To understand the vulnerability of patients with cancer to central line-associated bloodstream infections related to tunneled central venous catheters (CVCs), patients were asked to describe their line care at home and in clinic and to characterize their knowledge and experience managing CVCs. Forty-five adult patients with cancer were recruited to participate. Patients were interviewed about the type of line, duration of use, and observations of variations in line care. They also were asked about differences between line care at home and in clinic, precautions taken when bathing, and their education regarding line care. Demographic information and primary cancer diagnosis were taken from the patients’ medical records. Patients with hematologic and gastrointestinal malignancies were heavily represented. The majority had tunneled catheters with subcutaneous implanted ports. Participants identified variations in practice among nurses who cared for them. Although many participants expressed confidence in their knowledge of line care, some were uncertain about what to do if the dressing became loose or wet, or how to recognize an infection. Patients seemed to be astute observers of their own care and offered insights into practice variation. Their observations show that CVC care practices should be standardized, and educational interventions should be created to address patients’ knowledge deficits.
Methods
Setting and Sample

Dana-Farber Cancer Institute, a Boston-based comprehensive cancer center that serves adult and pediatric patients with solid tumors and hematologic malignancies, was the study site. In 2012, more than 348,000 clinic and infusion visits occurred with 319 nurses and 407 faculty physicians. Adult patients with long-term CVCs who were treated on two chemotherapy infusion units from July to August 2012 were identified. A research assistant approached the clinical nurse coordinators on each unit every day for assistance identifying patients who were suitable for interview. Exclusion criteria included inability to communicate in English, anxiety or emotional upset, or being asleep.

Six of 53 potential participants were excluded. Of the remaining 47 patients, 45 agreed to participate after the research assistant described the purpose of the study and length of the interview. Although the project was conducted as an improvement initiative rather than a research study, the authors were careful to advise patients that participation was voluntary, that information they provided would not be shared with their care team without the patient’s permission, and that they could end the interview at any time. Interviews varied in length from 5–30 minutes. Patients’ responses were recorded manually and then entered into an electronic spreadsheet for analysis.

Instrument Development

Because the authors were unable to identify a suitable survey tool, an instrument was developed for eliciting information about CVC care from the patient’s perspective. The instrument was informed by a review of the literature and meetings with frontline nurses, infection control practitioners, and patient safety experts. Infection control practitioners and patient safety experts reviewed the instrument for face validity and pilot tested it on the study units. It used a semistructured format with follow-up prompts.

The survey queried patients about the type of line, duration of use, problems encountered, and observations about variations in line care. It asked patients to characterize differences between line care at home and in the clinic, and precautions taken when showering or bathing at home. It also asked patients to describe how they were educated about the care of their central line and to assess its adequacy. The patients rated their confidence in caring for the line and their knowledge about what to do if the dressing became loose or wet, and they were asked to describe signs of infection. The authors also abstracted information from medical records (e.g., age, gender, insurance, primary cancer diagnosis).

Data Analysis

The authors tabulated social, demographic, and clinical characteristics. Members of the project team reviewed the survey responses and categorized them thematically. Certain questions were inapplicable to particular patients, depending on the type of line they used. Patients’ responses were tabulated, and illustrative, verbatim comments were selected by category.

Results

Patient Characteristics

The median age of the participants was 50–59 years (see Table 1). More men than women participated in the study, and the majority had private insurance. The cohort consisted primarily of patients with hematologic and gastrointestinal malignancies, reflecting the composition of the clinical unit where the project was conducted. Thirty-six patients had surgically implanted catheters with subcutaneous implanted ports (i.e., port-a-cath), including 13 whose catheters were accessed for home treatment or supportive care. The remainder (n = 9) had either surgically implanted cuffed tunneled CVCs (i.e., Hickman line) or peripherally inserted central catheters (PICC). Fourteen patients had a previous central line for cancer treatment.

