Pediatric Nephrology Co-Management at UNC Chapel Hill:
A Quality Improvement Project

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Abstract

**Research Question:** What variables impede or improve co-management of pediatric patients with nephrologic conditions who are referred to pediatric subspecialty services?

**Importance:** The need for pediatric nephrologists has grown faster than the workforce can expand to meet it, and 48% of pediatricians report too few specialists to meet the needs of their patients, with wait times on average of 6.7 weeks. General pediatricians are the initial providers of care for these patients before they are seen by pediatric nephrologists.

**Specific Aims:** I used the UNC pediatric nephrology referral service as a representative environment in which to gather data about areas of improvement for co-management. With the assistance of my faculty mentors, I surveyed primary care providers to determine their comfort with initial work-up and management of the most common conditions referred to UNC, and assessed ways to improve communication between offices, and clarity of management plans.

**Methods:** I used EPIC referral provider data to identify those who have previously referred patients to UNC pediatric nephrology. I then invited those providers to participate voluntarily in our web-based survey of their referral experiences. Recruitment methods included fax, office phone, and email addresses where information was available. Survey results were anonymous; in this preliminary analysis, I provide descriptive statistics such as counts, frequencies, and cross tabs with respect to EPIC access. I used Chi square tests to compare distance from UNC with satisfaction with wait time and received assessments, notes, and treatment plans. I accepted P values ≤ 0.05 to be statistically significant.
**Results:** Of the 177 potential providers who received recruitment messages, 10 responded, for a response rate of 5.6%. Most responders were female (70%), between 35 and 54 years old (60%), and practice in suburban settings (50%) less than 25 miles from UNC Health Care Pediatric Nephrology service in Chapel Hill, North Carolina (70%). Primary care providers with EPIC access receive copies of consultation notes more frequently than do those without, but also report receiving slightly too much communication. Most providers (80%) felt that the most valuable content in consultation notes is clear management plans and education about the patient’s diagnosis. Most providers (80%) are satisfied with the frequency and content of current communication with UNC Pediatric Nephrology. However, many are still uncomfortable with conditions including steroid-resistant and steroid-sensitive nephrotic syndrome, chronic kidney disease, and autoimmune disease. Many primary care providers (70%) are interested in receiving further education, which could be an opportunity to improve upon the PCP-specialist relationship and empower PCPs to co-manage and know when to refer their pediatric patients with nephrologic conditions. However, these findings are limited by the small response rate and the lack of identifying information to assess whether these respondents are representative of the larger population of referring providers. A larger survey sample would help us understand much more about this dynamic working relationship to enhance patient care and access, advance patient and provider education, and, ultimately, improve patient outcomes and provider satisfaction.
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Introduction

The need for pediatric nephrologists across the United States has grown because improvements in the care of complex, chronic pediatric conditions with significant kidney complications mean that children with kidney disease are more likely to survive and, thus, are more likely to need specialist care (Collins, Foley, Gilbertson, & Chen, 2015). This need has grown faster than the workforce can expand to meet it. A report from 2010 found that 48.1% of general pediatricians report too few pediatric nephrologists to meet the needs of their patients (Pletcher et al., 2010). In 2010 the National Association of Children’s Hospitals and Related Institutions reported that the average wait time to see a pediatric nephrologist was 6.7 weeks, and 52% of hospitals have longer than a 2 week wait for pediatric patients. In 2006, 16% of children have to travel more than 80 miles to see a pediatric nephrologist (American Academy of Pediatrics Committee on Pediatric Workforce, 2013).

The pediatric nephrology workforce faces a few specific challenges. First, the majority of providers are not full time clinicians because they practice at or are associated with an academic facility (Ad Hoc Committee, 1997; American Academy of Pediatrics Committee on Pediatric Workforce, 2013; Andreoli et al., 2005). Second, the geographic distributions of pediatric nephrologists and pediatric dialysis units are disproportionate. Certain states such as Wyoming and Montana do not have a board certified pediatric nephrologist located within the state, some states like Kansas have 1 per 1.4 million people, and other states like Massachusetts have 1 per 0.3 million people. This lack of consistent distribution of specialists means that many pediatric patients and their families must travel great distances to reach a pediatric nephrologist or pediatric dialysis facility (Andreoli et al., 2005; Satlin, Andreoli, & Schnaper, 2009). Third,
almost a third of current pediatric nephrologists plan to reduce or retire from clinical activities by 2018 and there is a trend of poor interest in the field among new trainees (American Academy of Pediatrics Committee on Pediatric Workforce, 2013).

Given the growing need for pediatric nephrology and the shrinking workforce, it is clear that the current paradigm of pediatric nephrology as primary manager of all children with nephrologic diseases is unsustainable. Instead, resources and attention should be directed toward improving co-management strategies between pediatric nephrologists and their primary care counterparts. The field of pediatrics has identified the importance of improving co-management strategies to resolve the workforce shortage seen across numerous pediatric subspecialties because this strategy makes better use of the existing workforce and empowers the specialist-generalist relationship. The rationale behind co-management is that the responsibility of initial kidney disease management typically lies with the primary provider or generalist, especially while patients are waiting for or are in between appointments. These providers are also the initial point of care for these patients, so it will be important to equip them with the tools they need to engage in high quality management and referral practices for their patients with serious nephrologic conditions. This could help to improve health outcomes among children with kidney-related diseases by providing PCPs with the resources for early detection, preliminary testing, and standard of care treatment for more prevalent nephrologic diseases.

As seen in the partial systematic review found in Appendix A, we lack data about specific ways to improve collaboration within co-management strategies to better meet the needs of providers and, ultimately, improve morbidity and mortality of their patients. While fragmentation of care still exists and has been shown to be insufficient in managing current levels of kidney
disease burdens, this practice intersection has not been studied in a meaningful way on the local, state, or national level within pediatric nephrology.

Little is known about the physician or health system variables that serve as barriers to collaborative care shared by specialists and primary care providers. This makes it challenging to improve upon or even assess the current quality of care, equity, and access to care for patients requiring specialists. Without identifying specific barriers to effective and timely care, especially in the context of a changing landscape of health care delivery, it will be difficult to develop formal models for PCP-specialist collaboration and co-management. The goal of my study was to assess current levels of communication and collaboration to identify areas of improvement for shared management of children referred to the Division of Pediatric Nephrology and Hypertension at the University of North Carolina at Chapel Hill and in its clinical services in UNC Health Care.
Background and Significance

Why does pediatric nephrology matter?

Chronic kidney disease (CKD) is recognized as a growing public health concern in the United States (U.S.): Healthy People 2020 included as one of its goals to “reduce new cases of CKD and its complications, disability, death, and economic costs (U.S. Department of Health and Human Services, 2010). In 2014 the Centers for Disease Control and Prevention (CDC) estimated that more than 20 million people may have some degree of CKD (Centers for Disease Control and Prevention, 2014). The incidence of CKD has been growing quickest among adults 65 and older, and this incidence in 2008 was more than double that in 2000 (National Institute of Diabetes and Digestive and Kidney Diseases, 2012).

The CDC’s Chronic Kidney Disease Surveillance Project was designed to document and monitor the CKD burden and risk factors over time within the U.S. population (Collins et al., 2015). Diabetes and hypertension are the leading causes of CKD among adults and oftentimes these diseases begin in childhood. Based on data from 1999 to 2010 the CDC estimates that 8.6% of children will have clinical hypertension by age 19, and 0.18% of children under 19 years old have diabetes mellitus. These children will be at greater risk of developing CKD and end stage kidney disease (ESKD) as adults, so it will be important to optimize their disease management earlier to slow or prevent this progression (Centers for Disease Control and Prevention, 2016; Collins et al., 2015).

Between 2009 and 2011 the prevalence of pediatric ESKD in the U.S. was 87 cases per million children, and the incidence was 15 cases per million children during this two year time
period. By 2020 the CDC estimates there will be just under 89 million children in the U.S. and, if prevalence estimates are correct, that means about 8,000 children will have ESKD by then (Centers for Disease Control and Prevention, 2016). While it is true that children make up at most 1% of the ESKD population in the U.S. pediatric ESKD patients are significantly different from their adult counterparts. The primary causes of ESKD among pediatric patients are congenital anomalies of the kidney and urinary tract followed by glomerulonephritis and cystic kidney disease, compared to diabetes and hypertension as the two leading causes in the adult population. Given the rapidly increasing prevalence of hypertension and complications of obesity, including diabetes and hypertension, raises concern for the earlier presentation of ESKD. These pediatric patients, their families, and their health care providers also face a multitude of other challenges including proper nutrition, medication compliance, downstream effects on growth and development, the child’s and family’s psychosocial adjustment to chronic disease, and scheduling health care amidst other pressing obligations like school or parents’ work. Treatment modality also differs, because pediatric ESKD patients primarily receive preemptive transplantation or peritoneal dialysis rather than hemodialysis (Andreoli et al., 2005).

While the increasing population of pediatric patients with ESKD places even more demands on the pediatric nephrology workforce there are also growing numbers of patients with kidney diseases requiring specialist input and management such as CKD, hypertension, and diabetes.

