Working with Young Adult Dialysis Patients:
Engaging the 18-30+ Age Group

Did you know?

- Young adults comprise only about 3% of the ESRD population. Thus, facility staff may not have a lot of experience caring for them.
- Young adults have poorer health outcomes as compared to other adult populations.
- Young adults may be embarrassed to admit they are on dialysis.
- Few young adults discuss their illness and dialysis with peers, an important source of support for this age group.
- Decreased physical ability challenges/frustrates this age group more than older patients.

Why do they miss so much treatment?

- The young adult age group is more likely to miss treatment and hide symptoms.
- Young adults may be more stressed by dialysis.
- Young adults are more confused about their illness.
- Young adults may deny their illness, refuse external assistance, and withdraw from social activities.
- Young adults have higher rates of depression and anxiety.
- They often feel like they don’t fit in at dialysis.
- Scheduling time for dialysis is challenging for young adults, as there may be competing demands for time such as work, school, children, etc.
Challenges for staff...

- Young adults have needs that largely differ from the rest of the patient population.
- Young adults can be very difficult to engage.
- Non-adherence and denial of illness may represent coping skills for this age group.
- Anxiety, depression, and challenging behaviors may result from a feeling of helplessness or loss of control.
- Anxiety may manifest in behavioral outbursts.

What can Staff Do?

- Keep in mind... Not only are these patients dealing with serious illness, this age group is still engaged in developmental tasks such as forming intimate relationships and gaining independence. Young adults’ brain development may be at a stage where risk-taking behavior is increased and problem-solving and long-term planning are difficult tasks.
- Education: Young dialysis patients may need additional education on illness, dialysis, symptom burden, staff roles and adherence from friendly and supportive staff.
- Root Cause Analysis: Patient anxiety or depression may often be interpreted as challenging behavior, while the root cause of the emotional distress is overlooked.
- Social Work Intervention: Therapeutic social work interventions, in the form of open and supportive communication can be extremely beneficial.
- Increase Self Efficacy: Staff can increase patient’s sense of self-efficacy by encouraging patient self-care, exercise, and vocational rehabilitation.
- Encourage Social/Peer Support: Social support has been shown to be very helpful for young adults. Young adults may want to talk to their dialysis peer group about their experiences. (See Resource Section).
- Modality change: Home modalities may increase a patient’s sense of control; allow flexibility, normalization, and time for socialization.
- Utilize Resources: The Resource Section may assist you in working with young patients

Staff Resources

Working with Young Adult Dialysis Patients 4/13/2012
The Renal Network, Inc.
The mission of The Network is facilitating the achievement of optimal wellness for renal patients. Network staff is available for inquiries or to help with resolution of patient issues.
www.therenalnetwork.org / 317-257-8265

Adherence Toolkit
The Network website provides educational tools on adherence as well as other patient issues.
http://www.therenalnetwork.org/services/non-adherence.php

Kidney Patient News
The Network maintains a patient-oriented web site that includes stories from patients, diet information and monthly updated information.
www.kidneypatientnews.org

AAKP
The American Association of Kidney Patients (AAKP) is a national non-profit organization founded by kidney patients for kidney patients.
www.aakp.org / 880-749-2257

NKF
The National Kidney Foundation provides information about kidney disease, free newsletters, and a peer mentoring program.
www.kidney.org / 800-622-9010

RSN
Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD).
www.rsnhope.org / 818-543-0896

Hopeline
This is a peer support phone line for dialysis patients run by the Renal Support Network.
1-800-579-1970

Life Options
This web site provides free booklets on renal rehabilitation topics such as employment and exercise. www.lifeoptions.org
Engaging the Young Adult Patient

Young adult dialysis patients, ages 18-30, comprise just 3% of dialysis patients. A recent study showed that renal teams do not differentiate between the young adult population and the rest of dialysis patients, although young adult needs and outcomes are quite different.

