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Evaluation of patients' experience and related qualitative outcomes in venous thromboembolism:

A scoping review

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ESSENTIALS

- Venous thromboembolism (VTE) treatment studies seldom evaluate outcomes related to patient experience, which are essential for improving patient-centered care in VTE
- This scoping review summarizes all published qualitative studies of VTE, with the aim of understanding the physical, psychological, and emotional impact of VTE as reflected from patients' perspectives
- Twenty-eight studies were summarized, which are representative of 436 participants across thirteen countries, and include a spectrum of VTE sub-populations
- Seven major themes were identified; several of these highlight important emotional and psychological impacts that may influence future research outcomes and patient education

ABSTRACT

Background: Venous thromboembolism (VTE) is a prevalent disease with high morbidity and mortality. VTE has well-documented physical sequelae, however the psychological and emotional impacts are seldom evaluated in randomized controlled trials.

Objective: We conducted a scoping review of published qualitative studies aiming to understand the physical, psychological, and emotional impact of VTE as reflected from patients' perspectives. This scoping review is part of a larger initiative to develop a core outcome set for VTE treatment studies.

Methods: A systematic literature search was conducted to identify qualitative studies assessing patient experience of VTE. Two authors independently screened titles and abstracts using Covidence systematic review software. Full text reviews were conducted independently by two study team members. A modified method of "thematic synthesis" was used to collate themes upon reading and re-reading of the publications.

Results: Our search strategy returned a total of 4944 citations; 28 were ultimately included in the analysis. The studies were conducted across 13 countries and representative of 436 participants including a spectrum of VTE sub-populations. There were seven major themes identified; *Acute Impacts: An Unforeseen Blow*, *Sustained Psychological Distress*, *Loss of Self: Life is Changed*, *Challenges of Thrombosis Management*, *Balancing Coping and Control*, *Negative Experience with the Medical System*, and *VTE in the Context of Other Conditions*.

Conclusions: The physical, psychological, and emotional impacts of VTE extend beyond objective outcomes typically evaluated in clinical trials. An improved understanding of the outcomes most important to patients will improve patient-centered care in VTE.

Keywords: venous thromboembolism, thromboembolism, venous thrombosis, pulmonary embolism, qualitative research, review, outcome assessment, health care

1. BACKGROUND

Venous thromboembolism, including deep vein thrombosis (DVT) and pulmonary embolism (PE), is the third-leading cause of vascular death worldwide and is responsible for a major global burden of disease¹⁻⁴. For survivors of VTE, post-thrombotic syndrome (PTS) manifesting as chronic limb swelling, discomfort, and less commonly skin ulceration, affects 20-50% of those with DVT^{6,7}. Post-PE syndrome affects 30-50% of those with PE and includes symptoms of chronic dyspnea, chest discomfort and decreased exercise tolerance, while chronic thromboembolic pulmonary hypertension (CTEPH) is a rare but serious consequence^{8,9}. The impact of VTE on mental health has been increasingly recognized¹⁰⁻¹². These long-term sequelae lead to significant morbidity, increased healthcare costs, and decreased quality of life (QOL)⁵.

Randomized controlled trials (RCTs) in VTE primarily evaluate physical outcomes of treatment including bleeding, VTE recurrence and death, while outcomes that focus on the beliefs, preferences and needs of patients are often not assessed¹³⁻¹⁶. Given the widespread impact of VTE disease, it is crucial to understand the lived experience of patients and whether this aligns with current trial outcomes. In a recent call to standardize outcomes across RCTs evaluating anticoagulation, Wang *et al.* emphasized a deficit in the assessment of quality-of-life domains, which are directly related to patient experience¹⁸. A quantitative scoping review has recently been conducted to capture outcomes assessed in VTE treatment studies and identified a deficit in studies evaluating the life impacts of VTE (unpublished data).

Qualitative research allows for patient experience to be richly characterized, including the exploration of psychosocial challenges and physical limitations of disease within the context of daily life¹⁷. By systematically understanding the outcomes and potential research questions that are most important to patients, we can better develop and conduct RCTs that are practice-changing and focus on improving patient care. As part of a larger initiative to identify a core outcome set for VTE research, we conducted a scoping review to summarize the impact of VTE disease as reflected from patients' perspectives.

2. METHODS

This protocol was developed to include all recommended methodological elements according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews¹⁹. The protocol of this scoping review is registered on Open Science Framework ([10.17605/OSF.IO/HAXV5](https://osf.io/HAXV5)).

2.1. Systematic Literature Search

We searched Ovid MEDLINE (1946 to July 30, 2020), EMBASE (1947 to July 30, 2020), APA PsycINFO (1806 to July 30, 2020), and CINAHL (1937 to July 30, 2020) without language restriction using MeSH terms and key words which broadly encompassed VTE and qualitative research (Supplementary Figure 1). References were screened for additional relevant studies.

2.2. Eligibility Criteria

Full-text studies of any qualitative design evaluating patient and/or carer experience of VTE were included. Studies that exclusively assessed pediatric patients, patients with unusual site thrombosis, or the experience of medical personnel were excluded. If a relevant article included participants other than our target population (ex. anticoagulation in atrial fibrillation and in VTE), only data specified as being from our population of interest was included; if our target population could not be independently evaluated then the article was excluded.

2.3. Study Selection and Full-Text Reviews

Two authors (LG, TT) independently screened titles and abstracts using Covidence systematic review software²⁰. Disagreements were resolved by discussion to reach consensus. The references of two related systematic reviews^{10,11} identified in the literature search were cross-referenced to ensure adequate capture by our search strategy. Full text review was conducted independently by two authors (LG, AK). Discrepancies were reconciled by discussion with a third author (LS).

2.4. Data Extraction and Synthesis of Results

Data extraction and synthesis was performed in keeping with thematic synthesis²¹. First, themes from the original studies were grouped according to surface-level similarities and differences (LG, AK) and reviewed by a third author (LS). Next, two authors (LG, AK) performed systematic line-by-line coding of the Results and Discussion from all studies to independently develop a set of 'descriptive themes' using QSR International NVivo 12 software²². These themes were merged into a preliminary

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set of conceptual ‘analytical themes’ by one author (LG), which were reviewed and refined by three authors (LG, AK, LS), in keeping with the process of constant comparative analysis methodology. Quotations were only coded in conjunction with the surrounding text. The preliminary conceptual ‘analytical themes’ were presented to twelve VTE physicians/researchers, a VTE research manager and two patient partners with personal VTE experience. Feedback was sought to ensure the themes were clear, consistent, and logically grouped. Following this feedback, the themes were regrouped twice in an iterative process (LG), with feedback from two authors (AK, LS). The final themes were reviewed by all authors.

All articles were reviewed for subgroup findings within Results or Discussion sections. Additionally, studies conducted exclusively on subgroups of young patients, women, PE, DVT, unprovoked VTE, and hospitalized patients, were analyzed for noticeable variance in themes.

2.5. Risk of Bias Assessment

The Critical Appraisal Skills Program (CASP) tool for qualitative research was completed to critically analyze the quality of each included study according to validity, methodology, analytic process, and overall impact to formulate a global evaluation of biases²³.

