



Understanding the Patient Experience of Peripherally Inserted Central Catheter-Related Deep Vein Thrombosis Using Interpretive Phenomenology

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ABSTRACT

The purpose of this interpretive phenomenological study was to determine what it means to patients to live with a peripherally inserted central catheter (PICC)-related deep vein thrombosis and to describe the influence of the experience on the individual's quality of life. The sample included 11 adult patients from an acute care setting who developed a PICC-related symptomatic thrombus between November 2014 and March 2016, using purposive sampling. Three distinct themes emerged from the data in this study: a loss of trust in health care providers, additional burdens to existing problems, and a yearning for understanding.

Key words: catheter, DVT, interpretive, lived experience, phenomenology, PICC, thrombosis

Deep vein thrombosis (DVT) is one of the most common complications of vascular catheters placed in a blood vessel for infusion therapy. It is estimated that 2% to 6% of patients who have a peripherally inserted central catheter (PICC) will develop a symptomatic DVT and that more than 40% will develop an asymptomatic thrombus.¹ Chopra et al² suggest that rates of thrombus formation associated with vascular catheters are significantly underreported and that the actual incidence of DVT overall is likely much higher.

DVT is the development of a blood clot, or thrombus, that adheres to the vessel wall and either partially or completely occludes the flow of blood in the vessel. Indwelling venous catheters create stasis, or a slowing of flow in the blood vessel, and this slowing of blood flow creates the potential for damage to the vessel endothelium.³ Once the endothelium, or the innermost layer, of the vessel is injured, the clotting cascade is initiated as a part of the

body's normal efforts to prevent bleeding. The resultant clot is referred to as a *thrombus*. Asymptomatic thrombosis means that a clot has formed in the vessel, but the patient does not have any explicit symptoms. This silent thrombus may result in scarring or sclerosis of the vessel over time, but the patient has not yet developed any outward symptoms of the vessel narrowing.¹

Conversely, patients may develop symptomatic thrombosis. Symptoms of this vessel narrowing or occlusion often present as swelling or pain in the extremity. Potential symptomatic sequelae associated with the development of thrombosis can also include loss of vascular access sites, body image alterations, catheter-related bloodstream infections, financial costs associated with long-term treatment of infection or DVT, postthrombotic syndrome, pulmonary embolus, and even death.⁴ The theoretic causes and incidence of thrombus development, rates of postthrombotic complications, and costs of medical treatments are all well defined in the literature within a variety of patient populations.^{5,6}

Studies that uncover what the experience of this phenomenon is like for unique individuals are currently nonexistent. Chopra et al² pointed out that PICC use has increased tremendously in recent years as treatment modalities have advanced for a variety of disease processes. Because the patient experience has not been documented and is not well understood, the patient experience of PICC-related DVT has little influence on catheter research and development, prescribing, or care and maintenance. The hypothesis for the study by Chopra

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et al² is that a better understanding of what it is like to live with a PICC-related DVT would inform these practices and offer patients a voice in their vascular access care.

This article consists of a discussion of the study problem and purpose, the research questions, and a literature review. A discussion of the study design and methodology is followed by a description of the process for interpretive analysis of the interview data using Ricoeur's 1991 theory⁷ of interpretation, which aids in ascribing meaning to the data. This is followed by a discussion of the findings in answering the research questions, suggestions for future research, suggestions for the practical application of the findings in the catheter procurement process, and a discussion of the strengths and limitations of the study.

STUDY PROBLEM

This study addressed a lack of understanding of the patient experience of catheter-related DVTs by health care providers. This lack of understanding propagates continued use of traditional decisions for product development, product purchasing and selection, device insertion, and care and maintenance of PICCs. These decisions are limited to what clinicians already know and are often based on clinician or organizational preferences. Therefore, patients have no voice in device utilization decisions, and their experiences don't influence the previously mentioned processes.²

Because clinicians inserting devices do not see the effects of developing a DVT associated with the catheter, they can erroneously assume that their processes are adequate and even optimally effective to meet the patient's needs. According to Chopra et al,⁸ providers continue to use traditional criteria for prescribing placement, and clinicians insert catheters with traditional or convenient techniques despite high DVT incidence rates, because of this narrow view of practice.

Quantitative research on causation and prevention measures can only partially address the problem because only the external empirical perspective is represented by quantitative study.^{9,10} If prescribers and inserters knew the influence of DVT development on patients' quality of life in specific and practical terms, decisions for prescribing, inserting, and caring for these catheters would be informed in a way that would lead to safer and more cost-effective PICC use. This thought is echoed by recent initiatives to increase patient and family involvement in health care decisions as a mechanism to improve safety and quality.¹¹ Throughout this work, the word *influence* is used to express a unique set of factors that affect the way an individual patient ascribes meaning to her or his experience.