*Despite their youth, young adults tend to have poorer health outcomes than other age groups. They therefore deserve attention and intervention by the dialysis staff caring for them.*

Poor health outcomes may be linked to the unique challenges and barriers facing this age group, which can lead to non-adherence with the dialysis prescription and behaviors that can cause disruption to the facility. Non-adherence or non-compliance may be the biggest issue connected with this population from the facility’s perspective.

Studies suggest that some of the reasons for non-adherence may be confusion and denial of illness, high rates of anxiety and depression, isolation from social contact with their peer group (the peer group being a very important protective factor), and inability to identify with the “typical” dialysis patient. Also, the brain’s prefrontal cortex, responsible for planning and problem-solving, is not thought to be fully developed until around age 25, causing difficulty with such tasks as problem-solving, emotional regulation, and long-term planning, among other factors. Further, this group may be juggling competing demands for their time such as school and young children.

Due to their small numbers, staff may have little experience working with this age group and may become frustrated following efforts to help the young adult patient. Staff reactions may include distancing and/or giving up, outrage, frustration, and parental feelings/actions.

When issues with this population surface, it is important to involve the whole interdisciplinary team to brainstorm and to participate in education and training. It can be especially important to enlist the help of the social worker. Open and supportive communication is beneficial for the patient and the social worker is also skilled in providing therapeutic intervention.

In addition to therapeutic social work intervention, young adults may need additional education about End Stage Renal Disease, dialysis and medications from friendly and supportive staff. Research shows that this age group is more confused about their illness, which is understandable when you consider the brain is not fully developed. This confusion may manifest as apparent apathy and non-adherent behaviors.

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It is also important to look at the root cause of the patient’s behavior(s) in order to develop effective interventions. Is the patient depressed or anxious? What are his/her supports and barriers? It is interesting to note that a patient’s anxiety may manifest in challenging, disruptive and/or non-adherent behavior. Often, the anxiety, or the root cause, is overlooked while the challenging behavior is met with limitations or behavioral agreements/contracts.

The following are some strategies for working with young adults:

1. Occasionally, employing short-term goal-setting that is not optimal for the patient or facility, with the intent of working towards long-term goals, may be effective. For example, rather than trying to get a non-adherent patient to be fully adherent, try encouraging the patient to stay an extra hour or add one more day.

2. Spend additional time with the young adult. Try to build a rapport that is relationship-centered and avoid being punitive. This may ease anxiety and depression if it is present.

3. Engage the young adult in discussions about their hopes and dreams and encourage these, as well as celebrate their important events. This may increase a sense of belonging.

4. Encourage shared decision-making. Explore with the young adult alternative options such as home dialysis to increase control and flexibility.

5. Try peer mentoring and assist the young adult to expand their social network. Again, the peer group has been shown to be very important to this age group.

6. Offer a schedule that fits around their priorities and streamline their medical regimen as much as possible.

7. Educate your staff on young adult development and behavior.

The Renal Network, Inc. is here to support and assist you with any concerns you may have regarding working with a young adult patient. Please contact the Patient Services Department at 317-257-8265.
References


5. Herzog, Julia, et al. (May 2012). *Evaluation of a Renal Team Learning Module On Working With Young Adult (YA) with Chronic Kidney Failure (CKD)*. Presented at NKF Spring Clinical, Washington, D.C.

ARE YOU A YOUNG ADULT DIALYSIS PATIENT?

If so, you are part of just three percent of the dialysis population. That means it’s likely you are the sole representative of your age group at your dialysis facility. Your age group is faced with special challenges. We are here to help you and to provide additional resources for you.

