Cancer-associated thrombosis: clinical implications arising from the experiences of cancer patients and their carers

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4-5 FOLD
Our research-SLR

A systematic literature review (SLR) of qualitative work on the experience of cancer-associated thrombosis (Benelhaj et al. 2018)

Five papers with 92 participants

Noble and Finlay (2005)
Mockler et al. (2012)
Seaman et al. (2014)
Noble et al. (PELICAN study, 2015)
Noble et al. (ALICAT study, 2015)
Key points of SLR

- Lack of knowledge of cancer-associated thrombosis
- Psychological burden
- Effects of treatments
Knowledge of risk

“but they don’t tell you you’re gonna get clots after chemo, that’s the one thing they haven’t, they never said, but we just put it down to... it’s just my breathing...”

“I was out of breath and I said to my partner, ‘I think we are going to hospital’ without panic because I knew that it was something that could be rectified effectively.”
“It frightened the life out of me, I was more scared of that than the cancer. You know blood clots can kill you like that! Cancer you’ve got a little bit of chance, you know.”

“Knowing [that it is a PE] reassures you a little, nevertheless... I knew I needed to go to the hospital as fast as possible.”
Effects of treatment

“The heparin is so much simpler than all the ****ing about with warfarin.”

“I used to spend my life travelling to hospital for a warfarin check ... sat in the car ... sat in the waiting room ... not much of a life really.”
Clinical implications of SLR

- Provide information about cancer-associated thrombosis routinely to patients at or soon after cancer diagnosis.
- Encourage patients to discuss how they are feeling about having thrombosis.
- Reassure patients that self-injection is manageable.
Our research-interviews

The *select-d* trial is a randomised, multi-centre pilot study of

**Dalteparin**

a low-molecular-weight heparin

**vs**

**Rivaroxaban**

a direct oral anticoagulant

Semi-structured interviews with cancer patients and their carer (Hutchinson et al. 2018)

37 patients and 9 carers
Key points of interview study

- Lack of knowledge of risk and delayed help-seeking

- Cancer patients find injections acceptable in the context of cancer, especially when given support to overcome initial anxieties

- Many carers are prepared to help with injections

- Patients find taking tablets easier, but would only choose tablets over injections if found to be as safe and effective
Lack of knowledge

“No-one had told me that it could happen, or if they had told me they hadn’t said it enough, not so you can remember them saying ‘Well the cancer might cause it’, or ‘the operation might cause it’ or ‘the chemo might cause it’.” P12

“I’d been in pain with my leg for a good week or so but you just think it’s part of the cancer.” P2
Psychological burden

“I was utterly astounded, quite honestly ... I thought ‘Wow, my God, it could have killed me’.” P3

“part and parcel of having cancer” (P23)

“I don’t think I had a lot of time to think about it because I was concentrating far more, or feeling more affected by the chemotherapy.” P11
Psychological burden of thrombosis without cancer

- Thrombosis is life-changing and traumatic
  
  *I think I’m suffering from post-thrombotic panic syndrome!* (Peter, 21; 2–11)

- Living with uncertainty and fear of reoccurrence

- Feeling let down by health services

- Positive changes and outcomes

If they’d treated me that Friday when I went in and I stayed in hospital, that clot wouldn’t have got as big. My symptoms weren’t anything compared to what they were on the Tuesday. It wasn’t swollen [down] to my foot. It was discoloured and painful but it was ten times better than it was three days later. They could have stopped me from having what I have now – post-thrombotic syndrome. I’m really angry! ‘Cos now I’ve got to live with this. (Fiona, 25; 5–10)

“I suppose taking a tablet is less problematic. But again the injections didn’t worry me at all.” P32

“Obviously you're covered in bruises so you don't look great, but I'm now covered in scars and colostomy bags and that sort of thing, it seems a very small price to pay. It becomes a bit relative really.” P21
A way for a carer to help

“It’s difficult; I don’t know what to say sometimes. I suppose when I’m giving the injections perhaps it was a way for me to think yeah, well at least I’m trying to do something.” Carer for P35
Deciding on type of medication

“I just do as I was bid. I have no medical knowledge at all and I just do as they say.” P28

“If a tablet would serve the same purpose then I would certainly sooner take a tablet, but...if the injections are an advantage then it’s worth putting up with the discomfort.” P11
Clinical implications of interviews

- Provide information about cancer-associated thrombosis routinely to patients at or soon after cancer diagnosis.
- Encourage patients to discuss how they are feeling about having thrombosis.
- Reassure patients that self-injection is manageable and give guidance to both patients and carers.
- Discuss with your patients what their preferences for type of medication are.
Helpful resources

- http://www.anticoagulationuk.org/prevention/cat
- http://www.anticoagulationuk.org/resources
- https://fabnhsstuff.net/fab-stuff/cancer-associated-thrombosis-tool-kit
References and links


Hutchinson A, Rees S, Young A, Maraveyas A, Date K, Johnson MJ. Oral anticoagulation is preferable to injected, but only if it is safe and effective: An interview study of patient and carer experience of oral and injected anticoagulant therapy for cancer-associated thrombosis in the select-d trial. Palliative Medicine. 2018 Nov 29 https://doi.org/10.1177/0269216318815377

EAPC blog https://eapcnet.wordpress.com/2019/05/08/how-do-cancer-patients-feel-about-different-types-of-anticoagulants-for-blood-clots/