2.6. Reflexivity Statement

The authors responsible for coding and analysis were a hematology resident physician with clinical experience treating VTE, an undergraduate student with little prior exposure to VTE, and a thrombosis physician/researcher. The larger study team includes thrombosis physician/researchers from different countries, a VTE research manager and two patient partners with VTE experience. Diversity within the research team allowed for inclusion of various perspectives, however, the authors acknowledge their inherent biases based on prior experience with VTE.

3. RESULTS

3.1. Search Results and Study Characteristics

Search results and study selection are presented in a PRISMA flow diagram (Figure 1). Of 3684 records screened, we included 28 studies that were published between 2005-2020, representing a total of 463 participants. Six studies included both patient and carer experience. No studies included carers as separate study participants²⁴⁻²⁹. Studies were conducted across 13 countries with the majority (21/28, 75%) taking place in Europe, 11 of which were in the UK, followed by North America (6/28, 21%). Several VTE subpopulations were examined, with cancer-associated thromboembolism (CAT) having

the largest representation (9/28, 32%). Table 1 contains a list of included articles with study characteristics and original published themes.

3.2. Themes

There were seven major themes identified with each theme comprising additional subthemes. These are described below and summarized in Figure 2.

3.2.a. Acute Impacts: An Unforeseen Blow

In the immediate period following diagnosis, the principal reaction was one of shock. Participants reflect upon the initial symptoms eventually found to represent a serious disease, which had often been misinterpreted by unsuspecting participants.

Initial Shock

The diagnosis of VTE was initially unexpected, “[...] like everything else, it’s a shock at first.”²⁴, and the implications of the disease were not easily conceptualized:

*“And then in the evening they called me from the hospital, they were looking at my pictures, and they could see blood clots in both my lungs. I was told to drive to the hospital straight away, and they had already been notified of my imminent arrival. And I hadn’t felt a thing! So that was quite a shock.”*³⁰

Participants from populations with known risk factors for VTE were often uninformed of their VTE risk, which further contributed to their disbelief upon retrospectively learning of their susceptibility, for instance in the context of hip surgery, “...DVT were never mentioned unfortunately”³¹ or cancer treatment “...I was never told that there was a risk of getting a blood clot”³².

Acute Pain, Swelling and Dyspnea

In the period preceding the diagnosis, a range of symptoms foreshadowing the VTE event were reported, most commonly leg pain, chest pain or dyspnea. In some cases, participants minimized or misattributed these symptoms, thinking it was “just a nasty bruise”³³, “pneumonia”²⁷, “pulled muscle or tendon”³⁴, “indigestion”³⁴, “bad cold”³⁴, “part of the cancer”²⁵, or “because of the chemo”²⁴. This delayed them from seeking care, and further contributed to the state of shock following diagnosis.

3.2.b. Sustained Psychological Distress

Once the implications of the disease were better understood, participants across studies, with one exception³⁵, developed distress and anxiety surrounding their VTE. These anxieties were most prominently related to fear of recurrence, the life-threatening nature of VTE, hypervigilance surrounding new symptoms and a sense that the disease is always lurking.

Fear of Recurrence

Participants reported ongoing fear of VTE recurrence, aware that a subsequent VTE event could be more devastating than the first:

*“Even though I was told that it can't happen again, as long as I take my medicine, it's still just not enough. It is the anxiety I think, the fear of knowing that this could happen again.”*³⁶

For some, this trepidation waned as time from VTE increased, while for others the risk of recurrence remained salient in the long-term:

*“I'm always at risk of it coming back. I know I'm always gonna suffer with them.”*³⁷

Perception of Threat to Life

Retrospectively, the potential lethality of VTE was recognized, and participants felt fortunate to have survived:

*“I was utterly astounded, quite honestly ... I thought ‘Wow, my God, it could have killed me’”*²⁵

Family members' reactions frequently amplified the seriousness with which the VTE event was perceived:

*“I did not especially feel that my life was in danger, but then I saw that my mother was so troubled”*³⁸

Symptom Hypervigilance

Participants were hyperaware of any new, potentially VTE-related symptoms following their event:

*“I think that the worst thing about having FVL [Factor V Leiden] is that every little ache and pain causes anxiety. Is it a DVT? Some other complication I haven't experienced yet?”*³⁹

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It was challenging for participants to discern when escalation of these concerns was warranted. New symptoms were pervasive and emotionally taxing, with one participant coining the term “*post-thrombotic panic syndrome*”⁴⁰ to describe this phenomenon.

Always Lurking

Life after VTE came with a persistent cognitive burden; a feeling that VTE “...*is always there, lurking*”³⁶. Participants ruminated about the risk of another event and reported living in a generalized state of alarm:

*“It was always on my mind. It made me more conscious of making sure that if I was on my own somewhere people knew...I taught my daughter nannies house number... just in case something did happen. It just makes me angry to think that no-one can tell me I won't have another one and now I have to live my life by this”*³³

There were many examples of participants using imagery to describe the emotional pervasiveness of VTE, “*like a cloud that floats in your mind*”³⁶, “*like germs*”⁴⁰, “*little black ghost*”³⁰, “*a sword over my head*”⁴¹, “*sword of Damocles*”⁴² or “*black cloud*”⁴². In one study, participants were asked to characterize VTE as an animal which led to several descriptions of predatory animals (snake, lion, bear) that hide in the shadows and pounce on unsuspecting victims.⁴³

3.2.c. Loss of Self: Life is Changed

An existential change to self was reported in life post-VTE, with the recognition of a new, more vulnerable self-image, prompting changes in behaviour and attitude. The root of this changed identity was multifaceted, with notable factors being sustained physical impairment, infiltration of daily life and routines, and impacts on decision-making for the future. For many, VTE prompted a reprioritization of life upon recognizing the fragility of health.

Sustained Physical Impairment

The post-VTE self is compromised by an impaired physical stamina as compared to the pre-VTE self:

*“Before I got these blood clots, I never got tired. I was like a Duracell battery; I could just keep on going all the time. And I can't now....”*³⁰

This ranged from profound debilitation to feeling like “...*I cannot reach that 100% so easily...*”⁴⁴. This decreased endurance was due to myriad symptoms, including dyspnea, leg pain, swelling, or generalized fatigue and lack of energy, leading to feelings of defeat and frustration:

“The lack of energy and being out of breath... it’s just so frustrating... Frustration of not being able to be where I should be, in my mind, you know?”³²

Infiltration of Daily Life

The effects of VTE altered the enjoyment of, and capacity to perform, daily activities. These impacts were far-reaching and affected many dimensions of daily life: work, school, sports, dating, diet, routines, family, and social interaction. This led to a global decrease in quality of life:

“I can adjust to a lot, but if I had gotten this ten years ago, I would have been on constant sick leave. I’ve decided that this can’t affect my life with family, work, and friends. I constantly suppress my discomforts; it reduces my quality of life. You know, quality of life is complex. For me, it’s the feeling of not doing what everybody else my age does. I can live with itching and heaviness, but my issue is the overall experience of my limitations.”⁴⁵

