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Infection Control and Bloodstream Infection Prevention: The Perspective of Patients Receiving Hemodialysis

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Abstract

Patients on hemodialysis, particularly those dialyzed through central lines, are at risk of acquiring bloodstream infections. Strategies to prevent bloodstream infections in patients on dialysis include educating patients about infection prevention, although patients' perspectives on this topic are not known. During focus groups conducted to explore these issues, patients reported that education on infection prevention should begin early in the process of dialysis, and that patients should be actively engaged as partners in infection prevention.

Keywords

Hemodialysis; patient education; infection control; bloodstream infections

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Introduction

Infections are a leading cause of hospitalization and death in patients on hemodialysis (U.S. Renal Data System [USRDS], 2012). Patients on hemodialysis are at particularly high risk for the development of bloodstream infections (BSIs) because of the need for repeated access of the bloodstream for dialysis (Patel, Kallen, & Arduino, 2010). For instance, the risk of a patient on dialysis for developing invasive infections from methicillin-resistant *Staphylococcus aureus*, most (86%) of which are BSI, is 100-fold greater than that of the general population (Centers for Disease Control and Prevention [CDC], 2007).

The CDC has published a list of core interventions for prevention of BSIs in patients on dialysis, which includes a recommendation to: “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” (Centers for Disease Control and Prevention, 2013). Patients on hemodialysis are therefore key partners in BSI prevention, but currently no literature describes their perspectives on infection control or their role in BSI prevention. We explored the attitudes and preferences of patients on hemodialysis regarding educating and engaging such patients in BSI prevention.

Methods

Three focus groups, each lasting 45–60 minutes, were conducted during February–March 2012 with a convenience sample of patient ambassadors from Dialysis Patient Citizens (DPC). DPC is a network of patients on dialysis or in the pre-dialysis phase, and their family members; patient ambassadors are members who have volunteered to represent DPC in their community. The focus groups were conducted by CDC staff using a standardized script of open- and closed-ended questions, allowing for multiple answers. After an initial pilot group was conducted, a modified version of the script was used for the two subsequent focus groups. Questions assessed understanding of infection control and BSI and solicited input about educating and engaging patients on dialysis in BSI prevention. Focus groups were conducted by telephone and answers transcribed in real-time by CDC staff. Responses were qualitatively coded by a group of CDC staff for emerging themes. The DPC patient ambassadors received no compensation or other incentives for their participation. The project was determined to a non-research activity (and exempt from Institutional Review Board review) after human subjects review from the National Center for Emerging, Zoonotic, and Infectious Diseases (CDC).

Results

Twelve DPC patient ambassadors from nine different states participated in focus groups. All were currently or formerly on dialysis. One had a functioning kidney transplant and 11 were receiving hemodialysis. The median duration on dialysis reported by participants was seven years (range: 4–31 years).

Participants were first asked, “What does infection prevention mean to you?” The most common responses referred to precautions taken by healthcare workers (42% of

participants), such as wearing gloves and proper environmental disinfection, and precautions taken by patients (42% of participants). As one participant explained: "It begins with me and continues in the center." Other responses included catheter care, being observant, and simply "[being] sterile." When asked specifically about vascular access infection prevention, the most common response, given by 67% of participants, was that it involved patients taking responsibility for their care, giving examples such as washing hands, checking that staff in the dialysis unit are using sterile equipment, and performing their own dressing and catheter care. The importance of adherence to proper practices was underscored by one participant who noted, "This is our lifeline. You need to make the time."

Next, participants were asked their perspectives on the best ways to educate patients on dialysis. One-on-one, patient-to-patient education was suggested by 50% of participants. One participant noted: "Dialysis clinics have a lot of oral culture (e.g., with patients talking in the lobby)." Another further explained: "Other patients... are relatable and they share stories; they have their own experiences about the consequences of not keeping [your] access clean." The remaining responses mentioned a variety of methods, such as print materials, DVDs, support groups, and classes. The specific topics participants perceived to be important included care of dialysis access, the risks of not following instructions, symptoms of BSI, and hand hygiene.

When asked how often teaching on infection control should be done, the most common responses were quarterly (25% of participants) and at least once/month (17% of participants). Other responses were that teaching should occur "as often as possible," at each visit, or at patient-dependent intervals. One participant also suggested that teaching should occur in response to breaches in infection control by patients that are observed by staff. Of the nine participants who provided input on when education should be initiated, eight (89%) agreed that teaching should begin on "day 1," or as early as possible in the process of preparing for dialysis.

