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Education and Support for Patients and Families with Pediatric Chronic Kidney Disease: A Community Service Project

Dulcey Amaia Milek
Bethel University

Emily Josephine Petersen
Bethel University

Aimie Beth Seehafer
Bethel University

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EDUCATION AND SUPPORT FOR PATIENTS AND FAMILIES WITH PEDIATRIC CHRONIC KIDNEY DISEASE: A COMMUNITY SERVICE PROJECT

A MASTER'S THESIS SUBMITTED TO THE GRADUATE FACULTY
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BY
DULCEY MILEK, PA-S
EMILY PETERSEN, PA-S
AIMIE SEEHAFER, PA-S

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Abstract

With any chronic illness, there may be difficulties that arise such as symptom control, medical management, and resource and support availability. In addition, pediatric populations may require more complex care due to the child's continuing development, the need for family involvement, and the eventual transition into adult healthcare. With that, the purpose of the community service project was to provide education and support for families living with pediatric chronic kidney disease (CKD), a chronic illness that affects children worldwide. By working with the National Kidney Foundation (NKF), the research team was able to build an educational track for the pediatric population at the NKF serving Minnesota's annual educational conference and create handouts to assist participants in caring for the child with pediatric CKD.

The research team and the NKF serving Minnesota identified the organization's needs, which included resources and education for the organization's pediatric population. After an extensive literature review and interviews with healthcare professionals in the pediatric CKD specialty, the research team developed a needs assessment to determine what material and information would be most beneficial to provide for families with pediatric CKD. Furthermore, the research team created four sessions for the participants to attend, which included kidney basics, kidney health and nutrition, transitional care from pediatric to adult care, and a networking session. In addition to organizing the entire pediatric track, the research team created educational handouts for the participants to utilize and bring home to implement daily. The handouts included information such as the functions of kidneys, nutritional guidance and kidney-friendly recipes, transitional care tips and medical organizational tables, and a list of support resources for families.

Upon completion of the conference, the research team provided a survey to the participants to determine if the information beneficial and practical for daily use. The NKF serving Minnesota was provided access to all handouts and materials provided at each of the sessions so the pediatric track can be further implemented at future educational conferences. The NKF also plans to post the handouts to their national website for families across the nation to access and utilize as additional resources.

Acknowledgments

This community service project would not have been possible without the direction, instruction, and counsel given by our committee chair, Lisa Naser, PA-C, and our committee member, Cindy Goetz, PA-C.

We would also like to extend our gratitude to the NKF for giving us the opportunity to provide education and support for the pediatric population they serve. We also wish to express our sincere gratitude and appreciation to the NKF serving Minnesota’s program manager, Katelyn Engel, MPH, RD, LD, for her partnership and invaluable guidance throughout the entirety of this project.

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Chapter 1: Introduction

Introduction

Currently, CKD is ranked the ninth leading cause of death in the United States with over 30 million citizens affected (“Kidney Disease,” 2017). More specifically, Becherucci (2016) states the following:

> Mortality rate in children with end-stage renal disease (ESRD) on dialysis is 30 to 150 times higher than the general pediatric population, and the life expectancy for a child on dialysis is 50 years less than a healthy child (p. 588).

Due to these statistics, it is evident that pediatric CKD is a debilitating disease that creates a severe burden for individuals and their families to live with. Not only does pediatric CKD have an unfortunate prognosis medically due to its systemic complications, but it also incorporates the need for psychosocial and familial support. For that reason, the focus of this community service project is to address the burdens on these families by creating educational materials for the population of pediatric CKD. Furthermore, the goal of implementing informational sessions and educational materials is to alleviate the struggles present in those with pediatric CKD and build a community of support for the parents. The following chapter addresses the background of pediatric CKD, a needs assessment for the pediatric CKD population, the purpose of the community service project, the significance of the lack of support and resources for patients and families with pediatric CKD, and definitions of common terms in the following community service project.

Background

Chronic kidney disease refers to a disease of the kidney characterized by a change in either structure or function. The definition of CKD is a glomerular filtration rate (GFR) less than

60 mL/min/1.73 m^2 or the presence of kidney damage for three months or more (Levey & Inker, 2018; O'Connell & Cogan-Drew, 2018). Chronic kidney disease is classified into five stages based on the GFR. Stage five signifies ESRD, which results in the need for either dialysis or renal transplant for the patient (Levy & Inker, 2018; Whyte & Fine, 2008).

In children, CKD is most often caused by congenital anomalies (Warady & Chadha, 2007). Because of this, many risk factors for children born with CKD correlate to preventative measures taken by the pregnant mother prenatally. Factors that increase the likelihood for a child to be born with CKD includes pregestational diabetes mellitus (DM) of the mother and obesity of the mother (Hsu, Yamamoto, Henry, De Roos, & Flynn, 2014). The principal concern regarding children with CKD is the systemic complications it can cause, the largest being an early onset of cardiovascular disease. With cardiovascular disease problems in children, there is a much higher risk of death (Wong, Moxey-Mims, Jerry-Fluker, Warady, & Furth, 2012). Other systemic complications associated with CKD include acidosis, hypervolemia, hypertension, dyslipidemia, left ventricular hypertrophy, anemia, and growth retardation (Wong et al., 2012).

Treatment of CKD focuses mainly on managing the associated complications and attempting to stop the progression of the disease. Therefore, management is multifaceted and requires a focused attention by healthcare providers and children, as well as their caretakers. The focus of education and management is often centered on nutrition, blood pressure control, lipid control, managing anemia, dosing medications based on kidney function, and preparation for renal replacement therapy when indicated (Srivastava & Warady, 2018).

Due to the many systemic complications of pediatric CKD, new research and advances are published frequently to decrease the progression of pediatric CKD. With that, many patients and families are unaware of the strides that medicine has made, requiring further education to families on advances in pediatric CKD care. Although some treatment methods, such as dialysis and transplant, are consistent with past regimens, many of the protocols have been reformulated to better treat CKD (Bertram et al. 2016). For example, new advances in dialysis, such as increased length of treatment, has shown to decrease comorbid effects in patients, ultimately allowing patients to live longer and healthier lives (Bertram et al., 2016). Similarly, new immunosuppressive agents and the availability of dieticians throughout transplant procedures have allowed kidney transplants to show high success rates with improved systemic functioning (Greenbaum, Warady, & Furth, 2009).

Not only have new protocols been established for dialysis and transplant, but modern advances in technology and pharmacologic treatments have also been implemented in care. Pharmacologic advances have been introduced to decrease the progression of disease in CKD patients (Sharbaf & Assadi, 2018). Additionally, new technology has been implemented to provide care in a more statistical and mathematically based manner to create consistent treatment protocols (Hayes & Allinovi, 2018). In general, the new improvements in care is important for patients and families to be aware of to build hope for a better future when surviving with pediatric CKD.

Even though pediatric CKD causes several systemic complications, another crucial burden of this disease is the impact it has on psychosocial effects, including familial support and patient involvement in care (Watson, 2014). Many of these struggles often become secondary in care management but leave a drastic impact on the patient and families involved. The psychosocial effects can be categorized into three characteristics: familial challenges based on research, feedback from patients and parents raising a child with CKD, and difficulties with child involvement in care both from a parental and patient perspective (Gutman et al., 2018; Tong, Lowe, Sainsbury, & Craig, 2008; Watson 2014).

Several of the psychosocial burdens stem from the lack of education in care. One study shows that an increased health literacy level of parents causes a decrease of disease progression in pediatric CKD compared to parents with deficient levels of education (Ricardo et al., 2018). Similarly, research in pediatric nephrology has shown that addressing characteristics of social life and support in medical care is crucial to improve the prognosis for patients with pediatric CKD, as well as the level of care team involvement (Watson, 2014).

In addition to studies proving the impact of psychosocial implications, parents and patients have presented feedback in focus groups to address the challenges of pediatric CKD. Many of the parents expressed burdens of uncertainty in care, lack of confidence in parenting, and a diminished quality of life (Tong et al., 2008). Other parents in the focus groups also expressed opinions of a lack of understanding from peers, as well as hardships with social life, work balances, chores, and medication management (Tong et al., 2008). In relationship to parental views, patients have also reported a lack of quality of life, as well as a decrease in social interactions and education due to the effects of pediatric CKD (Francis et al., 2018). Overall, many individuals articulated challenges that are not readily addressed in the care setting, which creates a need for family support options and education regarding pediatric CKD.

Lastly, another critical topic that is often a difficulty with pediatric care is the process of involving the child in care and knowing the barriers of this development. Both the parental views and the patients' views have been assessed, which sheds light on the intricacy of involving a child in care. In additional focus groups, some parents thought it was important to involve the patient in care, as it was the child's body; however, other parents expressed that the child was immature or unable to understand the scope of their disease (Gutman et al., 2018). In comparison to the parental view, patients also offered a perspective on care involvement. Some patients stated they felt overpowered by the provider or parent, which caused them to decrease their involvement in care, even though they would have preferred inclusion (Gutman et al., 2018).

Furthermore, it is crucial for providers and families to be educated on the social effects of pediatric CKD and to be provided resources to better care for the child in need (Watson, 2014). Many psychosocial effects not only affect the progression of care but can also lead to a decreased quality of life for both the patient and the families involved (Rees, Schaefer, Schmitt, Shroff, & Warady, 2017). Therefore, the following community service project is necessary for the advancement of pediatric CKD care and will assist the needs of families and patients by implementing support and educational material to address the correlating burdens. A needs assessment of the community service project was conducted to reflect the needs of parents and children living with pediatric CKD in order to create adequate support and educational materials.

Needs Assessment

Various needs assessments were conducted by the research team to further discover what educational and support materials were most essential for patients and families of pediatric CKD. An initial interview was set up with the program manager from the NKF serving Minnesota, Katelyn Engel, MPH, RD, LD (K. Engel, personal communication, September 7, 2018). The NKF is an organization established in 1964 with a mission of awareness, prevention, and treatment of kidney disease for all individuals (“History,” 2017). During this interview, the topics that were discussed included current educational conferences provided to patients of adult CKD and pediatric CKD, informational sessions introduced during the conferences, and future educational material the NKF would be interested in implementing (K. Engel, personal communication, September 7, 2018). The NKF had a great need for support and education for families and patients with pediatric CKD. Furthermore, the NKF wishes to implement these types of sessions into their annual kidney health conference, which provides an environment for patients and families to learn and interact with others (K. Engel, personal communication, September 7, 2018).

In addition, a survey was created by the research team to further gather data on what information would be most beneficial to these families during the informational sessions. The survey included educational topics of nutrition, exercise, social support, transitions from pediatric to adult care, insurance, preventative care, healthcare provider interactions, ESRD treatment options, and research and new advances in CKD. The survey also offered open-ended questions for both parents and children to answer that focused on families' and patients' largest challenges with pediatric CKD, as well as any additional information that they would like to share that had not already been addressed in the survey. Lastly, the survey incorporated questions that asked how parents were receiving their information on pediatric CKD and if they would wish to be involved in an advisory group to further implement material and support for families of pediatric CKD in the future.

Similarly, several interviews were conducted with pediatric CKD families, pediatric CKD nurses, a pediatric CKD social worker, a pediatric dietician, and a pediatric nephrologist. These interviews were carried out to further understand the needs for families and patients in the pediatric CKD population. Much of the information gathered in the interviews helped to establish what information is most useful, as well as gather advice on how the information should be provided to families.

Problem Statement

Due to the low prevalence of pediatric CKD and the lack of resources available for children and their families, educational materials are needed to provide support for families and patients with pediatric CKD. The resources implemented in this community service project will attempt to alleviate modifiable burdens and address demands for a better prognosis for pediatric CKD. Additionally, the support will help to ease the hardships of future patients and families with pediatric CKD.

Purpose

The purpose of this community service project was to evaluate the needs of children and families coping with CKD in order to implement direction and assistance for these needs. The community service project aims to understand the emotional and physical struggles resulting from CKD to promote and offer resources for these families. Another goal of the community service project was to implement materials and education for the NKF that can be utilized for future pediatric CKD families.

Significance of the Problem

The community service project is significant to healthcare workers, patients, and families who experience the effects of pediatric CKD. Kidney disease is extremely prevalent and well-studied throughout the world in adults (Centers for Disease Control and Prevention, 2017). Pediatric CKD, however, is much less prevalent, leaving a lack of resources available to pediatric CKD patients and their families (Master Sankar Raj, Garcia, & Gordillo, 2015). The lack of resources leads to several deficits, such as a decreased health literacy level of parents (Ricardo et al., 2018). As stated previously, decreased health literacy levels have been proven to increase the progression of pediatric CKD and cause negative patient outcomes (Ricardo et al., 2018). Not only can progression cause long term kidney damage, but it can also cause profound effects on the cardiovascular system that can be fatal (Wong et al., 2012). Adequate knowledge and awareness of pediatric CKD among patients and their families can encourage patients to better identify their risks and assist their providers in improved management of the disease. Awareness in children and families can additionally reduce negative psychosocial effects and ultimately result in a higher quality of life (Watson, 2014).

Definition of Terms

The following descriptions define terms used frequently throughout the following community service report.

Chronic kidney disease (CKD): A disease of the kidney characterized by a change in either structure or function, regardless of the cause, consisting of either a GFR less than 60 mL/min/1.73 m^2 or the presence of kidney damage for three months or more (Levey & Inker, 2018; O'Connell & Cogan-Drew, 2018).

Congenital anomalies: Birth defects, congenital disorders, or congenital malformations that can be either structural or functional and begin during pregnancy (World Health Organization, 2016).

End-stage renal disease (ESRD): Kidney failure treated with either dialysis or transplant (Levey & Inker, 2018).

Glomerular filtration rate (GFR): A measurement of kidney function (measured in mL/min/1.73 m^2), calculated using patient age, body weight, serum creatinine, gender, and other variants including serum albumin, blood urea nitrogen (BUN), ethnicity, and height, depending on the equation used (O'Connell & Cogan-Drew, 2018; Willems et al., 2013).

Hemodialysis: A process by which blood is extracted from a vein and processed through a filter, called a dialyzer, before being returned to an artery; hemodialysis filters wastes and water from the blood and assists in blood pressure control as well as mineral balance. Hemodialysis is usually done at a dialysis clinic but in some cases may be done at home (National Institute of Diabetes and Digestive and Kidney Diseases, 2018a).

Kidney damage: "Pathologic abnormalities, whether established via renal biopsy or imaging studies, or inferred from markers such as urinary sediment abnormalities or increased rates of urinary albumin excretion" (Levey & Inker, 2018, p. 1).