STUDY PURPOSE

The purpose of this study was to describe the influence of PICC-related DVT development on patients' quality of

life and to understand what it means to the patient to live with the influence of a DVT. Ascribing meaning to the lived experience of patients who develop a PICC-related DVT and recording the experiences of the patients in their own terms and from their own perspectives help personalize this phenomenon and ensure that patients have a voice in planning infusion care.¹² Studying and disseminating the patient experience of catheter-related DVT adds poignant and meaningful patient-focused information to the existing knowledge base for PICC prescribing, insertion, and care and maintenance best practices.¹³ Kuper et al¹⁴ describe the importance of understanding the meanings of experiences in planning clinical care that meets patient needs. This study's research questions echo Kuper and colleagues' assertions.

RESEARCH QUESTIONS

The main research question and 2 subquestions that this interpretive phenomenological study, based on Parse's¹⁵ theory of *human becoming*, aimed to answer included the following:

Overall Research Question

What is the lived experience of patients after discharge who develop a PICC-related DVT in the acute care setting?

Subquestions

1. What perceptions do patients who develop a PICC-related DVT in the acute care setting have regarding the influence on their quality of life?
2. What meaning do patients who develop a PICC-related DVT in the acute care setting ascribe to their experience?

DESIGN AND METHODOLOGY

To answer the research questions and understand the influence of PICC-related DVT on a patient's quality of life, this study included an interpretive phenomenological methodology. According to Lopez and Willis,¹⁶ interpretive phenomenology is philosophically based on the idea that people experience situated freedom. In essence, the meanings people ascribe to experiences are a function of their position or being in their unique lived world. These meanings then influence the choices individuals make. Evaluation of *lived thoroughness*, *evocativeness*, *intensity*, *tone*, and *epiphany* are textual features of interpretive phenomenology that van Manen¹⁷ suggested as a means to evolve from assessing merely a thematic meaning to a more expressive meaning of a phenomenon.

van Manen asserted that a "good phenomenological text has a way of making the reader see something"^{17(p345)} that illuminates the understanding of an everyday lived experience. The role of the researcher is to elicit the text from

the participant in the form of the spoken or written word in a manner that gives full expression to the experience. The researcher then uses the normative lived experience of that individual—as expressed in words, actions, and expressions—to describe the phenomenon and interpret meaning. The words, actions, mannerisms, and voice tones act as data sources that then can be analyzed for meaning. According to van Manen,¹⁷ even the simplest expressions hold a wealth of information. The interpretive hermeneutic methodology of phenomenological inquiry was, therefore, deemed optimal to achieve this study's purpose of uncovering the meaning of the lived experience of patients who develop a PICC-related DVT.

Population and Sample

The inclusion criteria limited patients for the study to adults discharged from an 1100-bed acute care academic medical center after developing a symptomatic PICC-related DVT within the previous 18 months. Potential participants were identified using a report of patients who had an upper extremity ultrasound and an indwelling PICC at the same time. Once thrombosis was identified on the report, the patients were added to a prospective participant list. The list was obtained by the researcher from the organization's clinical practice director.

Patients had to be capable of fully participating in the interview process by demonstrating an ability to converse in English and possessing adequate cognition to interact with the researcher.¹⁸ Purposive sampling was used since the common experiences of a group of individuals are necessary to glean understanding of the lived experience.¹⁹ To promote an adequate sample while maintaining efficiency, 11 participants were enrolled and enrollment ceased once data saturation occurred.²⁰ Data saturation is demonstrated when no new information is noted in subsequent interviews. Eleven participants were enrolled, and data saturation was noted preliminarily after 6 interviews. By the completion of the 11th interview, recurrent themes were easily identifiable from the data. Crouch and McKenzie¹⁸ described the utility of small sample sizes in qualitative research and asserted that the essence of an experience could be gleaned with fewer than 20 participants. Smaller sample sizes also offer participants and the researcher an opportunity to produce in-depth inquiry into the nature of their particular situation.

Purposive sampling is deliberate, but not random.²¹ Cases are selected because they are typical of the unique phenomenon under study. Purposive sampling is appropriate for phenomenological work because probability sampling for inferential statistics and generalization are unnecessary. Basic ethical principles of autonomy, confidentiality, beneficence, and justice were also preserved as the informed consent process was implemented after obtaining Duke University Health System institutional review board approval.

