

METHODOLOGICAL ARTICLE

# The use of qualitative methods in venous thromboembolism research

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## Abstract

**Introduction:** Qualitative research has been increasingly used in health care research to allow in-depth insights and understanding of patients' lived experiences for poorly understood phenomena. The psychological stress mechanisms underlying fear, dyspnea, and pain after venous thromboembolism (VTE) remain poorly understood. However, novice VTE researchers may not be familiar with the process of undertaking qualitative research.

**Objective:** The aim of this article is to describe the planning, methodology and execution of qualitative methods, using the example of patients' lived experiences during and after the diagnosis of VTE. We discuss challenges and solutions in implementing qualitative research methods in health care research.

**Methods:** Patients were recruited from the emergency department and clinic using in-person and phone contact. We used both in-person and video format to interview 24 patients. Interviews were guided by a set of questions to be explored but conducted to elucidate unique thoughts and opinions from patients.

**Results:** For recruitment, "cold-calling" was found to be largely unsuccessful. Many patients have preexisting diagnoses of anxiety and depression. Video interviews were found to be at least as effective as in-person interviews. Interviews revealed unique post-VTE experiences from all participants, with a wide range of impact on quality of life. Themes that were most common included perceptions of physician communication, fear of recurrence, and concerns of death.

**Conclusion:** A qualitative research approach can reveal individual experiences and psychosocial impact in patients diagnosed with VTE, which allow the researchers to better comprehend the complexity of this phenomenon and its impact in health care.

## KEYWORDS

challenges, methods, psychological stress, qualitative research, solutions, venous thromboembolism

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## Essentials

- Health care researchers may not be familiar with starting a qualitative study.
- Qualitative research was used to explore lived experiences in patients with blood clots.
- This provides a detailed account of the planning and execution of a qualitative project.
- Challenges and solutions are described to guide new researchers.

## 1 | INTRODUCTION

Despite the increasing acceptance of qualitative methods in health care research, qualitative methods have been slow to impact research and medical practice related to venous thromboembolism (VTE). Qualitative research, through detailed descriptions and open-ended approaches, offers a different approach to identify what is important for patients and to improve health care experiences. It allows researchers to reach areas that cannot be measured by quantitative research.<sup>1</sup> For patients with VTE, overutilization of emergency departments (EDs) is an example of a significant health care problem with high financial and human costs that could benefit from qualitative approaches.<sup>2</sup>

Qualitative research involves collecting and analyzing nonnumerical data to understand human experiences, conveyed by the expression of opinions, behaviors, concepts, beliefs, attitudes, and interactions with other humans.<sup>3</sup> Qualitative methods allow access to in-depth insights and understanding of real-world problems from the patient perspective and are particularly helpful when little is known about a topic, when quantitative results are unexpected, or when a problem, like overuse of EDs, proves to be persistent and recalcitrant to interventions. Qualitative methods do not require an a priori hypothesis, or preidentification of variables, making them ideal when a health services topic is poorly understood.<sup>4</sup> Qualitative methods are an important tool for health care, as they can identify the impact of social determinants such as sex, education, poverty, race, or religion on the conduct and outcomes of research.<sup>5,6</sup>

Over the past decade, there has been increasing attention to the quality and rigor of qualitative studies in health research generally, including methodological guidelines for qualitative health research. Checklists have been published to improve the reporting of research methods, coding, analysis, and results, as well as the interpretation of qualitative work, which allow a structured and reproducible critique of qualitative research (checklist for the current manuscript is provided in supplemental information).<sup>7</sup> Missing, however, from existing methods literature are detailed examples of how qualitative research methods can be applied and discussions of challenges, solutions, and adaptations.

Using the case of venous thromboembolism (VTE) research, we describe a qualitative approach to understand patients' lived experiences of VTE. The purpose of this article is to describe the application of qualitative methods, as well as challenges and solutions, in implementing qualitative research on health care topics. We first provide a detailed account of the planning and execution of a qualitative project and, second, describe challenges and solutions for future researchers selecting qualitative methods.

