Welcome to

Infections in Dialysis Centers: Understanding what Matters to Patients

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CDC, our planners, our presenters, and their spouses/partners wish to disclose they have no financial interests or other relationships with the manufacturers of commercial products, suppliers of commercial services, or commercial supporters with the exception of Dr. Bradley Warady and he wishes to disclose that he is a research sponsor for Baxter Healthcare.

Planning committee reviewed content to ensure there is no bias.

Content will not include any discussion of the unlabeled use of a product or a product under investigational use.

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PROGRAM DESCRIPTION:

- These presentations will highlight patients’ perspectives of healthcare associated infections (HAIs) in hemodialysis settings. Presenters will also discuss the prevention and management of infectious diseases in dialysis patients, as well as, implications for patient-centered care and engagement.

OBJECTIVES:

- Describe infection control techniques that reduce the risk and spread of healthcare- associated infections (HAI).

- Identify unsafe practices that place patients at risk for HAIs.

- Describe best practices for infection control and prevention in daily practice in healthcare settings.

- Apply standards, guidelines, best practices, and established processes related to safe and effective medication use.
Infections in Dialysis Centers: Understanding what Matters to Patients

Priti Patel, MD, MPH
Medical Officer
Division of Healthcare Quality Promotion, CDC

May 2, 2017
Set of 9 Interventions

Evidence-based CDC recommendations

1. Surveillance and feedback using NIHNS
Conduct monthly surveillance for ESRD and other dialysis units using CDC’s National Healthcare Safety Network (NHSN). Calculate facility rates and compare to rates in other NHSN facilities. Actively share results with front-line clinical staff.

2. Hand hygiene observations
Perform observations of hand hygiene opportunities monthly and share results with dialysis staff.

3. Catheter/vascular access care observations
Perform observations of vascular access care and catheter access quarterly. Assess staff adherence to aseptic technique when connecting and disconnecting catheters and during dressing changes. Share results with clinical staff.

4. Staff education and competency
Train staff on infection control topics, including access care and aseptic techniques. Perform competency evaluation for staff such as catheter care and accessing every 6-12 months and upon hire.

5. Patient education/engagement
Provide standardized education to all patients on infection prevention topics including vascular access care, hand hygiene, and techniques related to catheter use, recognizing signs of infection, and instructions for access management prior to leaving the dialysis unit.

6. Catheter reduction
Incorporate efforts, e.g., through patient education, vascular access coordination to reduce catheters by identifying and addressing barriers to permanent access utilization and catheter removal.

7. Chlorhexidine for skin antiseptic:
Use an alcohol-based chlorhexidine (CHG) solution as the first line skin antiseptic agent for central line insertion and during dressing changes.*

8. Catheter hub disinfection:
Scrub catheter hubs with an appropriate antiseptic after cap is removed and before accessing. Perform every time catheter is accessed or disconnected.

9. Antimicrobial ointment:
Apply antibiotic ointment or povidone-iodine ointment to catheter exit sites during dressing changes.***

* Povidone iodine (preferably with alcohol) or 70% alcohol-based alternatives for patients with chromosomal conditions.
** If closed needleless connector device is used, flush device per manufacturer’s instructions.
*** See information on selecting antimicrobial ointment for permanent catheter exit sites on CDC’s Dialysis Safety website [http://www.cdc.gov/dialysis/prevention-tools/core-interventions.html]. Use of chlorhexidine impregnated sponge dressing might be an alternative.

For more information about the Core Interventions for Dialysis Bloodstream Infection (BSI) Prevention, please visit [http://www.cdc.gov/dialysis/prevention-tools/core-interventions.html]
Featured Speakers

- **Allison Tong, MPH (Hons), MM, PhD**, Associate Professor, Principal Research Fellow, Sydney School of Public Health, The University of Sydney-Australia
  - Patient Perspectives on the Prevention and Management of Infectious Disease in Hemodialysis Units

- **Mark Unruh, MD, MS**, Professor and Chair, Department of Internal Medicine, Solomon, Gardner & Sterling Chair Section Chief, New Mexico VA Health System, Associate Director UNM Clinical and Translational Science Center, University of New Mexico School of Medicine
  - Approaches to Engage Dialysis Patients in Their Care and in Research

CDC Disclaimer: The findings and conclusions in this presentation are those of the presenter(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
Featured Speakers

