THE EXPERIENCE OF CARE:
PATIENTS AND PROVIDERS AS PARTNERS

Patient & Provider Engagement:
Forging True Partnerships and Changing the Culture
Moderator

Jay Ginsberg, MD, MMM
Southeastern Connecticut Nephrology Associates
Co-Chair, Quality Conference Planning Committee
Past-chair, Forum Medical Advisory Council
Past Board Member, Forum Board of Directors
THE EXPERIENCE OF CARE: PATIENTS AND PROVIDERS AS PARTNERS

A 3-part Webinar Series

Improving Patient Experience of Care:

- How to change the way we look at patient experience of care
- How to use new information to improve the patient experience of care
- Breaking down barriers to communication
ACKNOWLEDGEMENTS

American Association of Kidney Patients for their generous financial donation supporting this webinar series

Northwest Renal Network (#16) for supporting and coordinating the social work and nursing CEs
Acknowledgements

Thank you to...
Fresenius Medical Care-NA
DaVita
Dialysis Clinic, Inc.
National Renal Administrator's Association
Renal Physicians Association
The Patient Perspective:
What is the experience of care?
Are we asking the right questions?

The Provider Perspective:
What do we learn from experience of care surveys?
Can we do better?

Patient and Provider Engagement:
Forging true partnerships and changing the culture

September 14
October 19
November 9
WEBINAR #3

Patients & Provider Engagement

Forging True Partnerships & Changing the Culture

- Explain the importance of facility culture, as cultivated by staff and patients, as it relates to ESRD patient engagement
- Describe how peer mentoring supports patient involvement and improves the patient experience of care
- Discuss methods to incorporate life goals and values to improve the experience of care
Finding and Harnessing the Patient Voice

Jennifer E. Flythe, MD, MPH
University of North Carolina Kidney Center
Chapel Hill, NC
Frequent congregation
Shared interest
Inertia. Sadly, so many kidney patients just become complacent... the minute they step in-center [for dialysis], they’ve given up. [63y F]
PATIENT ADVOCACY

- Research priorities
- Clinical benchmarks
- Drug and device R&D
- Disease prevention
- Health Policy
- Funding
- Community education
Study Objectives

• To elicit knowledge and perceptions of chronic kidney disease (CKD)-related advocacy among hemodialysis (HD) patients

• To gather ideas for generating advocacy enthusiasm in the dialysis community

**CKD advocacy:** the act of speaking out on behalf of persons with CKD or on behalf of a CKD-related cause
Methods

• Semi-structured interviews

• Thematic analysis

• Selection criteria
  • Age ≥ 18 years
  • On dialysis ≥ 6 months
  • English-speaking

• Local (NC) dialysis facilities and national patient advocacy groups
<table>
<thead>
<tr>
<th>Interview Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dialysis, health and research experience</td>
</tr>
<tr>
<td>Perceptions of ability to influence care/health</td>
</tr>
<tr>
<td>Advocacy knowledge and perceptions</td>
</tr>
<tr>
<td>Personal advocacy experience</td>
</tr>
<tr>
<td>Advocacy motivations</td>
</tr>
<tr>
<td>Patient and interview characteristics</td>
</tr>
<tr>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Age (y)</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>Prior kidney transplant</td>
</tr>
<tr>
<td>Dialysis vintage (y)</td>
</tr>
<tr>
<td>Dialysis modality</td>
</tr>
<tr>
<td>In-center HD</td>
</tr>
<tr>
<td>PD</td>
</tr>
<tr>
<td>Home HD</td>
</tr>
<tr>
<td>In-person interview</td>
</tr>
<tr>
<td>Interview length (minutes)</td>
</tr>
</tbody>
</table>
Awareness and interest

• Generally aware that advocacy organizations and patient support groups exist but many unaware of how to connect with such groups

I think there’s a lot of people out there that want to do it, but they don’t know how to find each other. [51y M]

There’s none to get involved with. There’s many people that I’ve asked to see if there was something I could start up or something that I could participate in. They had no recollect of anything that would be out there for us. [69y F]
Motivations

- Help others
- Enhance quality of life, purpose
- Educational gains

I just felt I had to do something… It makes [me] feel better that I’m doing something for a greater good. [50y M]

Well it gives me a purpose… I mean, I’m not just trying to help myself. I’m trying to help other people because I know this is hard for us to go through. Hemodialysis is just difficult. [67y F]

I wanted to know more. Because sometimes I feel like patients have been left out of things. [41y F]
Importance of being asked

- Key figure invited participation
- In-person communication

So, I had an annoying, renal social worker who saw that I was depressed or being apathetic about the whole thing and unengaged. She explained to me that I need to be more involved since I’m the one being impacted. So, slowly but surely, she got me interested in various organizations and where there were gaps that I could fill. [51y M]

