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Major Article

What do patients say about their experience with urinary catheters and peripherally inserted central catheters?



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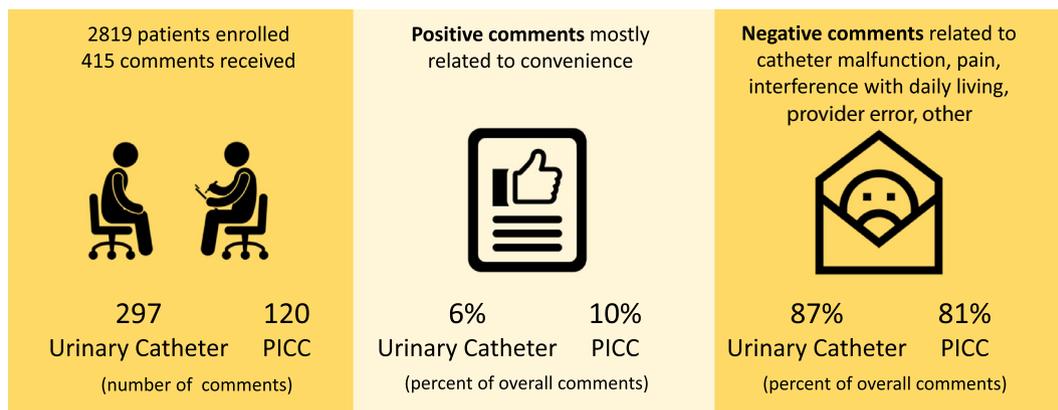
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Patient-reported Experiences with Urinary Catheters and Peripherally Inserted Central Catheters (PICCs)

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A B S T R A C T

Background: Little is known about the patient experience with urinary catheters or peripherally inserted central catheters (PICCs). We sought to better understand patient perspectives on having a urinary catheter or a PICC by reviewing open-ended comments made by patients about having either of these 2 devices.

Methods: As part of a larger study, we asked patients about certain catheter-related complications at the time of catheter placement and on days 14, 30, and 70 (PICCs only). In this larger project, we performed a structured assessment that included an open-ended question about other comments (initial interview) or problems (follow-up interview) associated with the device. For the current study, we conducted a descriptive analysis of these open-ended comments, classifying them as positive, negative, or neutral.

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Results: Positive comments about urinary catheters accounted for 9 of 147 comments (6%), whereas positive comments about PICCs accounted for 10 of 100 comments (10%). Positive comments for both catheter types were mostly related to convenience. More than 80% of comments about both types of devices were negative and fell into the following areas: catheter malfunction; pain, irritation, or discomfort; interference with activities of daily living; provider error; and other.

Conclusions: Our findings underscore the need to optimize the patient experience with placement, ongoing use, and removal of urinary catheters and PICCs.

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Indwelling urinary catheters and peripherally inserted central catheters (PICCs) are commonly used in U.S. hospitals. Both devices have specific therapeutic indications; however, they may also be used for provider or patient convenience. Inserting these devices is considered a minor procedure, usually performed by nursing personnel, although both types of catheters are also associated with a variety of potential complications (infectious and noninfectious).

Over the past several years, indwelling urinary catheters and PICCs have been the focus of numerous improvement initiatives to ensure appropriate use and to prevent device-related infections.^{1,2} Although these devices are critical for providing safe medical care, their potential complications extend beyond infections.^{3–6} Moreover, better understanding of the experiences of patients with these devices is essential for delivering safe, effective, patient-centered care.

Several qualitative studies have focused on the impact of living with a long-term, indwelling urinary catheter (either transurethral or suprapubic), often finding negative views associated with the device.^{7–11} Fewer studies have examined the perspectives of patients receiving indwelling urinary catheters during a hospital stay for short-term management, with somewhat mixed results. Quast et al, for example, found patients had generally positive perceptions, whereas Saint et al noted more negative experiences.^{3,12–14} However, studies that explore the patient perspective on having PICCs tend to report a more positive perspective.^{15–19} To our knowledge, no study has compared patient experiences involving both of these devices in a systematic way across multiple hospitals. Standard Press Ganey patient experience surveys (Press Ganey Associates, Inc, South Bend, IN) do not capture the experiences of patients with specific medical devices. Therefore, we conducted a descriptive analysis of patient comments associated with having an indwelling urinary catheter or PICC collected during a multicenter study of catheter-related complications, involving >2,500 hospitalized patients. This analysis helps us to better understand patient perspectives and identify whether additional efforts might be needed for enhancing the care and well-being of patients who receive these devices.