- Ronald J. Krokey, Patient Advocate, Former Dialysis Patient
  - Infection Prevention and Patient Engagement: A Patient’s Perspective

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The speakers’ slides will be provided to participants in a follow-up email.
Patient perspectives on the prevention and management of infectious disease in hemodialysis units

Dr. Allison Tong
The University of Sydney
e: allison.tong@sydney.edu.au

CDC Making Dialysis Safer Coalition Webinar
Tuesday May 2, 2017
Centers for Disease Control, Atlanta, United States
1. The need to understand patient perspectives
2. Patient’s experiences and perspectives on the prevention and management of infectious microorganisms in hemodialysis units
   (KHA-CARI Guidelines – Patient workshop)
3. Implications for patient-centered care
Patient-centered care: Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions. - Institute of Medicine
Do guidelines on infection control in hemodialysis units address patient priorities, needs and concerns?

- **Guidelines reviewed:** CDC, KDIGO, ERBP, UK Renal Association, CSN, NICE.

- Mostly on clinical/technical procedures (e.g. hand hygiene, personal protective equipment, cleaning and disinfection, patient isolation, screening, vaccination)

- NICE: use input from local patient and public experience for continuous quality improvement to minimize harm from healthcare-associated infections

- CDC: 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.
80% patients would be willing to help hospital staff with prevention of infection, but many would not feel comfortable asking a healthcare worker to sanitize their hands.
Lack of verbal and written communication about infection status was a major concern
Patients were not comfortable about asking questions
Reluctant to challenge staff about their practice
Scottish Renal Patient Experience Survey

For key to Figure 11, please see pages 13/14.

9.4 Comments about hand hygiene

187/1294 respondents provided 189 comments about hand hygiene. Just under a third of these were positive. Of the remaining comments, patient and staff hand hygiene drew the most comments (85), with the vast majority highlighting the variability in compliance among both staff and patients alike. Some raised concerns about visitors to the dialysis ward not following hand hygiene procedures.
Infection control and bloodstream infection prevention: the perspective of patients receiving hemodialysis

- **Ownership and personal responsibility** — “It is my life, if I am not going to take care...then who will?”

- **Own advocate for safety**

- **Patient-provider partnership** — “healthcare providers have to invite the patient to speak up and make it part of the culture.”
Clinical context

- Increased risk of exposure to infectious agents
- Frequent and extended vascular exposure, immune dysfunction, close proximity to other patients, hospitalization, contact with health workers
- Multidrug-resistant bacteria (MRSA, VRSA), bacteremia, blood-borne viruses (Hep B, C, HIV)
- Impact on wellbeing: social isolation, travel restrictions, disruption of care

Guidelines

- Epidemiology, benefits and harms of screening, transmission-based precautions, environmental controls
KHA-CARI Guidelines – Patient workshop

**Aim:** To identify the priorities of patients and caregivers to include in clinical practice guidelines on screening and management of infectious microorganisms in hemodialysis units.

**Patients/caregivers**

Present draft scope and content of guidelines to patients/caregivers

**WORKSHOP**

Identify patient priorities, needs, perspectives to include in guideline topics/content

**Guideline working group**

Evidence review

Draft guidelines

Compare patient priorities and draft recommendations

Revise guidelines to ensure the topic, scope and recommendations address patient priorities.
KHA-CARI Guidelines – Patient workshop

Participants

• Two HD units in Sydney, Australia
• Purposive sampling: age and clinical characteristics (screened, diagnosed, undergoing treatment)

Workshop

• Questions: experience of HD and screening for infectious disease; guideline topics and outcomes
• Recorded/transcribed
• Extract topics; thematic analysis to identify reasons
Participant characteristics (n=11)

• 9 patients, 3 caregivers
• 7 male
• 7 had been screened
• 4 diagnosed with infectious microorganism
  Blood-borne viruses 2
  Multidrug-resistant organisms 2
  Bloodstream infections 2
New guideline topics

1. **Privacy and confidentiality**
   - Disease notification
   - Exchange of patient information between staff

2. **Psychosocial care during and after disease notification**
   - Information
   - Ongoing support following diagnosis

3. **Quality of transportation**
   - Minimize cross-infection during transportation

4. **Psychosocial treatment of patients in isolation**
   - Inform about the reasons for isolation

5. **Patient/caregivers education and engagement**
   - Impact of infection on future treatment (dialysis, infection)
   - Transmission (to understand their own risk to others)

6. **Patient advocacy**
   - Empower patients to disclose information (express concerns anonymously)
Themes

Shock and vulnerability

Burden of isolation

Fear of infection

Respect for privacy and confidentiality

Confusion over procedural inconsistencies
“When they tell you, it just smacks you in the head, and you think how did I get that?”

