness, they were not included in the multiple regression analyses, which focussed on the relationships between HAI and R-IES scores and contemporaneous scores of the brief IPQ, present appraisal of threat associated with the VTE, the frequency of symptoms and treatment beliefs. Together, these explained 49 per cent of the variance in R-IES scores (adjusted  $R^2$ =.494, F(11, 145)=9.544, p < .001) and 40 per cent of HAI scores (adjusted  $R^2 = .400$ , F(11), (145) = 8.182, p < .001) (see Table 3). Significant predictors of R-IES scores were gender, threat reappraisal, timeline, lack of personal control, understanding the nature of VTE, the emotional representation of the VTE and frequency of symptoms. Significant predictors of HAI scores were gender, the impact of the VTE and (marginally) the emotional representation of the VTE.

#### Discussion

This is the first study of which we are aware to report long-term emotional and cognitive consequences of VTE. Although a definitive response rate for the sample cannot be determined, our estimate of the 'best' response rate based on registered members of the Lifeblood charity directly contacted about the study was high (70.5 per cent). Even with some additional questionnaire completion by more casual site visitors, a more conservative response rate is still likely to be significantly higher than for most web-based surveys, particularly those involving only one contact between researchers and potential respondents (e.g. Cook et al., 2000). However, it should also be noted that the sample involved users of a website designed to support individuals who had experienced a VTE. This sample clearly runs the risk of having higher levels of intrusive worries and negative psychological consequences of VTE than a more representative sample of patients who do not use such websites.

Nevertheless, the data indicate the possibility of high levels of previously unidentified and long-term psychological morbidity within this population and support previous research with similar findings in the shorter term (Etchegary et al., 2008; Moore et al., 2006). The duration of PTSD symptoms and health anxiety experienced by some participants suggests that any concerns in this vulnerable group may be longterm and stable over time. Clearly, a long-term cohort study of a sample of VTE patients following discharge from hospital is required to unequivocally determine levels of psychopathology in this population and to ensure appropriate gender representation in the sample.

Participants reported a range of causes of their VTE. They were asked to write these in a text box with no constraints of boxes limiting their response. As a result, most participants reported the causes in a sophisticated way, linking multiple pathways to the condition: for example, linking genetic risk with taking the pill, trauma followed by immobility in hospital, smoking and being overweight combined with genetic risk. Most causes were consistent with conventional medical explanations, although a very small minority, such as stress, were less compatible.

Analyses of associations between predictor variables and measures of health anxiety and PTSD symptoms allowed theoretical consideration of the data. As predicted by Joseph et al. (1997), these showed significant associations between retrospective reports of dissociation, threat and fear at the time of the VTE occurrence and measures of PTSD symptoms. In addition, contemporaneous regression analysis found post-traumatic symptoms to be significantly and independently associated with several beliefs about the consequences of the VTE, including a perceived long timeline, a lack of personal control over risk of further VTE, a continuing strong emotional response to the VTE and a lack of understanding about the risk of further VTE. They were also strongly associated with the frequency of continuing symptoms following the VTE. Together, these combined to form a composite perception of ongoing threat, which drove intrusive worries and other trauma-associated symptoms, and is consistent with Joseph et al. (1997) theoretical model of PTSD.

Less supportive of the theory were findings that reappraisal of the threat associated with the original event was less important than these variables, as was time since the event, the treatment beliefs held by participants and perceived medical control over their condition. Interestingly, these results mirror findings of contributors to high levels of intrusive health worries in a sample of people living with long-term risk for breast cancer (Bennett et al., 2010). In both groups, intrusive worries and/or PTSD symptoms were driven by the threat associated with the risk to future health and were not moderated by beliefs about the effectiveness of relevant medical treatments or the perceived effectiveness of ongoing treatment or surveillance strategies. Of note also was that high levels of health anxiety were associated with a markedly different pattern of psychological variables: the continuing impact on the individual's life and, to a lesser extent, the negative emotional consequences of the VTE. The former may involve the continued behavioural restrictions and symptoms including shortness of breath, leg swelling, pain, venous ectasia and skin induration. Thus, health anxiety may, as theorised by Salkovskis and Warwick, be associated with awareness and attention given to symptoms: although in this case, the symptoms may, at least in part, be a direct long-term consequence of the VTE.

These data present a significant challenge to any attempt to ameliorate any worries, additional post-traumatic symptoms or anxiety individuals may experience following VTE. They appear to be driven by a perception of threat to health and are relatively unaffected by potentially controllable factors such as participants' own or medical management of risk. Future-related health anxieties or concerns may be difficult to treat effectively even using complex cognitive behavioural interventions (e.g. McManus et al., 2012; Sørensen et al., 2011), and within this population do not appear to moderate spontaneously over time. Nevertheless, some degree of stepped care may be of benefit.

In an unreported section in the questionnaire, virtually all participants commented that they had received excellent medical care, but had received no preparation for the psychological consequences of experiencing a traumatic disease onset or of living with the risk of further problems. Nor were they prepared for the lifestyle changes they had to make. Accordingly, the provision of appropriate information about risk and risk reduction (based around an illness beliefs perspective of, for example, Petrie et al., 2007), the implications of ongoing symptoms and so on may be of benefit. Such an intervention could usefully incorporate simple coping strategies to help people manage worries. These may include simple distraction techniques (Phelps et al., 2013) or more complex approaches such as mindfulness which may be of particular value in helping people come to accept and not focus on their ongoing worries or anxieties. This level of information may be provided in a one-off session by nurses trained in counselling, health psychologists and so on. It may even be possible to provide some form of self-help literature that requires minimal professional input. For those who do not benefit from this approach and who have continuing and significant emotional problems, a longterm intervention based around the cognitive behavioural treatment of PTSD (e.g. Bisson et al., 2013) or health anxiety (e.g. Tyrer et al., 2014) may be necessary.

# Acknowledgements

We are extremely grateful for the support of *Lifeblood: The Thrombosis Charity*, who supported this research by actively engaging and encouraging registered users and visitors to their website to take part in the study.

# Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

## Note

 There is the potential for confusion between the nomenclature of illness anxiety (the *Diagnostic* and Statistical Manual of Mental Disorders (DSM) title) and health anxiety (Salkovskis model). In keeping with Salkvovskis' model, and because our analyses are not based on DSM diagnostic criteria, we have elected to retain the use of health anxiety throughout expect where these cut-offs are directly referred to.

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