Managing Long-Term Outcomes for Kidney Transplant Patients: An Integrated Needs Assessment

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Executive Summary

Since the first successful kidney transplant between identical twins in 1954, surgical techniques, pharmacotherapy, and organ donor registries have improved, making renal transplant the therapy of choice for a growing number of individuals.

Short-term care of kidney transplant patients focuses on suppressing the immune system to prevent the body from rejecting the new organ. This necessitates strong immunosuppressive medication that leaves the patient vulnerable to infection. Over time, the drug dosage is lowered and the risk of infection lessens, but kidney transplant recipients must take immunosuppressive medication for the rest of their lives. These drugs have serious adverse effects, including cancer, diabetes, bone disease, hypertension, dyslipidemia, and many other medical conditions. Physicians who manage the long-term care of kidney transplant patients must identify treatment that maximizes kidney function and averts rejection while simultaneously minimizing the risk of short- and long-term adverse effects.

In the United States, the increasing population with end-stage renal disease, better survival rates among transplant recipients, and advances in surgery and medicine that make transplant an increasingly viable option all contribute to the growing number of individuals living with a donor kidney. Increasingly, community nephrologists, urologists, and other health care professionals are expected to actively participate in the management of kidney transplant recipients, and more and more community-based primary care physicians see these patients in their daily practices. Consequently, communication, coordination of care, delineation of roles and responsibilities, and effective referral procedures are key issues in the management of transplant patients.

This integrated needs assessment was designed to:

- Provide a detailed review of evidence-based literature, published guidelines, research initiatives, and other sources of literature that inform evidence-based standards of care.
- Identify and quantify the attitudes and educational and behavioral needs of transplant surgeons, nephrologists, urologists, and associated health care professionals surrounding the care of patients with kidney transplants.
- Assess current clinical performance required of key health care providers to help assure long-term graft and patient survival.
- Identify learning preferences, including educational interventions preferred by transplant surgeons, nephrologists, urologists, and associated health care professionals.
- Quantify the forces, attitudes, and barriers to practice improvement and the corresponding readiness of physicians to change.

Addressing gaps surrounding the management of the kidney transplant patient requires a multifaceted evaluation of the forces that impact patient care so appropriate educational strategies can be designed. Identifying variables that impact physician behavior is key to meeting educational challenges and capitalizing on learning opportunities. This needs assessment project integrates data from the following sources to identify opportunities for physician education:

- Survey and analysis of clinical literature surrounding post-graft management and chronic care of kidney transplant patients.
- Review of relevant clinical guidelines on kidney transplant care.
- In-depth interviews with stakeholders, including transplant surgeons, nephrologists, urologists, and associated health care professionals.
- Analysis from a validated assessment tool completed by more than 200 specialists. The tool assessed clinician treatment behavior, perceived competency, barriers to care, clinical knowledge, and educational preferences.

This needs assessment was funded through an educational grant from Pfizer Medical Education Group. The project was completed using a collaborative process between the participating organizations; no one member could have completed this rigorous analysis without the challenge and support of the others. This spirit of collaboration should continue with continuing medical education professionals designing education and interventions to improve the ongoing care of kidney transplant patients.

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Literature Review

Sixteen thousand sixty-seven kidney transplants were performed in the United States in 2008.[5] Unfortunately, the number of patients needing transplants far exceeds the number of available organs. Between 1999 and 2008, the number of transplants increased 27 percent, while the number of patients in need of a kidney jumped 75 percent.[5] At the end of 2008, approximately 76,000 individuals were on the kidney transplant waiting list; during that same year, 4,500 people died waiting for a kidney to become available.[5 6] The Healthy People 2010 initiative aimed to have 30.5 percent of individuals with end-stage renal disease undergo transplant within three years; however, currently only 17.3 percent of patients meet the three-year goal.[7]

Recent advances in laparoscopic surgery, immunosuppressive techniques, and donor registries have resulted in an increase in living donor transplants, which almost doubled from 1996 to 2006.[4,1] However, almost two thirds of donated kidneys still come from deceased donors.[5] The growing shortage of available organs prompted increased use of expanded criteria donors (ECDs), who may have one or more "medical complexities" including older age, obesity, or hypertension.[8] In 2008, 22 percent of donations were from expanded criteria donors.[7] Detailed comparative outcomes data for these recipients remain scarce, although it is known that five-year patient survival rates are approximately 20 percent lower for ECD recipients.[1, 8]

In recent years, the average age for both donor and recipient transplant populations has increased, due to the aging population, the increased incidence of end-stage kidney disease among older adults, and improvements in medical care that make transplant an increasingly viable option.[1, 4, 5]

Prognosis

Kidney transplant is almost always the best option for patients with advanced kidney disease. Transplant patients live an average of 10 to 15 years longer than patients on dialysis.[9]
Short-term survival rates of transplanted kidneys, or grafts, are excellent; approximately 95 percent are functioning well one year after surgery.[6] Although short-term prognoses have improved considerably in recent years, improvements in long-term outcomes have been less significant (see Table 1).[1,4]

Most patients requiring a kidney transplant have end-stage renal disease stemming from a number of conditions, including diabetes (28 percent of active waiting list patients, as of 2008), glomerular disease (22 percent), and hypertensive nephrosclerosis (20 percent).[3] Over the last decade, the proportion of glomerular disease cases has decreased while diabetes and hypertensive nephrosclerosis have increased.[4]

	One year		Five years		Ten years	
	Graft survival	Patient survival	Graft survival	Patient Survival	Graft Survival	Patient survival
Living donor	99%	96%	91%	81%	77%	59%
Non-expanded-criteria donor	96%	92%	84%	72%	64%	46%
Expanded-criteria donor	92%	85%	72%	57%	47%	29%

Table 1: Kidney Transplant Outcomes[3]

The main cause of death with graft function (DWGF) is cardiovascular disease, which accounts for up to 55 percent of mortalities. Other major causes of death include diabetes, end-stage renal disease, infection, and cancer.[10]

Guidelines and Literature

The main evidence-based comprehensive clinical guideline for the ongoing care of kidney transplant patients is a 2009 publication from *Kidney Disease: Improving Global Outcomes* (KDIGO).[11] Results from 3,168 randomized control trials, 7,543 cohort studies, and 1,609 reviews informed the *KDIGO* recommendations, while previous publications on long-term management—such as part two of the European Best Practice Guidelines for Renal Transplantation, released in 2002—were based primarily on expert opinion.[12]

Some clinical guidelines that focus on kidney transplantation or kidney disease also include recommendations for long-term maintenance care. Select major clinical guideline documents are listed in Table 2.

Guideline Title	Organization	Year(s) of Publication
Caring for Australasians with Renal Impairment (CARI) Transplantation Guidelines[13]	Australian and New Zealand Society of Nephrology (ANZSN), Board of Kidney Health Australia (KHA)	2005-2010 (various)
KDOQI Guidelines for CKD Care and Dialysis Care[14]	National Kidney Foundation Kidney Disease Outcome Quality Initiative (NKF KDOQI)	2000-2009 (various)
Guidelines on Renal Transplantation[15]	European Association of Urology	2003 (full-text update 2009)
Immunosuppressive therapy for renal transplantation in adults[16]	National Institute for Clinical Excellence (NICE)	2004
European Best Practice Guidelines for Transplantation[17, 18]	European Renal Association, European Dialysis and Transplant Association	2000 (Part 1) ; 2002 (Part 2)
United Kingdom Guidelines for Living Donor Kidney Transplantation[19]	British Transplantation Society, the Renal Association	2000

Table 2: Clinical Guideline Documents for Kidney Transplantation and Disease

Although detailed recommendations are available to guide the management of kidney transplant patients, the strength of the recommendation statements and the quality of evidence to support them is less than optimal.[20] In the KDIGO guidelines, only 2 percent of recommendations were based on A-level quality evidence. This is particularly the case in the ever-changing pharmacological treatment of transplant patients. Future research, particularly randomized controlled trials, will clarify best practices and enable evidence-based practice recommendations.

Immunosuppressive Therapy

Immunosuppressive therapy is the most important component in the management of the kidney transplant patient. Unless the donor and recipient are identical twins, the recipient's immune system will recognize the graft as foreign material and reject it. Kidney transplant patients must take a complex regimen of drugs throughout their lives to prevent acute rejection and ensure the graft maintains function.

Prescribers must identify an effective drug regimen from a range of immunosuppressive therapy that attains adequate immunosuppression while minimizing short- and long-term adverse side effects, which can be quite serious.

At the time of transplant, induction therapy with one or more biologic agents is used to deplete or modulate T-cell responses.[11] Immunosuppressive medication is administered in gradually decreasing doses. Barring acute rejection, patients should be using the lowest planned doses at two to four months after transplantation.[11]

Long-term kidney transplant maintenance medication usually incorporates a calcineurin inhibitor (CNI), an antiproliferative agent or mTOR inhibitor, and frequently a corticosteroid. Many centers now offer steroid avoidance treatments using depletional induction agents.

- **Calcineurin Inhibitors (CNIs):** CNIS are usually initiated at the time of transplantation and are not typically withdrawn except in clinical studies. *KDIGO* guidelines recommend tacrolimus as the first-line CNI; cyclosporine is used as well.[11, 21] It is crucial to be aware of potential interactions between CNIs and other drugs, as high levels of CNIs can be toxic while low levels can contribute to graft rejection.[22]

- **Antiproliferative Agents:** Mycophenolic acid is available as mycophenolate mofetil and mycophenolate sodium. KDIGO guidelines suggest it as the first-line antiproliferative agent.[11] Azathioprine, which may cause fewer gastrointestinal side effects, is recommended by the National Institute for Clinical Excellence (NICE) guidelines. [23,16]

- **Corticosteroids:** Corticosteroids—including prednisolone and methylprednisolone—are used in induction therapy and have historically been a major component of long-term immunosuppressive maintenance. However, they are associated with significant adverse effects, including diabetes, hypertension, hyperlipidemia, and osteopenia.[21] Since these side effects can contribute to kidney transplant patients' already elevated cardiovascular risk, steroid-free maintenance therapy is becoming increasingly common.[24]

- **mTOR Inhibitors:** mTOR (mammalian target of rapamycin) inhibitors are another class of antiproliferative drugs that includes sirolimus and everolimus. If used, mTORs are typically initiated after the kidney has begun to function.[11]

Lifelong immunosuppressive therapy is needed to prevent rejection, but it is common for prescribers to substitute and modify the regimen to accommodate adverse effects, drug interactions, or co-morbid conditions.[23] When prescribing any medication to a kidney transplant patient, prescribers must consider potential pharmacokinetic or pharmacodynamic interactions to existing immunosuppressive therapy.[23]

Immunosuppressive drugs can cause or exacerbate a number of serious clinical conditions, including diabetes, dyslipidemia, hypertension, osteopenia, bone marrow suppression, gastrointestinal issues, and proteinuria.[11]

Monitoring Kidney Function

Among kidney transplant patients, one of the most serious complications is acute rejection of the organ. Acute rejection has become more rare in recent years; from 1996 to 2004, the number of patients treated for rejection in the first year after transplant dropped from 51 percent to 12 percent.[1] Nevertheless, early identification of acute rejection is critical, because if left untreated, it will eventually result in the death of the kidney. Risk factors for acute rejection include:

- Presence of a donor-specific antibody
- Delayed onset of graft function
- Number of human leukocyte antigen (HLA) mismatches
- Younger recipient age
- Older donor age

Clinical symptoms pointing to decreased kidney function can be the first sign of acute rejection; diagnosis is verified via kidney biopsy.

Graft function should be monitored closely—at the very least, every two months or more for the first two years and every three to four months thereafter.[25] After the graft is stable, kidney function can be assessed via the following measures:[11]

- Serum creatinine, measured every one to four weeks during the first year and every two to three months thereafter
- Urine protein excretion, measured every three months during the first year and annually thereafter
- Glomerular Filtration Rate (GFR) measured using a calculator such as the Modification of Diet in Renal Disease (MDRD) formula[25]

In the case of suspected kidney dysfunction, it is vital to conduct a kidney ultrasound test to evaluate renal blood flow and assess for obstruction. If rejection is occurring, elevated doses of immunosuppressive medication are indicated; if the problem lies elsewhere, increasing these medications compromises patient safety.

Adherence to Immunosuppressive Therapy

The term *adherence* refers to "the extent to which a person's behavior corresponds with the agreed recommendations from a healthcare provider".[26] The term is increasingly used in place of *compliance* in order to recognize the patient's agency in his or her health care. Medication adherence is a crucial issue among kidney transplant patients, because non-adherence will eventually result in graft rejection. It is estimated that half of late acute rejections and 15 percent of graft losses in organ transplant patients are associated with non-adherent behavior.[27-29]

Risk factors for non-adherence include psychiatric illness, substance abuse and other high-risk behavior, inadequate pre-transplant education and post-transplant follow up, and medication side effects. [30, 31] The complexity of immunosuppressive medication regimens contributes to inadvertent non-adherence when patients forget to take their medication or lose track of correct dosing. Adolescent patients who transition from pediatric to adult care are at particular risk for non-adherence.[11]

Specific data on adherence in kidney transplant patients are scarce. However, one meta-analysis of interventions to improve adherence in solid organ transplant recipients revealed that the most successful intervention used a team-based, multi-faceted approach including "patient-focused cognitive/educational, counseling/behavioral, and psychologic/affective dimensions" .[32] *KDIGO* guidelines recommend screening for non-adherence in high-risk patients as well as adherence education for kidney transplant patients and their families.[11]

Long-Term Complications in Kidney Transplant Patients

Kidney transplant patients are at higher than average risk for a number of conditions, including cardiovascular disease, diabetes, cancer, viruses, bone disease, and infection. These complications can originate from the primary kidney disease, the effects of immunosuppressive medication, or a combination of factors.

Cardiovascular Disease

The prevalence of hypertension in kidney transplant recipients ranges from 50-90 percent, while the prevalence of hyperlipidemia is 60–80 percent.[33-35,25] Some of these risk factors are present pre-transplant; patients with end-stage renal disease have 10 to 20 times the risk of cardiovascular morbidity and mortality compared to the general population.[23] Although risk factors for cardiovascular disease decrease after transplant, it remains the leading cause of mortality among kidney transplant recipients.

- Cardiovascular disease causes 25-55 percent of kidney transplant patient deaths.[10, 25, 36, 37]
- The rate of cardiovascular events among transplant patients is 50 times higher than that of the general population.[33]
- Three years after transplant, approximately two out of five patients will have experienced a cardiovascular event.[38]
- Cardiovascular risk is exacerbated by necessary immunosuppressive medications such as corticosteroids, CNIs, and mTOR inhibitors.[23]

There is no clear evidence for optimal blood pressure levels for kidney transplant patients. KDOQI and KDIGO guidelines suggest 130/80 mmHg, while the European Best Practice Guidelines document recommends 130/85 mmHg.[11, 23, 39,18]

Diabetes

Corticosteroids, CNIs, and other immunosuppressive drugs can affect insulin resistance, insulin production, and glucose metabolism.[23] Consequently, new onset of diabetes mellitus after transplant (NODAT) is common, affecting from 10 to 30 percent of adults in the first year after transplant.[11] Between NODAT patients and the many end-stage renal disease patients who had diabetes pre-transplant, a significant number of kidney transplant recipients are diabetic overall.

- Co-morbid diabetes has been associated with worse outcomes—including graft failure, mortality, and other complications—although the frequency and causal relationship of these factors is yet unclear.[11, 23]
- Kidney transplant patients with diabetes have two and a half times the risk of ischemic heart disease compared to those without diabetes.
- Onset of diabetes after transplant is associated with 60 percent higher chance of graft failure.
- Neuropathy, nephropathy, and retinopathy, and other vascular complications are more common in kidney transplant patients who have NODAT.

Cancer

Kidney transplant patients have a significantly elevated chance of developing certain types of malignancies. Overall, they are three to five times more likely to develop cancer than the general population.[40] One source estimates that within 20 years, cancer will surpass cardiovascular disease as the leading cause of death among transplant patients.[41]

The majority of cancers that affect kidney transplant patients are associated with viral infections. These include those associated with the human papilloma virus (HPV), such as vaginal and cervical cancers, as well as non-melanoma skin cancer, which occurs at 20 times the rate of non-transplant individuals.[42,43] Additionally, cancer may recur post-transplant, or, in rare circumstances, can be transmitted from the donor to the recipient.[40]

Some immunosuppressive medications, such as CNIs and azathioprine, can be carcinogenic.[40] Cancers with a standardized incidence rate (SIR) equal to or greater than three are likely caused or exacerbated by immunosuppressive medication. In these cases, decreasing the medication dose may prolong survival, but may also increase the risk of graft rejection.[11] Optimal strategies for decreasing or withdrawing immunosuppressive medications to treat cancer are unknown.[40]

- Cancers with high SIR (>5): Kaposi's sarcoma, vagina, non-Hodgkin's lymphoma, kidney, non-melanoma skin, lip, thyroid, penis, small intestine, eye
- Cancers with moderate SIR (>1-5): Lung, oro-nasopharynx, melanoma, colon, esophagus, larynx, cervix, bladder, multiple myeloma, stomach, leukemia, anus, liver, Hodgkin's lymphoma

Treatment of cancer in kidney transplant patients is complicated by immunosuppressive drugs and co-morbidities; consequently, prognosis for these patients is often poor. Care centers on screening and detection. Kidney transplant patients and their physicians should develop a screening plan based on personal risk factors. *KDIGO* guidelines recommend screening as normal for cervical, breast, colon and prostate cancers.[11] In order to reduce the risk of skin cancer, patients should limit UV exposure and undergo an annual dermatological examination.[11]

Bone Disease

Most kidney transplant recipients experience a loss in bone mineral density (BMD), which decreases rapidly within the first year and more slowly over time.[44,45] Consequently, kidney transplant patients have a fracture rate that is four times that of the general population.[23] The factors contributing to post-transplant bone disease are complex, but include immunosuppression—particularly with corticosteroids—and hyperparathyroidism.[23, 46] KDOQI guidelines recommend the monitoring of calcium serum levels, total CO_2, phosphorus, and plasma intact PTH following transplantation, as well as bone density measurement to screen for osteoporosis.[47]

Infection

Like all immunocompromised individuals, kidney transplant patients have an elevated risk of infection. During the six months following transplant, patients are most likely to contract post-surgical, nosocomial, or community-acquired infections.[46] Prophylactic antibiotic, antiviral, and antimycotic treatment can mitigate this risk.[46] Patients with poor graft function or rejection will require higher levels of immunosuppression, leaving them more vulnerable to opportunistic infections. Although risk decreases after approximately six months, transplant patients remain at risk for urinary tract infections, fungal infections, cytomegalovirus (CMV), and other infections.[21]

Fever in kidney transplant recipients can be a sign of infection, but can also signal graft rejection. Patients with fever should be carefully evaluated for differential diagnosis.[46]

Some immunizations can help prevent infection, but others are dangerous to kidney transplant patients; live vaccines—such as measles/mumps/rubella (MMR), smallpox, polio, and oral typhoid—can cause serious infection in patients on immunosuppressive medication and should be avoided.[11, 23] After six months post-transplant, inactive vaccines should be administered on a normal schedule.[11] It is recommended that kidney transplant recipients receive the influenza vaccine on an annual basis and the pneumonia vaccine every five years; additionally, some transplant centers recommend vaccination of family and health care workers to reduce the risk of infection transmission.[11,23]

Needs Assessment Overview

Needs Assessment Objectives

The behavior of physicians and health care professionals depends not only on skill and knowledge, but also on the clinical environment and the forces at play within that environment. For physicians and health professionals to change, systems and stakeholders must also change. This needs assessment was designed to:

- Identify barriers to best practice at individual and system levels
- Develop tools to assess the knowledge, attitudes, and practice gaps of those treating kidney transplant patients
- Assess the knowledge, skill, and/or attitude gaps of target learner groups related to the care of the kidney transplant patient
- Assess the similarities and differences in the knowledge, attitudes, and practice gaps of different groups of clinicians who treat kidney transplant patients (transplant surgeons, nephrologists, and associated health care professionals)
- Determine how various factors, including systems factors, work together to accelerate or impede physician and health care professional adherence to best evidence
- Identify optimal change strategies and the resources to close the identified gaps

Research Questions

The following questions regarding the care of kidney transplant patients were addressed during this study:

- How are physicians and health care professionals managing patients through the life of the graft compared to consensus statements and standards of care?
- How do clinicians perceive their own care of kidney transplant patients?
- What gaps in knowledge, attitude, skills, and behavior exist that can be addressed through education?
- What are the most appropriate formats for educational interventions?
- Do physician specialties vary in their knowledge, skills, attitudes, and behaviors when delivering care to kidney transplant patients?

Stakeholders

This comprehensive needs assessment focused on community nephrologists, transplant specialists (primarily nephrologists who practice at transplant centers), and transplant surgeons—including urologists, nephrologists and general surgeons—who manage care of kidney transplant patients.

Transplant coordinators and nurses who work with these patients were also included in the qualitative components of the needs assessment in order to provide a broader perspective of the physician needs

Needs Assessment Methodology

To identify the educational strategies needed to close the gaps in care, we first performed a thorough and detailed review of evidence-based literature, observational studies, guidelines, consensus statements, and research initiatives surrounding the care of kidney transplant patients (elements of which are outlined in the literature review on page 5). Subsequently, we employed a number of distinct needs assessment techniques to identify gaps and determine the barriers to providing optimal patient care. These techniques included in-depth interviews with stakeholders, focus groups with target audiences, a Change Readiness Inventory® (CRI), a knowledge assessment tool, and a practice assessment tool.

Individually, each needs assessment component provides a unique perspective into the actual and perceived needs of clinicians as well as their barriers to best practice. Moreover, the systematic and integrated evaluation of all needs assessment components identifies and validates knowledge, attitudes, competencies, current clinical practices, and external systems barriers.

All needs assessment methods were designed to reflect the diversity of the practice settings in which care is provided. The provider-focused needs assessment methodology described below provides a multi-dimensional perspective on educational needs; results may be used to inform the development of educational interventions and encourage maximal impact on educational, behavioral, and clinical outcomes.

Qualitative Assessment

Interviews

To better target the needs of the learner, 46 in-depth interviews were conducted with stakeholders who provide care to kidney transplant patients, including transplant surgeons, academic and community-based nephrologists, urologists, and transplant coordinators. They served to identify key issues and influences on clinical behavior, patient management, and educational needs. The interviews also helped identify touch points in the diagnosis, treatment, and long-term management of the kidney transplant patient as well as explore practice management issues that impact therapeutic decision-making.

Project partners used the resulting information gathered through the literature review to create an interview guide that was then reviewed by a clinical expert. Partners completed a total of 46 interviews, including sessions with 17 kidney transplant surgeons (10 of whom were urologists), 16 transplant

specialists, five community/referring nephrologists, seven transplant nurse practitioners or transplant coordinators, and one transplant medical social worker. The interviews were conducted by telephone and lasted approximately one hour; participants were compensated for their time. Researchers used existing partner relationships to access interview participants.

Focus Groups

Project partners conducted and moderated six focus groups in order to better understand the influence that each stakeholder group has on the clinical approach to and the long-term management of kidney transplant patients. This approach allowed researchers to discuss the topic areas of the one-on-one interviews in a group setting, explore the findings of each learner group, and develop the assessment tools for the quantitative phase of research.

- Two focus groups were conducted with transplant surgeons (urologists) in conjunction with the American Urological Association's Annual Meeting in Washington, D.C. (May 2011).
- Two focus groups were conducted with mixed-specialty teams affiliated with specific transplant centers in Detroit, MI (March 2011) and Birmingham, AL (April 2011). These teams included community nephrologists, transplant surgeons, transplant coordinators, and transplant specialists (nephrologists).
- Two focus groups were conducted in conjunction with the American Transplant Congress (May 2011). One group consisted of transplant surgeons and specialists, while the other consisted of transplant coordinators. These sessions served to revise and validate the practice assessment and knowledge assessment questions.

Quantitative Assessment

Information from the interviews and focus groups aided in developing and refining the online assessment tool, consisting of three distinct sections. Each section provided valuable quantitative information and, cumulatively, allowed analysis on the perceived and actual needs of the learners. The three sections of the assessment are highlighted below:

- *Change Readiness Inventory® (CRI):* The CRI measured attitudes, perceived needs, and barriers in clinical practices. The *clinical competencies* section was developed in cooperation with clinical experts from the American Society of Transplantation, referencing current literature. This section was used to establish the *perceived needs* of the target audience.

- *Knowledge and Practice Assessment tools:* These tools were designed to assess current knowledge and actual clinical behavior related to the long-term care of kidney transplant patients. The tools assessed a comprehensive baseline of physicians' knowledge and clinical care behavior in the management of immunosuppressive therapy as well as the recognition and treatment of common co-morbidities in transplant patients. The knowledge and practice assessment tools provided a self-report of clinicians' attitudes and behaviors surrounding the

delivery of care and collected details regarding specific treatment modalities and reasons for treatment choices. Results present a quantitative measure of clinician's knowledge and skill gaps.

- *Educational Preferences Assessment:* The final portion of the quantitative survey assessed educational preferences. Questions were designed to determine the best formats in which to present educational activities. This helps to identify the preferred topics, design, learning format, and platform for the target learner groups. From this information, educational planners may design interventions that provide the greatest potential to impact clinical practice and patient health.

Specific survey questions were developed by Healthcare Performance Consulting, the American Urological Association, and the American Society of Transplantation. Items were reviewed by clinical experts and validated with a sample of the target audiences. The survey was posted online and a link was disseminated via email to members of the three target audiences.

One survey was distributed to community nephrologists, recruited through ResearchNow (an online panel provider with a validated clinical panel), and transplant specialists, recruited through the membership of the American Society of Transplantation. A total of 197 surveys were distributed and 146 were returned, for a response rate of 74 percent. The transplant specialist group consisted of nephrologists with additional training in transplant medicine. All respondents were further screened to ensure that they matched the target audience and provided care to kidney transplant recipients.

A second survey, with slight differences in some questions, was distributed to 117 transplant surgeons. These physicians were recruited through the American Urological Association and had completed specialty training in urology. Sixty individuals responded for a total response rate of 51 percent. Additional data were collected from transplant surgeons at the AUA annual meeting, held in Washington, D.C., in May of 2011.

The complete text of the two surveys can be viewed in Appendices 2 (page 80) and 3 (page 90).

Qualitative Findings: In-Depth Interviews

The in-depth interviews and focus groups were designed to assess key issues and influences on the complex management of kidney transplant patients. The interviews identified numerous challenges in coordinating the care of patients throughout their transplant journey, from the community nephrologist's initial referral to a transplant center, to the subsequent transition of the patient back to the community nephrologist, to the continuing care of the patient for ongoing primary care issues.

Stakeholders stated that the management of kidney transplant patients is challenging, time-consuming, and often requires a great deal of communication and coordination of care. Major challenges include managing immunosuppressive therapy, managing co-morbidities that often worsen after transplant, patient adherence and compliance issues, and monitoring and screening for signs of organ rejection, cancer, infections, and osteopenia. The issues that were discussed were consolidated into key themes, exemplified by direct quotes gathered from interviewees.

Key Themes from the Interviews

Coordination and Continuity of Care

Care must be carefully coordinated between the community/referring nephrologist and the transplant center both before and after the transplant. A number of challenges, both systemic and personal, affect this coordination of care. Communication between various physicians who care for the patient is, at times, sub-optimal. Often, reports such as doctor visits, labs, or screenings are not communicated in a timely manner between the primary care physician, community nephrologist, and transplant center. For the first three months after transplant, patients are seen primarily by the transplant specialist and surgeon; after three months, care is typically transitioned to the community nephrologist and/or the primary care physician and other specialists.

Ideally, the transplant centers would see patients quarterly for one year post-transplant and once a year thereafter; in actuality, this schedule varies widely. Patient distance from the transplant center, access to a community nephrologist, and patient preference play a role in how post-transplant care is provided. Patients located far from the transplant center may not return as frequently. Ideally, the nephrologist monitors kidney function and frequently co-manages co-morbidities with a primary care provider or other specialist(s). However, some patients do not have access to a community nephrologist, and are cared for by a primary care provider; other patients who see a community nephrologist may or may not have a primary care doctor as well. Either one may manage cancer screenings, monitor for osteoporosis and risk of infections, and provide appropriate vaccinations. The transplant center most often manages any changes to immunosuppression, but relies on the community nephrologist or primary care provider to communicate lab results or other patient data.

Busy community nephrology practices may lose track of transplant patients after a period of time. Patient and family education is crucial to ensure that patients get the appropriate screenings and are alert to additional risks for illness and disease, such as osteoporosis, certain cancers, and infection. Patient understanding that immunosuppression places them at greater risk for these conditions contributes to their motivation and adherence to appointments and medication regimens.

The development of protocols and communication strategies to identify a lead physician in ordering surveillance testing would benefit providers and patients. Up-to-date patient information should be shared in a timely manner.

"Patient management post-transplant is the art and science of medicine – the challenge of balancing immunosuppression efficacy versus side effects, toxicity and patient tolerance."

Patient Diversity

Kidney transplant candidates represent a broad spectrum of patients: from relatively healthy to those with multiple co-morbidities and chronic diseases; from wealthy to poor; and from motivated to unmotivated. The ages of transplant patients range from teens to seniors, each presenting unique needs and challenges. Generally, younger patients tend to be less adherent. Pre- and post-transplant patient assessments by health care team members attempt to identify specific patient management issues.

Management of Co-Morbidities and Complicated Drug Regimens

Interviewees across all specialties note the many challenges in managing the multiple co-morbidities seen in transplant patients. Some of the most common co-morbidities include diabetes, kidney disease, hypertension and hyperlipidemia. Because most of these are treated with medication, the potential for drug interactions with immunosuppressive therapy is a major concern. Interviewees are apprehensive about pharmacies making generic substitutions, especially for immunosuppression medications that they feel may not be therapeutically equivalent. Interviewees also indicated that this switch confuses patients, since the pills may be a different color and shape. When asked about educational needs, participants listed 'improving their ability to manage multiple co-morbidities' and 'recognizing the signs and symptoms of drug interactions' as areas of interest.

"Pharmacy can change immunosuppression meds to generic willy-nilly, and it can be a problem for patients to recognize pills."

Patient Adherence

Clinicians across all specialties agree that patient adherence (patient compliance) is an important, challenging, and time-consuming issue that affects all members of the health care team (transplant surgeon, nephrologist, coordinator, social worker, pharmacist, community nephrologist, and primary care physician). The complexities involved in managing the transplant patient present a challenge to patient adherence. Numerous financial issues play a role as well, including loss of a job and/or changes in insurance coverage, the costs of multiple medications, the costs associated with numerous doctor and lab appointments, and periodic visits to the transplant center. According to the clinicians, taking time off work to go to doctors' appointments, traveling to the transplant center, and transportation costs all

were of concern to patients as well. Furthermore, patients may lose Medicare and/or Medicaid coverage at three years post-transplant.

Motivating patients to follow long-term, complex treatment plans is also a challenge. While younger patients and teens are often less adherent, family members play an integral part in ensuring that patients of all ages follow physician recommendations. If adherence is a concern, drug levels may be periodically checked to detect if the patient is taking his or her medications as prescribed. Some patients develop a strong, supportive relationship with the dialysis center staff and experience feelings of loss following transplant, which may affect adherence as well. Patients who are doing well post-transplant may skip follow-up appointments, lab work, and medications; though some can tolerate this, others will get into trouble. Frequently, patients are evaluated by a social worker pre-transplant to determine the likeliness of compliance post-transplant (e.g., was the patient compliant with dialysis, doctor's appointments, and lab work?).

Educational needs in this area include developing processes to educate patients and family members on the importance of long-term adherence and establishing communication guidelines, protocols, and adherence monitoring strategies. Helping patients access community resources that cover medication costs may also have a positive impact on patient adherence.

> "Compliance with medications long-term can be challenging. Patients who are doing well may skip doctors' appointments, lab work, and meds: some will get by, and some will run into problems."

Treatment Protocols and Guidelines

Treatment protocols and recommendations for patient follow up are developed by transplant teams (transplant surgeons and transplant specialists at each transplant center) and are based on clinical evidence from the literature as well as transplant center experience. Whenever possible, the transplant team develops standing orders and then customizes treatment based on individual patient needs. National guidelines are used to manage multiple co-morbidities, although most accepted national guidelines for chronic disease and co-morbid conditions are not specific to transplant patients. AST, *KDIGO* and KDOQI guidelines were mentioned as providing useful general recommendations for patients with chronic kidney disease, although there are fewer evidence-based guidelines specifically for transplant patients. Some clinicians were not aware of specific guidelines for transplant patients.

Interviewees report that they rely heavily on teamwork to develop and update protocols. Typically, protocols are reviewed on an annual basis or when there is a change in leadership at the transplant center, and revised as needed. Educational needs in this area include developing a mechanism to educate community nephrologists and primary care providers (PCPs) on any protocol changes. Because

community nephrologists and primary care clinicians may care for patients from multiple transplant centers with varying protocols, communication is vital to maintaining optimal patient care.

Immunosuppression and the Use of Steroids

The transplant team usually takes the lead in managing immunosuppression. The use of steroids varies among transplant centers. Most transplant centers use steroid minimization, rapid tapering, or steroid-free protocols (except for patients with underlying conditions, such as lupus). Centers report no change in patient outcomes with steroid minimization. Interviewees agree that it is a challenge to balance the risk for toxicity (over-immunosuppression) with the risk of rejection (under-immunosuppression). Patients who receive multiple transplants represent additional challenges, as they develop more antibodies and have a greater risk for graft rejection; therefore, every effort is made to encourage the first kidney transplant to last as long as possible. Most transplants are successful for at least five years. Years five to 10 post-transplant are often more difficult due to the long-term effects of immunosuppression and worsening co-morbidities. A transplant lasting 10 to 15 years is considered a very good result.

> "Managing the risk of toxicity due to over-immunosuppression vs. the risk of rejection due to under-immunosuppression is complex. A kidney transplant survival of five to 1 years is considered good."

Identifying potential drug interactions is a continual process. Risk factors and signs and symptoms of rejection must be frequently monitored (e.g., trends in creatinine levels, ultrasound if obstruction is suspected, biopsy if there are concerns about rejection, testing for BKV and CMV).

Interviewees expressed an interest in education related to best practice protocols, case studies on managing immunosuppression in first-time and repeat transplant patients, and how to manage adverse events related to over- or under- immunosuppression. Information on best practices and results for various steroid use protocols (steroid free, steroid minimization, and rapid tapering) would also be valuable.

> "There is consensus that avoiding or minimizing steroids is the right approach due to side effects and aggravating comorbidities, though there is variation on how this is done."

Most Recent Changes in Clinical Practice

When asked about recent changes in their practice, transplant specialists and surgeons stated that they were using fewer steroids, increasing testing for BKV (due to an increase in prevalence), and seeing more generic medication substitutions, especially the use of more generic immunosuppression agents.

Educational needs cited included helping community nephrologists and primary care providers identify the signs and symptoms of rejection and determining course of action when creatinine levels are rising. Best practices and case studies on when to do biopsies would also be helpful.