“I thought - where? How? I’ve been into hospital many times, so when did I contract it? How long have I had it? I had no idea.”

“It doesn’t just affect the patient; it’s also the partner - the husband or the wife. It impacts the whole family.”
Themes

Burden of isolation

“You can’t converse with anybody, you’re just by yourself. You feel as if you’re in prison, as if you’ve been convicted of murder and you’re in solitary.”

“The evidence might say you have to isolate them, but the guideline should say what you should do to make sure that the person isolated isn’t feeling stigmatized, upset, alone.”

“You could overcome the isolation with giving the patient something to do, or to look at. Just so you’re not in there by yourself with a bed and cabinet and that’s it, and a window to look out. You need some sort of activity to help you along.”
“They want to know where it’s come from and what it’s going to do to them. You want to find out answers. It’s scary.”

“Education is important. That was the thing about AIDS and HIV. People were freaking out, because they weren’t aware of how they could contract it.”

“Someone else has passed it onto you, so you’ve got no control over whether you pass it onto someone else.”
Themes

Respect for privacy and confidentiality

“The doctor comes to your bedside, he’s got the screens around and he says ‘you’ve got this and this and we’re going to do this and this’. But the other three patients in the ward can hear.”

“You should just assume anybody could have it [infectious disease], and make procedures appropriately. That way it takes away a bit of the stigma.”
“How do you tell me to wash my hands, clean up, make sure that’s all sterilized, this and that, but the chair that I’m about to go sit on, somebody else has been sitting on there. How do you know if it’s clean? Even the table where you put your coffee, that’s not even wiped down.”
Implications for patient-centered care

Respect patient privacy
• Protect confidentiality in communicating information

Provide education (early on)
• Prevalence/incidence, transmission
• Procedures for preventing infection (e.g. hygiene, anti-infective agents)
• Impact of infection on treatment/care

Empower patients
• Ability to express concerns anonymously e.g. audits, PREMS (NHS Scotland Patient Experience Survey)

Address psychosocial impacts
• Stigma
• Isolation/boredom
• Vulnerability

Draft guideline recommendations

“Include [staff] education about maintaining patients’ privacy where possible.”

“… auditing of hemodialysis patients’ opinions about screening, isolation, decolonisation and other infection control procedures to identify gaps in education, psychosocial concerns, threats to privacy and procedural inconsistencies surrounding infection control procedures from the perspective of the patients.”

9.1 Do the staff usually clean their hands either by washing them with soap and water or using alcohol gel before treating you?
□ Yes □ No □ Not sure

“Evidence around the psychosocial effects and potential harms of screening, isolating and decolonising hemodialysis patients with VRE is minimal.”
Patient Engagement in Clinical Research: Lessons for Dialysis Care

Mark Unruh, MD, MS
Professor & Chair of Medicine
University of New Mexico
New Mexico Veterans Hospital

CDC Making Dialysis Safer Coalition
Webinar Tuesday May 2, 2017 Centers for Disease Control, Atlanta, United States
Patient Engaged Research

• Background as a Clinician & Investigator
• Community-Based Participatory Research
• Patient-Centered Research
Patient-Centered Research

• Local patient boards participating in the entire process of research
• Regional or national patient advocates
• Boards that represent patients such as advocacy groups or pueblos
Cultural Influences