Characteristics of Research Study Participants

Study participants consisted of 5 females and 6 males ranging in age from 18 to 79 years, with a mean of 53 years and median of 51 years. Participants were interviewed between 1 and 18 months after development of the DVT. Two participants were interviewed at 2 months after development of the DVT, 2 were interviewed at 9 months, 2 were interviewed at 18 months, and 1 participant was interviewed at each of 1, 3, 4, 13, and 14 month(s).

Participants also had varying health conditions that necessitated PICC insertion and infusion therapy. Four participants received a PICC for chemotherapy as part of the treatment for nephrologic, gynecologic, and hematologic cancers. Four participants received a PICC to treat infections, 1 participant received a PICC to receive parenteral nutrition, 1 received a PICC to treat a cardiac rhythm abnormality, and 1 received a PICC to treat hemodynamic instability for blood pressure support after a major trauma.

This sample is largely representative of the major indications for PICC placement. The only major use for PICCs that was not represented by this sample was ongoing pain management therapy when needed in patients with poor vascular access.

The time from DVT diagnosis to study enrollment ranged from 1 to 18 months with a mean of 8.5 months and a median of 9 months. Sixty-eight potential participants met the inclusion criteria; 10 of those potential participants were deceased by the time the study began. The remaining 47 potential participants either declined to participate or did not respond to the mailing.

Data Collection and Analysis Process

Data collection consisted of audiotaped narrative, semi-structured interviews with 11 participants. Several of the participants asked whether the interviews could take place over the telephone, and others expressed concern about the distance they would have to travel to participate. As a result of the inquiries, the study was amended to allow for telephone interviews and payment for participant time, travel, and parking. Eleven participants were enrolled, and 9 of the 11 elected to participate exclusively by telephone.

The audiotaped interviews were transcribed verbatim within 14 days of the interview. Both the audiotape and the written transcriptions were used simultaneously and then periodically to analyze the data using an inductive approach. The transcripts were double-spaced, and each statement was reviewed and coded to the research questions as either a *perception*, a *depiction of the patient's lived experience*, or an *expression of meaning*. Field notes taken during the interviews and while reflectively writing during analysis were used to denote voice tone and context, which were implied but not explicitly stated. The notes were added to the transcription margin for reference.

An inductive approach was used that employed Ricoeur's hermeneutic arc⁷ to reflect back and forth from the text, the context, and the research questions to uncover subthemes

at a higher level of abstraction than originally stated by the participant. The unique and poignant experiences of each of the participants were grouped in subthemes within the individual interviews. Once data collection and analysis of the individual interviews were completed, a careful review of the subthemes by the researcher resulted in 3 emergent overarching themes that elucidated the meaning of the lived experience of PICC-related DVT for the participants. The analysis was validated by another nurse-researcher qualified in qualitative methodology.

FINDINGS AND INTERPRETATION

A loss of trust in health care providers, an additional burden to existing problems, and a yearning for understanding were the themes that were found embedded in the rich, thick descriptions provided by the data. Each of the themes offers a unique perspective of the experience, when interpreted from the context of PICC-related DVT. Table 1 proves exemplars of each theme. The distribution of theme frequency is included in Table 2.

Theme 1: Loss of Trust in Health Care Providers

Trust is foundational to healthy and mutual interpersonal relationships. The relationship between health care providers and patients is based on ethical principles that assume an active diligence to ensure beneficence.²² Much as ethical principles undergird practices for conducting research, fostering interpersonal relationships with patients based on mutual trust is a basic ethical principle for clinical practice that reflects the health care provider's duty to act in the best interests of the person being served.²³ Trust is multifaceted, and each individual comes to the relationship with preconceived ideas and expectations that complicate health care relationships, which are often hindered by their short duration and increasing pressures for throughput and efficiency in organizations. Participant P2 described the loss of trust in health care providers as a result of his experience of PICC-related DVT when he said: "They didn't advise me that it was one of the things that could happen. Evidently, it happens more than what I understood."

He went on to describe a lack of education and inconsistent information as components of that lack of trust. He stated:

They don't give you any education when you get the catheters, as far as things you need to do to avoid the blood clot. I was told the second time I received a PICC to go ahead and get up and be more active with my arm during the process of the time the PICC was in there. But nobody bothered to mention that to me until after I had the blood clot. The one thing it changed in me a lot was the confidence I had in ... [the hospital]. Truthfully, that's the only bad experience I've had in the hospital since I've been there.