**Pediatric Nephrology: a shrinking workforce**

The supply of pediatric nephrologists is currently insufficient and, given the growing demand for pediatric nephrologists and the rise in incidence of kidney diseases among pediatric patients, this shortage will only worsen over the next several years. Concerns about the present
and future insufficiency of the pediatric nephrology workforce led the American Academy of Pediatrics (AAP) to survey all 766 providers in 2013 who have ever been board eligible for pediatric nephrology or who were a member of the American Society of Pediatric Nephrology or the AAP Section on Nephrology. Of those surveyed, 504 responded. Only 409 of respondents practice pediatric nephrology at least part time and only 384 (93.9%) of these practice within the U.S. This means that 95 (18.8% of responders) no longer practice clinical pediatric nephrology. Those who practice at least part time spend just over half of their time dedicated to patient care (59%). This lack of practicing pediatric nephrologists with divided clinical time coupled with the disproportionate geographic distributions of providers and pediatric dialysis units contribute to current shortages (American Academy of Pediatrics Committee on Pediatric Workforce, 2013).

The AAP study found that the issues contributing to the future shortage were twofold: an older generation of current nephrologists and a lack of interest among new trainees. Compared with other pediatric subspecialists, pediatric nephrologists are the oldest group, with a mean age of 57.8 years in 2013. Over the next 5 years roughly a third of them plan to reduce or retire from clinical activities and many plan to increase their time dedicated to research (26%) and to administrative duties (19%) (American Academy of Pediatrics Committee on Pediatric Workforce, 2013). In anticipation of the country’s growing need for pediatric nephrologists the number of fellowship program spots increased in 2004 to encourage additional training. However, recent trends have shown that many of these spots are left vacant from year to year. In the 2011-12 and 2012-13 academic years 26 and 22 pediatric nephrology positions, respectively, were left vacant. From 2010 to 2014, 43% of positions went unfilled for first year pediatric nephrology fellows (Ferris et al., 2014; National Resident Matching Program, 2012). An estimated minimum of 30 to 40 newly trained pediatric nephrologists each year will be needed.
for the next decade just to sustain current workforce levels (Council of Pediatric Subspecialties, 2013).

To better understand why so many fellowship spots are left vacant Ferris, Iglesia, and Ko et al. performed a cross-sectional survey of 531 non-renal pediatric subspecialty fellows in 2014. A majority (60%) of participants perceived nephrology to be a difficult subject, and this was especially significant among female American medical graduates. When asked about disincentives to pediatric nephrology training, the most common response was a lack of a role model or mentor in the field (24%) followed by the field’s content being too difficult (22%). Significantly more male than female respondents believed the field had inadequate monetary compensation (24% vs. 8%) (Ferris et al., 2014). This is in agreement with estimates by Rochlin that calculated training and practicing in pediatric nephrology leads to a lifetime loss of income of $750,000 (Rochlin & Simon, 2011).

When Ferris et al. surveyed pediatric nephrology program directors a majority (60%) reported that it was difficult for them to recruit qualified trainees. Most of these program directors believed that income (68%) and workload (56%) were major disincentives to applicants, and over half (56%) of the programs have had at least one fellow in the last 10 years who did not complete his or her fellowship training. Among the fellows who completed their training under surveyed program directors, almost a fifth (19%, 35/183) did not actually return to the pediatric workforce, with almost half of these individuals (46%, 16/35) choosing to practice general pediatrics (Ferris et al., 2014). This work by Ferris et al. is indicative of a growing lack of interest in the field among future trainees, and a looming shortage of the pediatric nephrology workforce.
The demand for pediatric nephrologists across the U.S. has grown not only due to rising rates of CKD, ESKD, and other highly prevalent conditions with kidney-related complications, such as obesity, hypertension, and diabetes, but also because improvements in the care and life-expectancy of children with complex or chronic conditions with significant kidney complications means more need for specialist care. This anticipated need highlights the necessity of providers who are well trained in pediatric nephrologic diseases, whether this is through an adequate pediatric nephrology workforce or by effective co-management or coordinated efforts across specialties (Parker, Ibrahim, Shaffer, Rosner, & Molitoris, 2011).

**Current Guidelines and Measures Are Not Enough**

Many groups have offered potential solutions for the workforce shortage problem. Although numerous specialty societies and research bodies, most notably the American Society of Nephrology (ASN), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the National Kidney Foundation (NKF) offer disease-specific management guidelines it is unclear whether these guidelines are being followed appropriately by primary care providers or first line providers. A study in England assessing compliance to urinary tract infection work-up guidelines released by the National Institute of Clinical Excellence found that implementation was inadequate and inconsistent. The authors attribute these implementation barriers to complexity in the guideline’s criteria (Platt et al., 2015). However, with the growing administrative responsibilities and patient census that primary care providers (PCPs) must grapple with it is clear that PCPs may not always have the time for, or be comfortable with, specialist-produced guidelines.

Ideally when a patient is referred to a specialist the PCP will be provided with specific care guidelines or management protocols, but this is not always the case. When this oversight
occurs many PCPs are left with preventive guidelines and targets based on general population norms rather than accurate, disease-specific recommendations (Gupta, Unruh, Nolin, & Hasley, 2010). Similarly, many PCPs rely on the quality indicator measures selected by the Agency for Healthcare Research and Quality (AHRQ) to help direct the preventive care they provide to their patients with nephrologic conditions. PCPs may give more weight to these quality indicators than they do to more kidney disease-specific parameters. Compliance with the quality indicator for blood pressure measurement among diabetic patients is as high as 99%. For example, while referral for proteinuria in this patient population, a specialty society recommended practice, is drastically lower, at only 36%. Given the lack of correlation between the AHRQ quality indicators and high quality care for patients with nephrologic diseases, PCPs should be offered clear management guidelines and supplemental health parameters to provide better care for their patients with nephrologic conditions (Agency for Healthcare Research and Quality, 2016; Eilat-Tsanani, Reitman, Dayan, Mualem, & Shostak, 2014).

**Why will the co-management model work?**

Nephrology associations recommend early referral for complex conditions such as renal failure, since late referral to specialized care has been associated with worse health outcomes and higher medical costs (Mondry, Zhu, Loh, Vo, & Hahn, 2004). However, early referral may not result in earlier care, given the long wait to see a pediatric nephrologist. If the pediatric workforce continues to struggle to attract future trainees, then more needs to be done to offer appropriate management and care for these patients without overtaxing the already limited pediatric nephrology workforce. Other medical providers such as the primary care providers (PCPs) who are oftentimes the initial point of contact for patients with nephrologic diseases are vital to ensuring quality care. The need for and potential benefit of a strong partnership between
the primary care physician and nephrology provider is especially important in the management of CKD. Ensuring that there is an adequate workforce trained in management of pediatric nephrologic conditions to address this mounting public health problem will allow more patients to be cared for at earlier stages of disease with, it is to be hoped, consequent improvements in health outcomes and long term benefits (Baldwin, 2014).

This transition in treatment paradigms from the sole responsibility of specialists to the shared responsibility with PCPs is supported by both fields. Surveys by Yoon, McCool, and Filipp et al. about management of adolescents with hypertension found that hypertension specialists support the role of generalists in initially managing and then co-managing diseases alongside specialists (Yoon et al., 2015). Diamantidis, Powe, and Jaar et al. attempted to understand the ideal PCP-specialist collaboration model and surveyed a national sample of PCP and nephrology providers about hypothetical adult CKD management. This study found that a majority of PCPs and nephrologists (85% and 94%) favored collaboration, and only a third desired even more collaboration of at least every 2 to 3 months. Participants preferred specialist input to confirm the clinical evaluation, to offer guidance about further evaluation and testing, provide advice about medication management, and suggest nutritional advice. When asked about barriers to collaborative care fewer PCPs felt they had sufficient ancillary support for their CKD patients, and more nephrologists felt insurance was a barrier to referral. A majority of nephrologists reported that patients were referred too late, and a third felt patients were not on an optimized medication regimen (Diamantidis et al., 2011).

Most adult CKD patients are actually managed by their PCP, but many of these patients managed solely by PCPs do not receive recommended testing and can suffer worse clinical
outcomes for lack of timely nephrology input. For instance, urine albumin is an important test used to monitor kidney disease progression, yet among Medicare CKD patients, those who were managed by a nephrologist rather than a PCP were more likely to receive recommended testing with urine albumin (59% vs. 39%, respectively) or serum creatinine (94% vs. 92%, respectively) (U.S. Renal Data System, 2015). A similar trend of poor PCP adherence to guidelines is seen in a study by Boneparth and Flynn that found less than half of general pediatricians knew about guidelines for PCP management of adolescents with HTN (Boneparth & Flynn, 2009). This is also supported by Diamantidis’s findings that a majority of PCPs are unsure or unaware of referral guidelines. Chronic illness, such as CKD, could be an especially important area for co-management to improve specialist input while also maintaining the beneficial continuity of treatment with their primary care provider (Diamantidis et al., 2011).

Co-management and collaboration are also areas that could be improved upon with better communication content and frequency. Navaneethan, Aloudat, and Singh performed a systematic review and found that a lack of communication between nephrologists and the referring provider was associated with late referral for CKD patients (Navaneethan, Aloudat, & Singh, 2008). Similarly, Gandhi, Sittiq, and Franklin et al. found that a majority of providers feel that inadequate information is communicated between PCPs and specialists, and vice versa, which could be a source of provider frustration and a barrier to successful patient outcomes (Gandhi et al., 2000). By providing PCPs and specialists with the appropriate tools to navigate and optimize their working relationship we can remove the barriers to pediatric nephrology created by workforce shortages at the same time we provide better patient care and provider satisfaction.
Methods

The Sample

I used the UNC pediatric nephrology referral service as a representative environment in which to gather data about areas of improvement for co-management. I distributed a survey to family medicine and pediatric providers who have referred patients to pediatric nephrology services in 2016 and for whom I could locate email addresses or fax numbers. I identified potential survey participants using the Epic (UNC EHR) referral database, sorted by those providers who have referred a patient to UNC Children’s Nephrology since UNC’s Epic go-live on April 4, 2014. It should be noted that, due to the transitioning process to the new electronic medical record system Epic, it is possible that this database is not comprehensive and may not include all providers who have referred patients, especially those who did so within the first few months of the go-live date. The final number of referring providers I identified with the Epic referral database was 205. After I removed duplicates I had a population of 194 unique providers. I invited these clinicians to participate in the voluntary, web-based Qualtrics survey.

