

## ORIGINAL ARTICLE

# Communication at diagnosis of venous thromboembolism: Lasting impact of verbal and nonverbal provider communication on patients

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## Funding information

NIH/NHLBI K12 Emergency Care Research training program, Grant/Award Number: 133310

**Handling Editor:** Dr Lana Castellucci

## Abstract

**Background:** Establishing trust and effective communication can be challenging in the emergency department, where a prior relationship between patient and provider is lacking and decisions have to be made rapidly. Venous thromboembolism (VTE) represents an emergent condition that requires immediate decision making.

**Objective:** The aim of this paper was to document the experiences, perceptions, and the overall impact of health care provider communication on patients during the diagnosis of VTE in the emergency department.

**Methods:** This was a qualitative method study using semistructured interviews to increase understanding of the patient experience during the diagnosis of VTE and impact of the health care provider communication on subsequent patient perceptions.

**Results:** A total of 24 interviews were conducted. Content analysis revealed that certain aspects of health care providers' communication—namely, word choice, incomplete information, imbalance between fear over reassurance and nonverbal behavior—used to deliver and explain VTE diagnosis, treatment, and prognosis increases patients' fears.

**Conclusion:** These interviews elucidate areas for improvement of communication in the emergency care setting for acute VTE.

## KEYWORDS

communication, emergency treatment, fear, reassurance, venous thromboembolism

## Essentials

- Communication in emergency settings such as diagnosis of blood clots can be challenging.
- Providers should address concerns and educate with phrases that do not evoke fear.
- Providers' communication may cause harm by unnecessarily escalating fears and concerns.
- This study reveals opportunities to improve communication at time of blood clot diagnosis.

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## 1 | INTRODUCTION

The patient–health care provider relationship, fundamental to high-quality medical care, requires trust and effective patient–health care provider communication.<sup>1</sup> Due to the importance of trust, the practice of health care providers regarding truth-telling has evolved over the past 50 years. For example, the practice of nondisclosure is now generally considered out of date because it may represent health care provider paternalism that compromises patient autonomy.<sup>2</sup> Highly effective communication with patients can improve their health outcomes.<sup>3</sup> Moreover, a positive provider communication style has been found to lead to a better recovery and raising positive expectations about treatment outcomes appears to decrease pain experiences.<sup>4,5</sup> Healthcare providers thus face the challenge of educating patients about VTE and its risks without inciting unnecessary fear and anxiety when communicating the diagnosis and treatment plans to patients.

The concept of trust and communication is particularly important and challenging in the emergency care setting, where physicians must communicate treatment options, risks, and prognosis of life-threatening conditions within a short time frame. To further complicate the situation, in most cases the patient and emergency physician have not previously met. While technological advancements have improved diagnostic and prognostic accuracy in emergency care, better accuracy does not necessarily assuage the difficulty of balancing truth and hope.<sup>6</sup> All of this is particularly challenging when communicating clinical equipoise, a situation where two or more treatment options exist but neither is clearly superior. Providers need to communicate uncertainty and adequate information on disease mechanism, estimation of prognosis, and risks and benefits of each treatment option for the patient to make an informed decision. Ethical issues arise when patients do not have an adequate understanding that enables them to state their preferences or when providers communicate predictions with false clarity such that it does not appear that there is any choice to be made.

Most literature describing patient–health care provider communication has been done in the nonurgent setting where a prior relationship has been established.<sup>7–14</sup> However, almost no research has examined communication in emergency situations where the decision has to be made within hours. To address this knowledge gap, we report in this article the patients' experiences and perceptions about the patient–health care provider communication during and after the diagnosis of venous thromboembolism (VTE).

The majority of the patients diagnosed with nonsevere VTE, when treated with anticoagulation alone, experience good outcomes.<sup>15–20</sup> However, patients with severe acute VTE may benefit from the addition of invasive “reperfusion strategies.” Although current literature suggests that clinical equipoise and considerable controversy exists over this decision, if reperfusion strategies are likely to help, experts believe they should be initiated within a few hours of diagnosis.<sup>21–24</sup> The diagnosis of VTE and its treatment thus represent a model system of an emergent condition that requires immediate decision making under conditions of uncertainty regarding

optimal treatment choice and where both the failure to treat and the complications from treatment can be life threatening. Furthermore, most of these patients will present to the emergency department (ED), where a patient–health care provider relationship has not been developed or maintained.

