



PATIENT ENGAGEMENT LEARNING
& ACTION NETWORK

2014 Quality Improvement Activity

Patient and Family Group Meetings



END STAGE RENAL DISEASE
NETWORK OF TEXAS

2014 Quality Improvement Activity (QIA) Objectives

- To promote **patient and family groups** by teaching dialysis staff members:
 - How sustainable patient and family group meetings are **structured**
 - How to utilize **Facility Patient Representatives** to support sustainable patient and family group meetings
 - How patient and family groups improve patient **quality of life** and **Patient- and Family-Centered Care (PFCC)** in facilities
 - How patient and family groups **benefit facility staff** members

What is Patient- and Family-Centered Care?

- Nothing **ABOUT** me **WITHOUT** me!
- It means that we who offer health care stop acting like hosts to patients and families, and start acting like guests in their lives.
 - Don Berwick, former CMS administrator

Patient and Family Engagement

- What does it mean to dialysis patients?
 - “**Patient Engagement** is a patient being completely involved with their team, with the physician, the dietitian, social worker and tech when you’re in-center and being completely involved with everything that goes on as far as the dialysis treatment.”
 - “**Patient Engagement** is being able to ask questions about things you’re not familiar with like calcification.”
 - “**Patient Engagement** is not being afraid to ask questions. I’m learning that the only dumb question you have is the one you don’t ask. Don’t be afraid to ask and ask again until you understand.”

- 2013 PE LAN Patient Subject Matter Experts

Patient and Family Group Meetings

- **Patient and family group meetings:**
 - are regularly scheduled meetings
 - focus on the needs of a group of patients and their families
 - include at least one patient in the meeting planning process

- **Patient and family group meetings are held:**
 - in private to promote trust and confidentiality
 - primarily at the dialysis facility
 - at an offsite location if it is appropriate for a specific population
 - e.g. a dialysis facility and transplant center collaborate on a transplant support group held at the transplant center

Patient and Family Group Meetings

- Patient and Family Group Meetings include:
 - Patient Advisory Councils
 - Support Groups (for patient and/or care partner)
 - Patient Advocacy Groups
 - Vocational Rehabilitation Groups
 - New Patient Adjustment Groups
- Plan of Care meetings are NOT the same as Patient and Family Group Meetings!

Patient and Family Advisory Councils

- Creating an advisory council allows a facility to:
 - Understand and address patient and family concerns
 - Consider the voice of the patient in decision-making
 - Increase patient safety
 - Improve ICH-CAHPS scores by improving the patient experience of care
- Facilities with active patient and family advisory committees experience:
 - reduced errors
 - better health outcomes
 - increased patient loyalty

Support Groups

- Support groups address patient and family needs:
 - Social
 - Emotional
 - Psychological
- Support groups promote self-care and disease management
- Support groups improve the quality of life for individuals with kidney disease and their families

Patient Advocacy Groups

- Informed patients have the ability to advocate for quality care and improved patient experience of care
- Patient advocates can improve communication by serving as intermediaries between patients and staff
- Each facility should have at least one Facility Patient Representative (FPR), who may serve as an advocate for the other patients

Vocational Rehabilitation Groups

- Vocational Rehabilitation groups provide support, education, and resources to patients before, during, and after their return to the workforce.
- Facilities should consider this type of group if they have home hemo patients or workforce-age patients.

New Patient Adjustment Groups

- Individuals new to dialysis will benefit greatly from interaction with positive, engaged peers
- New patient groups enable patients with high health literacy to coach and/or mentor patients that are new to dialysis
- Individuals with ESRD can continue to enjoy a good quality of life through self-management
- Patients that model healthy behaviors often encourage new dialysis patients to become engaged in their care

How are sustainable patient and family group meetings structured?

- Patients are **involved in planning** and promoting the meetings
- The group's **purpose** matches the patients' **needs**
- Family members are treated... like **family!**
- Patients and families have an **incentive** to attend
- Staff and patients have **realistic expectations**
- Staff members, patients, and families hold each other **accountable**

Patient Self-care

- **“Self-care is defined as the actions individuals take:**
 - to lead a healthy lifestyle;
 - to meet their social,
 - emotional and
 - psychological needs;
 - to care for their long-term condition;
 - and to prevent further illness or accidents.”

Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Pat Educ Couns* 2002;48:177-87.

Benefits of Patient and Family Group Meetings

▪ Patients

- Patient and family group meetings increase **health literacy**
- Higher health literacy leads to better **self-care**
- Better self-care reduces **hospitalizations** and **missed treatments**
- Fewer missed treatments contribute to better **clinical outcomes**

▪ Staff

- Staff can hold educated patients **accountable** for lifestyle choices
- Patients that successfully manage their health require **less time and less energy** from staff



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Spread Awareness

- In the last six months (January 1 – June 30, 2014), the number of patient and family group meetings offered by this facility was **[Enter # of Groups]**
- Our facility offers the following type(s) of patient and family group meetings:
 - **[Add Group 1]**
 - **[Add Group 2]**
- The next patient and family group meeting is scheduled for:
 - **[Add Date]**
 - **[Add Time]**
 - **[Add Location]**
- The Facility Patient Representatives that co-facilitate our group(s) are:
 - MWF: **[Add Name]**
 - TTS: **[Add Name]**
- If a patient or family member has questions about our group meeting(s), please ask them to contact **[Add Staff Member's Name]**.

Patient and Family Group Resources

Patient and Family Advisory Councils

- Patient and Family Advisory Councils: A checklist for getting started. Institute for Patient– and Family –Centered Care, http://www.ipfcc.org/advance/IFCC_Advisoryworkplan.pdf.
- Working With Patient and Families as Advisors: Implementation Handbook. U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality, http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf.

Support Groups

- Meetings/Support Group. Renal Support Network, <http://www.rsnhope.org/meetingsupport-group/>
- Tips to Coping with Chronic Kidney Disease. National Kidney Foundation, http://www.kidney.org/patients/pdf/ff_su05.pdf.

Patient Advocacy Groups

- American Association of Kidney Patients, <https://www.aakp.org/advocacy.html>
- Dialysis Patient Citizens, <http://www.dialysispatients.org/advocacy>

Vocational Rehabilitation Groups

- Employment: A Kidney Patient's Guide to Working and Paying for Treatment. Life Options, <http://lifeoptions.org/catalog/>

New Patient Adjustment Groups

- Peer Mentoring. Network 8 , Inc. Patient Engagement Learning and Action Network, <http://www.esrdnetwork8.org/renal-disease-patient-information/patient-assets/LAN-Peer-Mentoring-Fact-Staff.pdf>
- Peer Mentoring. Northwest Renal Network's Patient & Family Engagement Learning and Action Network, <http://www.nwrenalnetwork.org/QI/LAN/PeerMentor.pdf>

Questions?



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Thank you!