The pervasiveness of VTE into routine life events contributed to the loss of self and was met with angst and anguish:

“I hate it really..., really upsetting really ‘cause I can’t do anything I used to do, like doing.”³³

Decision-Making for the Future

The realities of VTE were incorporated into imaginings of the future, altering dreams and plans previously in place. Long-term prospects regarding family planning and travel were most frequently mentioned:

“My husband would really like us to have another baby. I had IVF so the whole thing actually just now becomes, I don’t know, it’s another thing for me to think no I don’t want to do it again.”⁴⁶

“I used to be a frequent traveler, and had plans to live in a foreign country. I don’t think along those lines anymore. I doubt I’ll ever travel internationally again”³⁹

Reprioritization of Life

Life was recognized as precious and fragile by the more awakened, more realized post-VTE self. This changed perspective led participants to appreciate the value of each day, “...you live more conscious, more intensive...”⁴⁴, citing some positive changes following this traumatic diagnosis:

*“As horrible as it is, I’ve changed it for the positive now. I’ve had to take positives from it. For every negative there’s a positive. I’m a true believer in that. And I’ve just had to say right, that’s the case whatever it is, it’s not worth worrying about because I can spend another ten years worrying about it or ten years living.”*⁴⁰

3.2.d. Challenges of Thrombosis Management

Anticoagulation was felt to be an unpleasant experience overall, but a necessary inconvenience in preventing another VTE. Views on compression stockings were more controversial, with some participants experiencing great relief of symptoms and others citing only discomfort.

Burden of Anticoagulation

Anticoagulation was fraught with side effects, with participants feeling disdain that it comes with “...a lot of concessions”³². Each anticoagulant came with a catalogue of its own unique downsides, with the fear of bleeding being common to all:

*“Worse thing is having to go for blood checks and remember what dose of Warfarin to take on a night ... if I have an accident I am probably going to bleed to death before the ambulance gets here and I know that.”*⁴⁷

*“The injections are pretty bad... It hurts, not when you jab, after. I have a ball that doesn’t disappear, it hurts. Actually, I’m butchering myself.”*²⁶

Anticoagulation as a Necessary Inconvenience

When weighed against the risk of another VTE, anticoagulants were felt to be a “necessary evil”⁴⁸. Despite the disruptive side effects, anticoagulation was relied on as a lifeline:

*“Yeah, yeah because I am very, very concerned. If you miss it, it means you are going to get a clot. And I don’t know if it has anything to do with it, because my thigh was swollen and it was also coming up to my lungs. And that also frightened me. So, when they said warfarin, I made sure that I took it.”*⁴⁹

This was true for oral anticoagulants including vitamin K antagonists, as above, as well as injectable low-molecular-weight heparin (LMWH):

*“I really don’t feel like pricking myself, but if it’s that or dying, well, I’d rather prick myself.”*³²

Divided Views on Compression Stockings

Compression stockings were frequently mentioned, albeit with divided opinions regarding both efficacy and acceptability:

“They’re marvelous. When you’ve got fitted when they’re fitted rubbish and they’re falling down your leg and they’re not but when they’re all like measured. What a difference they make. Like every time I touch my leg it hurts especially when it swells, All over my leg hurts. When I’ve got that stocking on it doesn’t, does oh, it does hurt but not as much.”³⁷

3.2.e. Balancing Coping and Control

Efforts to cope with and take control over disease were ubiquitous. A desire to understand “*why me?*”⁴⁸ underlies the capacity of participants to cope with their disease. A variety of tactics were employed to feel control over VTE; empowerment through self-management and implementation of healthier lifestyle choices were the most consistently reported. Acceptance is often recognized as a powerful coping mechanism for moving forward.

Seeking A Cause: “Why Me”

There was a yearning to understand the cause of VTE:

“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.”⁴²

Participants felt that pinpointing a cause would provide peace of mind and perhaps allow for action to be taken, “*...because if you know, you can help yourself, you can fight*”⁴¹. When no clear explanation could be provided, causative theories were sometimes concocted whether based on evidence or not, for example, “*...I think when I get really stressed, I seem to get thrombosis, the last couple have been moving house... I personally think that it’s stress related.*”⁴⁷

Empowerment Through Self-Management

Participants who took ownership of their management gained a sense of control over their disease, feeling that “*...I am best in control if I control it myself...*”³⁶. This was established with the creation of rituals around anticoagulation administration, “*...if they say every 24 hours, I do it every 24 hours*”²⁷, but also in the self-monitoring of INR, self-adjusting of warfarin and in gaining the courage to self-inject LMWH:

“I choose to inject myself because I feel I can face the future on my own terms ... the DVT was terrible, I couldn't face the day.”⁵⁰

Healthier Lifestyle Changes

The adoption of healthier lifestyle changes was instituted by many participants as an intentional intervention to exert control over VTE and reduce risk of recurrence. Such measures included changing diet, increasing physical activity, losing weight, staying hydrated, working less, and reducing smoking and alcohol intake:

“Pulmonary embolism changed me in a couple of ways. I’m really trying to watch my cholesterol levels; I eat healthier foods now because of this. I take even more walks now than I used to, and I did a fair amount of walking a few years ago.”⁴³

Acceptance and Moving Forward

Many participants fostered acceptance of their disease and developed a sense of sanguinity about the future, acknowledging that full control over VTE is not possible:

“I guess it's sort of in the back of my mind. I don't let it influence my life. I have a regular life. You know, at first, you're maybe a little bit paranoid — oh, I can't do this and that anymore, but after a while, you just get into your regular life again. Life goes on right!”³⁵

3.2.f. Negative Experience with the Medical System

The journey through diagnosis and management of VTE was predominantly reported as an overall unpleasant experience. Frequent misdiagnosis and poor delivery of information led to decreased faith in healthcare providers. When unmet needs were later fulfilled, overall satisfaction improved.

Fracturing Faith in Healthcare Providers

Participants reported difficulties and delays in the diagnostic process, with frequent reports that their concerns had been dismissed:

“I was constantly back up there, each time I kept saying about my leg, in that first week and each time they looked at it and said no, it's not a DVT, it's not red, it's not swollen and I was sure that it was.”⁴⁶

Although VTE can be challenging to diagnose as more prevalent conditions with similar symptoms are often entertained first, misdiagnosis led to perceived incompetence or negligence of their healthcare providers:

*"I mentioned it to my OB and he blew it off"*³⁴

A Yearning for Information

Patient education about VTE was insufficient at the time of diagnosis, making it challenging to navigate necessary management decisions:

*"It's difficult to make a decision if you don't have the right thoughts in your head and they don't give them to you."*³¹

Information delivery was flawed in a multitude of ways, including inadequacy of information, inappropriate timing, and poor communication techniques, leaving participants feeling overall uninformed:

*"No, no I wasn't informed well... I was only told that I had an embolism and it had to be treated with heparin and that everything would be OK...and that's it. I took the treatment I was given and that was all."*²⁷

Unmet Needs

Participants reported interventions that, if available, would have reduced anxiety and improved overall satisfaction with their care. These stated desires often involved remedying the above inadequacies surrounding lack of information, but increased access to support was also frequently requested. Those who experienced improvement in these areas reported increased satisfaction:

*"The nurse was actually the first person to provide kind of an overview of what all this was about. I didn't get that at the hospital. No, I didn't really. And I was so grateful that I had that lifeline I could call, and I knew they [the nurses] were there, right?"*³⁰

3.2.g. VTE in the Context of Other Conditions

For those with a provoking condition for VTE, the event was interpreted uniquely in the context of their condition; cancer in nine studies^{24-29, 32,48,50}, but also pregnancy⁴⁶, inherited thrombophilia^{34,47}, and drug-use³⁷. Patients with CAT had diverse views of VTE relative to their cancer, the most frequent being that VTE was relevant only insofar as it impacted cancer treatment:

*"I don't think I had a lot of time to think about it because I was far more, I was concentrating far more, or feeling more affected by the chemotherapy."*²⁵

There was a spectrum, however, with one extreme feeling that "...it's nothing"³² compared to cancer. Others felt it was just another burden or "*the cherry on the sundae*"³², and some were alarmed at the more imminently life-threatening nature of VTE:

*“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 (clicks fingers), cancer you’ve got a little bit of chance, you know.”*⁴⁸

3.3. Exploratory Subgroup Differences

Two related studies commented on higher levels of health anxiety and symptoms of posttraumatic stress disorder in younger patients, when compared to older adults who were interviewed^{40,42}. Seven additional studies were conducted on participants with mean age ≤ 45 years, and reported prominent themes of health anxiety and emotional distress^{33,34,36-39,46}. Two of these seven studies suggested that younger age may have accounted for the increased psychological and emotional distress when contrasted to other studies^{33,36}. There were studies conducted on other subgroups of interest, including women^{34,39,46,47}, PE^{30,33,44,51}, DVT^{37,45}, unprovoked VTE³⁸ and hospitalized patients^{31,33}, however there were not enough data to facilitate cross-study comparisons.

3.4. Study Quality

According to the CASP checklist, 20 studies were high quality^{24-27,29,30,32,33,36,37,38,40,41,44-50}, four studies were moderate quality^{31,35,42,43}, and four were poor quality^{28,34,39,51} (Supplementary Table 2). Several of those rated moderate or poor received such a rating due to lack of information on the data collection and analysis process. In some studies, the assessment of overall VTE experience was a secondary outcome to a more specific aim^{25,34,38,41,44,47,49}.

4. DISCUSSION

We identified seven major themes representative of the 28 included studies. The first theme, *Acute Impacts: An Unforeseen Blow*, describes the initial shock experienced by patients, which evolved into *Sustained Psychological Distress* as participants had time to process the severity of this illness. *Life is Changed* portrays the complex ways in which VTE disrupted patients’ daily routines and planned life trajectory. *Challenges of Thrombosis Management*, describes the burden of anticoagulation which is ultimately recognized as a necessary inconvenience. Patients yearn to understand the cause of VTE and impart control efforts over the disease as explored in *Balancing Coping and Control*. The sixth theme, *Negative Experience with the Medical System*, describes the overall unpleasant journey of navigating the healthcare system, and the final theme, *VTE in the Context of Other Conditions*, explores how an underlying provoking condition impacts the experience of VTE.

To our knowledge, this is the first scoping review that summarizes all published qualitative studies evaluating patient experience with VTE. A scoping review methodology allowed for inclusion of all literature assessing patient lived experience in VTE to summarize the field. A previous combined quantitative and qualitative review was conducted to inform the American Society of Hematology (ASH) clinical practice guideline for management of VTE, but the qualitative arm was primarily used to complement the main study findings¹¹. Only five of the 15 qualitative studies included in the ASH review overlap with our 28 citations, as the majority were conducted in patients at risk of VTE. A 2018 systematic review and qualitative synthesis of CAT patient experience incorporated five studies, all of which are included in our review¹⁰.

We identified pronounced themes related to psychological distress and health anxiety in seven studies conducted on younger patients with VTE^{33,34,36-39,46}, supported by an additional two studies that noted a difference in psychological experiences between younger and older participants^{40,42}. Hypotheses to explain this phenomenon include lack of peer support and understanding, more pronounced journey of misdiagnosis due to a lower index of suspicion, disruption of routine events, and more limited life or disease experience from which to extrapolate effective coping mechanisms^{36,40,52}. Given limited data, no other subgroup comparisons within or across studies could be made.

There are inherent limitations when summarizing study-level qualitative data. Without access to the original interview transcripts from each study, we have only a small portion of the total data. We were careful to avoid reinterpreting individual quotations outside of the original study and used authors' descriptions of their generated themes in our analysis. Distinct populations encounter unique VTE-related challenges, and those represented in a minority of studies may not be comprehensively characterized, such as VTE in pregnancy. In contrast, the CAT population represents a large portion of the included studies, and the themes identified in this review may be biased towards this populations' perspective^{24-29,32,48,50}. In rare instances, the findings from individual studies were in opposition to the findings from the majority. The most striking example of this is Etchegary, et al. found that "*there were few long-term, serious psychosocial impacts of VTE*"³⁵, which is contradictory to almost all other included studies. Such differences in study findings highlight the value of synthesizing all available qualitative data in this review. We did not include the original study authors in our scoping review due to the complexity of data synthesis, but this is an area of future research with the potential for a patient-level data synthesis of all qualitative studies.

Although combining the findings of 28 studies increases the overall heterogeneity of the population, all studies were conducted in predominantly White countries in Europe and North America.

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Of studies that reported race, 98 of 104 participants were White^{25,31,34,39,40,42,46,47}. Cultural differences in experience and attitudes have been highlighted within the PELICAN series of CAT patients across several countries^{24,26-28}. The experience of patients outside of the European and North American continents, and of non-White patients, remains a gap in the literature. All studies were based out of tertiary/quaternary care centers and utilized a specialized thrombosis service, or else did not specify these details. It is thus unclear whether the experience of patients in a community-based, primary care setting is captured in this review.

Healthcare providers often focus on physical outcomes related to VTE for which clear investigations or treatment exist, such as persistent symptoms, VTE recurrence, or bleeding. The psychological and emotional sequelae, despite having profound impacts on overall well-being, are frequently overlooked and ignored. This scoping review identifies several aspects of VTE diagnosis and management that warrant acknowledgement by providers and for which patients desire improvement, including effective communication, appropriate educational resources, and psychological support.

Several studies have since been published that elaborate on areas of patient need. Two of these studies would have met our inclusion criteria, and both describe themes that are consistent with our findings^{12,53}. Both studies delve deeper into factors that predispose patients to overt psychological impacts of VTE, specifically highlighting the influence of provider communication techniques on the level of psychological distress, such as the use of alarmist language and misplaced metaphors. Thoughtfully adjusting the content and delivery of information at VTE diagnosis can have lasting effects on patient satisfaction^{12,53,54}.