Pearson and Raeke²³ described the difference between interpersonal relationships in health care and social normative relationships. In the context of this study, there were both interpersonal relationships with health care providers with trust that develops over time and social normative relationships in which the participant had preconceived ideas of how health care providers should act and perform their duties. The findings of this study revealed concerns from patients that act as barriers to trusting relationships in the health care context. Participants noted suspicions that mistakes were made in the device-ordering process, wondering whether another device would have been less likely to cause complications. They also noted inadequate communication and education that acted as barriers to trust.

Lee and Lin²⁴ hypothesized that diabetic patients who reported higher levels of trust in health care providers also would demonstrate more belief in their ability to accomplish self-care related to their diabetes. The authors defined this positive belief as self-efficacy. The authors further hypothesized that improved self-efficacy would have a positive influence on outcomes related to blood sugar levels, body mass index, and other diabetic complications. Their correlational study of 480 adult patients revealed a positive correlation between perceptions of trust and positive outcomes for these patients.

In the context of PICC-related DVT, eroding trust between patients and providers has the potential to negatively influence self-efficacy and health behaviors that include future encounters with the provider. By taking action to better inform patients and reduce DVT risk, trust can be engendered. Based on responses from participants in this study, self-efficacy was deemed an important part of daily life, and having developed the complication of PICC-related DVT undermined this. Participant P3 described the loss of self-efficacy that eroded her trust in providers when she said:

I lived alone for 12 years after my husband passed away, did everything for myself, was very active in church, went to water therapy 3 times a week, flew up here by myself in December and a week later couldn't walk, step—couldn't do anything for myself.

That is debilitating, physically and mentally. It's pretty much made me housebound.

Waljee and colleagues²⁵ used multiple logistic regressions to test correlations between patient satisfaction and trust in their surgeons when complications associated with breast reconstruction surgery occurred. Patients who experienced breast asymmetry postoperatively expressed mistrust in their surgeon, regretted their decision to have surgery, and felt they had been underinformed. Patients who experienced the complication of breast asymmetry also had a higher incidence of other complications. The findings of Waljee and colleagues' study²⁵ suggested that health care complications do erode trust between patients

TABLE 1**Exemplars Representing the Study's 3 Themes**

Theme	Exemplars Representing Each Theme
Theme 1 Loss of trust in health care providers	<p>I don't know if, I mean, they cause clots because ... I don't know if they flush them enough maybe? But I believe, I don't think it was flushed enough.</p> <p>So, when they removed it, and this is how they explained it to me. When they removed the PICC line, there could be some, you know a clot, a blood clot on the tip of the PICC line so when they remove it, it dislodges and now you have a blood clot in your arm.</p> <p>So back then, this was the first time I ever experienced it, I was adamant about even when I was at _____ [hospital], I knew ... make sure you flush that good.</p> <p>The pain in my side, I could not breathe. I thought they cracked a rib or something on the operating table. I don't know every time I tried, I could not breathe.</p> <p>Thirty minutes there that one time, they kept giving me oxygen and all that.</p> <p>I didn't know what to think, really. All I know I started hurting, but it's really sad if that's what it was. I guess that's what it was.</p> <p>Well I noticed with me, my arm was hurting. So, I was the one that brought it to their attention.</p> <p>It seems to be if that was an issue with the blood clots with the PICC then they should have been giving me something at the same time to make sure that I didn't have that blood clot. I'd have much rather gone through taking the shot or something to avoid the blood clot for 5 days [while] I was in the hospital than doing it for 90 days after that.</p>
Theme 2 Additional burdens to existing problems	<p>I had practically no use of my shoulder. In fact, I had surgery for a fall in October, 3 years ago. On the right arm ... so I have very limited use of my right arm and used my left arm a lot to facilitate the right arm. And my left arm got to where I couldn't use it at all. I still don't have real good use of it. The left arm has been injected because of the PICC line. I still have a lot of pain in that shoulder under the shoulder blade in the back seems like. It was almost like I was paralyzed from the shoulders down.</p> <p>I don't know because when it comes to home health I only have 9 weeks. I think I got about 6 more weeks left. Uh, when I was at _____ [hospital] a couple of weeks ago, they asked me would I be interested in getting my own machine, so I can check my INR myself. So, if they get that then, I guess I'll keep doing it and reporting the results—how it is.</p> <p>The PICC line did cause some clots but, you know, eventually I had to have a second surgery to put the IVC filter in, I had to have that in for 6 months I think and then they removed that, I mean, I told you I left the hospital with a very swollen sore arm. That left arm was swollen, after they removed that PICC line it was swollen for 6 months.</p> <p>Oh yes, oh my God, I mean, all kinds of stuff. In the hospital after ... the PICC line location was in my left arm around my biceps and they were giving me morphine patches, I mean my arm, my left arm was so sore for 3 months they treated that arm alone. Along with pain medications, were morphine patches to try to ease the pain. I was in the hospital for 3 months. I was released and I still fought with that arm for probably 3 months after being released from the hospital.</p>
Theme 3 Yearning for understanding	<p>I mean I think they were just trying to understand as well why the clot developed when I was already on blood thinner. That pretty much was the question. Well, I didn't understand why it developed if I was already on blood thinners. I assumed with the blood thinner already being taken that everything was fine. I can't understand why a blood clot still developed.</p> <p>Right, but now I remember after the surgery, one guy, I don't know if he was the doctor or ... I don't remember. Anyway, he come [sic] in the room and he said, "How much do you remember of this? How much do you remember?" And I said, "I remember you trying to put the needle in my arm." And he said, "I'll be back to talk to you," and he never come [sic] back. At that time, I didn't realize that I was having problems with my arm or anything.</p> <p>I went through a stage of getting ... is my arm going to be ... is this going to be it? Is it going to be that I gotta baby this arm from now on?</p>

