PEOC Community of Practice Call

Kidney Patient Advisory Council (KPAC)
April 18, 2018
Why Aren’t More Patients Utilizing Our Network’s Services: A deeper dive and discussion
Patient Panel

- Robin Blomberg, KPAC Member, Network #16
- Stephanie Dixon, KPAC Member, Network #2
- Joe Karan, KPAC Vice/Chair, Network #7
- Derek Forfang, KPAC Chair, Network #17
When I started dialysis, I didn’t expect I’d have to worry about the clinic that’s supposed to keep me healthy. I’ve seen bugs crawling in between the plastic that covers the light fixtures in the ceiling. I’ve had to call the health department many times to report roaches, blood stains, and lack of adequate cleaning. Dialysis equipment at my clinic malfunctions a lot. I’ve seen workers switch out a machine in the middle of another patient’s treatment because it is malfunctioning. I’ve talked to the clinic administrators to resolve these dangerous situations, but management changes so often that my concerns are always left unaddressed.
Identified clinical quality and safety issues itemized in the Corrective Action Plan issued to the center by the State Department of Health.

Assessed patient experience-of-care issues documented in the CAHPS In-Center Hemodialysis survey, the results of which the ESRD Network reported to the leadership of the dialysis center and its parent corporation, along with numerous recommendations.

Held group discussions and individual interviews with center staff to gather information on their perspectives and concerns regarding provision of care to dialysis patients.

What Were the Results?
Some patient experience issues identified in the patient complaints were:

- Language barriers between staff and patients
- Lack of interactions and communication between staff and patients
- Lack of staff professionalism
- Low staff morale due to stressful patient interactions
- High staff turnover with effects on continuity of care
- Staff gathering and talking and ignoring patients
CHAPTER 4
GRIEVANCES IN A PATIENT CENTERED CARE ENVIRONMENT

We need to understand both Patient Centered Care (PCC) and grievances. There are many definitions of PCC. Some have been created by healthcare organizations and some by advocacy groups. The Forum of ESRD Networks Kidney Patient Advisory Committee defines PCC as:

“Patient driven healthcare delivered in a way that is focused on an individual patient’s values and preferences and involves both sharing information and active shared decision making with patient, family/caregivers, and medical professionals to reach customized, individualized and realistically obtainable goals of care. This is an ongoing process, keeping in mind these goals may change over time.”

In Patient Centered Care:

✓ Patients and families are equal members of the treatment team who are expected to be engaged and share in decisions about their care.
✓ Knowing about their disease, its treatment, and options is a critical part of being able to be engaged.

In a Patient Centered Care environment:

✓ Information is freely offered
✓ Questions are encouraged
✓ Patients are consulted about changes and decisions
The Centers for Medicare & Medicaid Services (CMS) defines a grievance as:

“A written or oral communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party alleging that a Medicare covered ESRD service did not meet recommended standards of safety or civility, or professionally recognized clinical standards of care”.

So if someone feels that care is not safe, that staff is not civil, or that the care did not meet requirements, they may file a grievance about their care with the ESRD Network that covers their area and/or the State Health Department. You may, of course, contact your Network any time you have a question or concern.

Most of the time, problems don’t start out as a grievance. Patients may have questions or concerns, or feel they are not being treated with respect. They may feel that these concerns are not handled by the facility as quickly or as completely as they should be.

There is usually one person on staff that a patient or family member trusts and feels comfortable talking with when a problem comes up. This is the best place to start. In a true PCC environment, there should be several people like this, including at least one Facility Patient Representative (FPR). An FPR is a patient in the same center that has had some training and agrees to speak for patients with the leaders of the facility. One or more FPRs may be on the Governing Body of the facility or involved in a Patient-Family Council where patients, families and staff work together to create a welcoming environment. There may also be suggestion boxes that are used to collect ideas. In a PCC environment, a suggestion to improve is viewed as a successful partnership with an engaged patient.
In a PCC environment patients and families know how to address their concerns. All centers are required by Medicare to post information in common areas about how to file a grievance. This information will explain how to file a grievance at the facility, how to contact their ESRD Network and the State Health Department, and how to report unsafe practices. Many of the dialysis corporations have 800 numbers for grievances to be handled at a higher level than the facility.

If there is not a trusted person you feel you can talk to, or you are not satisfied with the way a complaint has been handled, you may contact either your ESRD Network or State Health Department to look into your complaint.