- Autonomy
- Beliefs
- Attitudes
- Practices
- Knowledge
- Communication
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<td>1</td>
<td>Shared Decision Making and Renal Supportive Care (SDMRSC)</td>
<td>Patients undergoing hemodialysis and families of patients.</td>
<td>Referred by social workers or clinicians.</td>
<td>12</td>
<td>Initially monthly, then quarterly.</td>
<td>Reply to the queries from investigators and partner in development of study goals, methodology and dissemination plan.</td>
<td>They were most involved in the planning process, but remain important sources of input.</td>
<td>Representatives from dialysis provider organizations, nephrologists, and dialysis social workers.</td>
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<td>2</td>
<td>NephCure Kidney Network for Patients with Nephrotic Syndrome (NKN)</td>
<td>Adult patients and parents of minors with primary nephrotic syndrome (n=6) and patient advocates (n=4).</td>
<td>Call for nominations through advocacy organization’s website.</td>
<td>10</td>
<td>Weekly e-digest; monthly steering committee calls; monthly workgroup calls.</td>
<td>Co-develop policies, operational plans; aid in implementation (peer-to-peer recruitment); review ancillary research projects; aid in communications and dissemination.</td>
<td>Roles did not change, but degree of involvement did. Originally, Steering Committee members also were required to be on ≥1 workgroup, modified approach to route interested patients to different roles (governance versus implementation).</td>
<td>Practicing clinicians (n=3), researchers (n=3), representatives from industry (n=2).</td>
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<td>3</td>
<td>Improving Patient Quality of Life and Caregiver Burden by a Peer-Mentoring Program for patients with CKD and Their Caregivers</td>
<td>Patients with CKD (stage 4 or 5) and caregivers.</td>
<td>Referred by social workers or clinicians.</td>
<td>5</td>
<td>Initially in focus group setting (for proposal review); during conduct of the study, within the context of periodic meetings.</td>
<td>Review the proposal; serve as members of the community advisory board (oversight of conduct of study) and members of the Patient and Caregiver Advisory Group.</td>
<td>No</td>
<td>Representatives of patient advocacy organization; clinicians; representatives of hospital administration; representatives of healthcare organizations.</td>
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Shared Decision Making and Renal Supportive Care

**AIM 1:** To improve EOL communication with a more diverse population of HD patients who are at high risk for death

**AIM 2:** To determine whether enhanced renal supportive care impacts the use of hospice services, location of death, and EOL planning.

**AIM 3:** To determine the effect of enhanced renal supportive care on quality of life/death and caregiver satisfaction with patient care in the last week of life.

Lewis Cohen, MD
Michael Germain, MD
Sarah Goff, MD, MS
John Griffith, PhD
Lisa Marr, MD
Nwamaka Eneanya, MD
Qualitative Findings

• Most patients reported that they had not discussed prognosis or ACP with their nephrologist or other members of the dialysis team.
  – 2 preferred not to have such discussions
  – majority said they would welcome them and/or desired them.

• Some patients reported having filled out paper work for “DNR”, but many had never handed the paperwork back in to their dialysis team; those that had were unsure of who on the dialysis team had this information or knew of their preferences.

Goff et al. CJASN 2015
Factors that may impact patients’ perspectives regarding ACP and prognostic discussions

- **Dialysis experience** “The dialysis just drains me down to nothing. It just zaps me. I’ll be good for a couple of hours afterwards and then I just sit in a chair and stare.” [UNM 5 patient, male, White]

- Patients described specific **Positive** and **Negative** aspects of their dialysis experience.

- “I don’t worry about it [ACP]... adjust it [dialysis] and run day by day and work with these nice people. I’ve been very happy here – never consider making a change.” [BMC 5, patient, male, White]

- “Right now I have a doctor that I basically haven’t ever been introduced to.” [BMC 3, patient, male, White]
Patients Provide Continuous Feedback

- Developed Protocol
- Guidance on the protocol
- Improved consent process
- Provided guidance on how to present study
- Great ideas for the next study
Rules of Engagement

• Expectations and commitment
• Guidelines for interactions
• Follow-up on recommendations
• Additional training
Operating a Patient Advisory Board

• Involved in the project longitudinally
  – meet every three months during the study period.
• The use of face-to-face meetings for patients
  – Hard of hearing or have Spanish as a preferred language
  – Four questions for each meeting, which will last between 45 to 60 minutes
  – Agenda written at a sixth grade level.
Maintain Engagement

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<th>Recommended Practice</th>
<th>Rationale</th>
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<td>Gain trust and continue to build trust</td>
<td>Develop trust in recruiting patients.</td>
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<td>Select patients for whom the research has important consequences</td>
<td>Patients with a vested interest in the topic</td>
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<td>Prepare patients for their role, responsibilities and the topic</td>
<td>Team provides education to patients on topic and role</td>
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<td>Utilize trained and neutral facilitator</td>
<td>Take advantage of skilled facilitators to create a safe atmosphere for discussion</td>
</tr>
<tr>
<td>Provide feedback on results and the ways that their input is being used</td>
<td>Acknowledge the contribution of patients</td>
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Benefits of Engagement

• Advocate for self
• Advocate for patient community
• Auditor of providers
• Provide ideas for providers and systems