## 2 | METHODS

### 2.1 | Design

This work employed a qualitative methods approach using semistructured interviews to gain a richer understanding of patients' experiences with the diagnosis of VTE and the overall impact of health care provider language on their perception of wellness.

A more detailed methods description of this study has been previously published.<sup>25</sup>

### 2.2 | Participants

Purposive sampling was used to identify participants from around the greater metropolitan area of a medium-sized Midwestern city. We used databases from the coagulation clinic and a registry kept of patients treated by the multidisciplinary pulmonary response team, as well as patients who participated in other VTE research studies by our group. We also used electronic medical records (First Net; Cerner, Kansas City, MO, USA) to survey patients presenting to a large academic urban ED and a public safety net hospital ED. We attempted to recruit a heterogeneous sample. The participants were between the ages of 18 and 70 years old, had different health care experiences (hospitalization, discharge from ED, received anticoagulation alone or reperfusion therapy) and had experienced a symptomatic VTE as a deep vein thrombosis (DVT), pulmonary embolism (PE), or both at least 6 months before enrollment. Recognizing that patient perceptions of communication may undergo dynamic change for several months after diagnosis. During this time, patients recover some degree of cardiopulmonary function and adapt to a life that includes need for anticoagulation medication and the highest risk of recurrence. We therefore focused on selecting patients who were at least 6 months after the most recent diagnosis, when they are more likely to have achieved steady-state health and emotional recall of events in hospital.

This study was approved by the local institutional review board (IRB). A waiver for recruitment was obtained from the IRB, and the participants were contacted by phone to participate in the study. The exclusion criteria included 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. A total of 160 participants met the criteria. We contacted participants by phone and were able to discuss the study with ≈30% of participants. Fifteen percent of participants agreed to participate. They were compensated with a Visa card for the ≈3 hours spent

completing the interviews (this included travel time, interviews, and completion of surveys).

## 2.3 | Interviews

A semistructured interview guide was developed upon review of the literature, the authors' experiences with patients with VTE, and three pilot interviews. Participants were asked to provide a detailed narrative in response to questions, with storytelling encouraged. The interview structure started with asking the participants to describe the time when they were diagnosed with VTE. This question was intended to serve as a warm-up for the interviewee because of its ease and likelihood of initiating the process of storytelling. This approach also helped the interviewer understand the mind set of active listening, paying attention to emotions and body language, while the interviewee recalled the events from the day of diagnosis. Follow-up questions were used for clarification and to encourage participants to elaborate on their initial answers. As participants discussed new information and ideas, they were incorporated into the interview. The interviewer was an internal medicine physician with VTE research experience. The interviewer was a female internal medicine physician who has both clinical care and research experience with VTE, as well as qualitative interview experience.

## 2.4 | Procedure and COVID adaptations

The initial design of the study was face-to-face interviews in a quiet, private location to lessen distractions to be able to read the participant's body language. However, halfway through the study (15 participants enrolled) the COVID-19 pandemic began, and state and local stay-at-home public health orders required changes to the interview approach. Therefore, subsequent interviews were conducted by a web conferencing platform (Zoom). Except for physical proximity, the face-to-face and Zoom interviews were conducted with identical format and verbal instructions.

