Effective Practices in RENAL CELL CARCINOMA Programs
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Renal cell carcinoma (RCC) is the most common type of kidney cancer, accounting for around 90% of all kidney cancers.\(^1\) Early stage renal cancers tend to have a better prognosis, while advanced (metastatic) cancers have a worse prognosis.\(^2\) At diagnosis, approximately 20 percent of patients present with metastatic renal cell carcinoma (mRCC).\(^3\)

ACCC established the Improving Quality Care in Renal Cell Carcinoma project to offer healthcare providers information to better care for patients with renal cell carcinoma and raise awareness among healthcare providers about the challenges related to this disease. Learn more at: accc-cancer.org/RCC.

- Increase awareness about the special needs of caring for less common cancers in the community setting, including how to stay up-to-date on the latest clinical information and treatment protocols around renal cell carcinoma.
- Identify effective practices, including education materials and resources, for supporting renal cell carcinoma patients through diagnosis, treatment, and follow-up, and how to best implement these effective practices in the community setting.
- Establish Community Resource Centers (CRCs) for renal cell carcinoma in which community-based programs with expertise in meeting the unique needs of patients with RCC are available to answer questions and provide direction to other programs.

The ACCC Center for Provider Education partnered with the Kidney Cancer Association (www.kidneycancer.org) and established an expert Advisory Committee to help guide the project. With the Advisory Committee’s input and oversight, ACCC developed a survey designed to:

- Assess the barriers to caring for patients with metastatic RCC
- Identify gaps in provider knowledge and resources about RCC
- Identify effective practices and components of a strong RCC cancer program.

(Note: 101 responses from programs were received. This represents approximately 5 percent of ACCC member programs contacted.)
HIGHLIGHTS OF THE ACCC 2015 RENAL CELL CARCINOMA SURVEY

Who Took Our Survey?

<table>
<thead>
<tr>
<th>Profession</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Physicians</td>
<td>58%</td>
</tr>
<tr>
<td>RNs</td>
<td>17%</td>
</tr>
<tr>
<td>Social workers</td>
<td>12%</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>8%</td>
</tr>
<tr>
<td>Physician assistants</td>
<td>2%</td>
</tr>
<tr>
<td>Nurse practitioners</td>
<td>2%</td>
</tr>
<tr>
<td>Dietitians</td>
<td>1%</td>
</tr>
</tbody>
</table>

Respondents Report These Challenges When TREATING Patients with mRCC

- Early recognition of toxicities and appropriate management: 83%
- Choosing the most appropriate agent among each line of therapy: 77%
- A lack of treatment pathways for mRCC: 74%
- Transitioning treatment across several lines of therapy: 61%
- Keeping current on the range of therapeutic options available: 60%

Respondents Report These Challenges When SUPPORTING Patients with mRCC

- Lack of regional experts in mRCC: 60%
- Managing transitions of care between healthcare settings: 50%
- Access to clinical trials for patient enrollment: 47%
- Lack of regional referral centers: 40%
- Access to local community resources: 34%
- Patients’ lack of compliance with treatment regimens and follow-up appointments: 34%

Respondents Report That They Treat Their mRCC Patient with:

- First-line therapy: 75%
- Second-line therapy: 67%
- Third-line therapy and beyond: 52%
- Refer mRCC patients to other facilities for treatment: 49%
When treating patients with mRCC, 31% of prescribing clinicians report that they are EXTREMELY CONFIDENT in identifying the most appropriate treatment options with first-line therapy.

**HIGHLIGHTS OF THE ACCC 2015 RENAL CELL CARCINOMA SURVEY**

**When Selecting First-line mRCC Treatments, Respondents Rated the Following Criteria as VERY IMPORTANT**

1. High efficacy in overall survival (71%)
2. Treatments which allow patients to continue their activities of daily living (68%)
3. Treatments that have high efficacy in patients with heavy tumor burden (64%)
4. Treatment with high efficacy in extending progression-free survival (PFS) (64%)

**When Selecting Second-line mRCC Treatments, Respondents Rated the Following Criteria as VERY IMPORTANT**

1. Treatments which allow patients to continue their activities of daily living (73%)
2. Treatments with high efficacy in producing progression-free survival (60%)
3. Treatments with high efficacy in producing objective tumor response (60%)

71% of multidisciplinary team members—including clinicians and non-clinicians—are MOSTLY to EXTREMELY CONFIDENT in discussing treatment planning for mRCC.