## 2 | DISEASE MODEL: VTE

The target condition for this work is VTE, defined as deep vein thrombosis (DVT), pulmonary embolism (PE), or both. VTE affects >600,000 individuals in the United States each year, causing considerable morbidity and mortality.<sup>8,9</sup> About 5% to 15% of patients with VTE have a recurrence in the first year if anticoagulation therapy is discontinued after 3 to 6 months.<sup>10</sup> By 10 years, approximately 40% of patients with unprovoked VTE will have experienced a recurrence, increasing risks for complications and mortality.

In addition to the risk of recurrence, ~30% of PE survivors develop substantial ongoing reductions in mental and physical health that greatly impair their quality of life.<sup>11-14</sup> If DVT is included, the number affected at least doubles, in part because of the impact of the postthrombotic syndrome, a chronic consequence of DVT characterized by leg swelling, pain, edema, venous ectasia, and skin induration.<sup>15</sup> Persistent symptoms likely amplify fears of recurrence,<sup>16,17</sup> and these fears, coupled with concerns about side effects of anticoagulants used to treat the condition, contribute to a lifelong cognitive and health burden. It is thought that persistent symptoms and fears may play a causative role in frequent ED visits. These visits can result in unnecessary testing that requires ionizing radiation, are costly (both financially and personally), and do not change plans of care. This low-value use of the ED contributes to the high long-term economic burden of VTE.<sup>18,19</sup>

Accordingly, this qualitative study was undertaken with the belief that qualitative methods can provide an opportunity for a better in-depth understanding of how and why the diagnosis of VTE may impact individuals and their use of the health care system.

## 3 | QUALITATIVE RESEARCH DESIGN

A qualitative method, in-depth individual interviews, was selected to allow for richly detailed data about the lived experiences of patients diagnosed with VTE and the psychosocial impact of VTE on patients. This approach was selected because there is little known about patients' lived long-term experience of VTE, and in-depth individual interviews (similar to other qualitative approaches) allowed our team to generate an explanation of a process of health care usage shaped by the views of a number of participants on this particular phenomenon.<sup>20</sup> For patients with VTE, limited prior research has described their goals, fears, expectations, values, concerns and anxiety.<sup>17,21-23</sup> This qualitative analysis allows us to describe the lived reality that consists of people's individual

experiences and how individuals interpret those experiences. Using textual data from interviews, the aim of this research was to generate explanations and theories on how individuals with VTE use health services.

We chose to use additional quantitative measures to more accurately describe participants' severity of VTE and comorbid conditions, such as anxiety, posttraumatic stress disorder, and postthrombotic syndrome, and quality of life after VTE. Quantitative self-administered surveys were administered immediately after the interview. The addition of quantitative measures to this primarily qualitative study allowed us to compare patients' experiences with more objective measures of disease severity and comorbidities.

## 4 | SAMPLING AND RECRUITMENT METHODS

Purposive sampling was used to identify participants. Purposive sampling is a nonprobability sampling approach in which informants are selected to capture a range of experiences and characteristics.<sup>4</sup> Ideally, informants will be willing to share their experiences and have good communication skills and the ability to reflect upon their experiences. For this study, we sought a range of ages, varied types and severity of VTE (PE only, PE and DVT, or DVT only). We also sought participants who had a wide variety of health care experiences, including those who were discharged home from the ED or had more intensive treatment (eg, reperfusion therapy), and those representing a wide range of VTE recurrences, time since diagnosis, and ED visits. See Table 1 for participant information.