**REALITY CHECK**

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<tr>
<th>If you contact the Network for help, THEY CAN:</th>
<th>If you contact the Network for help, THEY CANNOT:</th>
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<tbody>
<tr>
<td>✓ Give you names and phone numbers of people you can speak to at your clinic’s corporate offices.</td>
<td>✓ Force a clinic or doctor to accept a patient.</td>
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<tr>
<td>✓ Give you information about Medicare regulations and your rights under Medicare.</td>
<td>✓ Guarantee you can choose which staff members put your needles in.</td>
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<tr>
<td>✓ Contact the clinic and conduct a confidential investigation into your grievance, which may include one or more of the following actions:</td>
<td>✓ Change or get involved in anything that has to do with personnel policies and procedures.</td>
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<tr>
<td>‣ Request medical records</td>
<td>✓ Get a doctor, nurse or patient care technician “fired” or transferred.</td>
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<td>‣ Interview staff members or patients and asking for details about a grievance</td>
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<td>‣ If necessary, visit a clinic in person</td>
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<tr>
<td>‣ Confidential means we will not tell anyone at the facility or clinic your name, unless you give us permission to do so</td>
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CHAPTER 5
BARRIERS TO A SUCCESSFUL GRIEVANCE EXPERIENCE

There may be barriers that you might face through the Grievance Experience. This chapter will identify some of the most common. If you understand these barriers, you can solve problems faster and more effectively.

BARRIERS CAN BE CLASSIFIED IN ANY OR ALL OF THREE CATEGORIES
I. Barriers of Information and Awareness
II. Barriers of Trust and Confidence
III. Barriers of Strength and Ability

1. Barriers of Information and Awareness

1. Know your Patient Rights (Chapter 4)
2. Write your Concerns (sample forms are in pages 24 & 26)
   a. What happened?
   b. When did it happen?
   c. Who was involved?
   d. Who did you talk to about the concern?
3. Follow the Process (Chapter 6)
4. Evaluate how the Grievance Process worked
   e. Is the concern resolved?
   f. If not, are there any further steps you can take?

The first and most obvious barrier to be overcome is a lack of knowledge and understanding of the Grievance Process. The process, at times, can be involved and without a “roadmap” it is easy to get lost.

No two grievances are the same. The process can change from situation to situation and from grievance to grievance. A grievance may be as simple as a verbal complaint or as complicated as a formal complaint to a State Regulating Agency. If certain steps are followed, the grievance experience can be positive and effective.
Do patients know about the ESRD Networks?

54% of patients were aware of Network 17

Of those that were aware of Network 17:
35% learned about it from a poster
30% learned about it from staff
16% learned about it from brochures-
10% learned about it from another patient
Patient Comments

• I don't look at anything hanging up in the lobby.
• I saw the posters in the old clinic but not here. I pointed out where the posters are hanging.
• Too many posters make it overwhelming to focus on one. I ignore all of them
• Sees the food recipes
• They gave us booklets about ESRD Network 17
• I haven't paid that much attention.
• I think this place is fine.
• I am interested in knowing more. Make posters more comfortable to read
• I am blind so I cannot see posters well but staff tells me
• Staff is good about letting patients know about stuff
• I don't stay in lobby long so I don't know
• They go over this at beginning when first started dialysis
• Don't pay attention much to decorations in lobby
II. Barriers of Trust and Confidence

Trust and/or Fear of Reprisal

The most common concern expressed by patients is a fear of reprisal or payback. The fear of reprisal is a natural concern resulting from the vulnerability many patients feel. Unlike grievances filed with a hospital after a patient has been discharged, grievances filed with a unit are processed and investigated while the patient is still dialyzing on the premises.

Any and all grievances filed with your Network can be done:

1. Anonymously (no disclosure/no name given)
2. Confidentially (only the Network knows who you are)
3. With full disclosure (your name is attached to the grievance)

Filing without a name can help to ease this fear. But some Grievances are event specific and the grievant is often obvious. While CMS and the Networks do all that they can to lessen the fear of reprisal, grievances are often emotional. Both staff and patients are only human. Sometimes these emotions lead to poor decisions in talking with each other after a grievance has been filed.

While there have been some proven incidents of reprisal, most units are run professionally and make every effort to handle Grievances without emotion. Many units see this as a chance to improve patient safety and approval.

Confidence

Patients sometimes have a lack of confidence in their view of a concern. They may feel they are over-reacting to something they saw or that no one
Is there a Trust perception issue with the Networks?
“The accountability framework within which providers of dialysis care in the US operate requires strengthening. The Center for Medicare and Medicaid Services (CMS) funds a system of regional End-Stage Renal Disease (ESRD) Networks. Among the purposes of these organizations: Providing assistance to ESRD patients and providers; and, evaluating and resolving patient grievances. In the matter of involuntary discharge from dialysis, dialysis patient advocacy groups have compiled abundant documentation confirming that the ESRD Networks typically provide little meaningful patient support at a time of involuntary discharge. Meanwhile, CMS refuses to ensure that ESRD Networks are held accountable in meeting their prescribed responsibilities to patients. Curious.