**Has Your Program Seen an Increase in Patients and/or Caregivers Wanting to Discontinue Treatment?**

- No: 39%
- Yes: 27%
- Sometimes: 35%

**Percentage of Respondents ALWAYS USE These Treatment Guidelines for the Management of mRCC**

- National Comprehensive Cancer Network (NCCN): 65%
- American Society of Clinical Oncology (ASCO): 34%
- American Urological Association (AUA): 15%

**Do Your mRCC Patients Have Access to a Financial Advocate?**

- Have access: 68%
- Sometimes have access: 28%
- Do not have access: 4%

**Top 3 Elements Contributing to a Strong mRCC Program**

- A multidisciplinary cancer management team with all disciplines involved: 77%
- Presence of tumor boards: 50%
- Patient-focused decision making within the program: 50%
HIGHLIGHTS OF THE ACCC 2015 RENAL CELL CARCINOMA SURVEY

Based on PRACTICE NEEDS, Respondents Want Additional Information On...

- Advanced care planning (future healthcare decisions) 64%
- Clinical trial options 60%
- Treatment planning for locally advanced, unresectable disease 59%
- Second-line treatment options for advanced mRCC 59%
- Adherence strategies for oral medications 56%
- Diagnosis of mRCC 55%

Based on SUPPORTIVE CARE NEEDS, Respondents Want Additional Information On...

- Clinical trial information 72%
- Home and community support during treatment 68%
- Distress screening 68%
- Information on financial assistance and cost of care 67%
- Transitioning patients between care settings 67%

Respondents Report That These Educational Resources or Tools Would Be “MOST TO EXTREMELY USEFUL” in Treating Patients with mRCC

- Financial assistance tools (69%)
- Patient brochures explaining RCC (65%)
- Anatomical pictures or interactive videos of the kidney organs to illustrate the location of the disease at diagnosis and at subsequent visits (64%)
- Distress screening tools (59%)
- Assessment and tracking tools for newly-diagnosed patients (58%)
- Patient decision making tools (54%)
- Clinical trial information and online links (54%)

References


3. SEER Surveillance Epidemiology and End Results. Seer.cancer.gov.
Arizona Oncology Associates
Arizona

Arizona Oncology is one of the largest oncology groups in Arizona, with many community-based locations throughout the state including Chandler, Scottsdale, Deer Valley, Flagstaff, Glendale, Green Valley, Nogales, Oro Valley, Phoenix, Prescott Valley, Safford, Scottsdale, Sedona, and Tucson. Over the last two years, Arizona Oncology treated an average of 178 patients per year with a diagnosis of renal cell carcinoma (RCC).

Expertise in Clinical Trials

As an affiliate of US Oncology, one of the largest networks of integrated community-based oncology practices, Arizona Oncology has access to a wide network of cancer clinical trials. The practice also participates in a number of independent clinical trials. “Our research program has been one of our strengths, and we always try to have clinical trial options available to patients at various stages of disease,” said Christopher DiSimone, MD, PhD, medical oncologist at Arizona Oncology.

In addition to serving on the Genitourinary Committee of US Oncology for 10 years, Dr. DiSimone has served as a principal investigator in a number of GU-oriented trials, including renal cell carcinoma trials. Multiple members of the GU group at Arizona Oncology have experience as PIs on clinical trials, bringing their clinical trials expertise to their local patient population.

High enrollment in clinical trials in the last five years has allowed the practice access to a continual flow of new trials. This is a great benefit for cancer patients, particularly in communities like Tucson, where the options for local clinical trials may be limited.

A dedicated research staff, which includes a team of five research nurses, clinical research coordinators, and board-certified physicians, continually screen RCC patients who may be eligible for an open clinical trial. The research nurses handle the education, consent process, and navigation of patients on clinical trials, working collaboratively with physicians and patients before, during, and after treatment to monitor the patients. “That’s been a strong feature of our practice, and we’ve had an emphasis in hiring nurses as our primary points of contact in our research program. They’re highly educated and able to provide a lot of education for the patients,” said Dr. DiSimone.
Oral Education & Checklist

More than half (56 percent) of respondents to the ACCC Improving Quality Care in Renal Cell Carcinoma Survey indicated they wanted additional information on adherence strategies for oral medications.

Arizona Oncology uses a checklist and questionnaire with patients beginning oral oncolytic therapy to address possible compliance issues upfront and throughout treatment (see page 12). “The tool allows us to see if patient concerns have been addressed, to verify that patients understand how to take the medication, to confirm that the prescription is correct, and patients understand what to do if they miss a dose,” said Dr. DiSimone.

Usually, a nurse practitioner or physician assistant will go through the checklist with patients once they have been prescribed an oral agent. One component of the list addresses any financial barriers that may impede patients from receiving their medication.

Another item on the checklist lists the toxicities to go over with the patient. “Fatigue is one of the biggest issues that has to be addressed,” said Dr. DiSimone. In addition, RCC patients frequently experience oral ulcers and gastrointestinal issues from oral medication.