To capture a range of patient experiences, in particular recurrence and ED usage, we used several different recruitment approaches. We first used databases from a university hospital anticoagulation clinic (>50% patients with DVT only), a registry kept of patients treated with multidisciplinary pulmonary response team, as well as patients who participated in other VTE research studies by our group. We also used the electronic medical record (First Net; Cerner Corp., North Kansas City, MO, USA) to survey patients presenting to the IU Health Methodist and Eskenazi Hospital ED in Indianapolis to identify potential participants who were diagnosed with VTE at least 6 months prior. Participants were between the ages of 18 and 70 years who had experienced a symptomatic VTE as a DVT, PE, or both at least 6 months prior to the interview. Participants were excluded if they had a diagnosis of active cancer or known history of mental illness or other psychological diagnosis before the VTE with the exception of a diagnosis of anxiety or depression. This study was approved by a local institutional review board (IRB). This study was conducted in compliance with the ethical standards of the responsible institution on human subjects as well with the Helsinki Declaration.

The main challenge for the sampling and recruitment was the time and effort required to screen and enroll participants. To complete the 24 interviews, the first author (JHN) reviewed 620 charts

**TABLE 1** Clinical characteristics of participants

	Female (n = 15) (%)	Male (n = 9) (%)	Total (n = 24) (%)
<b>Age, y</b>			
<50	6 (25)	4 (16.5)	10 (41.5)
>50	9 (37.5)	5 (21)	14 (58.5)
<b>Race</b>			
Black	6 (25)	2 (8.5)	8 (33.5)
White	9 (37.5)	7 (29)	16 (66.5)
<b>Marital status</b>			
Married	6 (25)	6 (25)	12 (50)
Single	3 (12.5)	1 (4)	4 (16.5)
Divorced	3 (12.5)	1 (4)	4 (16.5)
In relationship/not married	3 (12.5)	1 (4)	4 (16.5)
<b>Time since VTE diagnosis, y</b>			
<2	4 (16.5)	5 (21)	9 (37.5)
>2	11 (46)	4 (16.5)	15 (62.5)
<b>Received thrombolysis</b>			
Yes	2 (8.5)	3 (12.5)	5 (21)
No	13 (54)	6 (25)	19 (79)
<b>Lifetime anticoagulation</b>			
Yes	8 (33.5)	6 (25)	14 (58.5)
No	7 (29)	3 (12.5)	10 (41.5)
<b>Type of VTE</b>			
PE	7 (29)	5 (21)	12 (50)
DVT	2 (8.5)	1 (4)	3 (12.5)
Both	6 (35)	3 (12.5)	9 (37.5)

Abbreviations: DVT, deep vein thrombosis; PE, pulmonary embolism; VTE, venous thromboembolism.

from the different VTE study databases for inclusion, exclusion, and sampling criteria. The time required for this screening process ranged from a few minutes (eg, when age was found to be an exclusion criterion) to 90 minutes (when the participants had a contradictory past medical history or unclear psychiatric history). To expedite this process, the participants with contradictory or unclear medical history were flagged to do a more detailed assessment of the exclusion criteria during the phone call. Ultimately, 160 participants met the criteria. After the participant met the inclusion criteria, the study personnel or the principal investigator (PI) then initiated phone calls to inquire about interest in participating. The time spent on phone calls varied from 1 minute (when calls were not answered, or the number was not in service) to 30 minutes (to explain the study to the participant and schedule the interview).

The second challenge was the original exclusion criterion of history of mental illness. The diagnosis of anxiety and depression excluded the majority of otherwise eligible patients. Simultaneously, documentation of mental health disorders was inconsistent and often incomplete, requiring PI investigation of

unexplained International Classification of Diseases codes in the absence of a documented formal psychiatric or even primary care mental health evaluation.<sup>24</sup> As a solution, we changed our original exclusion criteria of history of mental illness to known history of mental illness or other psychological diagnosis prior to VTE diagnosis with the exception a diagnosis of anxiety or depression. This change in the exclusion criteria increased the number of participants eligible to be called; however, these protocol changes only modestly helped the rate of recruitment because of pervasive problems with telephonic recruitment.