Peritoneal dialysis: A process by which blood is filtered inside the body. Peritoneal dialysis can be done at home and begins with insertion of a dialysis solution containing water, sodium, and other additives through a catheter in the patient's abdomen into the peritoneal space; while the dialysis solution is in the peritoneum, wastes and extra fluids are absorbed from the body. After a number of hours, depending on the type of peritoneal dialysis, the fluid and wastes are then removed through the catheter back into the empty bag (National Institute of Diabetes and Digestive and Kidney Diseases, 2018b).

Psychosocial: An adjective signifying involvement of both psychological and social aspects (Merriam-Webster, n.d.).

Conclusion

The medical management and psychosocial burdens of pediatric CKD varies greatly from adult CKD, yet very few educational resources exist for the pediatric CKD population. Due to the tremendous physical and psychosocial burdens placed on the children diagnosed with pediatric CKD and on their families, a great need exists for education and support for the pediatric CKD population. The goal of our community service project is to partner with the NKF in the development and distribution of informational sessions and educational materials on topics chosen by pediatric CKD patients and their families. The following chapter explores the current literature surrounding the background, medical management, and psychosocial issues concerning pediatric CKD.

Chapter 2: Literature Review

Introduction

The following literature review will give a brief background on CKD in adults, including staging, complications, diagnosis, and treatment. Pediatric CKD will then be discussed and will include common etiologies, risk factors, complications, management, recent advancements, and a comprehensive overview of the psychosocial burdens that are placed on children and adolescents with pediatric CKD and their families. Due to the burdens that are placed on children and adolescents with pediatric CKD and their families, the lack of time clinicians have for patient education, and the limited amount of pediatric CKD resources, a need for educational materials exists for this population. With incorporation of the information contained in this literature review, educational materials have the potential to improve psychosocial well-being in addition to beneficial medical outcomes of pediatric CKD.

Chronic Kidney Disease in Adults

Background. Chronic kidney disease refers to disease characterized by increasing loss of kidney function, as measured by GFR, due to a change in either structure or function (Levey & Inker, 2018; O’Connell & Cogan-Drew, 2018). In 2002, the NKF Kidney Disease Outcomes Quality Initiative (KDOQI) introduced a standardized definition and staging classification for CKD, defining the disease as a GFR less than 60 mL/min/1.73 m^2 or the presence of kidney damage for three months or more (Whyte & Fine, 2008). About 15% of adults in the United States are estimated to have CKD, of which the most common causes are DM, hypertension, glomerulonephritis, and polycystic kidney disease (Goodman & Peterson, 2009; O’Connell & Cogan-Drew, 2018).

A recent model predicting the lifetime incidence of CKD for those in the United States predicted that over half of adults ages 30 to 64 will develop CKD (Hoerger et al., 2015). Although the prevalence of CKD is expected to rise, about 96% of those with kidney damage or mildly reduced kidney function are oblivious to their condition (Centers for Disease Control and Prevention, 2017). Chronic kidney disease is more common in women than men; however, men are 64% more likely to develop ESRD (Centers for Disease Control and Prevention, 2017). African-Americans and Hispanics are also more likely to develop ESRD (Centers for Disease Control and Prevention, 2017).

Staging. CKD is classified into five stages in order to standardize and guide management of care. Table 1 outlines these stages. Patients in stage five are in kidney failure, otherwise known as ESRD, and are candidates for renal replacement therapy (RRT), consisting of either hemodialysis, peritoneal dialysis, or transplant (Levey & Inker, 2018).

Table 1

Stages of Chronic Kidney Disease

Stage 1	Normal GFR (>90 mL/min/1.73 m^2)
Stage 2	Mild Reduction in GFR (60-89 mL/min/1.73 m^2)
Stage 3a	Moderate Reduction in GFR (45-59 mL/min/1.73 m^2)
Stage 3b	Moderate Reduction in GFR (30-44 mL/min/1.73 m^2)
Stage 4	Severe Reduction in GFR (15-29 mL/min/1.73 m^2)
Stage 5	Kidney Failure (<15 mL/min/1.73 m^2)

Note. Adapted from “Definition and Staging of Chronic Kidney Disease in Adults,” by *UpToDate,* 2018 (https://www.uptodate.com/contents/definition-and-staging-of-chronic- kidney-disease-in-adults)

Complications. With CKD, damaged kidneys cannot properly filter blood, which causes excess fluid and waste accumulation within the body, resulting in further systemic complications (Centers for Disease Control and Prevention, 2017). Those with CKD are at a significantly increased risk of cardiovascular disease and stroke. Additional complications include anemia, infections, hypocalcemia, hyperphosphatemia, hyperkalemia with resultant arrhythmias, loss of appetite, hypertension, edema, pulmonary edema, and depression (Centers for Disease Control and Prevention, 2017). These complications may lead to death before a patient reaches ESRD (Levey & Inker, 2018).

Diagnosis. The gold standard for diagnosis of CKD is GFR measurement. The GFR measurement is based on patient age, body weight, serum creatinine, and other variants including serum albumin, BUN, gender, ethnicity, and height, depending on the equation used. Several different equations are used for adult GFR calculation, including the Cockcroft-Gault formula, Modification of Diet and Renal Disease equation (MDRD), and the Chronic Kidney Disease Epidemiology Collaboration equation (CKD-EPI). One study found that the MDRD best predicted mortality in older adults (Willems et al., 2013).

Another marker used to detect CKD is a urine albumin-to-creatinine ratio (UACR). The UACR is a urine test that assesses for albuminuria (UACR greater than 30 mg/g), which appears in the early stages of the disease (National Institute of Diabetes and Digestive and Kidney Diseases, 2010; O'Connell & Cogan-Drew, 2018). Other laboratory indications of CKD include proteinuria, which also usually appears in the early stages of CKD, and elevated creatinine and BUN, which are usually seen beginning in stage three (O'Connell & Cogan-Drew, 2018).

Management. Management of CKD focuses on reversing kidney damage whenever possible, though it is often irreversible, halting the progression of the disease, and controlling the associated complications (Srivastava & Warady, 2018). Treatment includes initiation of an angiotensin-converting enzyme (ACE) inhibitor or an angiotensin II receptor blocker (ARBs), which are medications that help slow the progression of renal disease (O'Connell & Cogan-Drew, 2018). In addition, management includes treating comorbid conditions such as hypertension, hyperglycemia, and hyperlipidemia, as well as weight control and cessation of tobacco. Anemia is another common problem with CKD; therefore, erythropoietin, iron supplements, and antiplatelet therapy are often utilized. Patients also need to strictly control their diet due to dysfunctional filtration from the damaged kidneys. Furthermore, physicians need to be cognizant of renal drug dosing. Lastly, dialysis and renal transplant are indicated in patients with ESRD (O'Connell & Cogan-Drew, 2018).

Pediatric Chronic Kidney Disease

Etiology. Most of the data on CKD has focused on ESRD in adulthood. The amount of information available and studies that have been conducted on pediatric CKD is limited. Therefore, the etiology of CKD in the pediatric population is not fully understood. Early detection and understanding of the disease is critical in preventing progression, predicting prognosis, and being able to offer direction to children and their families (Harambat, Van Stralen, Kim, & Tizard, 2011).

Part of the reason that children who have CKD have so little information about their disease is because it was not previously well-defined for the pediatric population. However, the 2002 KDOQI definition of CKD provided a classification of CKD that was based on GFR and relevant to children (Whyte & Fine, 2008). Pediatric GFR is determined by a pediatric GFR calculator (O'Connell & Cogan-Drew, 2018). The staging for pediatric CKD is the same as adult CKD staging, as labeled in Table 1 (Srivastava & Warady, 2018). Though the definition of CKD is applicable to most children, the definition is limited in that it does not pertain to children under two years of age due to continual renal maturation (Harambat et al., 2011).

While the two primary causes for CKD in adults are DM and hypertension, the most common cause of CKD in children is congenital anomalies. However, in less developed countries, CKD is usually caused by infectious or acquired diseases (Warady & Chadha, 2007). As stated by the North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS), who receives voluntary information from pediatric nephrology centers and includes information from over 7,000 children, congenital anomalies of both the kidneys and urinary tract make up 48% of the etiology of pediatric CKD. Following congenital anomalies, glomerulonephritis causes 14% of pediatric CKD cases, while 10% are caused by hereditary nephropathies. These causes of CKD also vary with age. Glomerulonephritis is much more common in children older than 12 years old, while congenital anomalies are prevalent in the younger population of children (Harambat et al., 2011). Some common examples of congenital anomalies in children that may lead to CKD include double ureter or ureteral duplication, ureteropelvic junction obstruction (UPJ), horseshoe kidney or renal fusion, posterior urethral valves and prune belly syndrome (PBS), and obstructive/non-obstructive renal dysplasia (Rodriguez, 2014). Additionally, the cause of CKD varies across races. One example is that glomerulosclerosis is three times more common in African-Americans, especially in young adolescents (Harambat et al., 2011).

Risk Factors. Due to the strong association of pediatric CKD with congenital anomalies, many risk factors pertain to prenatal care. One study found that low birth weight and maternal pregestational DM were significantly associated with renal dysplasia/aplasia, one of the congenital causes of pediatric CKD. The same study also found that low birth weight, maternal gestational DM, and maternal obesity associated heavily with obstructive uropathy, another congenital cause of pediatric CKD (Hsu, Yamamoto, Henry, Roos, & Flynn, 2014). Additionally, Tasic et al. (2016) found secondhand smoke and hyperuricemia were risk factors in children developing CKD.

Systemic Complications. Significant complications are associated with pediatric CKD including growth retardation, acidosis, hypervolemia, hypertension, dyslipidemia, and anemia. These complications all contribute significantly to the onset of cardiovascular disease, which is the leading cause of death in children with ESRD (Wong et al., 2012). Thus, blood pressures have to be precisely controlled in children with CKD to prevent death from cardiovascular disease. Hypertension is more prevalent among children who are African-American, children who are obese, children who have a shorter duration of CKD, children with elevated serum potassium, and children with a glomerular cause of CKD. Left ventricular hypertrophy (LVH) is a common finding in anyone with CKD (Wong et al., 2012).

Research has found that 45% of children with CKD also have dyslipidemia. Therefore, it is strongly recommended that those affected with CKD, especially children, be screened for dyslipidemia (Wong et al., 2012). Furthermore, anemia has been linked to CKD and must be both monitored and treated appropriately. The most readily detectable effect of pediatric CKD is growth retardation (Wong et al., 2012). Growth retardation in pediatric CKD patients occurs because most congenital anomalies are associated with low birth weight, which affects growth. Those who are affected by growth retardation are treated with nutritional and/or growth hormone therapy (Wong et al., 2012).

Medical Management of Pediatric Chronic Kidney Disease

Kidney Damage Reversal. Currently, no cure for pediatric CKD exists and kidney damage is rarely reversible. However, some kidney damage may be reversible if originally due to decreased renal perfusion or use of nephrotoxic pharmacological agents (Srivastava & Warady, 2018). In these cases, management is focused on reversing hypovolemia and avoidance of nephrotoxic drugs, such as non-steroidal anti-inflammatory drugs (NSAIDs) and diagnostic agents such as contrast materials, aminoglycosides, amphotericin B, cyclosporine, and tacrolimus (Srivastava & Warady, 2018). The following sections will be focused on slowing or stopping the progression of the disease in addition to managing the associated complications.

Nutrition. The kidneys are a vital part of absorption and excretion regulation; therefore, nutrition deficiencies are prevalent in those with pediatric CKD. A team of skilled physicians, nurses, dieticians, and other healthcare professionals are needed in managing successful nutrition plans. In children, this may be due to anorexia, nausea and vomiting from the uremia, and/or a poor appetite (Whyte & Fine, 2008). Proper nutrition is vital in the pediatric CKD population because the children affected are at risk for improper growth. Vitamins are lost during dialysis treatment, so children need to take dietary supplements such as folic acid, trace minerals, and B complexes (Whyte & Fine, 2008). For infants and young children with CKD, formulas that have high energy and lower electrolyte contents have been made and utilized by families. These children have electrolyte imbalances because bicarbonate is not reabsorbed by the non-functional or misstructured kidneys (Whyte & Fine, 2008). Electrolyte imbalances lead to metabolic acidosis, which causes proteins to break down and calcium to be released from the bone. The bones then become weaker from the lack of calcium storage, which affects the already challenged growth of the child. Thus, bicarbonate replacement is needed (Whyte & Fine, 2008).

Although previously believed to be true, a study showed that a low-protein diet does not affect growth of children with CKD (Wingen, Fabian-Bach, Schaefer, & Mehls, 1997). However, an excess of protein in a child’s diet can be hard on the kidneys and cause progression of pediatric CKD. Therefore, optimal protein consumption is necessary to allow adequate growth of the child without damaging the kidneys (Whyte & Fine, 2008).

Sodium requires a similar balance. Hyponatremia can lead to both dehydration and stunted growth. However, hypernatremia can lead to higher blood pressures and water retention that may cause fluid buildup in the body, including the lungs (National Institutes of Health, 2011). In a randomized crossover trial of dietary sodium restriction in those with stage three-four CKD, an improvement was shown in both blood pressure and hydration status (Saran et al., 2017). This situation is the same with potassium and phosphorous. Fluid control and electrolyte balance is important in children with CKD because the kidneys play such a large role in hydration, dehydration, and regulation of chemical elements essential to the body (National Institutes of Health, 2011). In the case of growth failure, management focuses on resolving nutritional deficiencies and acid-base balance improvement. In cases of refractory growth failure with severe disease, the patient undergoes growth hormone therapy (Whyte & Fine, 2008).

Exercise. Due to the link between CKD and cardiovascular disease, it is essential that children try to stay as healthy as possible. Regular aerobic exercise is recommended in children with CKD (Srivastava & Warady, 2018). This includes activities such as running, walking, biking, and swimming. In addition to the preventative care this provides, it gives the child psychological benefits (National Institute of Diabetes and Digestive and Kidney Diseases, 2014). Exercise should not be limited in children with CKD, even those on dialysis or children who have had kidney transplants (National Institute of Diabetes and Digestive and Kidney Diseases, 2014).

Blood Pressure and Lipid Control. Strict control of blood pressure has been proven to slow the progression of CKD in children and adults alike. Due to the overwhelming evidence supporting this preventative and protective management, screening for high blood pressure in children and adolescents is of utmost importance. In the case of hypertension concurrent with proteinuria in pediatric CKD, ACE inhibitors and ARBs have been shown to slow progression of pediatric CKD more than other hypertensive pharmacotherapies (Srivastava & Warady, 2018).