The study was reported in accordance with the Consolidated Criteria for Reporting qualitative research checklist.<sup>26</sup>

## 2.5 | Analysis

Transcripts were reviewed for accuracy and completeness and then uploaded into Nvivo software. Content analysis was carried out because little is known about the lived experiences during and after the diagnosis with VTE. The first steps in the analysis involved using codes from previous research; however, the majority of the codes were developed during transcript analysis based on emerging issues and thoughts surrounding the participants' experiences and not the perspective of the coders. Then, the codes were refined by groups and subdivided based on similarities and differences among codes to consequently create or relabel categories. Also, part of the analysis

**TABLE 1** Clinical characteristics of participants

	Female (n = 15)	Male (n = 9)	Total (n = 24)
Age, n (%)			
<50 y	6 (25)	4 (16.5)	10 (41.5)
>50 y	9 (37.5)	5 (21)	14 (58.5)
Race, n (%)			
Black	6 (25)	2 (8.5)	8 (33.5)
White	9 (37.5)	7 (29)	16 (66.5)
Comorbidities, n (%)			
Hypertension	4 (16.5)	5 (21)	9 (37.5)
Diabetes	3 (12.5)	2 (8.5)	5 (21)
Rheumatological disease	4 (16.5)	3 (12.5)	7 (29)
Asthma	1 (4)	1 (4)	2 (8)
Time since VTE diagnosis, n (%)			
<2 y	4 (16.5)	5 (21)	9 (37.5)
>2 y	11 (46)	4 (16.5)	15 (62.5)
Received thrombolysis, n (%)			
Yes	2 (8.5)	3 (12.5)	5 (21)
No	13 (54)	6 (25)	19 (79)
Lifetime anticoagulation, n (%)			
Yes	8 (33.5)	6 (25)	14 (58.5)
No	7 (29)	3 (12.5)	10 (41.5)
Type of VTE, n (%)			
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.

was to establish how the categories and subcategories were interconnected with one another.

Finally, patterns were identified within the data and the analysis focused on a broader level from which the defined themes were developed. The themes were discussed and interpreted by two authors (JH, MT). Interpretation was influenced by the authors' perspectives and preunderstanding of the relevant literature. One coder (JH) was a practicing physician, while the other (MT) was a fourth-year medical student. These themes were used to create a preliminary model of the patient experience and later tested against the analyzed transcripts to create a final model of patient experiences of VTE. In this study, the interviewer and coders had no prior clinical relationship with any of the participants.

## 3 | RESULTS

Between June 2019 and May 2020, 24 participants were interviewed (see Table 1 for participants' characteristics). The interview sessions required an average of 75 minutes. Content analysis revealed a major

theme labeled “increased anxiety/stress after communication,” which was influenced by the following categories: word choice used by health care providers, inferences created by nonverbal behavior during the patient–health care provider interaction, provider explanations that were perceived to be incomplete, and imbalance between fear and reassurance. These categories influenced the overall theme in dynamic ways as shown in Figure 1. Participants generally indicated feelings of inadequate communication resulting from difficulty understanding the providers’ explanations and not receiving enough information to resolve the patient’s natural curiosity.

### 3.1 | Word choice used by health care providers

Participants reported that the words used by health care providers to communicate their diagnosis, treatment, and prognosis caused anxiety. Medical jargon, misplaced metaphors, and alarmist language were identified by participants as sources of anxiety. Some participants described how their health care provider used medical jargon to explain their condition without realizing that the meaning was not clear to the patient.

And I didn’t know what the heck they were talking about. They said deep vein thrombosis and pulmonary embolism. I knew what a blood clot was. Did I know what pulmonary embolism was? NO. They explained it was a blood clot in your lung. And you know,

didn’t go it’s huge, small, or whatever. They just said that’s what it is.

(59-year-old man)

The only thing that I ever have trouble understanding is if they start throwing out the big medical words and then I’ll just have them tell them to dumb it down for me.

(33-year-old man)

Participants also described the use of frightening metaphors by health care providers to warn them of imminent doom.

He goes, you’re a walking time bomb, we need to get you in for surgery right away.

(60-year-old man)

Participants interpreted the use of alarmist language as a way to convey a sense of urgency, which generated more fear and anxiety. One participant interpreted this as a “scare tactic.” This type of language was mainly used by health care providers when they were explaining treatment options or prognosis, making the participants feel as if they did not have other options for treatment or time to make decisions.

**P:** But anyways, I’ve had three different encounters with the doctors since my stay, and they all said that I would have to take it for the rest of my life.