We were able to obtain a waiver from the IRB for recruitment but found that the “cold-call” telephone contact method proved to be highly inefficient.<sup>25</sup> Approximately 14% of telephone numbers had disconnected service. An additional 51% of participants were unable to be reached. In 75% of these cases, the caller left at least one voice message and never received a call back. Nineteen percent answered the first phone call and asked to be called another time but did not answer the subsequent call. Fifteen percent refused to participate in the study. The remaining 6% of calls were never answered or the voicemail was full.

Additional opportunity cost resulted from 27% of scheduled interviews who failed to show, with only two of those participants completing the interview after rescheduling. In an attempt to improve outcomes, every participant was called at least three times on different days, at different times. A minimum of three calls were made to numbers not obviously disconnected with an average of six to seven calls per patient. Despite strenuous effort and protocol modifications, the recruitment effort required 9 months to complete interviews with the first 15 participants. After the coronavirus disease 2019 (COVID-19) pandemic began, and state and local stay-at-home public health orders began, the number of participants who answered the phone calls increased, and within 2 months, 13 individuals agreed to participate. Because of the convenience of virtual interviews, we were able to retain a higher proportion of participants, and nine completed interviews. However, two participants were unable to complete the interview due to lack of access to computer, smartphone or internet, and two participants did not answer the day of the interview. One of them was reached later again but declined to complete the interview due to being admitted to the hospital, and the second participant never answered the calls to be rescheduled.

## 5 | SAMPLE SIZE

Qualitative sample size is determined by thematic saturation rather than mathematical calculation. Thematic saturation is the point at which the interviewer has uncovered the full range of perspectives in the population interviewed, and subsequent interviews no longer uncover new ideas. It is dependent upon a variety of factors, including the purposive sampling approach and the diversity of perspectives in the purposive sample. We had originally planned on 30 interviews. However, with a total of 24 interviews, we felt that

we achieved thematic data saturation, based on repetition of statements and themes.

## 6 | STUDY PROCEDURES

The initial design of the study was to interview all participants face to face to facilitate the development of rapport between the interviewer and interviewee, reduce distractions, and allow the interviewer to read the participant’s body language.

However, to adapt to the public health orders related to COVID-19, interviews were switched to a web conferencing platform (Zoom; Zoom Video Communications, San Jose, CA, USA) after the first 15 interviews. We adapted the same structure, identical format, and verbal instructions for COVID-19–adapted video interviews and tracked the duration and content of these video interviews to compare to face-to-face interviews. The duration of the interview remained identical after the transition from face-to-face interviews to a web conferencing platform (Zoom). Overall, the web conferencing offered logistical advantages. The access to geographically remote participants, the reduction on travel expenses for participants and interviewer, and savings on setup cost were key advantages.

Nonetheless, we identified a few challenges with the web conferencing platform. Two participants were unable to be enrolled because they did not have access to the necessary technology (Internet/smartphone/computer). The ability to establish a natural, relaxed conversation and observe body language was significantly reduced with two participants who used a cellphone for the video call. This was largely because the participants were holding the cell phone in their hands throughout the interview, which focused the camera only on their face and took away the ability to observe nonverbal cues. Finally, one participant who had never participated in a videoconference seemed distracted by the process. This was evidenced by the participant’s inability to focus on the verbal conversation and requiring frequent redirection throughout the interview. The participant seemed fixated on the video display, often fixing the hair and asking whether the interviewer could see and hear well.

For the face-to-face interviews, participants were interviewed individually in a quiet and private office with no others present, not bright lights and neutral background to avoid distractions. A “Do Not Disturb—Interview in Progress” sign was placed outside the door to minimize interruptions. When the interview was done by a web conferencing platform, the interviewer used the same place and the participants were asked to be in a location that would ensure privacy and prevent interruptions.

Two audio recorders were used during each interview to ensure that the interview was recorded completely and accurately and to allow the PI to focus during the interview. None of the interviews required a repeat session. All interviews were transcribed verbatim by a professional transcriptionist. None of the transcripts were returned to the participants.