<table>
<thead>
<tr>
<th>TABLE 1. Sample Characteristics (N = 45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>Less than 40</td>
</tr>
<tr>
<td>40–49</td>
</tr>
<tr>
<td>50–59</td>
</tr>
<tr>
<td>60–69</td>
</tr>
<tr>
<td>70 or greater</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Insurance type</td>
</tr>
<tr>
<td>Private</td>
</tr>
<tr>
<td>Medicare</td>
</tr>
<tr>
<td>Medicaid or self-pay</td>
</tr>
<tr>
<td>Government</td>
</tr>
<tr>
<td>Disease type</td>
</tr>
<tr>
<td>Lymphoma</td>
</tr>
<tr>
<td>Colorectal</td>
</tr>
<tr>
<td>Leukemia</td>
</tr>
<tr>
<td>Pancreatic</td>
</tr>
<tr>
<td>Myeloma</td>
</tr>
<tr>
<td>Gastric, esophageal, or biliary tract</td>
</tr>
<tr>
<td>Brain tumor</td>
</tr>
<tr>
<td>Myelodysplasia</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Type of central venous catheter</td>
</tr>
<tr>
<td>Port-a-cath with no home access</td>
</tr>
<tr>
<td>Port-a-cath with home access</td>
</tr>
<tr>
<td>Hickman</td>
</tr>
<tr>
<td>Peripherally inserted central catheter</td>
</tr>
<tr>
<td>Number of months since line placement</td>
</tr>
<tr>
<td>0–2</td>
</tr>
<tr>
<td>3–6</td>
</tr>
<tr>
<td>7–12</td>
</tr>
<tr>
<td>13–24</td>
</tr>
<tr>
<td>25 or greater</td>
</tr>
<tr>
<td>Previous central line</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>
**Practice Variation and Concerns**

Most patients observed more similarities than differences in the way that clinicians cared for their central line. A patient with a port-a-cath said, “I wouldn’t say that they were all identical to each other, but ultimately they all cover the same requirements: flushing it, cleaning it, putting the needle in.” Another patient with a port-a-cath said, “I’ve only had it done a couple of times, but it seems pretty much the same. One [provider] might be a bit slower and another one a bit faster.”

However, 13 of the 45 respondents noted differences in how the clinician cleaned the hub, their familiarity with the device, their care in checking the location of the catheter, the use of dated labels on the line, the degree of care used to avoid hurting the patient, and staff members’ occasional frustration when the line did not work properly (see Table 2). One patient with a Hickman line said,

There are different techniques in the lab around how they clean it. Some people are very particular about keeping it clean, and others wipe it off very quickly. Other than how people clean and prepare it, everyone else sets it up the same.

A patient who had a port-a-cath with a home infusion pump said,

Today I had someone who cleaned it really well. She really got right in there. She put this sticker [with initials on it, placed just below the clamp] on too. See, [the neighboring patient with a port-a-cath] doesn’t have the sticker. Other times, people don’t clean it so well.

A minority of patients said that clinic or homecare staff cared for the line in a way that concerned them. Seven respondents noted a concern, including failure to clean or flush the line appropriately, failure to allow alcohol to dry, failure to use ethyl chloride topical anesthetic, pain, or concern about staff members’ ability to get the catheter to work. A patient with a Hickman line said,

It’s just some nurses that I’m not used to don’t scrub the cap properly, or [use mask and glove] when changing the dressing. Some scrub it hard, but others just give it a quick wipe. I like it scrubbed hard. I mean, it goes straight to my heart. Probably, like, a quarter don’t do it properly.

A patient with a port-a-cath said,

This was early on, maybe six months into it, the nurse forgot to flush it and I picked up on it. I usually get the smell and taste of it in my mouth, and that time I didn’t have it, so I asked her if she’d flushed it and she said she hadn’t. She fixed it up. That was one incident early on.

Another patient with a port-a-cath said,

One time I didn’t have the [ethyl chloride] spray. He said he didn’t do it that way. He had his reasons, and others have theirs. He said “I don’t use the spray.” I think it was because it exposes everyone in the room; it stays in the air for a while.

