

Retaliation for Filing Grievances—Does it Exist? It Does if the Patient Says it Does.

Tip Sheet and Team Activity

Background

As a dialysis professional, you may bristle at the mention of retaliation against a patient who voices a concern about their care. “Retaliate against a patient? *Never!*” “Why should patients worry?” You want the best for all of your patients, and you and your staff are committed to offering them the best quality of care at all times, right? That may not always be clear to your patients; remember, their perception is your reality.

The federal regulations, as stated in the End Stage Renal Disease (ESRD) Conditions for Coverage, *are* clear about the issue of retaliation; and in accordance with those regulations, you certainly make sure to educate your patients about the different options available to them to file a grievance. You assure them that there is no need to worry about retaliation if they voice a concern about their care to you. However, not all of your patients believe what they are being told. Your assurances offer little to no comfort to those patients who end up calling the Network to file a grievance, in spite of your efforts to assure them. A number of these callers simply cannot get past the fear of retaliation by dialysis staff. They do not have faith that their concern(s) will be fully investigated and addressed, even after assurances offered by the Network. These are the same patients who *aren’t* talking to you at the facility level either. These patients remain anxious and questioning of the care they receive from you and your staff. While they may be talking to other patients at your facility about their concerns, their questions and concerns are not being addressed in an effective and meaningful way. This, in turn, can compromise the care giving relationship and jeopardize the building of trust and collaboration between the dialysis care team and patient that is so important.

Patient Feedback

The question is, how do *you* define retaliation? You might be surprised to know how patients define retaliation and to know not only that many patients feel that retaliation exists, but also that it occurs routinely.

We wanted to know what patients think about the issue of retaliation, so we asked the members of our Patient Advisory Committee (PAC). This committee is a group of knowledgeable patients who represent all six states in our service area: Arizona, Colorado, New Mexico, Nevada, Utah, and Wyoming. The length of time they have been on treatment for ESRD ranges from 1 to over 20 years. Their range of treatment spans all modalities and treatment settings, from large dialysis organizations to small hospital-based dialysis units. We asked them to share their points of view and experiences with voicing care concerns at the facility level by asking two questions: “Does retaliation exist in dialysis facilities?” and “What can dialysis facility managers and staff do to address the fear of retaliation that holds many patients back from voicing concerns about their care?” A compilation of patient responses follows.

Does retaliation exist in dialysis facilities?

- “Retaliation is occurring. I’ve experienced it. It’s often subtle, for example, patients can be ignored when making a simple request. Sometimes staff stop talking with you.”
- “I need dialysis to be a safe haven. I have felt isolated after voicing a concern. My support system (at dialysis) is the staff, so it hurts when they stop talking to me.”
- “I always get anxious before bringing up a concern. There’s always retaliation.”
- “The PCTs have a lot of power. They can make sure a PCT you’re comfortable with won’t stick you.”
- “I have received comments from a manager and nurse that feel like a threat, such as, ‘if you’re not happy here, you can always transfer to another facility.’ Or, I’ve been ‘encouraged’ (in reality it felt like being pushed) to do a modality change. I don’t want to change facilities or modalities. I want things to work well here. Don’t they want the same thing?”
- “It’s too risky to talk directly about your concerns to the staff who are putting needles in your arm. They can hurt you. When you’re afraid of the staff, there is no trust.”
- “It’s uncomfortable when English isn’t the dialysis caregivers’ primary language—staff talk to each other in their native language. You don’t know what or who they are talking about. How can I trust them?”
- “When there is constant staff turnover, there is not much conversation from the staff. They’re too busy. How can I trust staff who I don’t know and who don’t take the time to get to know me?”

What can dialysis facility managers and staff do to address the fear of retaliation that holds many patients back from voicing concerns about their care?

- “It is very important to have one-on-one dialogue to build a relationship and build trust in the relationship. If this doesn’t exist, it’s difficult for both parties to have a conversation about a concern. Patients will be fearful and staff will be defensive.”
- “At my current facility I feel valued and a part of the team. I trust them because:
 - They take the time to get to know me. Staff tell me what they are doing before they do it.
 - PCTs apologize when the needle sticks hurt me and I cry. They don’t get defensive or upset.
 - Staff understand that I’m human and don’t expect perfection from me on the treatment plan.
 - Staff don’t tower over me and talk down to me. They sit down at my level, eye level, and pull the chair in close to create as much privacy as possible.
 - Staff do a great job of explaining things.”

- “Staff often respond defensively to a patient who is expressing a concern, especially when the patient is feeling a lot of emotion—fear, anger, frustration. It would be helpful if staff would simply listen and allow the patient to fully express their feelings before reacting.
- “Ask patients who have utilized the internal grievance process to talk to other patients at the facility and let them know there will not be retaliation if they speak up about a concern.”
- “Offer different ways for patients to express their concerns. For example, make an anonymous form available, perhaps use a suggestion box, or have an electronic way to express concerns.”