METHODS

Study design and data collection

We conducted a descriptive analysis of patient comments, which were collected as part of a prospective observational study of patients, who had an indwelling urinary catheter or PICC placed at 1 of 4 U.S. hospitals, between August 2015 and August 2017.^{3,4} The study enrolled patients with a catheter (urinary or PICC) placed during hospitalization and focused on device-associated complications as determined by patient self-report and medical record review. Each patient was enrolled following insertion of either a urinary catheter or a PICC, but could only be enrolled in 1 device group during the same hospitalization. Patients were asked about device-associated complications within 3 days after placement and during follow-up assessments at days 14, 30, and 70 (PICCs only), even if the device had been removed or the patient had been discharged, through brief, structured interviews conducted either in-person or by telephone. At the conclusion of each interview, the research coordinator asked if

the patient had any other comments (initial interview) or problems (follow-up interview) associated with the device that had not been discussed. This analysis focused on the comments volunteered by patients in response to this open-ended question; the reported results are therefore distinct from the published findings from the structured interview questions.⁴ The 4 study sites were 2 Veterans Affairs medical centers and 2 academic medical centers in Michigan and Texas. This project had Institutional Review Board approval at all sites.

Data analysis

The responses and comments of patients were recorded by the research coordinators. Some comments were recorded verbatim, whereas others were reported from the perspective of the coordinator, ie, “The patient reported that...” Two co-authors (JV and TR), neither of whom had been involved in data collection, classified each statement as positive, negative, neutral, or “exclude.” Positive comments referred to perceived benefits of patients having the urinary catheter or PICC, whereas negative comments referred to patients’ perceived problems with the device, including interference with daily activities, malfunction, discomfort, and provider error (on insertion or removal). If a single response had both positive and negative components, these were counted as a response in each category. An example of a neutral comment was, “Everything is normal, no issues.” The exclude category was used for comments that were either off topic or discussed a condition that was not related to presence of the urinary catheter or PICC. For example, “Still has very little energy, which was said to be as a result of a prolonged recovery from the staph infection,” fell into the exclude category. Categorizations were checked by the lead author (BWT) and another co-author (KEF), independently. The entire research team reviewed and resolved any discrepancies in classifications. In addition to classifying the comments, we used an iterative process involving multiple team members and discussion by the full study team to group the comments about each type of catheter by topic.

RESULTS

We enrolled 2,819 patients into the overall study; 2,276 with indwelling urinary catheters and 543 with PICCs. From these patients, we received 415 responses to the open-ended invitation to discuss “other complications.” Two of these comments had both a positive and a negative component, leading to 297 urinary catheter and 120 PICC-related comments. After excluding irrelevant comments, positive comments by patients about their urinary catheters accounted for 9 of 147 comments (6%), whereas positive comments about PICCs accounted for 10 of 100 comments (10%). More than 80% of comments about both types of devices were negative (87% for urinary catheters and 81% for PICCs). Because there were so few positive comments, all of these are presented in [Table 1](#), whereas a representative selection of the negative comments appears in [Table 2](#).

Topics arrived at by consensus upon review of all patient comments were convenience; catheter malfunction; pain, irritation, or discomfort; interference with activities of daily living; provider error;

Table 1
Positive comments about urinary catheters or PICCs (all)

Topics	Urinary catheters	PICCs
Patient convenience	<ul style="list-style-type: none"> • Because of his urgency issue at night, he wishes it was still in. He is having to wake up all night, stand up, and use the urinal. With the catheter, he would be able to sleep at night. • He also said that it was a relief to have the catheter right after the surgery so he didn't have to worry about having to use the bathroom or a urinal. • I used to wear a diaper and change it 5 times a day. The catheter is nice to have. 	<ul style="list-style-type: none"> • The PICC was very nice to have, it was better than having an IV. • Actually the patient misses having the PICC line. Has been stuck many times due to treatments and would rather have the PICC line. • I much prefer having a PICC line over peripheral IV's. • It seems to be functioning well, I have not had any problems. It's great to have it in. • No, but I like it so far, I want another one when I come back in, in 2 weeks. • They had to readjust it, but it's working pretty good. It was about an hour-and-a-half procedure. This PICC is saving my life. • Some nurses had trouble drawing blood out of PICC, otherwise convenient for receiving drugs. • Everything ran smooth, I healed, and it was a good experience. • It's better than getting stuck all the time, it's the greatest invention since sliced bread. • It's convenient, better than getting poked all the time.
Catheter malfunction	None	None
Pain, irritation, discomfort	None	None
Activities of daily living	None	None
Provider error	None	None
Other	<ul style="list-style-type: none"> • I liked the catheter, it was my first one. • Everything went pretty good. • It's been perfect, it's the same catheter. • This is the first time I ever had one, but everything turned out great, it was a good experience. • It was my first experience with a catheter, it wasn't too bad. • Feels like I am urinating better now. 	None