Abnormal lipid metabolism is another common systemic effect of pediatric CKD. Therefore, it is recommended by the American Academy of Pediatrics and the American Heart Association that all children with CKD be screened for dyslipidemia (Srivastava & Warady, 2018). Treatment for dyslipidemia in children should be focused on diet and exercise. If the patient is older than 10 years old and diet and exercise are not controlling lipid profiles, statin therapy may be considered (Srivastava & Warady, 2018).

Managing Anemia. The recommendation for hematocrit maintenance is 33% to 36%, and the recommendation for hemoglobin maintenance is 11.0 to 12.0 g/dL (Srivastava & Warady, 2018; Whyte & Fine, 2008). The importance of hemoglobin management in pediatric CKD cannot be overstated as one study found a significant association between higher hemoglobin levels and improvement in all categories concerning quality of life (Finkelstein et al., 2009). Although clinicians should strive to increase low hemoglobin levels, caution should be taken not to increase levels too significantly, as an increase in risk of stroke has been found with hemoglobin greater than 12 to 13 g/dL (O'Connell & Cogan-Drew, 2018). Oral or intravenous iron should be administered in the case of low hemoglobin levels (Srivastava & Warady, 2018). In cases of persistent or severe anemia, erythropoietin may be indicated and given one to three times per week based on hemoglobin levels. Maintaining proper hemoglobin levels will not only improve quality of life, but will also improve cognitive development, cardiac function, and exercise tolerance (Whyte & Fine, 2008).

Renal Dosing. Due to the kidney's role in pharmacokinetics, disease of the kidney requires alternate dosing for a significant portion of commonly used medications, including antihypertensives, hypoglycemic agents, antimicrobials, analgesics, and statins. Dosage of medications that require renal dosing is usually modified by reducing dosage amounts or lengthening the dosing interval. Doses are based on creatinine clearance or GFR. An online calculator should be used to determine proper dosing for patients with pediatric CKD (Munar & Singh, 2007).

Renal Replacement Therapy. Renal replacement therapy is indicated in the case of ESRD; options include hemodialysis, peritoneal dialysis, or transplant. Kidney transplantation is the preferred method of RRT, with many children and families choosing to undergo preemptive transplant without prior dialysis, as some studies have shown better outcomes (Whyte & Fine, 2008). Although short-term outcomes of transplant are often successful, some factors contribute to unexpected kidney graft failure. The two main factors leading to kidney graft failure are transitions from pediatric to adult care and poor adherence to immunosuppressive treatment (Bertram et al., 2016). Contrary to kidney transplant, chronic dialysis in ESRD patients is not often indicated in childhood; therefore, not many dialysis facilities are equipped for pediatric dialysis, making pediatric dialysis modality selection difficult and expensive. Due to these factors, morbidity and mortality are higher with dialysis than transplantation (Rees et al., 2017).

Primary Care Physicians. With the consideration of treatment options for pediatric CKD, emphasis must be placed on the role of primary care clinicians, as early stages are often managed in primary care settings. Only about 500 pediatric nephrologists are currently practicing in the United States, a shortage that is also occurring with nephrology physicians worldwide (Kalantar-Zadeh, 2017). Due to this shortage, educating pediatric CKD patients and their families is imperative so they are better equipped to work with their primary care clinician in managing the child's care.

Chronic Kidney Disease Treatment Advances

Although management of CKD continues to improve, advancements in protocols and treatments are necessary to help ease the burden of pediatric CKD. Recent improvements have been made to existing treatments. Additionally, novel technologies and medications have been developed to decrease side effects and improve patient outcomes.

Some of the main causes for improved outcomes of pediatric CKD include enhanced dialysis treatments, upgraded transplant procedures, and new protocols for diet and nutrition (Greenbaum, Warady, & Furth, 2009). Due to new advances in dialysis treatment, death rates have decreased to 30%, likely suggesting that children on dialysis survive CKD compared to others who are not on this treatment regimen (Bertram et al., 2016). Other clinical studies suggest that an increased time period on dialysis may decrease cardiovascular effects, which is one of the most detrimental comorbidities of CKD (Bertram et al., 2016). Not only has the improvement of dialysis treatment limited the severity of the disease, but it has also decreased the prevalence of kidney transplants. If severe, however, kidney transplants have shown to provide significant improvements to patients with CKD, especially when compared to healthy individuals without chronic illness. One of the main reasons for excellent outcomes is due to current immunosuppressive regimens in order to suppress the body from destroying the foreign organ (Bertram et al., 2016). Without the use of immunosuppression, a kidney transplant would not be as successful as it is today. By enduring kidney transplantation, patients see effects such as improvements in neurocognitive functions, such as attention and processing, as well as systemic effects of decreased cardiovascular risks (Greenbaum, Warady, & Furth, 2009). Lastly, the heightened protocol of diet and nutrition management has helped to stabilize patient side effects and maintain hemodynamic levels of the body (Bertram et al., 2016). Many resources, such as dieticians and websites, have helped aid families with finding protocols to follow and nutritional foods to eat. Although the regimens have been available to patients for several years, the new knowledge and heightened procedures have allowed patients to further decrease the complications of CKD (Bertram et al., 2016).

Not only have specialists worked on improving current treatment methods, but new pharmacologic agents have been researched and implemented to treat CKD. A study published in the journal of *Pediatric Nephrology* found that by adding allopurinol, a medication for hyperuricemia, as a part of the treatment regimen of pediatric CKD, the serum uric acid levels decreased, blood pressures decreased, and the GFR increased (Sharbaf & Assadi, 2018). Since the trial did not produce adverse reactions in patients, this treatment was considered a beneficial medication for new treatment options (Sharbaf & Assadi, 2018).

In addition to new drug advances, technology for CKD treatment has also been a popular topic amongst researchers. One example of a new technology in treatment is the use of artificial intelligence (AI) algorithms with machine aids. The use of AI algorithms for treatment creates a "consistent proficiency in highly complex tasks" (Hayes & Allinovi, 2018, p. 1625). A study published in the journal of *Pediatric Nephrology* analyzed the use of an AI machine learning to optimize target weight in children with CKD. The study followed 14 children on hemodialysis and utilized the AI machine to better regulate cardiovascular effects to target weight goals (Hayes & Allinovi, 2018). With the use of the AI machine, patients saw a decrease in post-dialysis blood pressures from the 77th percentile to the 60th percentile. Additionally, four out of the 14 patients decreased the use of hypertensive medications, and three out of the 14 patients found reduction in intradialytic symptoms (Hayes & Allinovi, 2018).

In conclusion, improved dialysis treatment, medications, and technology are just a few of the new advancements that have been proven effective for treatment of pediatric CKD. Researchers are continuously discovering new methods for treatment and relief of pediatric CKD symptoms. Continual research provides hope for patients living with pediatric CKD, as well as their families.

Support for Families of Pediatric Chronic Kidney Disease

Familial Challenges. In clinical practice, pediatric CKD can be a very debilitating and serious condition with multiple causes, risk factors, systemic effects, and treatment methods. However, the psychosocial aspect of pediatric CKD is an additional burden on many families that vastly affects the prognosis and mortality of the child, and often is not thoroughly addressed in patient care. Not only does addressing familial needs in clinical practice help alleviate the struggles with pediatric CKD, it also provides the family with optimism and direction when supporting this chronic illness.

Prior to implementing familial support into patient care, a crucial quality that must first be assessed is the health literacy levels of the parents or individuals caring for the patient. A study published in the *Journal of Pediatric Nephrology* discovered that health literacy levels of parents had drastic effects on the child's progression of CKD (Ricardo et al., 2018). Currently, "health literacy is defined in Healthy People 2010 as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions'" (Ricardo et al., 2018, p. 1759). The following study analyzed the health literacy level of parents caring for pediatric CKD children to determine if the level of parental health literacy increased or decreased the child's progression of CKD (Ricardo et al., 2018). A cohort of 367 pediatric CKD patients were followed for an average of 3.7 years, which included medical workups of CKD severity prior to and following the study period. Additionally, all parental health literacy levels were analyzed for each pediatric patient at the start of the study using a Short Test of Functional Health Literacy (Ricardo et al., 2018). The study determined that parents with an increased health literacy level directly correlated with a decrease in the patient's disease progression by roughly 30% (Ricardo et al., 2018). Furthermore, the study identified a crucial, unrecognized risk factor in patient care due to parental health literacy and its detrimental effect of rapid progression (Ricardo et al., 2018).

As evidence is presented, education is shown to play a key role when providing adequate care to patients. Not only did Ricardo et al. (2018) identify the health literacy effect on pediatric CKD progression, it also analyzed the demographics of all participants. The study found that those who reported lower health literacy levels identified as racial minorities or parents of low socioeconomic status (Ricardo et al., 2018). The pertinent characteristic of social and ethnic qualities establishes a need for addressing medical care to all individuals, especially those with little access to available resources. Education should not be a deteriorating factor in pediatric CKD care and is a topic that should be addressed in all aspects of care.

When discussing support needs for families with pediatric CKD, the conversation revealed that education is necessary for quality care and healthy lifestyles. Although health literacy may be one challenge for those caring for a patient with pediatric CKD, many other challenges other than medical complications are present. Some of these challenges include psychosocial support, patient-provider interactions, optimal team practice, available resources, and transitioning to adult care (Watson, 2014). Each of these topics provides different adversities based on the individual and family involved, but nevertheless are large feats for families to endure.

In an educational review written by Alan R. Watson, a professor and researcher at the University of Nottingham in pediatric nephrology, states that management of the “psychosocial prescription” is a critical part in patient care and may be just as important as the medical treatment of care (Watson, 2014, p. 1169). The psychosocial prescription includes methods such as multidisciplinary team practice, patient interaction and knowledge of care, and family involvement (Watson, 2014). Watson (2014) continues to explain that it is vital for patients to be involved in the decision-making process of care, but it is also crucial that providers address characteristics of sibling support, social interaction, and home lifestyles in order to provide the patient with greater outcomes and a better prognosis. To reiterate the concept of educational needs in pediatric CKD practice, Watson perfectly states that “a better-informed patient makes better informed decisions” (Watson, 2014, p. 1170).

Although the discussion of the support needs of pediatric CKD families may initially appear simple, it is difficult to implement these goals into actual practice. One method that has shown to improve patient care is the involvement of child life specialists and psychologists while preparing patients for procedures and treatments (Watson, 2014). Often, these professionals are overlooked in medical practice but are extremely necessary for optimal care. By incorporating child life specialists and psychologists into the child’s care, a communication gap is decreased between families and providers, and an opportunity for a general needs assessment is given to the family, including monetary issues, psychiatric difficulties, and travel (Watson, 2014). Similarly, the multidisciplinary team extends to family social workers and therapists to help ease the burden on families with pediatric CKD, allowing more opportunities for involvement and support from the medical team (Watson, 2014).

While psychosocial support and multidisciplinary teamwork may help alleviate some stressors in family care, there is a continuous neglect of available resources for families and patients who have pediatric CKD (Rees et al., 2017). Currently, quality of life scores are among some of the lowest for patients with pediatric CKD compared to many other chronic illnesses (Rees et al., 2017). In particular, depression is one of the most common comorbid psychiatric conditions for patients who need dialysis and hospital treatment frequently (Rees et al., 2017). Much of this depression stems from the lack of social interaction with other individuals, as well as family tension and stress due to extensive care. In addition to psychiatric disorders, many patients suffer delayed autonomy after enduring traumatic treatments throughout childhood (Rees et al., 2017). A study conducted after 30 years of follow-up found that 30% of adults 30 years or older, who had pediatric CKD, are still residing at home with their parents. Additionally, those with pediatric CKD also struggled finding employment and opportunities to financially survive as an independent adult (Rees et al., 2017).

Lastly, transitioning from pediatric care to adult care is a daunting task for many patients and families because they do not know what to expect or how to prepare. In almost all cases, patients who undergo transplant or dialysis are often required to maintain a long-term regimen of care, which will inevitably require transitioning to the adult healthcare system (Bertram et al., 2016). A specific instruction presented in the article *Kidney Disease in Children: Latest Advances and Remaining Challenges* was for patients to be involved during the entirety of the transition process, which includes education centered on topics of treatment changes, provider modifications, and patient involvement (Bertram et al., 2016). A supplementary focus illustrated by the International Society of Nephrology and the International Pediatric Nephrology Association was the need for partnerships between pediatric nephrologists and adult nephrologists when transitions take place (Bertram et al., 2016). Overall, the necessity for an open line of communication between disciplines is a crucial factor in determining outcomes of pediatric CKD care.

Even though pediatric CKD produces several challenges for families and patients regarding support and educational needs, only a few organizations have created resources to help ease this burden for families. One example of an organization supporting pediatric CKD patients is the NKF ("Children with Chronic Kidney Disease," 2017). The NKF has created beneficial and user-friendly websites for families with pediatric CKD. Some examples of articles listed on the website include management of medication for teens, nutrition for children with CKD, and kidney health tips for kids. The NKF also offers psychosocial support for pediatric CKD patients and families through a page on their website titled *Children with Chronic Kidney Disease: Tips for Parents*; this page contains tips for active participation in the child's care, how to help control the child's care, education on pediatric CKD, and how to share the experience of pediatric CKD with others ("Children with Chronic Kidney Disease," 2017). To further illustrate tips found on the website, the NKF states that in order to actively be involved in a child's care, one helpful method is to write down all the information of the child's past medical history, including medications and dates of all events. By completing this task, not only will it help create a sense of connection to the child's condition, but also will make a new provider transition feel much easier and more manageable. The NKF also offers events nationwide that allow pediatric CKD families to connect with others experiencing the same challenges ("Children with Chronic Kidney Disease," 2017).

Overall, pediatric CKD not only presents with many challenges, but is also a draining condition on family members due to the lack of support provided to this small population of individuals. Familial support is an essential factor in the management of CKD and is a challenge that is often not dealt with or addressed in the scope of care. Although some organizations have established a need for resources in this population, many patients and families are left without guidance, and continue to struggle through the course of pediatric CKD.

Feedback From Parents. Living with pediatric CKD can hinder autonomy and decrease quality of life. However, many of the prior studies analyzed research based on clinical practice. Although the results of previous studies were not necessarily inconsistent with challenges that families face, they did not include a true feedback analysis of the patient and family members' viewpoints and experiences. In two studies, published in the *American Journal of Kidney Disease* and *Pediatrics*, qualitative data on patient and family encounters and experiences are incorporated to further investigate the challenges faced by all pediatric CKD families (Gutman et al., 2018; Tong et al., 2008). Between both studies, three common themes of feedback were found, which highlighted challenges based on psychological burdens, social insufficiencies, and environmental strains (Gutman et al., 2018; Tong et al., 2008).