Educational programs typically focus on anticoagulation management; however, our study results suggest that this should be expanded to recognize VTE as a disease with many impacts⁵⁵⁻⁵⁷. Education and patient support are integral at all time points across a patient's VTE journey. Baddeley *et al.* reported how a patient-designed educational video shown at a cancer clinic improved patient and nursing understanding of VTE and decreased time to symptom presentation⁵⁸. After a VTE, education should include normalization of the anxiety and fear that comes with a diagnosis of VTE and information on available psychological support. Our theme of *Sustained Psychological Distress* highlights the importance of addressing psychological outcomes long after the initial VTE presentation. Further study is required to determine how and when to provide tailored VTE education.

Together with a quantitative scoping review, the outcomes from this study will be used to develop a comprehensive core outcome set for VTE treatment studies by informing qualitative interviews and a modified Delphi exercise. Patient involvement in all stages of research ensures that

research goals align with the needs of patients, the most significant stakeholders in this disease, and improves patients' trust in research outcomes^{59,60}. Patients' experience-based knowledge on the physical, psychological, and emotional journey through VTE is integral to incorporate into future research and patient care.

AUTHOR CONTRIBUTION

All authors contributed to the concept and design of the study under the supervision of L. Skeith. L. Genge developed the search strategy, conducted the abstract screening, full text review, data analysis and drafted the initial manuscript. A. Krala conducted the full text review and data analysis. T. Tritschler developed the search strategy and conducted the abstract screening. G. Le Gal, N. Langlois, S. Dubois, C. West, and L. Duffett provided revisions to the intellectual content at various timepoints during study design, theme development, and drafting the manuscript. All authors revised and approved the final draft of the manuscript.

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DISCLOSURES

All authors declare that they have no actual or potential conflicts of interest relevant to this work.

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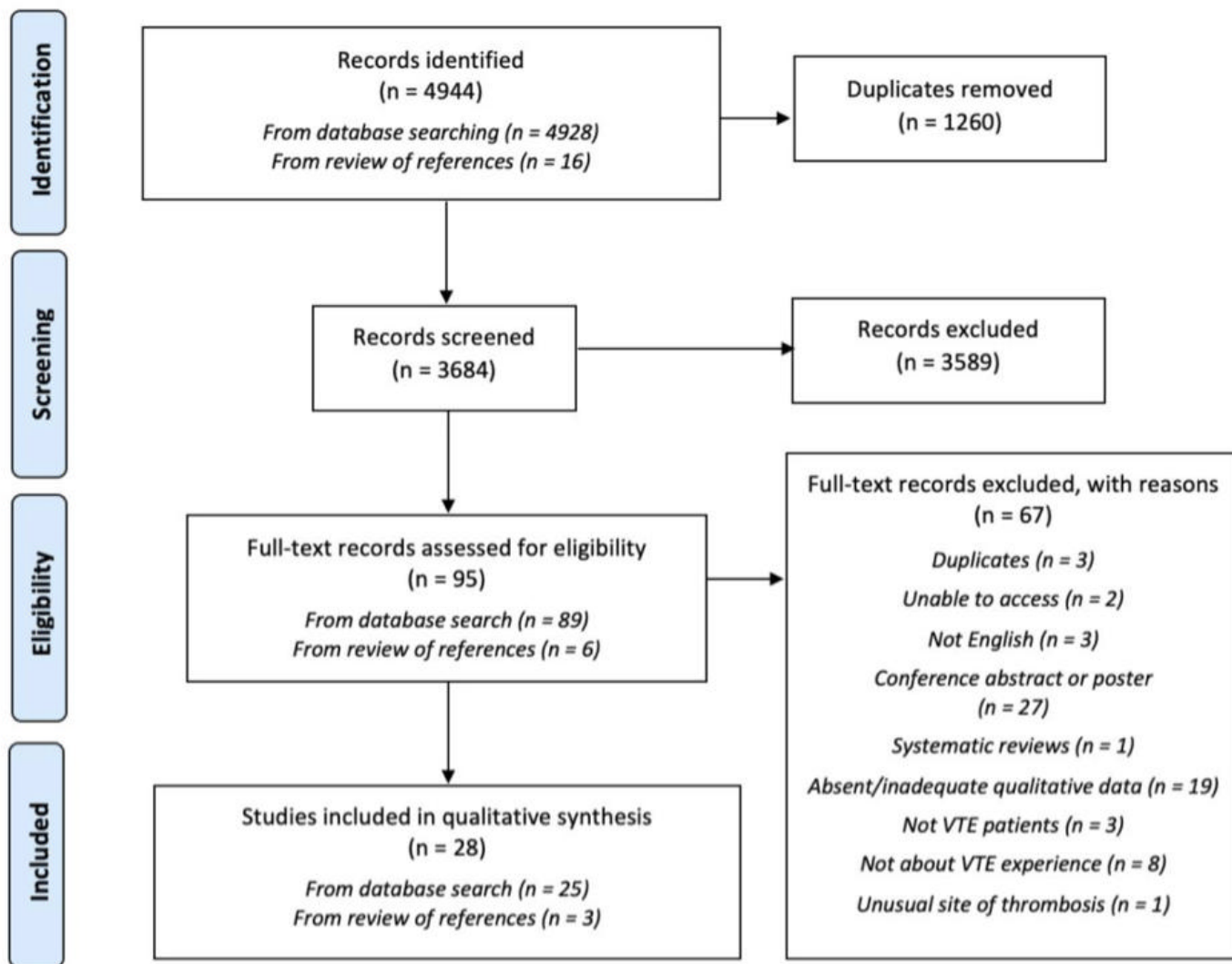
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JTH_15788_Figure 1 - PRISMA Flow Diagram - No Caption - compressed.tiff