Confidence and Competence of Community Nephrologists

There is considerable variation in community nephrologists' knowledge, interest, and confidence in managing kidney transplant patients. This may be related to the number of years the physician has been in clinical practice, his or her experience in managing transplant patients, and the physician's relationship with the transplant center. There have been many changes in the transplant field over the past 10 years, and some physicians have not kept up to date. Some interviewees from all specialties felt that some older community nephrologists may not refer patients for transplant soon enough. Some nephrologists feel that patients should try dialysis for a period of time before considering a transplant.

Educational Opportunities for Community Nephrologists

Community nephrologists and primary care providers often have busy practices that make it difficult to stay up to date, and some interviewees felt that transplant patients "fall through the cracks". Interviewees reported working with primary care practices who see a high volume of patients and community nephrologists who are often busy with dialysis patients, who are considered the "bread and butter" of a community nephrology practice. Since community nephrologists get little training in managing transplant patients, educating them on recent changes in pre- and post-transplant patient management would be beneficial. Interviewees also felt that educating primary care physicians may be challenging, since they are often too busy to deal with the complex issues facing transplant patients.

> "Community nephrologists are best positioned to manage the transplant patient long term, but often need help with managing comorbidities, immunosuppression, monitoring kidney function, and recognizing patients with chronic kidney disease or impaired kidney function even if creatinine is good."

Based on the interviews, potential topics for community nephrologists and primary care physicians include:

- Managing complex drug regimens
- Managing multiple co-morbidities
- Recognizing signs and symptoms of inappropriate immunosuppression
- Balancing side effects of immunosuppression (effect on viral infections, co-morbidities)
- Reinforcing the importance of consistently monitoring serum creatinine to identify trends and compare to baseline
- Stressing the importance of monitoring for BKV and/or CMV
- Performing an ultrasound if an obstruction is suspected or if creatinine is increasing

- Providing information and data on changes to biopsy protocols, including doing a biopsy if there is an unexplained creatinine trend or a suspected BKV infection
- Identifying and addressing drug interactions
- Monitoring for signs and symptoms of rejection
- Encouraging timely referral back to the transplant center
- Providing tips on patient education to ensure adherence
- Stressing coordination of care issues and establishing ongoing relationships with transplant coordinators

Educational Opportunities for Transplant Center Physicians

Educational topics directed specifically toward transplant center physicians, including surgeons and specialists, may include:

- Managing chronic co-morbidities in the transplant patient
- Best practices and case studies on immunosuppression and steroid use
- Managing drug interactions
- Improving processes and communication with referring physicians, both pre- and post-transplant

Qualitative Findings: Learner-Specific Focus Groups

The focus groups allowed researchers to specifically target individual clinician groups to confirm interview findings and further explore the unique educational needs and opportunities of each specialty.

Urologist (Transplant Surgeon) Focus Groups

Specific findings for urologists include the following:

- Challenges facing urologists in the management of kidney transplant patients center around co-morbidities and non-adherence to medication regimens.

> "We are transplanting more comorbid people all the time…cardiovascular disease, diabetes, obesity, coming in with prior events in all these categories is challenging."

- Urologists monitor for acute rejection by evaluating and continually monitoring the kidney function of the patient.

- Urologists use various signs to identify non-adherence to medication regimens: profiling patients, observing dialysis levels, checking weekly blood work, monitoring calcium levels, assessing the patient's financial situation, and using a database that alerts clinicians when patients miss appointments for blood work.

- Nearly all urologists in each group indicate that cultivating good relationships with nephrologists and dialysis centers is key in the continuity of care.

> "I have to have a good relationship with my area nephrologists, not only for the good of the patient, but also so that the nephrologist will continue to refer his patients to my clinic for transplant and work with me in making sure patients are seen by the transplant centers at the earliest possible time."

- Finally, urologists indicated two areas of need regarding education and the expansion of transplantation within urology.

    1. The creation of a clinical guideline that covers the long-term (including pre-transplant) care of the kidney transplant patient is essential.

> "There is a great need for the AUA to develop a comprehensive guideline that speaks to not only the long term care of transplant patients, but also helps general urologists identify certain risk factors associated with kidney transplant."

    2. For transplant surgeons, all urologists indicated a marked need for the AUA to promote the subspecialty of transplantation among urologists, which starts with the residency programs.

> "There are not enough people with urology experience that are conducting transplants. That is due to lack of training, lack of exposure during their residency, and the lack of intrinsic value that transplantations have; the residents don't know that transplants change these people's lives."

Transplant Center Focus Groups

Focus groups assessing transplant center staff revealed that systemic issues related to coordination of care are particularly troublesome. While transplant center clinicians have electronic health records available to them, the community physician may not, or electronic systems may not integrate. Regardless, communication and coordination is burdened by the need to record, review, and manage records that are partially on paper and partially electronic. Transplant coordinators spend hours a day pulling together patient information that would ideally be gathered by a system.

Additional issues identified included:

- Inadequate staffing to manage the patient load. Transplant coordinators may be responsible for up to 700 patients and cannot adequately monitor and oversee that number.
- Increasingly shrinking resources for providing care to patients who cannot afford it.
- Substitution of generic medications increases patient confusion, decreases adherence, and confuses assessment of efficacy.
- Community nephrologists, primary care physicians, and other specialists who care for kidney transplant patient have conflicting wishes about "who takes care of what." It is difficult for the transplant center clinicians to balance the differing needs and desires. As an end result, clinical responsibilities tend to be handled on a case-by-case basis.
- Community nephrologists would like more tools and resources to help with preventive care, such as charts for appropriate cancer screenings or reminder systems for immunizations. Tools that can summarize and simplify ongoing preventive or chronic health issues would be used and appreciated.

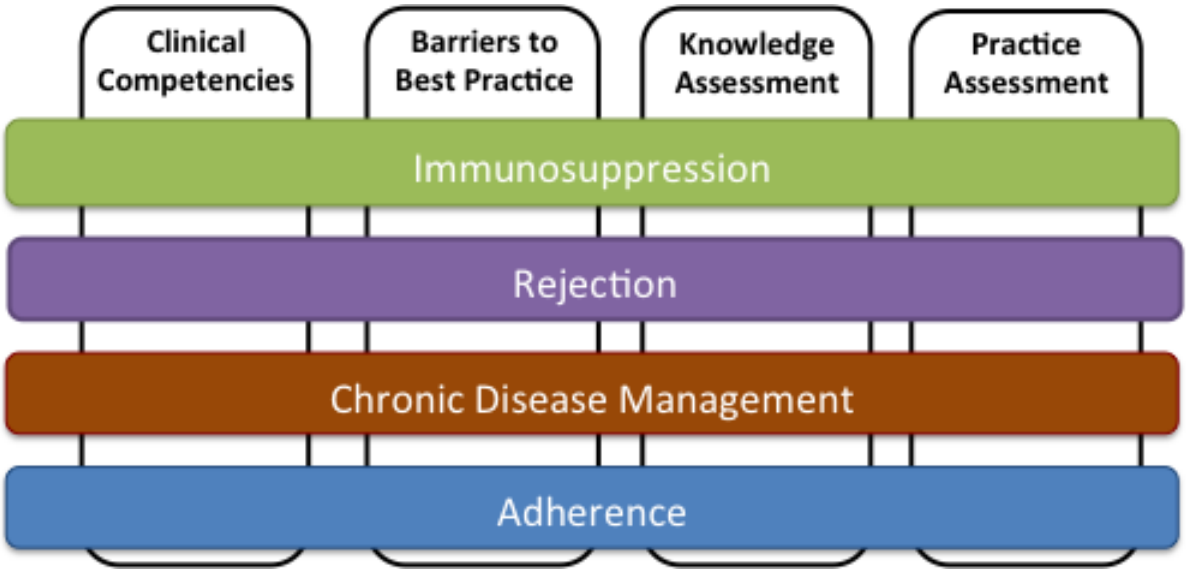
Development of Quantitative Survey Instrument

After all in-depth stakeholder interviews and focus groups were complete, project partners completed a careful review and analysis of all available data in order to create a framework for a qualitative physician survey. Researchers determined that the most relevant issues in patient care could be categorized into four overarching themes:

1. Selection and management of immunosuppression therapy,
2. Risk and detection of graft rejection,
3. Chronic care of the kidney transplant patient (including management of co-morbidities and chronic disease), and
4. Patient adherence to therapy.

All sections of the quantitative survey were designed to collect further data in each of these four topics, as illustrated in the following graphic. Throughout this document, charts and items that relate to each

topic will be color-coded according to the graphic below: *immunosuppression* is green, *rejection* is purple, *chronic disease management* is maroon, and *adherence* is blue.



Quantitative Findings: Overview and Demographics

The individual quantitative assessment tools—which assessed competency, barriers to best practice, knowledge, and practice—were combined into a single survey in order to define relationships between knowledge, clinical practices, competencies and barriers. The relationship between these items is shown below in **Table 3**. While some items overlap and correlate, they may be grouped into 4 basic categories: **Immunosuppression**, **Rejection**, **Chronic Care**, and **Patient Adherence**. The groups and related charts will be color-coded throughout this report to reflect this correlation. Qualitative findings and educational implications also fall neatly within these categories, and will be organized and color-coded accordingly.

Competencies	Barriers	Knowledge Questions	Practice Questions
Immunosuppression			
C1....select an effective immunosuppressive drug regimen that attains adequate protection of the kidney allograft against rejection. C2....minimize short- and long-term adverse side effects of immunosuppressive medications. C3....identify potential interactions between immunosuppressive agents and other medications.	B1. I do not always have access to the patient information that I need to make the best decision about patient management. B3. We are not able to utilize the best therapies due to cost constraints. B4. Many patients cannot afford the treatments that will keep them healthy. B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient.	K1,K2,K3, K4,K7	P1, P2, P3
Rejection			
C4....identify risk factors for acute rejection. C5....detect signs and symptoms of acute graft rejection by monitoring creatinine levels. C6.... attain an allograft biopsy to determine if rejection is occurring.	B1. I do not always have access to the patient information that I need to make the best decision about patient management. B2. Access to the transplant center is limited. B4. Many patients cannot afford the treatments that will keep them healthy. B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient. B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management.	K5	P3
Chronic Care			
C7....coordinate with other specialists or primary care physicians to manage co-morbid conditions (diabetes, hypertension, cardiovascular disease). C8....use screenings to detect cancer in the transplant patient. C9... monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH). C10....mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic	B1. I do not always have access to the patient information that I need to make the best decision about patient management B2. Access to the transplant center is limited and causes problems. B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient. B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as	K6, K8, K9, K10, K11, K12	P5, P6, P7, P9, P10

treatment. C11....appropriately vaccinate six months post-transplant using inactive vaccines.	we should. B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management. B9. Coordination of care for co-morbid conditions causes problems.		
Adherence			
C12....identify risk-factors for non-adherence to medication regimens. C13....effectively communicate risks of non-adherence to patients and family	B4. Many patients cannot afford the treatments that will keep them healthy. B5. Patients are not honest with me about adherence to their treatments	No related knowledge questions	P8

Table 3: Relationships Between Competencies, Barriers, and Knowledge/Practice Questions (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Demographics

The assessment was distributed to each of the three target specialties. Responses were distributed evenly between the three specialty groups (Figure 1, below).

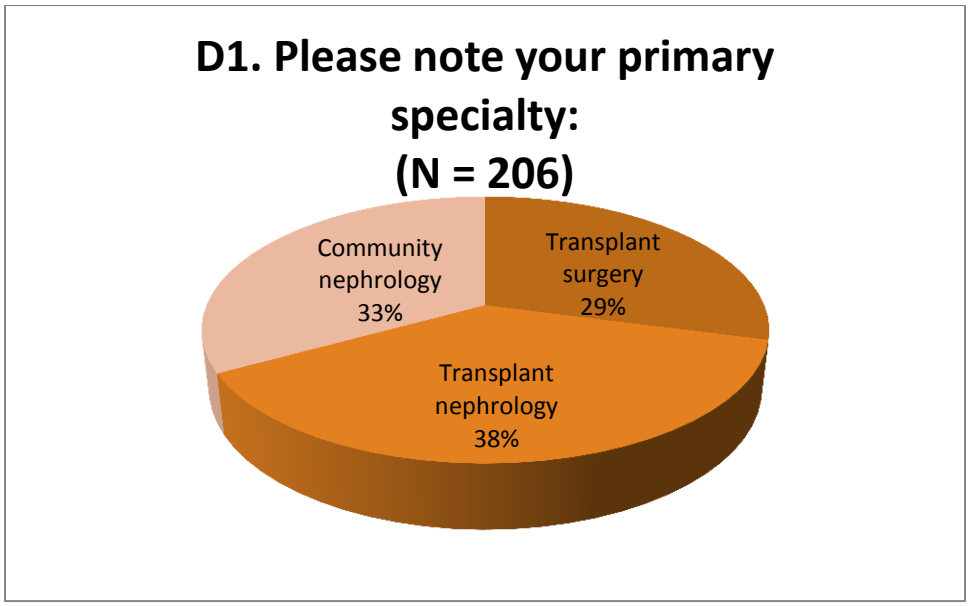


Figure 1: Primary Specialty

There is significant variation in the number of transplant patients seen by each specialty in a typical week. Transplant specialists see the highest number, followed by transplant surgeons. Community nephrologists see the fewest transplant patients (Figure 2).

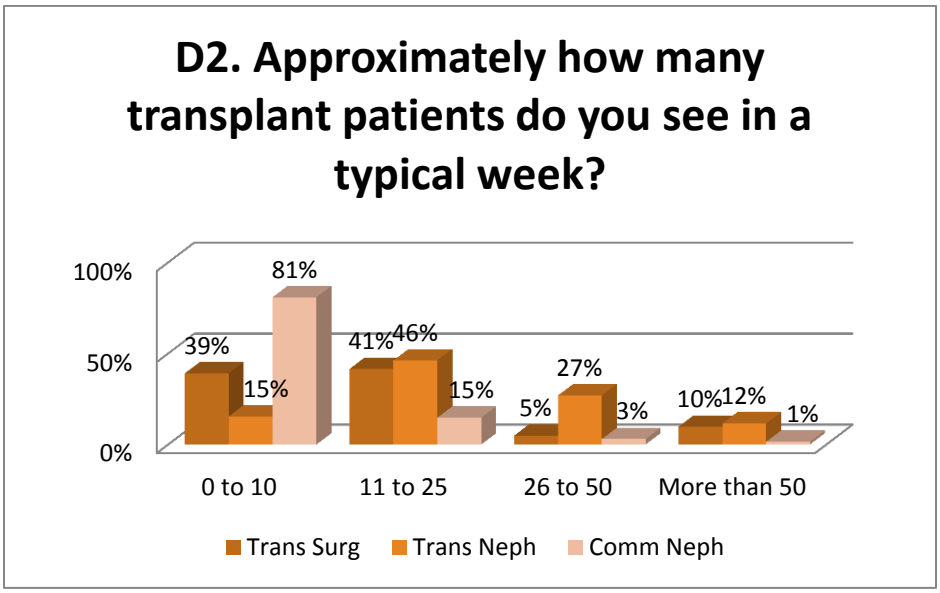


Figure 2: Patients Seen in a Typical Week

Quantitative Findings: Community Nephrologists

Change Readiness Inventory® - Perceived Needs and Barriers

The competencies are a series of statements that represent the abilities needed to successfully manage kidney transplant patients. These competencies were developed from clinical guidelines, current literature, and expert opinion. Physicians were asked to consider the following statements, then indicate both their *present* and *desired* levels of ability (from *1=low* to *5=high*) in performing each task.

Please rate your *present* and *desired* ability to:

C1. Select an effective immunosuppressive drug regimen that attains adequate protection of the kidney allograft against rejection.
C2. Minimize short- and long-term adverse side effects of immunosuppressive medications.
C3. Identify potential interactions between immunosuppressive agents and other medications.
C4. Identify risk factors for acute rejection.
C5. Detect signs and symptoms of acute graft rejection by monitoring creatinine levels.
C6. Attain an allograft biopsy to determine if rejection is occurring.
C7. Coordinate with other specialists or primary care physicians to manage co-morbid conditions (diabetes, hypertension, cardiovascular disease).
C8. Use screenings to detect cancer in the transplant patient.
C9. Monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH).
C10. Mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic treatment.
C11. Appropriately vaccinate 6 months post-transplant using inactive vaccines.
C12. Identify risk-factors for non-adherence to medication regimens.
C13. Effectively communicate risks of non-adherence to patients and family

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

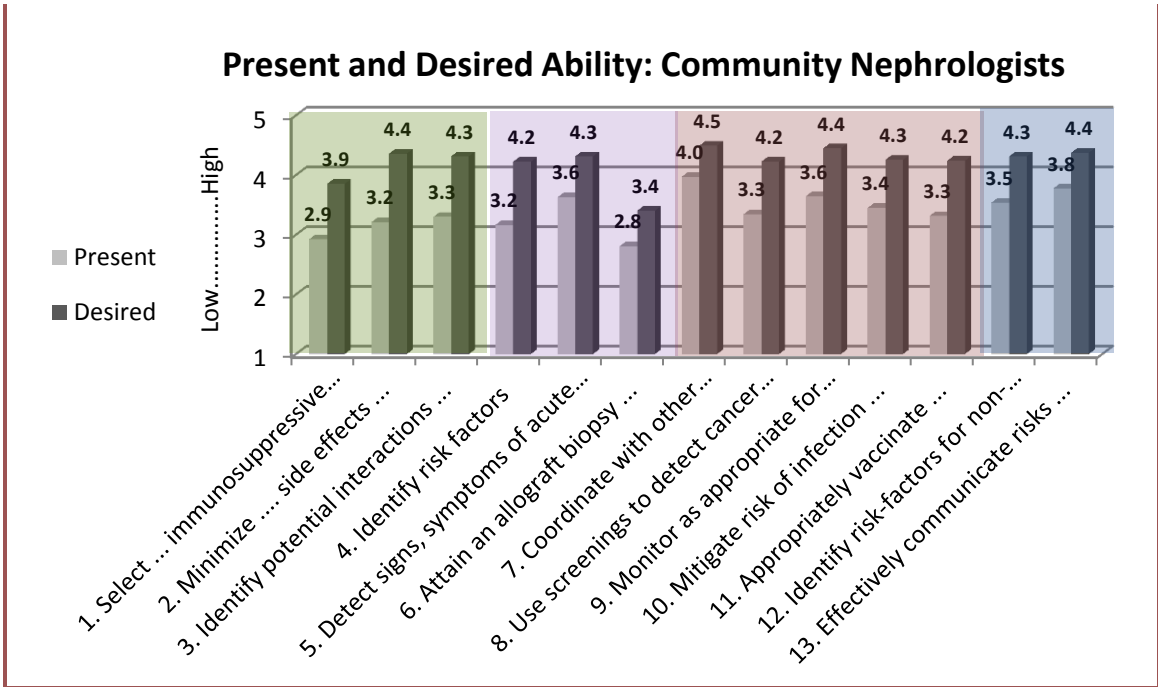


Figure 3: Community Nephrologist Present and Desired Competencies (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Figure 3 shows community nephrologists' average rating of their own present and desired abilities. The average *desired ability* ratings range from 3.9 to 4.5, averaging 4.2 on a one to five scale. This is a somewhat lower average than desired competencies in most other clinical areas, which average closer to 4.5. This may reflect the fact that some community nephrologists prefer not to care for transplant patients and see no need for high skill levels in this area. Additionally, some community nephrologists rarely see transplant patients due to adequate coverage by transplant specialists and thus may not need high competencies in this area. The average *present ability* was 3.4 on the five-point scale, with a range of 2.8 to 4.0.

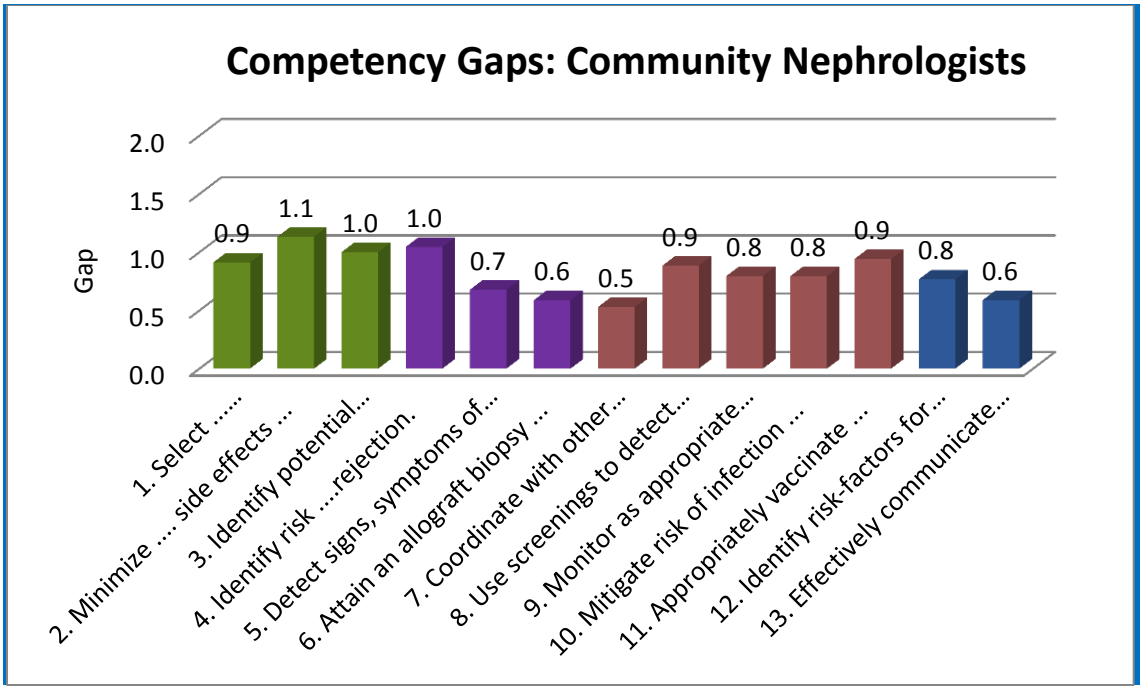


Figure 4: Community Nephrologist Competency Gaps (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

The *perceived need* of each competency is the difference, or gap, between physicians' ratings for *present* and *desired* levels of ability. In other words, this number represents the difference between "what is" and "what ought to be." A gap of 0.5 is presumed to be important, with gaps of 1.0–2.0 considered ideal for clinician education. A gap smaller than 0.5 indicates low motivation to learn and change, while a gap higher than 2.0 may represent a level of change that the physician believes to be unattainable or impractical.

The average gap, or perceived need, of this competency set is 0.8 (Figure 4); individual gaps ranged from 0.5 to 1.1. All 13 of the perceived competency gaps are higher than 0.5 and are thus considered important for continuing education. Three fall within the ideal range of 1.0–2.0. Physicians realize that change is needed in this clinical area of medicine and are motivated to make practice changes. The three areas of highest perceived need are:

- C2. Minimize short- and long-term adverse side effects of immunosuppressive medications
- C4. Identify risk factors for acute rejection
- C3. Identify potential interactions between immunosuppression agents and other medications

These results indicate that the community nephrologists' biggest concern with kidney transplant patients is in the area of appropriate immunosuppression that is effective, yet minimizes side effects. This mirrors concerns expressed during the in-depth interviews.

Barriers to Best Practice

Barriers to best practice are real or perceived issues that may prevent physicians from applying best practice. Knowledge of the nature and magnitude of these barriers helps educational designers address them within the scope of interventions, and in doing so, encourage change in physician performance as well as change in knowledge and skill. These barriers were identified using expert opinion, data from the in-depth interviews, and literature on physician change.

The next set of statements represents barriers to best practice when managing transplant patients. Please rate each statement according your level of agreement as to whether the item represents a barrier to effective management of transplant patients. (*1=Strongly Disagree*, *5=Strongly Agree*)

B1. I do not always have access to the patient health information that I need to make the best decisions about patient management.
B2. Access to the transplant center is limited.
B3. I am not able to utilize the best therapies due to cost constraints.
B4. Many patients cannot afford the treatments that will keep them healthy.
B5. Patients are not honest with me about adherence to their treatments.
B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient.
B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as we should.
B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management.
B9. Coordination of care for co-morbid conditions causes problems.

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

Figure 5 shows the list of statements arranged in order of respondents' highest perceived barriers. The bars to the right represent the percentage of respondents rating the barrier high (four or five on the five-point scale), indicating agreement. The bars to the left represent the percentage of respondents rating the barrier low (one or two), indicating disagreement.

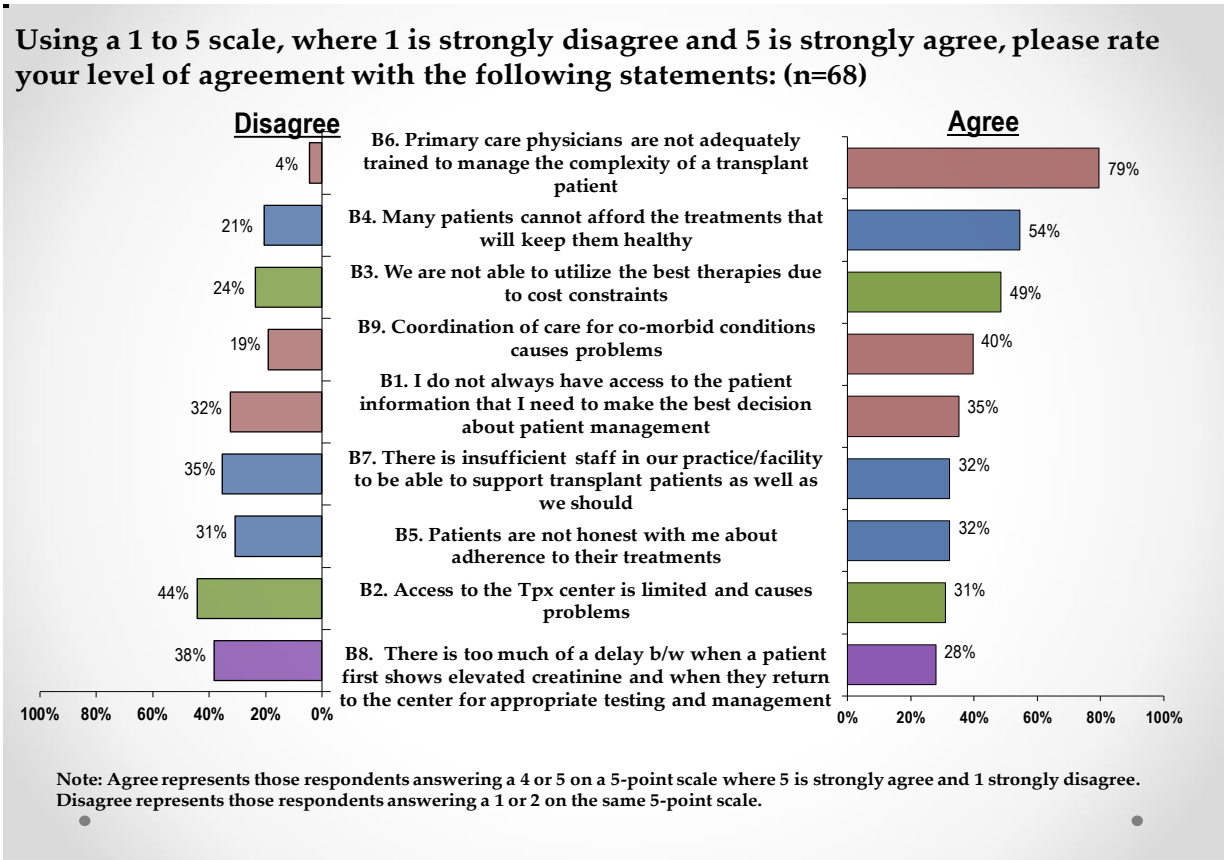


Figure 5: Community Nephrologist Barriers to Best Practice (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Barrier 6, *Primary care physicians are not adequately trained to manage the complexity of a transplant patient*, had both the highest percent of agreement and the lowest percent of disagreement. Clearly, this barrier stands out as a strong impediment to best practice in caring for these patients. The next two highest barriers, 4 and 3, both represent different aspects of cost constraints. Interviewees in all specialties mentioned that cost of medications often becomes a barrier when Medicare coverage expires at three years post-transplant. This contributes to lack of adherence and the clinical problems that result.

A high percentage of respondents also indicated strong agreement with Barrier 9, *Coordination of care for co-morbid conditions causes problems,* and Barrier 1, *I do not always have access to the patient information I need*. These two items are closely related in that patient information is a crucial link in the coordination of care. Closely correlated (r=.51) with Barrier 9 is Barrier 2, *Access to the transplant center is limited*. Although this barrier was rated high by a smaller percentage of community nephrologists, it is clear that access to the transplant center is a key factor in coordination of care for patients. This also emerged as a common theme during the interviews.

Knowledge Assessment

The Knowledge Assessment portion of the survey consisted of 14 questions designed to assess knowledge that is directly related to the clinical competencies defined above. Each question relates to a specific clinical competency.

Community nephrologist scores on the knowledge questions averaged 64 percent (Figure 6). This clearly indicates a knowledge deficit that could benefit from educational initiatives. It will be important to demonstrate this deficit to community nephrologist learners.

The entire text of questions and answers may be found in Appendix 2 (Page 80).

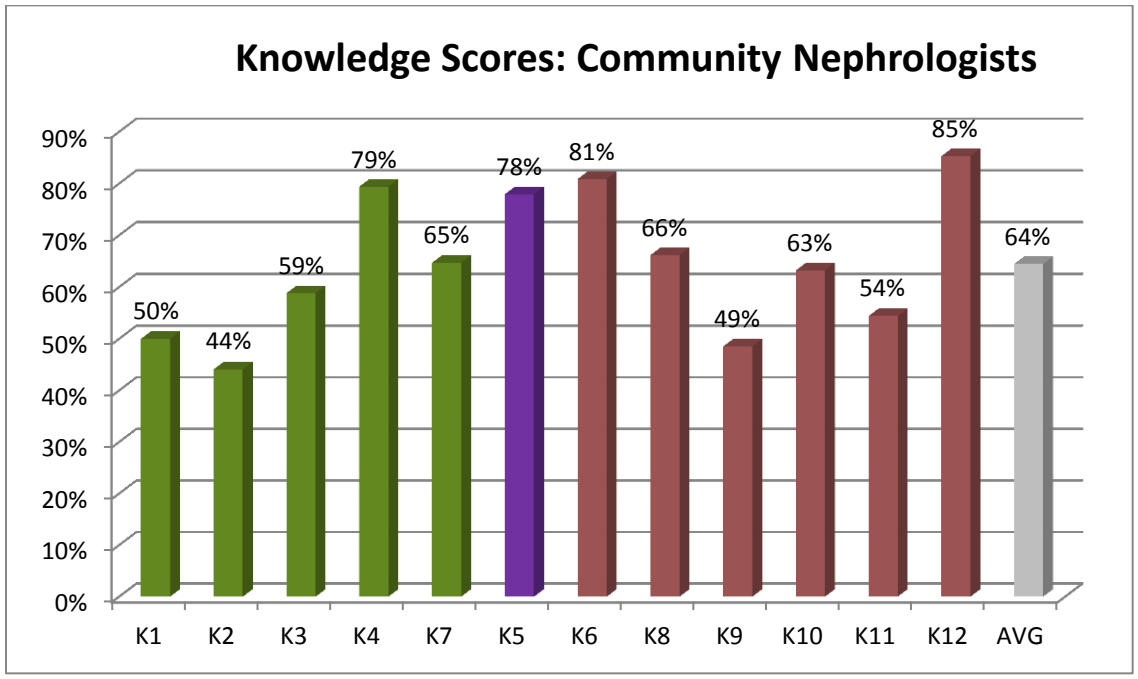


Figure 6: Community Nephrologist Knowledge Score (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

The community nephrologists scored less than 50 percent on questions K1, K2, and K9. These items correlate most closely with competencies related to immunosuppression management (competencies C1, C2, and C3), and acute rejection (competencies C4 and C5). The gaps between present and desired ability were also highest in these competencies, indicating that perceived needs closely align with actual needs of community nephrologists in these areas.

Practice Assessment Questions

The practice assessment questions were designed to assess actual clinical practices of the respondents. The results may be compared to best practices to establish real needs and their relationships to perceived needs and knowledge gaps. A selection of key practice question responses is shown below, with the remainder appearing in Appendix 4 (Page 100).

One item of the assessment addresses attitude: **A1. How comfortable are you monitoring immunosuppression?** On a one to five scale, (*1=very uncomfortable* and *5=very comfortable*), community nephrologists averaged 2.97. This represents nearly the midpoint of the scale, showing that on average community nephrologists are neither comfortable nor uncomfortable monitoring immunosuppression.

When asked about their role in managing immunosuppression, responses varied widely. Thirty-five percent said they play no role whatsoever, while 47 percent said that they monitor and adjust dosages as needed (Figure 7). These responses represent two very different groups of learners whose educational needs regarding immunosuppression will differ considerably.

P1. Mrs. Jones received a kidney transplant 3 months ago and has returned to your clinic to establish follow-up. What would your role be in managing her immunosuppression? (select all that apply)

I play no role in immunosuppression.
I monitor her immunosuppression and adjust dosages as needed to maintain the set targets.
I change immunosuppression medications as needed.
I let the patient decide between the community physician and the transplant center for managing immunosuppression.

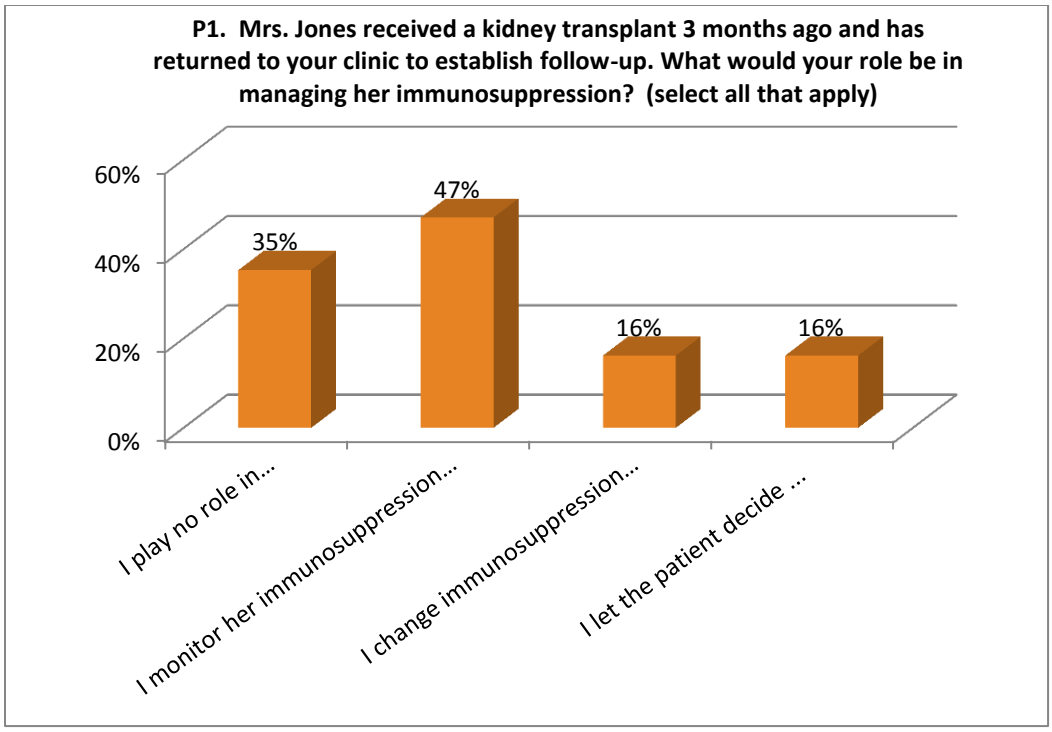


Figure 7: Community Nephrologist Role in Immunosuppression Management

When asked about their preference for managing the stable post-transplant patient (P4, Figure 8), the vast majority of respondents prefer to co-manage with the transplant center.