Psychological burdens can be a detrimental side effect of pediatric CKD and are illustrated in a study analyzing 358 patients and their parents by self-reported challenges and experiences (Tong et al., 2008). The category of psychological burdens includes personal feelings and emotions felt by the parents caring for pediatric CKD children. Most parents in the analysis struggled with shock and uncertainty in the preliminary stages of diagnosis. They also reported a lack of confidence in the ability to provide sufficient care to their child (Tong et al., 2008). In the study, a collection of quotes were documented from the parents' perspective that further described the psychological challenges they faced on a regular basis. In particular, one parent states, “Having someone depend on you is smothering… it’s like somebody’s trying to take your life… and I’ve got to get out of the situation I’m in… I’m fighting for air here and you don’t know how to get out” (Tong et al., 2008, p. 354). Similar to this vivid description, parents who participated in a focus group study for the *American Journal of Kidney Diseases* reported that they also felt a sense of “false hope” and “unrealistic” expectations based on their lack of knowledge and uncertainty after their child’s diagnosis (Gutman et al., 2018, p. 552). Additionally, parents also expressed emotions of decreased physical well-being, which included fatigue and loss of personal freedom (Tong et al., 2008).

Secondly, the social aspect on families with pediatric CKD was also significant in the parents’ experiences. In the CKD focus group study, one parent stated that she had to pull her child out of school due to frequent hospital visits and dialysis treatment. Without social interactions, patients lack socialization skills. In another response from a teenage girl waiting on the transplant list, she stated that she was sad because her parents would not allow her to throw a quinceañera due to the possible abrupt opportunity for a kidney transplant (Gutman et al., 2018). Clearly, many families prioritize pediatric CKD based on need, causing social interactions to frequently become neglected. Similarly, parents reported a lack of understanding from friends and families as a challenge throughout care. Parents explained that friends and family did not always understand the magnitude of the condition and resented parents for a lack of socialization (Tong et al., 2008). The study also reported that siblings would sometimes show resentment and jealousy towards the chronic illness that was controlling time and effort of the parents (Tong et al., 2008).

Lastly, environmental strains on the parent were another common theme for those caring for a child with pediatric CKD (Tong et al., 2008). In general, environmental strains include a large scope of other significant challenges that present over time (Tong et al., 2008). Parents expressed that tasks such as household cares, medication management, diet and exercise, transportation, and education of the disease were minor responsibilities that had a huge impact on heightened stress and tension in the family (Tong et al., 2008). For example, some parents described that financing transportation to and from hospital visits was daunting after a small period of time (Tong et al., 2008). Additionally, parents also had difficulties finding a balance between caring for the child and performing necessary household duties, such as grocery shopping, cleaning, and cooking. Parents also felt they were not provided with enough resources for support and information on CKD in general, which made it challenging to know the effects of pediatric CKD (Tong et al., 2008).

It is beneficial to understand that providers are not the only individuals that see the deficits surrounding support and care for pediatric CKD. Patients and families also express challenges from minor tasks to drastic lifestyle changes. Since parents are the primary caregivers with this population, it is important to grasp the opinions they share in order to provide the most appropriate care.

Child Involvement in Care: Parental Perspectives. A frequently asked question in the pediatric CKD community is whether parents should, or should not, allow their child to be involved in care, and to what extent should they be involved (Gutman et al., 2018). Opinions regarding this question can be divided between parents, depending on parenting style and amount of protection wanted for their child. With that, both the benefits and drawbacks of child involvement will be analyzed to fully understand best parenting practices when raising a child with CKD.

In general, literature portrays that child involvement is necessary and should take place during hospital visits and throughout all medical care ("Children with Chronic Kidney Disease," 2017; Watson, 2014). In a focus group study of 34 patients and 64 parents, results showed that some parents valued the child's right to be involved and make decisions in care because it is the child's body (Gutman et al., 2018). One example was demonstrated when a parent of a CKD patient stated, "There is a time when you don't want the control, you don't want to have to make the decision, and you have to push it back onto them" (Gutman et al., 2018, p. 554). In comparison, parents also felt that it was important to involve the child in care, so the child was aware of the consequences of their chronic illness and understood how to manage CKD when the child becomes independent in the future (Gutman et al., 2018). A qualitative analysis that evaluated parents raising children with chronic illnesses found that parents involved children in their own care to teach children consequences of their decisions made in order to understand the complexity and effects of a chronic disease (Miller, 2009). Additionally, not only did parents choose to include children in their own care, but parents also respected the notion of providers including patients in care (Gutman et al. 2018). In Gutman et al. (2018) it was discovered that parents appreciated encouragement from providers, as it showed the clinician was interested in the patient's autonomy and prepared the child for adult CKD care.

Although most parents found benefit in collaborative care with the child, parents also expressed boundaries as to how involved the child should be due possible damaging effects. Several parents analyzed in Gutman et al. (2018) contemplated the idea of keeping their child "in the dark," as parents did not know how to inform the child of the prognosis and treatment (p.

555). Many parents who allowed the child to be involved in care stated that they would need to intervene if they felt the child's decision would result in irreversible consequences (Gutman et al., 2018). Parents constantly contemplated between overprotection and the child's freedom of choice. Parents stated that they were less likely to include the child in decision-making when the parent felt tired, had other responsibilities such as other family or work tasks, or if the child was inattentive (Miller, 2009). As demonstrated in previous studies, parents have difficulty balancing child involvement (Gutman et al., 2018; Miller, 2009).

Pediatric Chronic Kidney Disease Difficulties: Patient Perspective. Quality of life and patient involvement are two factors that have a vital impact on experiences of patients with pediatric CKD. Almost all individuals strive for a high quality of life, which is often stripped away from pediatric CKD patients (Francis et al., 2018). Through a cross-sectional study of 375 pediatric CKD patients, it was discovered that over 77% of those with beginning stage CKD reported decreased quality of life scores compared to the average population; about 86% of patients on dialysis reported even lower scores (Francis et al., 2018). Throughout this study, quality of life was measured by the patients' perception of cognition, pain, emotion, financial burden, and home-life struggles (Francis et al., 2018). In a related study, 55 patients with pediatric CKD in Greece were also compared to healthy children based on quality of life scores (Dotis et al., 2016). The study found interesting results, which showed that children with an age range of eight to 11 years old had higher social acceptance scores compared to ages 12 to 18, which had low social acceptance scores (Dotis et al., 2016). When comparing both studies, it is evident that children living with pediatric CKD struggle to live a standard lifestyle and to gain social acceptance from peers.

In addition to poor quality of life, many pediatric CKD patients struggled with control over care and parental views. One patient broadly stated, “It’s annoying when parents think they know what’s going on by saying, ‘Oh, well I can tell that you’re….’ You’re not inside of me, I know how I feel” (Miller, 2009, p. 259). Most patients felt that parents were overprotective and spoke for the child, when the child could easily speak independently (Gutman et al., 2018; Miller, 2009). Children also stated that they had difficulty voicing their opinion because they felt their view was unimportant, especially when views conflicted with parental opinions (Gutman et al., 2018). Another struggle that is commonly presented with children is the introverted approach to care. Many children expressed that they are too shy to ask questions about care and felt refrained to ask questions based on how they would be judged by the clinician (Gutman et al., 2018). An example demonstrated in Gutman et al. (2018) included a patient who did not want to take prescribed medications because of the nausea it would cause her; however, both the parents and clinician forced the patient to visit a psychologist for noncompliance with medications.

The challenges of patients and family members center around different opinions, a lack of knowledge, and communication deficits (Miller, 2009). At times, parents appear overpowering to patients, causing them discomfort in their involvement with care (Gutman et al., 2018). Some patients do not feel trusted, which causes decreased participation (Gutman et al., 2018). A solution to this problem, as stated in Miller (2009), is to incorporate a parent-child collaborative decision making model, which allows for open communication and problem-solving in care between the patient and parents (Miller, 2009). In order for both parents and patients to maintain involvement, both parties must strive for enhanced communication to improve quality of life and disease prognosis (Miller, 2009).

Conclusion

Chronic kidney disease is not only difficult to manage, but it also has a significant effect on the patients and families affected. Although CKD is demanding for all individuals to endure, pediatric CKD specifically incorporates multiple other unique challenges, such as psychosocial burdens and patient involvement in care. With the systemic and debilitating effects of pediatric CKD, it is crucial that patients understand the preventative measures necessary, as well as all treatment options available (Watson, 2014) . Similarly, in order to find hope with pediatric CKD, it is beneficial to discover new advances or regimens for better survival. The medical aspect of pediatric CKD is very draining for all individuals, including family members and patients, which is why it is beneficial to educate and support these families (Watson, 2014). Lastly, not only does pediatric CKD leave lasting side effects medically, but also causes hardships with social interactions (Gutman et al., 2018). In order to understand the severity of pediatric CKD, etiology, risk factors, systemic complications, management of care, advances in treatment, and psychosocial effects of patients and families were analyzed in detail to grasp the complexity and burdens within pediatric CKD, as well as recognize the strength and resilience of those affected. The following chapter will discuss the methods used to create and implement informational sessions and educational materials at the NKF pediatric CKD conference in March of 2019.

Chapter 3: Methodology

Introduction

According to the NKF, one in seven American adults are estimated to have CKD in the United States (National Kidney Foundation, 2017). The NKF has been a valuable support system for those with adult CKD by providing many informational resources and events. On the contrary, pediatric CKD in the United States is rare and resources are less readily available through the NKF, particularly resources regarding networking and educational events for patients and families with pediatric CKD.

As a result, the purpose of the community service project was to fill the need for support for families with pediatric CKD. Support was provided by creating a pediatric track to an educational conference about CKD organized by the NKF. Additionally, educational handouts were made pertaining to each seminar topic to allow families to take home the information presented at the conference. The educational handouts will be implemented as resources for the NKF to utilize at future events and online.

Rationale for Project

The prevalence of CKD is radically lower in the pediatric population than in adults and requires a significantly different medical management and treatment plan (Master Sankar Raj et al., 2015; National Kidney Foundation, 2017). Due to the low prevalence of pediatric CKD, few resources exist for pediatric CKD patients and their families to learn more about the disease process and complicated medical management. The NKF expressed their desire to meet the educational needs, but they have not yet been able to due to the NKF's limited resources. The goal of the community service project was to create informational sessions and educational handouts designed to educate patients and their families in areas identified as most beneficial by healthcare workers in nephrology and pediatric CKD families. By offering educational resources, this community service project hopes to decrease the burden of pediatric CKD and ultimately improve patient and family quality of life.

Population

CKD is defined as any disease resulting in an increasing loss of kidney function due to a change in either kidney structure or function (Levey & Inker, 2018; O'Connell & Cogan-Drew, 2018). CKD includes a variety of disorders, of which the most prevalent in the pediatric population are congenital anomalies, glomerulonephritis, and hereditary nephropathies (Harambat, Stralen, Kim, & Tizard, 2011). In general, pediatric CKD includes individuals under the age of 18; however, the age of transition from pediatric to adult CKD healthcare varies based on the patient (Pediatric Nephrologist, personal communication, November 27, 2018). The population of the community service project included patients with pediatric CKD and their families who were physically able to attend the educational event organized by the NKF on March 31, 2019 in St. Paul, Minnesota. All advertising for the informational session was carried out by the NKF serving Minnesota.

Project Plan and Implementation

The purpose of the community service project was to implement an educational pediatric CKD track in an annual CKD educational conference sponsored by the NKF, which had previously been implemented only for adults with CKD. The research team helped create content for pediatric CKD informational sessions and educational handouts. A need for the pediatric CKD track was initially established after the research team met with the program manager from the NKF serving Minnesota, Katelyn Engel, MPH, RD, LD (K. Engel, personal communication, September 7, 2018). During the interview, it was determined that the NKF serving Minnesota had implemented several educational conferences for the adult CKD population, but no educational events were established for the pediatric CKD population. Furthermore, the NKF agreed to work with the research team and showed interest in implementing a pediatric CKD track in order for patients and families of the pediatric CKD population to receive adequate support and education (see Appendix A). The educational conference, titled *Kidney Social Summit*, was a free conference available to all CKD patients and families and took place on March 31, 2019 in St. Paul, Minnesota. The various tracks available to participants at the conference included a new CKD diagnosis track, a dialysis track, a transplant track, and a pediatric CKD track. As stated, the research team created content and material for the pediatric CKD track at the *Kidney Social Summit* educational conference.

Prior to developing material and content for the various informational sessions, the NKF provided contact information to the research team for several pediatric CKD experts, healthcare professionals, and parents of pediatric CKD patients to gather further information about pediatric CKD. Several interviews were conducted by the research team, which included meeting with a pediatric nephrologist, a pediatric dialysis nurse, a pediatric CKD dietician, a pediatric dialysis social worker, and a parent whose child was diagnosed with pediatric CKD to assess the overarching needs of the pediatric CKD population. An IRB application was submitted and approved by Bethel University to ensure the privacy and protection of all individuals who participated in the interviews (see Appendix B). A list of prepared questions was formulated prior to interviewing the individuals to ensure consistency of information (see Appendix C). Prior to interviewing each of the individuals, an informed consent was signed verifying the interviewees' confidentiality of information, privacy, and right to discontinue the interview at any time (see Appendix D). All signed consent papers were kept in a locked cabinet in the Bethel

University Physician Assistant office. Any information recorded in the interviews was stored on a research team member's password protected computer and was destroyed upon completion of the community service project. The interviews were conducted at the University of Minnesota Masonic Children's Hospital in areas open to the public. Each specialist offered different viewpoints on pediatric CKD, as well as helpful advice as to what each informational session should address. In addition to the information obtained in the literature review, the information collected in the interviews was utilized to help create informational session content and educational handouts for the pediatric track in the educational conference.