**I:** They told you that?

**P:** Yeah, but I think that was just probably one time, was probably more of a scare tactic because I quit taking mine (anticoagulant).

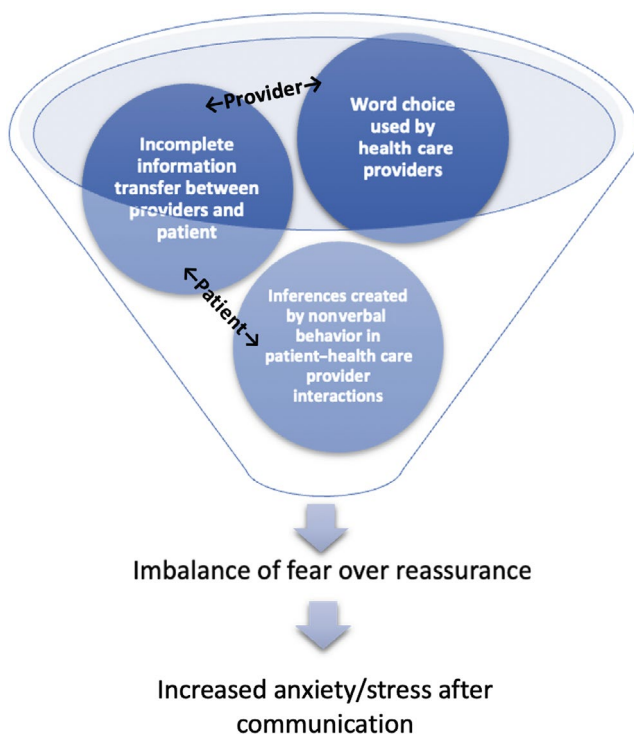
(33-year-old man)

Because for somebody to stand over you and tell you you’ve got to have this surgery now, because if not, without it you’re going to die, and with it there’s a possibility you could die, so it was like, Wow, are you serious? And I think I just broke down and cried. And I couldn’t think no more after that.

(51-year-old woman)

So a whole bunch of doctors kept coming here asking me questions and looking at me and trying to figure out and it was like, man, you’re in pretty bad shape, but you look like you are all right. And I’m like, I feel all right besides the leg. But you know, I mean, that’s when I realized it was like really serious even though I don’t feel it, I just got like a cramp in my leg. But the way these people are running around and talking about sticking something inside of me and I’m like, oh no, wait. And, but it was, and I don’t get too nervous, but I was a little nervous, you know?

(41-year-old man)



**FIGURE 1** Model of how categories influenced the major theme

Then they told me it was like we don't mean to come in here, but usually somebody in your situation would be on a respirator and 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.

(41-year-old man)

### 3.2 | Inferences created by nonverbal behavior

Participants often described making inferences about their situation based on providers' nonverbal communication, which resulted in heightened anxiety and confusion. Providers' facial expressions were often used to gauge the severity of the situation. Participants grew increasingly concerned as more physicians entered the room to conduct their examinations, as they equated this busy environment with a poorer prognosis. Some participants even described feeling neglected as the environment grew busier. Months to years later, participants were able to recount the moment they began to realize the severity of their situation.

And like, I mean, once they start showing a little more concern with facial expressions or whatever, then it's like I can take it, just cut to the chase and tell me what you know is going on.

(60-year-old man)

We were laughing and joking, and then all of a sudden, all the nurses got serious and started running around. And I'm like, well nobody's talking to me, what's wrong? But you know, I mean, that's when I realized it was like really serious even though I don't feel it, I just got like a cramp in my leg.

(41-year-old man)

Except like he said, you have a saddle, and I thought, what is that? But they were all in a hurry and they were bringing machines and do this and hook me up and all that, and I didn't have a chance to say, please explain exactly what that means. I don't understand. All I know is I have blood clots in my lungs. So, I didn't really, there really wasn't an opportunity to just sit down and have a conversation with somebody. They all had a job to do, and they were all busy and stepping on one another practically.

(65-year-old woman)

I was like, what's going on? They got this many doctors in there because I've been in the emergency room before for other things. But I've never had that many doctors come in at one time.