The original study protocol aimed to recruit providers primarily via email and office phone, and this study was deemed exempt by the Institutional Review Board of the University of North Carolina (IRB No. 16-0637). I sought email addresses via the UNC Directory, publicly accessible information online, and by office phone calls requesting the provider’s email address. However, this method of recruitment proved limiting, with a majority of offices refusing to provide email addresses. My faculty mentors and I requested a modification of our IRB exemption to include recruitment via office fax, and the IRB determined that this modification did not change the study’s exempt status. I sought fax numbers through publicly accessible
information online and by office phone calls requesting this information. I attach both forms of recruitment messages as Appendix A2.

After the original recruitment email message and fax message, I sent one follow-up email message and two follow-up faxes at one week intervals. Among my 194 unique providers were 4 whom I subsequently excluded because they practice on a military base, leaving a population of 190 potential providers. Thirteen providers were excluded because they were not contactable through the follow-up period with confirmed failure of both email and fax. Scenarios of confirmed failure included a returned fax from the office stating that the provider no longer worked there and undeliverable emails, or a failure of all faxes and undeliverable emails. This left 177 potential providers who received recruitment messages, of whom 10 responded. Overall the adjusted response rate after excluding those survey links that were undeliverable was 5.6%. This low response rate might have been the result of our inability to offer any form of inducement to participate, or potential respondents may not have been willing to respond to a student. In further research, my faculty mentors and I will seek strategies to improve response. Because we promised anonymity and did not collect identifying information, I have no way of knowing whether respondents are representative of the population of referring providers.

**Questionnaire development**

The survey was designed to determine provider comfort with initial work-up and management of the most common conditions referred to UNC, ways to improve communication between offices, and clarity of management plans. For the purposes of our study I defined providers as those with MD, DO, PA, and NP degrees. The survey included 4 fixed-choice questions about provider demographics and resources, 3 condition-specific questions, 5 provider
satisfaction questions, and 2 continuing education questions. The survey is attached within the methods Appendix A2.

Analysis

All responses are anonymous. Because the response rate is low and the number of completed surveys is small, my analysis includes only descriptive frequencies and cross tabs based on EPIC access. I used a Chi square test to compare distance from UNC with satisfaction with wait time and received assessments, notes, and treatment plans. P values ≤ 0.05 were considered to be statistically significant.

Results

Response Rate

Of the 177 potential providers who received recruitment messages, 10 responded, resulting in an adjusted response rate after excluding those survey links that were undeliverable of 5.6%

Respondent Demographics and Practice Characteristics

Characteristics of the study population are summarized in Table 1. Most providers were female (70%), between 35 and 54 years old (60%), and practice in suburban settings (50%) less than 25 miles from the Pediatric Nephrology service at UNC (70%). Providers were evenly distributed across years in practice since completing residency or fellowship. Most providers (80%) referred 5 or fewer patients per year.
**Condition-Specific Responses**

All providers (100%) reported encountering all conditions (as seen in Table 2) in the last 6 months, and when asked about specific conditions, all providers (100%) reported encountering hematuria, proteinuria, and urinary tract infection. When asked about comfort level with initial work-up and management (as seen in Table 3), providers felt most uncomfortable with CKD (20% very, 40% somewhat) followed by steroid-resistant nephrotic syndrome (20% very, 30% somewhat) and steroid-sensitive nephrotic syndrome (10% very, 40% somewhat), autoimmune disease (10% very, 30% somewhat), and congenital anomalies of the kidney and urinary tract (10% very, 10% somewhat). Almost all providers felt comfortable working up and managing urinary tract infection (90% very, 10% somewhat) followed by proteinuria (60% very, 40% somewhat), hematuria (60% very, 40% somewhat), and hypertension (40% very, 50% somewhat). When comparing frequency of patient referral to comfort with CKD (Table 4) it appears that most providers (5/6, 83%) who reported feeling uncomfortable and a majority (2/3, 66%) of those who felt comfortable referred 5 or fewer times per year. When comparing frequency of patient referral to comfort with HTN (Table 5) all providers reported feeling comfortable and a majority of these (7/9, 78%) also refer 5 or fewer times per year.

When asked about current wait times, a third of providers were dissatisfied (30%) and a third were satisfied (10% very satisfied, 20% satisfied). Providers were relatively satisfied with the received assessment notes and treatment plans (30% very satisfied, 40% satisfied). These scores are presented in Table 6.

**EPIC Access**

As seen in Table 7, most providers (60%) had access to EPIC; this is unsurprising, given that most respondents are within 25 miles of UNC. I asked providers a number of
communication questions, to which they could respond along a 100-point scale, where 0 equaled “never” and 100 equaled “always.” Frequency of consultation notes is skewed, with a median (76.5) much higher than was the mean (62.5). This distribution is probably attributable to EPIC access, since those with access received consultation notes significantly more frequently (with EPIC: median 73.7 with IQR 49 vs. no EPIC: median 50.0 with IQR 61.5, ttest p = 0.274). This can be visualized in Figure 1. Overall, providers were satisfied with the amount of communication (positively skewed, mean 51.9 > median 50), but when this was stratified by EPIC access those with EPIC access said they received slightly too much communication (with EPIC: median 51.5 with IQR 50.0 vs. no EPIC: median 40 with IQR 40.0, ttest p = 0.235). This can be seen in Figure 2. The results are not significant, likely because of the very small sample size, but they are suggestive.

Communication Methods

Most providers responded that having clear management plans in consultation notes and having education about the patient’s diagnosis in the consultation notes were most valuable (80% for both methods, as seen in Table 7). Among those providers who are within the UNC Health Care System, almost all providers (median 100 with IQR 14.0) preferred communication within EPIC. Overall, the most preferred method was fax (mean 95.9 with st dev 7.8, ttest p = 0.254), followed by email (mean 77.5 with st dev 45, ttest p value = 0.423), with telephone trailing (mean 67.8 with st dev 25.5, ttest p value 0.248). Stratifying data by EPIC access does not change the ranking of the communication methods but those with EPIC reported higher (but statistically insignificant) scores for each method (as seen in Figure 3).
Continuing Education

Overall, as summarized in Table 6, most providers (70%) were interested in receiving continuing education about pediatric nephrology conditions. Among those who were interested, most (85.7%) wanted education about all of the potential conditions. When asked about selecting individual conditions, more than a third requested information on pediatric proteinuria, hypertension, hematuria, and acute glomerulonephritis.

Discussion

Consistency with Current Literature

Although there is limited literature about co-management with pediatric nephrologic conditions, as described in Appendix A1, this study’s findings are consistent with Diamantidis et al. who suggested PCPs’ lack comfort or confidence in managing CKD (Diamantidis et al., 2011). However, this study’s findings are in contrast to the findings of Boneparth and Flynn and Yoon et al. about PCP discomfort in managing adolescent hypertension (HTN). Instead, as seen in Table 3, this study found that HTN is among the top 4 suggested nephrology conditions that providers feel most comfortable treating. Based on our findings (as seen in Table 4 and Table 5) our study did not find support that there was a relationship between level of comfort and frequency of referral for the two conditions mentioned in current literature, CKD and HTN. However, our findings were very limited by our low response rate and therefore more data should be collected or additional studies performed to better understand this potential association.
All providers (100%) reported encountering all conditions (as seen in Table 2) in the last 6 months, and when asked about specific conditions, all providers (100%) reported encountering hematuria, proteinuria, and urinary tract infection. When asked about comfort level with initial work-up and management (as seen in Table 3), providers felt most uncomfortable with CKD (20% very, 40% somewhat) followed by steroid-resistant nephrotic syndrome (20% very, 30% somewhat) and steroid-sensitive nephrotic syndrome (10% very, 40% somewhat), autoimmune disease (10% very, 30% somewhat), and congenital anomalies of the kidney and urinary tract (10% very, 10% somewhat). Almost all providers felt comfortable working up and managing urinary tract infection (90% very, 10% somewhat) followed by proteinuria (60% very, 40% somewhat), hematuria (60% very, 40% somewhat), and hypertension (40% very, 50% somewhat). When comparing frequency of patient referral to comfort with CKD (Table 4) it appears that most providers (5/6, 83%) who reported feeling uncomfortable and a majority (2/3, 66%) of those who felt comfortable referred 5 or fewer times per year. When comparing frequency of patient referral to comfort with HTN (Table 5) all providers reported feeling comfortable and a majority of these (7/9, 78%) also refer 5 or fewer times per year.