Most interviews lasted 75 minutes and were followed by completion of five questionnaires: Generalized Anxiety Disorder Scale, Posttraumatic Stress Disorder Checklist, Pulmonary Embolism Quality of Life questionnaire, Villalta Scale for Diagnosing Post-Thrombotic Syndrome, and the Concerns About Recurrence Scale–VTE.

## 7 | INTERVIEWER CHARACTERISTICS

In qualitative work, we found it important to be attentive to the interviewer characteristics as well as the interviewer-interviewee relationships. In this study, the interviewer had no prior clinical relationship with any of the 24 participants. We felt that it was important for the interviewer to not be the patient's medical provider because we wanted patients to be free to express negative as well as positive experiences with the health care system and to not feel pressured to participate. However, we did feel that it was important for the interviewer to have prior knowledge on the topic (in this case VTE) and research expertise. The interviewer was a female internal medicine physician, has both clinical care and research experience with VTE, as well as both clinical and qualitative interview experience.

## 8 | INTERVIEW GUIDE DEVELOPMENT

Interview guides for qualitative research range from completely unstructured to highly structured. We opted to use a semistructured approach, in which all participants were asked the same main questions, but the interviewer followed up with different probing questions, depending on the answer to the main question. The use of a semistructured approach enabled us to cover all pertinent areas but also allowed participants to bring up topics we had not previously considered and to provide a high degree of detail.

Our preliminary interview guide was developed on the basis of pertinent information gathered from a review of the literature.<sup>16,22,23</sup> Then, the interviewer conducted three pilot interviews to test the guide. These pilot interviews allowed us to refine existing questions. Questions that did not work well were dropped, and questions were added on the basis of participant feedback. We set up our questions to encourage participants to tell their story. In contrast to questions that allow short or single-word answers, a storytelling approach allowed a more detailed narrative. The use of a semistructured guide enabled flexibility to ask questions that incorporated new information and to follow new ideas as they came up in the interview.

## 9 | INTERVIEW PROCESS

While the goal of the qualitative interview is to feel like a conversation, the emphasis is on active listening. At the beginning of the interviews, the roles were clarified: The participant was counseled

that the interviewer would ask questions but mostly listen and the interviewee should do the majority of the talking. The interviewer stated that the interview was intended to be conversational with no expectation of right or wrong answers.

The interview structure started with asking the participants to describe the time when they were diagnosed with VTE. We deliberately asked the interviewee to tell us their "story" of VTE both to serve as a warm-up for the interviewee because of its ease and allow for often unexpected details that come from storytelling. Probing questions were used to elicit details of the story.

The interviewer then inquired about the participant's knowledge of VTE to compare his or her knowledge at the time of the diagnosis with his or her current knowledge. As the interview progressed, the interviewer posed more challenging questions involving life-changing aspects due to the diagnosis, concerns and fears about the diagnosis, and coping mechanisms and emotional support, which also presented challenges to the interviewer.

A strength and a challenge in qualitative interviewing is the ability of the interviewer to identify and explore discrepancies in the participant's stories. For example, when participants were asked about mental health after VTE diagnosis, most participants denied having any anxiety, worry, or concern after the diagnosis; however, the same participants described signs of anxiety, fears, concerns, and worries after the diagnosis throughout the interview. In these situations, the interviewer would ask the same question using more neutral words, avoiding words clearly aligned with mental health, such as anxiety, worry, depression, or stress, in attempt to overcome their reluctance to endorse anxiety or worry about the disease. For example, the interviewer might ask: "What comes to your mind?"; or "What do you think when you start having shortness of breath or chest pain or leg pain?"; or "Tell me about changes in your life after the blood clots." This discrepancy was more prevalent with male participants, and we hypothesized that this might be related to the perceived stigma of a mental health diagnosis.