You have to have someone who motivates them or interests them, puts a little bug in their ear. [69y F]
Advocates vs. non-advocates

• Advocates tended to have greater education and income than non-advocates
  ➢ **BUT** resource barriers were overcome by many motivated patients who reported sparse personal resources

• Regardless of advocacy classification, almost all participants felt that their personal abilities to participate in advocacy were on-par with the abilities of other patients
  ➢ **Disconnect** between patient and provider perceptions of ability

• Most non-advocates were never invited to participate
  ➢ **Selective invitations** may contribute to low participation levels
Patient suggestions for promoting advocacy

- In-person invitations
- Information delivered by patients to patients
- Incentives and enablers

I think knowing that they could make a difference; that their opinions matter and just having them feel they’re somewhat empowered to make a difference. [68y M]

I don’t want no Internet. I just want it to be verbal, [so] I can talk to people like you’re talking to me. [41y F]

They’re in the chair, they don’t want other people to get in the chair, so they would speak from their personal point of view what it’s been like to them. [64y M]
Patient suggestions for promoting advocacy

<table>
<thead>
<tr>
<th>Incentives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Food, entertainment, prizes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Enablers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Dialysis facility as event location</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient-led, patient-designed events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and education programming</td>
</tr>
<tr>
<td>Support groups</td>
</tr>
<tr>
<td>Social events</td>
</tr>
</tbody>
</table>
Patient-led, patient-designed events

- Capitalize on shared experiences
- Provide education
- Provide opportunity for patients to be heard
- Empower patients
- Demonstrate potential impact with past examples
Importance of dialysis facility culture

I think clinics that have mentors and involve patients in how the clinic runs get more patients engaged and involved. It’s hard, if you’re at a clinic and you’re not engaged, to all of a sudden jump on board with some organization -- I think that’s a difficult leap. The dialysis experience itself needs to be somewhat positive, as much as it possibly can be at least. So I think it all starts at the clinic level. [49y M]

I think I would let the patients help design it… I think it might be a different answer for every center. [60y M]
Summary

• Untapped potential patient advocacy in dialysis community
• Need for education and outreach
• Avoid selective invitations (be inclusive)
• Importance of local, in-person, patient-led initiatives

Sometimes, you just have to talk to them. [69y F]
Patient Provider Collaborations: Practical Applications Using Peer to Peer Mentoring

Jennifer St. Clair Russell, PhD, MCHES
Duke University

November 9, 2016
How did this begin?

- Funded by Medicare
- May 2014 – December 2015
- Governmental Task Leader Shiree Southerland, PhD, RN, BSN
- Contracting Officer’s Representative Edwin Huff, PhD, MA
Where was the program?

- University of Virginia Lynchburg Dialysis

- 249 in-center patients
  - 43 chairs
    (includes 1 isolation chair)
  - 6 shifts

- 53 home patients

- Only facility in Lynchburg
How did *Peer Up!* work?

- 4 month Program (March – June 2015)
- Mentor/Mentee pairs
- “Bookend” program with social mixers
- Training required for Mentors
What did the participants do?

- Peer pairs asked to talk at least once per week during intervention (total of 16 interactions for program period)
  - At least 2 meetings per month in-person (total of 8 in-person meetings for program period)
  - Remaining meetings can be by phone or email

- Peer meetings were held at the facility (in the treatment bays or lobby) or offsite, if mutually agreeable

- Mentors completed a meeting log after each interaction capturing information such as length of visit, location, topics discussed, use of any informational materials, and any referrals to staff
What were the results?

- **Mentees**
  - Increases in...
    - Knowledge
    - Self-Efficacy
    - Social Support
    - Dialysis Support
    - Quality of Life
  - Decrease in...
    - Missed Appointments

- **Mentors**
  - Increases in...
    - Knowledge
    - Dialysis Support
    - Dialysis Self-Management
How can I implement **Peer Up!**?

Contents include...

- Program Background & Overview
- Program Management
- Recruitment & Retention
- Mentor Training
- Patient Support Resources
- Assessments/Evaluation

[www.esrdnet5.org/Peer-Up!-Program-Toolkit](http://www.esrdnet5.org/Peer-Up!-Program-Toolkit)
Questions???