Abbreviations: INR, international normalized ratio; IVC, inferior vena catheter; PICC, peripherally inserted central catheter.

and providers. They also suggested that having a complication increases the likelihood of other complications.

In the context of PICC-related DVT, the findings of Waljee and colleagues lead to concerns that patients who develop a PICC-related DVT may be at higher risk for developing other health complications. Although DVT is a known complication of PICC placement, many of the participants in this study felt they either had not been informed or had been underinformed of the risk. Participants felt the development of the DVT was an adverse event that occurred in the course of treating their underlying illness, which worsened their overall condition.

Duclos and colleagues²⁶ used focus group interviews to study 16 patients who had experienced an adverse event related to their health care. The findings of the study suggested that timeliness of communication about any adverse event positively influenced whether a patient continued the relationship with her or his provider after the event. Trust is perceived differently by each individual based on a person's expectations in her or his situated lived world,²⁷ and patients in Duclos and colleagues' study²⁶ deemed transparent communication about complications important.

TABLE 2**Theme Frequency Distribution**

Theme 1: Loss of Trust		Theme 2: Additional Burden to Existing Problems		Theme 3: Yearning for Understanding	
Participant	Number of Exemplars	Participant	Number of Exemplars	Participant	Number of Exemplars
P1	8	P1	6	P1	7
P2	3	P2	6	P2	2
P3	2	P3	9	P3	1
P4	2	P4	6	P4	3
P5	3	P5	7	P5	1
P6	1	P6	3	P6	1
P7	1	P7	4	P7	1
P8	5	P8	6	P8	4
P9	3	P9	4	P9	2
P10	3	P10	10	P10	2
P11	0	P11	5	P11	1
Total	31	Total	66	Total	25

In the context of PICC-related DVT, several of the participants in this study reflected that they wished they had been given more accurate and timely information after the DVT developed. Participant P5 reflected on being at home after her hospitalization with inadequate information regarding the DVT. She said:

It was scary, because, I mean, that is something that could go to my heart. It might come back. I'm constantly checking my body, over and over to see if I could see anything that might be a sign of a blood clot. And that is very tiresome.

Health care providers can believe they are protecting their patients by limiting the information they provide, but the findings of this study support timely and full disclosure of DVT development related to PICCs, and active follow-up after discharge, as an adjunct to facilitating trust.

Theme 2: Additional Burdens to Existing Problems

The theme of additional burdens to existing problems emerged from the data as participants described their experiences in terms of disruption to their daily routines, financial hardship, disruption of their ability to participate in pleasurable activities, long-term pain, alterations in self-care ability, fear for the future, and constant reminders of their illnesses.

All participants in the study shared a common trait. Each had a health care problem that necessitated placing a vascular access device for infusion therapy. Whether the therapy was parenteral nutrition, chemotherapy, antibiotics, or hemodynamic management, the underlying condition represented a stressful set of circumstances that influenced the participant's life world. The participants unanimously described the PICC-related DVT as an additional burden to

already-trying circumstances. Participant P1 described the additional burden this way:

It was just ... I play golf. I couldn't play golf if my arm was hurting. But I got to where I felt better. I went out and was going to [play golf]. The heart doctor said, just take your time and see what you can do. I played a few holes, but I couldn't get that arm to go round where you're supposed to. I couldn't play because of the ... well my health too, but my arm wouldn't let me pull my clubs around like I should have. And now, since it's just quit hurting, it's been ... I haven't played any golf, but I'm hoping to get back at it this summer.