P4. In transplant patients with a stable post-transplant course, I prefer:

... to independently manage care after they are released by the transplant center
... to co-manage with the transplant center indefinitely
... the transplant center to manage until they develop progressive graft failure requiring return to dialysis

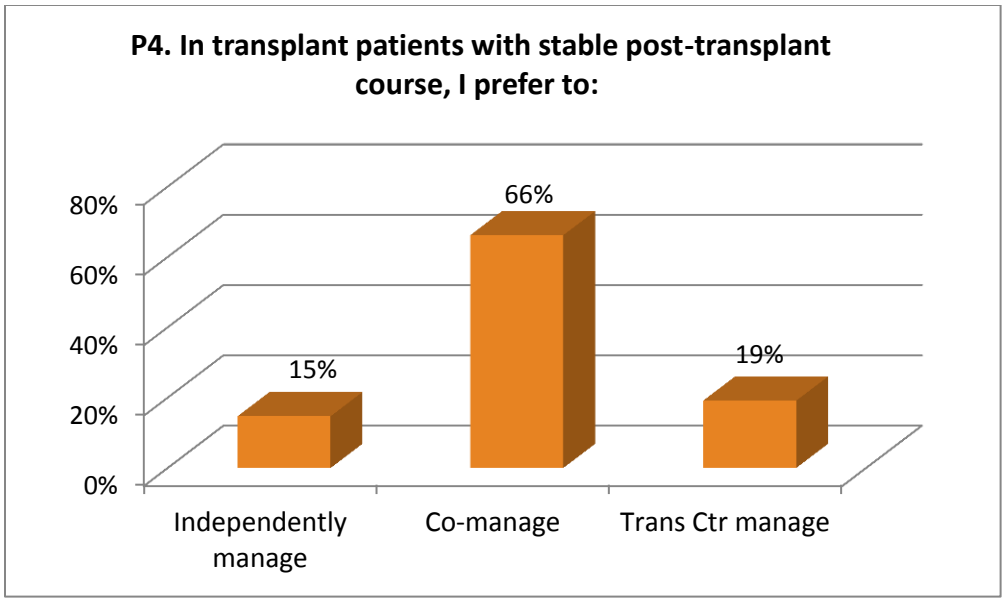


Figure 8: Community Nephrologist: Role in Post-Transplant Management

When asked to rate their responsibility in a variety of preventive care issues (P5, Figure 9), the responses of community nephrologists varied. They rated hypertension management highest, followed by lipid management; the lowest responsibility was that of dermatology issues, at 3.8 on the five-point scale.

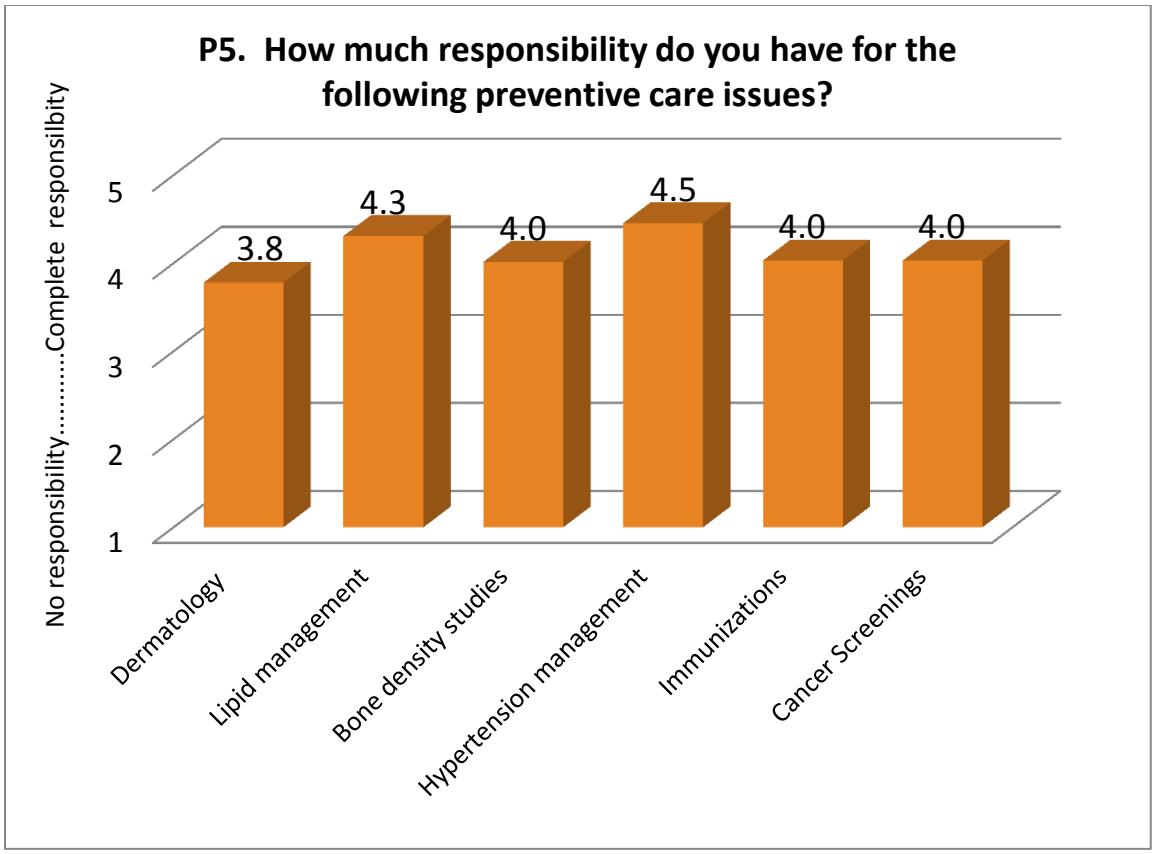


Figure 9: Community Nephrologist Preventive Care

Vaccinations are a fundamental part of the preventive care that is crucial to maintaining good health. They are particularly important with the transplant population due to immunosuppression. While most community nephrologists indicate that they administer influenza and pneumonia vaccines, fewer reported administering hepatitis B or Tdap (tetanus, diphtheria, and pertussis) vaccines (Figure 10).

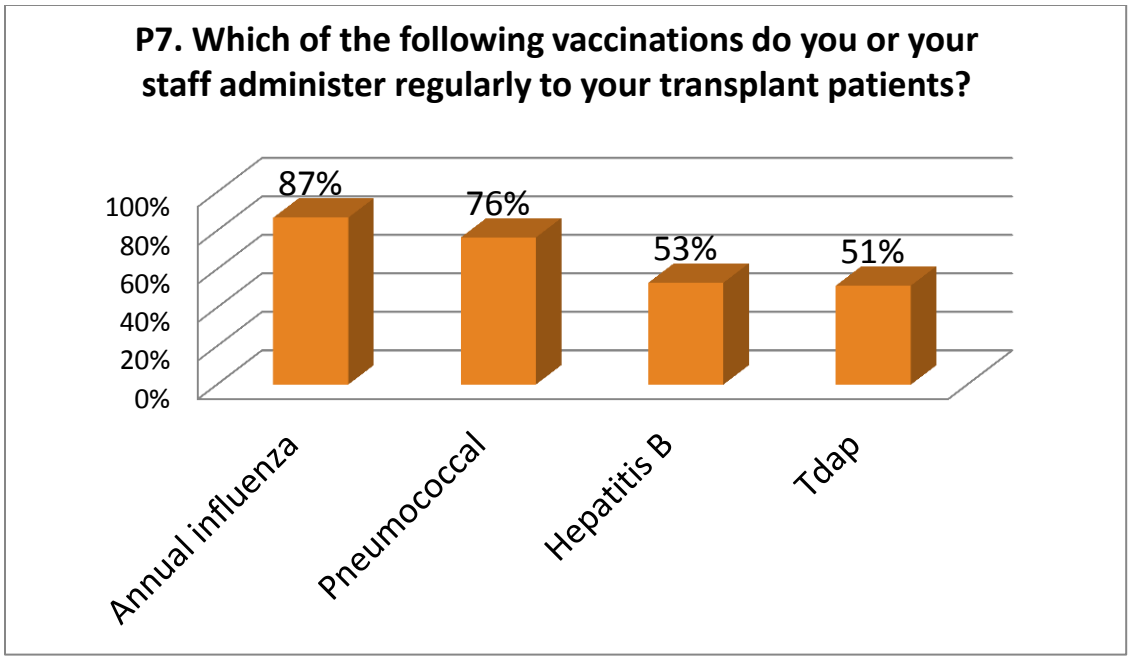


Figure 10: Community Nephrologist Regular Vaccinations

Because transplant recipients are at higher risk for bone disease, respondents were asked which monitoring methods they routinely use (P9). Although there were a variety of responses, most respondents use methods in accordance with existing guidelines (Figure 11).

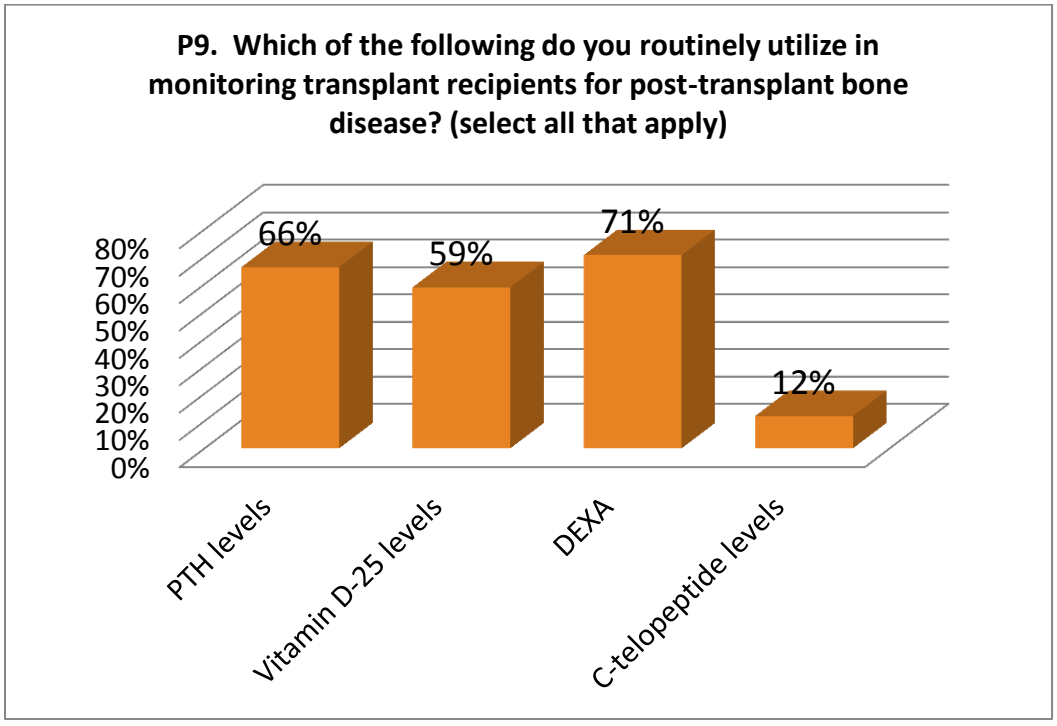


Figure 11: Community Nephrologist Bone Disease Monitoring

BK viremia is of particular concern in transplant patients and has been more prevalent in recent years. Although KDIGO recommendations call for monthly screenings for three to six months post-transplant and every three months afterward for the first year, only 21 percent of respondents follow this schedule (Figure 12). Forty-four percent follow a less rigorous schedule. Many of the 13 percent "other" responses were in compliance with or more rigorous than the recommended schedule.

P10. How often do you screen for BK viremia after kidney transplant?

1. Weekly for 4 weeks
2. Monthly for 3-6 months
3. Every 6 months indefinitely
4. Screen only if evidence of graft dysfunction present
5. Not applicable
6. Other (specify) _____

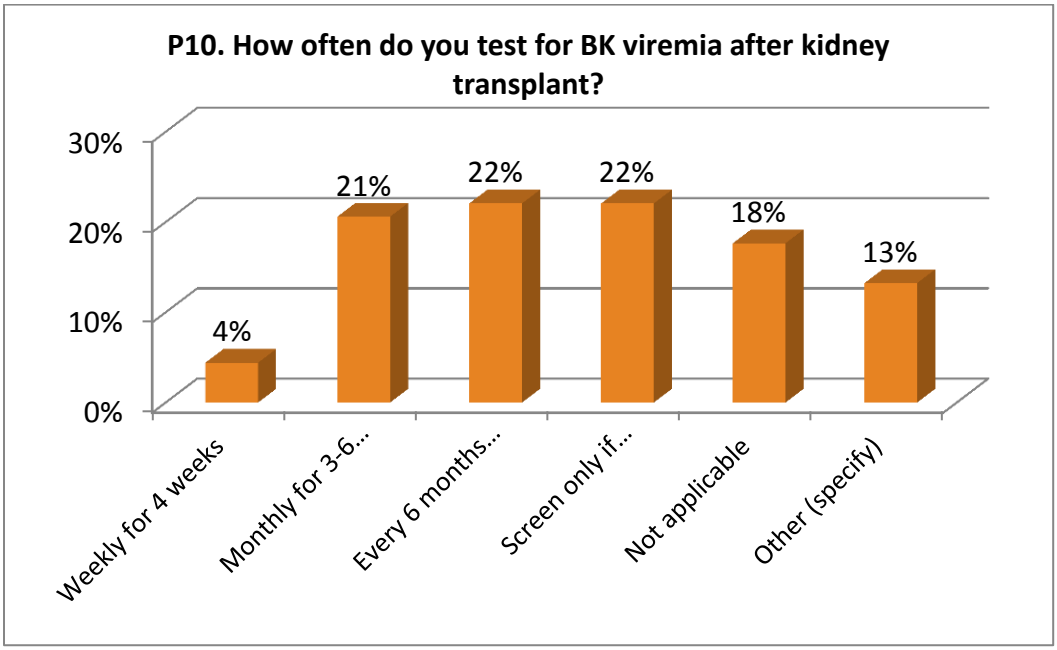


Figure 12: Community Nephrologist BK Viremia Testing

Educational Preferences

Survey respondents were asked a series of questions about their educational preferences. While it is important to consider their preferences in order to encourage participation in educational activities, educational preferences do not necessarily follow educational needs.

Community nephrologists were asked in which areas they believed the current body of knowledge and literature is inadequate to guide them in best practices (Figure 13). Only 15 percent feel that the current body of knowledge and literature is adequate. This is a perception that may represent a barrier to participation in continuing education and should be considered when planning and promoting continuing medical education and continuing professional development activities.

E4. In which of the following areas do you feel the current body of knowledge and literature is inadequate to guide you in the best care of the transplant patient. (check all that apply)

1. The current body of knowledge and literature is adequate to guide me in all of these areas.
2. Immunosuppression
3. Management of side effects
4. Co-morbid conditions
5. Drug interactions

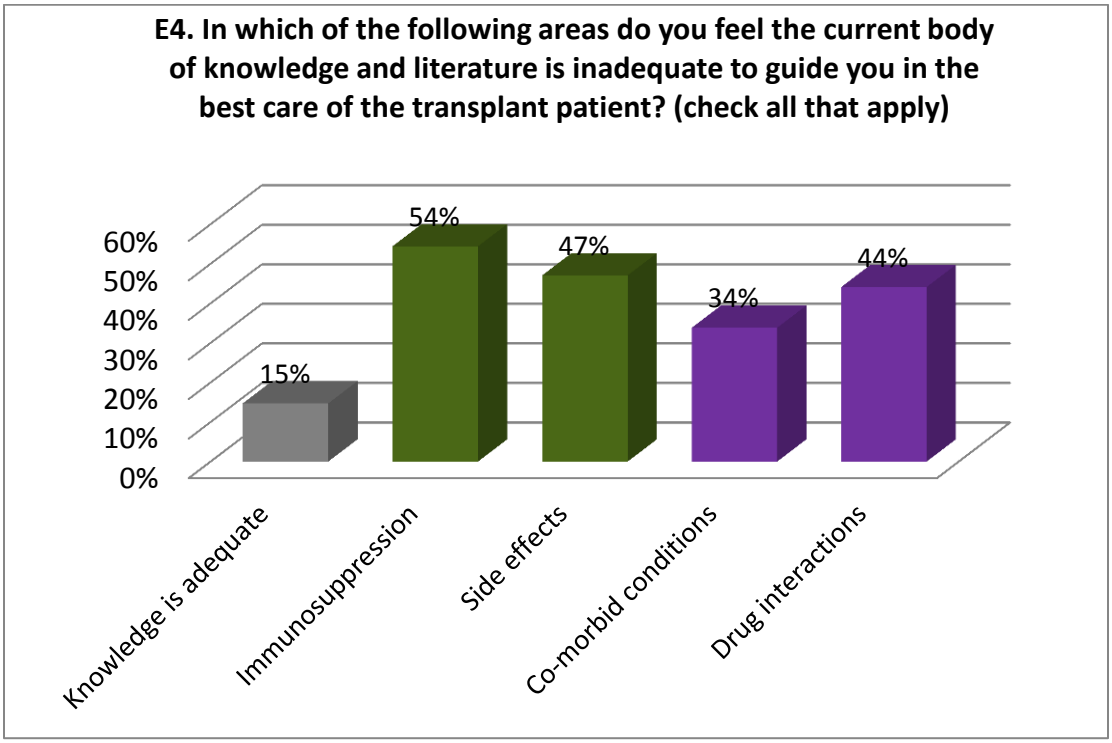


Figure 13: Community Nephrologist Knowledge and Literature (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Respondents were presented a list of topics related to management of kidney transplant patients and asked to indicate up to three areas of their most likely participation during their next continuing education activity (Figure 14).

E3. Please select up to three (3) topics you are most likely to select for your next CME activity.

1. Immunosuppression update
2. Drug-drug interactions in the kidney transplant patient with chronic disease such as hypertension and diabetes.
3. Managing adverse effects of immunosuppression
4. Appropriate monitoring of the kidney transplant patient
5. Titration of immunosuppression therapy
6. Managing chronic conditions such as hypertension and diabetes in the kidney transplant patient
7. Screenings and tools for preventive care in the transplant patient
8. Increasing adherence in the transplant patient
9. Other _____

The most frequently selected topics were:

- Immunosuppression update
- Appropriate monitoring of the kidney transplant patient
- Screenings and tools for preventive care in the transplant patient

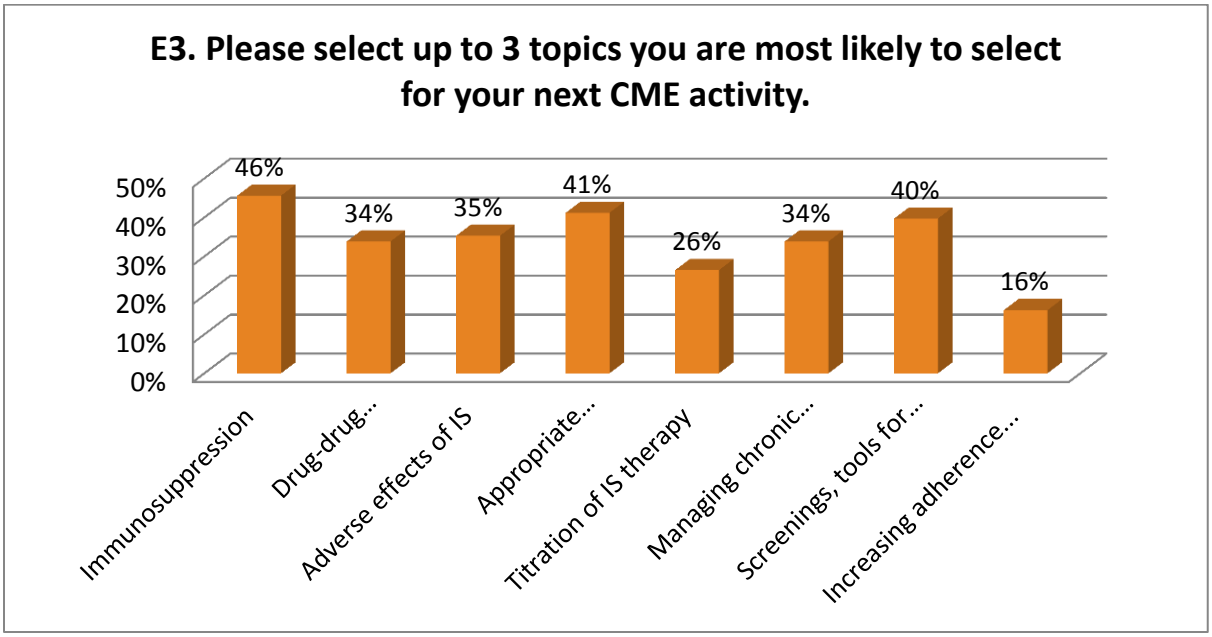


Figure 14: Community Nephrologist Topics for Next CME Activity

When asked to rate the importance of various attributes of educational activities, responses showed little difference between them (Figure 15).

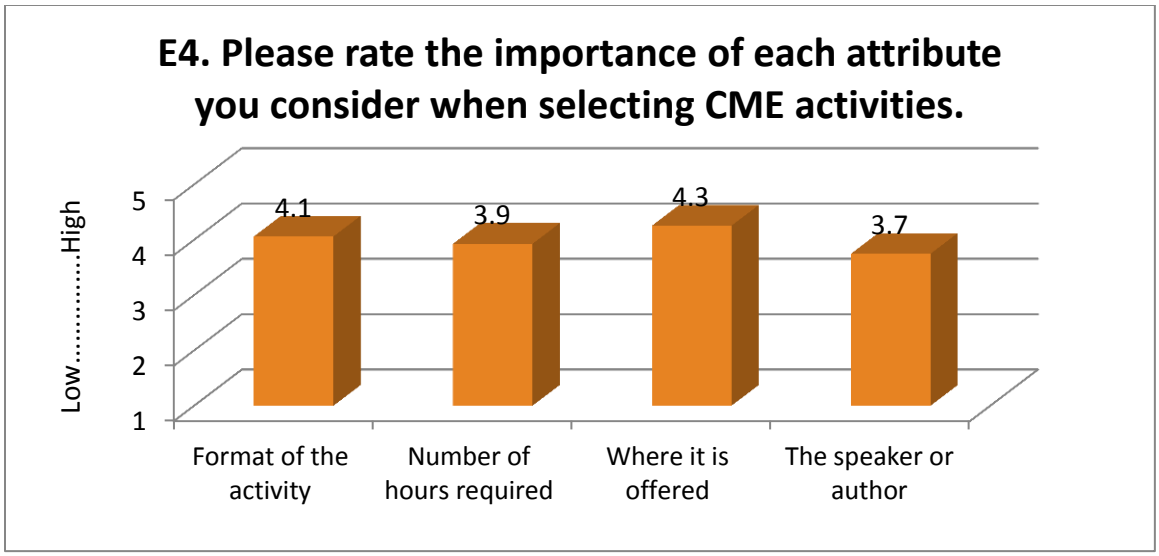


Figure 15: Community Nephrologist Attributes of CME Activities

The survey also queried learners about the format of their most recent educational activity (Figure 16). This provides a rough indication of the type of activity in which community nephrologists are most likely to participate. There was a broad distribution of responses; the highest single category is *web-based activities with no live component*, with 35 percent of the respondents indicating recent participation.

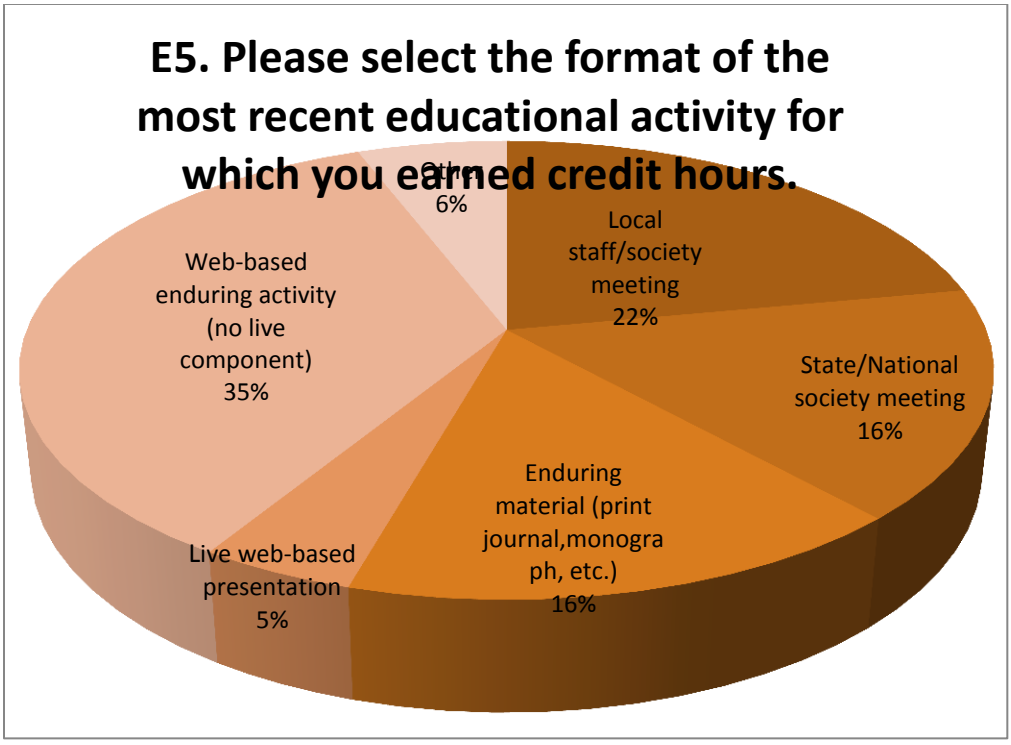


Figure 16: Community Nephrologist Format of Most Recent Educational Activity

Summary of Findings: Community Nephrologists

Table 4 summarizes the findings for community nephrologists in terms of each of the four assessment categories. Community nephrologists have high real and perceived needs in all areas. They also experience a number of barriers that prevent them from applying best practices to their care of transplant patients.

Topic	Perceived Need	Knowledge Gap	Practice Gaps	Barriers
Immunosuppression	All related competencies	Yes	Yes	PCP not adequately trained Cost of medications Adherence to regimen
Rejection	All related competencies	Yes	Yes	PCP not adequately trained Cost of medications Adherence to regimen
Chronic Care	All related competencies	Yes	No	Adherence to regimen Coordination of care Management of co-morbidities
Adherence	All related competencies	Yes	Yes	Cost of medications Adherence to regimen

Table 4: Community Nephrologist Summary Table (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Quantitative Findings: Transplant Specialists

Change Readiness Inventory® - Perceived Needs and Barriers

The competencies are a series of statements that represent the abilities needed to successfully manage kidney transplant patients. These competencies were developed from clinical guidelines, current literature, and expert opinion. Physicians were asked to consider the following statements, then indicate both their *present* and *desired* levels of ability (from *1=low* to *5=high*) in performing each task.

Please rate your *present* and *desired* ability to:

C1. Select an effective immunosuppressive drug regimen that attains adequate protection of the kidney allograft against rejection.
C2. Minimize short- and long-term adverse side effects of immunosuppressive medications.
C3. Identify potential interactions between immunosuppressive agents and other medications.
C4. Identify risk factors for acute rejection.
C5. Detect signs and symptoms of acute graft rejection by monitoring creatinine levels.
C6. Attain an allograft biopsy to determine if rejection is occurring.
C7. Coordinate with other specialists or primary care physicians to manage comorbid conditions (diabetes, hypertension, cardiovascular disease).
C8. Use screenings to detect cancer in the transplant patient.
C9. Monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH).
C10. Mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic treatment.
C11. Appropriately vaccinate 6 months post-transplant using inactive vaccines.
C12. Identify risk-factors for non-adherence to medication regimens.
C13. Effectively communicate risks of non-adherence to patients and family.

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

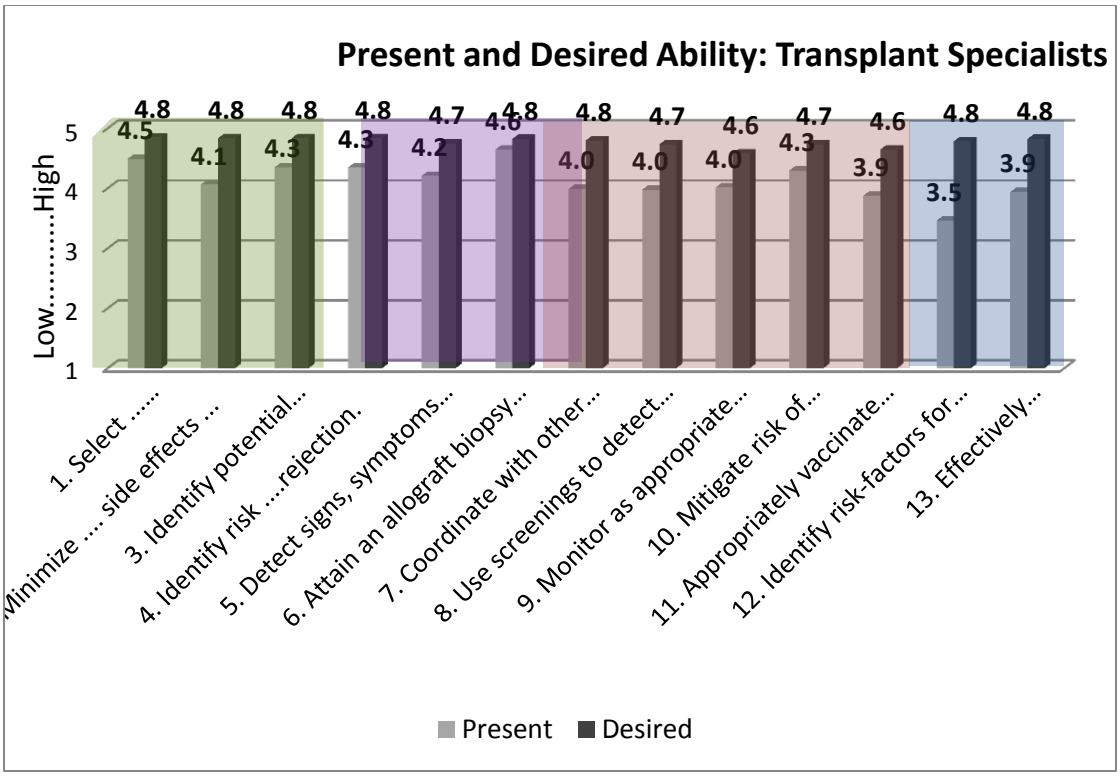


Figure 17: Transplant Specialist Present and Desired Competencies (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Figure 17 shows transplant nephrologists' average rating of their own present and desired abilities. The average *desired ability* ratings range from 4.6–4.8, averaging 4.8 on a one to five scale. This is similar to what is often seen for the average of desired clinical competencies, with little variability. This reflects a high and consistent desire to excel in every area of managing the transplant patient. The average *present ability* was 4.1 on the five-point scale, with a range of 3.5 to 4.6. There is greater variation in the present abilities as compared to the desired abilities, as is common with self-rated competencies.

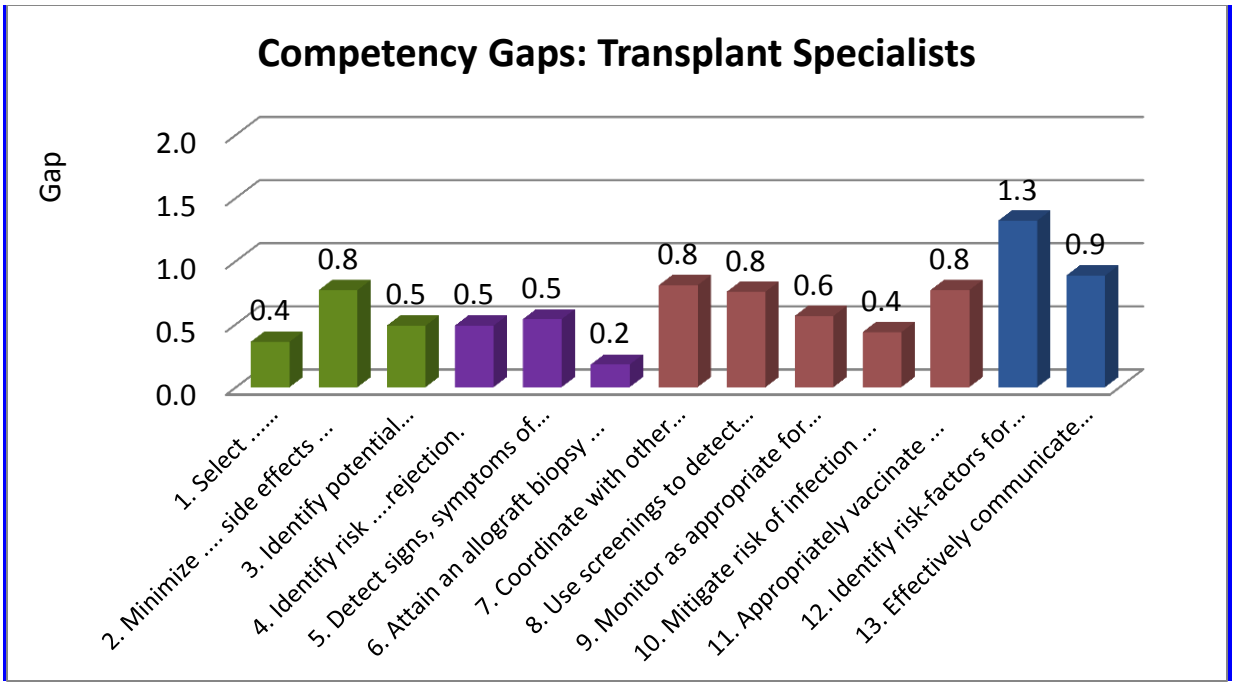


Figure 18: Transplant Specialist Competency Gaps (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

The *perceived need* of each competency is the difference, or gap, between physicians' ratings for *present* and *desired* levels of ability. In other words, this number represents the difference between "what is" and "what ought to be." A gap of 0.5 is presumed to be important, with gaps of 1.0–2.0 considered ideal for clinician education. A gap smaller than 0.5 indicates low motivation to learn and change, while a gap higher than 2.0 may represent a level of change that the physician believes to be unattainable or impractical.