The first interview conducted was with a pediatric nephrologist from the University of Minnesota Masonic Children' Hospital. Some of the key points she discussed that she thought were crucial to pediatric CKD education were the transition process from pediatric healthcare to adult healthcare, basic kidney education, and understanding common medications in pediatric CKD, as well as what each medication does for the body (Pediatric Nephrologist, personal communication, November 27, 2018). More specifically, she discussed how many families are not prepared enough for the transition process and described the difficulties families face with access to emotional and economical support resources (Pediatric Nephrologist, personal communication, November 13, 2018). A second interview was conducted with a group of healthcare professionals, including a social worker, a dietician, and a registered nurse, who work in the pediatric dialysis center at the University of Minnesota Masonic Children's Hospital (Registered Dietician, Registered Nurse, & Social Worker, personal communication, November 16, 2018). Although most of the information the dialysis group discussed reiterated the advice of the pediatric nephrologist, the dialysis healthcare professionals offered additional information, including strict diet plans a patient with pediatric CKD must follow, physiology basics of kidneys, burdens patients and families endure, such as explaining CKD to others, struggles with interconnectedness between siblings and friends, and the lack of knowledge surrounding transitional care (Registered Dietician, Registered Nurse, & Social Worker, personal communication, November 16, 2018). Additionally, the dialysis healthcare professionals offered many resources that parents may be unaware of to assist with support needs (Registered Dietician, Registered Nurse, & Social Worker, personal communication, November 16, 2018). The last interview conducted was with a parent of a child with pediatric CKD to assess her viewpoint of pediatric CKD, the burdens her family is faced with, and education she would find most useful (Pediatric CKD Parent, personal communication, November 27, 2018). In general, her biggest concerns with pediatric CKD were the lack of community, due to the small population of patients, and the need for networking with other parents (Pediatric CKD Parent, personal communication, November 27, 2018). She also stated it would be beneficial to know more about kidney health and support resources available for parents and families with pediatric CKD (Pediatric CKD Parent, personal communication, November 27, 2018).

The content of the informational sessions was determined by the interviews with the healthcare professionals and a parent in addition to the literature review. It was determined amongst the research team and the NKF that the four informational sessions represented in the pediatric CKD track would include: *Kidneys 101, Transitional Care, Kidney Nutrition for Kids, and Pediatric CKD Networking*. The research team implemented each of the sessions by working with the NKF to find speakers with expertise in pediatric CKD who spoke on behalf of each of the topics. The research team also assisted with content creation for the sessions, as well as educational handouts for the participants.

During each of the informational sessions, educational handouts were also available for families to take home and utilize to ease difficulties with pediatric CKD. Different handouts were created for both adults and children in attendance to make the information more approachable and pertinent for the participants. The research team created the content for each of the educational handouts and the handouts were designed by the NKF's graphic design team. In the *Kidneys 101* session, a handout, titled *Kidney Basics*, on basic kidney anatomy, kidney physiology, and kidney facts was available, as well as a kidney coloring page for children (see Appendix E & F). During the *Transitional Care* session, a handout on *5 Steps to Ease the Transition from Pediatric to Adult Healthcare* was provided to participants. Also, in the *Transitional Care* session, medical organizational charts were available for families to help organize medications and provider information (see Appendix G & H). The *Kidney Nutrition for Kids* session included two handouts. The first hand-out, titled *KIDney-Friendly Tips*, included nutritional tips for kids and the second handout contained three recipes that were both child- and kidney-friendly (see Appendix I & J). The last session, *Pediatric CKD Networking*, was offered primarily for parents and guardians to connect with other pediatric CKD families in similar circumstances. In the networking session, a resource handout, titled *Pediatric Track: Support Resources for Families,* provided a list of various resources to address the support needs for pediatric CKD families (see Appendix K).

As the conference concluded, all participants were asked to complete a survey created by the NKF and research team to evaluate the sessions, content, and handouts that were presented throughout the day (see Appendix L). An IRB application was submitted and approved by Bethel University to ensure the privacy and protection of all participants who completed the post-conference survey (see Appendix M). The survey included an informed consent verifying the participants confidentiality of information, privacy, and right to discontinue the survey at any time. The surveys were stored in the NKF program manager's locked office, and were destroyed upon completion of the community service project. The purpose of the survey was to determine whether the information presented in the sessions was beneficial and educational, and whether the handouts were helpful resources for families with pediatric CKD. Both the NKF and the research team evaluated each of the responses and discussed what went well at the conference, as well as aspects that may be improved for future educational pediatric CKD events. In addition, all educational handouts will be uploaded to the NKF website for all pediatric CKD patients and families to utilize across the nation.

Potential Project Barriers

A few potential barriers may limit the community service project's validity. Pediatric CKD has a low prevalence in the United States, affecting less than an estimated 1% of children based on national registries (Master Sankar Raj et al., 2015). Due to the low prevalence of pediatric CKD, the population size studied in the community service project was undersized. Additionally, conference participants and resultant survey responses were only from Minnesota, which causes a potential for undifferentiated responses. Another possible limitation in the project was a poor survey response and poor attendance at the informational event in March of 2019. However, the informational sessions will serve as groundwork for future pediatric CKD informational sessions the NKF intends to hold annually.

Project Tools

Educational handouts were created for every session in the pediatric track for families to take home. All handouts were written at or below a sixth-grade reading level to accommodate a majority of the population and were reviewed by the NKF's program manager. The first session handout, *Kidney Basics* (see Appendix E), was made using sources from the literature review and was sent to a pediatric nephrologist to review. The handout includes basic facts about kidneys and their role as a major organ in the body that filters blood and removes waste. A coloring page of the kidneys was also created for young children to use during the session (see Appendix F). The next session on transition of care focused on transitioning from pediatric healthcare to adult healthcare. Although the session may have been irrelevant to some families with young children who have CKD, a handout, *5 Steps to Ease the Transition from Pediatric to Adult Healthcare,* was still distributed to all families, as they may someday have to transition to adult CKD healthcare (see Appendix G). The handout includes tips for parents on how to actively involve their child in care and decision-making to ease the transition process. The handout was also based on the literature review and was sent to a pediatric CKD social worker to review before completing. Additionally, the session distributed organizational charts to help organize medications and provider information (see Appendix H).

The third session, which included a handout on nutrition, titled *KIDney-Friendly Tips*, highlights foods to avoid and foods to incorporate within the pediatric CKD child's diet (see Appendix I). The handout was created based on information from the interview with a pediatric dietician and the literature review. Three simple kidney-safe recipes were also distributed to families during the nutrition session and include tacos, macaroni and cheese, and chili (see Appendix J). The purpose of providing recipes was to assist families in implementing what they learned during the session at home. The recipes are kidney-friendly versions of foods children commonly enjoy eating. The two nutrition handouts were sent to a registered dietician to review before finalizing.

Lastly, the final session focused on networking for parents and guardians of pediatric CKD patients. A handout, titled *Pediatric Track: Support Resources for Families*, was distributed and contains resources where parents can find support and connect with other families and healthcare providers (see Appendix K). The resource list was compiled from a previous document the NKF created but was modified based on the literature review and suggestions from the individuals interviewed. The resource list includes the NKF's Facebook page, a new pediatric CKD online community, a blog series, and more. After the conference, handouts will be utilized by the NKF as a part of their resources for families with pediatric CKD. To assess the effectiveness of the four sessions, a survey was given at the end of the conference (see Appendix L). The conference may be modified in future years based on survey results to better support families with pediatric CKD.

Conclusion

From the needs assessment, it was concluded that families dealing with pediatric CKD desired more interaction from other families in addition to education in nutrition, transitional care, and basic kidney knowledge. Partnering with the NKF provided an ideal platform for providing support for the pediatric CKD population, as an educational CKD conference already takes place annually. To make a longer-lasting impact on the pediatric CKD population, educational handouts were made based on the literature review and interviews with a parent and healthcare professionals in pediatric CKD. The handouts created were also reviewed and edited by a nephrologist, a social worker, and dieticians to ensure accuracy and appropriate language for those unfamiliar with medical terminology. To analyze the impact of the conference, a survey was given to participants in attendance. The following chapter will discuss information gathered from the interviews with pediatric CKD specialists and feedback received from the post-conference survey distributed at the educational conference.

Chapter 4: Discussion

Introduction

The community service project aimed to serve patients and families with pediatric CKD by establishing a pediatric track to an educational conference held annually by the NKF serving Minnesota. Educational handouts were also created for the conference, future conferences, and the NKF's website to be utilized for the pediatric CKD population nationally. Throughout the chapter, the results of the community service project will be discussed based on survey feedback from participants of the pediatric CKD track. The survey sought to analyze information such as the effectiveness of the handouts created for the participants, the content of the informational sessions, and resources provided during the conference. Limitations of the community service project will be examined as well as further projects to better provide for the pediatric CKD population at future conferences.

Summary of Results

A significant need exists for resources and support for the pediatric CKD population due to the low prevalence of disease (Master Sankar Raj et al., 2015). The research team discovered the need for resources and support through discussions with the NKF serving Minnesota's program manager. A needs assessment confirmed the significance of the problem through a literature review, a discussion with a parent of a child with CKD, and interviews with various medical professionals who work with pediatric CKD patients. The research team was able to hear firsthand how the lack of resources and support is affecting pediatric CKD patients and their families and, subsequently, how much could be gained from readily available, quality, relevant information about pediatric CKD. The research team believes that as information and support become more readily available for pediatric CKD, patients and their families will have the opportunity to become more autonomous and improve their quality of life.

The research team sought to increase the amount and availability of information by means of a community service project. The goal of the community service project was to create relevant educational handouts and add a pediatric CKD track to the NKF serving Minnesota's annual Kidney Social Summit educational conference. The research team first conducted a literature review and then met with a parent of a child with CKD and healthcare professionals in the pediatric CKD field in order to determine what educational needs were most pressing. The four most frequent topics that arose regarding how to best support children and families with pediatric CKD included a basic overview on the function and structure of the kidneys, nutrition modifications for children with CKD, tips to ease the transition from pediatric to adult healthcare, and the lack of networking parents feel they have with other families with pediatric CKD. Therefore, the research team decided to not only host informational sessions to discuss these topics with families, but to also provide handouts that could be taken home and utilized daily. The first handout, titled *Kidney Basics*, provides a simple summary on the purpose of the kidneys as a filtering system for the body. The handout outlines the anatomy of the kidneys as well as a few fun facts about the organ. The next handout, titled *KID-ney Friendly Tips,* presents kidney-friendly substitutes for common foods children eat, such as processed meat and salty snacks. From the literature review, it was apparent that nutrition adjustments are one of the most difficult changes to make in families with pediatric CKD. As the kidneys become damaged, the filtering system progressively worsens causing an accumulation of toxins within the body. One of the best ways to manage kidney damage is by limiting certain nutrient groups such as sodium, potassium, protein, and phosphorus in the diet (Whyte & Fine, 2008). Information regarding these nutrient groups and their deleterious effects on the kidneys are also given in the handout. Additionally, transitional care information was gathered from the literature review and organized into a handout titled *5 Steps to Ease the Transition from Pediatric to Adult Healthcare*. A medication organizational chart was also provided to participants to give children with pediatric CKD more autonomy in their medical care in regards to keeping track of their medications and the providers they see. The last handout created by the research team, titled *Pediatric Track: Support Resources for Families*, provided networking and resource options for families. After completion, the handouts were edited by various healthcare professionals within the pediatric CKD field.

The Kidney Social Summit took place in St. Paul, MN on March 31, 2019 and contained the following four tracks: a new CKD diagnosis track, a dialysis track, a transplant track, and a pediatric CKD track. Each track contained four forty-five minutes sessions. The pediatric CKD track held the following sessions: *Kidneys 101, Kidney Nutrition for Kids, Transitional Care*, and *Pediatric CKD Networking.* Speakers for the conference sessions were determined the NKF serving Minnesota's program manager. At the start of the conference, each participant in the pediatric CKD track received a folder assembled by the NKF serving Minnesota containing the educational handouts made by the research team.

While approximately 140 people attended the Kidney Social Summit, only three people in total attended the sessions within the pediatric CKD track. The efficacy of the conference was assessed through a program evaluation survey given at the end of the conference to all who attended the entirety of the pediatric CKD track. Due to the low survey response of only one participant, conclusions regarding the efficacy of the pediatric CKD track cannot be drawn. It should be noted, however, that the survey response was favorable and indicated that all sessions and handouts were helpful; no comments or suggestions were given.

Prior to the community service project, the NKF serving Minnesota expressed they did not have the resources to create education and support for the pediatric CKD population. After completion of the community service project, the NKF serving Minnesota was grateful for the work of the research team, despite the low pediatric CKD track attendance. The NKF serving Minnesota plans to implement the pediatric CKD track at future Kidney Social Summit conferences and hopes to expand their advertising for the event so more patients and families can be reached. The NKF also plans to publish the educational handouts on their website and will send the handouts to other NKF offices throughout the country. The research team sincerely hopes the educational handouts and future educational conferences will be utilized and ultimately improve the quality of life of patients with pediatric CKD and their families both now and in the future.

Limitations

The goal of the community service project was to identify the needs of the patients and families dealing with pediatric CKD and to provide resources in partnership with the NKF serving Minnesota for the pediatric CKD population. However, there were a few limitations that occurred throughout the community service project. The main hindrance was the number of individuals that attended the pediatric CKD track of the conference. Currently, there is a small number of people in the Midwest with pediatric CKD, and even fewer individuals were contacted about the Kidney Social Summit educational conference. The research team was not a part of the advertising for the event since it was organized by the NKF serving Minnesota, and did not have any control over the number of participants who attended. Although the small number of participants was somewhat expected as it was the first time the pediatric CKD track was implemented, the attendance and survey response from the educational conference was poor. However, all of the resources are available for future conferences and attendance is expected to grow in subsequent years.

Another limitation of the educational conference was the irrelevance of the *Pediatric CKD Networking* session due to low attendance. The networking session was cut from the conference, as it was not necessary, since there was not enough participants to fully engage in conversation and networking. However, the handout titled *Pediatric Track: Support Resources for Families* was still provided for participants to take home and connect through the resources listed on the handout. The research team hopes that with a growth in attendance the *Pediatric CKD Networking* session will be more beneficial in the future.

Other than the two limitations that arose, the additional portions of the Kidney Social Summit conference and the creation of the educational handouts went as planned. The first three informational sessions were well implemented, and the speakers were very informative. Additionally, the educational handouts contained all of the material the research team had assembled from the literature review and needs assessment along with appealing graphics and a consistent layout. The research team is excited for the advancement of the pediatric CKD track at the NKF serving Minnesota's annual CKD educational conference and is hopeful the educational handouts will provide education and support nationally through the NKF's website.

Further Projects

In partnership with the NKF serving Minnesota, the research team was able to provide support and resources for patients and families with pediatric CKD. When initially meeting with the NKF organization, there were a few other populations that could have used further support, including adults with CKD, as it is quite common. Additionally, those who need a kidney transplant and diabetic patients are also populations who could have benefited from a community outreach project. However, the research team decided on the pediatric population due to the lack of resources available compared to the other populations.

Although the research team concluded that an established educational conference was the best way to deliver information to patients and families with pediatric CKD, the setting could have been made more appealing to a younger population. Coming up with engaging activities for children may be beneficial to increase attendance. Additionally, offering childcare may alleviate some families' barriers to attending the educational conference.

