

Psychological effects of suffering a Venous Thromboembolism

Paul Bennett & Rachael Hunter
University of Swansea

p.d.bennett@swansea.ac.uk

The prevalence of problems...

	One month (n = 43)	Six months (n = 19)
HADS		
Anxiety	36.4%	40%
Depression	19.6%	20%
IES (PTSD)		
Clinically relevant	23.3%	21.1%
Clinical diagnosis	16.3%	15.8%
HAI		
Health anxious	44.4%	50%
Hypochondriasis	24.4%	37.4%

Individual lives.... missed diagnosis

Missed diagnosis (4/12) : lack of trust of doctors – difficult to repair
 anger and frustration
 poorer adjustment to experience of VTE & treatment

“that’s one thing I’m a bit sceptical about. I think, come on! Telling me it was muscular! Twice!! Yeah, I’m not...irritated. I just go to the GP [now] and think [rolls his eyes]. Shall we say I’ve lost a little bit of confidence in them”... And you think, do they really know what they’re doing ? I don’t know. Probably they don’t.”. Male 68y.

“It was physically really hard, and I think it was the most painful thing I’d ever had. It was really really bad. And again it keeps going back to that negligence because they let it get that bad. It wasn’t that bad on the Friday when I first went into hospital. It wasn’t half as bad as it was on the Monday you know? It was a massive difference between them 3 days and they had given me that klexane it would have started to shrink the clot that night. I wouldn’t have gone through that. And I’m adamant my leg wouldn’t be like it was today. Because 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”. Female, 25y

Individual lives.. Being young

Younger people: more likely to become 'expert patients' and want control over treatment
more aware and concerned by implications of condition and long-term anticoagulation
more analytic in their understanding of condition and treatment
less able to talk to family and friends (who are less sympathetic) or to see as part of 'getting older'

"being younger it does have a bigger impact. Because it's unexpected. When you're younger you don't think I'll fall, and all of a sudden I'll have clots in my lungs...I think it needs a lot more [information about] if you are feeling like you're on your own, and there's no you can talk to.... You can't just walk up to someone and [say] have you had a PE? And their like, what?". Female, 18y

"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 them 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. You can get ulcers and things and I don't want that". Female, 25y

"[skydiving's] actually something I'd really like to do but I can't now. But when you're older... you might want to go when you're 80 but you're less likely to. And I think when you're older your less likely to get a tattoo, get a piercing. Go and have a drink with your friends. I think the implications are the things that impact you in different ways". Female, 18y

The wider experience...

- “Post-thrombotic panic syndrome”

“Because it’s so similar to, the symptoms, as a PE that’s the problem. If it wasn’t just, if a blood clot was something that just happened in your leg a panic attack wouldn’t worry me. But because if you read the symptoms of a panic attack and the symptoms of a PE, I’m sure they’re very different when you’re going through them but if you read them, they are the same. Chest pains, can’t breathe, heart racing. And cos of what I’ve got it’s just sort of ironic that I’ve got something that can give you that. So I am, 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”. Female, 25y

- Recurring memories

“to be fair I think about it every day because of work. My boots are out there and I still do the same thing on the step. Putting them on there [where it happened]. And every time you go to do it you think, ‘oh yeah, this is where it really kicked in’. Male, 68y

The wider experience...

- A life of uncertainty and a need for clarity

“I thought I would have another scan to see if the clot has broken up and gone... This not knowing still plays with your mind, everyday”. Male, 57y.

“I think well, what the long term effect of this is you know. Is it going to shorten my life x years? Or you know, has it had an effect upon that? I sometimes dwell on that”. Male, 56y

“I think there should be a nurse. Not so much a doctor, but like a clinical nurse who,[] before your discharged should not go in depth, but say ‘this is what’s happened’. ... Female, 45y



The wider experience...

- Treatment: problems and tensions

*“It’s not just black and white. It is kind of...that’s one thing, but there’s about 12 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]”. Female, 18y*

“I’m positive I’m gonna be a lucky one. As long as I, that’s why 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. It decreases your risk of major bleeds massively, and clots. So it’s a no brainer for me. And that’s what I throw back at them every time”. Female, 25y

The wider experience...

- Growth and finding meaning

“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 you’re brain and you think, ‘oh god it’s really not as bad as that!’”. Female, 45

“I just wish I could meet the people that saved my life and thank them. They are the reason I am becoming a nurse; so I can give back and try and get some closure”. Female, 33y.

“It wouldn’t have happened to me if I’d known about it. I would have injections to stop the clot from happening. Now my kids can do that so they’ll hopefully never gonna have a clot because they’re gonna know to prevent. Even if, and if they have children themselves and have a girl. They’ll know! So I’m glad it happened to me and not them, my kids, you know. So I’m sort of protecting them now. Now we all know about it. So that’s positive in a way”. Female 25 yrs

In summary....

- People with VTE appear particularly vulnerable to anxiety and panic related to physical symptoms (“*post-thrombotic panic*”).
- **Patients who have experienced missed or late diagnosis** may require extra support. They may have daily, chronic symptoms which serve as reminders of the VTE and reinforce negative emotions associated with that late diagnosis.
- **Younger VTE patients** experience more loss, adjustment and future worries. They may be lifelong users of anticoagulants and health care services, with implications for overall wellbeing and quality of life.
- Need to support VTE patients cope by providing:
 - information about VTE
 - clarity (not certainty)
 - support

What next?



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A pack to support your recovery from thrombosis

This pack has been developed because we know that having a thrombosis, a deep vein thrombosis (DVT) or a pulmonary embolism (PE), can be a difficult time for people. People have told us that are often left with a lot of questions and uncertainties, as well as feelings of worry. We hope this pack will answer some of those questions and support you in your recovery after thrombosis.

This pack has been developed by researchers at Swansea University with the advice and support of Haematology professionals at Nevill Hall



Part A: Thrombosis & its treatment





Contact details

- If you are interested in hearing more about the intervention, please do get in touch:

Prof Paul Bennett P.D.Bennett@swansea.ac.uk

Dr Rachael Hunter 130333@swansea.ac.uk