“The key is that early on, when you start the medications, you need to see RCC patients frequently: weekly, or bi-weekly, until you get them set with a good schedule and minimal side effects,” advised Dr. DiSimone. Compliance issues are also addressed with the checklist. For example, are patients missing any dosages and if so, why? Patients are often non-compliant when they experience toxicities, making frequent appointments an important part of oral adherence.

Other suggestions from Arizona Oncology to improve adherence include instructing patients to keep a journal and tracker for prescription refills. Arizona Oncology goes the extra step towards mitigating missed refill issues by offering in-office dispensing.

All newly-diagnosed cancer patients receiving chemotherapy meet one-on-one with an oncology nurse for a formal chemotherapy education session prior to the start of treatment; proof of patient education is documented in the patient’s electronic health record. The educational material includes but is not limited to:

- Extensive patient education material
- Disease- and drug-specific information
- Drug monographs
- Dietary information
- Potential side effects
- Chemotherapy education book
- Chemotherapy education sheet

- Lab value and low blood count information
- Neutropenic precautions
- Support information related to the specific disease.

This information (provided in English) is available in over 100 different languages via translation through the ENLASO Translation support resource.

Prior to the initiation of chemotherapy, each patient meets with an Arizona Oncology Patient Benefit Representative (PBR) to discuss patient out-of-pocket responsibilities and address patients’ financial questions. The PBRs assist patients with applications for budgeted payments, financial support, and additional payment sources, such as Medicaid.

Supportive Care

Arizona Oncology supportive care services include a nutritionist, acupuncture, massage, cancer support groups, and survivorship. Survivorship discussions begin at diagnosis and continue through the end of treatment. The development of a formal survivorship program has been extremely beneficial for patients. “We equip our patients with the necessary information to address the long-term effects of treatment and provide continued clinical and non-clinical after-treatment patient support,” said Roberta Kafora, RN, MSN, OCN, director, Practice & Clinical Operations at Arizona Oncology.

The Arizona Oncology Foundation raises money primarily to provide financial support for patients experiencing financial barriers. Transportation to and from treatment or appointments can be an issue that the Foundation is able to alleviate with gas cards or monetary assistance, as well as outreach to community programs such as the American Cancer Society’s Road to Recovery.

In terms of general financial assistance, Arizona Oncology employs financial counselors who work to obtain assistance for patients with co-pays or burdensome medical expenses. Dr. DiSimone said the practice has seen great success in this area, with a majority of patients paying little to nothing out-of-pocket for oral medication. This success stems from the hard work of the financial counseling staff in seeking foundation assistance, pharmaceutical company assistance, or obtaining free drugs through programs for uninsured patients.

Arizona Oncology also offers palliative care as part of their comprehensive compassionate care. Palliative care nurse practitioners work closely with the multidisciplinary team to coordinate compassionate care at all stages of their cancer treatment and during follow-up care. The practice also has a well-established relationship with a local hospice service for patients requiring this type of care.
A PERSONALIZED, MULTIDISCIPLINARY APPROACH TO RCC TREATMENT

Fox Chase Cancer Center
Philadelphia, Pennsylvania

Collaborative multidisciplinary care, access to clinical trials, and an emphasis on developing personalized treatment plans tailored to each individual patient have led the Fox Chase Cancer Center Kidney Department to be one of the leaders in the northeast. One of the nation’s first cancer hospitals and one of the first to receive NCI designation as a comprehensive cancer center, Fox Chase is now part of the Temple University Health System. As a tertiary referral center, Fox Chase treats a high number of patients with renal cell carcinoma (RCC); the surgery group typically performs between 200-300 kidney cancer-related procedures annually.

A Personalized Approach Through Multidisciplinary Care

Within the Genitourinary Oncology group, the kidney cancer team comprises approximately 20 providers: medical, surgical, and radiation oncologists, in addition to advanced care practitioners and the nurse navigation team. Among these are several national leaders in kidney cancer research including Robert Uzzo, MD, who led the steering committee for the American Urological Association guidelines for the management of localized kidney cancer. The team also holds multidisciplinary meetings outside of tumor boards on a regular basis to discuss emerging data in recent clinical trials, and evaluate new research opportunities.

The nurse navigators serve as the first point of contact for new patients. As “gatekeepers” the navigators decide, based on the presumed stage of disease, whether patients are first seen by surgery or medical oncology.

“We’re entering the era of personalized medicine,” said Marc Smaldone, MD, MSHP, assistant professor of Urologic Oncology, Department of Surgery at Fox Chase. Treatment decisions for patients presenting for the evaluation of locally advanced and metastatic renal cancer can often be complex decisions. “A personalized approach to treatment requires a multidisciplinary evaluation at the initiation, either at diagnosis or referral. That helps to determine the role and timing of targeted therapies and immunotherapies and what the role of surgical therapy might be,” said Dr. Smaldone. All of these decisions depend on the nature of presentation, the burden of disease, pre-existing medical and cancer history, and histology of the primary tumor.