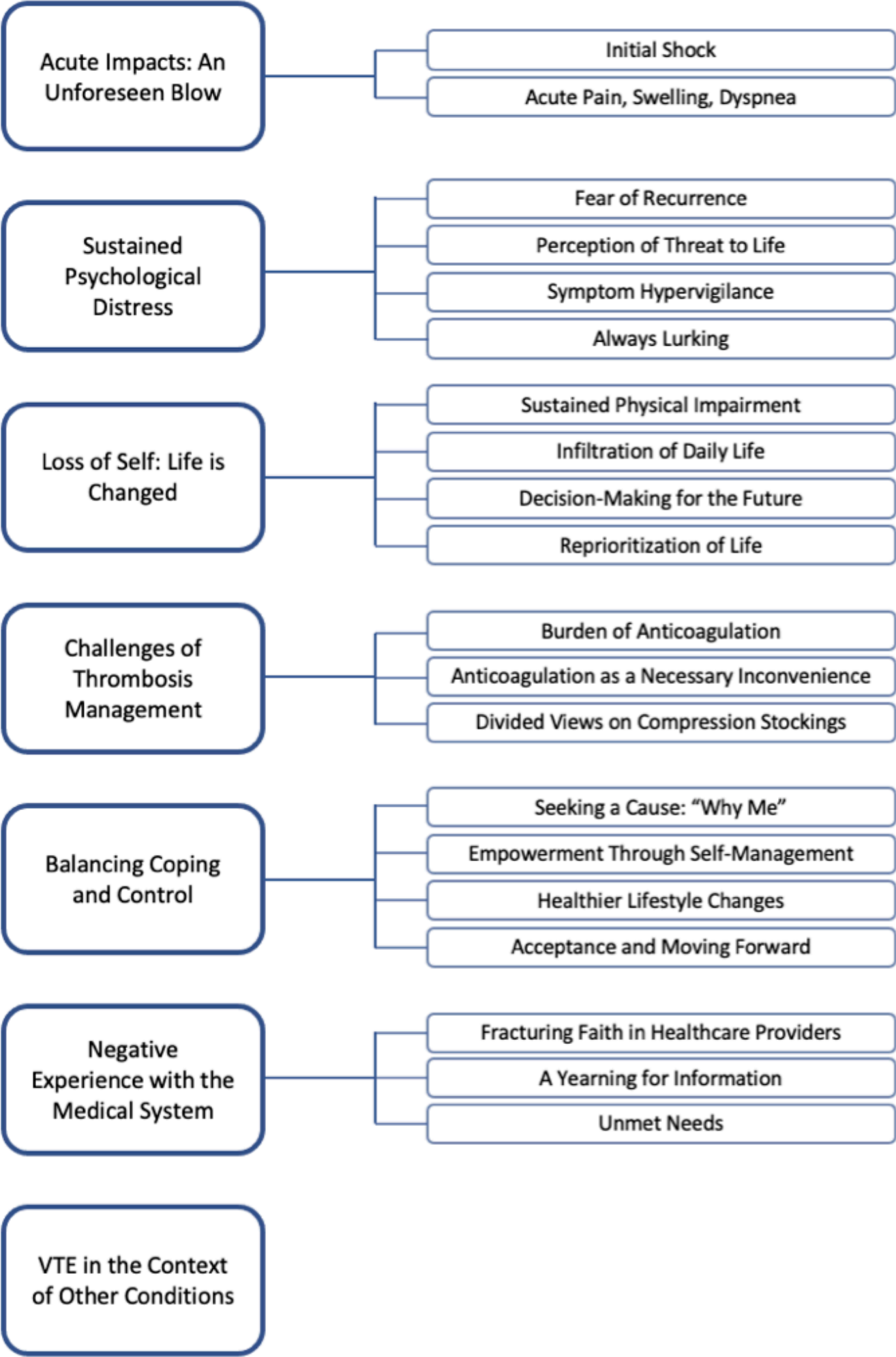


Table 1. Summary and characteristics of included articles

Publication	Country	Setting and Data Collection Method	Number of Participants	VTE Population	Analysis / Theoretical Framework	Stated Themes
Bartoli-Abdou JK, et al. (2018) <i>Thromb Res.</i> 162:62–8.	UK	Anticoagulation clinic; Two separate focus groups for VTE patients	5 VTE (10 AF excluded)	Patients switched from VKA to DOAC <i>Mean age 61 (range 44-77)</i> <i>4M, 1F</i>	Framework Analysis	(1) Indication Specific Anticoagulation Prioritization (2) VKAs: A Necessary Inconvenience (3) DOACs: the Anticoagulant of Choice (4) Monitoring DOAC Therapy (5) Adherence to DOACs (6) Provision for Access to Specialist Services Long Term
Cohn DM, et al. (2009) <i>J Thromb Haemost.</i> 7(6):1044–6.	Netherlands	Participant home; Semi-structured interview	10	PE <i>Mean age 53 (range 31-84)</i> <i>4M, 6F</i> <i>10 PE</i>	Not specified	Not specified as ‘themes’ Common findings cited as: shortness of breath/difficulty in breathing, fatigue, fear of recurrence after discontinuing anticoagulant treatment, more readily emotionally disturbed, more social isolation than prior to the PE.
Cornford C, et al. (2019) <i>Qual Health Res.</i> 29(11): 1641–50.	UK	Healthcare setting; Semi-structured interview	19	DVT secondary to injection drug use <i>Mean age 40</i> <i>14M, 5F</i> <i>19 DVT</i>	Qualitative Data Analysis Described by Miles and Huberman (1994)	(1) DVT Meaning Making Subthemes: Beliefs About Causes, Treatment, Prevention of Further DVTs (2) Embodied Experience Subthemes: Symptoms at Diagnosis, Long-term Bodily Experiences, The Experience of Using Support Hosiery (3) Shamed Identity Subthemes: Delays in Presentation to Hospital, Stigmata, Interaction With Others, Interactions With Health Care Workers, Suggestions Made for Improvements
Engeseth M, et al. (2019) <i>J Thromb Haemost.</i> 17(10): 1707–14.	Norway	Clinic; Focus group interviews	16	Lower-limb VTE with evidence of PTS <i>Age > 30</i> <i>11M, 5F</i> <i>16 DVT</i>	Kvale and Brinkman's Method for Thematic Analysis	(1) Agonizing Discomforts (2) Skin Changes (3) Fluctuating Heaviness and Swelling (4) Post-DVT Concerns Subthemes: Fear of DVT Recurrence, Health Services Failing to Meet Patients' Expectations, Psychological and Social Restrictions
Etchegary H, et al. (2008) <i>Thromb Res.</i> 122(4):491–500.	Canada	Setting not specified; Semi-structured interview	13	VTE within past 2 years <i>Mean age 58 (range 38-71)</i> <i>5M, 8F</i> <i>8 DVT, 2 PE, 3 both</i>	Analysis using Method of Constant Comparison	(1) Zones of Relevance Subthemes: Initial Event and Short-term Management, Travel, Thrombosis in the Context of Other Illness (2) Psychosocial Impacts of Thrombosis Subthemes: Social (Family Communication, Insurance Difficulties), Cognitive (Searching for the Cause, Perceived Risk of Another Event), Emotional, Behavior (Compliance, Lifestyle Changes, Symptom Watching), Health Services (The Price of Illness Management and Service Provision), Thoughts on Genetic Testing
Feehan M, et al. (2017) <i>Inside Patient Care.</i> 5(3).	USA	Online; Online bulletin board discussion	17	VTE > 3 mo ago <i>Age > 18</i> <i>5M, 12F</i> <i>7 DVT, 5 PE, 5 both</i>	Not specified	(1) Emotional Impact of VTE Diagnosis (2) Patient Education About Medication Therapy (3) Explicit Transition Plans Reduce Stress and Fear (4) Monitoring Can Be Reassuring or Frustrating (5) Risk for VTE Recurrence (6) Depression and Anxiety (7) Projective Imagery Conveys VTE Risk
Font C, et al. (2018) <i>Support Care Cancer.</i> 26(9):3233–9.	Spain	Participant home or outpatient clinic; Semi-structured interviews	20	New diagnosis of CAT (≥ 2 mo prior) <i>Mean age 62 (range 38-83)</i> <i>13M, 7F</i> <i>7 DVT, 10 PE, 3 other</i>	Framework Analysis	(1) The Distressing Experience of CAT Subthemes: Impact on Family, Impact on Concept of Self (2) Communication Needs Subthemes: Lack of Information, Unanswered Questions (3) Living with CAT Subtheme: Getting on with Life/Ritualization
Ge E, et al. (2019) <i>Thromb Res.</i> 183:86–90.	UK	Home or hospital; Semi-structured interview	9	Pregnant and up to 6 weeks post-partum <i>Mean age 33 (range 24-40)</i> <i>9W</i> <i>5 DVT, 4 PE</i>	Giorgi's Five Step Method of Descriptive Analysis	(1) Challenges in Establishing a Diagnosis (2) Dealing with Diagnosis (3) Coping with Treatment (4) Fears for the Future