A patient with a port-a-cath said, “Oddly enough, there’s one person in the lab that never seems to be able to get it to work. I don’t know their name, and even if I did I wouldn’t tell you. It could just be chance.”

**TABLE 2. Survey Responses and Common Affirmative Responses (N = 45)**

<table>
<thead>
<tr>
<th>Questions and Responses</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Have you noticed that different people care for the line differently?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>25</td>
</tr>
<tr>
<td>No response or not applicable</td>
<td>7</td>
</tr>
<tr>
<td>• Some are quicker or do not clean the catheter as thoroughly.</td>
<td></td>
</tr>
<tr>
<td>• Some are slower and very careful about keeping it clean.</td>
<td></td>
</tr>
<tr>
<td>• Some are more experienced and try harder to get it to work.</td>
<td></td>
</tr>
<tr>
<td>• Sometimes it hurts more or staff worry about hurting you.</td>
<td></td>
</tr>
<tr>
<td><strong>Have you ever noticed anything about the way staff cared for your line that you were concerned about or thought was unusual?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>38</td>
</tr>
<tr>
<td><strong>How did you learn about what to do at home?</strong></td>
<td></td>
</tr>
<tr>
<td>Some kind of teaching</td>
<td>13</td>
</tr>
<tr>
<td>Was not taught</td>
<td>7</td>
</tr>
<tr>
<td>No response or not applicable</td>
<td>25</td>
</tr>
<tr>
<td>• Nurse demonstrated how to do it.</td>
<td></td>
</tr>
<tr>
<td>• Written material</td>
<td></td>
</tr>
<tr>
<td>• Nurse demonstrated, and patient repeated.</td>
<td></td>
</tr>
<tr>
<td>• Patient taught partner(s) or family member(s).</td>
<td></td>
</tr>
<tr>
<td><strong>If the dressing became loose or open on one side before it was scheduled to be changed, what would you do?</strong></td>
<td></td>
</tr>
<tr>
<td>Would do something</td>
<td>21</td>
</tr>
<tr>
<td>No response or not applicable</td>
<td>24</td>
</tr>
<tr>
<td>• Call the center.</td>
<td></td>
</tr>
<tr>
<td>• Put tape on it.</td>
<td></td>
</tr>
<tr>
<td>• Depends on the timing of next scheduled appointment</td>
<td></td>
</tr>
<tr>
<td>• Depends on how open it was</td>
<td></td>
</tr>
<tr>
<td>• Call the homecare company.</td>
<td></td>
</tr>
<tr>
<td>• Go to the cancer center.</td>
<td></td>
</tr>
<tr>
<td><strong>What do you do when showering or bathing at home?</strong></td>
<td></td>
</tr>
<tr>
<td>Use something to cover it.</td>
<td>16</td>
</tr>
<tr>
<td>Do not shower or bathe.</td>
<td>6</td>
</tr>
<tr>
<td>Try to avoid it or wash around it.</td>
<td>4</td>
</tr>
<tr>
<td>No response or not applicable</td>
<td>19</td>
</tr>
<tr>
<td><strong>Do you know what symptoms might be present if your line was infected?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>31</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td>No response or not applicable</td>
<td>1</td>
</tr>
<tr>
<td>• Fever</td>
<td></td>
</tr>
<tr>
<td>• Redness</td>
<td></td>
</tr>
<tr>
<td>• Pain, discomfort, or irritation</td>
<td></td>
</tr>
<tr>
<td>• Swelling</td>
<td></td>
</tr>
<tr>
<td>• Drainage or leakage</td>
<td></td>
</tr>
<tr>
<td>• Low energy, losing energy, or brain stops functioning</td>
<td></td>
</tr>
<tr>
<td><strong>What do you find is the most difficult part about caring for your line or having a line?</strong></td>
<td></td>
</tr>
<tr>
<td>At least one problem</td>
<td>28</td>
</tr>
<tr>
<td>No problems</td>
<td>17</td>
</tr>
<tr>
<td>• Sleeping</td>
<td></td>
</tr>
<tr>
<td>• Getting up and forgetting that it is attached</td>
<td></td>
</tr>
<tr>
<td>• Showering or bathing</td>
<td></td>
</tr>
<tr>
<td>• Getting bumped by young children</td>
<td></td>
</tr>
<tr>
<td>• Dislike the look of it</td>
<td></td>
</tr>
<tr>
<td>• Keeping it clean and remembering to flush it</td>
<td></td>
</tr>
</tbody>
</table>

