Psychological effects of suffering a Venous Thromboembolism

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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









• "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

• 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



• 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

• 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?











Part A: Thrombosis & its treatment



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 <u>Nexill</u> Hall

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Coping with thrombosis

Thrombosis can occur out of the blue, with little or no warning and so it can be a real shock for people. A serious illness like a thrombosis can make us feel sad, frightened, worried or even angry. It can be a life threatening condition and at the time you may have feared for your life which can be a very scary experience and one that can play on your mind a lot. For other people it worries them less. For many people it is only later, after the thrombosis that you find yourself thinking about what happened and how serious it was. This can be distressing and hard for other people to understand. While you may at times feel very lucky to be alive, you may also fee very emotional and sad which can be confusing.



In this next section we will describe how the shock of having a thrombosis and coping with it can cause some people to feel anxious about the frombosis returning, or about their health in general. This is completely normal and we will provide information to help you understand why this happens, and some strategies to help you cope with those feelings.

Thrombosis and anxiety

A serious illness like thrombosis can affect every area of your life. Some people have few problems as a result of their thrombosis, but for many it can be big shock that can have a big impact on them. It may knock your confidence and leave you feeling worried about your health, your safety and the future and this may be hard to share with other people. Even if you have never been someone who worried in the past, sudden illness can leave you feeling vulnerable. You might feel that you can't talk to anyone because you don't want to worry them or that your worries are silly, which they are not. Worries like these are actually very common for people who have experienced thrombosis.

It is understandable that after a thrombos's many people feel anxious or worried about being ill again. Thrombos's usually occurs out of the blue and the shock can make us feel nervous and 'on edge' for quite a while afterwards. This is a very normal reaction and one which will usually go away in time. However, this feeling of anxiety can make us very alert and focused on our body and any unusual feelings we may get. Many people who have had a thrombos's say it can be hard to tell the difference between feelings of anxiety and symptoms of a thrombos's, and this can be scary for them.

What does it feel like to be anxious?

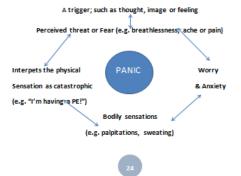
Anxiety feels like:

- panic attacks
- · constant worrying thoughts, often about the thrombosis and its treatment
- fearing the worst, for example, that you will have another thrombosis or that we might die
- being very aware of our heart beating (palpitations)
- tension and pains in our muscles

- being unable to relax
- sweating
- breathing too fast (hyperventilating)
- feeling dizzy
- feeling faint
- indigestion and diarrhoea.

Understanding panic attacks

Anxiety often comes hand-in-hand with panic attacks, which are sometimes called anxiety attacks. Many people report having panic attacks after a thrombosis. A panic attack is our body's natural response to danger and they are common for people who have experienced something dangerous like a life threatening illness or a big shock. A panic attack is our body's own response to that danger; it's a response called the 'fight or flight' response. 'Fight or Flight' gets our body ready to defend itself by making our heart beat faster, to pump blood to our muscles so that we have the energy to run away or fight off danger. It works like this:



Contact details

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

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