The average gap, or perceived need, of this competency set is 0.6 (Figure 18). The individual gaps for each competency ranged from 0.2 to 1.3. Ten of 13 gaps are over the 0.5 level and should be carefully considered for educational interventions. Only one gap is in the ideal range between 1.0 and 2.0 *(C12. Identify risk-factors for non-adherence to medication regimens*). The second highest gap also relates to adherence (*C13. Effectively communicate risks of non-adherence to patients and families*). Physicians realize that change is needed in adherence-related competencies and are highly motivated to make practice changes in this area.

Barriers to Best Practice

Barriers are real or perceived issues that may prevent physicians from applying best practices. Knowledge of the nature and magnitude of these barriers helps educational designers address them within the scope of the interventions, and in doing so, encourage change in physician performance as

well as change in knowledge and skill. These barriers were derived from expert opinion, data from the in-depth interviews, and literature on physician change.

The next set of statements represents barriers to best practice when managing transplant patients. Please rate each statement according your level of agreement as to whether the item represents a barrier to effective management of transplant patients. (*1=Strongly Disagree*, *5=Strongly Agree*)

B1. I do not always have access to the patient health information that I need to make the best decisions about patient management.
B2. Access to the transplant center is limited.
B3. I am not able to utilize the best therapies due to cost constraints.
B4. Many patients cannot afford the treatments that will keep them healthy.
B5. Patients are not honest with me about adherence to their treatments.
B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient.
B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as we should.
B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management.
B9. Coordination of care for co-morbid conditions causes problems.

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

Figure 19 shows the list of statements arranged in order of respondents' highest perceived barriers. The bars to the right represent the percentage of respondents rating the barrier high (four or five on the five-point scale), indicating agreement. The bars to the left represent the percentage of respondents rating the barrier low (one or two), indicating disagreement.

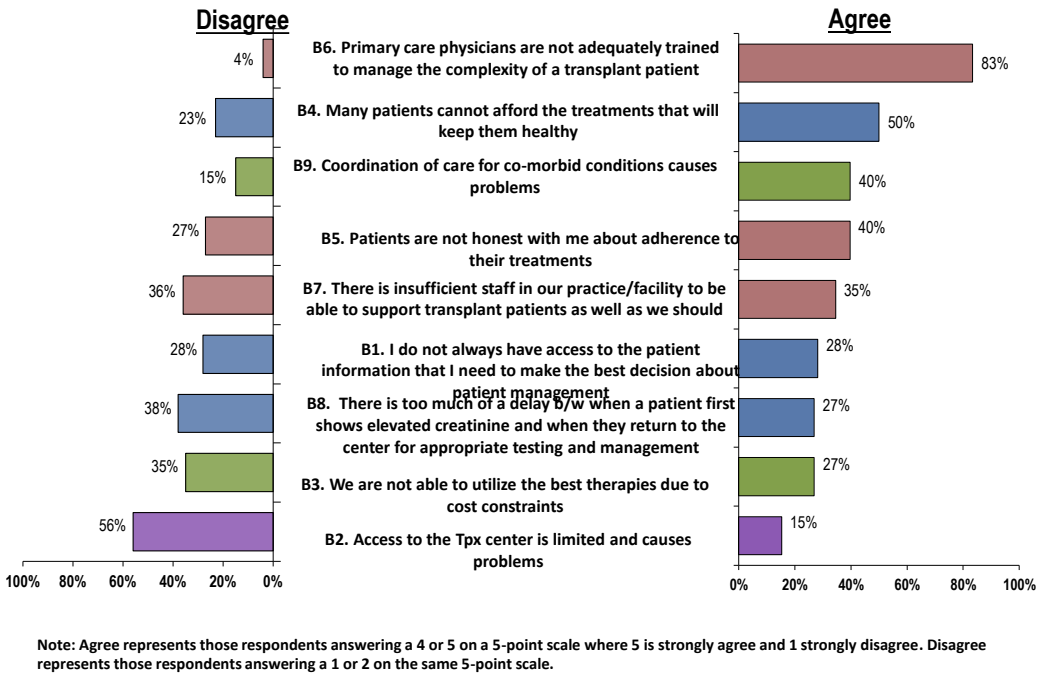


Figure 19: Transplant Specialist Barriers to Best Practice (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Barrier B6, *Primary care physicians are not adequately trained to manage the complexity of a transplant patient*, had both the highest percent of agreement and the lowest percent of disagreement. As with the community nephrologists, this barrier stands out as a strong impediment to best practices in caring for kidney transplant patients. The next highest barrier, B4, represents a cost constraint: *Patients cannot afford the treatments that will keep them healthy.* This was also a high barrier with community nephrologists; however, with transplant specialists there was also a large group (23 percent) that indicated disagreement with this statement. This may reflect centers with more support personnel (transplant coordinators, social workers) who are often able to find sources of free or low-cost medications for patients.

A high percentage of respondents also strongly agreed with Barrier 9, *Coordination of care for co-morbid conditions causes problems* and Barrier 5, *Patients are not honest with me about adherence to their treatments.* These barriers emerged as common themes during the interviews.

Knowledge Assessment Questions

The Knowledge Assessment portion of the survey consisted of 14 questions designed to assess knowledge that is directly related to the clinical competencies. Each question relates to a specific clinical competency.

In contrast to community nephrologists, transplant specialists are highly knowledgeable in immunosuppression. The only questions that posed any difficulty were those related to chronic disease (Figure 20).

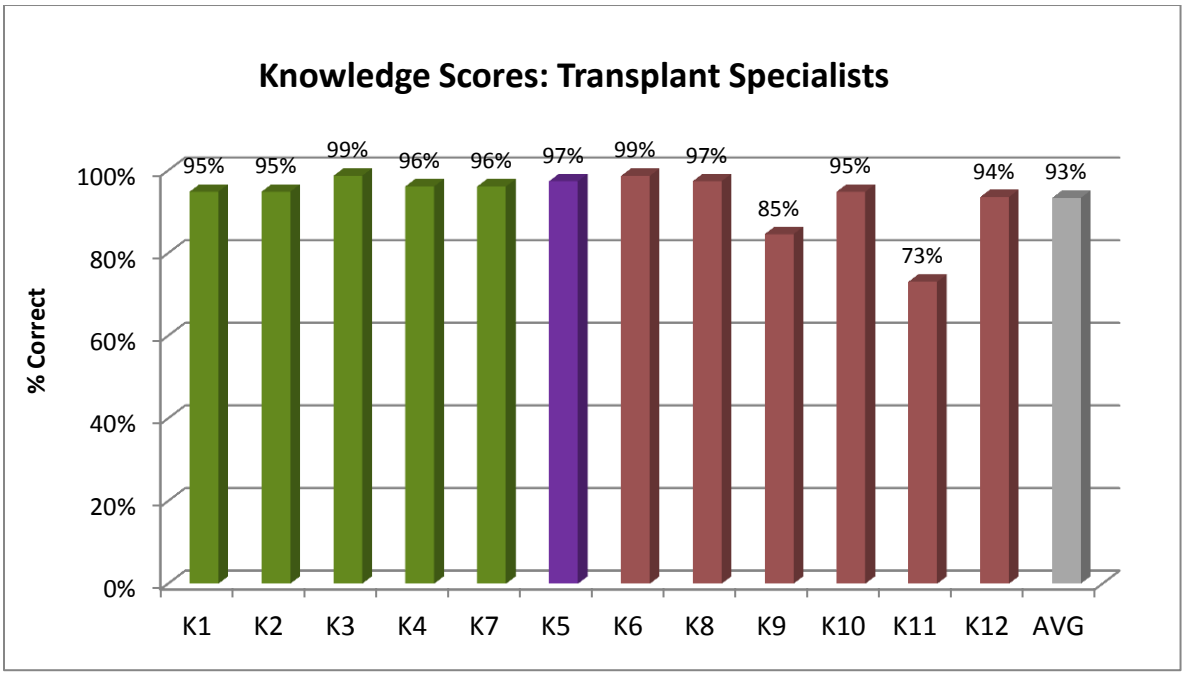


Figure 20: Transplant Specialist Knowledge Scores (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Practice Assessment Questions

The practice assessment questions were designed to assess actual clinical practices of the respondents. The results may be compared to best practices to establish real needs and their relationships to perceived needs and knowledge gaps. Responses to select practice questions are shown below, with the remainder appearing in Appendix 4 (Page 100).

Transplant specialists were asked to indicate the percentage of their patients that see a community nephrologist outside of their institution. Only a quarter of respondents estimated that more than 50 percent of their patients see a community nephrologist (Figure 21). This is important because interviewees indicated that, while they encourage patients to have a community nephrologist, many do

not. Chronic care issues that would be managed or coordinated by a community nephrologist must then be managed by the transplant center.

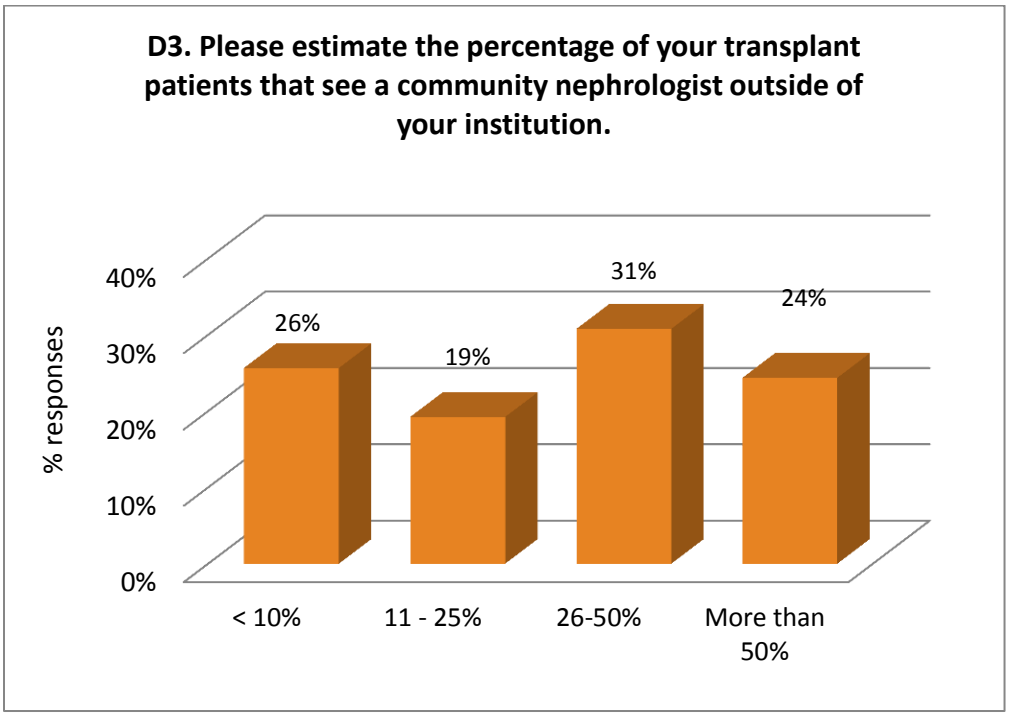


Figure 21: Transplant Specialist Estimates of Patients with a Community Nephrologist

When asked to rate their responsibility in a variety of preventive care issues (P5, Figure 22), transplant specialists varied in their responses. They rated responsibility for hypertension management highest (4.5 on a scale from one to five), followed by lipid management (4.0). This is the same distribution of responses as the community nephrologists, but considerably lower perceived responsibility overall for preventive care issues. They expressed the lowest level of responsibility for cancer screening, which rated at 3.4 on the five-point scale.

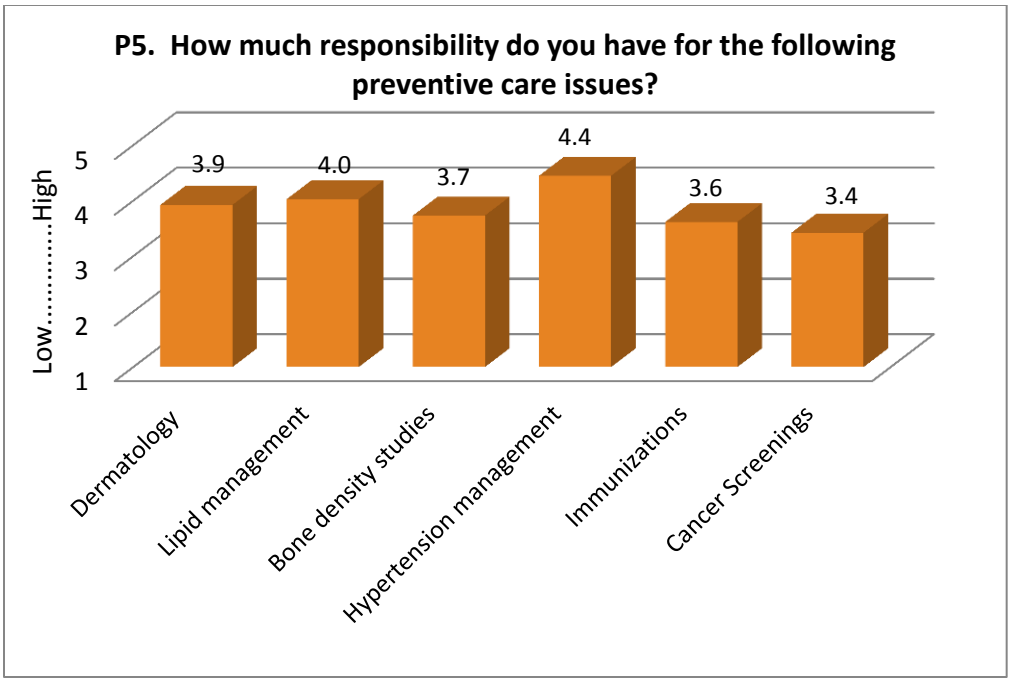


Figure 22: Transplant Specialist Responsibility for Primary Care

Vaccinations are a fundamental part of the preventive care that is crucial to maintaining good health. They are particularly important with the transplant population due to immunosuppression. While most transplant specialists indicate that they administer influenza vaccines, far fewer indicated that they administer pneumonia, hepatitis B or Tdap vaccines (Figure 23). These are much lower percentages than those expressed by community nephrologists.

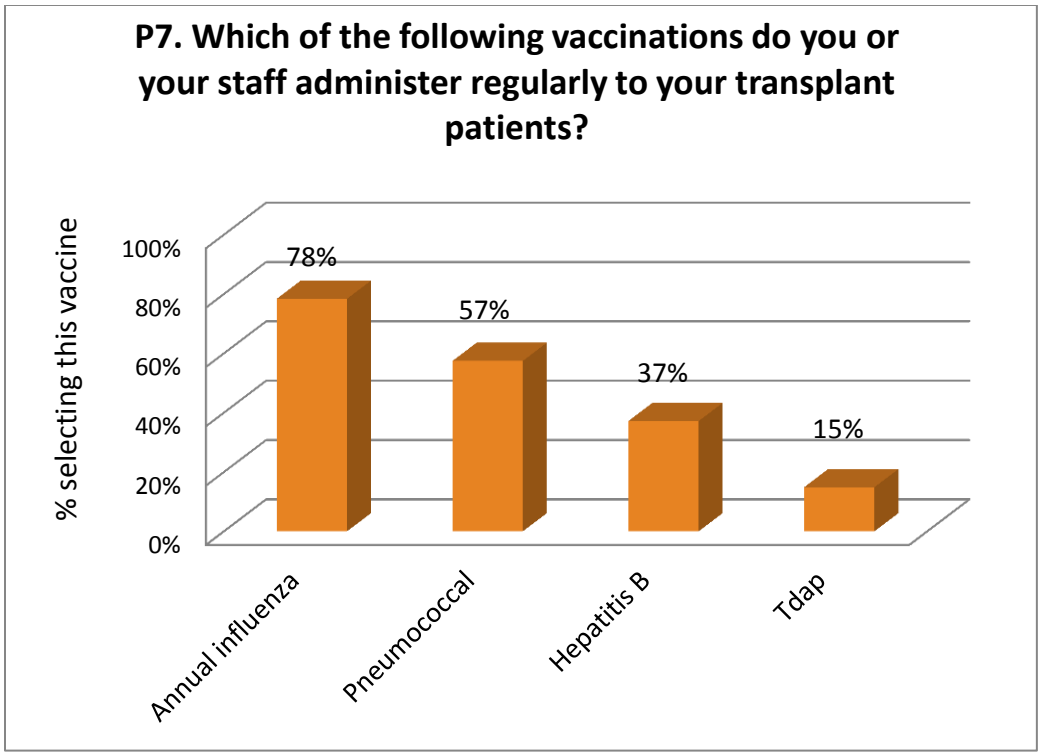


Figure 23: Transplant Specialist Responsibility for Vaccinations

Because transplant recipients are at higher risk for bone disease, respondents were asked which monitoring methods they routinely use. Although there were a variety of responses, most respondents use methods in accordance with existing guidelines (Figure 24). Responses were similar to those of the community nephrologists, although transplant specialists selected more options overall.

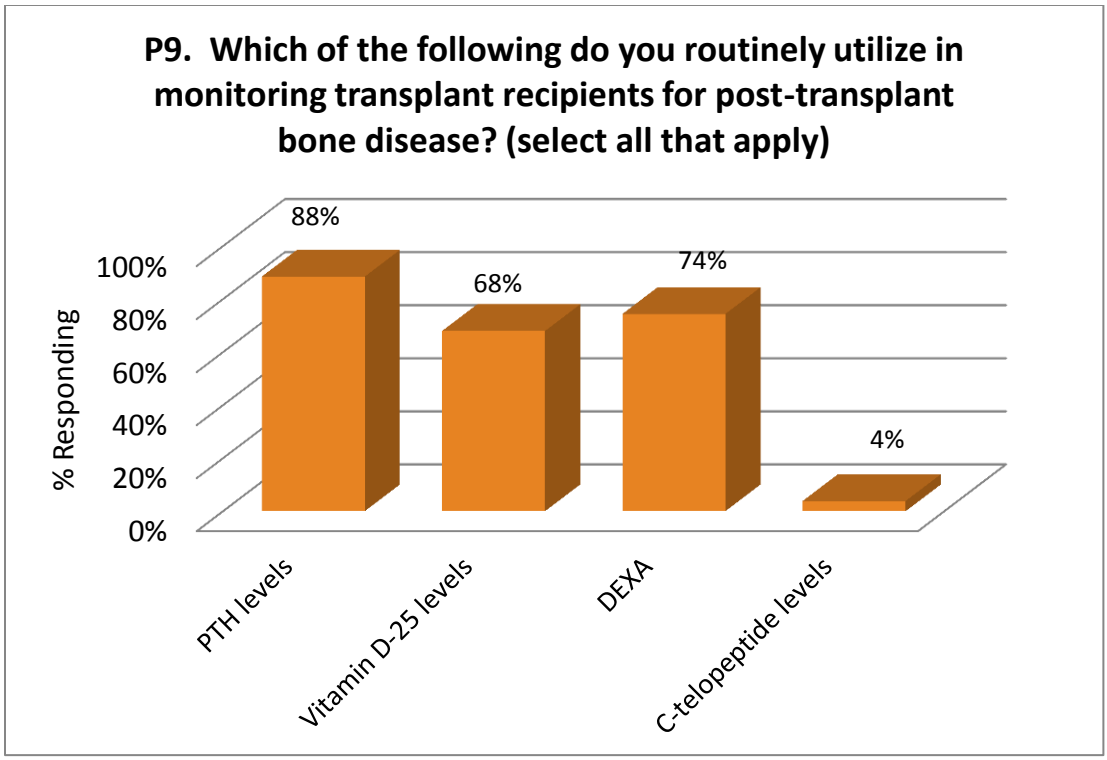


Figure 24: Transplant Specialist Bone Disease Monitoring Methods

BK viremia is of particular concern in transplant patients and has been more prevalent in recent years. Although KDIGO recommendations call for monthly screenings for three to six months post-transplant and every three months afterward for the first year, only 32 percent of respondents follow this schedule (Figure 25). However, as with community nephrologists, many of the "other" responses were in compliance with or more rigorous than the recommended schedule. However, 12 percent indicated that they screen *only if there is evidence of graft dysfunction*.

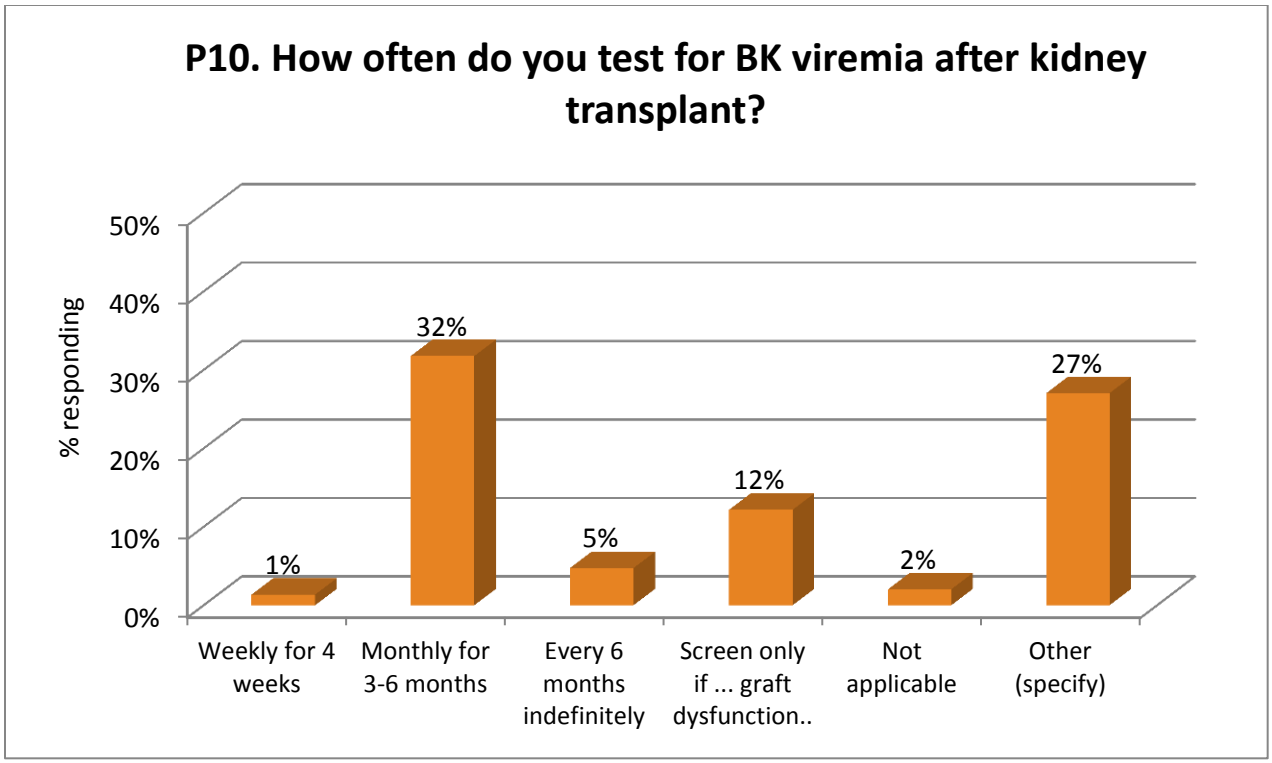


Figure 25: Transplant Specialist Monitoring for BK Viremia

Educational Preferences

Survey respondents were asked a series of questions about their educational preferences. While it is important to consider their preferences to encourage participation in educational activities, educational preferences do not necessarily follow educational needs.

Transplant specialists were asked in which areas they believed the current body of knowledge and literature is inadequate to guide them in best practices (Figure 26). Twenty-six percent feel that the current body of knowledge and literature is adequate. This is higher than community nephrologists (15 percent), but still may represent a barrier to participation in CME and should be considered when planning and promoting CME activities. Fifty-three percent selected *co-morbid conditions*; these specialists may appreciate exposure to the most recent evidence-based data on co-morbidities in transplant patients.

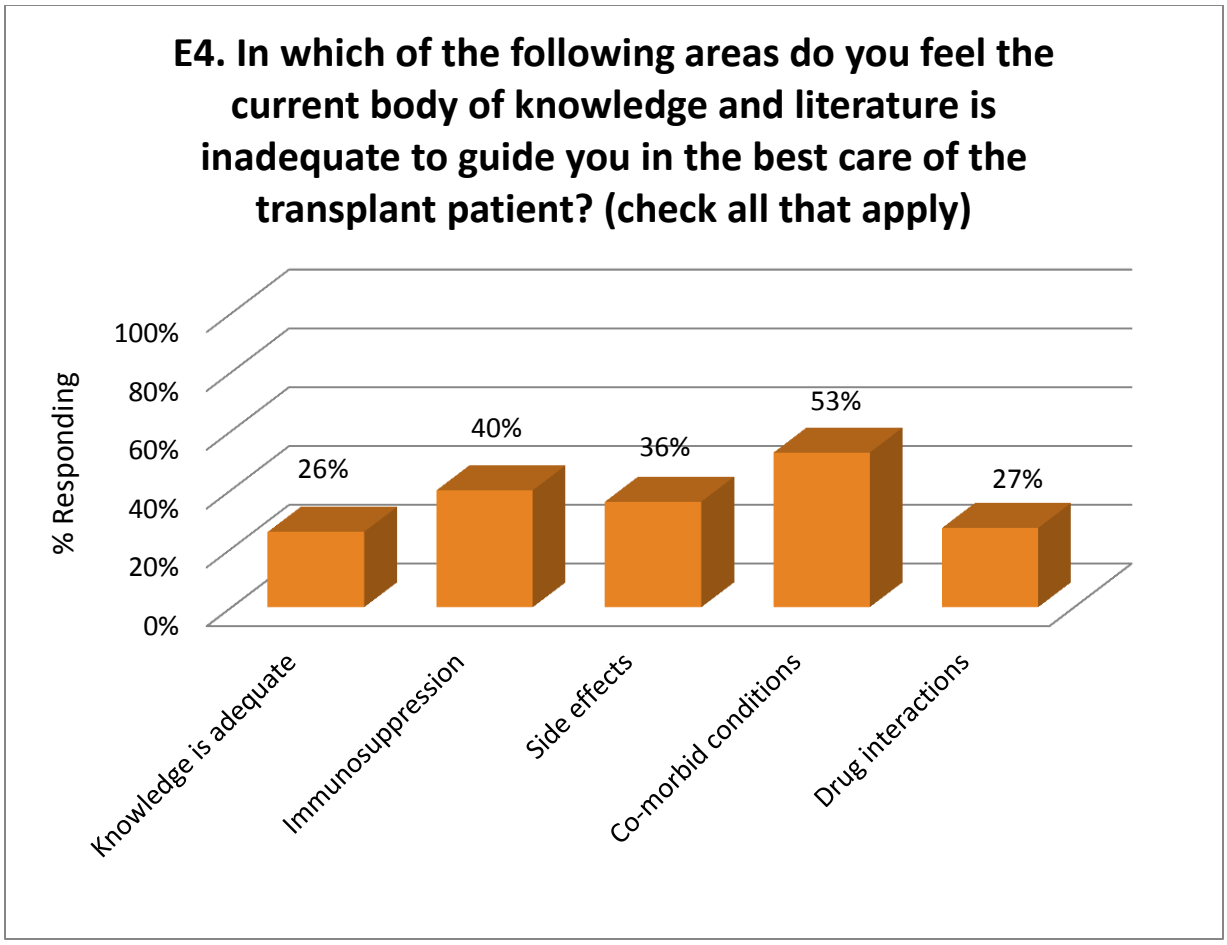


Figure 26: Transplant Specialist Knowledge and Literature

Respondents were presented a list of topics related to management of kidney transplant patients and asked to indicate up to three activities that they were most likely participate in (Figure 27). The choices available to participants were:

1. Immunosuppression update
2. Drug-drug interactions in the kidney transplant patient with chronic disease such as hypertension and diabetes.
3. Managing adverse effects of immunosuppression
4. Appropriate monitoring of the kidney transplant patient
5. Titration of immunosuppression therapy
6. Managing chronic conditions such as hypertension and diabetes in the kidney transplant patient
7. Screenings and tools for preventive care in the transplant patient
8. Increasing adherence in the transplant patient
9. Other _____

The most frequently selected topics were:

- Immunosuppression update
- Titration of immunosuppression therapy

- Appropriate monitoring of the kidney transplant patient

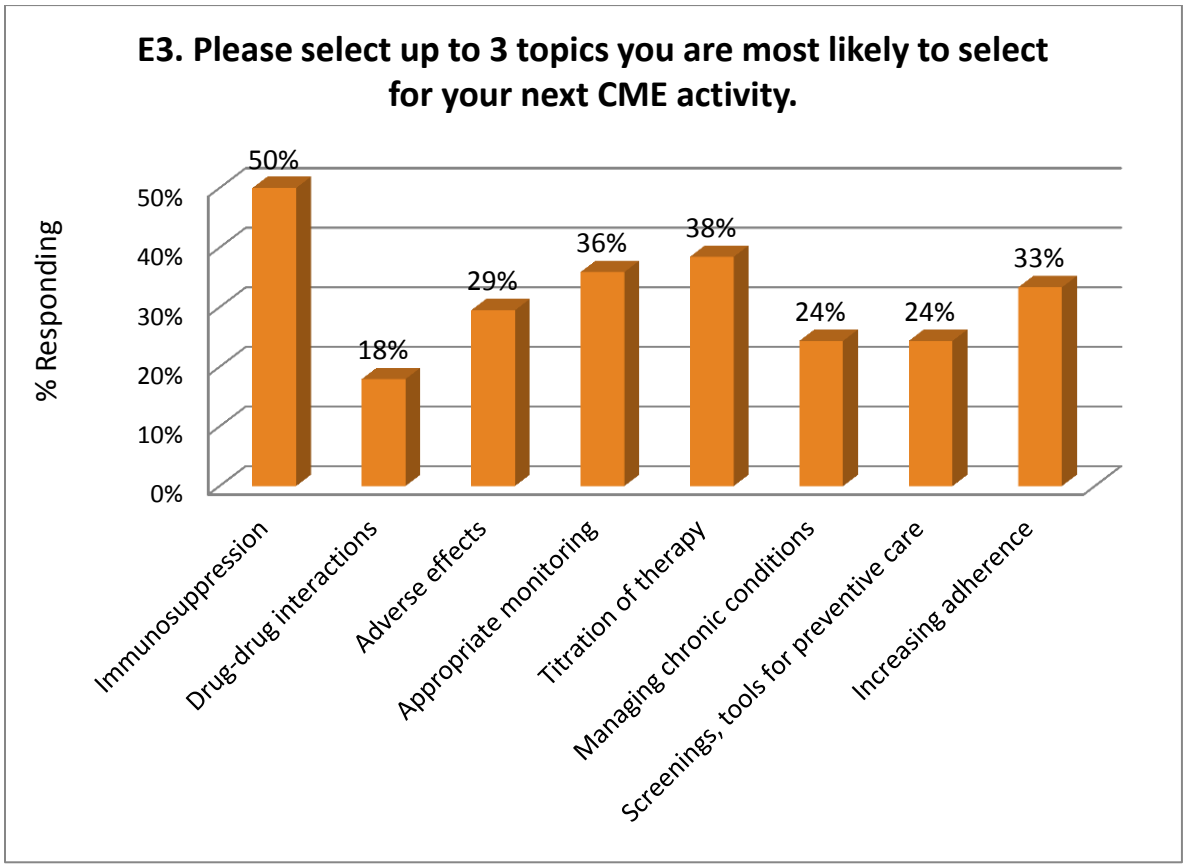


Figure 27: Transplant Specialist Topics for Next CME Activity

When asked to rate the importance of various attributes of educational activities, responses showed little difference between them (Figure 28).

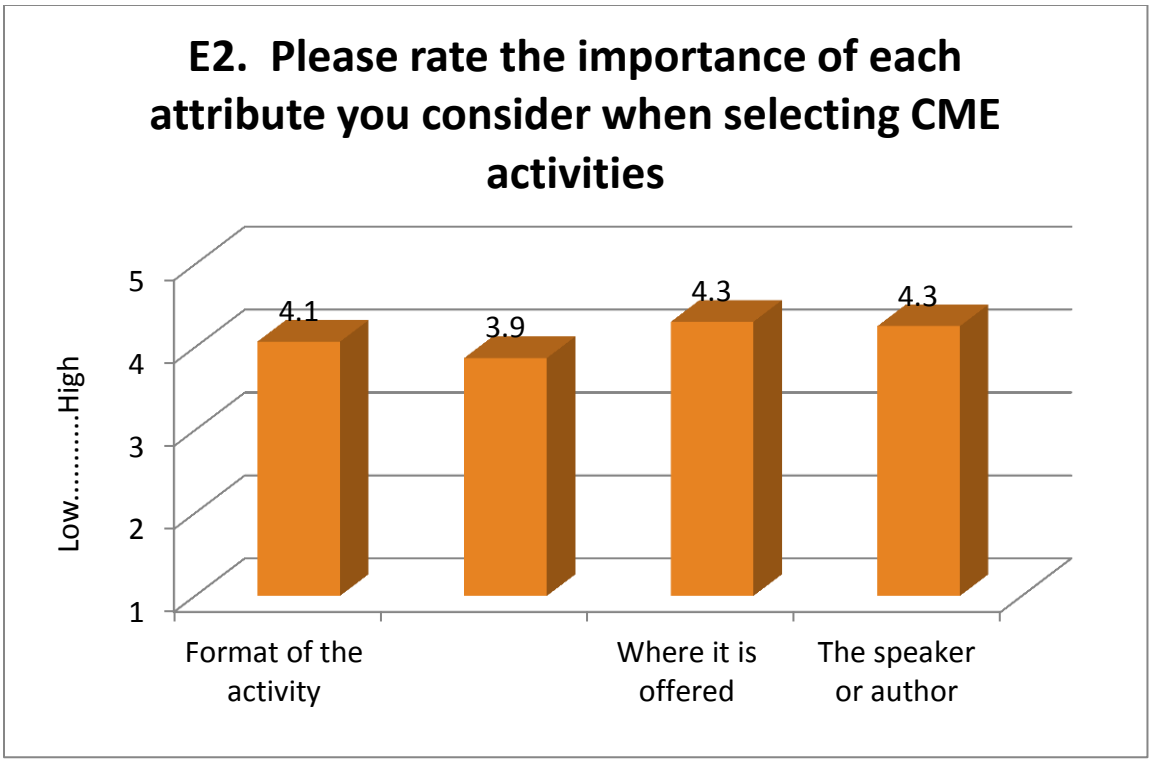


Figure 28: Transplant Specialist Attributes of CME Activity

The survey also queried learners about the format of their most recent educational activity (Figure 29). This provides a rough indication of the type of activity in which transplant specialists are most likely to participate. Transplant specialists overwhelmingly indicated state and national society meetings, with 54 percent of responses. All other categories of educational activity were selected much less frequently.