IV, intravenous; PICCs, peripherally inserted central catheter.

and other. Most positive comments about either type of catheter were related to convenience (Table 1). Specifically, for urinary catheters, patients appreciated the freedom from diapers, urinals, or trips to the bathroom, particularly after surgery, "I used to wear a diaper and change it 5 times a day. The catheter is nice to have." Similarly, patients appreciated PICCs for bringing relief from peripheral IV placements and blood draws, "It's better than getting stuck all the time, it's the greatest invention since sliced bread." A few positive comments on urinary catheters fell into the other category, including the statement that 1 patient felt the experience of being catheterized had improved his ability to urinate after removal, "Feels like I am urinating better now."

The negative comments were more varied in content and covered a range of topics (Table 2). Urinary catheter malfunctions mentioned by patients included leaks, "Hose had a few cracks in it, so it would leak everywhere," as well as improper positioning leading to poor drainage. One patient went to great lengths to ensure that his catheter would drain, "The patient hangs upside down to move the catheter so that it will drain. He hangs for a few seconds, and when he turns upright, it drains properly." Comments in the pain, irritation, and discomfort category for urinary catheters focused on actual pain, "It hurt going in and coming out." In contrast, PICC-related comments in this category more often mentioned itching and irritation at the catheter insertion site, "Although not really a problem, I do have to stop myself from scratching around it when it gets itchy." Both device types interfered substantially with activities of daily living for some patients; urinary catheter patients cited difficulty turning in bed or walking, whereas PICC patients mentioned problems with dressing or showering. Patients mentioned provider errors upon insertion and removal of both types of catheters, some with serious consequences. One urinary catheter patient was left with a false passage after a botched insertion, and the metal skin securement hooks of the type of PICC used at 1 site led to painful and failed removal attempts.

Similarities between the positive and negative comments from patients on both types of devices, organized by topic area, are shown in Table 3.

DISCUSSION

Urinary catheters and PICCs are generally placed to facilitate the delivery of medical care. Overall, the patient perspective on having either type of these medical devices is more nuanced than previously appreciated. Although the wording of our open-ended question on follow-up calls tended to solicit responses about problems related to having one of these devices, patients also identified some positive aspects of their experiences. For example, an unexpected finding was that some patients appreciated the convenience of having a urinary catheter, particularly those who were recovering from surgery or those with underlying voiding difficulties. Patients with PICCs similarly appreciated the relief from IV placement and needlesticks for blood draws, when the PICC was functioning properly. Both types of devices, however, also resulted in pain and discomfort and interfered with daily living. Likewise, the comments from patients clearly articulated certain challenges from the patient perspective upon both device insertion and removal.

Patients' comments about both urinary catheters and PICCs spanned a number of topic areas. Prior literature about patients with both types of catheters has generally focused on patients with long-term device use, and these reports suggest that the experiences of patients can change after a period of initial adaptation.^{11,15} In contrast, our findings highlight specific issues for patients who had just received new devices, and for those with urinary catheters generally for short-term use. In addition to concerns related to pain and discomfort and how the device negatively impacts certain daily activities, many patients mentioned errors that were made by the health care provider both upon device insertion and removal. For example, 1 patient with a urinary catheter stated that he, "experienced great pain, level 10, with the catheter removal. ...the nurse pushed the catheter further into his bladder while trying to remove it, and she had to have a doctor remove it." A patient with a PICC also had a traumatic removal, "The doctor didn't know how to remove the new PICC line catheters. He caused the patient pain, level 6, and bruising. ...The doctor had to go find someone who could take out the PICC line."