It is shocking, then, that in the United States, it is estimated that over 1,000 patients annually are involuntarily discharged from their dialysis clinics. Further, they are often “blackballed” from other local clinics. The consequences for such patients, predominately African-American, are dire. A patient may be unable to find a local clinic that will accept them, thereby being required to travel great distances to receive their thrice-weekly dialysis.”

KevinMD.com Article: Involuntary discharge from dialysis: A health care practice like no other written by Robert Allan Bear, MD Jan, 2017
“I will not insult you with the fact that the ESRD Networks are the main players in these discharges and provide the legal way to “dump” a patient. I thought they were for quality of care of the patients. Patients speaking out on care are fearful of retaliation. Patients discharged have no appeal process and die.”

-Excerpt from Dialysis Advocates Blog
Fear of Retaliation
Does retaliation exist in your facility?

- Yes: 10.00%
- No: 80.00%
Do you believe the fear of retaliation prevents patients in your facility from speaking up about care concerns?
What do you think about the issue of retaliation against patients who speak up about a problem in your dialysis facility?

• I think that at times grievances can be misunderstood because teammates get too close to the patients and instead of stepping back and listening objectively to the concerns of the patients they take grievances as a personal affront which can make the environment strained.

• Most patients are scared of complaining and never speak up

• It is a real issue that needs to be monitored

• happens sometimes
What do you think about the issue of retaliation against patients who file a formal grievance about your facility with the Network or State Survey Agency?

- I feel like if a patient files a formal complaint, that some staff will be upset if it's about them.
- Again, sometimes people take things the wrong way, and a problem can be solved, if it is truly a problem it should be corrected to help the facility improve for all patients.
- I have not witnessed this first hand, but have heard that patients are concerned about this and is one of the biggest concerns as to why they don't file.
- Sometimes, honestly, it is hard to ignore those to complain every week to us, or the Network, or the State about the same issues that we have tried to resolve for them and offered multiple options. It becomes very tiresome for staff and staff do feel like they don't want to work with that patient.
I am wondering how many of you have experienced retaliation --- we are seeing more and more patients complaining of this aspect that is deep rooted in many facilities -- Retaliation comes in many forms, shapes and sizes - - a simple example is the patient who brings forth a concern related to his/her treatment --- the staff's response is a simple facial expression, shoulder shrugging, nodding of the head e.g. moving the head to the left and right showing dissatisfaction with what the patient has stated and various other body language demonstrated -- These, aforementioned, send a clear message to the patient "DO NOT ASK THAT AGAIN OR BRING IT TO MY ATTENTION" -- This starts the chain of patients fear to speak out when there is a problem with care..
else cares. Some may feel that they can’t change the system and that their voice won’t make any difference anyway so why bother.

After thinking about it, if you decide that your concern deserves a grievance, don’t second guess the power of one voice. For every one that speaks up, there may be several that have been too uninterested or too afraid to speak up. If no one steps forward to be heard, nothing will improve.

“You should never second guess the power of one voice”

III. Barriers of Strength and Ability

Perhaps the least recognized barriers to a successful grievance are those of strength and ability. The Grievance process is never easy and can be made even harder by the very things we are working to improve and preserve – the health and vitality of the patient.

Certain groups of patients face greater barriers, such as:

1. Patients in poorer health

2. Patients without the energy to complete the process

   *Dealing with ESRD by itself is a draining situation. Many patients are tired and using all of their energy just coping with the basic needs of life. When the stress of filing a Grievance is added, it may seem like too much to get through.*

3. Patients with language barriers

4. Patients with ethnic or cultural barriers

   *If a language barrier exists, making your concerns known and understood will be much more difficult. Being able to present your point of view well and understand the other side becomes less likely with a language barrier.*
Patient Experience
Robin Blomberg
Patient Experience

Stephanie Dixon
What more should we do?

• NKF Spring Clinical Session (4/12/2018)
  “Grievances: Creating a Safe Environment for Patients to Speak Out”
  Anne Pugh & Derek Forfang

• Forum KPAC Retaliation Subcommittee

• Forum Webinar May 2\textsuperscript{nd} – Community Event

Registration Information:
Next Steps?

Thank you for having us

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