**Strengths and Limitations**

Some of the strengths of this study include the creation of the questionnaire as a measurement tool to meet the goals of this study. By collecting primary data I was able ot design a survey most appropriate to the goals of the study, rather than being limited to secondary data sources. Primary data collection also enabled me to control exactly to whom the survey was released and include only those providers who are within the UNC catchment area. This is important since there can be significant geographical, regional, and demographic variability in the frequency of specific nephrologic conditions and severity at presentation. By keeping the
respondents limited to these providers it may be easier to draw certain conclusions since state health policy will affect all of these providers.

The main limitation was the low response rate of 5.6%. The low response rate may have been restricted by the reliance of the EPIC referral database to identify the initial source population. Using this method to identify potential respondents proved challenging because this contact information could be up to two years old and included only provider name, mailing address, and office number. The database did not include email addresses and these had to be manually searched. It is also possible and likely that non-primary care providers were included within this referral database since pediatric specialists, such as pediatric dermatology and pediatric ear, nose, and throat, who see similar patient populations may also refer directly to UNC Pediatric Nephrology. Finally, this study did not include inducements to participate, nor was it supported by any credentialing body or by UNC Health Care. Providers may have been unwilling to respond to a student.

The external validity is limited since the responding providers are mostly female, practice in suburban areas, and are within 25 miles of UNC Chapel Hill. Additionally, responder bias is a possibility since I have no data from non-responders. I hypothesized that those who are greater distances from UNC Chapel Hill may face the most communication or access barriers, but the low response rate and relatively close proximity of those who did respond prevents me from drawing any conclusions.

**Implications**

This study demonstrates the gaps in current literature and the many challenges faced by researchers in collecting information about the very important concept of co-management of complex chronic disease in pediatric patients. From the practice perspective this research
suggests that primary care providers wish to receive more education on nephrologic conditions, either in the form of continuing education or through more patient-related information within consultation notes. The differential, but not significant, findings related to EPIC access suggest that pediatric nephrologists can do more to educate their primary care colleagues.

Given the very low response rate in this study, which also makes statistical significance unlikely, we need to determine how to improve response rates in a context of limited research resources. We need to know what variables improve the PCP-specialist relationship or burden or prevent it, especially for providers located further away from the specialist’s practice location. This will be important to better meet the needs of underserved patient populations who may rely even more heavily on their primary care provider for most of their medical management. Once identified, these suggested improvements should then be implemented to see whether they improve patients’ health outcomes and satisfaction.

**Conclusion**

This study found that most providers who responded are satisfied with the frequency and content of current communication with UNC Pediatric Nephrology. However, many are still uncomfortable with several conditions, including steroid-resistant and steroid-sensitive nephrotic syndrome, chronic kidney disease, and autoimmune disease. At the same time, many primary care providers are interested in receiving further education, which could be an opportunity to improve upon the PCP-specialist relationship and empower PCPs to co-manage nephrologic conditions. Both PCPs and pediatric nephrologists are necessary, and their collaboration is critical, to enhanced patient care and access, better patient and provider education, and, ultimately, improved patient outcomes and provider satisfaction.
References


doi:10.1007/s11606-010-1354-5 [doi]


Table 1. Demographics: North Carolina referring providers

<table>
<thead>
<tr>
<th>Category</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Decline to answer</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>34 or younger</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>35-54 years old</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>55-64 years old</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>65 or over</td>
<td></td>
</tr>
<tr>
<td>Missing (-)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Years in practice since completing residency or fellowship</td>
<td></td>
</tr>
<tr>
<td>5 or fewer years</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>More than 5 but fewer than 10 years</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>More than 10 years but fewer than 20 years</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>20 or more years</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Years referring patients to UNC Pediatric Nephrology</td>
<td></td>
</tr>
<tr>
<td>5 or fewer years</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>More than 5 but fewer than 10 years</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>More than 10 years but fewer than 20 years</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>20 or more years</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Practice Setting</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Suburban</td>
<td>5 (50%)</td>
</tr>
<tr>
<td>Rural</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Distance from UNC Chapel Hill Pediatric Nephrology</td>
<td></td>
</tr>
<tr>
<td>0 to 25 miles</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>26 to 50 miles</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>51 to 75 miles</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>76 to 100 miles</td>
<td></td>
</tr>
<tr>
<td>More than 100 miles</td>
<td></td>
</tr>
<tr>
<td>Approximate number of patients referred per year to UNC Pediatric Nephrology</td>
<td></td>
</tr>
<tr>
<td>0 per year</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>5 or fewer per year</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>More than 5 per year</td>
<td>1 (10%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
<table>
<thead>
<tr>
<th>Condition</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All of the above</td>
<td>10 (100%)</td>
</tr>
<tr>
<td>Hematuria</td>
<td>10 (100%)</td>
</tr>
<tr>
<td>Proteinuria</td>
<td>10 (100%)</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>10 (100%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Congenital anomalies of the kidney and urinary tract</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Acute glomerulonephritis</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Acute kidney injury</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Autoimmune disease</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Steroid-sensitive nephrotic syndrome</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Steroid-resistant nephrotic syndrome</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Henoch-Schonlein Purpura with renal involvement</td>
<td>1 (10%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Table 3. Comfort with initial work-up and management of specific conditions

These responses are listed in descending order starting with those conditions that respondents felt the most uncomfortable with and ending with those that they are the most comfortable with. This order is based on the percentage of respondents who answered very uncomfortable followed by somewhat uncomfortable, neither, somewhat comfortable, and finally very comfortable.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Uncomfortable</th>
<th>Neither</th>
<th>Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very (%)</td>
<td>Somewhat (%)</td>
<td>Neither (%)</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>2 (20%)</td>
<td>4 (40%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Steroid-resistant nephrotic syndrome</td>
<td>2 (20%)</td>
<td>3 (30%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Steroid-sensitive nephrotic syndrome</td>
<td>1 (10%)</td>
<td>4 (40%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Autoimmune disease</td>
<td>1 (10%)</td>
<td>3 (30%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Congenital anomalies of the kidney and urinary tract</td>
<td>1 (10%)</td>
<td>1 (10%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Henoch-Schonlein Purpura with renal involvement</td>
<td>4 (40%)</td>
<td>1 (10%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Acute kidney injury</td>
<td>4 (40%)</td>
<td>1 (10%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Acute glomerulonephritis</td>
<td>2 (20%)</td>
<td>4 (40%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td></td>
<td>1 (10%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
<td></td>
<td>5 (50%)</td>
</tr>
<tr>
<td>Hematuria</td>
<td></td>
<td></td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Proteinuria</td>
<td></td>
<td></td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td></td>
<td></td>
<td>1 (10%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Table 4. Comfort with CKD and frequency of patient referral

This data compares the 9 responding providers’ reported comfort with initial work-up and management of CKD with the approximate number of patients that they report referring each year to UNC Pediatric Nephrology. Chi square test was performed with respondents who reported being Uncomfortable or Comfortable and comparing these groups to frequency of referral. Results were not significant (p = 0.28).

<table>
<thead>
<tr>
<th>Approximate number of patients referred per year to UNC Pediatric Nephrology</th>
<th>Uncomfortable</th>
<th>Neither</th>
<th>Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very (%)</td>
<td>Somewhat (%)</td>
<td>Neither (%)</td>
<td>Somewhat (%)</td>
</tr>
<tr>
<td>0 per year</td>
<td>1 (11%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 or fewer per year</td>
<td>2 (22%)</td>
<td>3 (33%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>More than 5 per year</td>
<td></td>
<td></td>
<td>1 (11%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Table 5. Comfort with hypertension (HTN) and frequency of patient referral

This data compares the 9 responding providers’ reported comfort with initial work-up and management of CKD with the approximate number of patients that they report referring each year to UNC Pediatric Nephrology. Chi square test was performed with respondents who reported being Uncomfortable or Comfortable and comparing these groups to frequency of referral. Results were not significant (p = 1.00) given all responders felt comfortable with HTN.

<table>
<thead>
<tr>
<th>Approximate number of patients referred per year to UNC Pediatric Nephrology</th>
<th>Uncomfortable (%)</th>
<th>Neither (%)</th>
<th>Somewhat (%)</th>
<th>Very (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 per year</td>
<td></td>
<td></td>
<td></td>
<td>1 (11%)</td>
</tr>
<tr>
<td>5 or fewer per year</td>
<td>1 (11%)</td>
<td>5 (56%)</td>
<td>5 (56%)</td>
<td>2 (22%)</td>
</tr>
<tr>
<td>More than 5 per year</td>
<td></td>
<td></td>
<td></td>
<td>1 (11%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Table 6. Satisfaction with current wait times and information received

These responses are listed in descending order starting with those conditions that respondents were the most dissatisfied with and ending with which they are the most satisfied. This order is based on the percentage of respondents who answered very dissatisfied followed by dissatisfied, neither, satisfied, and finally very satisfied.

<table>
<thead>
<tr>
<th></th>
<th>Very Dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wait time to appointment</td>
<td></td>
<td>3 (30%)</td>
<td>4 (40%)</td>
<td>2 (20%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Assessments, notes, and treatment plans you receive from the Pediatric Nephrology Clinic</td>
<td></td>
<td>3 (30%)</td>
<td></td>
<td>4 (40%)</td>
<td>3 (30%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Table 7. EPIC access and Communication
In the questionnaire answers for frequency of consultation notes were continuous from 0 (never receive notes) to 100 (always receive notes). The responses for satisfaction with amount of communication were also continuous from 0 (too little) to 100 (too much communication). The p value from the independent t-test comparing those with and without EPIC access is presented.