The continuation of the pediatric CKD track at the Kidney Social Summit will be decided by the NKF serving Minnesota. The organization would need to expand event advertising to patients and families with pediatric CKD and maintain a relationship with the speakers for the future. All of the resources made by the research team for each session can be utilized for subsequent years.

Conclusion

Although CKD is the ninth leading cause of death amongst adults in the United States with many resources available, there are very few resources and little support available for the pediatric CKD population since the population size is small ("Kidney Disease," 2017). Due to the lack of available resources for the pediatric CKD population, the research team chose to partner with the NKF serving Minnesota to create an educational conference and provide support and resources for families with pediatric CKD. Prior to creating the conference, the NKF serving Minnesota expressed a need in their organization for more support and resources for their pediatric population, and offered the opportunity to implement a pediatric CKD track in their annual CKD educational conference. After interviewing several healthcare specialists and experts in pediatric CKD, as well as completing an extensive literature review of pediatric CKD needs, a needs assessment was established, and the research team was able to create educational handouts and informational sessions for families with pediatric CKD. The educational conference included four informational sessions along with handouts that were provided during each of the sessions. The informational sessions included content such as kidney basics, healthy kidney nutrition, transitional care, and networking. Several of the handouts that were provided to participants included relevant tables, charts, and helpful tips that are important to know when providing care to a child with CKD.

Although the participant size was small for the pediatric track, the resources and handouts created by the research team was deemed helpful by the participants and will be utilized in future educational conferences and available for other pediatric CKD families on the NKF national website. The research team felt that the handouts created accurately addressed the burdens that are experienced by the pediatric CKD population. After interviewing specialists and a parent, it was apparent that the pediatric CKD population has many needs that are not always addressed or available in care, therefore the research team attempted to address as many needs as possible to ease any struggles these families may be experiencing. Upon completion of the conference, the research team was thrilled by the reactions from participants and from the NKF organization, as they were very grateful for the service the research team provided. In the future, the research team hopes the handouts and informational sessions will be continued and will be expanded to other families throughout the Midwest, and possibly throughout the nation. The ultimate goal of the community service project was to implement resources and support for pediatric CKD families and the research team feels that goal was exceptionally surpassed.

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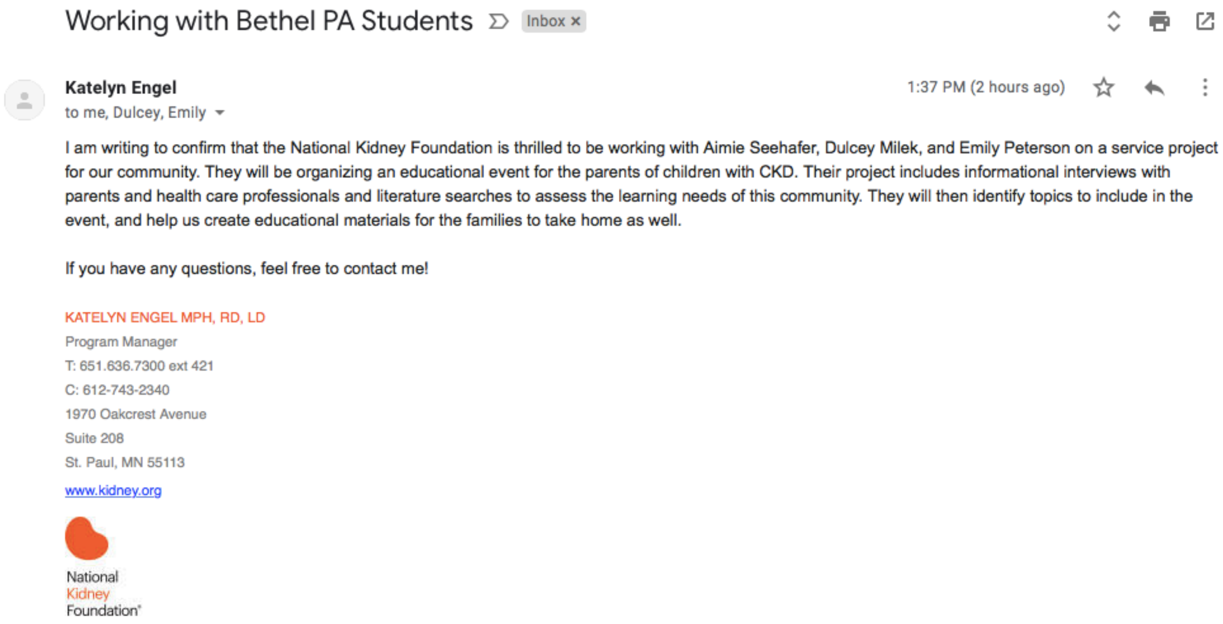
APPENDIX A:

National Kidney Foundation Permission Letter



Working with Bethel PA Students

Katelyn Engel

I am writing to confirm that the National Kidney Foundation is thrilled to be working with Aimie Seehafer, Dulcey Milek, and Emily Peterson on a service project for our community. They will be organizing an educational event for the parents of children with CKD. Their project includes informational interviews with parents and health care professionals and literature searches to assess the learning needs of this community. They will then identify topics to include in the event, and help us create educational materials for the families to take home as well.

If you have any questions, feel free to contact me!

KATELYN ENGEL MPH, RD, LD
Program Manager
T: 651.636.7300 ext 421
C: 612-743-2340
1970 Oakcrest Avenue
Suite 208
St. Paul, MN 55113
www.kidney.org

National
Kidney
Foundation®

APPENDIX B:

Interview IRB Approval

BETHEL UNIVERSITY

Institutional Review Board
3900 Bethel Drive
PO2322
St. Paul, MN 55112

November 13, 2018

Emily Petersen
Bethel University
St. Paul, MN 55112

Re: Project FA-06-18 Education and Support for Pediatric Chronic Kidney Disease; A Community Service Project

Dear Emily,

On November 13, 2018, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form documentation, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until November 12, 2019.

Sincerely,

Peter Jankowski, Ph.D.
Chair, Bethel University IRB

APPENDIX C:

Interview Questions

Interview Questions

1. How is a child with CKD's life different from other children?
2. How involved are families in patient's care?
3. What questions are frequently asked by this population?
4. What is the biggest burden you see in families dealing with this pediatric CKD?
5. What is the biggest burden of the patient?
6. What is the primary focus of treatment?
7. What are some common barriers you see in receiving treatment?
8. What do you believe are important lifestyle changes to address in this population?
9. What is the recommended nutrition regimen for this population?
10. What are some techniques you utilize to create healthy eating habits in children?
11. What is the recommended exercise regimen for this population?
12. What are common systemic effects with pediatric CKD?
13. What new treatment options are being researched for care?
14. What is the transition from pediatric to adult care like? Is this a difficult process for patients?
15. What is the most important topic children and families should be educated on about this disease?
16. What do you think is the best way to relay information to families (surveys, pamphlets, etc.)?
17. What do you enjoy most about this population?
18. What has surprised you the most about this population?
19. Do you feel patients struggle with talking about their disease with others?
20. How often do you provide resources for support in the care setting?
21. Do you have recommendations on reliable informational resources to include in our educational materials?
22. What do you wish would be addressed in care that is currently not?
23. What current support groups do you utilize?
24. Do you involve your child in care management, and at what level of involvement?
25. What advice do you have for other families caring for children with CKD?
26. What is the largest burden of pediatric CKD from a social workers perspective?
27. What do you appreciate about your healthcare providers and care teams?

APPENDIX D:

Interview Informed Consent

Evidence Based Medicine and Research II
Informed Consent

To whom it may concern,

We are Physician Assistant students from Bethel University's Physician Assistant Program, conducting a research and community service project in partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. Our research and community service project is working with the National Kidney Foundation (NKF) to investigate the needs of patients and families with pediatric chronic kidney disease (CKD). With this information, we hope to create informational materials to educate and support those managing pediatric CKD.

You were selected as a possible participant in this study because of your expertise in this area. If you decide to participate, we will ask about your experience working with pediatric CKD. This will take around an hour and will only be a one-time interview. With your consent, we will record the interview for recall purposes only. Any information obtained in connection with this research and community service project that can be identified with you will remain confidential and will be disclosed only with your permission. In any written reports or publications, no one will be identified or identifiable and only aggregate data will be presented. All audiotaping will be stored on a password coded computer, and will be destroyed after completion of the research and community service project.

Your decision whether or not to participate will not affect your future relations with the Bethel University Physician Assistant Program or the National Kidney Foundation in any way. If you decide to participate, you are free to discontinue participation at any time without affecting such relationships.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the community service project and/or participants' rights, or wish to report a research related injury, please call any of the following:

Emily Petersen, Researcher: 612-723-2860
Aimie Seehafer, Researcher: 612-310-7589
Dulcey Milek, Researcher: 507-450-2836
Lisa Naser, MS, PA-C, Research Chair: 651-635-8679

You will be offered a copy of this form to keep.

We understand that you have an extremely busy schedule and your time is limited. Please realize that your participation is vital to the success of this research and community service project. The information that you provide is essential to the validity of this project. Thank you in advance for your input in this community service project. If you have any questions, please contact any team members.

Thank you again for your help.

Sincerely,

Dulcey Milek, Emily Petersen, and Aimie Seehafer

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without prejudice after signing this form should you choose to discontinue participation in this study.

Signature Date

____

Signature of Investigator Date

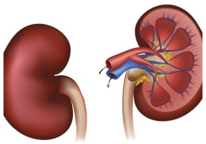
____

APPENDIX E:

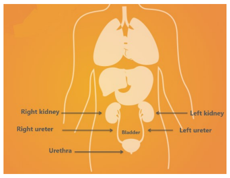
“Kidneys Basics” Educational Handout

National
Kidney
Foundation™

Kidney Basics



Most people have two kidneys, each about the size of your fist and shaped like a bean. Your kidneys are below your ribs, just above your lower back.



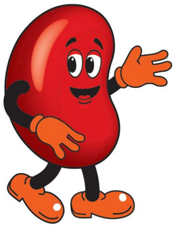
WHY DO YOU NEED KIDNEYS?

- **To filter your blood** in order to…
    - ◊ **Remove waste products**, like urea and ammonium that your body doesn't need.
    - ◊ **Control the balance of minerals** like sodium, calcium, phosphorus, and potassium that keep your heart and muscles functioning
    - ◊ **Control the fluid balance** in the body, to help all your organs work right.
    - ◊ **Control acid-base balance**, or pH: The pH in the blood helps to make sure the cells in your body function properly.
- **To make red blood cells,** which carry oxygen to the body's tissues giving you energy.
- **To control your blood pressure** by making a hormone called renin, which also controls salt and water balance.
- **To activate vitamin D** for calcium production, which keeps your bones healthy.

WHAT HAPPENS WHEN YOUR KIDNEYS AREN'T WORKING PROPERLY?

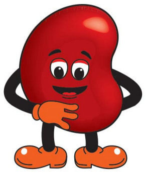
When the kidneys are damaged, they can't filter blood well. Waste products can build up in your body, making you sick. The kidneys also can't do their other jobs, like control your blood pressure or make vitamin D, and this can cause other health problems like heart disease, anemia, and bone problems.

FUN FACTS ABOUT YOUR KIDNEYS!

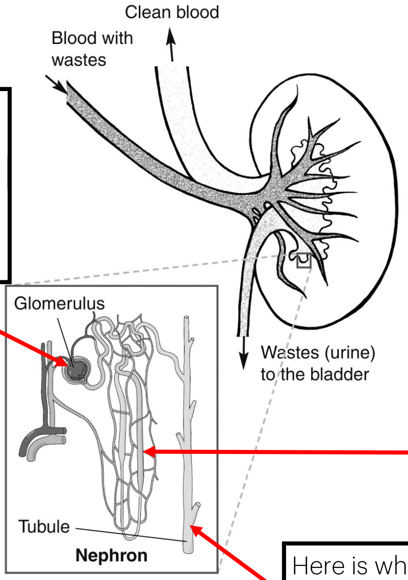


- About 1/5th of the blood that is pumped with each heartbeat goes directly to your kidneys.
- Your kidneys sort through about 150 quarts of blood per day and filter out about 1-2 quarts of waste products and extra fluid, which leave your body as urine.
- All the blood in your body is filtered by your kidneys every 30 minutes.
- One healthy kidney can do the work of two.

HOW DOES THE KIDNEY FILTER BLOOD?



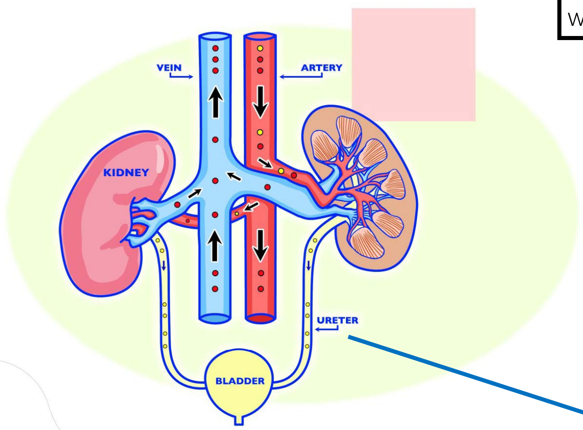
Each kidney has about one million tiny filters called nephrons. The nephron has two main parts: a glomerulus and a tubule. After the glomerulus filters the blood, the tubule works to remove more waste products and adds water and nutrients that the blood needs.



Here is the glomerulus, the part of the nephron that filters out the waste and extra water your body doesn't need.

Here is where the water and nutrients your body needs are added back to the blood from the tubule.

Here is where the tubule removes the waste products and water your body



The waste products and extra fluid that are filtered out leave the nephrons and are taken to your bladder through small tubes called ureters. This fluid leaves your bladder as urine.