Golemi I, et al. (2019) <i>Int Angiol.</i> 38(4):284–90.	USA	Location of regular support group; Semi-structured interview via five focus groups	20	Hospital-associated VTE <i>Mean age 67 (range 46-81) 10M, 10F 11 DVT, 2 PE, 7 both</i>	Inductive Framework Analysis	(1) Concerned about Limited Disease Knowledge (2) VTE Awareness in the Healthcare System (3) Incomplete Communication During Transitional or Follow-Up Care
Haxaire C, et al. (2015) <i>PLoS One.</i> 10(11): e0142070.	France	Outpatient clinic; Face-to-face interview	10	Episode of at least one unprovoked VTE <i>Mean age 37 (range 24-60) 2M, 8F 3 DVT, 7 PE</i>	Qualitative Interpretive Approach, combining Thematic Analysis with Constant Comparison	(1) Concerns About Initial Symptoms and Suspicion of VTE (2) Underestimation of Potential Life-Threatening Episode Once Being Managed in Emergency (3) Possible Biographical Disruption with Inability to Cope with the Event (4) Secondary Prevention Attitudes Motivated by Remains of the Episode and Favoring General Prevention Attitudes
Højen AA, et al. (2016) <i>Nurs Res.</i> 65(6):455–64.	Denmark	Participant home or hospital; Informal and semi-structured interviews	12	Adolescents and young adults <i>Mean age 25 (range 17-33) 3M, 9F 3 DVT, 1 PE, 8 both</i>	Phenomenological Hermeneutical Approach influenced by Ricoeur's Interpretation Theory	(1) A Creeping Loss of Youth Immortality (2) The Perception of Being Different (3) To Live with a Body in a State of Alert (4) Symptom Management Insecurity
Hunter R, et al. (2017) <i>Br J Health Psychol.</i> 22(1):8–25.	UK	Participant home; Semi-structured interviews	12	First-time VTE in past 6 months <i>Mean age 53 (range 18-69) 5M, 7F 3 DVT, 4 PE, 5 both</i>	Inductive Thematic Analysis	(1) VTE as Life-Changing and Traumatic Subthemes: Living with Post-Traumatic Stress, VTE as Life-Changing, Living Under the Cloud of Uncertainty (2) Living with Uncertainty and Fears of Reoccurrence Subthemes: Living Under the 'Cloud' of Uncertainty, Awareness of Own Mortality, Worries and Uncertainty About Treatment (3) Feeling Let Down by Services Subthemes: Misdiagnosis and its Implications, Feeling Alone and Abandoned, Lack of Information and Communication, Worries and Uncertainties About Treatment (4) Positive Outcomes and Changes Subthemes: Acknowledging the Positive Impact of VTE, VTE as a Catalyst for Fundamental Changes in Self
Hunter R, et al. (2019) <i>BMJ Open.</i> 9(2):e024805.	UK	Setting not specified; Semi-structured interviews	11	First time VTE patients interviewed for Hunter, 2017 – 3 mo from initial interview <i>Mean age 53 (range 18-69) 4M, 7F 3 DVT, 3 PE, 5 both</i>	Inductive Thematic Analysis	(1) Life Changing and Forever Changed Subthemes: A Different Life, Changing Expectations (2) The Trauma of Care Subthemes: Lack of Care in Primary Care, Trust: Lost Broken and Regained (3) Thrombo-neuroses Subthemes: 'Post-Thrombotic Panic', The 'Matrix' of Anxiety and Uncertainty, a Private Struggle With Emotion (4) Through Adversity Comes Growth Subthemes: Cumulative Adversity: The Hero's Journey, 'Enlightenment'
Hutchinson A, et al. (2019) <i>Palliat Med.</i> 33(5): 510–7.	Britain	Participant home or via telephone; Semi-structured interviews	37	CAT on at least 2 mo of therapy <i>Age range 40-89 17M, 20F</i>	Framework Method	(1) Reaction to Diagnosis (2) Impact of Cancer-Associated Thrombosis on Everyday Life (3) Experiences of Anticoagulation Therapy Among Cancer-Associated Thrombosis Patients and Their Carers Subthemes: Experience of Taking Direct Oral Anticoagulants, Experience of Having Low-Molecular Weight Heparin (4) Approaching the Risk-Benefit Balance of the Two Different Ways of Anticoagulation Administration
Kirchberger I, et al. (2020) <i>Respir Med.</i> 167: 105978.	Germany	Took place "at the Chair of Epidemiology"; Five focus groups (2-5 people/group)	18	PE Patients <i>Median age 56 9M, 9F 18 PE</i>	Grounded Theory Approach	(1) Progressing Dyspnea and Pain as Prodromal and Acute Symptoms (2) Physical Well-Being: Persisting Dyspnea and Loss of Fitness (3) Mental Well-Being: Depression, Fears, and Threat Monitoring (4) Daily Life: Exhaustion which Improves Over Time (5) Social Life Between Ignorance and Overprotection (6) Medication: Anticoagulants as Lifesavers and Threat (7) Health Care Subthemes: Quick versus Delayed Diagnosis, Life Alone by Healthcare Providers, Unsupportive Healthcare System