A second challenge in qualitative interviews on health services is that often informants do not know basic knowledge about their own health care condition. This raises both practical and ethical concerns. In a successful qualitative interview, the interviewer and interviewee build a relationship of trust, and when there is that level of trust, interviewees are often more willing to make themselves vulnerable and disclose lack of knowledge or ask for assistance in understanding their conditions when they would not have otherwise. In our study, a subset of participants had questions about their disease or treatment during the interview. While the goal of qualitative interviews is for the participant to express their feelings, perceptions, and decisions based on their current knowledge, a competing obligation is to resolve misinformation that may negatively affect a person's health. In our study, the interviewer addressed these questions when all research procedures (interview and questionnaires) were completed to prevent the answer from influencing the participant's opinions/beliefs during the interview. For example, the interviewer might say, "I am going to table your question for now, but we will come back to it at the end of the interview—is that OK with you?"

All interviews ended with the interviewer asking if the participants had any experiences or information related to VTE to share that had not been asked. This was done to make sure the participants had the opportunity to share anything that may have been missed in the interview but also to reiterate the value of their opinion. The majority of participants felt everything they wanted to discuss was covered in the interview.

## 10 | CODING AND ANALYSIS

All the transcripts were reviewed by the investigator for accuracy and completeness and then uploaded into NVivo software (QSR International, Melbourne, Australia). NVivo allowed for an organized and structured approach to the coding process as it facilitated categorization and comparison of the codes for data analysis.

Using two or more independent coders, or “double coding,” is one way to improve validity. Some more structured qualitative approaches involve calculating interrater reliability. However, in exploratory qualitative research, such as our study, discussion is more frequently used to resolve differences.

Inductive coding is deriving codes from the data. Deductive codes are predefined codes that come from previous research. The form of coding used should fit the goals of the research. In our study, codes were developed in several phases by two authors (JHN and MT) using a blended approach of deductive and inductive codes.<sup>26</sup>

This approach kept the coding process open to interesting new data while remaining connected to the scarce data currently available on this topic. Initial deductive codes were drawn from a review of the literature. However, some of those codes were adjusted as novel and potentially important information was elicited. The majority of the codes were developed through an inductive approach while coding participants’ transcripts, which allowed the codes to remain accurate and relevant, representing the reality of the participants as opposed to the beliefs of the researchers.

The first phase of code development used a descriptive approach, which identified emerging issues and concepts surrounding the participants’ experiences. The second phase involved constructing patterns in the data. This process consisted of identifying and refining the codes by groups and subdividing similar and unrelated codes and creating and relabeling categories. In the last phase, the results were further analyzed to determine how the new categories and subcategories were interrelated with one another.

An important analytic step is the development of a codebook. In qualitative work, codebooks organize codes (themes or concepts) and typically include codes, subcodes, a definition of the code, and example from the transcript and a description of when to use it or not use it (inclusion/exclusion criteria for the codes). Definitions for codes were developed by reviewing all corresponding coded text. Similar codes were combined, and infrequent codes were dropped. Inclusion and exclusion criteria were developed after comparing codes to prevent overlap. Once a draft

**TABLE 2** Codebook example

Themes	Definition	When to use	When not to use	Examples
Concerns of death	Patients describe their fear of death at the time of diagnosis of VTE and/or their continued fear of death	Patient reports a concern about the possibility of dying as a result of VTE	Patient describes concerns about death as a result of treatment	“I guess my biggest fear is that I just walk around one day, grow a clot, and drop dead” “My biggest fear is dying from it”
Other concerns	Patient describes other concerns (different than death) directly related to VTE	Any other concerns developed after and secondary to the diagnosis of VTE (incomplete resolution of VTE, effects on family)	Patient describes concerns about treatment, effects of treatment, recurrence, or death	“The scariest part for me was I wasn't sure if it (clot) would like move to the baby” “I was worried about it (clot) moving”
Increased stress after communication with health care provider	Patient discussed the negative impact that verbal communication about VTE with their health care provider had on them	Patient reported that their stress or anxiety level increased due to communication about VTE with their health care provider (diagnosis, risk factors, prognosis, treatment, future plans)	Patient discusses nonverbal communication that increased stress (facial expressions, gestures, tone of voice)	“When somebody tells you are the most interesting patient in the emergency room, that's probably not a good thing” “And then they (health care provider) told me, we don't mean to come in here, but usually somebody in your situation would be on a respirator and he can barely breathe on his own; and I'm like well you guys are like supposed to be helping me but you're scaring me”