<table>
<thead>
<tr>
<th>EPIC access</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Most valuable communication content</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having clear management plans in consultation notes</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>Having education about the patient’s diagnosis in the consultation notes</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>Having a concise summary letter instead of a full consultation note</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Just getting consultation notes</td>
<td>3 (30%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current communication levels</th>
<th>Overall</th>
<th>EPIC access</th>
<th>No EPIC access</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of consultation notes received</td>
<td>Median: 76.5 IQR: 61 Mean: 62.5 St Dev: 37.6</td>
<td>Median: 90.5 IQR: 49 Mean: 73.7 St Dev: 36.1</td>
<td>Median: 50.0 IQR: 61.5 Mean: 45.8 St Dev: 37.9</td>
<td>0.274</td>
</tr>
<tr>
<td>Satisfaction with amount of communication</td>
<td>Median: 50 IQR: 12 Mean: 51.9 St Dev: 31.6</td>
<td>Median: 51.5 IQR: 50 Mean: 61.2 St Dev: 33.3</td>
<td>Median: 40 IQR: 40 Mean: 33.3 St Dev: 20.8</td>
<td>0.235</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Preferred communication method</th>
<th>Overall</th>
<th>EPIC access</th>
<th>No EPIC access</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax</td>
<td>Median: 100 IQR: 9 Mean: 95.9 St Dev: 7.8</td>
<td>Median: 100 IQR: 0 Mean: 100 St Dev: 0</td>
<td>Median: 95.5 IQR: 14.5 Mean: 92.8 St Dev: 9.5</td>
<td>0.254</td>
</tr>
<tr>
<td>Email</td>
<td>Median: 100 IQR: 45 Mean: 77.5 St Dev: 45</td>
<td>Median: 100 IQR: 0 Mean: 100 St Dev: 0</td>
<td>Median: 55 IQR: 90 Mean: 55 St Dev: 63.6</td>
<td>0.423</td>
</tr>
<tr>
<td>Telephone</td>
<td>Median: 50 IQR: 41 Mean: 67.8 St Dev: 25.5</td>
<td>Median: 91 IQR: 52 Mean: 80 St Dev: 27.8</td>
<td>Median: 50 IQR: 0 Mean: 50 St Dev: 0</td>
<td>0.248</td>
</tr>
</tbody>
</table>

Within Epic, if you are within the UNC Health Care System | Median: 100 IQR: 9 Mean: 93 IQR: 14 St Dev: 14 |
Figure 1. Frequency of consultation notes received, by EPIC access
Figure 2. Satisfaction with amount of communication, by EPIC access

Satisfaction with Amount of Communication

EPIC Access

No EPIC Access
Figure 3. Helpfulness of communication methods, by EPIC access

**Helpfulness of Communication Methods**

- Fax
- Email
- Telephone
- EPIC

- Has EPIC Access
- No EPIC Access
Table 6. Continuing education interest and topics
These responses are listed in descending order with most frequent responses of interest (highest) to least frequent responses of interest (lowest).

<table>
<thead>
<tr>
<th>Interested in continuing education about pediatric nephrologic conditions</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>No</td>
<td>3 (30%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Among those who answered yes, desired conditions covered:</th>
<th>N (% out of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All of the above</td>
<td>6 (85.7%)</td>
</tr>
<tr>
<td>Proteinuria</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Hematuria</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Acute glomerulonephritis</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Acute kidney injury</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Henoch-Schonlein Purpura with renal involvement</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Autoimmune disease</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Steroid-sensitive nephrotic syndrome</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Steroid-resistant nephrotic syndrome</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Congenital anomalies of the kidney and urinary tract</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

SOURCE: Author’s survey of referring providers.
Appendix A1, Limited Systematic Review

Methods

Focused question. What variables impede or improve co-management of pediatric patients with nephrologic conditions referred to pediatric subspecialty services?

Within this review the term ‘co-management’ was considered synonymous with any collaborative efforts between primary care providers and specialists who, in this case, were pediatric nephrologist. This decision was due to the fact that comanagement is a relatively new term in the literature, does not exist as a MeSH term and therefore may not always be included in study indexing or keywords, and is inconsistently used in the literature. Primary care providers was also defined broadly as any qualified medical individual who provides primary health care, including physician’s assistants and nurse practitioners. This broad way of defining co-management was in hopes of capturing a wide variety of interventions and variables that affect the effectiveness of comanagement.

Study selection. Only those articles whose study population were primary care providers of pediatric patients and pediatric nephrologists were included in the study. Studies were excluded if results were not stratified and less than 50% of patients were pediatric patients or less than 50% of referral conditions were for nephrologic conditions. Studies were also excluded if they did not assess the interaction between primary care providers and pediatric nephrologists. Studies were excluded if they were not in the United States due to variations in health care delivery models and systematic differences between countries.

The study types that were included were limited to randomized controlled trials, other controlled clinical trials, time series, studies that were controlled either before or afterwards, or
cross-sectional survey based studies. This is because in order to understand whether variables improved comanagement a control group or comparison group of some kind was needed. Survey based studies were included only if they included questions that asked the provider to reflect back on their experience prior to the implementation of these variables. Studies were excluded if they were reviews or secondary data rather than offering primary data.

The study outcomes that were included were the effectiveness of specific co-management variables in strengthening or weakening the working relationship between primary care providers and pediatric nephrologists. This effectiveness would ideally include health outcomes such as less frequent kidney disease exacerbations, but intermediate outcomes of slowed nephrologic disease progression were also included because these require a shorter study duration. Studies were excluded if they did not actually report outcome data or mention the specific variables that they studied.

Articles were included only if full text was available, they were published in or translated into English, and human data were included. Articles were excluded if it was grey literature including conference abstracts, dissertations, popular press articles, letters, commentary, or editorials.

Consultation”[Mesh] OR “Referral” OR “Consultation”) AND (“Pediatrics”[Mesh] OR “pediatrics” OR “pediatrician” OR "Primary health care"[MeSH Terms] OR "Physicians, Primary Care”[Mesh] OR generalists[Text Word]) AND (“Nephrology”[Mesh] OR "Nephrologist” OR “Nephrology”). The search was limited to articles published between the earliest date of the available PubMED article and 5/22/2016 when the search was updated. All references of articles that met all of the inclusion criteria were manually searched to find other relevant studies.

**Data Extraction and Synthesis.** One reviewer independently assessed all articles resulting from the PubMED search for adherence to inclusion criteria. Once a study was fully included it was critically assessed for quality and the following information was collected: study population, intervention, and method of assessment.

**Results**

The PubMED search resulted in 566 articles, with 0 duplicates. Of these, 488 articles were excluded at title and abstract review, resulting in 78 articles that were assessed at full text for eligibility. From this 76 articles were excluded at full text review, with the most common reason being wrong study type (31 studies), wrong study population (21 studies), and non-English language (10 studies). This left 2 articles that successfully met all inclusion criteria and were used for data extraction. All of the references for these articles were manually searched for articles to see if they met inclusion criteria, and 5 were identified. Only 1 additional relevant article meeting inclusion criteria resulted with 4 excluded at full text review (Figure A-1).
Study design and study population. All 3 of the articles included in the review (Boneparth & Flynn, 2009; Diamantidis et al., 2011; Yoon et al., 2015) were cross-sectional surveys. Boneparth and Flynn surveyed 89 general pediatricians who had referred to Montefiore Medical Center’s subspecialty pediatric clinics as well as a “convenience sample” of pediatricians attending a continuing education conference, resulting in a 30% response rate. Yoon surveyed 399 specialists, including 179 pediatric nephrologists, who were obtained from the American Medical Association (AMA) Physician Masterfile, a “comprehensive database of licensed physicians in the United States that includes both AMA members and nonmembers,” resulting in a 61% response rate (Yoon et al., 2015). Diamantidis surveyed 124 PCPs which included general internists and family physicians and 120 nephrologists also identified from the AMA Physician Masterfile, and resulting in a 31.7% response rate.

Clinical patient population assessed. Survey questions by Boneparth and Flynn and Yoon et al. focused on the clinical scenario of adolescents with hypertension, while Diamantidis offered the case scenario of an adult patient with CKD. While this scenario does not involve a pediatric patient with kidney disease the Diamantidis et al. paper was included because the study population included family physicians who may encounter both adult and pediatric patients with kidney disease.

Major categories of results. These include: desire for collaborative care, PCP comfort (in evaluation and treatment), barriers (both to collaboration or to PCP comfort), and guidelines (either compliance or suggested collaboration guidelines).
Desire for collaborative care. All three studies suggested their study populations supported some degree of collaborative care.

- Boneparth and Flynn reported that most general pediatrics refer more than two thirds of their adolescent patients with HTN to a specialist, and almost all incorporate some routine screening into their well child checkups.

- This desire for collaboration is most notably seen in the study by Diamantidis which found that 94% of nephrologists and 85% of PCPs desired collaborative care, with almost a third of these individuals desiring more frequent collaboration of at least every 2 to 3 months.

- The results from Yoon were more mixed, with 51% believing PCPs should independently make hypertension diagnosis and just over 40% believing PCPs should monitor BP control. While 41% believed PCPs should monitor medication side effects while under specialist direction, 41% also believed this responsibility should be left independently to the specialist. Yoon’s results from the surveyed pediatric nephrologists suggested a larger scope of practice for the specialist with a majority believing only the specialist should work up the patient for secondary causes, initiate antihypertensive medications, or change medication dosage and type.