(56-year-old man)

### 3.3 | Incomplete information by health care providers

The majority of participants reported that at the time of diagnosis they had no prior knowledge about blood clots and that health care providers failed to adequately explain their condition even after requests for clarification. Some participants expressed a desire for more transparency regarding the severity of their condition. These reflections led participants to search for more information in other sources such as the Internet or friends, which often heightened fear and led to the development of new worries.

That's what the doctor told me, take it every morning and don't miss. I said, what happens if I miss? He said don't miss, that was all he said.

(56-year-old woman)

But you know, they're not being too, they talk about the risk. So they'd say, well there's a risk of internal bleeding if we go with the catheter route. They never came out and said it would be lethal. It would be lights out or whatever. They just said, there's a risk of internal bleeding and you know, it wasn't gonna be like how bad it was or could they stop it or once they turn that stuff on, is there a way to turn it off quickly if I start bleeding out? There wasn't that much discussion.

(59-year-old man)

I did look up saddle, and I was still, because I thought, nobody ever explained that. It makes me feel like a horse, saddled. It sounds silly, I know, that's just my weird brain, but I could never really find any information on it. I've never seen anything on the Internet as far as I could see, of how that in particular will affect you in the future. I just kinda wait and see type thing.

(65-year-old woman)

**P:** But that kind of scared my husband. The idea that they were taking me by ambulance was like, whoa, why are they doing this?

**I:** Did you ask them why they were doing that?

**P:** No. I figured they knew what they were doing.

**I:** Okay. And what was the reason to transfer you to XXX Hospital?

**P:** They didn't really tell me that either.

(65-year-old woman)

### 3.4 | Imbalance between fear and reassurance

Participants report that their lack of understanding about their diagnosis or treatment influenced their safety perception and the care that they were receiving, which heightened their threat perception. If verbal communication did not provide needed answers, participants relied on nonverbal cues from their providers and

environments. Overall, participants in this situation experienced more fear than reassurance.

I was nervous, a little anxious. I didn't know... before I and they did the ultrasound, they knew what was or had a good feeling what it was. They wanted an ultrasound to confirm it. But, so that Friday night I was a little nervous. I remember I went up to my girlfriend's unit [in the hospital]. I was like, am I okay to go home? Like nobody's home, so if this thing moves or whatever, you're going to find me in bed when you get home.

(39-year-old man)

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.

(32-year-old woman)

Conversely, participants' sense of safety increased when their health care providers thoroughly explained their diagnosis and their medical decision making in layman's terms. When these conversations occurred during the time of diagnosis or before treatment was provided, participants were more comfortable with their providers and the recommended treatment.

He was explaining what he was going to do and what the treatment was going to be, and he was sending me to the hospital to treat me. So, I was pretty confident the way Dr XXX had approached it. He just made me feel at ease, so I felt better, and I trusted in what he was saying.

(57-year-old woman)

Dr XXX explained everything so thoroughly to my family, my sons and their wives and my husband. My sister came down to kind of stand by and listen to what was being said, so everybody had the information, and they answered any questions we had, and I just feel very fortunate that I had the care that I had.

(56-year-old woman)

## 4 | DISCUSSION

Our findings revealed that health care providers can inadvertently communicate with patients diagnosed with VTE in ways that fail to inform them about the disease process, cause harm by unnecessarily escalating fear and concerns, and lead to ambiguity and uncertainty causing persistent anxiety. Other studies have shown that lack of

adequate understanding may drive patients to seek information from potentially dubious sources.<sup>27,28</sup>

Our findings highlight opportunities to improve communication in patients with acute VTE in the emergency care setting. Using basic language and avoiding medical jargon improves patient understanding, which prevents the development of barriers between the provider and patient and enables patients to participate in decision making.<sup>29,30</sup> Patient familiarity with medical terminology does not necessarily equate to a comprehensive understanding of disease processes. To provide a simple and clear explanation, providers should break down information about diagnosis and treatment into digestible components and constantly check the patient's understanding of each component. The provider should then address concerns and educate with neutral words and phrases that do not evoke dread. For patients who do not ask any questions, providers should offer common questions asked by other patients such as, "Many patients want to know about why they had a blood clot." The provider should then answer this question. This technique may help the patient develop questions of his or her own.

