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Support Group Creation and Maintenance Best Practices:

*Supporting the mental health needs of patients,
family members and caregivers through support
groups*

August 8, 2019

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Agenda:

- **Overview of the Network**
- **Patient and Family Engagement Goals**
- **Implementation and Maintenance of Support Groups**
 - Association between Dialysis Patients and Depression
- **Best Practice Facility**
- **Patient Feedback**
- **Closing Remarks**

Learning Objectives

- Learn new ways to implement support groups
- Understand the role of support groups in the patients' overall satisfaction of services
- Recognize the aspects of support groups that your facility has already implemented

Network Overview

About the Network

“The Mission of the IPRO End Stage Renal Disease (ESRD) Network Program is to promote health care for all ESRD patients that is safe, effective, efficient, patient-centered, timely, and equitable.”

ESRD Network 2 supports over 30,000 dialysis patients and conducts a series of patient/family engagement, grievance processing, education and quality improvement activities.

Patient Services Department

The Network's Patient Services Department evaluates and resolves grievances from patients, their families, and their representatives. We also provide technical assistance to dialysis facilities to help them effectively meet the needs of their ESRD patients.

- **Technical assistance can include intervention implementation, resource distribution on how to effectively meet the psycho-social needs of their patients, and improving patient satisfaction of services.**

Patient and Family Engagement

Patient and Family Engagement Goals

- **Increasing patient inclusion in dialysis facilities during QAPI meetings**
- **Increasing facilities allowing patients to provide feedback on care-planning policies**
- **Implementation and maintenance facility based support groups**

PFE Goal:

Implementation and Maintenance of
Support Groups

Depression and Dialysis

“One in five people will be affected by mental illness in their lifetime. About 22.1% of American adults fit the criteria for a mental disorder ⁽²⁾. More than 10% of American adults have a depressive disorder and 13.3% are diagnosed annually with an anxiety disorder ⁽²⁾. The incidence of mental illness among dialysis patients is believed to be higher, it has been suggested that more than 44% of dialysis patients met the criteria for depression” (Prescott,2006)

- **“Depression: the overlooked complication of kidney disease”**
 - Depression is associated with:
 - Association of depressive symptoms and morbidity
 - Increased mortality
 - Higher peritonitis rates
 - Increased hospitalization (Cukor, 2017)

Support Groups

Support Groups provide patients and family members the opportunity to share personal experiences, feelings, coping mechanism with likeminded individuals

- **A well facilitated support group will help a patient or individual to heal after a trauma or a traumatic loss**
 - Support groups guide individuals in the mourning and adjustment period
 - Allows them to share their experiences in the own time and in their own way
 - Reconnect with their new lifestyle

Steps to Creating a support group

- **Tuning in to your audience**
- **Organizing a group**
- **Establishing guidelines**
- **Maintaining Confidentiality**
- **Creating a safe place for feelings**
- **Respecting Boundaries**
- **Supporting the phases of recovery and healing
(Bronson, 2019)**

Best Practice Facility



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Dialysis Support Groups

Creation and Maintenance

Kimberly Ward, LMSW

DaVita East Islip Dialysis

NEEDS ASSESSMENT

- This was completed by the social worker and the social work intern speaking with the patients chairside.
- Questions included: what day, time, topics, and location the patients would prefer.

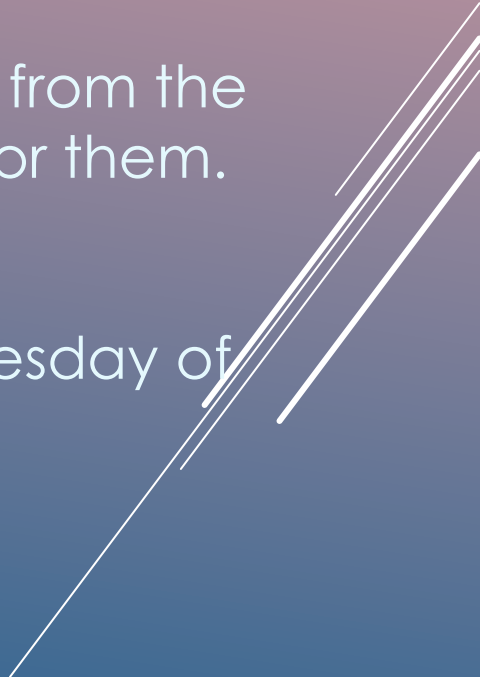
FINDINGS



After reviewing and comparing results from the needs assessment, there were some consistencies among the answers regarding location, day, time and topics.

I continue to meet with patients and discuss what their preferences are and if they have changed from the original needs assessment.

HOW WE STARTED

- Based on the needs assessment, we started meeting on Saturdays.
 - After each group, we requested feed back from the patients on how the day and time worked for them.
 - The group day was changed to the third Tuesday of each month to create more consistency.
 - Be flexible based on patients needs.
- 



GROUP AGENDA

An agenda was developed for each group based on the requests from the patients the month prior. This included:

- ❖ Ground Rules
- ❖ Introduction/ice breaker
- ❖ Requested topics to review (understanding kidney disease, coping skills, diet, quality of life, blood test definitions from kidney smart, quality of life, and symptom management.)
- ❖ Reviewed any additional, questions, concerns, grievances from the patients.
- ❖ Then closed with a relaxation technique (ie. Deep breathing, visualization, progressive muscle relaxation, guided imagery.)

