Beyond Webster:
Defining What Patient and Family Centered Care Really Means to the Renal Community and the Renal Patient

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Do you feel your organization/facility currently embraces Patient/Family Centered Care?

- Yes: 101
- No: 2
DEFINING PATIENT AND FAMILY CENTERED CARE

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Patient Centered Care:

is 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.

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Patient’s Perspective: Lessons Learned

What was Good?
• Support and Encouragement from Staff
• Abundance of Information
• Coordination of Benefits

What Could be Better?
• Information when I need it, how I need it
• Transitions of Care
• Good for Business ≠ Good for Every Patient
• Metrics do not improve patient “performance”
Patient’s Perspective: Lessons Learned

What is the Reality?
- Living with a chronic illness is not unlike being in a long-term relationship
- It’s not about you, it’s about me

How Do We Bridge the Gap?
- Patient understanding and focus shifts as variables are introduced
- More stable = Less Risk Tolerant
- More unstable = More Risk Tolerant
- Leverage our story telling culture
Patient and Family Centered Care

Meeting the Metrics of the QIP

- Patient engagement necessary to meet the QIP measures
- Patient and family involvement in the development of the POC vital to the facility meeting the QIP measures
- Patient and family engagement can help with patient adherence which translates into improved outcomes
• Largest non-profit dialysis provider in the U.S.
• Founded in 1971 (44 yrs ago)
• Serving over 17,000 patients with kidney disease
  ➢ Over 2,600 patients with CKD
  ➢ Over 14,800 patients on dialysis
• In more than 230 clinics
• Across 28 states
If I had Kidney Disease...

- “I want to avoid dialysis”
- “Please tell me what I can do to make it less likely that I will need dialysis”
If I need to start dialysis, can you push back the time that I need to start?

- Can you slow progression of my CKD?
- Can you wait to start me on dialysis until I have symptoms?
If I had Kidney Disease...

- I would like to know my choices in therapy, and I would like to discuss them early, so I have time to decide
- And I want to know that one of my choices is not to choose dialysis
If I had Kidney Disease...

- I would like to receive a kidney transplant
  - Can you help me get on a transplant list?
  - Can you help with talk with others about organ donation?
If I choose dialysis, I want my care to fit my schedule instead of being required to fit my schedule to my dialysis care.

Can you tell me more about home dialysis?
If I had Kidney Disease...

- I want to be able to die with dignity
  - If the burden of my treatment outweighs its benefit, please help me to find a palliative care provider and a hospice provider
**Conclusion**

- QIP and Five Star are important, but are only a floor.

- If we have a five star clinic without a QIP penalty, but then stop and do not look at ways to further improve care, we are not providing patient centered care.

A renal community collaboration  March 23–24, 2015
If you have Kidney Disease in SC

- CKD Clinic
  - One on One Care
  - Education and Navigation Services
  - Stage 1 – 5
  - Long term follow up

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If you have Kidney Disease in SC

- Focus is on each individual’s needs
  - Diabetes, Hypertension, Obesity, Cardiac Health, Kidney Health, CKD Complications and Modality and Access
  - Medication Therapy Management
  - Nutritional education and counseling
  - Education provided at the right time and place on the right level for each person
Empowering Patients To Live Their Dreams