PCP comfort. All three studies found that a majority of PCPs do not feel comfortable managing nephrologic conditions such as CKD and HTN in adolescent patients.

- Boneparth and Flynn found that many general pediatrics (40%) do not feel comfortable treating adolescents with HTN, and this is mostly due to a feeling of lack of expertise followed by a concern that they will potentially miss a case of secondary HTN.
• Diamantidis found that around three fourths of PCPs, but significantly more nephrologists, believe their medical care slows CKD.

• According to Yoon, only half of pediatric nephrologists believed that family physicians were comfortable diagnosing and managing adolescent hypertension, and a majority (75%) believed general pediatricians were uncomfortable doing this.

**Barriers.** Many identified barriers are a lack of familiarity with medication regimens, lack of sufficient support staff, or specialist expectations that are not met by the PCP upon referral or collaboration.

• Boneparth and Flynn found that most (93%) do not start pharmacologic treatment in managing adolescents with HTN, and almost half (58%) reported that the reason was because they were unfamiliar with these medications.

• Diamantidis et al. reported that the largest barrier faced by just over half of PCPs, compared to less than a third of nephrologists, was a lack of sufficient ancillary support to care for their CKD patients. A majority of nephrologists believe patients are referred too late and just under a third believe that patients are on inappropriate medications when they enter their care. One barrier to referral reported more frequently by nephrologists (20% vs. 7% PCPs) was insurance.

• Yoon et al.’s scope of practice findings are likely due to the reported barrier that almost a third of pediatric nephrologists believe PCPs do not appreciate the need to treat HTN in adolescents, overrefer based on inaccurate BP readings, or wait too long to refer.

**Guidelines.** Many PCPs are not familiar with or do not consistently follow guidelines. PCPs and nephrologists also have many shared beliefs for desired guidance (confirm clinical evaluation,
additional testing, medication regimen, and nutritional advice) but nephrologists believe more
direction should be given to PCPs about predialysis or renal replacement therapy preparation.

- Boneparth and Flynn asked about respondent’s familiarity with the Fourth Report’s
  recommendations, a set of published guidelines for general pediatricians, and found that
  less than half (46%) knew about the guidelines. Those who were familiar with the
  guidelines were less likely to feel uncomfortable about managing adolescents with HTN.
  Providers also had varying degrees of guideline application, with most initial screening
  being incorporated but not follow-up guidelines.

- Diamantidis et al. reported that a majority of PCPs did not know referral guidelines. Both
  PCPs and nephrologists desired guidance to confirm clinical evaluation, additional
  testing, medication regimen, and nutritional advice. However, significantly more
  nephrologists than PCPs desired the communication of guidance about predialysis or
  renal replacement therapy preparation.

- Yoon et al.’s findings about guidelines may be the most applicable to this review given
  all surveyed participants were pediatric nephrologists. Almost all respondents desired
  PCPs to use multiple methods to verify elevated BP and defined this as BP ≥ 95th
  percentile on 3 separate visits. This likely is related to the perceived barrier that PCPs
  over-refer based on inaccurate BP readings. Most of these specialists wanted PCPs to
  obtain specific initial testing (urinalysis, electrolytes, and complete blood count) prior to
  referral.
Threats to internal validity:

- **Selection Bias.** Yoon and Diamantidis both used the AMA Physician Masterfile to obtain a national sample, and this sampling strategy had less selection bias by offering the opportunity to contact both AMA members and non-members. In contrast, Boneparth recruited only those providers who had referred to Montefiore Medical Center’s subspecialty pediatric clinics as well as a “convenience sample” of pediatricians attending a continuing education conference, which increases the potential of confounding in these limited study populations. All three studies have the potential for ascertainment bias due to low response rates (30% to 61%) and differences that may exist between responders and nonresponders. Only Diamantidis compared the demographics between these groups to show that this bias was minimal in their study.

- **Measurement Bias.** None of the surveys had been previously validated, and the clinical scope of each survey was different with Boneparth and Yoon questioning providers about adolescent HTN and Diamantidis looking at theoretical CKD management. Given the subjective nature of these survey questions they are also all susceptible to reporting bias. Additionally, in Diamantidis’ study many of the questions about barriers to collaboration were asked only to nephrologists despite the fact that PCPs were included in the study, so these particular barriers are only seen from the specialists’ perspective.

**Discussion**

This systematic review revealed four key findings. The first is that both PCPs and nephrologists desire more and improved collaborative care, but the exact scope of practice and responsibilities for each field are less clear. This knowledge is useful to support strategies that hope to improve
communication and quality of care coordination, co-management, and collaboration between these two fields.

The second key finding is that a majority of PCPs do not feel comfortable managing nephrologic conditions in pediatric patients, and this is most frequently due to a perceived lack of expertise. This may be due to a lack of sufficient training in these conditions which could be improved upon with either continuing medical education opportunities for physicians in practice or better incorporation of these topics for future trainees.

The third key finding is that PCPs believe major barriers include their lack the knowledge of appropriate medication regimens as well as a lack of sufficient support staff for their chronic, complex patients such as those with CKD. From the specialist perspective many nephrologists also believe referred patients are on inappropriate medications upon referral, but this could be improved upon simultaneously with strategies aimed at developing PCP comfort. Specialists also view the frequency or appropriateness of nephrology referral as a barrier with many nephrologists reporting that their input is sought out too late in the progression of the disease while others believing that PCPs overrefer based on inaccurate BP readings. This barrier could be addressed by improving or clarifying the specialists’ expectations for initial testing or diagnosis confirmation that should be performed prior to referral or specialist input.

This leads into the fourth key finding which is that the current guidelines targeted towards PCPs are unknown to many providers or are not consistently followed. Many of these guidelines focus primarily on diagnostic thresholds and management steps, while both PCPs and specialists support further specialist-provided guidance about confirming the PCP’s clinical evaluation, outlining additional testing needed, educating PCPs about appropriate medication regimens, and providing nutritional advice for these specific patient populations. More
nephrologists than PCPs believe they should provide guidance about predialysis or renal replacement therapy preparation. Building from these suggested topics and incorporating them into well-communicated guidelines could be an effective first step in empowering the PCP to primarily manage or collaboratively care for pediatric patients with nephrologic conditions.

**Limitations**

As mentioned previously internal validity of all three studies may have been affected by ascertainment bias due to low response rates (30% to 61%) and differences that may exist between responders and nonresponders. Only Diamantidis analyzed differences between responders and non-responders and found that differences were minimal. All three studies also used surveys that had not been previously validated and are susceptible to reporting bias, both of which may affect the validity of their survey measurements.

Another limitation of this review was in the decision to narrow the scope of the study population to only providers who have the opportunity to care for pediatric patients. The rationale behind this decision was that there are many different variables to consider when treating pediatric and adolescent patients, including barriers due to family limitations such as transportation, the influence of family decision-making rather than patient autonomy, lack of compliance such as with adolescent patients. Additionally, since pediatric patients with nephrologic conditions occur at a much lower rate than their adult counterparts and due are caused by different etiologies, such as congenital abnormalities rather than HTN and diabetes, PCPs may be much less comfortable managing these patients with minimal specialist input. However, as seen in Figure A-1 there were 25 full-text articles that were excluded due to the wrong study population. Many of these studies used only adult nephrologists and general
internists rather than family physicians who also have the potential to see pediatric patients. There are clear ethical and practical barriers to studies that involve pediatric patients, and this decision may have drastically reduced the number and variety of analyzed studies.

In many ways this review may also have been limited by the literature itself, since the idea of comanagement and collaboration of care is a relatively new concept and, to our knowledge, no studies exist that look broadly at the many factors and variables that affect the PCP and pediatric nephrology working relationship. While an initial 571 articles were screened, a majority of these were excluded solely on title and abstract review.

Lastly, the external validity of this review may be limited due to the included articles’ study populations and clinical scope. Boneparth’s recruitment of only referring providers narrows the application of their findings to other populations outside of the Montefiore Medical Center’s catchment area. Their inclusion of some pediatricians attending a continuing education conference also may have biased their findings because these providers may be more supportive of PCP autonomy or educational opportunities about nephrologic disease management. The respondents within each study were also very limited in the perspective that the provide, with Boneparth’s study including only PCPs and Yoon’s study including only pediatric nephrologists. Only Diamantidis’ study collected both the PCP and nephrologist perspective, but asked theoretical questions about management rather than collecting more objective data such as medical records to confirm the type of testing performed prior to referral. The clinical scope of the three included studies also narrows the external validity of this review, because surveys by both Boneparth and Yoon focused on the adolescent patient with HTN and Diamantidis looked only at the theoretical management of a patient with CKD. Both of these diseases are very specific and more chronic in nature. Due to this restriction, the findings from these studies may
not be applicable to more acute kidney diseases requiring specialist collaboration or other chronic kidney diseases.