**Personal Statements, Feelings and Experiences of Young Adult Patients**

- Questioning, why is this happening to me?
- I don’t feel well.
- I feel depressed.
- I feel overwhelmed and fearful.
- The anxiety is endless and I worry constantly.
- I have a very short fuse, especially at dialysis.
- Feeling, I don’t always understand what doctors and the staff at my dialysis center are telling me.
- Staff is on me about showing up for dialysis and staying the full time, and my diet, medications, etc.
- I need and deserve a day off from dialysis.
- My friends don’t get it and I feel pretty alone.
- All of the patients at dialysis are older.
- I wonder what my future is going to be like.
Helpful Hints

Set a goal. This could be a daily goal of something you are going to do each day or it could be a short or long-term goal. Goal-setting helps you to have a plan for the day as well as for the future. The following article addresses goal setting with chronic illness.  
www.improvingchroniccare.org/downloads/selfmanagementpaper.doc

Social support is important. Check if your dialysis unit, the local hospital, or your community has a peer support program. (Check out the Resource Section).

Treatment modalities should be considered. This includes hemodialysis, both in-center and home, peritoneal dialysis, nocturnal dialysis, and transplant. Some patients find that peritoneal dialysis or home dialysis offer greater freedom and flexibility. Check out www.homedialysis.org to learn how home dialysis can improve your health and outlook.

Exercise can be very beneficial to your overall well-being. Exercise can help decrease the fatigue and weakness associated with dialysis and helps with stress. Talk with your doctor or social worker about starting an exercise program. This link contains several stories attesting to the benefits of exercise and also a guide to getting started.  
www.therenalnetwork.org/services/exercise.php

Spirituality can include connecting to church, religious groups, prayer, meditation, and relaxation techniques. Spirituality may enhance coping and personal well-being. The following article addresses spirituality and chronic illness.  
http://findarticles.com/p/articles/mi_m0CTG/is_1_19/ai_n6072019/

Work if you can, it can help financially as well as with your feelings of independence and self-worth. If you’re working or considering going to work, you and your social worker can review resources to help you.  
http://www.therenalnetwork.org/services/rehabq.php

Take a class that interests you and helps you focus on other interests. This could be a college or community class such as photography, video gaming, art, theater, or a yoga class. It could also be a course on a topic such as Positive Attitude, Anger Management, Stress Management, or Organizational Skills. There are also web-based classes available.

Ask for help! Forty percent of dialysis patients have depression at some point and the rate may be even higher for your age group. It can be treated and you may find a support group or counseling helpful. You also can talk to your social worker, doctor, or nursing staff about how you’re feeling. Also, your social worker may be a good resource for financial and insurance information, work opportunities, transportation, and many other topics.  
Patient Resources

The Renal Network, Inc.
The mission of The Network is facilitating the achievement of optimal wellness for renal patients. Network staff is available for inquiries, to locate resources or to help with resolution of patient issues. You will find resources on such topics as exercise, vocational rehabilitation, quality of life, patient stories regarding fistulas, and self-management.

www.therenalnetwork.org / 1-800-456-6919

Renal Outreach
Subscribe to Renal Outreach. It’s a free patient newsletter with helpful tips and patient stories and information about dialysis. Call The Renal Network, Inc. at 1-800-456-6919, ask for Katie and tell her you would like a subscription, or sign up to receive an electronic version at http://therenalnetwork.org/resources/newsletters.php

Kidney Patient News
The Network maintains a patient-oriented web site that includes stories from patients, family members, diet information and monthly updates.

www.kidneypatientnews.org

AAKP
The American Association of Kidney Patients (AAKP) is a national non-profit organization founded by kidney patients for kidney patients. They have an annual conference where you also can meet other patients and learn the latest information.

www.aakp.org / 1-880-749-2257

RSN
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www.rsnhope.org

Hopeline
This is a peer support phone line for dialysis patients run by the Renal Support Network. 1-800-579-1970

NKF
The National Kidney Foundation provides information about kidney disease, free newsletters, and a peer mentoring program.

www.kidney.org
Dialysis Patient Citizen
DPC provides patient education and advocacy to improve the quality of life for all dialysis patients.
www.dialysispatients.org / 1-866-877-4242

Internet Forums for Dialysis Patients
www.Davita.com
www.Ihatedialysis.com
www.ktalk.org