The two most trusted sources for education were reported to be nurses (25% of participants) or the nephrologist (25% of participants), although participants indicated that physicians were unlikely to have time to devote towards education. In addition, 17% of participants acknowledged that, regardless of position, "someone who takes the time" to educate patients would be considered a trusted source for education. Other trusted sources mentioned included other staff in the hemodialysis unit (e.g., technician, social worker, dietician, physician assistant), other individuals in the patients' lives (e.g., family members, other patients), and the patient's self.

Participants agreed unanimously that patients should have a role in infection prevention. Half of participants further explained that patients should take ownership and personal responsibility for preventing infections. For example, one participant stated: "It is my life... if I am not going to take care... then who will?" Participants also stressed the importance of being their own advocate for their safety. They explained that "it is our right" and also noted a pragmatic reason for taking responsibility for preventing infections: no one else is present all the time to provide the care they can provide for themselves. Specific perceived responsibilities mentioned by participants were to speak up when they notice something

wrong, to be observant when receiving hemodialysis, and to follow guidelines. Finally, one participant suggested that creating a partnership between patients and healthcare providers was crucial: “Healthcare providers have to invite the patient to speak up, and make it part of the culture.”

At the end of the focus groups, participants were asked what one piece of advice they would share regarding educating patients on dialysis to prevent vascular access infections. Participants provided a variety of responses, listed in Table 1.

Discussion

To our knowledge, this is the first report describing the perspectives of patients on hemodialysis on infection control and infection prevention. Indeed, a MEDLINE search for the terms “dialysis,” “infection,” and “education” lists articles about education of patients on peritoneal dialysis but not of those on hemodialysis. Key findings were that patients believed that education on infection control and bloodstream infections should begin early in the process of dialysis with regular reinforcement, covering topics such as following guidelines and taking proper precautions; that patient-to-patient discussion was considered to be a useful method to educate patients; and that patients believed they needed to take personal responsibility for their care.

Responses overall were highly convergent, even across focus groups. A theme that recurred during the focus groups was that patients should advocate for their own safety and speak up when problems are noticed. For this approach to succeed, it is important for healthcare providers to create a culture within the dialysis unit where patients are comfortable voicing concerns. Notably, this finding holds particular implications for the nephrology nursing community: nurses were identified as one of the most trusted sources of education for patients and play a critical role in establishing the culture of a dialysis unit (Molzahn, 1997).

Taken together, these results suggest that the patients’ role in infection control might be not only to ensure that they themselves are following proper precautions, but also to help promote providers’ adherence to infection control practices. Analogous results have been reported from literature relating to hand hygiene. When patients are educated and empowered to monitor whether their providers have washed their hands, provider adherence to hand hygiene improves (McGuckin, Taylor, Martin, Porten, & Salcido, 2004; McGuckin et al., 1999, 2001). However, these studies also suggest that it can be difficult to establish a culture where patients feel comfortable speaking to their providers (Lent et al., 2009).

The primary limitations with these results relate to generalizability of these self-reports. The focus groups involved a small convenience sample of patients. Additionally, all participants were DPC patient ambassadors, whose perspectives on patient education/engagement might differ from those of other patients on hemodialysis.

Notwithstanding these limitations, this report helps to provide a framework for understanding how to educate and engage patients on hemodialysis in infection control and BSI prevention. CDC has created tools to help staff educate patients regarding infection prevention and involve patients in prevention of bloodstream infections, and is targeting the

trusted educators named by focus group participants for input and outreach. Further work is needed to evaluate the impact of these interventions on process measures and patient outcomes. Such work can establish how best to forge a strong partnership between patients on dialysis and their providers to improve patient care.

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Biographies

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Table 1

Answers given by focus group participants in response to the question: “What one piece of advice would you share regarding educating patients on dialysis to prevent vascular access infections?”

• Ask questions/get informed	• Protect your access: “It is your lifeline.”
• Follow guidelines	• Provide reminders to staff and patients
• Inspect the access site and report changes to staff	• Read the handouts
• Be observant	• Dedicate staff for health education
• Be your own self advocate/speak up	• Patients should educate other patients
• Teach patients consequences (e.g., of getting an infection or not following guidelines)	• Partner with patients in infection control activities (e.g., patients performing audits of infection control practices)

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