Sources:

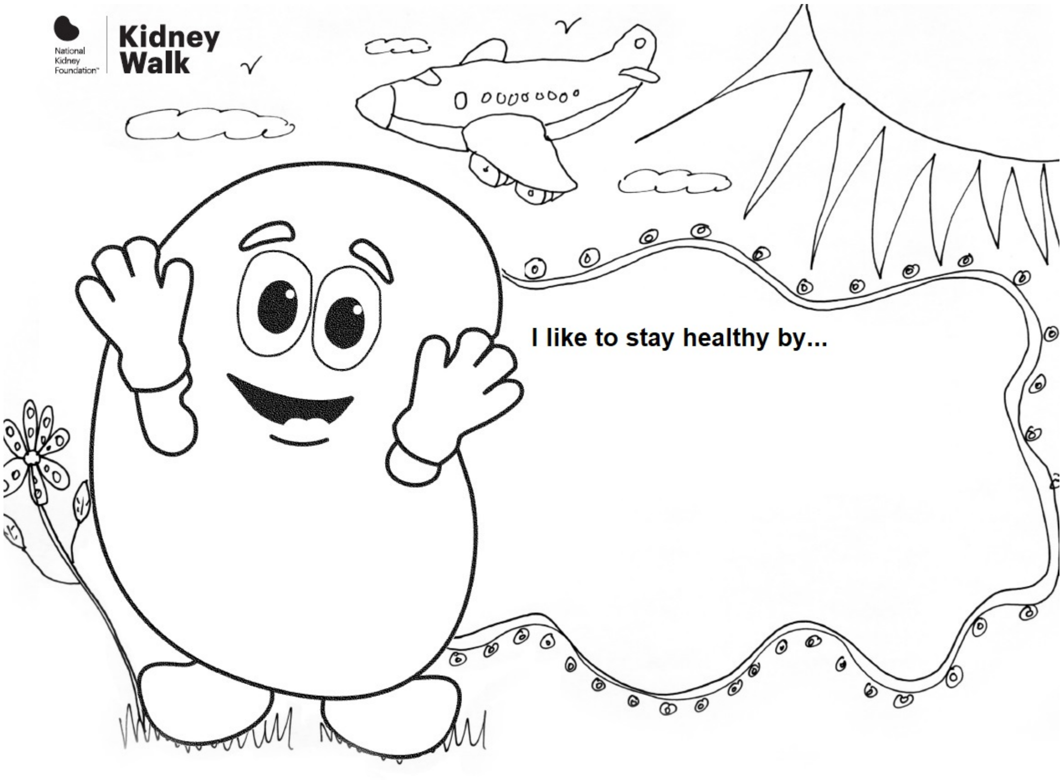
Centers for Disease Control and Prevention. US Department of Health and Human Services. (n. d.). *FAQs. Retrieved from https://nccd.cdc.gov/ckd/Help.aspx?section=F*

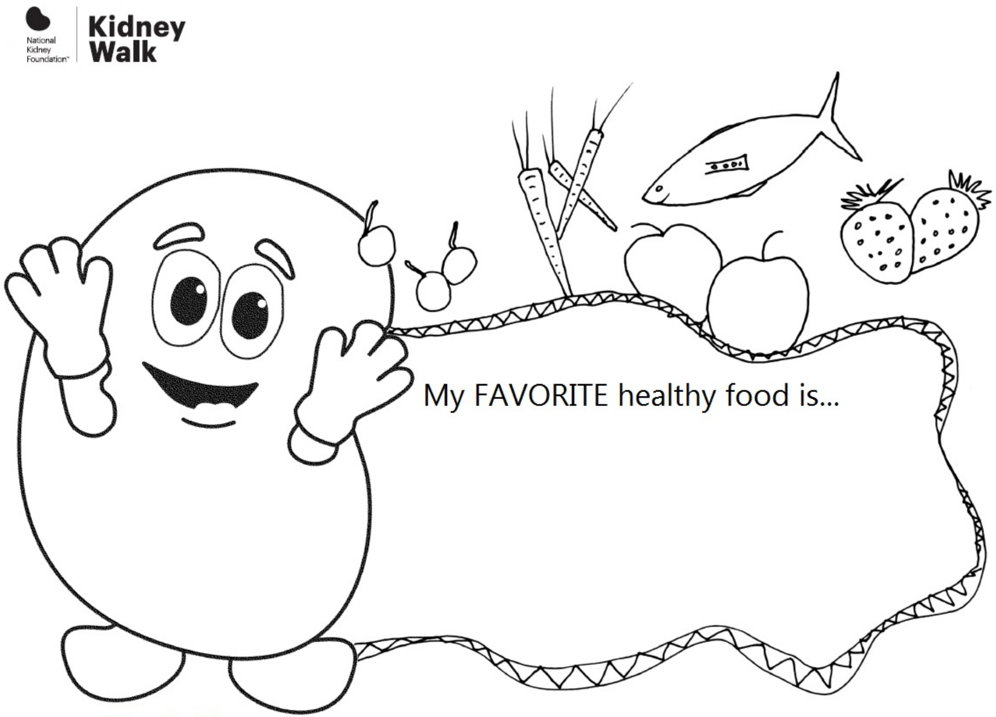
Chalouhy, C. E. (2017). Kidney anatomy. Retrieved from https://emedicine.medscape.com/article/1948775-overview#a7

National Institute of Diabetes and Digestive and Kidney Diseases. (2018). Your kidneys & how they work. *U.S. Department of Human Health and Services. Retrieved from https://www.niddk.nih.gov/health-information/kidney-disease/kidneys-how-they-work*

APPENDIX F:

Kidney Coloring Pages





Sidney the Kidney

APPENDIX G:

“5 Steps to Ease Transition from Pediatric to Adult Healthcare” Educational Handout

National
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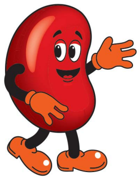
Transitioning from Pediatric to Adult Healthcare

TIPS TO KNOW ABOUT YOUR TRANSITION



- Appointments may become less frequent
- Patient independence is required
- Adult healthcare includes a wide range of patient ages
- Physicians manage more patients at one time due to the vast population size

5 STEPS TO EASE THE TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE

1. Stay Educated
    a. You cannot make the best medical decision if you aren't knowledgeable about your health conditions.
    b. It is important to understand how your kidneys function and how your CKD affects your body.
    c. Learn how your medications help your body.
    d. Use smartphone apps or online resources to help learn more about kidney health and manage your diet and medications.
2. Be Involved in the Decision-Making Process
    a. Practice open communication between you and your providers to ask questions and build relationships. Do more talking and let your parent or guardian listen.
    b. Stay involved and take control in your medical decisions.
    c. Start making decisions independently and participate in your care.
    d. Sign up for online access to your medical chart, to stay educated on your medical records.
3. Practice Independence Prior to Transition
    a. Practice going to appointments alone. Write down what was discussed and any changes that were made to your care plan. If necessary, have your parent call the staff at the appointment to verify the information.
    b. Begin scheduling appointments on your own. Order and pick-up medications by yourself. Travel to the clinic independently.
    c. Practice taking your medications at the correct time without any reminders or help from adults.
    d. Grocery shop and make meals on by yourself. Practice selecting healthy foods that fit into your prescribed diet.

4. Keep All Medical Information in an Organized Folder
    a. Create a list of all medications you take, including the name of the medication, time of day it is taken, dosage, and reason for taking it.
    b. Create a list of all your health providers. Include their name, contact information, specialty, purpose for visiting them, and location of their clinic.
    c. Create a list of any past surgeries, including date, surgeon's name and contact information, reason for surgery, and other pertinent details.
    d. Create a list of any allergies you have, including type of reaction and date last reaction took place.
    e. If needed, create a list of your medical equipment, including company name, contact information, and prescribing physician's name and contact information.
    f. Make sure all your insurance information is accessible. This includes the member ID card and contact information of the insurance company.
    g. Download smartphone apps or set notifications to help with medication or appointment reminders.
5. Ask Questions! Ask for Help!
    a. Remember that any questions that don't get asked may not be answered. So, speak up, and ask any your provider any questions that you may have.
    b. Ask your provider about all topics, such as medications and treatment options. Talk about transitioning to adult care and other unfamiliar topics.
    c. Use other professionals such as nurses, social workers, and dietitians to gather more information. They can give you a different perspective and helpful tips for a successful transition to adult care.
    d. All providers and staff members are available to support you and answer any questions you have. Don't be afraid to ask for assistance!

Resources

Teen Advisory Committee. (2002). One Step at a Time: Your Guide to Making the Move from Pediatric to Adult Care [Pamphlet]. Boston, MA: Boston Children's Hospital.

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. Pediatrics, 121(2), 349-360. doi:10.1542/peds.2006-3470

Watson, A. R. (2014). Psychosocial support for children and families requiring renal replacement therapy. Pediatric

APPENDIX H:

Medical Organizational Charts

MEDICATION MANAGEMENT

Medication Name	Time Taken	Dose of Medication	Reason for taking medication	Prescribing Physician

WHO'S MY DOCTOR

Provider Name	Contact Information	Specialty	Number of Years Providing Care	Location of Employment

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info@kidney.org • 800.622.9010 • kidney.org

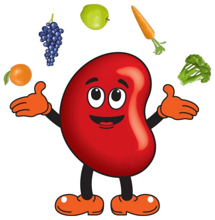
APPENDIX I:

“KIDney-Friendly Tips” Educational Handout

National
Kidney
Foundation™

Healthy Eating and Chronic Kidney Disease

KID-NEY FRIENDLY TIPS



-There are 4 main nutrient groups: sodium, potassium, protein, & phosphorus

-Eat homemade and fresh food and limit the amount of processed food

-Talk to your doctor or dietitian about specific recommendations

-Portion size matters! Many foods can fit into the CKD diet if the portion size is adjusted

SODUM

Sodium is a mineral found naturally in most foods and is the major part of table salt. Sodium helps balance how much fluid your body keeps and also regulates nerve and muscle function.

Why limit sodium?

When kidneys do not work correctly sodium and fluid can build up. This can cause:
-High blood pressure
-Fluid weight gain
-Thirst
-Swelling of fingers or ankles
-Puffiness around the eyes
-Shortness of breath

Tips to keep a low sodium diet

-Cook with herbs and spices instead of salt
-Read food labels and choose those foods low in sodium
-Avoid salt substitutes and specialty low-sodium foods made with them because they can be high in potassium
-When eating out, ask for meat or fish without salt. Ask for gravy or sauces on the side. These can have lots of salt.
-Limit the use of canned, processed and frozen foods
-If salt is listed in the first five ingredients, the item is probably too high in sodium!

Tips when grocery shopping

- Know how much sodium you are allowed each day. Remember that there are 1000 milligrams (mg) in 1 gram.
- For example, if your diet prescription is 2 grams of sodium, your limit is 2000mg per day. This is equal to just 1 tsp of table salt! Consider the sodium content of all food to be eaten that day to make sure you don't go over.
- Look at the package label and check the serving size. Nutrition values are listed per serving, which may be less than the actual amount you will eat.

  ****Aim for foods with 250mg of sodium or less per serving. ****
- Compare labels of similar products. Select the lowest sodium level for the same serving size.

POTASSIUM

Potassium is a mineral that helps keep your heart and muscles working properly.

Why limit potassium?

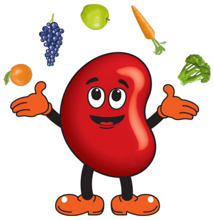
Having too much potassium in your blood can cause serious problems with your heart.

Tips to keep a low potassium diet

-Serving size is very important because almost all foods have some potassium in them. A large amount of a low-potassium food can turn into a high-potassium food
-Limit portion size of fruit juice as a small amount can contain a lot of potassium, even from low potassium foods like apple juice.
-Eat a variety of foods, but in moderation
-To have more choices when eating out, avoid higher-potassium fruits and vegetables during the day beforehand
-You can reduce the amount of potassium in foods through a cooking process called leaching. Ask your dietitian how many servings of leached vegetables are safe for you to eat.
-Avoid french fries and other fried potatoes

Tips when grocery shopping

- Choose medium and low potassium fruits and vegetables whenever possible. Apples, berries, pineapple, and grapes are good fruit options. Carrots, green beans, cucumbers, and bell peppers are some low potassium vegetable options.
- Check the nutrition facts AND the ingredient list! Potassium may be listed on the nutrition facts, but it is not required. If potassium not listed, *it does not mean that there is none in that food*. Check the ingredient list of high potassium ingredients
- Ingredients are listed in order by weight, with the item of the most weight listed first. If potassium chloride is in the ingredient list, it has a high potassium content.
- When reading nutrition labels, in general, % of potassium means:
  - Low = Under 100 mg or less than 3%
  - Medium = 101–200 mg or 3–6%
  - High = 201–300 mg or 6–9%



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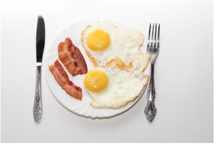
PROTEIN

Protein is one of the three nutrients used as energy sources (calories) for your body. It is an important building block in bones, muscles, cartilage, skin, and blood. However, in kidneys that do not work well, they lose the ability to filter out protein waste and it starts to build up in the blood. A balance of protein intake is essential. Protein intake varies based off of your body size, your kidney problem, and the amount of protein that may be in your urine.



Why is a balance of protein important?

Too much protein can build up in your blood and cause

- -Nausea
- -Loss of appetite
- -Weakness
- -Taste changes

Too little protein can cause:

- -Malnutrition
- -Stunted growth

Tips on maintaining a healthy protein diet

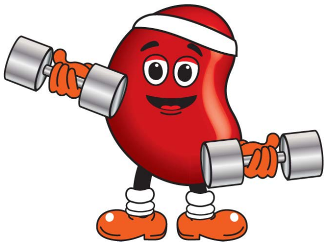
Your doctor may recommend a protein restriction, plant-based proteins may be gentler on your kidneys

Fresh, unprocessed meat/chicken/fish is the best option. These are lower in sodium.

When you're on a protein restriction, it is important that the protein you do eat is nutrient dense and high quality!

In general a good portion size of a protein food, is a deck of cards or the palm of your hand.

Talk to your doctor and/or a dietitian for specific recommendations!



PHOSPHORUS

Phosphorus is a mineral found in bones. Along with calcium, phosphorus helps build strong, healthy bones, and keeps other parts of your body healthy.

Why limit phosphorus?

Too much phosphorus in your blood can cause changes that pull calcium out of your bones, making them weak. High phosphorus and calcium levels also lead to dangerous calcium deposits in your blood vessels, lungs, eyes, and heart.

Tips to keep a low phosphorus diet

-Use milk substitutes, like rice milk, or non-dairy creamers in place of milk in cereals, coffee, and many sauces-- **Make sure they do not have any phosphorus additives!**

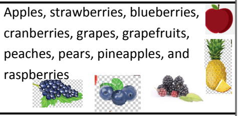
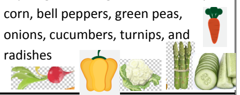
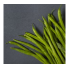
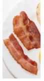
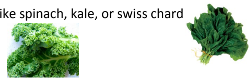
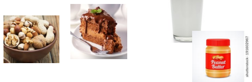
-Serving size is very important because most foods have phosphorus. Remember, a large amount of a low-phosphorus food can turn into a high-phosphorus food

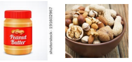
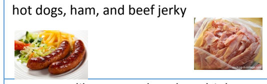
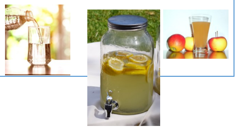
-Watch out for food additives containing phosphorus. They are often found in packaged snack foods, processed meats (hot dogs, pepperoni), baking powder, cake donuts, cake mixes, pasta products, and puddings.