“Experience is not the enemy: It is the hubris that is often a by-product of experience that is our greatest enemy.” Liz Wiseman
Generate a Culture of Safety

• Become a student of safety
• Engage patients and staff to improve safety
• Partners in providing high quality care
  – Expectations and culture
  – Feedback on experience of care
  – Providing ideas and inspiration for ongoing improvements
  • https://www.ted.com/talks/eric_dishman_health_care_should_be_a_team_sport
Strategies to engage hemodialysis patients in infection prevention: a patient’s perspective

Ronald J. Krokey
Patient Advocate, Former Dialysis Patient
Conversation Starter to Prevent Infections in Dialysis Patients

- Co-developed by CDC and AAKP
- Started with a CDC draft of topic areas and questions
- Conducted focus groups with patients to get their feedback on the most important infection prevention topics
- Can be used by patients, family members, or staff to initiate a conversation

How does this facility involve patients and their families in infection control activities? Are patients encouraged to speak up when they see a concerning practice (for example, a staff member who does not wash her hands)?

Dialysis centers should educate and empower patients to help prevent infections and support a safe care environment. Talk to your social worker or facility administrator for ideas on how you can get involved.
Conversation Starter to Prevent Infections in Dialysis Patients

Try it Today!

Does this facility use the CDC recommendations to help prevent infections?

Regular use of CDC resources and recommendations can keep patients free of getting serious infections. Best practices include monitoring staff and patient hygiene and proper hand washing, training staff, and asking patients in learning about these practices. Facilities should use these recommendations and pass on their staff feedback to know how they are doing. More information can be found at www.cdc.gov/dialysis/prevention-tools.

Does this facility handle cleaning dialysis stations in between patient treatments? Specifically, are dialysis stations cleaned while a patient is still in the chair?

Dialysis stations need proper cleaning to prevent the spread of germs between patients. CDC has standards for facilities to follow to make sure every station is safe for the next patient. Some stations did not start until the patient had completed their dialysis treatment and left the station. More information can be found at www.cdc.gov/dialysis/prevention-tools.

Does this facility use a new, disposable dialyzer (or artificial kidneys) with each dialysis treatment? If not, can a patient opt out of using the dialyzer?

In some dialysis units, the dialyzer must be thoroughly cleaned and disinfected after each use and cannot be reused. Talk to your doctor about whether you could use a disposable dialyzer instead of a reused one.

How does this facility support patients to use a fistula instead of a catheter as early in their treatment as possible?

Fistulas are preferred when possible, but sometimes it is medically necessary to use a catheter for dialysis. However, catheters can lead to serious infections and other problems. Policies and protocols are varied for most patients. Talk to your care team about what is right for you. More information can be found at www.askmd.org/dialysis/understanding-your-medically-necessary-options.html.

If there was an outbreak in this facility how would the facility communicate with patients? How would the facility handle a partner with others such as the health department?

Contagious germs can spread through dialysis centers. Finding an outbreak is sudden increase in numbers of sick persons early and starting dialysis health care to stop the spread of infection.
Facility Certificate

Insert organization's name here.

HAS USED THE CONVERSATION STARTER TO PREVENT INFECTIONS IN DIALYSIS PATIENTS

Our patients are encouraged to start a conversation today!
Learn more at www.cdc.gov/dialysis/patient

Question and Answer Session

Please submit your questions via the chat window, located on the lower left-hand side of the webinar screen.
Upcoming ASN Nephrologists Transforming Dialysis Safety (NTDS) Webinar

Targeting Zero Infections: Where Do We Begin?

Join the first Nephrologists Transforming Dialysis Safety (NTDS) webinar series to learn how to stop and prevent the spread of deadly infectious diseases.

Webinar 1 Title: Targeting Zero Infections: Where Do We Begin?
Date: Tuesday, May 23, 2017
Time: 12:00 PM-1:00 PM EDT

Speakers:
- Alan S. Kliger, MD, Yale New Haven Health System
- Priti R. Patel, MD, MPH, Centers for Disease Control and Prevention (CDC)
- Leslie P. Wong, MD, MBA, FASN, Cleveland Clinic

REGISTRATION IS FREE – REGISTER TODAY

https://www.asn-online.org/NTDS/
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    - [www.cdc.gov/tceonline](http://www.cdc.gov/tceonline); Access Code: **WC0502**
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