Almost all participants cited additional financial burdens related to the DVT. Pharmacy copayments for long-term anti-coagulants were the most frequently noted financial burden in this sample. Anticoagulant treatment of DVT typically lasts for 12 or more weeks and requires twice-daily injections of unfractionated heparin (Lovenox) or warfarin therapy.² Pain associated with the injections, as well as disruption of business, family, and social routines to complete the injections, also added to the burden. In addition, the treatments themselves represented an additional emotional burden. Participant P2 described the financial and emotional burdens:

The fact that I was then going to have to go through 2 shots a day for the next 3 months in my stomach. It fouled up every possible schedule that we used to be on, because now I have to arrange to take a shot every 12 hours.

And the fact that we've got them scheduled morning and evening means that, for instance, this morning, I had to change an appointment until after the time that I had my shot. I had to reschedule my whole day based on the fact that I had to take a shot in the morning—had to get that taken before I could meet someone for breakfast.

For the simple reason, that [in] a lot of cases my wife is helping to give me the shot, so she has to be available as well. And the fact that we take it certain times of the day, as they instructed us to take it certain times of the day, then that makes it difficult for us to schedule dinner, meetings, and everything else. So, it is very cumbersome on the family. Financially, it just adds to another one of the co-pays on prescriptions that we are having to go through.

They've told me that I'm going to be taking these shots for 90 days. And at that point my doctor can decide if he changes that. So, my insurance company will not allow me to have that prescription for 90 days. They'll allow it to be done for 30 days, and then it has to be renewed. So, every 30 days, I'm paying another co-pay for insurance. In addition to that, I'm running to the drugstore and everything else every 30 days because of it.

Casais et al²⁸ studied 905 patients who received anticoagulation therapy for venous thromboembolism, atrial fibrillation, and postoperative mechanical heart valve replacement. The cross-sectional study was designed to determine patient perceptions of long-term anticoagulation on quality of life. The study's findings revealed that patients who were not satisfied with their medical attention and whose daily routines were altered as a function of the need for anticoagulation had negative perceptions about their quality of life.

Every patient in the current study required long-term anticoagulation as a result of a PICC-related DVT. Many of the participants also expressed dissatisfaction with the care they received and the alterations in their quality of life. The study lends support to the findings of Casais et al²⁸ and suggests that long-term anticoagulation is an additional burden to existing problems for patients. Based on this finding, it becomes clear that timely education and ongoing information are indelibly intertwined with patient perceptions of quality of care. Current literature validates this tenet as well.²⁹

Theme 3: Yearning for Understanding

A tentative hopefulness for complete recovery was a common subtheme of the yearning for understanding throughout participants' responses. According to Funk et al,³⁰ understanding is comforting and creates a sense of security for patients and families undergoing serious illness. Participants in this study yearned for understanding and exhibited a need to make sense of their experience. Participant P1 expressed this yearning for understanding, laced with tentative hopefulness for recovery, when she stated:

It made me mad. I don't know if I need to know or not, but yeah, yeah, I think I would have liked for them to tell me. I've been through enough.

I'm doing better. I still have problems, it is not all under control, but it is better. All in all, I think I'm good. But now it doesn't hurt, so I think it's going to be okay ... I don't know. I'm blessed to be alive.

Ljungberg et al³¹ studied the influence of education and peer mentoring on medical complications associated with spinal cord injuries. Patients who received education about potential complications and follow-up information about complications after they occurred were more likely to report improved self-efficacy, and also demonstrated fewer complications and medical visits. This quasi-experimental study revealed the relationship between communication and perceptions of self-efficacy, as well as the positive relationship between self-efficacy, perception, and complication reduction.

All of the participants in this study were already dealing with health care issues and illnesses that presented hardship, fear, and upheaval into their lives and the lives of their loved ones. In their experience, the complication of PICC-related DVT brought an additional burden to already-weighty circumstances. In listening to their stories, it seemed that a nebulous breaking point was approaching, and none was quite sure whether further complications might carry her or him to that point. Yearning for understanding arose from that unknown.

Over and over, participants described skepticism about the decisions made by providers in prescribing the PICC and disappointment at the lack of information they received regarding risks and benefits of the catheter. Participants also recounted the burdens—financial, emotional, physical, and relational—that resulted from having to live with the effects of the DVT. Their lived experiences left them with a yearning to better understand causation within the experience and to reflect on how the experience could have been different.