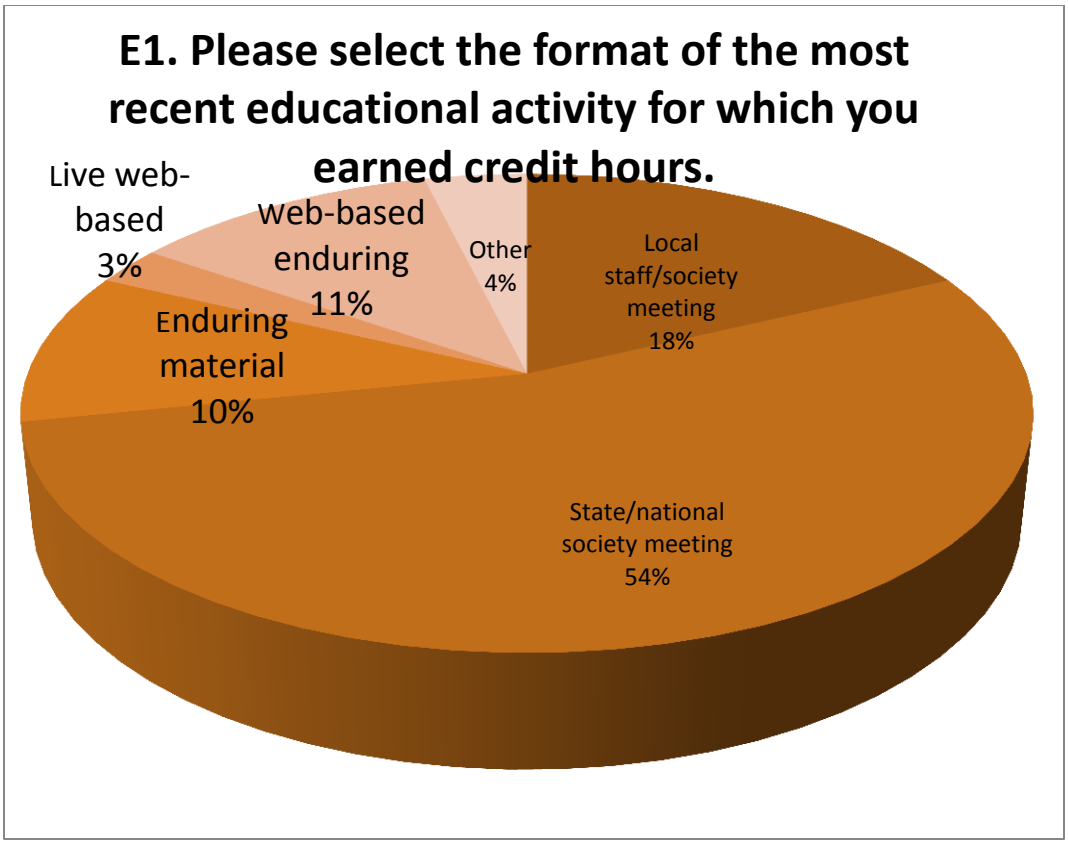


Figure 29: Transplant Specialist Most Recent Educational Activity

Summary of Findings: Transplant Specialists

Topic	Perceived Need	Knowledge Gap	Practice Gaps	Barriers
Immunosuppression	Minimize side effects Detect...acute rejection	No	No	Multiple protocols Cost of medications Adherence to regimen
Rejection	Detect...acute rejection	No	No	Cost of medications Adherence to regimen
Chronic Care	Coordinate with other specialists. Use screenings... Monitor for osteoporosis.. Appropriately vaccinate...	Yes	Yes	Adherence to regimen Coordination of care Management of co-morbidities
Adherence	Identify risk-factors for non-adherence Effectively communicate risks of non-adherence	No	Yes	Cost of medications Adherence to regimen

Table 5: Transplant Specialists Summary of Findings (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Quantitative Findings: Transplant Surgeons

The transplant surgeons who participated in the quantitative section of the needs assessment received a slightly different version of the survey than the community nephrologists and transplant specialists. However, many of the questions were identical. The full survey instrument can be viewed in Appendix 30 (page 90).

Importance of Clinical Competencies

C1. Select an effective immunosuppressive drug regimen that attains adequate protection of the kidney allograft against rejection.
C2. Minimize short- and long-term adverse side effects of immunosuppressive medications.
C3. Identify potential interactions between immunosuppressive agents and other medications.
C4. Identify risk factors for acute rejection.
C5. Detect signs and symptoms of acute graft rejection by monitoring creatinine levels.
C6. Attain an allograft biopsy to determine if rejection is occurring.
C7. Coordinate with other specialists or primary care physicians to manage co-morbid conditions (diabetes, hypertension, cardiovascular disease).
C8. Use screenings to detect cancer in the transplant patient.
C9. Monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH).
C10. Mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic treatment.
C11. Appropriately vaccinate 6 months post-transplant using inactive vaccines.
C12. Identify risk-factors for non-adherence to medication regimens.
C13. Effectively communicate risks of non-adherence to patients and family

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

Unlike the other two learner groups, transplant surgeons were not asked to list their present and desired levels of competency for each item; instead, they were asked to rate the importance of each area. Data were collected from urologist learners at a live session during the AUA 2011 annual meeting; participants indicated the importance of each competency using an audience response system (ARS).

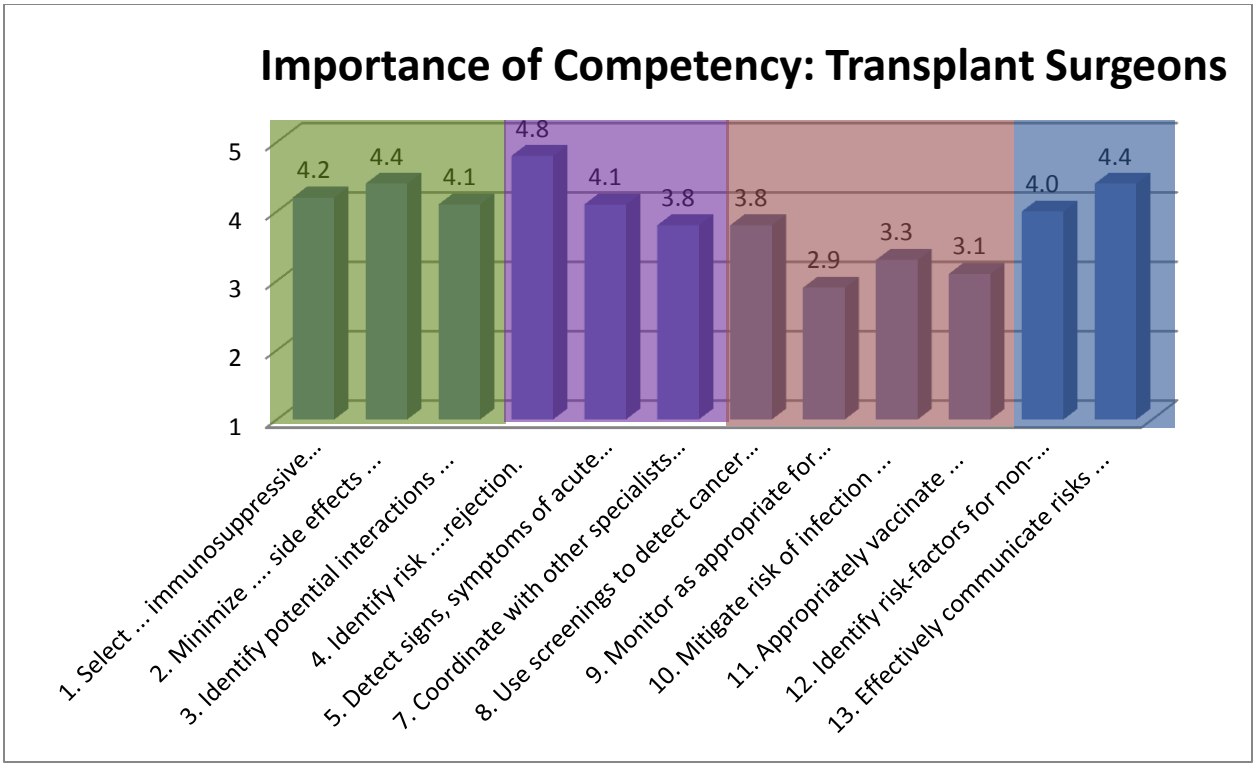


Figure 30: Transplant Surgeon Present and Desired Competencies (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Urologists place varying degrees of importance each competency. Several items rated lower than an average of 4.0 on a five-point scale (Figure 30):

C9. Monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH).

C8. Use screenings to detect cancer in the transplant patient.

C11. Appropriately vaccinate 6 months post-transplant using inactive vaccines.

C7. Coordinate with other specialists or primary care physicians to manage co-morbid conditions (diabetes, hypertension, cardiovascular disease).

C10. Mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic treatment.

Barriers to Best Practice

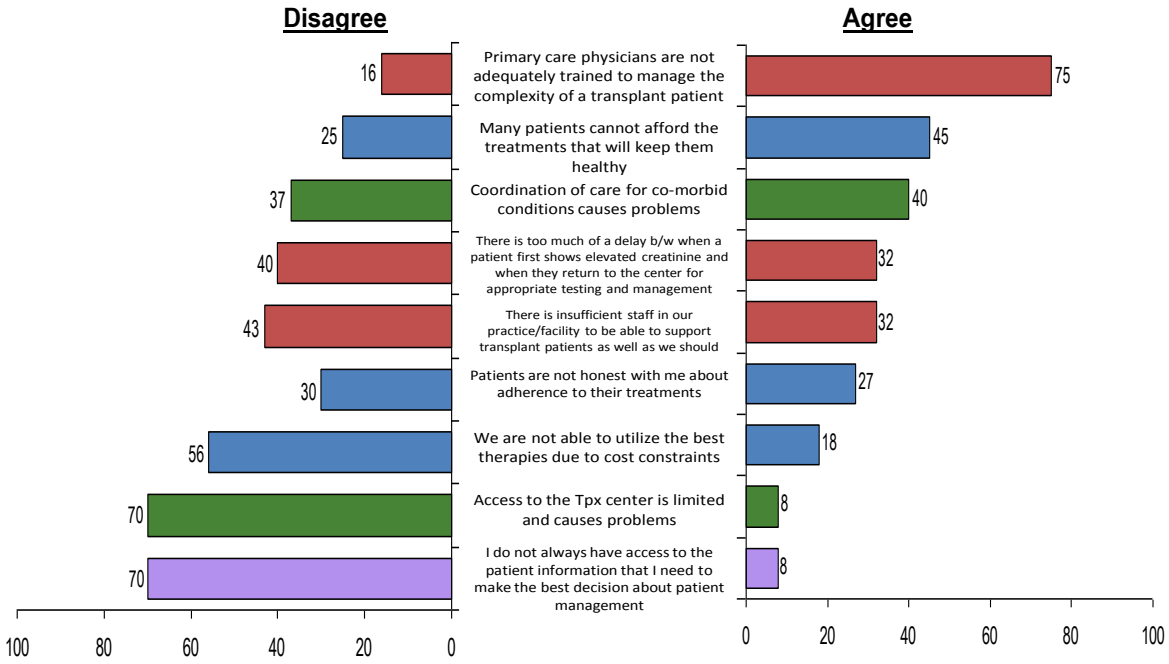
Barriers are real or perceived issues that may prevent physicians from applying best practices. Knowledge of the nature and magnitude of these barriers helps educational designers address them within the scope of the interventions, and in doing so, encourage change in physician performance as well as change in knowledge and skill. These barriers were derived from expert opinion, data from the in-depth interviews, and literature on physician change.

The next set of statements represents barriers to best practice when managing transplant patients. Please rate each statement according your level of agreement as to whether the item represents a barrier to effective management of transplant patients. (*1=Strongly Disagree*, *5=Strongly Agree*)

B1. I do not always have access to the patient health information that I need to make the best decisions about patient management.
B2. Access to the transplant center is limited.
B3. I am not able to utilize the best therapies due to cost constraints.
B4. Many patients cannot afford the treatments that will keep them healthy.
B5. Patients are not honest with me about adherence to their treatments.
B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient.
B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as we should.
B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management.
B9. Coordination of care for co-morbid conditions causes problems.

Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence

Figure 31 shows the list of statements arranged in order of respondents' highest perceived barriers. The bars to the right represent the percentage of respondents rating the barrier high (four or five on the five-point scale), indicating agreement. The bars to the left represent the percentage of respondents rating the barrier low (one or two), indicating disagreement.



Base: Total respondents
Note: Agree represents those respondents answering a 4 or 5 on a 5-point scale where 5 is strongly agree and 1 strongly disagree. Disagree represents those respondents answering a 1 or 2 on the same 5-point scale.
Q.1 **Using a 1 to 5 scale, where 5 is strongly agree and 1 is not at all agree, please rate your level of agreement with the following statements:**

Figure 31: Transplant Surgeon Barriers to Best Practice (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Only one item garnered agreement from more than half of respondents: *B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient* (see Figure 31). The only other two barriers with which transplant surgeons agreed rather than disagreed were *B4. Many patients cannot afford the treatments that will keep them healthy* and *B9. Coordination of care for co-morbid conditions causes problems*.

Although fewer than half of transplant surgeons agreed with these two barriers, qualitative data suggest that they are indeed a problem that transplant surgeons must deal with in the long-term management of kidney transplant patients.

Knowledge Assessment

Prior to completing the knowledge questions, respondents were asked to indicate clinical aspects of transplant in which they felt the current body of knowledge and literature is “inadequate” to guide them in the best care of the transplant patient (Figure 32).

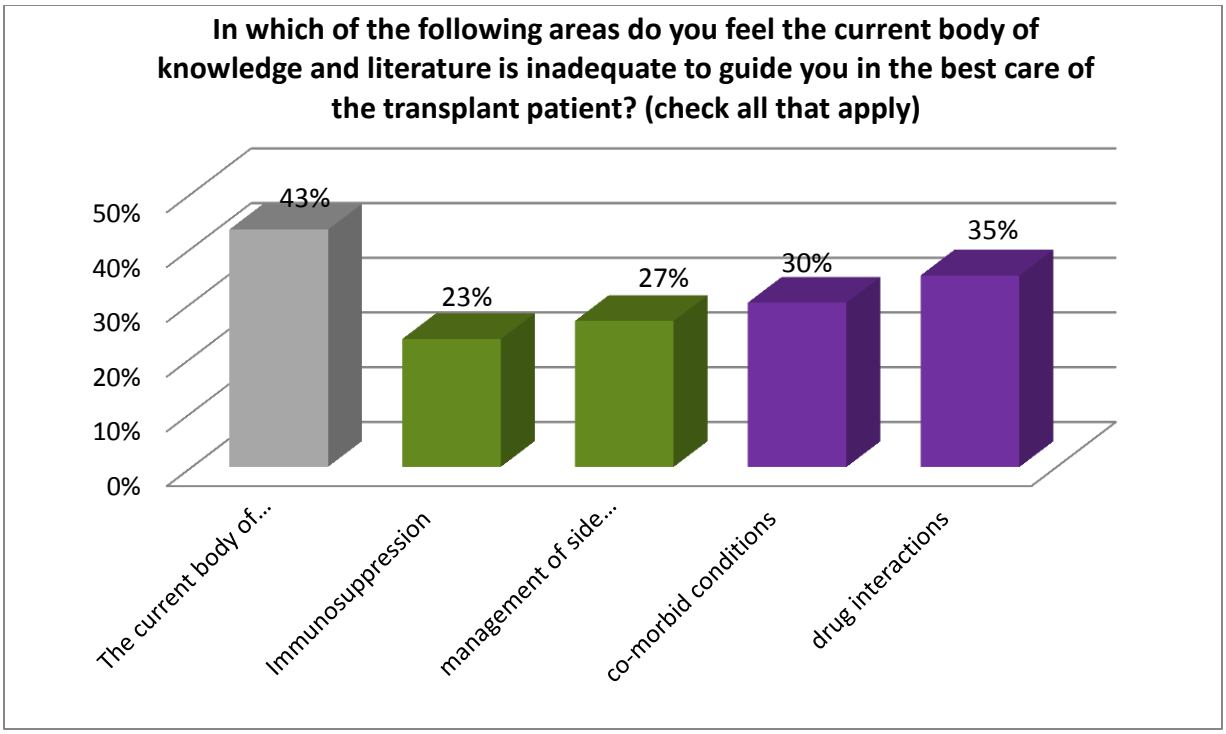


Figure 32: Transplant Surgeon Current Body of Knowledge and Literature (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Only 43 percent of the transplant surgeons indicated that *the current body of knowledge and literature is adequate*. The remainder of responses were divided, with *drug interactions* and *co-morbid conditions* selected as being inadequate by approximately one-third of transplant surgeons, while *Immunosuppression* and *Management of side effects* were rated as inadequate by about a quarter of respondents.

Subsequently, transplant surgeons were asked 12 knowledge-based questions concerning the long-term care of kidney transplant patients. Figure 33 represents the percentage of transplant surgeons correctly answering each question, with an additional score for the average percentage correct for all knowledge-based questions. The full text of the questions can be viewed in Appendix 3 (page 90).

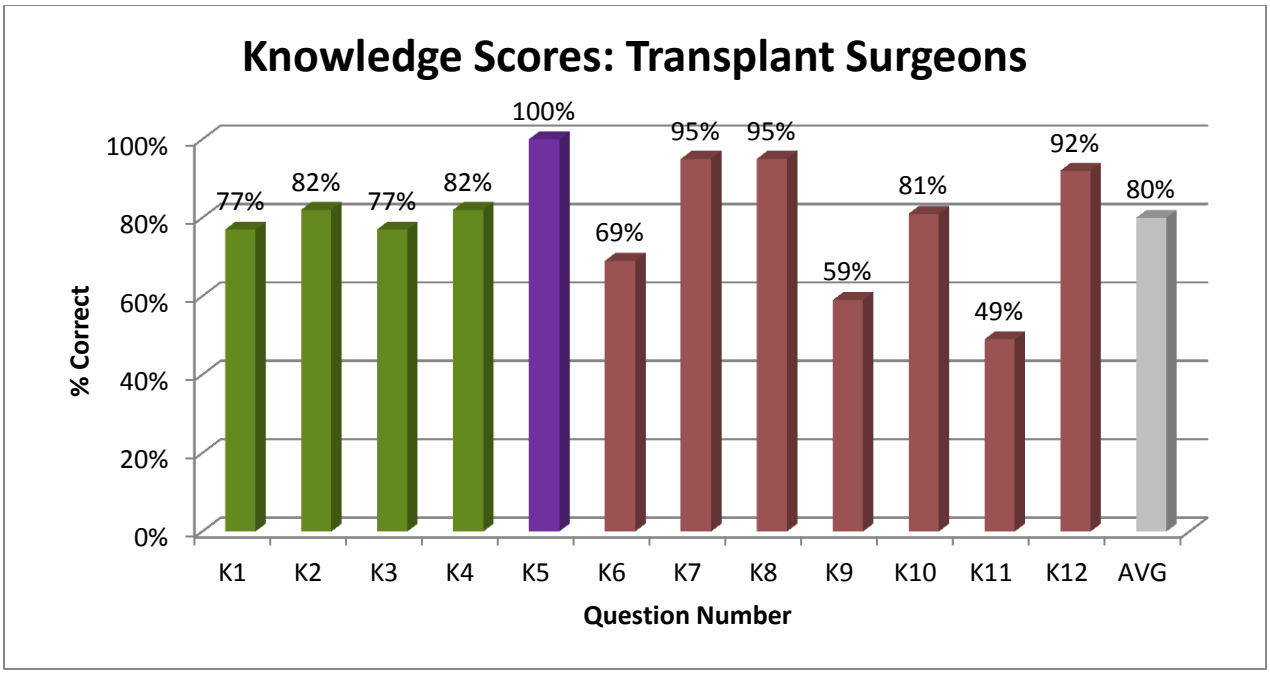


Figure 33: **Transplant Surgeon Knowledge Questions (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)**

Transplant surgeons' scores on the knowledge questions averaged 80 percent (Figure 33), while the score for one question fell below 50 percent. This clearly indicates need for additional knowledge-based educational efforts that could positively impact this population.

Practice Assessment Questions

The practice assessment questions were designed to assess actual clinical practices of the respondents. The results may be compared to best practices to establish real needs and their relationships to perceived needs and knowledge gaps. A selection of key practice question responses is shown below, with the remainder appearing in Appendix 6 (Page 108).

The first item of the practice assessment addresses attitude: **How comfortable are you monitoring immunosuppression?** On a one to five scale, (*1=very uncomfortable* and *5=very comfortable*), transplant surgeons averaged 3.83. This represents slightly above the scale midpoint, showing that on average transplant surgeons are more comfortable than uncomfortable monitoring immunosuppression.

Nearly half of transplant surgeons (48 percent) play no role in immunosuppression at three months post-transplant, which confirms findings from the qualitative phase of the research. The remaining transplant surgeons either monitor immunosuppression and adjust dosages as needed to maintain the set targets (43 percent), or change immunosuppression medications as needed (28 percent) (see Figure 34).

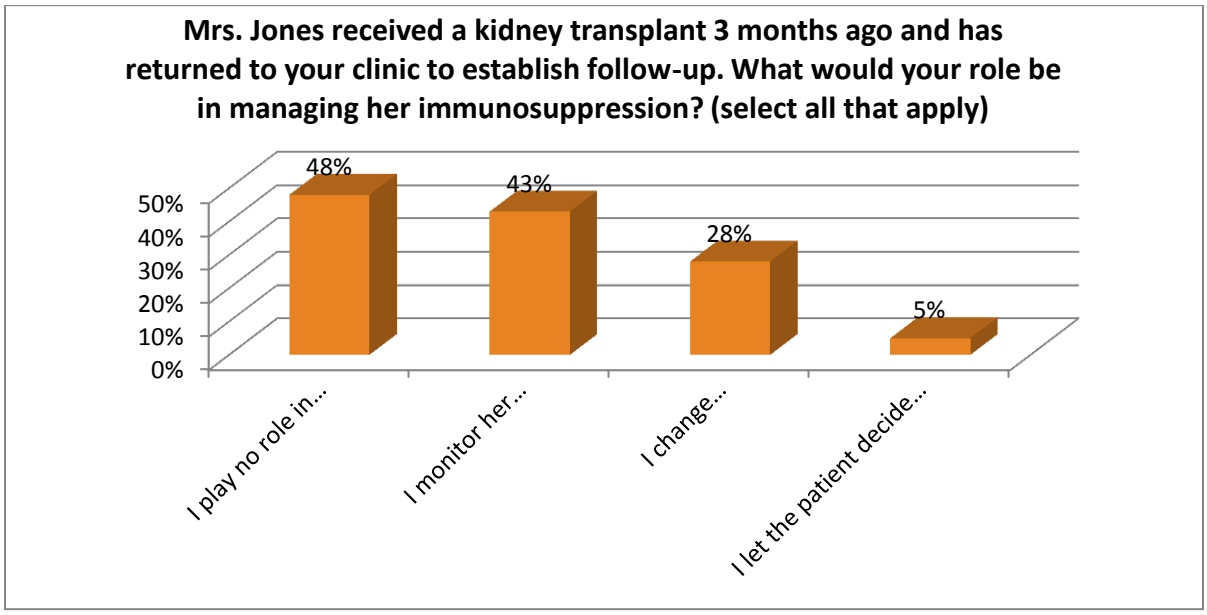


Figure 34: Transplant Surgeon Role in Immunosuppression Management

The majority of transplant surgeons (68 percent) prefer to independently manage their patients after they are released from the transplant center. Just over a quarter (27 percent) prefer to co-manage with the transplant center indefinitely, and very few (5 percent) prefer the transplant center to manage the patient until they develop progressive graft failure, requiring return to dialysis (see Figure 35).

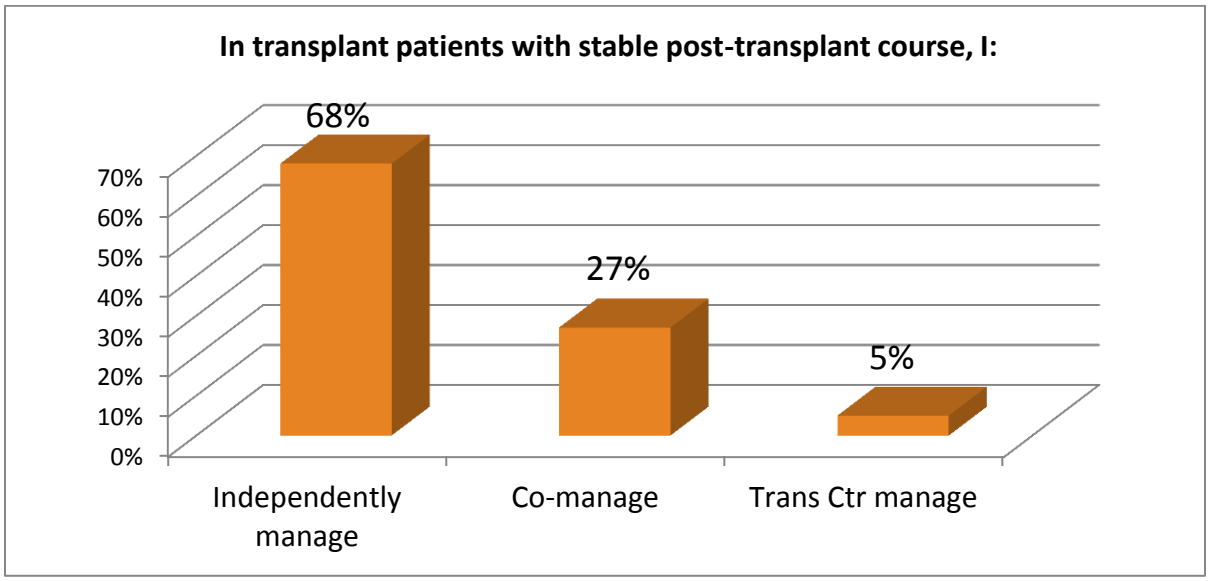


Figure 35: Transplant Surgeon Role in Managing Stable Transplant Patients

When managing long-term care of kidney transplant patients, the majority of transplant surgeons do not have the responsibility for the preventive care issues shown in Figure 36. Of the six preventive care issues rated, none rated three or higher on a five-point scale (where one indicates no responsibility and

five indicates complete responsibility). As shown in the qualitative assessment, most preventive care issues were coordinated by the nephrologist or patient's primary care team.

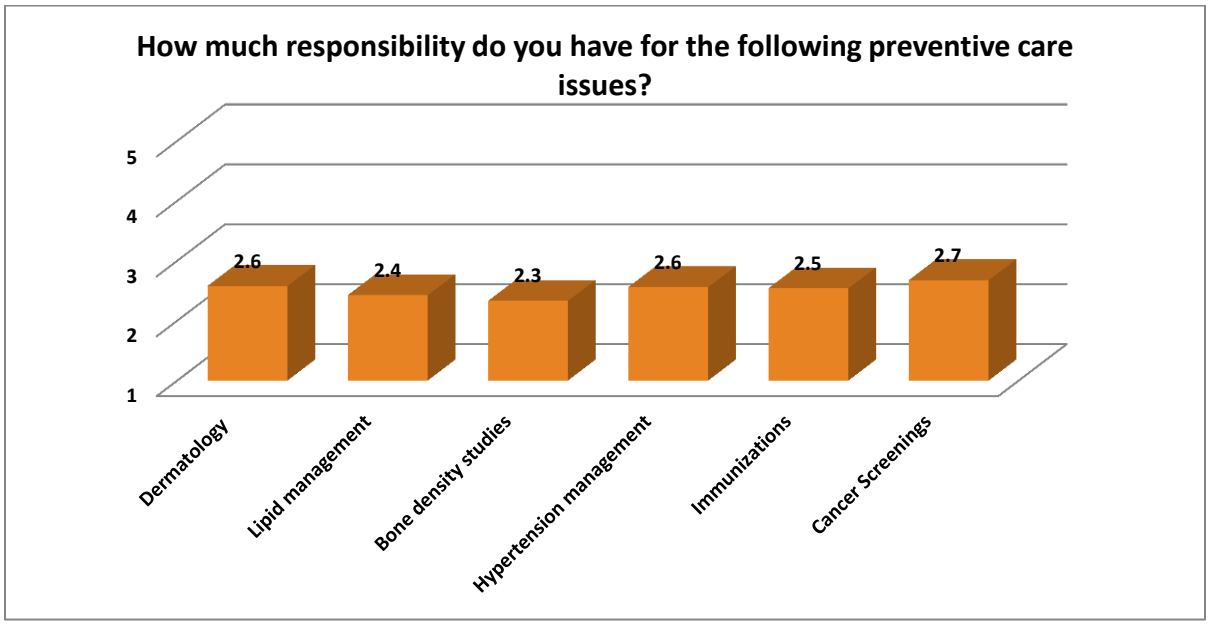


Figure 36: Transplant Surgeon Responsibility for Preventive Care Issues

When asked which vaccinations transplant surgeons administer to their patients, nearly all indicated they administer the annual influenza vaccination (94 percent), while just under two-thirds administer pneumococcal (64 percent) and approximately half administer hepatitis B (56 percent). Only one in five indicate they administer Tdap to their kidney transplant patients (See Figure 37).

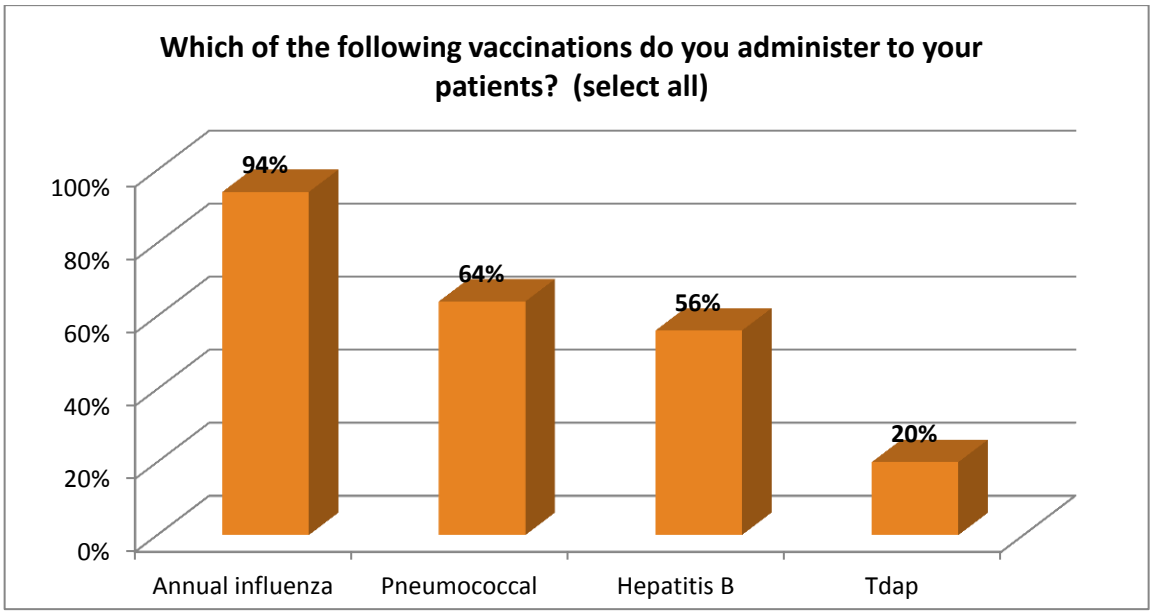


Figure 37: Transplant Surgeon Responsibility for Vaccinations

Because transplant recipients are at higher risk for bone disease, respondents were asked which monitoring methods they routinely use. Although there were a variety of responses, most respondents utilize methods in accordance with existing guidelines. Nearly three-fourths (74 percent) of transplant surgeons routinely utilize DEXA scans to monitor transplant patients for post-transplant bone disease. Just over half also use PTH levels (56 percent) andVitamin D-25 levels (51 percent), and few use C-telopeptide levels (3 percent) (See Figure 38).

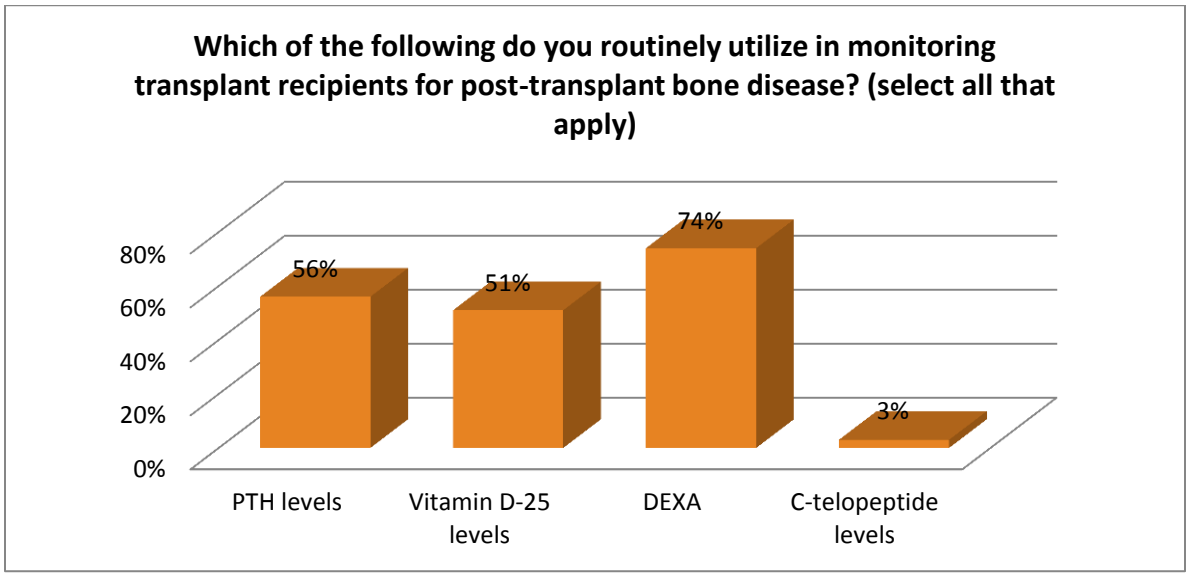


Figure 38: Transplant Surgeon Monitoring for Bone Disease

BK viremia is of particular concern in transplant patients and has been more prevalent in recent years. *KDIGO* recommendations call for monthly screenings for three to six months post-transplant and every three months afterward for the first year. The majority of transplant surgeons screen for BK viremia monthly for three to six months after the kidney transplant (44 percent), while significantly fewer screen only if evidence of graft dysfuntion is present (26 percent) or every 6 months indefinitely (15 percent) (See Figure 39).