Jennifer St. Clair Russell
Email: Jennifer.Russell@duke.edu
Phone: 919-668-2362

Mid-Atlantic Renal Coalition
Nancy Armistead, Executive Director
narmistead@nw5.esrd.net
Website: www.esrdnet5.org
Phone: 804-320-0004

This work was performed under CMS Contract Number HHSM-500-2013-NW05C. The conclusions and opinions expressed and methods used herein are those of the author and do not necessarily reflect CMS policy.
Practical Approaches to Identifying Patient Goals & Values

Dori Schatell, MS
Executive Director
Medical Education Institute
Goal-Setting: How to Motivate Your Patients to Move Forward

Dori Schatell, MS
Executive Director
Medical Education Institute
MEI Mission: Help people with chronic disease learn to manage and improve their health.
What We’ll Cover

- Challenges to working with ESRD patients
- The importance of MOTIVATION & HOPE
- How to help patients move toward their goals
Challenges to Working with ESRD Patients
DIALYSIS IS A TSUNAMI IN PATIENTS’ LIVES
STRONG EMOTIONS ARE NORMAL
TERROR, ANGER, DEPRESSION...
PEOPLE CAN’T LEARN WHEN THEY ARE SCARED

Importance of Motivation & Hope
HOPE & DIALYSIS ADJUSTMENT

N=103 UK adults on dialysis\(^1\)

Higher levels of hope predicted:
- Less anxiety
- Less depression
- Reduced burden of kidney disease
- Better mental functioning

“Hopefulness could serve to lessen the emotional impact of ESRD and treatment by empowering the individual to reframe threats as challenges”

\(^1\)Billington E et al. 2008 *Br J Health Psychol.* 13:683-99
HOW Do We Offer Hope?

- Help patients reach THEIR life goals
- Teach ALL of the treatment options
- MATCH treatment to preferred lifestyle
- Share stories of successful patients
- Foster peer support
CMS Requires Dialysis to be Patient-centered

- 494.70(a) (Vtag 456): The patient has the right to be informed about and participate, if desired, in all aspects of his or her care

- 4949.80(a) (Vtag 512): The patient’s comprehensive assessment must include, but is not limited to, evaluation of the patient’s abilities, interests, preferences, and goals, including the desired level of participation in the dialysis care process, the preferred modality and setting, and the patient’s expectation for care outcomes
Make Your Clinic More Patient-Centered

- Care for *yourself* so you can give the most to your job
- Introduce yourself
- Explain what you are doing
- Give choices
- Get an interpreter when needed

Patient-Centered Care Improvement Guide – Picker Institute
http://www.planetree.org/Patient-Centered%20Care%20Improvement%20Guide%202010.10.08.pdf
<table>
<thead>
<tr>
<th>Not so good</th>
<th>Much better</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, or I can’t</td>
<td>What I can do is…</td>
</tr>
<tr>
<td>I don’t know</td>
<td>I’ll find out for you</td>
</tr>
<tr>
<td>That’s not my job</td>
<td>I’ll get someone to help</td>
</tr>
<tr>
<td>You’re right, this stinks</td>
<td>I understand your concern</td>
</tr>
<tr>
<td>That’s not my fault</td>
<td>Let’s see what we can do about this</td>
</tr>
<tr>
<td>We’re short-staffed</td>
<td>Tell me how I can help</td>
</tr>
<tr>
<td>I’m busy right now</td>
<td>I’ll be with you in just a moment</td>
</tr>
</tbody>
</table>

Patient-Centered Care Improvement Guide – Picker Institute
http://www.planetree.org/Patient-Centered%20Care%20Improvement%20Guide%202010.10.08.pdf

**Foster a Collaborative Atmosphere in Your Clinic**
WE Are All Patients, Too!

Do unto others as you would have them do to you
How to help patients move toward their goals
What is a Goal?

- VISION for how things should be
- Important TO THE GOAL SETTER
- Can be SHORT, MEDIUM, or LONG-TERM
How Do You Learn Patients’ Goals?

- ALLIGN – Show that you care. Build a relationship.
- ASK “What Matters to You?” - They may tell you
- LISTEN – “I wish I could…” “I used to love…”
- COACH – “It seems like you might want to…”
Break Goals into Steps

Good Goals Are:

- Concrete
- Measurable
- Realistic
- Time-limited
- Accountable

Help Patients Match Treatment Options to Their Life Goals

If your kidneys fail, dialysis can save your life.
But, dialysis is not just a medical treatment.
It can also affect every aspect of your lifestyle.

This tool will help you choose the right treatment for you so you can feel your best and live the way you want to.

www.mydialysischoice.org
CONCLUSIONS:

- ESRD causes chaos and a storm of emotions
- Hope—and motivation—help people cope & move forward
- We can help patients by helping them set and reach goals
AUDIENCE POLLING QUESTION
Use the “Question” box on your GoToWebinar panel to submit your questions.

All unanswered questions will be reviewed by our co-chairs and speakers; they will be summarized in a Q & A document which will be posted to the Forum website after the webinar.
THANK YOU FOR JOINING US

Recordings and Slides of Each Webinar
Available at the Forum Website

www.esrdnetworks.org