**Conclusion**

Both primary care providers and pediatric nephrologists support improved collaboration and guidelines that include broader management recommendations. However, literature is lacking about standardized variables that improve communication or effectiveness of these specialist-generalist relationships, and current studies focus on the management of specific diseases rather than the broad category of nephrologic diseases. Therefore, future studies should attempt to identify these factors or variables that support or detract from the interactions between pediatric nephrologists and PCPs. Future guidelines should be better communicated to the PCP workforce, implementation should be more consistent, and sufficient ancillary support should be provided to help providers care for those patients with the most complex medical and social needs. for those patients encompass
Figure A-1. Systematic review flow diagram

Articles identified through database searching (PubMed) 
(n = 566)

Articles identified through manual search 
(n = 5)

Articles screened after duplicates removed 
(n = 571)

Excluded at title and abstract review 
(n = 488)

Full-text articles assessed for eligibility 
(n = 83)

Excluded at full-text review 
(n = 80)
- Wrong study type (n = 31)
- Wrong study population (n = 25)
- Wrong reported outcomes (n = 4)
- Non-English language articles (n = 10)
- Grey literature (n = 2)
- No full text available (n = 8)

Final set of studies used for data extraction 
(n = 3)
<table>
<thead>
<tr>
<th>Population</th>
<th>Themes/Results</th>
<th>Threats to Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Desire for collaborative care</strong></td>
<td>82% refer a majority (≥2/3) of their adolescent HTN patients to subspecialist</td>
<td>Low power</td>
</tr>
<tr>
<td></td>
<td>94% incorporate recommended routine BP screen into well-child visits by 3 years old</td>
<td>Ascertainment bias (no comparison between respondents and potential respondents)</td>
</tr>
<tr>
<td><strong>PCP comfort</strong></td>
<td>40% “uncomfortable” in evaluating and treating hypertensive adolescents</td>
<td>Reporting bias</td>
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<tr>
<td></td>
<td>Reasons:</td>
<td>PCP perspective only</td>
</tr>
<tr>
<td></td>
<td>• Lack of expertise: 73%</td>
<td>Scope was HTN only</td>
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<td></td>
<td>• Potential to miss a case of secondary HTN: 34%</td>
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<tr>
<td></td>
<td>• Adolescents lost to follow-up: 17%</td>
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<tr>
<td></td>
<td>• Unfamiliar with anti-HTN medications: 3%</td>
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<tr>
<td><strong>Barriers</strong></td>
<td>93% do not routinely initiate pharmacologic treatment for adolescent HTN</td>
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<tr>
<td></td>
<td>Reasons:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Unfamiliar with anti-HTN medications: 58%</td>
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<td></td>
<td>• Concerned about side effects: 18%</td>
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<tr>
<td></td>
<td>• Adolescent noncompliance: 17%</td>
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<td></td>
<td>• Prefer subspecialty referral: 15%</td>
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<tr>
<td></td>
<td>• Uncertainty about long term risks of HTN in pediatric patients: 11%</td>
<td></td>
</tr>
<tr>
<td><strong>Guidelines</strong></td>
<td>46% had read/heard about The Fourth Report’s recommendations (<em>guidelines for pediatricians for diagnosis, evaluation, and treatment of HTN in children/adolescents)</em></td>
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</tr>
<tr>
<td></td>
<td>• Among those who had read or heard about it only 33% felt “uncomfortable” (vs. 54% among those who had not heard of it)</td>
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</tr>
<tr>
<td></td>
<td>• Varying application of guidelines:</td>
<td></td>
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<tr>
<td></td>
<td>▪ 94% incorporate routine BP screen into well-child visits by 3 years old</td>
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<tr>
<td></td>
<td>▪ 88% diagnose HTN after 3 elevated BP measurements</td>
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<tr>
<td></td>
<td>▪ Do not agree with recommendations</td>
<td></td>
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<tr>
<td></td>
<td>▪ After initial elevated BP, only 52% repeat BP in next month (recommendation: within 1-2 weeks), 9% wait 3+ months to repeat BP</td>
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<tr>
<td></td>
<td>▪ Diagnostic studies: &lt;25% perform recommended studies after initial evaluation (urine culture, renal ultrasound, echocardiogram, ophthalmologic exam)</td>
<td></td>
</tr>
<tr>
<td>National sample from AMA Physician Masterfile</td>
<td>Ascertainment bias (but did compare to nonresponders)</td>
<td></td>
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<tr>
<td>-----------------------------------------------</td>
<td>-----------------------------------------------------</td>
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</tr>
<tr>
<td>124 PCPs (from set of 178 PCPs with 89 general internists, 89 family physicians)</td>
<td>Reporting bias</td>
<td></td>
</tr>
<tr>
<td>120 nephrologists</td>
<td>Many collaboration barriers were only asked to nephrologists</td>
<td></td>
</tr>
<tr>
<td>Study design: cross-sectional mail or internet survey with CKD patient scenario</td>
<td>PCP and Specialist perspective</td>
<td></td>
</tr>
<tr>
<td>Response rate: 31.7%</td>
<td>Scope was only CKD (case scenario was of an adult with CKD)</td>
<td></td>
</tr>
</tbody>
</table>

### Desire for collaborative care
- 94% nephrologists and 85% PCPs desired collaborative care
  - 29% of these desired more frequent (at least every 2 to 3 months) collaboration

### PCP comfort
- 76% PCPs (vs. 94% nephrologists) believe their medical care slows disease

### Barriers
- 55% PCPs (vs. 28% nephrologists) feel they lack sufficient ancillary support to care for their CKD patients
- 53% Nephrologists believe patients referred too late
- 29% Nephrologists believe patients are on inappropriate medications
- 20% Nephrologists (vs. 7% PCPs) believe insurance is a barrier to referral
- 9% Nephrologists believe their practice is too full to accommodate early CKD patients

### Guidelines
- Knowledge of referral guidelines, no or unsure: PCPs 64%, nephrology 20%
- Types of guidance preferred by both:
  - Confirming appropriate clinical evaluation (94% PCPs, 95% Nephrologists)
  - Additional evaluation/testing (94% PCPs, 93% Nephrologists)
  - Medication regimen (91% PCPs, 96% Nephrologists)
  - Nutritional advice (78% PCPs, 89% Nephrologists)
- Guidance significantly preferred by nephrologists:
  - Predialysis/renal replacement therapy preparation (52% PCPs, 73% Nephrologists)
  - Electrolyte management (46% PCPs, 81% Nephrologists)
  - Other CKD-related illnesses (2% PCPs, 45% Nephrologists)
| National sample from AMA Physician Masterfile | **Desire for collaborative care** |
| - 179 pediatric nephrologists (also 220 pediatric cardiologists) |  |
| - 01/2014 to 05/2014 |  |
| - Study design: Cross-sectional mailed survey |  |
| - Response rate 61% |  |
|  | **PCP comfort** |
|  | - Adolescent HTN diagnosis/management |
|  |   o 75% believe general pediatricians are somewhat or very uncomfortable |
|  |   o 50% believe family physicians are somewhat or very comfortable |
|  | **Barriers** |
|  |   - Perceived major problems |
|  |     o 30% believe PCPs do not appreciate the need to treat HTN in adolescents |
|  |     o 28% believe PCPs overrefer due to inaccurate BP readings |
|  |     o 27% believe PCPs wait too long to refer |
|  |     o 13% believe PCPs do not identify white coat HTN |
|  | **Desired BP threshold for referral** |
|  |   o 92%: BP ≥ 95th percentile on 3 separate visits |
|  | **Desired testing by PCP before referral** |
|  |   o 65% want PCPs to obtain urinalysis, electrolytes, and CBC before referral |
|  |   o 32% want to do testing themselves |

**Desire for collaborative care**
- 42% believe PCP should monitor BP control under specialist direction
- 41% believe PCP should monitor medication side effects under specialist direction

PCPs should do independently
- 51% believe PCPs should independently make hypertension diagnosis

Specialists should do independently
- 41% believe specialists should independently monitor medication side effects
- 65% believe specialists should independently work up patient for secondary causes
- 75% believe specialists should independently initiate antihypertensive medications
- 74% believe specialists should independently change medication dose/type

**PCP comfort**
- Adolescent HTN diagnosis/management
  - 75% believe general pediatricians are somewhat or very uncomfortable
  - 50% believe family physicians are somewhat or very comfortable

**Barriers**
- Perceived major problems
  - 30% believe PCPs do not appreciate the need to treat HTN in adolescents
  - 28% believe PCPs overrefer due to inaccurate BP readings
  - 27% believe PCPs wait too long to refer
  - 13% believe PCPs do not identify white coat HTN

**Guidelines**
- Desired practices before referral
  - 99% want PCPs to verify elevated BP with multiple methods before referral
  - 40% want PCPs to try lifestyle changes for 3-6 months
  - 26% want PCPs to rule out white coat HTN
  - 3% want PCPs to start antihypertensive medications
- Desired BP threshold for referral
  - 92%: BP ≥ 95th percentile on 3 separate visits
- Desired testing by PCP before referral
  - 65% want PCPs to obtain urinalysis, electrolytes, and CBC before referral
  - 32% want to do testing themselves

Abbreviations: AMA, American Medical Association; PCP, primary care physician; BP, blood pressure; HTN, hypertension; CBC, complete blood count.

Ascertaining bias (no comparison with nonresponders)
Reporting bias
Specialist perspective only
Scope was only adolescent HTN
References


Appendix A2, Methods

Figure 1. Email recruitment message

Dear Colleague,

We are writing you today from the UNC Pediatric Nephrology Service. Thank you for participating in our efforts to improve the care of our shared patients. This very brief survey is a first step in our efforts to improve communication and shared management of children referred to the division of Pediatric Nephrology and Hypertension at the University of North Carolina at Chapel Hill.

This survey is intended for referring primary care providers including physicians, physician assistants, and nurse practitioners. This is a research study that has been deemed exempt by the Institutional Review Board. You are anonymous in this survey, and no information will be collected that could be used to link any responses to your identity.