Table 2
Negative comments by patients about urinary catheters or PICCs (selected)

Topics	Urinary catheters	PICCs
Patient convenience	None	None
Catheter malfunction	<ul style="list-style-type: none"> • The Pt stated that the catheter sometimes drains slowly and pressure builds up in his bladder and causes him pain. Turns out, the bag wasn't low enough, so the tube wasn't draining. • The Pt stated that the leg bag is too small, so it doesn't hold enough. The catheter is also leaking. The Pt stated that he wasn't given any instruction on how to handle a leak, so he looked up information on the Internet. He is having to use adult incontinence products because of the leaking catheter. 	<ul style="list-style-type: none"> • The PICC line flushes okay, but the nurse/doctor is not able to draw blood from the PICC line so the patient is still having to endure blood sticks. • The PICC line began bleeding spontaneously. No obvious preceding event as participant was sitting watching TV at home. • Pt stated that his PICC line fell out while he was asleep.
Pain, irritation, discomfort	<ul style="list-style-type: none"> • It hurt going in and coming out. • Pt states "It hurt so much." Wishes he never had the thing in the first place and wishes to never have one again. Would like to know why a catheter was ordered for him since he had no problem urinating in the first place. • When it was in, it was really uncomfortable. 	<ul style="list-style-type: none"> • Pt stated that the home health nurse used a stronger PICC line bandage which caused his skin to get red and irritated. • Although not really a problem, I do have to stop myself from scratching around it when it gets itchy. • Pt was allergic to glue on the dressing, so skin was irritated initially and PICC kept coming out a little bit each time the nurses changed the dressing. • Very uncomfortable to have something sticking out of your arm for over a month. • Bruised and a little swollen where midline was placed. • Area where PICC was placed is numb. • He has been out of the hospital a few days and his entire arm is swollen and his shoulder is bruised.
Activities of daily living	<ul style="list-style-type: none"> • Pt found the catheter to be extremely uncomfortable especially while sleeping. Couldn't turn over well. Felt it was getting caught and tugging which caused discomfort. • Had trouble with catheter pulling every time I moved and there was nothing I could do about it. • Made it difficult to start walking after surgery. 	<ul style="list-style-type: none"> • Arm hurts so bad, can't use left arm, can't put on a bra • I can't get it wet so I have difficulty taking showers. It's not easy to deal with. • It's just annoying that it's there, I have to be careful when taking showers and doing other activities. It hurts from time to time.
Provider error	<ul style="list-style-type: none"> • When the nurse placed the second catheter, he did not use gloves. I have a urinary tract infection, and other problems with the catheter. • The operating room nurse created a false passage when trying to insert the catheter. • When they removed it, they had a problem getting the balloon to deflate. 	<ul style="list-style-type: none"> • During this last insertion the nurse had a lot of difficulty placing the PICC. A doctor was called to attempt to place it, but they could not successfully insert the PICC. • The PICC line was removed after X-ray showed that the tip was in the lower neck. • Pt stated that the home health nurse coming to his house doesn't seem to know how to dress the PICC line. The gauze is always rolling up, and they have to come out and re-dress it. • The only complications I had was when the nurse tried to take the PICC out and was not able to, and I had to go to the emergency room to have them take it out. • Patient stated that his home health nurse said that the PICC line removal is a little more complicated now. The metal anchors at the end require the line to be removed by someone who is trained in removing this new type of PICC line. • Patient stated that the doctor didn't know how to remove the new PICC line catheters. He caused the Patient pain, level 6, and bruising. The Patient stated that her arm hurt for 2 days, and the doctor had to go find someone who could take out the PICC line. • The scab where the PICC entered the skin has not healed yet. • Never want to have another PICC line again. • If the hospital had better PICC covers or protection, that would be great. If they had better cotton elastic bands to go over the PICC, that would help because the one I have is terrible. • The ability to keep it covered is a problem. The cover they gave me does not work and I try different things to keep it covered up. It's really difficult. • Every time I get my antibiotics, I can feel it right in the center of my chest. It stays with me for about 30 minutes after the antibiotic is complete.
Other	<ul style="list-style-type: none"> • Since having the catheter removed, I am getting up every 1–2 hours at night to urinate. This was not happening prior to the catheter. • Pt stated that for the first 2 weeks after the catheter removal, she had issues with her urinary stream stopping and starting. It is back to normal now. • Pt stated that he noticed his urine had a foul smell 1 week after the catheter was removed. He has had a urinary tract infection before, and he recognizes the smell. 	