Team Activity:

Understanding Retaliation From the Patient's Perspective

Prior to reviewing patient feedback on retaliation and the “Building Patient Trust” tip sheet with your staff, ask them the following questions. Encourage them to be forthcoming, and let them know there will be no repercussions. Take notes for later comparison.

- What do you think about the issue of retaliation against patients who speak up about a problem in the dialysis facility or file a formal grievance about your facility with the Network or State Survey Agency?
- How do you define retaliation?
- Does retaliation exist in your facility?
 - How do you know?
- Do you believe the fear of retaliation holds patients in your facility back from speaking up about care concerns?
 - How do you know?

After reviewing the tip sheet with your staff:

- Ask the first three questions again. Did staff answer the questions differently?
- Ask staff to identify three things that can be done to help patients trust there will be no retaliation if they speak up about a problem or file a grievance at the facility, Network, or State Survey Agency.

Discuss with staff how to handle a situation when they know that a patient has complained about something one of them did or didn't do. Pose these questions:

What if the complaint were about something that *you* did or didn't do?

- How would you feel? (e.g., angry, embarrassed, sad, anxious, afraid, hurt, disappointed)
- What would you do with those feelings?
 - Would you express them privately? To family, coworkers, the manager, the patient, or other patients?
- Would you feel differently toward the patient who made the complaint?
- What would you do with those feelings?
- Knowing that feelings can impact behavior, how would you act toward the patient knowing about the complaint that was made?
 - Would you pretend you didn't know about the complaint and interact with the patient like nothing had ever happened?

- Would you address the issue directly with the patient?
- Would you wait for direction from the manager?
- Would you be reluctant to talk to the patient?
- Would you be reluctant to provide care to the patient?
- What would you need, and from whom, in order to manage any discomfort in the relationship with the patient or awkward moment in caring for the patient who made the complaint?

What if the complaint is about something that *one of your coworkers* did or didn't do?

- How would you feel? (e.g., angry, embarrassed, sad, anxious, afraid, hurt, disappointed.)
- What would you do with those feelings?
 - Would you express them privately? To family, coworkers, the manager, the patient, other patients?
- Would you feel differently toward the patient who made the complaint?
 - What would you do with those feelings?
- Knowing that feelings can impact behavior, how would you act toward the patient knowing about the complaint that was made?
 - Would you pretend you didn't know about the complaint and interact with the patient like nothing had ever happened?
 - Would you address the issue directly with the patient?
 - Would you wait for direction from the manager?
 - Would you be reluctant to talk to the patient?
 - Would you be reluctant to provide care to the patient?
 - What would you need, and from whom, in order to manage any discomfort in the relationship with the patient or awkward moment in caring for the patient who made the complaint?

Building Patient Trust Tip Sheet: *Based on Patient Feedback*

- **Earn patients' trust.**
 - Trust is not a given, it is earned through the development of these relationships.
 - Mutual trust reduces patient fear and staff defensiveness.
- **Make your patients feel that they are a valued part of the team.**
 - Let them know they are a partner in their care.
- **Explain things.**
 - Talk to your patients about what you are going to do before you do it so they know what to expect.
- **Be considerate.**
 - Acknowledge a patient's pain or discomfort. Apologize when you can tell that a needle stick hurts them.
 - Respond genially when a patient tells you that you have hurt them.
 - Speak the same language as your patient when addressing others whenever possible.
- **Be understanding of your patients' challenges in following their treatment plans.**
 - Expect occasional failures and recognize that perfection is an ideal, not a reality.
- **Create a sense of inclusiveness and privacy.**
 - Sit down and speak to patients at eye level.
 - When possible, pull your chair in close to create as much privacy as possible.
- **Listen actively, compassionately, and completely.**
 - Allow a patient to express his or her concern without interrupting.
 - Try not to react negatively.
- **Allow the patient to express his or her emotions.**
 - Actively listen when patients need to vent their fear, anger, and/or frustration.
- **Let patients tell other patients that there won't be retaliation if they speak up about a concern.**
 - Ask patients who have utilized the internal grievance process successfully to talk to other patients at the facility.
- **Offer different ways for patients to express their concerns about treatment or care.**
 - Provide an anonymous form or suggestion box.
 - Offer an electronic process to express concerns.

For the Facility Administrator/Clinic Manager

As the administrator or manager of your facility, it is ultimately your responsibility to ensure that patients feel valued and safe in your facility. Consider:

- How you will monitor changes in staff behavior and/or facility processes that have been identified and agreed upon during this activity.
 - Who will be responsible for monitoring and ensuring change occurs?
- How you will know that you've been successful in decreasing patient fear of retaliation for filing a grievance.
 - Determine how you can measure and document the change.
- Whether or not you need other tools or materials from the Network in order to ensure that retaliation is not occurring in your facility.