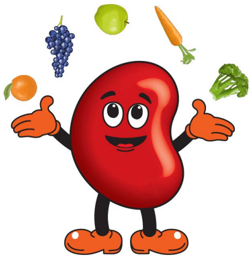
—Look for words with "phos" in the ingredients label. Examples: Phosphoric acid, Pyrophosphate, Sodium Tripolyphosphate

NUTRITION TIPS FROM OTHER PARENTS

Use this section to jot down tips you learned from other parents!

SODIUM		**POTASSIUM**	
INSTEAD OF THIS…	**HAVE THIS!**	**INSTEAD OF THIS…**	**HAVE THIS!**
Table salt 	Fresh or dried herbs and spices like basil, bay leaf, curry, ginger, sage, and thyme, 	Bananas, melons, oranges, nectarines, kiwis, mangos, papayas, prunes, and pomegranates 	Apples, strawberries, blueberries, cranberries, grapes, grapefruits, peaches, pears, pineapples, and raspberries 
Seasonings like soy sauce, teriyaki sauce, garlic salt, and onion salt 	Fresh seasonings like garlic, onion, lemon juice, pepper, and Mrs. Dash blends 	Avocadoes, broccoli, brussels sprouts, sweet & white potatoes, parsnips, pumpkin, winter squash, and tomatoes 	Asparagus, cabbage, carrots, celery, corn, bell peppers, green peas, onions, cucumbers, turnips, and radishes 
Most canned foods including soups, juices, and vegetables 	Fresh fruits, vegetables, homemade or low-sodium soups, and canned food without added salt 	Dried beans and peas, refried beans, legumes, and lentils 	Green or wax beans 
Ham, salt pork, bacon, sauerkraut, pickles, and olives 	Fresh beef, veal, pork, poultry, fish, and eggs 	Deep colored or leafy green vegetables like spinach, kale, or swiss chard 	Iceberg lettuce, romaine lettuce, or cabbage, 
Salted snack foods like chips and crackers 	Unsalted popcorn, pretzels, plain tortillas, and corn chips 	Milk, yogurt, nuts, seeds, chocolate, granola, and peanut butter 	Dairy substitutes, Rice, pasta, bread, white cake, and cookies without nuts or chocolate 

PROTEIN		**PHOSPHORUS**	
INSTEAD OF THIS…	**HAVE THIS!**	**INSTEAD OF THIS…**	**HAVE THIS!**
Processed and packaged meats like salami, hot dogs, ham, and beef jerky 	Fresh chicken, pork, fish, tofu, eggs or beef 	Milk, cheese, yogurt, cottage cheese, ice cream, custard, and pudding 	Rice milk or other non dairy substitutes such as almond milk or coconut beverage, vegan cheeses, sherbet, shaved ice, or popsicles, 
Chicken patties, fish sticks, or chicken nuggets 	Veggie burgers, tofu or soy products, fresh, unbreaded chicken or fish 	Nuts, seeds, peanut butter, and beans 	Popcorn, tortilla chips, pretzels, or crackers 
		Processed and packaged meats like salami, hot dogs, ham, and beef jerky 	Fresh chicken, pork, fish, and beef 
		Beverages like cocoa, chocolate drinks, and dark cola drinks 	Lemonade, light- colored sodas, fruit juices (apple or grape), and rice milk 



APPENDIX J:

Kidney-Friendly Recipes

Renal-Safe Macaroni and Cheese

Yield: 4 portions Serving size: 1/2 cup

Ingredients:

- 2 cups of elbow, shell, or bowtie pasta
- One 5-ounce jar of Kraft® Pimento Cheese spread made with cream cheese
- One 4-ounce can of Ortega® diced green chilies (rinsed and drained)
- Pepper to taste, if desired

Preparation

1. Cook the noodles in boiling water without salt or butter until the noodles are al dente.
2. Drain the noodles. While the noodles are hot, add the pimento cheese spread and the chilies.
3. Stir until the cheese spread is melted into the noodles.
4. Serve hot. Add pepper at the table for taste, if desired.

Nutrients per serving

- Calories: 196
- Protein: 6g
- Carbohydrates: 25g
- Sodium: 227 mg
- Potassium: 83 mg
- Phosphorus: 74 mg

Renal and Renal Diabetic Food Choices

- 1 starch
- 1 fat
- 1/2 milk
- Carbohydrate choices: 2

Helpful hints

- To get more protein, add browned and drained ground beef (dialysis only).
- Most cheese spreads are very high in sodium and phosphorus. The pimento spread in this recipe is made with cream cheese instead of processed cheese. (Look for the Philadelphia® brand cream cheese logo on the label). This is what keeps the sodium and phosphorus content low enough for a renal diet. Avoid bottled or canned spreads made with processed cheese.

UW Health. (2016). *Kidney health: kidney diet for kids* [PDF file]. Retrieved from https://www.uwhealth.org/healthfacts/parenting/511.pdf

Terrific Tacos

Yield: 6 servings
Serving size: 1 taco

Ingredients

- 6 corn taco shells
- 1/2 pound lean ground beef
- 1 tablespoon canola oil
- 1 cup onion, chopped (divided use)
- 1 garlic clove, minced
- 1 teaspoon chili powder
- 1/2 teaspoon black pepper
- 1/4 teaspoon ground cumin
- 1/4 teaspoon Tabasco® sauce
- 3/4 cup lettuce, shredded
- 1/3 cup tomato, chopped
- 1/3 cup sharp cheddar cheese, shredded

Nutrients per serving

- Calories: 240
- Protein: 10g
- Carbohydrate: 14g
- Sodium: 182 mg
- Potassium: 214 mg
- Phosphorus: 135 mg

Preparation

1. In a large frying pan, brown ground beef over medium heat. Drain well, remove from pan, and set aside.
2. Heat oil in pan. Add 1/2 cup chopped onion and cook until clear. Add garlic, cook, and stir for one minute.
3. Add cooked beef back into pan. Stir in chili powder, pepper, cumin and Tabasco® sauce. Remove from heat and prepare tacos.
4. Add 1/4 cup meat mixture inside each taco shell. Top with 2 tablespoons of lettuce, 1 tablespoon each tomato, cheese, and the rest of the onion.

Renal and Renal Diabetic Food Choices

- 1 meat
- 1 starch
- 1/2 vegetable, low potassium
- 1-1/2 fat
- Carbohydrate Choices: 1

Helpful hints:

- Select cheese that has the word "natural" on the package. Avoid processed cheese due to higher sodium and phosphorus contents.

UW Health. (2016). *Kidney health: kidney diet for kids* [PDF file]. Retrieved from https://www.uwhealth.org/healthfacts/parenting/511.pdf

Turkey Vegetable Chili

Yield: 6 Servings

Serving size: 3/4 cup

Ingredients

- Nonstick cooking spray
- 1 tablespoon canola or olive oil
- 1 pound lean ground turkey
- 1/2 cup onion, chopped
- 2 cloves fresh garlic, minced fine
- 2 cups zucchini squash, chopped
- One 14-ounce can stewed tomatoes, crushed
- 2 teaspoon chili powder
- 1-1/2 teaspoons cumin
- 1-1/2 teaspoons paprika
- 1/4 teaspoon cayenne pepper
- 1/4 teaspoon black pepper

Nutrients per serving

- Calories: 164
- Protein: 17g
- Carbohydrate: 6g
- Sodium: 214 mg
- Potassium: 517 mg
- Phosphorus: 189 mg

Preparation

1. Spray pan with cooking spray and add oil.
2. Sauté ground turkey, onion, garlic, and zucchini until zucchini is tender.
3. Drain excess liquid well.
4. Add stewed tomatoes and spices.
5. Simmer covered for about 1/2 hour.

Renal and Renal Diabetic Food Choices

- 2 meat
- 2 vegetables, medium potassium
- Carbohydrate Choices: 1/2

Helpful Hints:

- Two medium zucchini yields about 2 cups.
- Use lean ground beef instead of turkey if you wish.
- Serve over cooked rice or pasta for a filling meal.
- Be sure to count as 2 servings of vegetables in your daily meal plan to allow for the potassium in this recipe. If you are on a low-potassium diet, stick closely to the serving size above.

For more kidney-friendly recipes, sign up for “My Food Coach” on the NKF’s website!

Resources

UW Health. (2016). *Kidney health: kidney diet for kids* [PDF file]. Retrieved from https://www.uwhealth.org/healthfacts/parenting/511.pdf

APPENDIX K:

“Pediatric Track: Support Resources for Families” Educational Handout

National
Kidney
Foundation®

Kidney Social Summit: Pediatric Track: Support Resources for Families

Kidney disease can strike at any age. The National Kidney Foundation (NKF) has many programs and initiatives for children, teens, and families affected by kidney disease, and for the healthcare professionals who serve them.

RESOURCES FOR PARENTS AND FAMILIES

Pediatric Kidney Disease Blog Series

nkfadvocacy.wordpress.com
and **speaknowforkids.org/blog**

This blog series has stories about caregivers and families living with a child with pediatric CKD.

NKF Cares

Toll-free **855.NKF.CARES** (855.653.2273)
or email **nkfcares@kidney.org**

NKF Cares Patient Help Line, offers support for families affected by kidney disease by phone and email, in English and Spanish.

Online Communities

https://healthunlocked.com/nkf-parents

NKF online communities offer a safe and supportive place where families and caregivers can share experiences, ask questions, and get answers related to kidney health, kidney disease, transplantation, and living organ donation. Participation is free and anonymous.

NKF Facebook

Follow us on Facebook for articles, events, and more– www.facebook.com/NKFminnesota

THE BIG ASK: THE BIG GIVE

kidney.org/livingdonors

This platform helps people find a way to ask for a kidney and supports people considering donating. It helps parents find a living kidney donor by sharing the story of their child's need for a transplant.

OTHER ONLINE RESOURCES

Family Voices of MN

www.familyvoicesofminnesota.org/

CONNECTED is a free state-wide parent-to-parent peer support program provided by Family Voices of Minnesota for families whose children have chronic or complex special healthcare needs or disabilities.

Nephkids

https://www.cybernephrology.ualberta.ca/nephkids/

Nephkids is a listserv, an interactive email group of parents of children with chronic kidney disease of all varieties.

Renal Support Network

www.RSNhope.org

Renal Support Network (RSN) empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and make friendships that last a lifetime.

American Kidney Association of Kidney Patients

https://aakp.org/support-groups/

The American Association of Kidney Patients is dedicated to improving the quality of life for kidney patients through education, advocacy, patient engagement and the fostering of patient communities.

National
Kidney
Foundation®

info@kidney.org • 800.622.9010 • kidney.org

APPENDIX L:

Program Evaluation Kidney Social Summit: Pediatric Track

Your Opinion Matters!

Thank you for attending the National Kidney Foundation's Kidney Social Summit. Please take a few minutes to complete this brief survey. Your opinions are important to us and will help us adapt the program.

This survey is given by Physician Assistant students from Bethel University's Physician Assistant Program. These students are conducting a research and community service project in partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. The research and community service project is working with the National Kidney Foundation to investigate the needs of patients and families with pediatric chronic kidney disease (CKD). The pediatric track was created to help educate and provide support for patients and families with pediatric CKD.

In any written reports or publications, no one will be identified or identifiable and only collective data will be presented. You are free to stop completion of the survey at any time. Your decision whether or not to participate will not affect your future relations with the Bethel University Physician Assistant Program or the National Kidney Foundation in any way.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the community service project and/or participants' rights, or wish to report a research related injury, please contact the NKF.

1. Please mark which box best describes you:

   ☐ CKD Patient, not on dialysis

   ☐ Dialysis Patient

   ☐ Transplant Recipient

   ☐ Support Person/Family Member

   ☐ Healthcare provider

   ☐ Other ____________________________

2. Overall, how would you rate the seminar?

   ☐ Excellent

   ☐ Good

   ☐ Fair

   ☐ Poor

3. How did you hear about the Social Summit?

   ☐ Dialysis Clinic/Doctor's Office/Transplant center

   ☐ Facebook Post

   ☐ NKF email/website/newsletter

   ☐ Friend/Family member/Word of mouth

   ☐ Other

4. How do you rate each of the sessions you attended?	Very Helpful	Helpful	Somewhat Helpful	Not Helpful	Did Not Attend
Kidneys 101	☐	☐	☐	☐	☐
Kidney Nutrition for Kids	☐	☐	☐	☐	☐
Transitional Care	☐	☐	☐	☐	☐
Pediatric CKD Networking	☐	☐	☐	☐	☐

If you marked “Not Helpful”, please tell us why:

5. How do you rate each of the educational handouts provided?	Very Helpful	Helpful	Somewhat Helpful	Not Helpful	Did Not Attend
Kidney Basics	☐	☐	☐	☐	☐
KIDney-Friendly Tips	☐	☐	☐	☐	☐
KIDney-Friendly Recipes	☐	☐	☐	☐	☐
5 Steps to Ease the Transition from Pediatric to Adult Healthcare	☐	☐	☐	☐	☐
Medical Organizational Charts	☐	☐	☐	☐	☐
Pediatric CKD: Support Resources for Families	☐	☐	☐	☐	☐

If you marked “Not Helpful”, please tell us why:

6. Please rate the following:	Excellent	Good	Average	Fair	Poor
Location of Seminar					
Time of Seminar					
Day of Week of Seminar					
Time of Year of Seminar					
Food /Beverages Served					

7. Please list any topics you would like to learn more about at future patient seminars:
____

____

____

8. Please list any additional comments you have about the Kidney Social Summit.
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APPENDIX M:

Survey IRB Approval

February 6, 2019

Dulcey Milek, Emily Petersen and Aimee Seehafer;

As granted by the Bethel University Human Subjects committee as the program director, I write this letter to you in approval of Level 3 Bethel IRB of your project entitled: "Education and Support for Patients and Families with Pediatric Chronic Kidney Disease: A Community Service Project." This approval is good for one year from today's date. You may proceed with data collection and analysis. Please let me know if you have any questions.

Sincerely,

Wallace Boeve, EdD, PA-C
Program Director
Physician Assistant Program
Bethel University
w-boeve@bethel.edu
651 308-1398 cell
651 635-1013 office
651 635-8039 fax
http://gs.bethel.edu/academics/masters/physician-assistant