IMPLICATIONS FOR ORGANIZATIONAL LEADERS

Quality, patient satisfaction, efficiency, and sustainability are key variables in the equation for developing successful health care programs in today's marketplace.³² Although finance is just part of the equation when delivering quality care, financial stability empowers providers to innovate and is a considerable part of overall success.³³

In the context of this study, participants were often provided lifesaving treatments that resulted in deep gratitude. Even in the context of the patients' gratitude for what they received and perceived positively, there was disappointment related to developing the PICC-related DVT and the associated additional burdens. Leaders cannot take the negative perceptions of consumers lightly in the face of the changing health care landscape.³⁴ Every consumer of health care represents market share. The brand and financial sustainability of an organization are built on the perceptions of consumers.³⁵ The consequences of failing to take action to recover the patient experience when perceptions of quality are marred by complications can be disastrous, and firsthand knowledge of the experience is foundational to taking action.³⁶

Human Becoming

Using the theory of *human becoming*³⁷ as the framework for this study meant understanding Parse's basic tenet that the patient experience should inform every facet of nursing care. From the decision to use a PICC for the intended therapy to the selection of the device and the insertion site, this study's framework is founded on the presupposition that the patient has a right to participate fully in the entire plan. Holloway and Wheeler³⁸ described the innate vulnerability patients have merely as a result of their dependent role at times of acute illness. Today, clinicians and providers often tell patients they need a PICC without providing sufficient information about alternative therapies, alternative devices, or the risks of complications.³⁹ This assertion was supported by many participants' responses.

By practicing in this fashion, clinicians effectively stunt what Parse describes as the multidimensional interplay of the person with the environment to arrive at an optimal level of health as defined by the person.¹⁵ When providers deprive individuals of information or when the providers themselves are deprived of information regarding the outcomes of their clinical decisions, this rhythmic interplay of experience, feedback, and choice is seriously hampered. The study tenets are based on an assumption that patients are entitled to participate in their care and in the decisions that affect their care. For that reason, *human becoming* was an appropriate framework for this study of patient experience. The participants' experiences inform health care providers and leaders that patients expect not only to be listened to but also to be educated and engaged more fully in the decision-making process. Health care providers must help them *become*.

Recommendations for Practice

Infusion nursing as a specialty has a long-held tradition of leading the way to set standards for clinical practice in an area that until recently has had little formal attention or research. In many organizations, the provision of infusion therapy is delegated to generalist nurses as a part of the normal and routine functions of intravenous administration of fluids and medications, and withdrawing samples for laboratory testing.⁴⁰ Both the infusion nurse and the generalist nurse need to be armed with information about the influence of PICC-related DVT on patients' quality of life as they interact with the providers who order the vascular access devices. This information will help the team formulate and carry out a vascular access plan of care.

Going forward, this qualitative understanding of the meaning of PICC-related DVT and its influence on quality of life can be included in the evidence base. Until now, the patient's experience has influenced the *Infusion Therapy Standards of Practice*⁴¹ in general assertions that patients should be educated and that teach-back methods should be used to ensure understanding.

Practical recommendations to bridge the communication and education gaps that are represented by these

findings include the following: formation of a standard scripted assent process, standard preinsertion and post-DVT development education for patients and families, collaboration between the prescriber and the infusion nurse to determine the optimal device for the patient's infusion needs, and post-DVT follow-up before and after discharge.

Minimally, patient and family education should include written and verbal teaching for the indication for the PICC; potential complications, including thrombosis; as well as alternative devices and their risks and benefits compared with PICCs.

The creation of a standard assent form that cues the nurse performing the insertion to ask questions and assess the patient's comfort level with understanding the risks, benefits, alternatives, and care procedures can help engender trust and facilitate strategic communication between the inserter and the prescriber. In this context, the nurse performing the insertion would engage the patient in a discussion of the assent items and contact the prescriber should the patient express reservations or a lack of understanding. Standardized assent information and scripting could reduce any variation in information and engender trust.²²

Active efforts to uncover preconceived ideas about health care providers' roles in decision making and standardizing information and training among health care team members can also play an important role in establishing and maintaining trust.

Understanding that PICC-related DVT development creates another burden for the patient, in addition to existing problems, can inform expert vascular access nurses inserting PICCs to use extreme caution when assessing the need for a PICC, as opposed to another type of device. If the clinician inserting a PICC is never faced with the experience of a PICC-related DVT from the patient's perspective, the risks of complications can perceptually become numbers rather than unique and emotion-filled experiences that influence everyday life. Armed with an understanding of the serious alterations to daily life that can occur with PICC-related DVT, the nurse can access other evidence-based resources to determine the best device with the lowest associated complication risk to meet the patient's infusion needs.⁴² In addition, once a DVT is diagnosed, assessment for assistance with financial support for needed medications and the potential need for counseling should be considered by the nurse and the provider. A social work consult may be necessary to explore postdischarge needs related to the sequela of the thrombus.