Kimmy Vuong, a medical student completing her Masters of Public Health, will be analyzing the data from this survey for her master’s paper research, and we will be happy to provide you with a copy of the paper should you wish. Her advisors are Dr. Sue Tolleson-Rinehart and Dr. Keisha Gibson. Their email addresses are suetr@unc.edu and keisha_gibson@med.unc.edu. Kimmy’s email address is kim_vuong@med.unc.edu. Any of us will be happy to answer your questions about this survey or the improvement project.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

The survey is located here: https://unc.az1.qualtrics.com/SE/?SID=SV_cvBSh8laB47cxRX or at the shortened link here: https://goo.gl/NREayy

Sincerely,

Kimmy Vuong, BS

Sue Tolleson-Rinehart, PhD

Keisha Gibson, MD, MPH
Dear Colleague,

We are writing you today from the UNC Pediatric Nephrology Service. Thank you for participating in our efforts to improve the care of our shared patients. We invite you to participate in a brief survey that is a first step in our efforts to improve communication and shared management of children referred to the division of Pediatric Nephrology and Hypertension at the University of North Carolina at Chapel Hill.

This survey is intended for referring primary care providers including physicians, physician assistants, and nurse practitioners. This is a research study that has been deemed exempt by the Institutional Review Board. You are anonymous in this survey, and no information will be collected that could be used to link any responses to your identity.

Kimmy Vuong, a medical student completing her Masters of Public Health, will be analyzing the data from this survey for her master’s paper research, and we will be happy to provide you with a copy of the paper should you wish. Her advisors are Dr. Sue Tolleson-Rinehart and Dr. Keisha Gibson. Their email addresses are sue.tr@med.unc.edu and keisha_gibson@med.unc.edu. Kimmy’s email address is kim_vuong@med.unc.edu. Any of us will be happy to answer your questions about this survey or the improvement project.

If you would prefer to receive the link to this survey by email, please email kim_vuong@med.unc.edu and this message will be sent to you via email.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

The survey is located at the shortened link here: https://goo.gl/NREayv or at the full link here: https://unc.az1.qualtrics.com/SE/?SID=SV_cvBSn8laB47cxRX

Sincerely,

Kimmy Vuong, BS

Sue Tolleson-Rinehart, PhD

Keisha Gibson, MD, MPH
Figure 3. Questionnaire

Master's Paper: Pediatric Nephrology Comanagement Survey

Q24 Dear Colleague, We are writing you today from the UNC Pediatric Nephrology Service. Thank you for participating in our efforts to improve the care of our shared patients. This very brief survey is a first step in our efforts to improve communication and shared management of children referred to the division of Pediatric Nephrology and Hypertension at the University of North Carolina at Chapel Hill. This survey is intended for referring primary care providers including physicians, physician assistants, and nurse practitioners. This study has been deemed exempt by the Institutional Review Board ****. You are anonymous in this survey unless, for some reason, you wish to identify yourself to us. Kimmy Vuong, a medical student completing her Masters of Public Health, will be analyzing the data from this survey for her master's paper research, and we will be happy to provide you with a copy of the paper should you wish. Her advisors are Dr. Sue Tolleson-Rinehart and Dr. Keisha Gibson. Their email addresses are suetr@unc.edu and keisha_gibson@med.unc.edu. Kimmy's email address is kim_vuong@med.unc.edu. Any of us will be happy to answer your questions about this survey or the improvement project. By clicking below, you are consenting to answer the survey questions, but you may quit at any time.

Q33 Please choose an option below -- thank you!
○ I am willing to take the survey (1)
○ I do not want to take the survey (2)

If I do not want to take the survey... Is Selected, Then Skip To End of Survey
Q7 Which of the following best describes your practice? You may interpret "urban, suburban, and rural" as you choose.
- Urban (1)
- Suburban (2)
- Rural (3)
- Other, please describe (4)

Q8 How far is your clinic from the UNC Chapel Hill Pediatric Nephrology clinic?
- 0 to 25 miles away (1)
- 26 to 50 miles away (2)
- 51 to 75 miles away (3)
- 76 to 100 miles away (4)
- More than 100 miles away (5)

Q9 How many patients do you generally refer to UNC Pediatric Nephrology per year?
- 0 patients per year (1)
- 5 or fewer patients per year (6)
- More than 5 patients per year (7)
Q10 Now we want to turn to the kinds of conditions you see in your clinic. How often have you encountered the following nephrologic conditions amongst your patients within the last 6 months? Please check all that apply.

- Hypertension (24)
- Hematuria (25)
- Proteinuria (26)
- Steroid-sensitive nephrotic syndrome (27)
- Steroid-resistant nephrotic syndrome (28)
- Congenital anomalies of the kidney and urinary tract (29)
- Urinary tract infection (30)
- Urinary incontinence (31)
- Acute kidney injury (32)
- Acute glomerulonephritis (33)
- Henoch-Schönlein Purpura with renal involvement (34)
- Autoimmune disease (35)
- Chronic kidney disease (36)
- ALL OF THE ABOVE (37)
Q11 How comfortable do you feel with the initial work-up and management of the following nephrologic conditions?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Very comfortable (1)</th>
<th>Somewhat comfortable (2)</th>
<th>Neither comfortable nor uncomfortable (3)</th>
<th>Somewhat uncomfortable (4)</th>
<th>Very uncomfortable (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension (23)</td>
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<td></td>
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<tr>
<td>Hematuria (24)</td>
<td>○</td>
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<td></td>
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<tr>
<td>Proteinuria (25)</td>
<td>○</td>
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<td></td>
<td></td>
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<tr>
<td>Steroid-sensitive nephrotic syndrome (26)</td>
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<td></td>
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<tr>
<td>Steroid-resistant nephrotic syndrome (27)</td>
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<tr>
<td>Congenital anomalies of the kidney and urinary tract (28)</td>
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<tr>
<td>Urinary tract infection (29)</td>
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<td></td>
</tr>
<tr>
<td>Urinary incontinence (30)</td>
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<tr>
<td>Acute kidney injury (31)</td>
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<tr>
<td>Acute glomerulonephritis (32)</td>
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<tr>
<td>Henoch-Schonlein Purpura with renal involvement (33)</td>
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</tr>
<tr>
<td>Autoimmune disease (34)</td>
<td></td>
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<tr>
<td>Chronic kidney disease (35)</td>
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Q13 These questions are about your experience with referring your patients to UNC Pediatric Nephrology.

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<thead>
<tr>
<th></th>
<th>Very satisfied (1)</th>
<th>Satisfied (2)</th>
<th>Neither satisfied nor dissatisfied (3)</th>
<th>Dissatisfied (4)</th>
<th>Very dissatisfied (5)</th>
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<td>Wait time to appointment</td>
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<td>(1) Assessments, notes,</td>
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<td>and treatment plans you</td>
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<td>receive from the Peds</td>
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<td>Nephrology Clinic (2)</td>
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</table>

Q30 Before we ask about further communication, do you have access to UNC’s electronic medical record (EPIC)?
  ○ Yes (1)
  ○ No (2)
  ○ Not sure (4)

Q22 How often do you receive copies of consultation notes for your patients from UNC Pediatric Nephrology? Please use the bar below to choose the usual frequency of receiving consultation notes. Zero means you never receive notes, and 100 means you always receive notes, and you may choose any number in between to indicate frequency.
  _____ I see consultation notes from UNC Peds Nephrology... (1)

Q34 And about how satisfied are you with the AMOUNT of communication with UNC Peds Nephrology? Please use the slider bar below to tell us whether you are getting too much communication, too little, or whether it is about right.
  _____ Level of communication (1)

Q28 What CONTENT in our communication is or would be most VALUABLE to you? Please check all that apply.
  ☐ Just getting the consultation notes (1)
  ☐ Having clear management plans in the consultation notes (2)
  ☐ Having education about the patient's diagnosis in the consultation notes (3)
  ☐ Having a concise summary letter instead of a full consultation note (4)
Q35 Finally, how do you prefer to RECEIVE the communications? Please use the slider bars to tell us how helpful or unhelpful each of these forms of communication is.

_____ Fax (1)
_____ Email (2)
_____ Telephone (3)
_____ Within Epic, if you are within the UNC Health Care System (4)
Q19 We are nearly done! Would you be interested in continuing education about pediatric nephrologic conditions?
   - Yes (1)
   - No (2)

If Yes is selected, then skip to the question to which conditions would you like to...
Q1 Last questions! Would you mind telling us how old you are? Please choose from one of the groups below.
- 34 or younger (4)
- 35-54 (5)
- 55-64 (6)
- 65 or over (7)

Q6 And for how many years have you been practicing since you completed residency or fellowship?
- 5 or fewer years since finishing my training (1)
- more than 5 but fewer than 10 years (2)
- more than 10 years but fewer than 20 years (3)
- 20 or more years in practice (4)

Q26 And for how many years have you been referring your patients to UNC Peds Nephrology?
- 5 or fewer years (1)
- more than 5 but fewer than 10 years (2)
- more than 10 but fewer than 20 years (3)
- 20 years or more (4)

Q3 Are you...
- Male (1)
- Female (2)
- Other, please describe (3) __________________________
- Decline to answer (4)

Q25 Thank you very much for taking the time to fill out this survey! We appreciate your willingness to respond! If you have any other comments, or want us to contact you, please put your name below. We will separate your name from the rest of the data in our analysis. Thank you again!

Q23 Do you have any suggestions or recommendations about improving co-management and care coordination between your office and UNC Pediatric Nephrology?