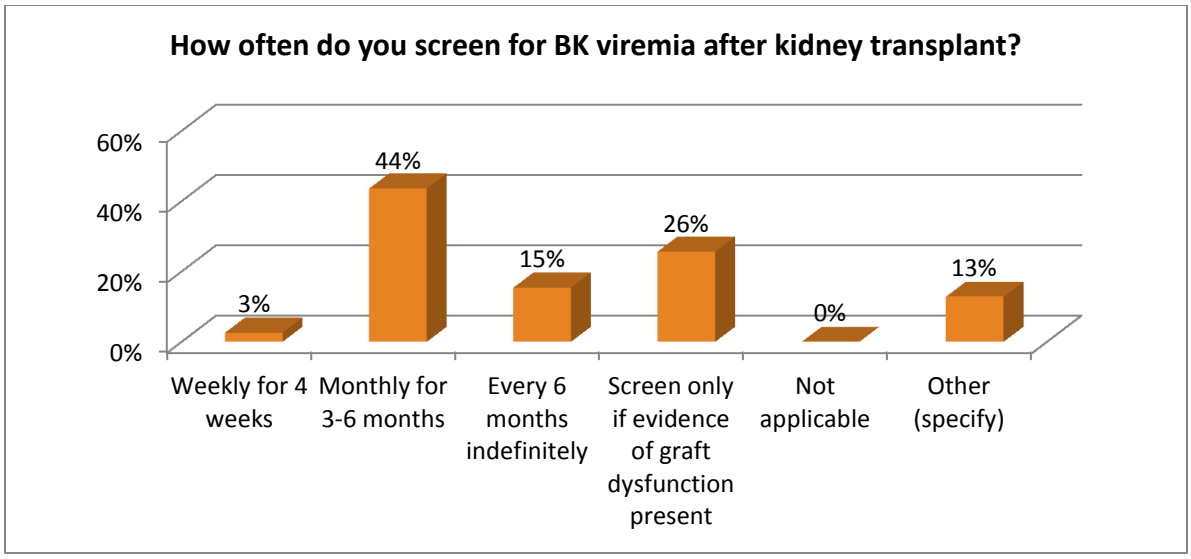


Figure 39: Transplant Surgeon Screening for BK Viremia

Transplant surgeons' practices regarding renal allograft biopsies are mixed. Nearly the same amount would confer with the center that performed a patient's transplant to decide whether or not to proceed with a kidney allograft biopsy (46 percent) as would order renal allograft biopsies if there is concern of dysfunction (42 percent). Just over a third (35 percent) would perform renal allograft biopsies themselves (See Figure 40).

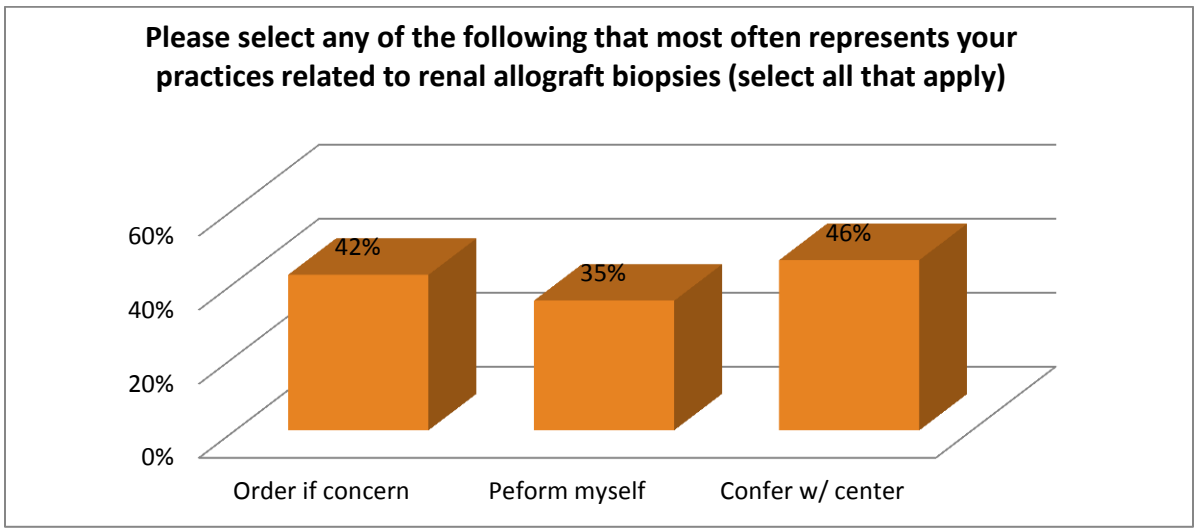


Figure 40: Transplant Surgeon Renal Allograft Biopsy Practices

Nearly all transplant surgeons (85 percent) indicate that they use prophylaxis with acyclovir or valganciclovir depending on donor/recipient serologies for post-transplant CMV. Few indicate that they use preemptive therapy (6 percent) or treatment only (6 percent) (See Figure 41).

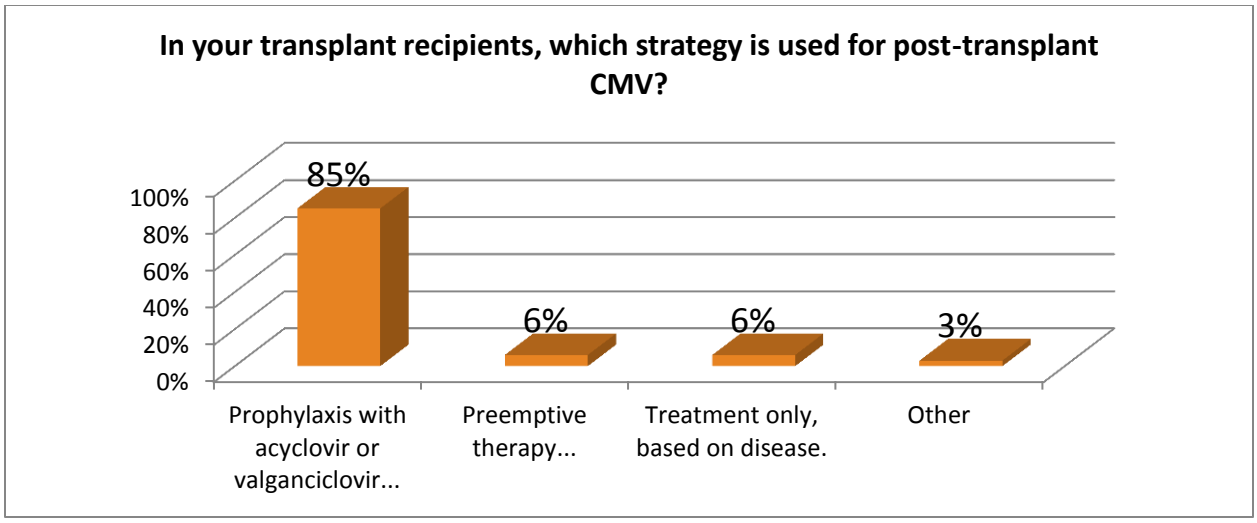


Figure 41: Transplant Surgeon Strategies for cytomegalovirus (CMV)

Transplant surgeons were asked to select up to three measures they rely on the most to monitor adherence to therapy. Nearly half use blood medication levels or attendance at clinic visits (44 percent), while approximately one fifth use compliance with routine laboratory testing (21 percent) or prescription refill records (17 percent). Only one in 10 transplant surgeons relies on self-reported adherence (See Figure 42).

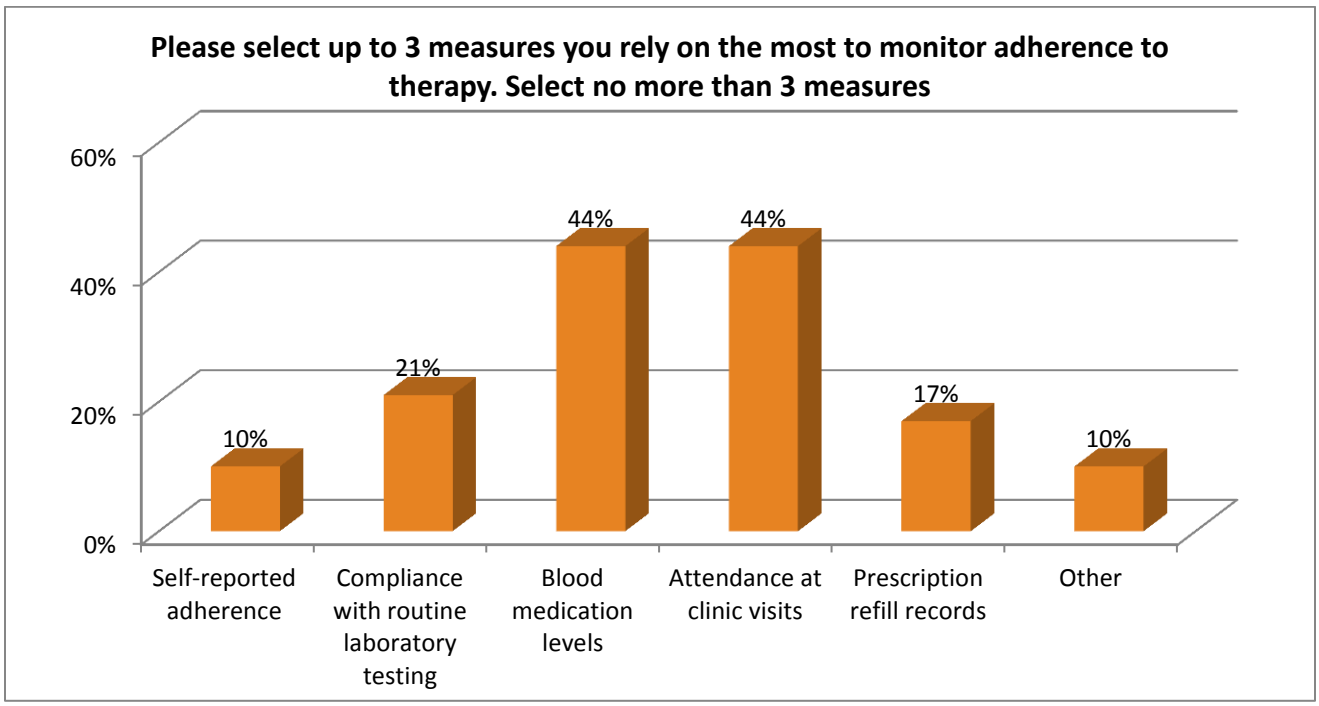


Figure 42: Transplant Surgeon Adherence Monitoring

Summary of Findings

Topic	Perceived Need	Knowledge Gap	Practice Gaps	Barriers
Immunosuppression	- Minimize side effects -Identify potential interactions	Yes	Yes	- Multiple protocols - Limited number of patients - PCPs not adequately trained
Rejection	None	No	No	- PCPs not adequately trained - Delay between elevated creatinine levels and when return to center
Management of Chronic Disease	- Coordination w/ PCPs - Use screenings to detect cancer - Monitor for osteoporosis - Mitigate risk of infection - Appropriately vaccinate	Yes	Yes	- PCPs not adequately trained - Adherence to regimen - Coordination of care - Access to patient information
Adherence	- Identify risk factors for non-adherence - Effectively communicate risks of non-adherence	No	No	- Cost of medications - Adherence to regimen

Table 6: Transplant Surgeon Summary of Findings (*Immunosuppression*, *Rejection*, *Chronic Disease*, *Adherence*)

Implications for Continuing Education

The educational implications of the needs assessment findings for for community nephrologists, center-based transplant specialists, and urology transplant surgeons share the common themes of immunosuppression, rejection of risk and monitoring, chronic disease management, and patient adherence. This section highlights areas where each subspecialty group demonstrates unique educational needs.

The majority of specialists prefer that every kidney transplant patient have a competent community nephrologist who can manage his or her care. However, there is considerable variation in who actually provides the majority of care. Some communities have no nephrologist, and some nephrologists prefer not to manage transplant patients. Thus, a portion of the routine and chronic care of these patients falls upon transplant centers and/or primary care physicians. The recommendations made here may apply equally to the community nephrologist, the family medicine or general internist, and other specialists (cardiologist, gastroenterologist, etc.) who manage kidney transplant patients.

All three learner groups identified the item *Primary care physicians are not adequately trained to manage the complexity of a transplant patient* as a major barrier to patient care. This barrier stems from lack of subspecialists that are available to provide the long-term monitoring and chronic disease management that transplant patients require. While education may be needed for this group, our needs assessment focused on specific learner needs within the domain of community nephrologists, center-based transplant specialists, and urology transplant surgeons.

Immunosuppression

Community nephrologists identified the greatest area of real and perceived need surrounding immunosuppression. Eighty-five percent of community nephrologists report playing a role in managing immunosuppressive medication. Based on the interviews and focus groups, much of this barrier relates to the drug regimen: adjusting doses, monitoring for rejection, etc. Community nephrologists are not equipped to manage these issues, yet because of access or cost issues, they may be responsible for them. These findings are consistent with the topics that are most preferred by community nephrologists: immunosuppression updates and appropriate monitoring.

Education of the community nephrologist should emphasize the “basics” of current immunosuppressive therapy, the adverse effects of the drugs, common interactions with medications used to treat co-morbidities and chronic illnesses, and issues with generic substitution.

Transplant specialists, on the other hand, are well versed in immunosuppression. They perceive that they are quite competent and desire to be highly competent managing immunosuppression. Their

highest perceived needs relate to minimizing side effects. Education on immunosuppression should focus on new developments, therapies, and regimens. Knowledge-based educational formats will be sufficient to attract participation and engage these specialists.

Transplant specialists can play an important role in providing best standards of care to community nephrologists, and, ultimately, the primary care community.

As with community nephrologists, the greatest area of real and perceived need for transplant surgeons is in the area of immunosuppression. Survey results indicate that 52 percent of these surgeons have a role in immunosuppression; this topic is one of the highest *perceived* educational needs as assessed by the Change Readiness Inventory. Immunosuppression also represents the greatest area of *real needs*, as shown by the knowledge assessment tool, where four scores were below the 80 percent threshold that defines adequate knowledge. Based on the interviews and focus groups, many barriers to best care relate to the immunosuppression regimen: adjusting doses, monitoring for rejection, etc. Like community nephrologists, transplant surgeons are not equipped to manage these issues, but they may be responsible for them. These findings are consistent with the topics that are most preferred by transplant surgeons: immunosuppression updates and appropriate monitoring.

Education of transplant surgeons should emphasize the “basics” of current immunosuppressive therapy, adverse effects of drugs, common interactions, and issues with generic substitution. Surgeons would value clinical guidelines in immunosuppression**.**

Rejection Risk Assessment and Monitoring

The educational need for appropriate rejection risk assessment and monitoring is closely related to the need in immunosuppression. For community nephrologists, items related to these areas (competencies, barriers, knowledge) were significantly correlated with each other ($r \geq 0.5$, $p \leq .05$).

Education for community nephrologists should include immunosuppression combined with focus on reducing the risk of rejection through assessment and appropriate monitoring. The second highest perceived need identified is *Identify risk factors for acute rejection*, while the second most commonly selected topic for medical education was *Appropriate monitoring of the kidney transplant patient*.

Transplant specialists have important perceived needs in the detection of acute rejection and will respond to topics in this area.

Transplant surgeons indicated that they had inadequate knowledge and resources to assess and monitor rejection, citing drug interactions as a specific gap in knowledge. Educational programs focusing on knowledge of specific therapies would be beneficial for this group of transplant surgeons.

Chronic Care

Community nephrologists agree that they have a strong role in managing chronic care issues. They take the most responsibility for management of hypertension and lipids and feel responsible for the management of co-morbidities such as infection and bone disease. However, community nephrologists vary widely in the roles that they play with respect to chronic disease and co-morbidities in the transplant patient.

Community nephrologists feel that current literature and knowledge in chronic disease in the kidney transplant patient is inadequate. Admittedly, this is not a widely studied area; however, there are good evidence, guidelines, and consensus on best practices, of which community nephrologists may not be aware. Education should be focused on these areas and marketing efforts should emphasize new evidence and best practices.

As the expert in transplant medicine and immunosuppression, the transplant specialist holds the key role in ensuring overall appropriate management of kidney transplant patients. Competency gaps indicate that they perceive need in patient chronic disease management. Interventions can be designed and implemented to facilitate better coordination of care. Tools and processes may be developed to ensure that patients undergo appropriate monitoring, screening, testing and follow-up care. Processes and systems can be implemented to ensure that the right information reaches the appropriate clinician at the most opportune time.

These tools, resources, systems, and processes must be driven by the transplant center. Community nephrologists, primary care physicians, and other specialists all have their own ways of working with patient information; therefore, the onus falls upon the transplant center to develop and implement a cohesive system.

Transplant surgeons play a collaborative role with community nephrologists in managing chronic care issues. The majority of transplant surgeons indicated they are not responsible for managing each of the six preventive care issues surveyed.

These findings confirm qualitative data suggesting that the management of many chronic diseases is coordinated between the community nephrologists and/or primary care physicians, and that the patient is no longer being actively managed by the transplant surgeon by three to six months post-transplant.

Two fifths (43 percent) of transplant surgeons feel that current literature and knowledge about chronic disease in the kidney transplant patient is adequate. Education on chronic disease management should focus on best evidence and be relevant to the relatively short-term care provided by transplant surgeons.

Transplant centers can play a significant role in developing tools and resources that enhance coordination of care for these patients. Creating processes to share and coordinate care—and developing tools, resources, and education to facilitate those processes—should help to improve management of chronic disease in these patients.

Adherence

Allograft rejection is sometimes related to adherence issues. Perceived needs and barriers related to adherence were rated highly by community nephrologists, transplant specialists and transplant surgeons. All are aware of the role that adherence plays in the success of immunosuppression, organ rejection, and chronic care management. They report that adherence is closely linked to socioeconomic factors and recognize the unique adherence risks in young adult populations due to resistance and in the older populations due to confusion and the multiplicity of medications. Adherence should be addressed in all educational activities as a key factor in allograft survival. Tips and tricks to increase adherence should be part of the common curriculum of managing the transplant patient. This should include the identification of risk factors for non-adherence, the communication of health risks to patients and caregivers, and the signs and symptoms of non-adherence.

The cost of care emerged as a key factor influencing patient adherence. Physicians in the community may not be well connected to resources that provide medications and care for those who cannot afford it. Some aspect of educational activities should focus on the identification and use of available resources so that they are accessible to community physicians as well as transplant centers.

Educational Attributes

Community nephrologists do not strongly favor any particular attribute of educational activities (format, venue, faculty, setting). When asked about their most recent educational activity, they showed an even distribution of formats and venues, with 38 percent participating in live local/state/ national activities and 35 percent participating in a web-based enduring activity. Educational activities should be implemented in a variety of formats and settings to attract the broadest interest and participation by community nephrologists, primary care physicians, and other clinicians who care for kidney transplant patients.

Transplant specialists are most attracted to live specialty meetings at the state or national level. They will also participate in other formats for topics related to new immunosuppression therapies, minimizing side effects, and increasing patient adherence.

While transplant surgeons were not directly asked their preferences for educational activities in this survey, research conducted by the AUA in 2010 indicates that as with community nephrologists, urologists do not strongly favor any particular attribute of educational activities (format, venue, faculty,

setting). When asked their preferred method of receiving continuing education, AUA urologists preferred an even distribution of formats/venues, with 29 percent preferring in-person at a specific location and 35 percent preferring a web-based enduring activity. The remaining 36 percent indicated they were unsure and that their answer depended on the course topic. That said, educational activities should be implemented using a variety of formats and settings to garner the broadest possible interest and participation by transplant surgeons and primary care physicians who care for kidney transplant patients.

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Appendix 2: Quantitative Assessment Tool: Community Nephrologists and Transplant Specialists

Thank you for your willingness to participate in this assessment. It should take you less than 10 minutes. This will help AST and other organizations to plan and implement effective medical education activities.Your responses to this survey are entirely confidential, and no personally identifiable information will be collected. Please click Continue to get started.

Practice Profile

D1. Please note your primary specialty:
Transplant surgery

Transplant nephrology

Community nephrology

Other (please specify) _____

(Screening - Community Nephrologists only, terminate if no) Do you manage any post-transplant patients (kidney)?
Yes

No

D2. Approximately how many kidney transplant patients do you see in a typical week?
0 - 20

21 - 40

41 - 60

More than 60

D3. (Transplant Specialists only) Please estimate the percentage of your transplant patients that see a community nephrologist outside of your institution.
Less than 10%

11-25%

26-50%

More than 50%

D4. Please select your type of practice
Solo

Single specialty group

Multi-specialty group

Hospital transplant center

Other _____

D5. (CN only) How far away is the transplant center to which you refer the greatest number of patients?
less than 50 miles

51 - 100 miles

101 - 150 miles

151 - 200 miles

More than 200 miles

D6. (CN only) How many different transplant centers do you routinely refer patients to?
1

2

3 or more

Clinical Competencies

The next series of items represents clinical competencies related to management of the transplant patient. Please rate your Present Ability in the left-hand column, and your Desired Ability in the right-hand column.

Present Ability[Low,High]

	1	2	3	4	5
C1. Select an effective immunosuppressive drug regimen that attains adequate protection of the kidney allograft against rejection.	❑	❑	❑	❑	❑
C2. Minimize short- and long-term adverse side effects of immunosuppressive medications.	❑	❑	❑	❑	❑
C3. Identify potential interactions between immunosuppressive agents and other medications.	❑	❑	❑	❑	❑
C4. Identify risk factors for acute rejection.	❑	❑	❑	❑	❑
C5. Detect signs and symptoms of acute graft rejection by monitoring creatinine levels.	❑	❑	❑	❑	❑
C6. Attain an allograft biopsy to determine if rejection is occurring.	❑	❑	❑	❑	❑
C7. Coordinate with other specialists or primary care physicians to manage comorbid conditions (diabetes, hypertension, cardiovascular disease).	❑	❑	❑	❑	❑
C8. Use screenings to detect cancer in the transplant patient.	❑	❑	❑	❑	❑
C9. Monitor as appropriate for osteoporosis (calcium serum levels, phosphorus, bone-mineral density, and plasma intact PTH).	❑	❑	❑	❑	❑
C10. Mitigate risk of infection by appropriate use of prophylactic antibiotic, antiviral and antimycotic treatment.	❑	❑	❑	❑	❑

C11. Appropriately vaccinate 6 months post-transplant using inactive vaccines.	❑	❑	❑	❑	❑
C12. Identify risk-factors for non-adherence to medication regimens.	❑	❑	❑	❑	❑
C13. Effectively communicate risks of non-adherence to patients and family.	❑	❑	❑	❑	❑

Barriers

The next set of statements represent barriers to best practices when managing transplant patients. Please rate each statement according your level of agreeement as to whether the item represents a barrier to effective management of patients in pain.

Please indicate your level of agreement to the following statements: (1= strongly disagree, 5=strongly agree)

Barrier Questions (B1 – B12)	Strongly Disagree1	2	3	4	Strongly Agree5
B1. I do not always have access to the patient health information that I need to make the best decisions about patient management.	❑	❑	❑	❑	❑
B2. Access to the transplant center is limited.	❑	❑	❑	❑	❑
B3. lI am not able to utilize the best therapies due to cost constraints.	❑	❑	❑	❑	❑
B4. Many patients cannot afford the treatments that will keep them healthy.	❑	❑	❑	❑	❑
B5. Patients are not honest with me about adherence to their treatments.	❑	❑	❑	❑	❑
B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient.	❑	❑	❑	❑	❑
B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as we should.	❑	❑	❑	❑	❑
B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management.	❑	❑	❑	❑	❑
B9. Coordination of care for co-morbid conditions causes problems.	❑	❑	❑	❑	❑

Practice Assessment

P1. (CN only) Mrs. Jones received a kidney transplant 3 months ago and has returned to your clinic to establish follow-up. What would your role be in managing her immunosuppression? (select all that apply)
I play no role in immunosuppression.

I monitor her immunosuppression and adjust dosages as needed to maintain the set targets.

I change immunosuppression medications as needed.

I let the patient decide between the community physician and the transplant center for managing immunosuppression.

A1.

	Very Uncomfortable 1	2	3	4	Very Comfortable 5
How comfortable are you in monitoring immunosuppression?	❑	❑	❑	❑	❑

P2. (CN only) Ms. Smith is a 23-year-old African American female who received her second deceased donor kidney transplant for ESRD due to lupus nephritis 6 months ago. Her post-transplant course was complicated by one episode of acute cellular rejection. She is maintained on tacrolimus, mycophenolate moffetil and prednisone. She comes to you asking if she can stop the prednisone as she has heard of transplant recipients who are not taking it. How would you respond to her request?
Contact the transplant center that performed the transplant to obtain their opinion

Advise her to taper the prednisone by 1 mg per week until she is off completely

Stop the prednisone given her young age and potential for long term complications of corticosteroid therapy.

Advise her that she should stay on it given her medical history

P3. (CN only) Please select any of the following that most often represents your practices related to renal allograft biopsies:
I order renal allograft biopsies if there is concern for allograft dysfunction.

I perform renal allograft biopsies myself.

I confer with the transplant center that performed a patient's transplant to decide whether or not to proceed with a kidney allograft biopsy.

Other (specify) _____

P4. (CN only) In transplant patients with a stable post-transplant course, I prefer :
... to independently manage care after they are released by the transplant center

... to co-manage with the transplant center indefinitely

... the transplant center to manage until they develop progressive graft failure requiring return to dialysis

P5. How much responsibility do you have for the following preventive care issues?

	No responsibility 1	2	3	4	Complete responsibility 5
Dermatology consultations	❑	❑	❑	❑	❑
Lipid management	❑	❑	❑	❑	❑
Bone density studies	❑	❑	❑	❑	❑
Hypertension management	❑	❑	❑	❑	❑
Immunizations	❑	❑	❑	❑	❑
Cancer Screenings: colonoscopy,mammogram, PSA, etc.	❑	❑	❑	❑	❑

P6. (Transplant Specialists only) In your transplant recipients, which strategy is used for post-transplant CMV?
Prophylaxis with acyclovir or valganciclovir depending on donor/recipient serologies

Preemptive therapy: initiate antiviral medication if laboratory evidence for CMV replication

Treatment only, based on disease.

Other

P7. Which of the following vaccinations do you or your staff administer regularly to your transplant patients?
Annual influenza

Pneumococcal

Hepatitis B

Tdap

Other

P8. Please select up to 3 measures you rely on the most to monitor adherence to therapy. Select no more than 3 measures.
Self-reported adherence

Compliance with routine laboratory testing

Blood medication levels

Attendance at clinic visits

Prescription refill records

Other

P9. Which of the following do you routinely utilize in monitoring transplant recipients for post-transplant bone disease? (select all that apply)
PTH levels

Vitamin D-25 levels

DEXA

C-telopeptide levels

P10. How often do you screen for BK viremia after kidney transplant?
Weekly for 4 weeks

Monthly for 3-6 months

Every 6 months indefinitely

Screen only if evidence of graft dysfunction present

Not applicable

Other (specify) _____

Knowledge Assessment

K1. You are seeing a 36-year-old 8 months out from a deceased donor kidney transplant. You note that there is significant albuminuria. Which of the following medications could be contributing to this?
Tacrolimus

Cyclosporine

Azathioprine

Sirolimus

K2. Which of the following medications is most likely to contribute to a patient's dyslipidemia?
Sirolimus

Tacrolimus

Mycophenolate Mofetil

Belatacept

K3. Which of the following medications would preclude the use of allopurinol for hyperuricemia?
Azathioprine

Mycophenolate mofetil

Cyclosporine

Tacrolimus

K4. You would like to start a kidney transplant patient on clarithromycin. What will happen to the blood level of tacrolimus if the dose is not changed?
The tacrolimus level will increase

The tacrolimus level will decrease

There will be no change

Tacrolimus has to be stopped as it is contraindicated with clarithromycin

K5. A 68-year-old white male who received a kidney transplant from his wife 10 years ago for end stage renal disease due to polycystic kidney disease has had diarrhea for the past three days. He did not take his medications for two of those days. Presents to you feeling light headed. Blood pressure seated was 126/76, and on standing 90/55. Laboratories reveal a creatinine of 2.6 (baseline 1.5). What would you do?
Give intravenous fluids and biopsy immediately to exclude rejection.

Encourage oral fluid intake and biopsy immediately to exclude rejection.

Give intravenous fluids and biopsy only if creatinine does not decrease the following day

Proceed with a biopsy to exclude concomitant rejection even if the creatinine decreases the following day.

Other (specify) _____

K6. John receives a kidney transplant and requires anti-hypertensive therapy post-transplant. Which of his pre-transplant anti-hypertensive medications would be expected to increase tacrolimus levels?
Diltiazem

Carvedilol

Lisinopril

K7. Which of the following medications has the strongest association with the development of post-transplant diabetes?
Sirolimus

Tacrolimus

Mycophenolate mofetil

Cyclosporine

K8. Which is the leading cause of death in the transplant recipient?
Malignancy

Cardiovascular disease

Infection

Cerebrovascular disease

K9. For the kidney transplant recipient, what cancer has the risk most similar to the age- matched general population?
Kidney

Colon

Non-melanoma skin

Lymphoma

K10. Which is the correct virus-associated malignancy pair?
BKV-bladder cancer

HHV-6-Kaposi sarcoma

EBV-Post transplant lymphoproliferative disease

CMV-colon cancer

K11. The agent used for pneumocystis prophylaxis with the highest propensity for hemolytic anemia in select individuals is:
Dapsone

TMP/SMX

Pentamadine

Atovaquone

K12. Mark is a 65 year old male who wishes to update his immunizations. He asks if he should avoid any of the following. Which of the following would you tell him is/are UNSAFE? (select all that apply)
Injected influenza

Varicella zoster

Tetanus

Pneumovax

Educational Preferences

E1. Please select the format of the most recent educational activity for which you earned credit hours.
Local staff/society meeting

State/National society meeting

Enduring material (print journal,monograph, etc.)

Live web-based presentation

Web-based enduring activity (no live component)

Other

E2. Please rate the importance of each attribute you consider when selecting CME activities?

	Not Important 1	2	3	4	Very Important 5
Format of the activity (presentation, interactive small group, live webinar, self-study, etc.)	❑	❑	❑	❑	❑
Number of hours required to complete the activity	❑	❑	❑	❑	❑
Where it is offered (on-line, local meeting, national meeting, etc.)	❑	❑	❑	❑	❑
The speaker or author of the activity	❑	❑	❑	❑	❑

E3. Please select up to three (3) topics you are most likely to select for your next CME activity.
Immunosuppression update

Drug-drug interactions in the kidney transplant patient with chronic disease such as hypertension and diabetes.

Managing adverse effects of immunosuppression

Appropriate monitoring of the kidney transplant patient

Titration of immunosuppression therapy

Managing chronic conditions such as hypertension and diabetes in the kidney transplant patient

Screenings and tools for preventive care in the transplant patient

Increasing adherence in the transplant patient

Other _____

E4. In which of the following areas do you feel the current body of knowledge and literature is inadequate to guide you in the best care of the transplant patient. (check all that apply)
The current body of knowledge and literature is adequate to guide me in all of these areas.

Immunosuppression

management of side effects

co-morbid conditions

drug interactions

This completes the survey. Thank you for your participation. Please click on Submit below to record your responses.

Appendix 3: Quantitative Assessment Tool: Transplant Surgeons

Using a 1 to 5 scale, where 5 is strongly agree and 1 is not at all agree, please rate your level of agreement with the following statements:

	Strongly Agree 5	4	3	2	Strongly Disagree 1	Don't Know
B1. I do not always have access to the patient information that I need to make the best decision about patient management						
B2. Access to the Tpx center is limited and causes problems						
B3. We are not able to utilize the best therapies due to cost constraints						
B4. Many patients cannot afford the treatments that will keep them healthy						
B5. Patients are not honest with me about adherence to their treatments						
B6. Primary care physicians are not adequately trained to manage the complexity of a transplant patient						
B7. There is insufficient staff in our practice/facility to be able to support transplant patients as well as we should						
B8. There is too much of a delay between when a patient first shows elevated creatinine and when they return to the center for appropriate testing and management						
B9. Coordination of care for co-morbid conditions causes problems						

E4. Which of the following areas do you feel the current body of knowledge and literature is inadequate to guide you in the best care of the transplant patient. (check all that apply)

- Immunosuppression
- management of side effects
- co-morbid conditions
- drug interactions
- the current body of knowledge and literature is adequate to guide me in all of these areas.
- None of the Above

P1. Mrs. Jones received a kidney transplant 3 months ago and has returned to your clinic to establish follow-up. What would your role be in managing her immunosuppression? (select all that apply)

- I play no role in immunosuppression.
- Monitor her immunosuppression and adjust dosages as needed to maintain the set targets.
- Change immunosuppression medications as needed.
- Let the patient decide between the community physician and the transplant center for managing immunosuppression.

P2. Ms. Smith is a 23-year-old African American female who received her second deceased donor kidney transplant for ESRD due to lupus nephritis 6 months ago. Her post-transplant course was complicated by one episode of acute cellular rejection. She is maintained on tacrolimus, mycophenolate moffetil and prednisone. She comes to you asking if she can stop the prednisone as she has heard of transplant recipients who are not taking it. What would you do? (select all that apply)

- Contact the transplant center that performed the transplant to obtain their opinion
- Advise her to taper the prednisone by 1 mg per week until she is off completely
- Stop the prednisone given her young age and potential for long term complications of corticosteroid therapy.
- Advise her that she should stay on it given her medical history

A1. Using a 1 to 5 scale, where 5 is extremely comfortable and 1 is not at all comfortable, how comfortable are you in monitoring immunosuppression?

	Extremely Comfortable 5		4	3	2	Not At All Comfortable 1
Monitoring Immunosuppression						

A2. Using a 1 to 5 scale, where 5 is highly involved and 1 is I have no role, please indicate your role with respect to adjusting immunosuppression therapy?

	Highly Involved 5	4		3		2		I Have No Role 1
Adjusting Immunosuppression Therapy								

A3. Using a 1 to 5 scale, where 5 is highly involved and 1 have no role, What is the appropriate role of the community nephrologist with respect to adjusting immunosuppression therapy?

	Highly Involved				Have No Role
	5	4	3	2	1
Nephrologist Role in Adjusting Immunosuppression Therapy					

P3. Please select any of the following that most often represents your practices related to renal allograft biopsies:

- I order renal allograft biopsies if there is concern for allograft dysfunction.
- I perform renal allograft biopsies myself.
- I confer with the transplant center that performed a patient's transplant to decide whether or not to proceed with a kidney allograft biopsy.

P4. In transplant patients with a stable post-transplant course, I:

- Prefer to independently manage care after they are released by the transplant center (after 3 months post-transplant)
- Prefer to co-manage with the transplant center indefinitely
- Prefer the transplant center to manage until they develop progressive graft failure requiring return to dialysis

P5. How much responsibility do you have for the following preventive care issues?

Complete

	Responsibility 5	4	3	2	No Responsibility 1
Dermatology consultations					
Lipid management					
Bone density studies					
Hypertension management					
Immunizations					
Colonoscopy, Mammogram, PSA,					

P6. In your transplant recipients, which strategy is used for post-transplant CMV?

- Prophylaxis with acyclovir or valganciclovir depending on donor/recipient serologies
- Preemptive therapy: initiate antiviral medication if laboratory evidence (eg. positive CMV PCR) for CMV replication
- Treatment only, based on disease.

P7. Which of the following vaccinations do you administer regularly to your transplant patients?

- Annual influenza
- Pneumococcal
- Hepatitis B
- Tdap

P8. Please select the 3 measures you most commonly use to monitor adherence.