Mahé I, et al. (2020) <i>Thromb Res.</i> 194:66–71.	France	Patient home or outpatient clinic; Semi-structured interviews	24	New diagnosis of CAT (≥ 2 mo prior) <i>Mean age 69 (range 51-83)</i> 6M, 18F 9 DVT, 13 PE, 2 both	Framework Analysis	(1) Information Needs Subthemes: Minimal Information Given, Low Levels of Distress (2) Doctor-Patient Relationship Subthemes: Doctor is Always Right, To Treat, Not Inform (3) Non Acceptance of LMWH Subthemes: Side Effects, Nurse Injecting
Mockler A, et al. (2012) <i>Oncol Nurs Forum.</i> 39(3):E233-240.	Canada	Inpatient unit and outpatient clinic; Semi-structured interviews	10	CAT within the past 1 year <i>Mean age 56 (range 35-78)</i> 6M, 4F 5 DVT, 5 PE	Thematic Analysis	(1) Initial Reaction to VTE Subthemes: Seeing VTE as a Life Threat, Having Past Experience with VTE, Viewing VTE as the “Cherry on the Sundae” (2) Coping with VTE Subthemes: VTE Being Overshadowed by Unresolved Cancer-Related Concerns, Perceiving VTE as a Setback in Cancer Care, Holding Certain Attitudes about VTE Treatment
Moore T, et al. (2008) <i>J Health Psychol.</i> 13(6):776–84.	UK	Private room near the thrombosis centre; Semi-structured interviews	6	Women with VTE episode occur before diagnosis of hereditary thrombophilia <i>Median age 52 (range 28-73)</i> 6F 4 DVT, 2 PE	Interpretive Phenomenological Analysis	(1) The Impact of Heritable Thrombophilia on Causal Models of VTE (2) Primary Control Efforts (3) Secondary Control Efforts
Noble SIR, et al. (2005) <i>Palliat Med.</i> 19(3):197–201.	UK	Inpatient unit, outpatient clinic or participant home; Semi-structured interviews	40	CAT in metastatic cancer patients followed by palliative care service, on LMWH <i>Mean age 54 (range 32-76)</i> 18M, 22F	Constant Comparison Method	(1) Acceptability of LMWH (2) Simplicity of Administration (3) Freedom (4) Optimism Minor Theme: Bruising
Noble S, et al. (2014) <i>BMJ Open.</i> 4(4):e004561.	UK	Participant home; Semi-structured interviews	9	Previously hospitalized for first-time symptomatic PE <i>Mean age 45 (range 26-72)</i> 5M, 4F 9 PE	Interpretive Phenomenological Analysis	(1) Life-Changing Event Subthemes: Shock/Distress at Uncertainty, Loss of Self, Changes in Focus or Direction, Avoidance Behaviours (2) PTSD Subthemes: Flashbacks, Numbing of Memories, Hypervigilance (3) Support Needs Subthemes: Information, Empathy, Access to Support
Noble S, et al. (2015) <i>Patient Prefer Adherence.</i> 9:337–45.	UK	Participant home; Semi-structured interviews	20	New diagnosis of CAT (≥ 2 mo prior) <i>Mean age 68 (range 53-81)</i> 10M, 10F 8 DVT, 9 PE, 3 both	Framework Analysis	(1) Life Before CAT Subthemes: Lack of Knowledge of VTE in the Context of Cancer, Patients Unaware of Risks of Thrombosis or Symptoms to Look Out For, Limited Awareness Amongst Healthcare Providers (2) Diagnosis and Treatment of CAT Subthemes: Initial Reaction of Shock, Little Information (3) Living with CAT Subthemes: Getting on with Life, Ritualization
Noble S, et al. (2020) <i>Res Pract Thromb Haemost.</i> 4(1):154–60.	Canada	Participant home; Semi-structured interviews	20	New diagnosis of CAT (≥ 2 mo prior) <i>Mean age 63 (range 39-74)</i> 10M, 10F 7 DVT, 10 PE, 2 both, 1 other	Framework Analysis	(1) Traumatic Nature of CAT (2) Information Needs (3) Acceptability of LMWH (4) Incidental PE (5) Access to Medicines
Parrott R, et al. (2015) <i>J App Comm Res.</i> 43(2):203–21.	USA	Online; Life reflection interview	20	Women with first-time VTE <i>Mean age 43 (SD 12 years)</i> 20F	Constant Comparative Open-Coding Method	(1) Empowerment from Past Struggles: Coping in the Shadow of Genetic Susceptibility Subtheme: “If I knew then what I know now”: Disclosure Avoidance and Wishful Thinking (2) Fallout Linked to Thrombosis Severity Subthemes: Life Changed, Not just Physically, but Also Mentally: Life Shifts and Haunting Stories, Uncertainty About Life, Blood, Relationships and the Future: Managing Fear of Making Mistakes (3) Harnessing Control to Avoid Future Harm Subthemes: Making Meaning of Diagnosis and Taking Personal Protective Actions: Walking with Vigilant Angels, “I’m responsible for preventing the recurrence of DVT in my family”: Duty to Inform

Parrott R, et al. (2015) <i>J Health Commun.</i> 20(1):35–42.	USA	Online; Life Reflection Interview	20	Women with first-time VTE <i>Mean age 43 (SD 12 years) 20F</i>	Drawing on aspects of Problematic Integration Theory and a Grounded Theory Approach	(1) Ambiguous Symptoms and Certain Dread Before Diagnosis: Perceived Causes (2) Divergence in Diagnosis: A Long and Winding Road to Accurate Diagnosis (3) The Feminine History in Awareness of Family History for Thrombosis
Rolving N, et al. (2019) <i>Thromb Res.</i> 182:185–91.	Denmark	Participant home or hospital; Semi-structured interviews	16	First-time acute PE (within 6-12 mo) <i>Mean age 63 (range 34-78) 10M, 6F 16 PE</i>	Analysis guided by the Interpretive Description Approach	(1) Everyday Life After Acute Pulmonary Embolism Subthemes: What's Wrong with Me?, A Changed Identity (2) Needing the Healthcare System Subthemes: Going Through the Mill, Medication as a Lifesaver (3) The Aftermath Subthemes: My Strength was Depleted, Being Alert to Bodily Signals of an APE, Anxiety and Distress, Coping with the Aftermath (4) The Staying Healthy Challenge Subthemes: Taking Health for Granted, Handling Physical Activity (5) Relations Subthemes: Involving Next of Kin, Family and Work Roles
Seaman S, et al. (2014) <i>Patient Prefer Adherence.</i> 8:453–61.	UK	Participant home; Semi-structured interviews	14	Palliative cancer patients with CAT, on LMWH <i>Mean age 68 (range 52-84) 6M, 8F 6 DVT, 8 PE</i>	Thematic Content Analysis	(1) Impact of VTE Subthemes: Symptom Burden of VTE, VTE in the Context of Cancer, Impact on Activities of Daily Living (2) Acceptability of LMWH Subthemes: Necessary Inconvenience, Systematic Approach to Injections (3) Views on NOACs Subthemes: Efficacy Paramount, Willing to Engage in Clinical Trials
Vegni E, et al. (2013) <i>Patient Educ Couns.</i> 90(3):386–91.	Italy	Department of Clinical Psychology; Semi-structured interviews	15 VTE 4 with thrombophilia but no VTE	Tested for inherited thrombophilia <i>Mean age 55 (range 24-76) 6M, 13F</i>	Interpretative Phenomenological Analysis	(1) The Clinical Problem Subthemes: Unhealthy Blood, Family Issue (2) The Thrombophilia Test Subthemes: Knowing for the Sake of Knowing, Knowing for the Sake of Doing, Not Knowing
Woulfe T, et al. (2020) <i>Thromb Res.</i> 189:35–8.	New Zealand	Participant home; Semi-structured interviews	20	New diagnosis of CAT (≥ 2 mo prior) <i>Mean age 69 (range 51-83) 10M, 10F 6 DVT, 13 PE, 1 other</i>	Framework Analysis	(1) Information Needs Subthemes: Lack of Meaningful Information Prior to Diagnosis of CAT, Information Needs at Diagnosis, Stoic Approach to Illness and Information (2) Management of CAT Subthemes: CAT Managed Independently of Cancer, Lack of Ownership of CAT, Default to Primary Care

Acronym expansion: AF = atrial fibrillation, CAT = cancer associated thrombosis, DVT = deep vein thrombosis, ITT = inherited thrombophilia testing, LMWH = low molecular weight heparin, NOAC = novel oral anticoagulant, PE = pulmonary embolism, PTS = post-thrombotic syndrome, SD = standard deviation, VKA = vitamin K antagonist, VTE = venous thromboembolism