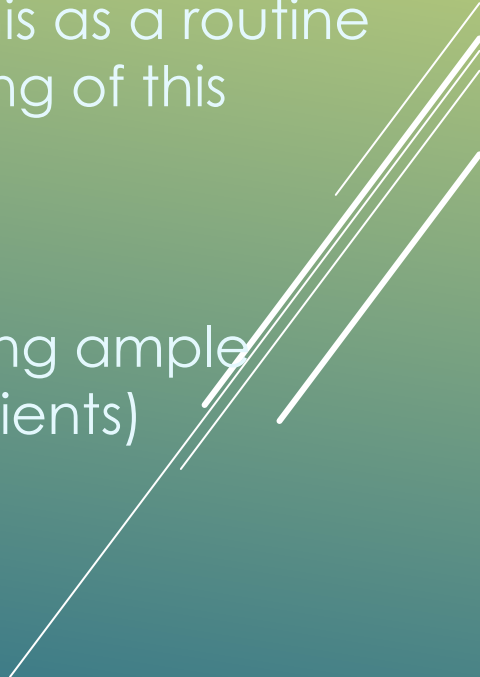
BARRIERS

- Transportation issues, difficulties with transportation being covered or family not being able to transport the patient.
- Inclement weather impacting attendance
- Language accommodations
- Managing Social Work workload and a support group.
- Lack of attendance impacting other patients wanting to come back to the support group

ADDRESSING THE BARRIERS

- ❖ Transportation: This can be a barrier on any regular day, but we can avoid this impacting our patients by being proactive.
- ❖ Inclement weather: Communicate with the patients of any changes or if the meeting will still be held.
- ❖ Language accommodations: Translation services, family, friends to sit in and interpreter

ADDRESSING THE BARRIERS CONT.


- ❖ Social Work caseload: It can be difficult incorporating a support group into our clinic. Incorporating this as a routine discussion in our rounding can lessen the feeling of this becoming an additional task.
 - ❖ Lack of attendance: Consistency and providing ample notice is key. (Idea: hand out fliers for the patients)
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DIALYSIS SUPPORT GROUP FLIER



- ❑ The flier was hung in the lobby area and handed out to patients a week prior.
- ❑ Patients were also provided a copy when a referral was made for community resources
- ❑ The flier was also distributed to other DaVita centers in the community.


SUCCESSFUL PRACTICES

- Get the patients involved!
 - Utilizing all resources- include your team
 - Interns-Taking interns from colleges each year has been a valuable addition.
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SUCCESSFUL PRACTICES CONT.

- Reminders for the patients.
- Finding a patient advocate/PAC representative to be involved in the support group.
- Having guest speakers has been a great way to educate patients in a different light.
- Don't give up!

POSITIVE OUTCOMES

- ❖ Sense of community
 - ❖ Form new relationships
 - ❖ Having a support system
 - ❖ Learning coping skills and relaxation techniques
 - ❖ Improvements in blood work and fluid management
 - ❖ Modality education peer to peer
- 

Imagine
With all
your mind.
Believe
With all
your heart.
Achieve
With all
your might.

LET US GIVE OUR
PATIENTS THE
ABILITY TO
BENEFIT FROM A
SUPPORT
GROUP
RESOURCE!

Decorative white lines consisting of several parallel diagonal strokes in the bottom right corner of the slide.

Patient Feedback

NPFE LAN Support Group

The NPFE LAN took live polls from patients to fully understand their interest and perspectives of support groups:

- If the name “support groups” deterred participants
- If patients were open to participating in alternative support variations
 - Online
 - Telephone
- The topics that they were most interested in discussing in their support group
 - Mental Health
 - Treatment Options
 - Caregiver Burnout
 - Transplant process
 - Treatment Modalities

Call to Action

- **Conduct an informal assessment of your target audience**
 - Tune in and observe the conversations that are being discussed in the lobby
 - Gauge their interest
 - Use the overall themes as the foundation for the support groups
- **Assess the previously discussed barriers, try to create the support group to counteract these barriers**
 - I.E. Transportation is a potential barriers
 - Start a telephone or online support group
- **Engage your facility's patient advocates, allow them to engage in informal support groups with patients.**
- **Expect to get a package from the Network with on Write-Poster, other materials that were previously cited throughout the presentation**

Best Practice Contest

On September 18 the Network will be choosing a facility that has demonstrated best practice strategies in the implementation of a support group, patient inclusion in QAPI, and patient feedback in care planning.

- By the first week of September please start submitting a short description of how your facility incorporated the strategies discussed in this presentation to foster a support group
- The Winner will receive a certificate, and will be acknowledged in our next Patient and Family engagement presentation on September 25, 2019 and our monthly PFE Newsletter.
- E-mail: dandrews@nw2.esrd.net

Questions or Comments?



Thank You!

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References

Bronson, M. (2019). What Do You Need to Start Your Own Support Group? Retrieved from <https://www.phoenix-society.org/resources/entry/start-your-support-group>

Cukor, Ph.D D. (2017). Depression: The Overlooked Complication of Kidney Pain. Retrieved from <http://www.kidneyfund.org/assets/pdf/training/depression-and-kidney-disease.pdf>

Prescott, M. (2006). Managing mental illness in the dialysis treatment environment: A team approach. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/17168057>