- Self-reported adherence (from patient or family)
- Compliance with routine laboratory testing
- Blood medication levels
- Attendance at clinic visits
- Prescription refill records
- Other (please specify)

K13. A 65-year-old male patient with ESRD from polycystic kidney disease has had a living unrelated kidney transplant from his then 50-year-old wife for 10 years. He is maintained on tacrolimus and mycophenolate mofetil without corticosteroids. Renal allograft function has been excellent without any proteinuria and no history of rejection. He has had recurrent squamous cell cancers of the skin. He comes to you to ask if he should take less immunosuppression. What would you advise?

- He should continue on the current regimen
- He should stop the mycophenolate mofetil and take only tacrolimus
- He should take sirolimus in place of tacrolimus
- He should stop mycophenolate mofetil and start taking prednisone 5 mg daily

K1. You are seeing a 36-year-old 8 months out from a deceased donor kidney transplant. You note that there is significant albuminuria. Which of the following medications could be contributing to this?

- Tacrolimus
- Cyclosporine
- Azathioprine
- Sirolimus

K2. Which of the following medications is most likely to contribute to a patient's dyslipidemia?

- Sirolimus
- Tacrolimus
- Mycophenolate Mofetil
- Belatacept

K3. Which of the following medications would preclude the use of allopurinol for hyperuricemia?

- Azathioprine
- Mycophenolate mofetil
- Cyclosporine

Tacrolimus

K4. You would like to start a kidney transplant patient on clarithromycin. What will happen to the blood level of tacrolimus if the dose is not changed?

- The tacrolimus level will increase
- The tacrolimus level will decrease
- There will be no change
- Tacrolimus has to be stopped as it is contraindicated with clarithromycin

K14. Which of the following is not a risk factor for acute cellular rejection?

- Older recipient age
- Second kidney transplant
- African American heritage
- HIV infection
- Previous pregnancies

K5. A 68-year-old white male who received a kidney transplant from his wife 10 years ago for end stage renal disease due to polycystic kidney disease has had diarrhea for the past three days. He did not take his medications for two of those days. Presents to you feeling light headed. Blood pressure seated was 126/76 an on standing 90/55 Laboratories reveal a creatinine of 2.6 (baseline 1.5). What would you do?

- Give intravenous fluids and biopsy immediately to exclude rejection.
- Encourage oral fluid intake and biopsy immediately to exclude rejection.
- Give intravenous fluids and biopsy only if creatinine does not decrease the following day
- Proceed with a biopsy to exclude concomitant rejection even if the creatinine decreases the following day

K6. John receives a kidney transplant and requires anti-hypertensive therapy post-transplant. Which of his pre-transplant anti-hypertensive medications would be expected to increase tacrolimus levels?

- Diltiazem
- Carvedilol
- Lisinopril
- Clonidine

K7. Which of the following medications has the strongest association with the development of post-transplant diabetes?

- Sirolimus
- Tacrolimus
- Mycophenolate mofetil
- Cyclosporine

K8. Which is the leading cause of death in the transplant recipient?

- Malignancy
- Cardiovascular disease
- Infection
- Cerebrovascular disease

K9. For the kidney transplant recipient, what cancer has the risk most similar to the age-matched general population?

- Kidney
- Colon
- Non-melanoma skin
- Lymphoma

K10. Which is the correct virus-associated malignancy pair?

- BKV-bladder cancer
- HHV-6-Kaposi sarcoma
- EBV-Post transplant lymphoproliferative disease (PTLD)
- CMV-colon cancer

P9. Which of the following do you routinely utilize in monitoring transplant recipients for post-transplant bone disease? (select all that apply)

- PTH levels
- Vitamin D-25 levels
- DEXA
- C-telopeptide levels

K11. The agent used for pneumocystis prophylaxis with the highest propensity for hemolytic anemia in select individuals is:

- Dapsone
- TMP/SMX
- Pentamadine
- Atovaquone

K15. KDIGO recommendations for screening for BK viremia by nucleic acid testing (PCR) after kidney transplant is:

- Weekly for 4 weeks
- Monthly for 3-6 months
- Every 6 months indefinitely
- Screen only if evidence of graft dysfunction present

K12. Mark is a 65 year old male who wishes to update his immunizations. He asks if he should avoid any of the following. Which of the following would you tell him is/are UNSAFE? (select all that apply)

- Injected influenza
- Varicella zoster
- Tetanus
- Pneumovax

E5. What do you think the greatest educational need is for your colleagues related to managing kidney transplant patients?

5

6

E6. How can the AUA better serve Urologists who are involved in Kidney Transplantation?

- Work with Residency Program Directors to include Transplantation in training
- Educate young urologist on the speciality of Transplantation
- Be a vocal advocate for Urologists in the field of transplantation
- Provide more educational courses in the field of transplantation at the AUA Annual Meeting
- Provide stand alone educational courses in the field of transplantation
- Other (please specify)

E7. Using a to to 5 scale, where 5 is extremely important and 1 is not at all important, how important is it for the AUA to become more active in promoting the specialty of transplantation within Urology?

	Extremely Important				Not At all Important	
	5	4	3	2	1	Don't Know
Importace of AUA Promoting Transplantation Within Urology						

D2. Approximately how many transplant patients do you see in a typical week?

- 0 - 10
- 11-25
- 26-50
- More than 50

D3. Please estimate the percentage of your transplant patients that see a community nephrologist outside of your institution.

- Less than 10%
- 11-25%
- 26-50%
- More than 50%

D4. Type of practice

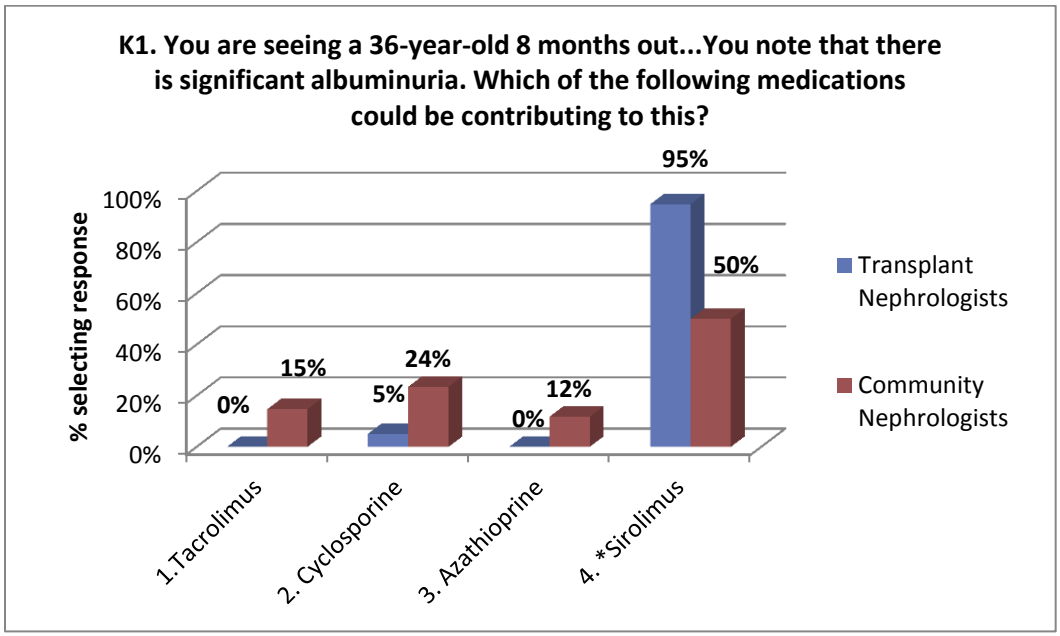
- Solo
- Single specialty group
- Multi-specialty group
- Hospital transplant center
- Other (please specify)

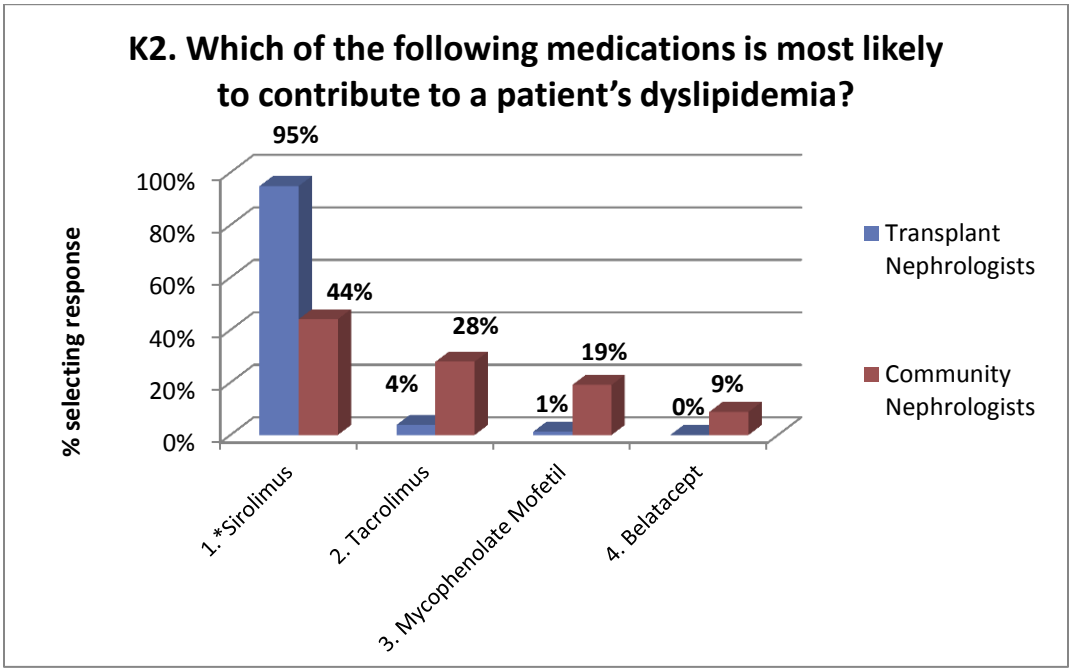
D7. Average travel distance for transplant patients under your care:

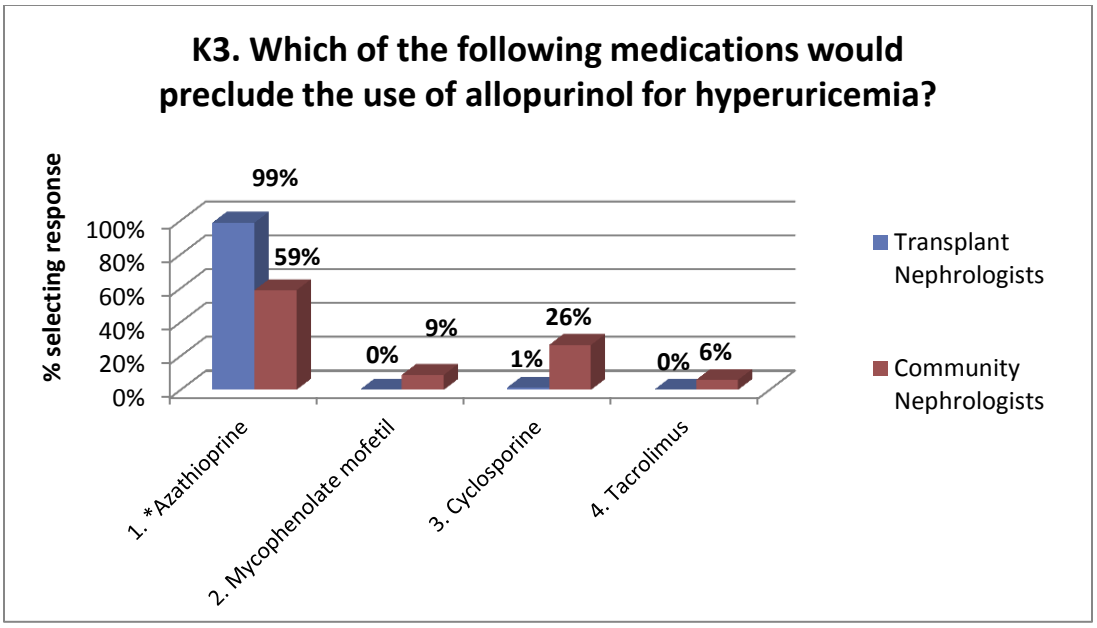
- 0-10 miles
- 11-25 miles
- 26-50 miles

More than 50 miles

Appendix 4 : Additional Community Nephrologist and Transplant Specialist Data Charts






K3. Which of the following medications would preclude the use of allopurinol for hyperuricemia?
% selecting response
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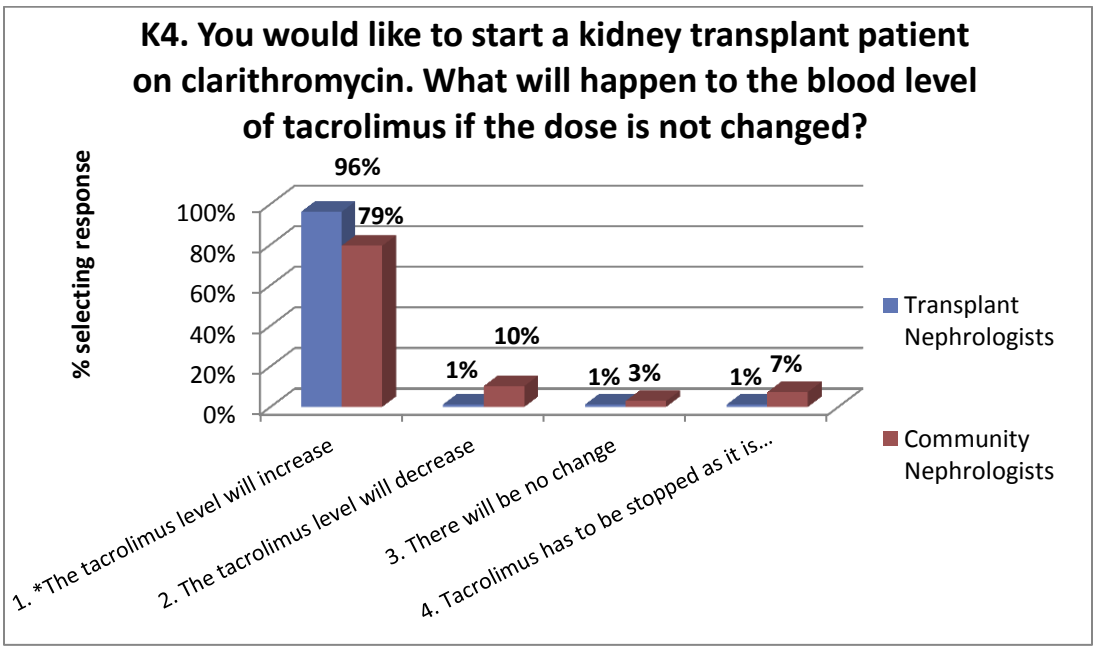
1. *Azathioprine
2. Mycophenolate mofetil
3. Cyclosporine
4. Tacrolimus
Transplant Nephrologists
Community Nephrologists


K4. You would like to start a kidney transplant patient on clarithromycin. What will happen to the blood level of tacrolimus if the dose is not changed?
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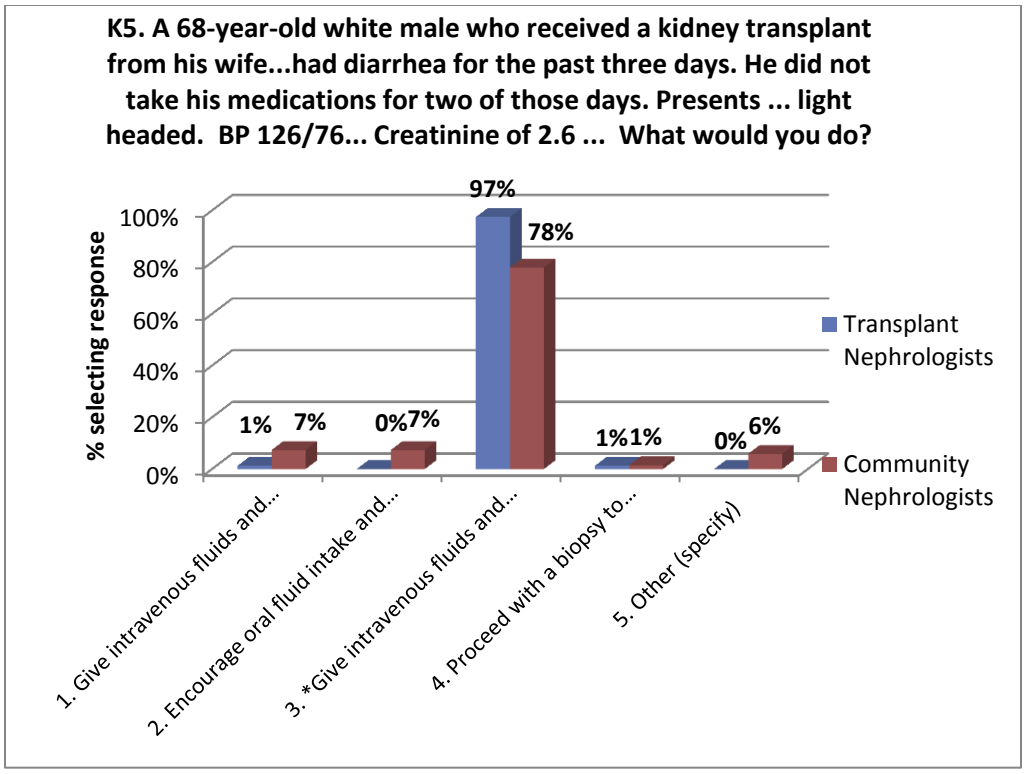
1. *The tacrolimus level will increase
2. The tacrolimus level will decrease
3. There will be no change
4. Tacrolimus has to be stopped as it is...
Transplant Nephrologists
Community Nephrologists


K5. A 68-year-old white male who received a kidney transplant from his wife...had diarrhea for the past three days. He did not take his medications for two of those days. Presents ... light headed. BP 126/76... Creatinine of 2.6 ... What would you do?
% selecting response
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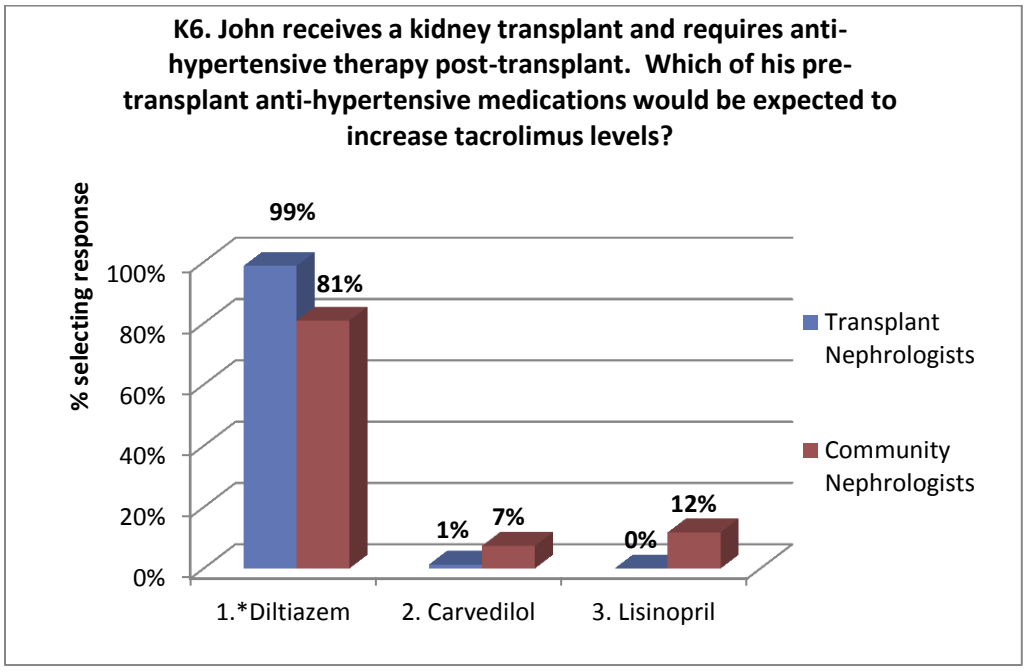
Transplant Nephrologists
Community Nephrologists
1. Give intravenous fluids and...
2. Encourage oral fluid intake and...
3. *Give intravenous fluids and...
4. Proceed with a biopsy to...
5. Other (specify)


K6. John receives a kidney transplant and requires anti-hypertensive therapy post-transplant. Which of his pre-transplant anti-hypertensive medications would be expected to increase tacrolimus levels?
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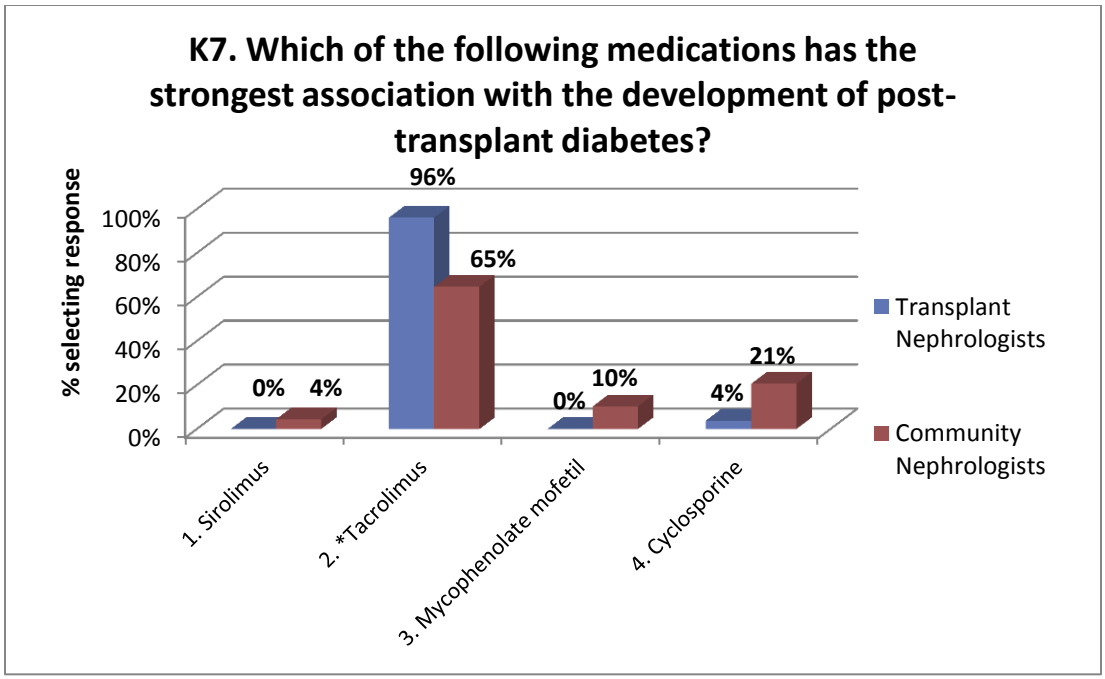
Transplant Nephrologists
Community Nephrologists
1.*Diltiazem
2. Carvedilol
3. Lisinopril


K7. Which of the following medications has the strongest association with the development of post-transplant diabetes?
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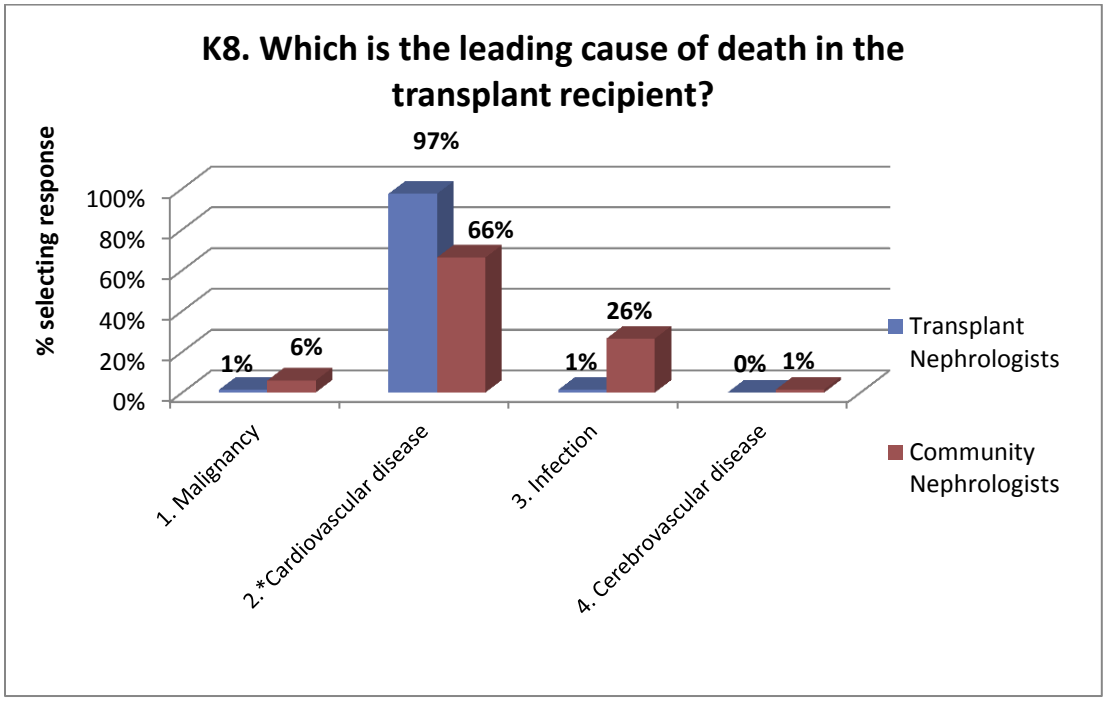
21%
1. Sirolimus
2. *Tacrolimus
3. Mycophenolate mofetil
4. Cyclosporine
Transplant Nephrologists
Community Nephrologists


K8. Which is the leading cause of death in the transplant recipient?
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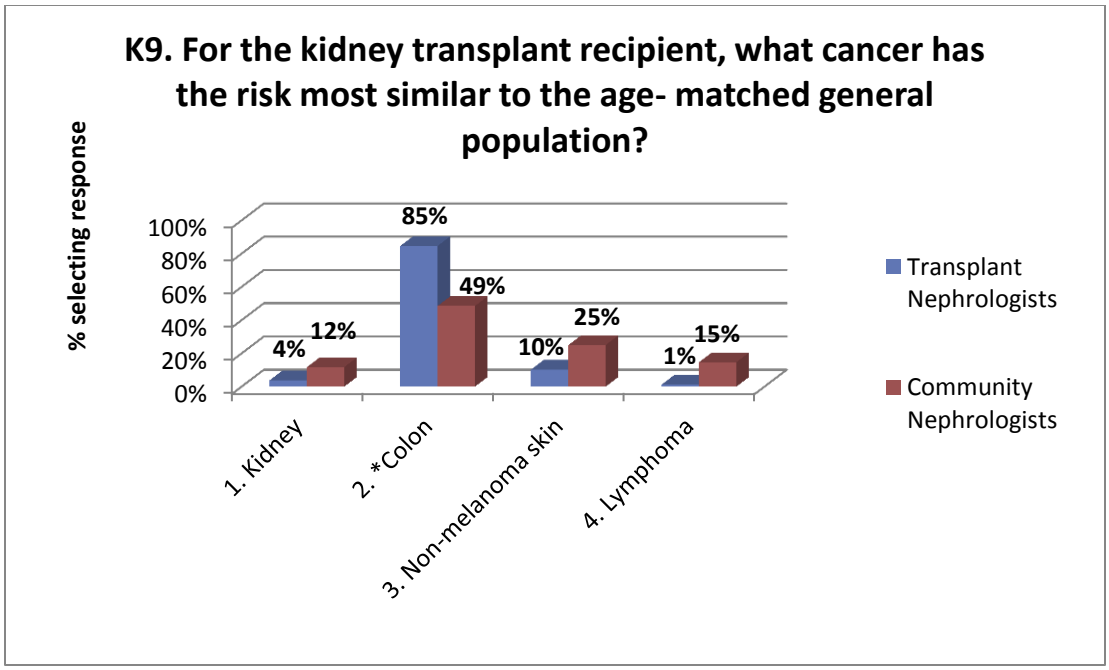
1%
1. Malignancy
2. *Cardiovascular disease
3. Infection
4. Cerebrovascular disease
Transplant Nephrologists
Community Nephrologists


K9. For the kidney transplant recipient, what cancer has the risk most similar to the age- matched general population?
% selecting response
100%
80%
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4%
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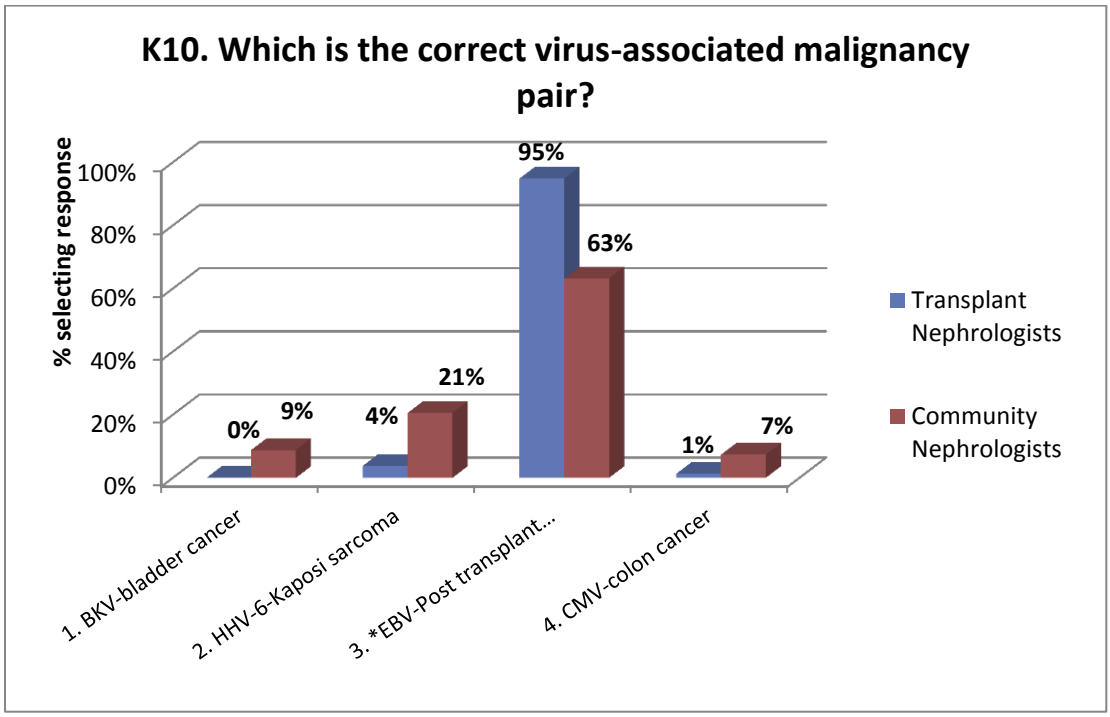
85%
49%
10%
25%
1%
15%
1. Kidney
2. *Colon
3. Non-melanoma skin
4. Lymphoma
Transplant Nephrologists
Community Nephrologists


K10. Which is the correct virus-associated malignancy pair?
% selecting response
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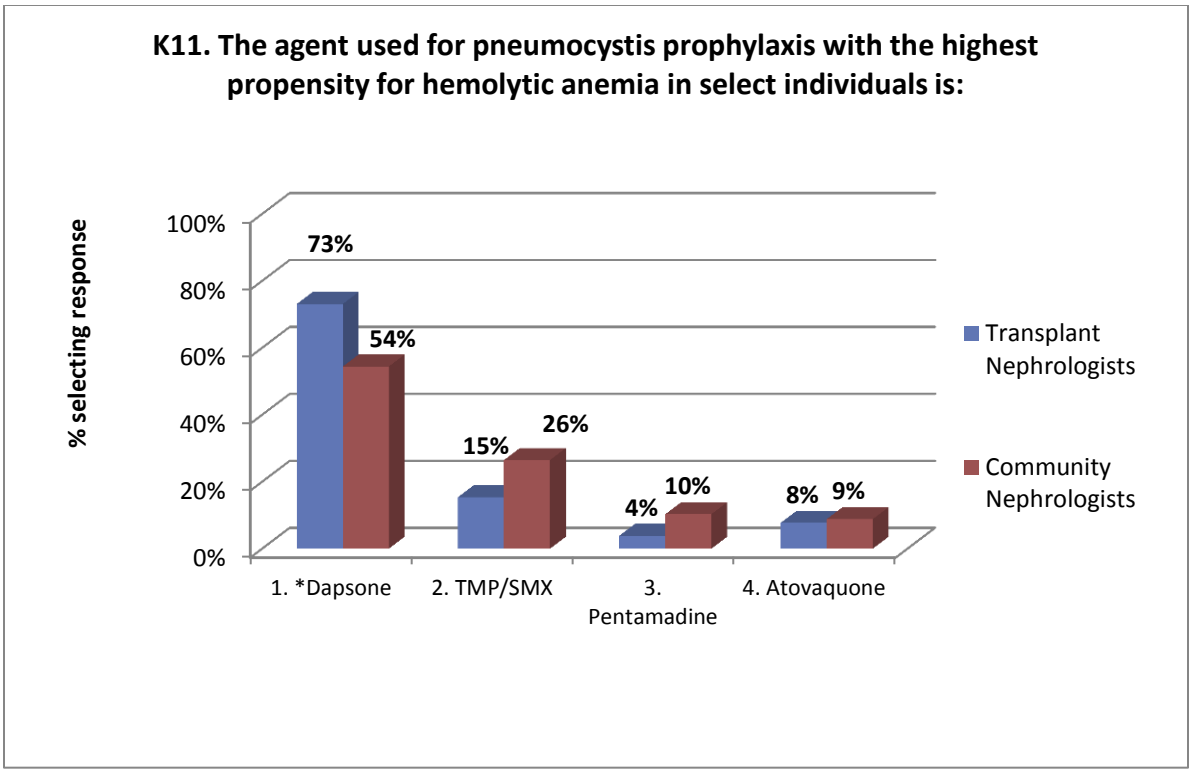
0%
9%
4%
21%
95%
63%
1%
7%
1. BKV-bladder cancer
2. HHV-6-Kaposi sarcoma
3. *EBV-Post transplant...
4. CMV-colon cancer
Transplant Nephrologists
Community Nephrologists