TABLE 3 Themes

### Themes and stories about patients' VTE lived experiences

#### 1. Increased anxiety by physician communication

##### Patient 6

"So, I was worried about, and the way they made it sound, it was like you cut yourself, even if you're brushing your teeth and your gums start bleeding, go to the hospital. I'm like, so I was anxious about that, nervous, especially at work, but I told everybody I was working with if I started bleeding get me to the hospital. But so, I was just nervous. I didn't know. I didn't understand fully what could happen."

##### Patient 7

"I was very uneasy. Because I feel like I'm a project at that point, and they're not really sure what's going on with me. It was kind of unnerving, I guess for me, because I'm like you guys, literally, I was so dangerous 10 minutes ago I wasn't allowed to walk to the restroom by myself, but now I'm healthy enough that I can go home? All within a 4-hour time span or whatever that is. So it was a little scary for me."

#### 2. Fear of recurrence

##### Patient 12

I: "Do you currently have any fears for a blood clot happening again?"

F: "Oh, yeah, that's always in the back of my mind."

##### Patient 7

"How often do I think about it? It's always kind of, it's probably like a cancer patient, right? Like they probably always wonder, like even after they're supposedly in remission, even though they don't want to vocalize it every single day and jinx themselves or something. That's probably always at the back of your mind."

#### 3. Concerns of death

##### Patient 2

"So, and then I'd walk up the hill and I'm like, oh, it's so terrible. So I think I'd go back and forth and I'm trying to retrain my thoughts that you don't have a clot anymore, you really can do this. But then I get out of breath, and I feel like, oh, it was a blood clot, I'm going to die."

##### Patient 1

"The next one is probably going to be the widow maker. That'll be the end."

##### Patient 16

I: "What was your reaction when they told you that you had a blood clot?"

F: "I was scared because he said I had so many and one was close to my heart. So, yeah, I was scared. I panicked."

I: "You were scared. Why?"

F: "Because I thought I was going to die."

of the codebook was developed, it was applied to the remaining transcripts and revamped when new codes were developed. The codebook underwent five revisions before both authors agreed on a satisfactory version. See Table 2 for an example of the codebook.

In our project, all transcripts were independently coded by two authors (JHN and MT). An important part of qualitative work is the explicit recognition of what the interviewers/coders brings to the table. The coders filter data through their own experiences, creating interpretations of the data. In our study, one coder was a practicing physician, while the other was a fourth-year medical student. This was an explicit choice, so that the coders would understand the

medical information and the difference between necessary care and overuse. Some argue that qualitative researchers should be outsiders, unconnected with the phenomena under evaluation, and that only an outsider can be sufficiently impartial. However, we argue that, whether insider or outsider, the interviewer always brings a specific lens to the interview. Instead, the goals should be an explicit acknowledgment of one's perspective and self-awareness on the part of the interviewer.

For the first six transcripts, both coders met in person to review and code transcripts together. The coders spent ≈15 hours analyzing the first transcript, learning to navigate NVivo, initiating the development of the codebook, creating new codes and discussing consistency of judgments between coders. Coding time progressively decreased with each transcript. As the coders became more familiar with NVivo, more codes were developed and readily available for application to each transcript and few differences between coders arose. After transcript six, both coders independently reviewed and coded each transcript. Then, the coders began online meetings (via Zoom) to establish consensus on the codes, formulate a general description of the analysis, and to discuss emerging themes for each transcript. For codes identified later in the coding process, earlier transcripts were reanalyzed for the novel codes. Differences among coders were resolved by discussion. If the coders could not come to consensus, a third person (JAK) provided a third opinion to help reach a final decision.

