

Preventing Bloodstream Infections in Hemodialysis Patients: the Patient Perspective

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Background

CDC's Core Interventions for Dialysis BSI Prevention

What Healthcare Institutions Can Do:

4. Patient education/engagement

Provide standardized education to all patients on infection prevention topics including vascular access care, hand hygiene, risks related to catheter use, recognizing signs of infection, and instructions for access management when away from the dialysis unit.

Background

- ❑ **Dialysis patients are key stakeholder in bloodstream infection prevention**
- ❑ **Little known about hemodialysis patients' perspectives regarding bloodstream infection prevention and infection control**

Focus Groups (Methods)

- ❑ **Three focus groups, each <1 hour long**
 - Assessed understanding of infection control and bloodstream infections
 - Solicited input about educating and engaging dialysis patients in BSI prevention
- ❑ **Participants selected among Dialysis Patient Citizens' Patient Ambassadors**
- ❑ **Conducted by CDC staff using standardized script**
- ❑ **Qualitatively coded by a group of CDC staff for emerging themes**

Description of Participants

- ❑ **12 participants from 9 different states**
- ❑ **Dialysis type:**
 - 1 with kidney transplant
 - 11 receiving hemodialysis
 - 1 home HD
 - 1 with catheter
- ❑ **Length of time on dialysis ranged from 4–31 years**

RESPONSES

What does infection prevention mean to you?

Most common responses

❑ Precautions taken by healthcare workers

- “Wearing gloves”
- “The smell of bleach on the machines and chairs”
- “I think of how the staff cares for me.”

❑ Precautions taken by patients

- “It begins with me and continues in the center”

Other responses

❑ Catheter care

- “The catheter is the ‘life access.’ Whether a fistula or catheter, it is your ‘life access.’”

❑ Being observant

❑ “Sterile”

What does vascular access prevention mean to you?

- ❑ **Most common response: patients taking responsibility for their care**
 - Keeping appointments, washing hands, bringing sterile equipment, performing own dressing and catheter care, following guidelines

Other responses:

- ❑ **Keeping access clean**
 - “Take care of the site as a surgeon would”
- ❑ **Taking time (not rushing)**
 - “This is our lifeline. You need to make the time.”
- ❑ **Healthcare providers taking precautions**
- ❑ **Educating patients**

What are the best ways to educate dialysis patients?

Most common mode suggested:

❑ **One-on-one, patient-to-patient**

“Dialysis clinics have a lot of oral culture with patients talking in the lobby”

What are the best ways to educate dialysis patients?

❑ Other examples and methods suggested:

- Print materials/handouts
- DVD
- One-on-one, healthcare provider to patient
- Support group
- Infection control class
- Visual or tactile learning
- Signage
- Other patients' stories
- Patients modeling behavior
- "Basic information at the start of hemodialysis and then follow with more in-depth information. In the panic of starting [dialysis], it's hard to hold onto in-depth education."

❑ Some respondents acknowledged that not everyone learns in the same way.

Topics perceived as important

- **Variety of responses**
 - Access care
 - Awareness of risk
 - Symptoms of infection
 - Washing hands



How often should be infection control teaching be done?

- ❑ **Participants were convergent regarding ongoing nature**

“Education needs to be ‘often and hard’ Repetitive, repetitive”

- ❑ **Suggested frequencies:**

- Quarterly
- At least once/month
- Patient dependent

- ❑ **Some suggested having teaching be each visit or “as often as possible,” or to have teaching occur in the event of an infection control breach**

When in the process of dialysis should it be initiated?

- ❑ **Concept of “Day 1”—widespread agreement**
 - “On diagnosis”
 - “As soon as access placed”
 - “At orientation”
- ❑ **Participants also recounted emotions and fears when first being initiated on dialysis**
 - “I was scared to death”
 - “You are so frightened, you will listen to what they have to say”
 - “The problem is patients are overwhelmed right off the bat. People are 'lost in the shuffle,' unless someone takes the time. It's frightening for a new patient.”

Who are the most trusted sources to educate/communicate this information?

- ❑ **Wide variety of answers**
 - Doctor – “but they don’t have the time”
 - Nurse

- ❑ **“Someone who takes the time,” regardless of position**
 - “Patients appreciate when someone takes the time for them.”
 - “Those who take extra time make a big difference.”

Who are the most trusted sources to educate/communicate this information?

❑ Other responses:

- Other patients: “The most trusted source is other patients because they are relatable and they share stories; they have their own experiences about the consequences of not keeping access clean. ‘My access is my lifeline’ is not something all patients understand.”
- Self: “Everything I know I taught myself”
- Family members
- Depends

❑ “Needs to come from all sources in the unit from patient to doctor.”

❑ Other trusted sources included: tech, social worker, dietician, physician assistant

Should patients have a role in preventing infections/infection control? Why/why not?

- ❑ **All agreed: “Yes”**
- ❑ **Most respondents explained that patients should take ownership and personal responsibility for preventing infections**
 - “It is my life... if I am not going to take care... then who will?”
- ❑ **Patients need to be their own advocates**
 - “It is my right as a patient.”
- ❑ **Patient is present all the time**

What are patient roles and perceived responsibilities in preventing infections?

Common themes:

❑ **Speak up**

- “Patients need to learn that they need to speak up if they see something wrong.”

❑ **Be observant**

❑ **Follow guidelines (e.g., washing hands, keeping appointments)**

❑ **Other suggestions included:**

- Bring their own dedicated equipment, keep documentation, help other patients/be a patient advocate, be informed (in general)
- Partnership with healthcare providers: “Healthcare providers have to invite the patient to speak up, and make it part of the culture”

What one piece of advice would you share regarding educating dialysis patients to prevent vascular access infections?

Answers varied but reflected common themes from previous questions

- Ask questions/get informed
- Follow guidelines
- Inspect access and report changes to staff
- Be observant
- Be your own self advocate/speak up
- Teach patients consequences
- Protect your access: "It is your lifeline"
- Provide reminders to staff and patients
- Read the handouts
- Dedicate staff for health education
- Patients should educate other patient
- Partner patients in infection control activities (e.g., patients performing audits of infection control measures)

Limitations

- ❑ **Self-report**
- ❑ **Not generalizable**
 - Small convenience sample of patients
 - Patients are DPC patient ambassadors

Summary

- ❑ **Education on infection control and bloodstream infections should begin early in the process of dialysis and with regular reinforcement on following guidelines/precautions (e.g., access care)**
- ❑ **Patient-to-patient discussion in dialysis centers considered to be useful method of education**
- ❑ **Recurring theme of patients advocating for their safety**
 - Patient responsibility to speak up when issues are noticed
 - Desire for healthcare workers to facilitate patient comfort in speaking up

“It begins and ends with the patient. We’re the potential victim of an infection, so it starts with us.”

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Questions?