CASE STUDY

Two brothers, born one year apart, were diagnosed with cystinosis, an inherited condition resulting in abnormal disposition of cystine in multiple body tissues. Cystinosis can cause rickets, acidosis, and renal calculi.

At the ages of 15 and 16, both underwent kidney transplant. The 15 year old received a living unrelated donor kidney and his brother received a deceased donor kidney. Due to non-adherence to the medication and therapy protocol, the younger brother lost his kidney to rejection and underwent a transplant nephrectomy two years later. He is now on HD three times weekly. The older boy, despite adherence and multiple interventions suffered ongoing acute rejection. One year after transplant he had a transplant nephrectomy and was started on PD. PD was not successful and HD was started.

Each brother takes a medication to treat the cystinosis, multiple blood pressure medications, vitamin supplements, and multiple immunosuppressants, including prednisone. The cystagon is dosed four times daily, immunosuppressants are dosed twice daily, and supplements are taken with meals and snacks.

The male siblings are raised by a single father following a divorce in their early childhood. The father claims to have little to no support from family and friends. He has full-time employment, but leaves work for all dialysis and doctor appointments. His youngest son is also seeking mental health support and requires transportation to and from those visits. The family lives about an hour from the dialysis unit and the health care team offices. The father makes every effort to stay on track with laboratory testing, medication regimens, and dietary guidelines, but finds this increasingly difficult with teenage boys.

As the boys near adulthood, they have become less responsive to the health care team. One sibling has left home numerous times without his medications and without maintaining contact with his family or health care team. Therefore, transitioning care to the adult nephrology team has been difficult.

Despite these difficulties, there have been successes with the older boy. He is being re-referred for a kidney transplant. Additionally, the biological mother has recently increased her involvement with the brothers and has obtained employment in a dialysis center.

**Nursing Diagnosis**

Studies show that parents of children on dialysis have increased psychological stress and marital strain compared to those parents with children having renal transplants and that low treatment adherence is associated with anxiety, depression, adolescence, increased duration of dialysis, low socio-economic status, and single parenthood (Aldridge, 2008). A few of the nursing diagnosis related to parenting a child with a kidney disease are care giver role strain, ineffective coping, powerlessness, anxiety, and interrupted family processes.

Care giver role strain. Some of the characteristics of this diagnosis are illness severity and instability, significant home care needs, caregiver knowledge deficit and disruption of personal life, caregiver time demands, no respite for caregiver and caregiver unaware of or unable to access resources because of availability and/or cost. Nursing assessment of the relationship of caregiver and care recipient, communication patterns and overall health of all parties establish the need for interventions such as individually tailored education and learning regarding disease process, encourage shared responsibility among all family members for home care needs, use of available community resources, teaching stress-reduction, and acknowledgement of caregiver role and value.

*Ineffective coping*

. Some of the characteristics of this diagnosis are inability to make decisions and ask for help and physical symptoms (overeating or lack of appetite, chronic fatigue, headaches, depression, and insomnia). Nursing assessment of presence of characteristics, stressors, past coping mechanisms, and problem-solving abilities establish the need for interventions such as encouraging individual (whether patient or family member) to identify their own strengths and abilities, assist in problem solving and setting realistic goals, provide outlet for feelings and concerns, encourage communication, and teach adequate diet and exercise, relaxation, and other positive activities.

*Powerlessness*

Some of the characteristics of this diagnosis are knowledge deficit and perceived loss of control. Nursing assessment and intervention may help determine areas that can be changed and those that cannot and help provide opportunities for decision-making.

*Anxiety*

Some of the characteristics of this diagnosis are uncertainty of outcomes, unfamiliar treatments, and a feeling of restriction. It is important to assess the level of anxiety and provide interventions through problem solving, decreasing demands on care giver/family, and support positive coping strategies.

*Noncompliance*

Some of the characteristics of this diagnosis are knowledge deficit, physical side effects, and denial. The nurse may need to help the family understand the medical plan, clarify confusing issues, and organize a behavior “contract”, if necessary. A social work consult might also prove beneficial.

*Interrupted family processes*

Some of the characteristics of this diagnosis are inability to meet family members physical, emotional, and/or spiritual needs, poor communication, and ineffective family decision-making. Nursing assessment includes family members’ perceptions of problem, family strengths, coping skills and developmental and/or cultural factors. Encouragement of family members to explore feelings, empathize with other family members, set realistic goals and seek resources or family counseling, if necessary, are all possible interventions.

Given the magnitude of medical, psychological, social, etc issues facing the family of a child with chronic kidney disease, the nurse relationship may be most beneficial in helping to determine the areas of life most affected by the renal failure and work on short and long term goals toward minimizing negative effects and reaching positive outcomes (Mapes, Callahan, & Richie, 2001).