Additionally, an understanding that PICC-related DVT means a yearning for understanding can empower nursing to proactively engage in therapeutic communication to allow patients to voice their experiences and concerns. This understanding will also act as an impetus to actively engage patients and families after discharge to foster the information sharing that facilitates perceptions of security.⁴³

Based on the findings that participants yearn for understanding as they experience the influence of PICC-related DVT, it is recommended that providers actively look for opportunities to have follow-up conversations with patients who develop DVTs related to PICCs. The conversations should include information about the DVT, plausible explanations for causation, future prevention, treatment, and a mechanism for determination of eventual resolution. The creation of teaching sheets related to managing a DVT and providing a list of trustworthy electronic resources for information regarding DVT management can be helpful in meeting the need to understand.

Proactive DVT Prevention

Health care organizations spend significant portions of their fiscal budgets in procuring products and supplies to provide care. Many organizations use group purchasing organizations to leverage buying power and to obtain advantageous pricing for medical supplies. In this process, manufacturers will often bundle their products in a package and offer lower pricing. These processes and practices can be a barrier to organizations purchasing PICCs that provide the lowest risk of DVT development.

Decisions for product contracting and procurement are often made by people trained in contracting, and information about the patient experience may not be readily available to these groups. This study's findings reveal that patients who have developed a DVT related to a PICC expect that catheter thrombogenicity and DVT risk will be carefully considered along with costs when making procurement decisions.

STUDY LIMITATIONS

Qualitative studies are limited by a variety of factors, including the natural setting in which they occur. In this study, the majority of participants opted to participate via a telephone interview, which may have allowed them more freedom to answer the interview questions honestly and fully apart from the researcher's physical presence. However, telephone interviewing did limit the researcher's ability to assess body language and facial expressions during the interviews, and it could not account for the possibility of interruptions. These limitations were mitigated by listening intently and carefully, taking field notes of pauses as the participants reflected on a particular idea, noting changes in voice tone, and carefully capturing actual phrasing in the transcription of the data. Additionally, participants were allowed to schedule the telephone calls for their convenience.

No study can include the entire population, and this study is limited by the acute care setting in which it was performed.⁴⁴ The sample included participants who had developed a PICC-related DVT in a tertiary care setting, which could influence the experience of the participants. The sample of 11 participants represented 17% of the

potential participants who met the study's inclusion criteria. The portion of the sample who agreed to participate could have been influenced by their general level of health at the time of contact. Access to mail and telephone equipment also could affect individual ability to participate. The participants' physical distance from the acute care facility where the study was conducted acted as a limiting factor, as well. Participants who lived closer to the facility may have been more inclined to participate. The sample excluded children, but did include participants of varying ages and elapsed time from participants' DVT diagnosis to their interview about their experience.

In qualitative research in general and interpretive phenomenological research in particular, the researcher is a research instrument. The expertise of the researcher acts to enlarge the study rather than diminish it.⁴⁵ In this study, the researcher's expertise in the infusion nursing specialty and with the insertion, care, and maintenance of PICCs afforded an interpretive advantage.

This study also may have been limited by the rationale of the participants when they were deciding whether to participate. For example, the participants may have opted to participate as a way of repaying the hospital for taking care of them. Their responses could have been biased based on their feelings about their care. The study also may have been limited if there were participants who chose not to respond because they were too sick or too angry to do so.

RECOMMENDATIONS FOR FUTURE RESEARCH

There is significant research in the literature that offers insight into the incidence, economic burden, and risk factors associated with PICCs. However, there is limited information about the influence of complications associated with PICCs and the effect those complications have on patients' quality of life. Recommendations for future research include replication of this study in multiple settings with an emphasis on quality of life and self-efficacy measures to confirm the transferability of the findings.

In discussing the findings of this study with other vascular access and infusion nursing experts, it became apparent that the perceptions and attitudes varied widely. Hence, qualitative studies that describe the perceptions and attitudes of nurses who insert and care for PICCs, as those attitudes influence their practice, would be useful as well. It also would be valuable to use a correlational design to determine whether a relationship exists between levels of trust with health care providers and time to recovery from illness. If there is a correlation, a case could be made to improve mechanisms for fostering interpersonal relationships in the health care arena as an adjunct to quality outcomes.

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