While research has shown that the use of metaphors and hyperbole may improve communication, our findings indicate that the use of metaphorical expressions to explain medical concepts can evoke fear.<sup>31,32</sup> For example, the phrase "you are a walking time bomb" to describe a patient with VTE may be used to convey the severity of the situation and the importance of initiating treatment before "the bomb" goes off. While well-intentioned, such language increases the patient's anxiety level instead of his or her understanding, especially if used without a comprehensive explanation of VTE and the treatment. Other phrases that contain excessive hyperbole (and are implicitly self-gratuitous) is the direct statement or variation of "...you could have died if we did not make this diagnosis today" or "I've seen patients die from what you have." Instead, providers should speak about clots as being "safely treated if promptly diagnosed," which also serves to reinforce the importance of seeking medical attention should future symptoms occur. The following is an example of a less anxiety-provoking statement: "If diagnosis is delayed too long, blood clots can be dangerous and, in rare cases, even fatal." Health care providers should be aware that metaphors and hyperbole are often useful in clarifying the diagnosis or treatment, but they should not be used to intensify fear.

Finally, participants reached many conclusions about their diagnosis and prognosis based on nonverbal communication. Often, participants experienced an increase in anxiety after making inferences based on body language. Health care providers should monitor their own nonverbal communication and consider how it might be impacting the patient. This study was not designed to determine how nonverbal actions could be improved, but other studies have suggested that providers should be seated, relax their facial muscles, use a neutral tone of voice, maintain eye contact, and nod to show understanding when discussing important medical information.<sup>33</sup> Furthermore, participants in this study experienced increased levels of anxiety from their environment, especially after being examined by multiple physicians. This was seen mainly in participants with more severe VTE when a pulmonary embolism

response team (PERT) was a part of their care. This raises awareness that PERT teams must work together toward the best practice in the treatment of the clot, but also to address the fears and questions held by the patient.

A limitation to this study includes that the sample is limited to one city in the US Midwest and lacked ethnic diversity. The sample tended to skew away from patients with mental illness, severe comorbidities, and low socioeconomic status. Our sample is only from two hospitals, and we are unable to differentiate how the recollection of conversations are affected by differing practices between institutions in regards to evaluation of patients diagnosed with PE, variety of therapeutics, presence of PERTs, number of PERT members, counseling, and discharge/follow instructions. This observational work had no control over the influence of the ED environment on patient recall, which could have contributed to perceptions, depending on the pace and acuity of any given day. The interviews were only from patients and allow no insight into the awareness or intentions of clinicians. We included three DVT participants to allow comparison of their experiences with patients with PE. We recognize that three participants did not meet the criteria for saturation but allowed a preliminary comparison. DVT represents the more minor spectrum of the VTE, but still can lead to serious health problems. Also, they are largely treated the same and share ongoing uncertainties surrounding the use of anticoagulation.

## 5 | CONCLUSION

This qualitative study revealed multiple opportunities for improvement of communication in emergency care of patients with acute VTE including the use of layman's words and breaking information down to simple components, while avoiding jargon, metaphors, and hyperbole. Providers should be aware that their nonverbal communication can contribute to the patient's stress response. Future qualitative studies could continue to explore ways to improve communication from the perspective of patients and providers including ways to improve external, systemic factors that negatively impact patient-provider communication.

## ACKNOWLEDGMENTS

The manuscript for this article was read and approved for submission by all authors.

## RELATIONSHIP DISCLOSURE

The authors declare no conflicts of interest.

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**How to cite this article:** Hernandez-Nino J, Thomas M, Alexander AB, Ott MA, Kline JA. Communication at diagnosis of venous thromboembolism: Lasting impact of verbal and nonverbal provider communication on patients. *Res Pract Thromb Haemost.* 2022;6:e12647. doi:[10.1002/rth2.12647](https://doi.org/10.1002/rth2.12647)