Note. Respondents were allowed to choose more than one answer.
Patient Education

Patients described how they were educated about the care of their central line and assessed the adequacy of the education. Nineteen participants recalled learning what to do to care for the line at home from care providers at the cancer center, during a hospitalization, from a homecare provider, or from another source. Thirteen patients described the methods of instruction, including nurse demonstration, use of written materials, the patient teaching other family members after a nurse demonstration, and using a video. Multiple modalities often were employed.

A patient with a Hickman line said,

They instructed us a bit before we went home. They told us not to get it wet, and a bit on the technique how to flush it. Home care also showed [my family] the technical part of how to flush it.

One patient who had a port-a-cath with a home infusion pump said,

The first three times, I had it done here. The first time, they did it. Then I did part of it. Then I did all of it, with the nurse watching. They send you home with a sheet of paper with all the steps to do.

Most patients felt that the training was sufficient, but two respondents said that they were cautious at first. One of those patients with a Hickman line said, “Yeah, I mean, the first time was sketchy. You feel like you’re not doing it right, but you figure it out.” Another cautious patient who had a port-a-cath with a home infusion pump said, “They walked through it with me. The first time, I was a little slow. I don’t think we were terrified; we were cautious. If there had been any sort of complications, we’d have come in.”

To assess the adequacy of teaching, the authors asked patients what they would do in certain scenarios (e.g., if the dressing became loose, if it became wet, if they suspected a line infection). If the dressing became loose or open before a scheduled change, the majority of respondents said that they would call or visit the cancer center, a primary care physician, a homecare company, or a local hospital. Others said they would assess the situation or use tape or Tegaderm™. One patient with a port-a-cath said “I’d probably just tape it up myself, just to make sure that the port was secure. I’m not grossed out by it.” All of those responses were judged to be appropriate.

Many had experience with washing or bathing at home. Many were careful not to wash near the catheter, to avoid showering or bathing while the port was accessed, or to use plastic wrap to protect the area. Few had experienced a wet dressing, but many expressed confidence in their ability to deal with this scenario. A patient with a PICC line said, “You’d have to change it. We have a dressing kit at home. I think I could do it if I had to.” However, others expressed some apprehension. A patient who had a port-a-cath with a home infusion pump said, “To be totally honest, I don’t know. I’d probably panic.”

A majority of patients knew the symptoms that may manifest if a line were infected (e.g., fever, redness, pain, swelling). However, 13 patients were unaware of symptoms that would signal infection. One patient with a port-a-cath said, “I don’t know anything about it. I’m hoping I’ll never find out. I’m sure they told me, but I don’t remember.”

Challenges

Most patients affirmed the value of having a CVC in place. One patient with a port-a-cath described it as a “blessing.” Another with a port-a-cath said it was a “godsend.” Many wished they had known about CVCs and received one earlier in their treatments because it simplified phlebotomy and medication administration. One patient with a port-a-cath said, “There’s no difficult part. I wish I was born with one.” Another patient with a port-a-cath said, “I’ve thought it’s not much to do to take care of it. Myself and the port have gotten along really well.”

However, 28 participants described at least one difficulty in having or caring for a CVC. They noted problems with sleeping, showering, bathing, and forgetting about being tethered. One patient who had a port-a-cath with a home infusion pump said,

It’s just kind of awkward to make sure I don’t get hung up on it. Sleeping is no problem. I just unwrap it. We figured that out on the first night. It did fall off the bed once. It felt like an anchor.