K11. The agent used for pneumocystis prophylaxis with the highest propensity for hemolytic anemia in select individuals is:
% selecting response
100%
80%
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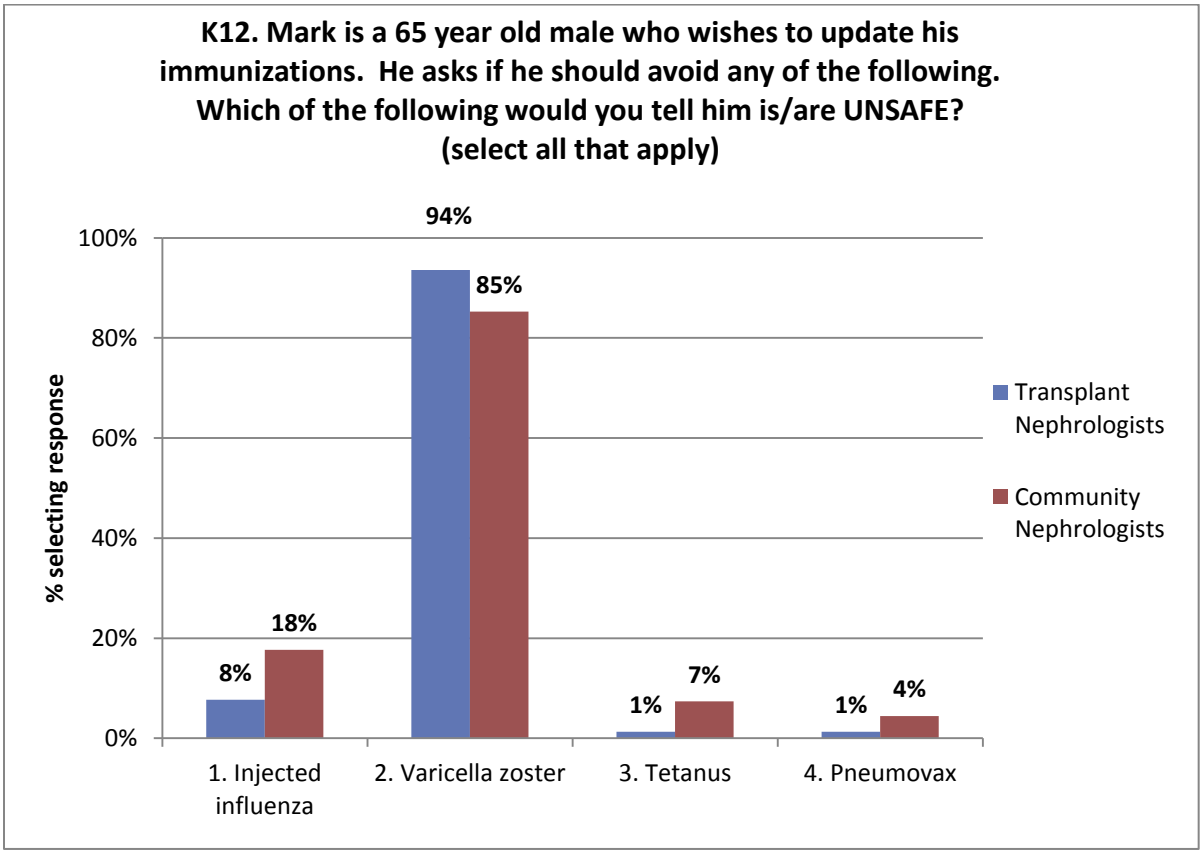
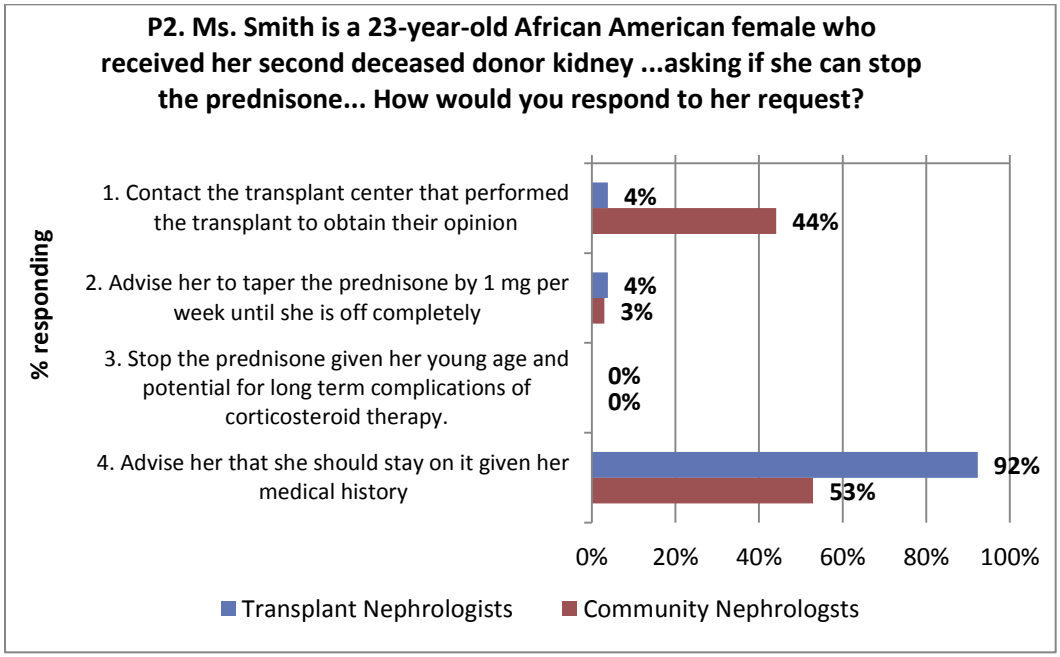
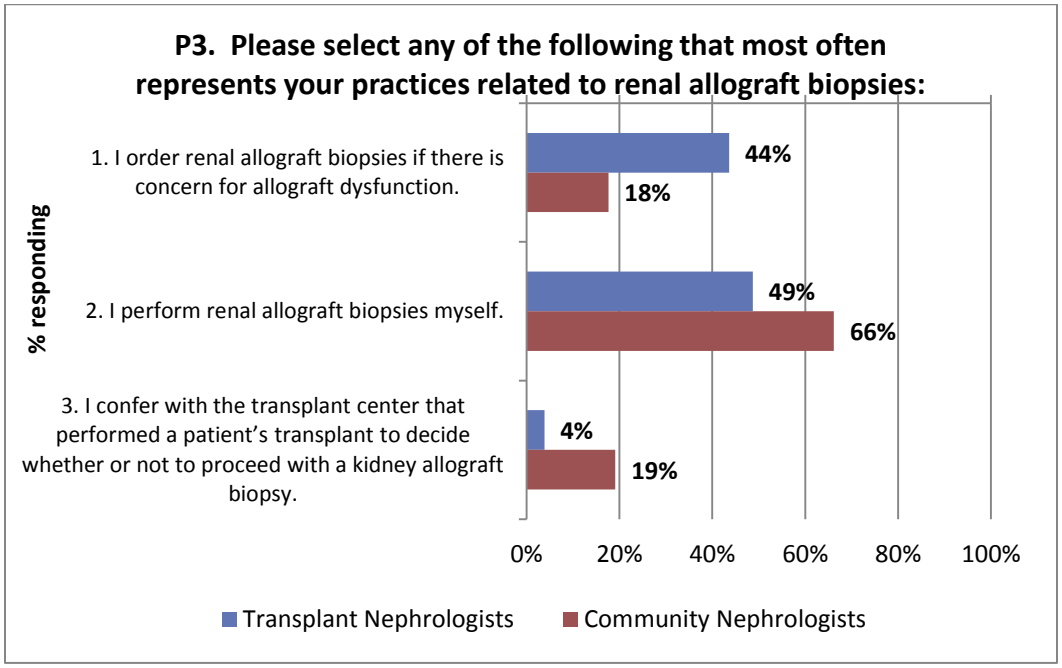
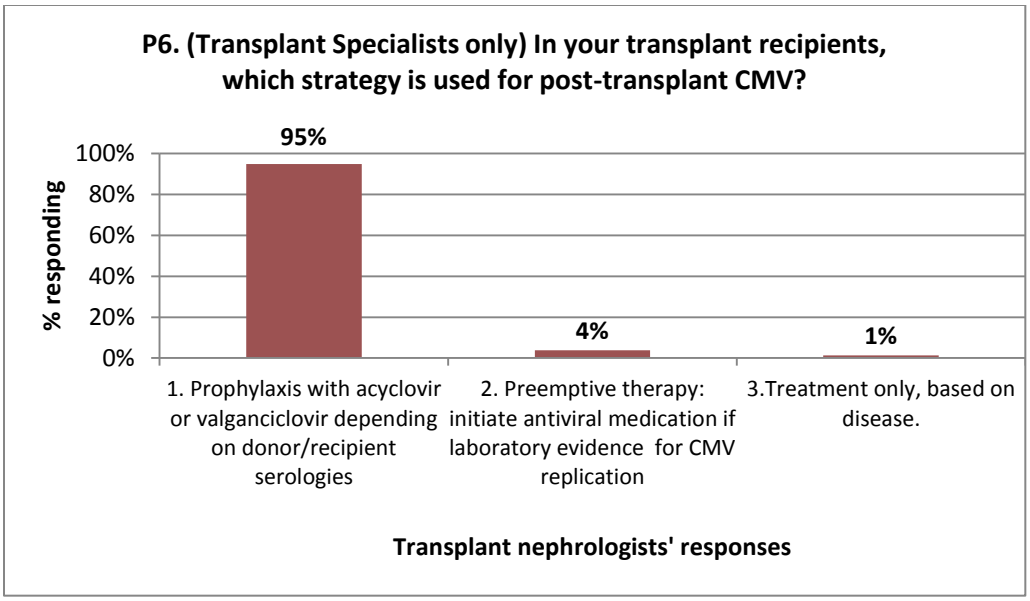
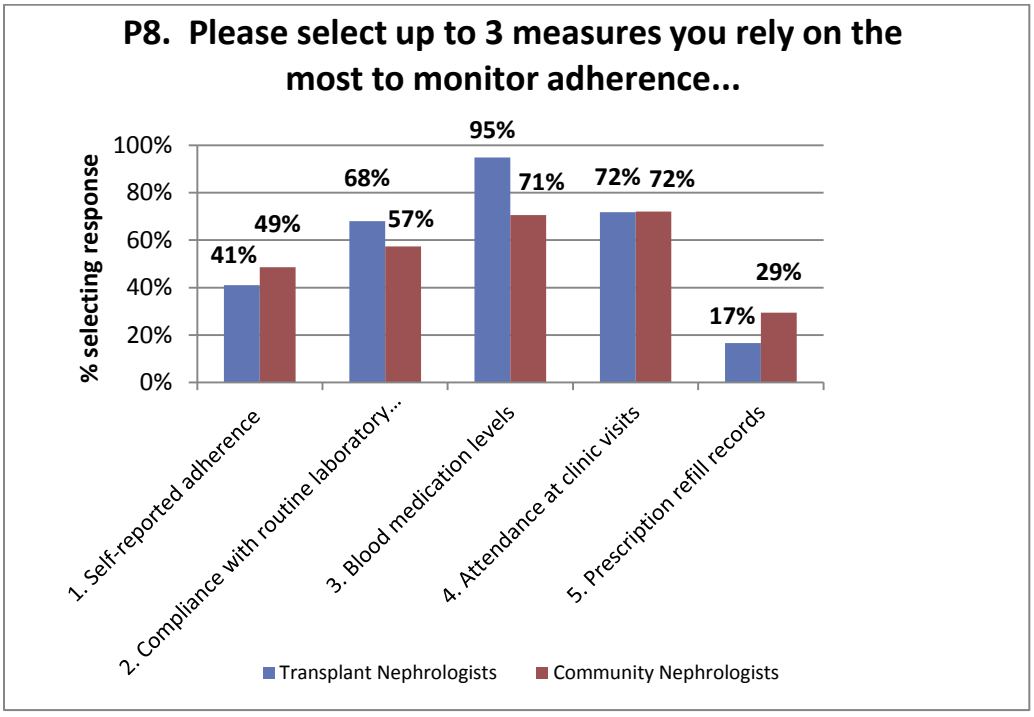
73%
54%
15%
26%
4%
10%
8%
9%
1. *Dapsone
2. TMP/SMX
3. Pentamadine
4. Atovaquone
Transplant Nephrologists
Community Nephrologists


K12. Mark is a 65 year old male who wishes to update his immunizations. He asks if he should avoid any of the following. Which of the following would you tell him is/are UNSAFE? (select all that apply)
% selecting response
100%
80%
60%
40%
20%
0%
94%
85%
18%
8%
7%
1%
4%
1%
1. Injected influenza
2. Varicella zoster
3. Tetanus
4. Pneumovax
Transplant Nephrologists
Community Nephrologists

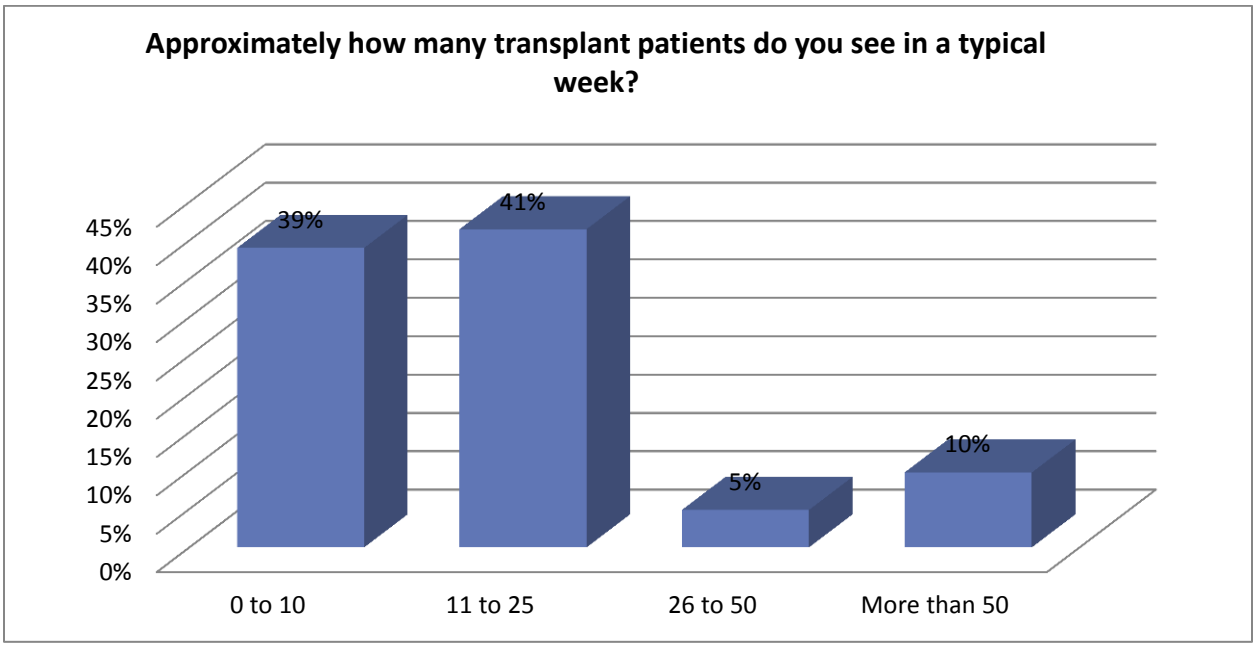

P2. Ms. Smith is a 23-year-old African American female who received her second deceased donor kidney ...asking if she can stop the prednisone... How would you respond to her request?
% responding
1. Contact the transplant center that performed the transplant to obtain their opinion
4%
44%
2. Advise her to taper the prednisone by 1 mg per week until she is off completely
4%
3%
3. Stop the prednisone given her young age and potential for long term complications of corticosteroid therapy.
0%
0%
4. Advise her that she should stay on it given her medical history
92%
53%
0%
20%
40%
60%
80%
100%
Transplant Nephrologists
Community Nephrologsts

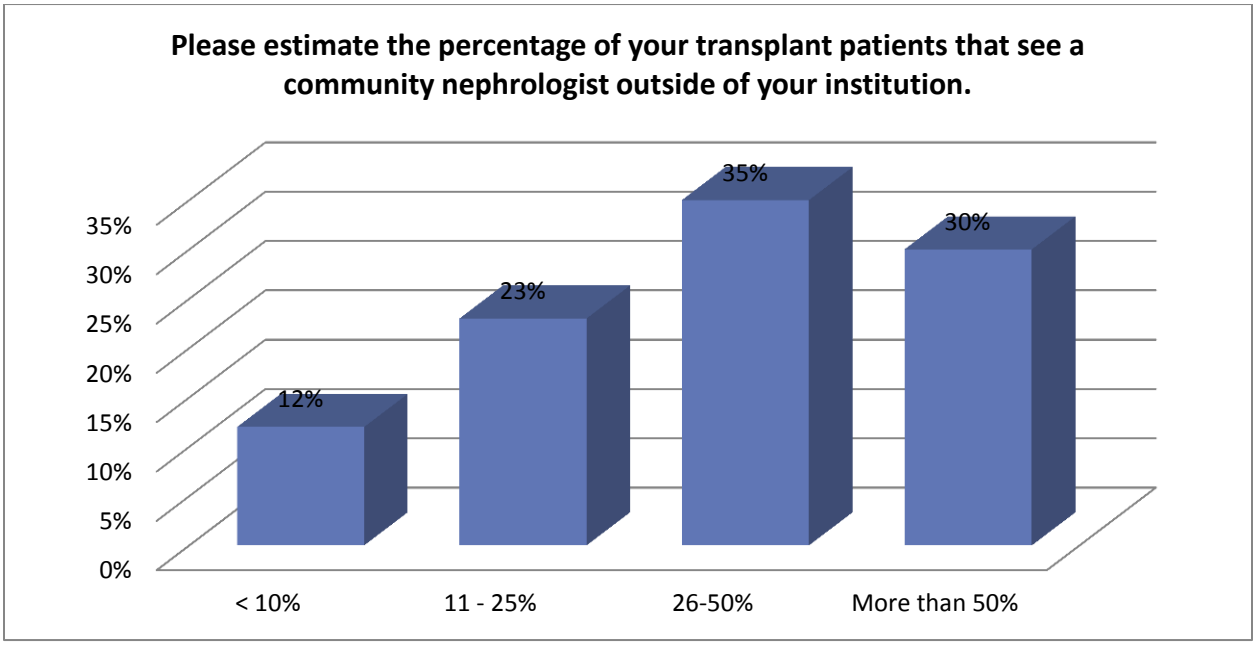

P3. Please select any of the following that most often represents your practices related to renal allograft biopsies:
% responding
1. I order renal allograft biopsies if there is concern for allograft dysfunction.
44%
18%
2. I perform renal allograft biopsies myself.
49%
66%
3. I confer with the transplant center that performed a patient's transplant to decide whether or not to proceed with a kidney allograft biopsy.
4%
19%
0%
20%
40%
60%
80%
100%
Transplant Nephrologists
Community Nephrologists

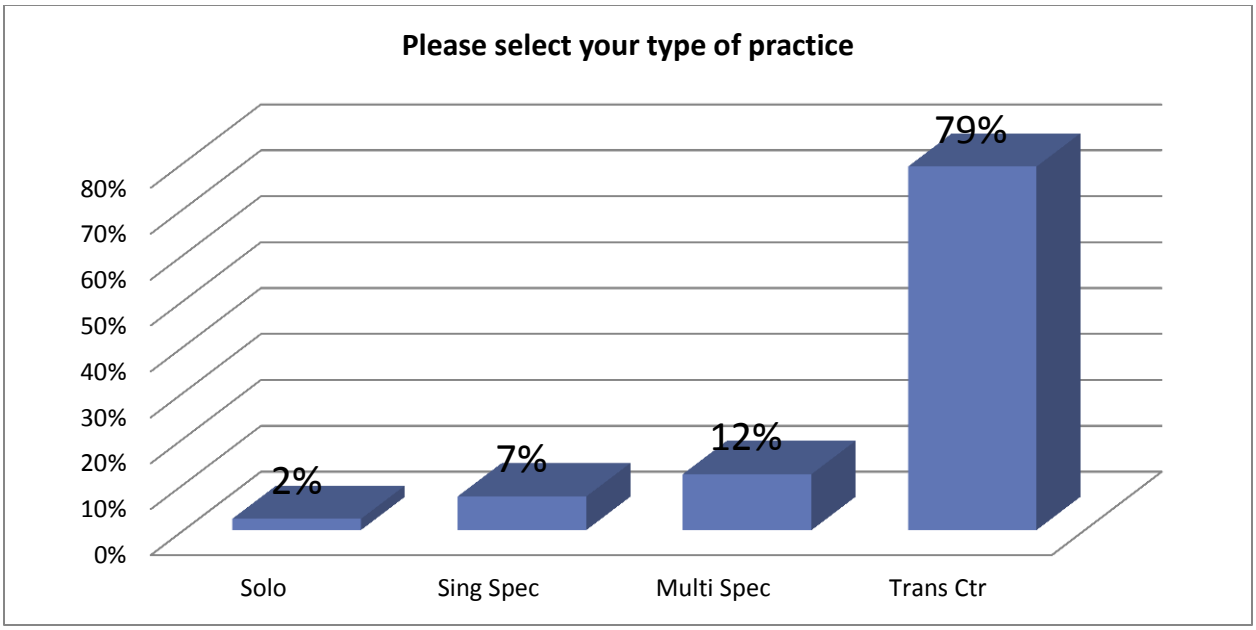

P6. (Transplant Specialists only) In your transplant recipients, which strategy is used for post-transplant CMV?
% responding
100%
80%
60%
40%
20%
0%
95%
4%
1%
1. Prophylaxis with acyclovir or valganciclovir depending on donor/recipient serologies
2. Preemptive therapy: initiate antiviral medication if laboratory evidence for CMV replication
3.Treatment only, based on disease.
Transplant nephrologists' responses


P8. Please select up to 3 measures you rely on the most to monitor adherence...
% selecting response
100%
80%
60%
40%
20%
0%
41%
49%
68%
57%
95%
71%
72%
72%
17%
29%
1. Self-reported adherence
2. Compliance with routine laboratory...
3. Blood medication levels
4. Attendance at clinic visits
5. Prescription refill records
Transplant Nephrologists
Community Nephrologists

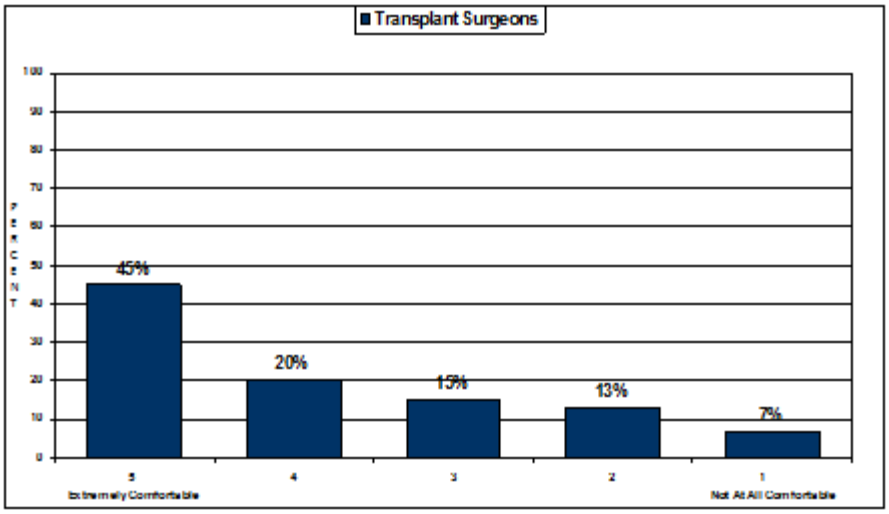
Appendix 6.: Additional Transplant Surgeon Data Charts



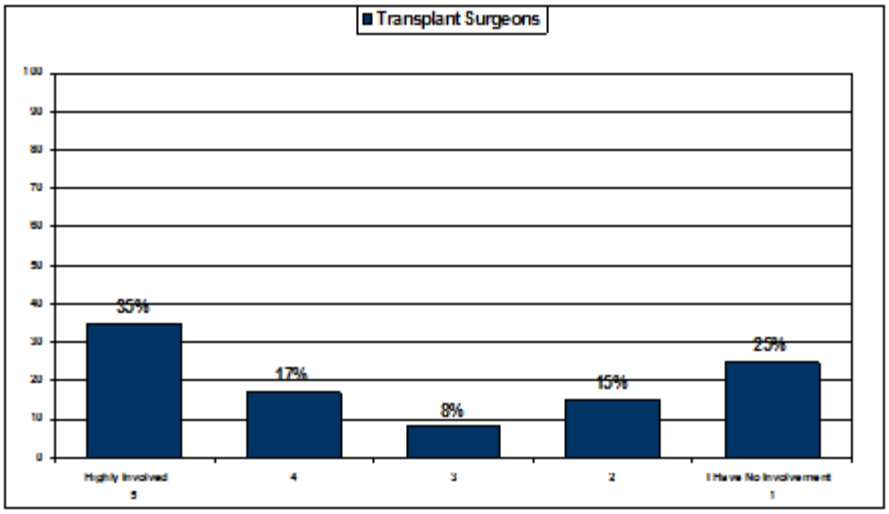



Please select your type of practice
80%
70%
60%
50%
40%
30%
20%
10%
0%
2%
7%
12%
79%
Solo
Sing Spec
Multi Spec
Trans Ctr

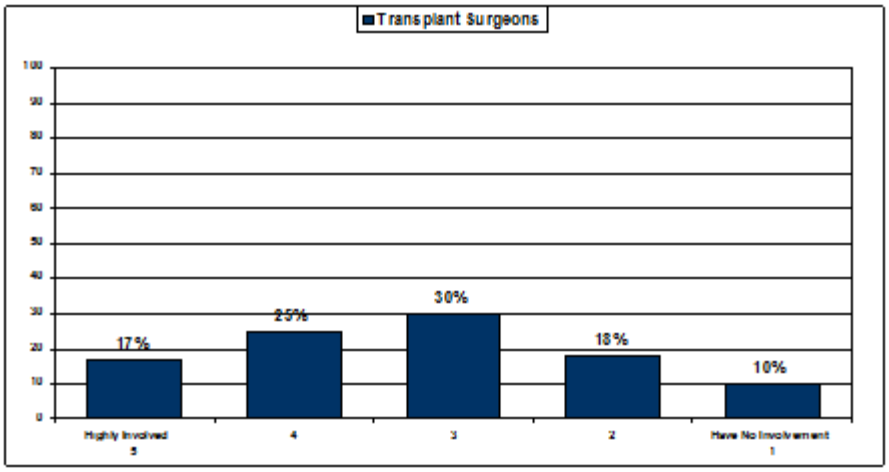
Comfort Level Monitoring Immunosuppression



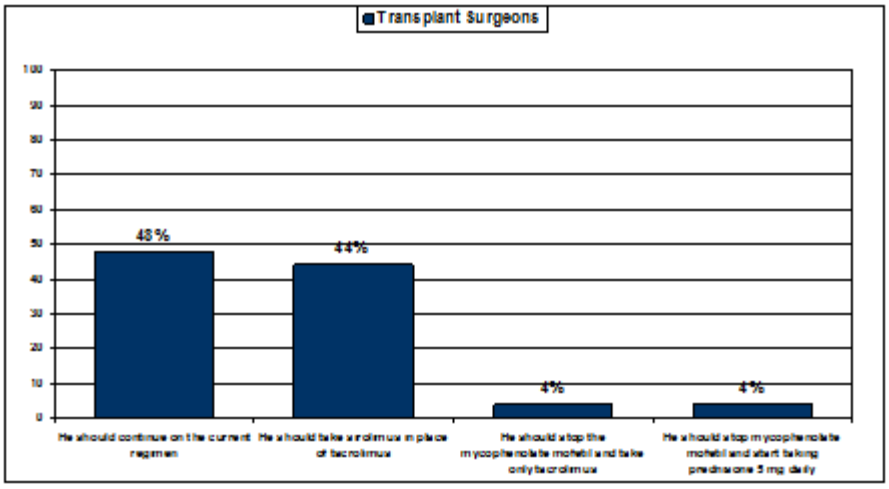
Level of Involvement with Adjusting Immunosuppression Therapy



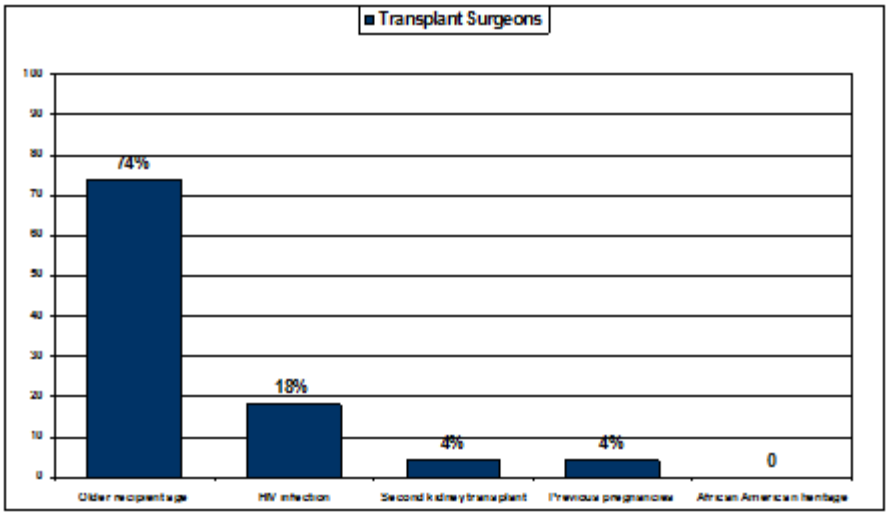
Appropriate Level of Involvement for Community Nephrologist with Respect to Adjusting Immunosuppression



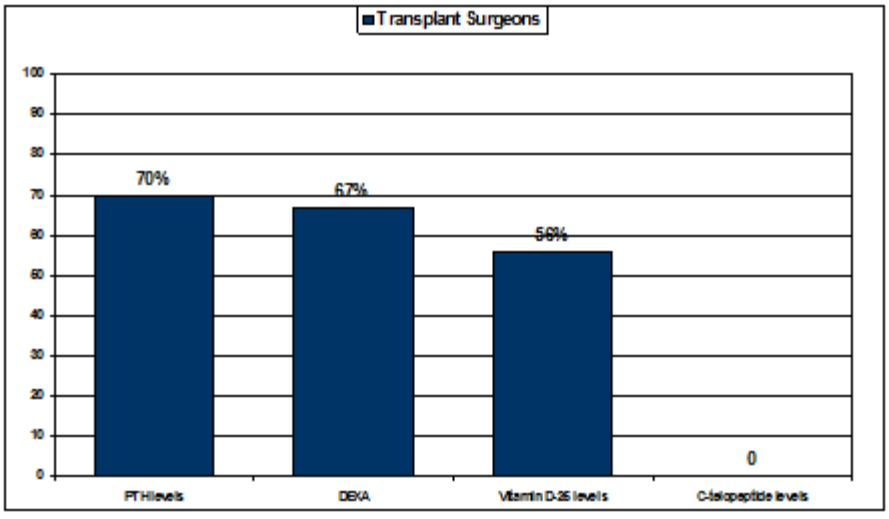
A 65-year-old male patient with ESRD from polycystic kidney disease has had a living unrelated kidney transplant from his then 50-year-old wife for 10 years. He is maintained on tacrolimus and mycophenolate mofetil without corticosteroids. Renal allograft function has been excellent without any proteinuria and no history of rejection. He has had recurrent squamous cell cancers of the skin. He comes to you to ask if he should take less immunosuppression. What would you advise?

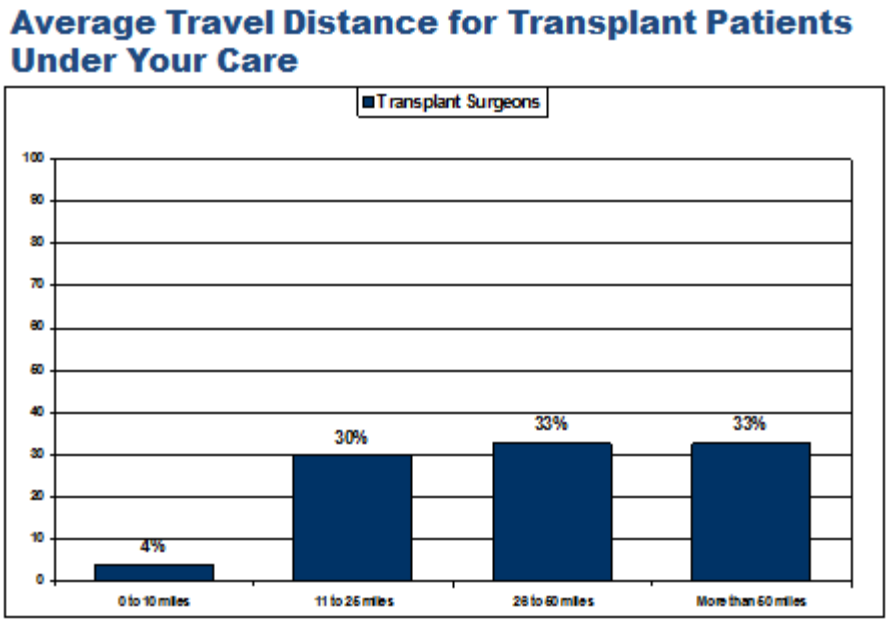


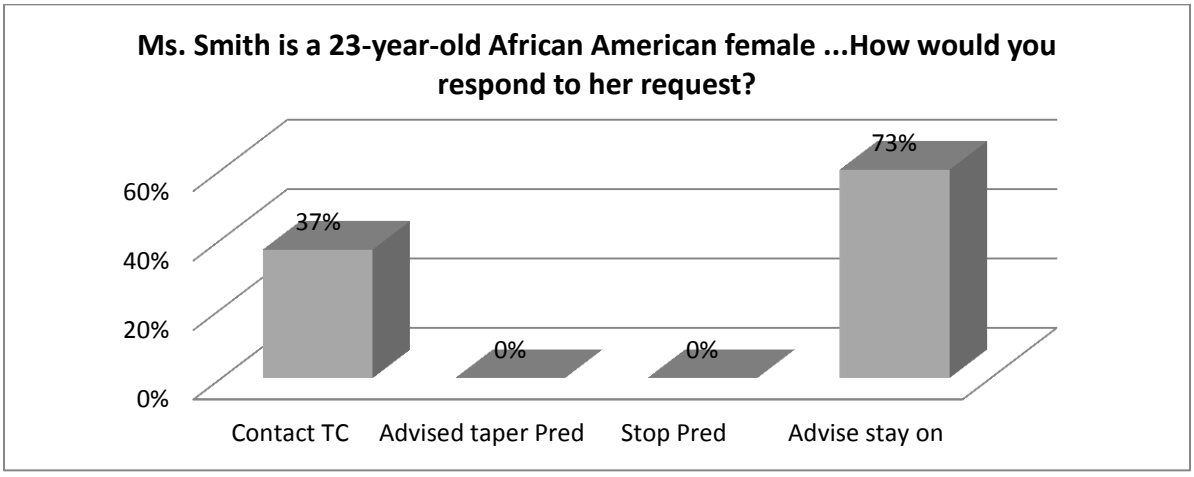
Which of the following is not a risk factor for acute cellular rejection?



Which of the following do you routinely utilize in monitoring transplant recipients for post-transplant bone disease?




Average Travel Distance for Transplant Patients Under Your Care
Transplant Surgeons
100
90
80
70
60
50
40
30
20
10
0
4%
30%
33%
33%
0 to 10 miles
11 to 25 miles
26 to 50 miles
More than 50 miles


Ms. Smith is a 23-year-old African American female ...How would you respond to her request?
60%
40%
20%
0%
37%
0%
0%
73%
Contact TC
Advised taper Pred
Stop Pred
Advise stay on