A myriad of qualitative analytic approaches exist, ranging from a straightforward thematic analysis to more complex methods such as grounded theory or phenomenology. We chose to use content analysis because little is known about the psychosocial experiences during and after the diagnosis with VTE. This analysis will help identify patterns and common topics in the data.<sup>27</sup> The identification of specific components of patients' experiences with VTE will influence the care and support of patients with VTE. Excerpts of transcripts, key themes (also called higher-order codes) were developed by grouping and analyzing similar codes. The relationship among these themes were examined to create a model of the patient experience. Patterns were identified within the data that conveyed a collective experience. However, multiple models emerged from the data in part, owing to differing patient experiences and in part to different author perspectives. Preliminary models were tested against subsequently analyzed transcripts and revised to create a final model of patient experiences of VTE.

Some of the themes that we found associated with the lived experiences of patients diagnosed with VTE and the psychosocial impact of VTE on patients were (i) increased anxiety/stress after communication with health care provider, (ii) fear of recurrence, and (iii) concerns of death.

*Increased anxiety/stress after communication with health care provider.* Our results suggest that health care providers can unintentionally communicate with patients with VTE in way that fails to inform them about their disease process, and cause harm by unnecessarily escalating fear and concerns, which lead to ongoing anxiety. See Table 3 for patient quotes.

**Fear of recurrence.** Most of the participants that we interviewed had increased fears that the blood clot may return, described as a fear that is “always in the back of my mind.” This fear was triggered mostly by physical signs/symptoms and was associated with increased anxiety. Patients with unprovoked VTE seem to have higher levels of anxiety due to the unknown cause for the VTE. It is noteworthy that these participants seem to have higher reliance on medication because they considered the medication as a “lifesaver.” See Table 3 for patient quotes.

**Concerns of death.** Participants express concerns of death at different stages. Some of them reported this concern at the time of the VTE diagnosis and during the acute treatment; some realized later that they could have died; and some patients had a constant feeling of threat to their life, with the idea that the “next one” will be fatal. See Table 3 for patient quotes.

## 11 | FINAL THOUGHTS—QUALITY, TRANSPARENCY, AND VALIDITY

In quantitative research, the goal is to have a generalizable sample. In qualitative research, the goal should be transparency in sample selection.<sup>28</sup> With transparency in purposive sampling, the question is not whether qualitative results can be broadly applied to the whole population but whether the researchers have been transparent enough in the detail about sampling and research procedures that a reader feels that results can be applied to their own population. In addition to transparency, further validity assessments include the following: (i) acknowledgement of the researcher perspective; (ii) participant checks or presenting the data to participants to see if they feel that it reflects their reality; and (iii) triangulation or using two or more different types of data to see if results are similar.

This report provides methodologic guidance for the implementation of individual qualitative interviews to capture patients' lived experience of a medical diagnosis associated with overuse of ED resources. Our goal in providing details on study design, sampling, interviewing, and analysis is to make qualitative research accessible to quantitative researchers.

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### RELATIONSHIP DISCLOSURE

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### AUTHOR CONTRIBUTIONS

JH conceived of the study and designed the work, collected data, performed data analysis and interpretation, drafted the article, and provided final approval of the version to be published. MT collected data, performed data analysis and interpretation, and provided final approval of the version to be published. AA performed data analysis and interpretation, offered critical revision of the article, and provided final approval of the version to be published. MO performed data analysis and interpretation, offered critical revision of the article, and provided final approval of the version to be published. JK conceived of the study and designed the work, performed data analysis and interpretation, offered critical revision of the article, and provided final approval of the version to be published.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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