PICCs, peripherally inserted central catheters; Pt, patient.

Another salient theme in the literature on patients with long-dwelling catheters (both urinary and PICCs) is that patients are not told what to expect nor given adequate information about how to perform self-care with the catheter in place.^{8,15} We also saw this unmet information need in our patients, such as the patient with the leaking urinary catheter who sought information on the Internet about how to handle the leak, and the patients who tried multiple approaches to keep their PICCs covered. In agreement with previously published literature, the selection of which patients receive these devices is done by the provider, with little input from the patient.¹⁵ Our patients' comments suggest that the patients hope to play a more active role in deciding whether they receive such devices in the future, "Never want to have another PICC line again." We received a similar comment from a patient who had a urinary catheter, "I never want another Foley catheter." However, patients may not have much say in whether they receive a urinary catheter, as urinary catheters are generally placed without a formal consent process. In certain situations, the patient may not be aware that the catheter is being placed (particularly if placed in the operating room), as noted

by a patient, "He didn't know he was going to have a catheter." Although PICC placement requires patient consent, the consent process focuses on the insertion process and relevant complications. In neither case is the patient generally advised about what to expect after the device is in place. This information gap represents an opportunity for both physicians and nurses to provide device-related, patient-centric education during device insertion, maintenance, and removal activities. Time spent on educating patients about what to expect may, therefore, lead to improved patient satisfaction scores and fewer readmissions for device complications.

The main limitation of our study is that the comments from the patients during the follow-up assessments were in response to a question about other problems. This phrasing by design was intended to surface additional complications given the focus of the study. Interestingly, this question seemed to prompt comments that were also positive. Nonetheless, patients who did not respond to this last open-ended interview question may have had nothing they considered a problem, whereas the patients who did respond may have had stronger feelings about the indwelling device or may have been more

Table 3
Comparative subtopics for comments about urinary catheters and PICCs

Topic	Urinary catheter subtopics	PICC subtopics
Patient convenience	<ul style="list-style-type: none"> • Decreased need to get to the bathroom • Management of incontinence 	<ul style="list-style-type: none"> • Better than having an IV • Decreases needle sticks
Catheter malfunction	<ul style="list-style-type: none"> • Leaking • Slow drainage 	<ul style="list-style-type: none"> • Unable to draw blood • Bleeding • Dislodgement • Itching
Pain, irritation, discomfort	<ul style="list-style-type: none"> • Pain on insertion • Pain while wearing • Pain on removal 	<ul style="list-style-type: none"> • Irritation from dressings • Uncomfortable • Bruising • Swelling • Numbness
Activities of daily living	<ul style="list-style-type: none"> • Impaired sleep • Impaired mobility 	<ul style="list-style-type: none"> • Impairs use of arm • Hard to shower • Gets in the way of activities
Provider error	<ul style="list-style-type: none"> • Improper technique upon placement (with consequences of urinary tract infection and false passage) • Improper technique upon removal (balloon deflation) 	<ul style="list-style-type: none"> • Improper technique upon placement (failed insertion, tip in wrong place) • Unable to dress PICC line properly
Other	<ul style="list-style-type: none"> • Change in urinary patterns • Suspected UTI 	<ul style="list-style-type: none"> • Improper technique upon removal (skin securement hooks) • Scab at PICC site • Dressing/cover issues • Sensation of antibiotic infusion

PICCs, peripherally inserted central catheters.

outspoken in general. However, all patients who enrolled in this study were competent to provide informed consent, and the research coordinators presented the interview questions uniformly across all study sites and to all patients interviewed. The main strength of our study is that what the patients told us provides a snapshot into their daily experience with a urinary catheter or PICC, which is a perspective rarely captured in the hospital environment or after hospital discharge through standard measures of patient experience, such as Press Ganey surveys.

CONCLUSIONS

Our prospective study has important clinical implications. Medical devices such as urinary catheters and PICCs are often essential to delivery of modern medical care. However, health care providers may not consider the impact these devices will have on patients, and patients receive inadequate preparation for what to expect during device placement, while the device is in place, and during device removal. Our findings reinforce the importance of placing these devices only when medically necessary, and not for convenience of the health care team. Patients should have a voice in the discussion of device necessity and anticipated removal. Both providers and patients are often unprepared for the difficulties of catheter insertion or removal. Future efforts to improve the experience of those requiring catheters appear necessary.

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