A patient who had a port-a-cath with a home infusion pump said, “The only thing is carrying that stupid thing around. And hugs—they hurt. The other week, [my wife] came over and gave me a big, strong hug, and it really hurt.”

Others noted practical problems, such as de-accessing the port unintentionally and port malfunctions. One patient who had a port-a-cath with a home infusion pump said, “Last time the needle fell out while I was at home. I think it was the way it was taped up. I called them and they re-established it.” Another patient who had a port-a-cath said, “With the first one, I’d have to jump around to get it to work sometimes. This one is beautiful. This one is good.”

Four respondents experienced a CLABSI, but they generally took the expected complication in stride. One patient with a port-a-cath who experienced a CLABSI said,

It got infected after two weeks. Had a week at the [hospital]. They put in a PICC, and then they had to bring me back again a few days later to rewire it, to make sure it wasn’t going to cause any more problems. It was only accessed once during that two-week period.

Another patient who had a port-a-cath with a home infusion pump who experienced a CLABSI said, “They just had some bacteria in one of the ports, so I’m just off two weeks on antibiotics.”

Patients offered several recommendations for the cancer center to improve the experience of having a central line. Five patients said they desired more information and education about the availability and use of CVCs, and six said they wanted more consistent care by staff, including cleaning and injection technique. Three patients expressed the desire for more product choices, such as small bags or better attachments to allow for more convenient home administration.

Discussion

In this exploratory project, information was elicited from adult patients with cancer about the use and care of CVCs. The authors learned that patients were astute observers, readily identifying variation in practice among nurses. A minority of patients expressed uncertainty about what to do if the dressing became loose or wet, or how to recognize signs of infection.
Patients’ observations suggested at least two opportunities to reduce the risk of CLABSIIs associated with CVCs in immune-compromised hosts. First, the observations highlighted opportunities to standardize line care. Nurses working in the same organization, in the same unit, and treating patients with similar conditions performed line care in ways that were readily discernible by patients. Those differences in care may reflect inconsistent training and oversight, a lack of consensus in the profession about the components of appropriate care, practice drift, individual style, or a combination of factors. Eliciting patients’ observations of care on a routine basis may help nurse leaders identify opportunities to educate frontline staff and standardize care.

Second, patient education may play a critical role in line safety in patients with CVCs. Some patients described knowledge deficits regarding loose dressings, wet dressings, and signs of infection. Several remembered receiving instruction, but had not retained the information. By asking patients how they would manage common CVC-related scenarios, oncology nurses could update ongoing patient assessments and provide targeted education and training. Moller, Borregaard, Tvede, and Adamsen (2005) demonstrated a greater than 50% reduction in the rate of CVC-related infections among patients with hematologic malignancies who received individualized, supervised education regarding the care of Hickman lines.

**Implications for Practice**

- Ask patients about their central line care to identify improvement opportunities.
- Standardize central venous catheter care to minimize practice variation.
- Teach patients how to address loose or wet dressings and signs of infection.

Oncology nurses can play a critical role in all of those matters, drawing on past patient education resources available from the CDC ([www.cdc.gov/HAI/bsi/CLABSI-resources.html](http://www.cdc.gov/HAI/bsi/CLABSI-resources.html)).

**Limitations and Conclusion**

The current project’s generalizability is limited by the small number of respondents and the potential for selection bias. Patients at the cancer center in the current study may not be representative of patients with cancer elsewhere. Participants in the current study may be more or less articulate and observant than the general population. Like any interview survey, responses also were susceptible to recall and social desirability bias. Despite those potential limitations, the authors believe that eliciting patients’ observations about their own care is very valuable. Many patients are astute observers of their care, and nurses can learn from their observations.

**References**


of Infection Control, 39 (Suppl. 1), SI-534.


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2. What were the outcomes or recommendations for practice, education, administration, and/or research based on the evidence presented?
3. Which of the recommendations would you consider implementing in your setting? Why or why not?
4. What would be the next steps in applying the information presented in the article in your setting?

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Primer on Immuno-Oncology (Continued from page 317)