For renal cell carcinoma patients presenting with complex histories, each case is reviewed and a conference is attended by medical, surgical, and radiation oncologists; radiologists; and pathologists. Then, the group develops a tailored personalized treatment plan. At the same time, the patient is also screened for clinical trial eligibility.

The recently developed Cancer Genome Institute at Fox Chase is focused on the importance of gene mapping to determine precise medical treatment for individuals.

“In particular, kidney cancer is where a lot of the research efforts here are being led,” shared Dr. Smaldone. In addition to optimizing personalized therapy, Fox Chase is also directing efforts towards the development and implementation of tools to measure patient-centered outcomes focused on the patient’s cancer treatment experience and measuring quality of life.

“Ask Me About Clinical Trials”

The clinical trials program is a major component of cancer care at Fox Chase. “We constantly have a changing and growing portfolio of clinical trials, particularly for kidney cancer,” said Daniel Geynisman, MD, assistant professor, Medical Oncology at Fox Chase. In addition to many investigator-initiated studies and a robust Phase I clinical trials program, Fox Chase also participates in a number of consortium groups and works with pharmaceutical companies for clinical trials using some of the newest and most promising drugs. This allows Fox Chase to offer patients a wide variety of kidney cancer clinical trials, including trials for patients at high-risk prior to surgery and for patients at high-risk after surgery, as well as metastatic, neoadjuvant, and salvage trials.

“Our group’s philosophy is that at the time of initial evaluation, and then at various time points during their subsequent care, each patient is evaluated and screened for all eligible clinical trials along the continuum of their cancer care,” said Dr. Smaldone.
All patients on clinical trials have a dedicated research nurse assigned to them, in addition to the regular clinic nurse and their physician or PA, further emphasizing the team approach to cancer care.

The nurse navigators also play a role in the initial screening process since a substantial number of patients come to Fox Chase for a specific clinical trial. (There is a universal philosophy at Fox Chase to promote clinical trials accrual; to generate patient engagement, staff members wear buttons that say “Ask Me About Clinical Trials.”)

Managing All Aspects of Care

“There’s a growing recognition that survivorship needs of cancer patients are often overlooked,” said Dr. Smaldone. “A cancer diagnosis and the need for subsequent treatment substantially impacts many factors besides a patient’s direct physical health: their mental status, health behaviors, their professional and personal identity, and certainly anxiety regarding their financial standing."

At Fox Chase, the treating physician serves as the point of contact responsible for recognizing survivorship needs and then directing patients to the appropriate supportive services. These supportive services are a collaborative effort between social work, physical therapy, financial support services, psychiatry, pain management, palliative care, and a number of other groups. Fox Chase established disease-specific support groups across different service lines in addition to specific programs to address common concerns such as:

- Cancer-related fatigue
- Cancer pain syndromes
- Cognitive dysfunction
- Anxiety and depression
- Drug and alcohol dependence
- Sexual dysfunction.

The psychosocial effects of treatment and financial strain can impact compliance with treatment and also post-treatment surveillance regimens, Dr. Smaldone noted. Keeping these issues in mind is key to addressing patients’ survivorship concerns and directing them to available supportive resources.

Treatment Side Effects: Patient Education & Expectations

Addressing treatment side effects and toxicities are paramount when caring for RCC patients. “The drugs that we often use for kidney cancer are oral drugs and so the toxicities a lot of the time may happen insidiously and at home,” explained Dr. Geynisman. He advises setting very explicit expectations with patients on oral therapies; these patients know they can call the cancer center at any time with questions or issues about their medication. Patients at Fox Chase have access to a 24-hour phone number to reach a staff member if an issue occurs, including side effects associated with any type of systemic treatment or radiation treatment, complications related to surgical care, or any adverse outcomes that can interrupt compliance with a treatment plan. To promote adherence, Dr. Geynisman advocated seeing RCC patients frequently when they are initiated on therapy to make sure no dose adjustments are needed, as early recognition of treatment toxicities is crucial to maintaining the continuum of cancer treatment.

Another challenge to treating RCC patients is interruption of cancer care caused by transitioning between healthcare systems. Dr. Smaldone credited the Fox Chase nurse navigation team as being the most valuable resource between community providers and Fox Chase practitioners at the time of diagnosis or referral. These navigators coordinate getting all the information from the referring physician, including whether or not the patient was hospitalized, length of diagnosis, any imaging reports, and having their slides sent to pathology. Care transitions can also happen post-treatment, so Fox Chase takes steps to avoid interruptions in the longitudinal management of RCC patients’ chronic health conditions. Fox Chase has a Care Transitions Clinic that is staffed by their hospitalist service. This helps to ensure that inpatient care records are directed to each patient’s primary care physician following discharge. Hospitalists communicate with the primary care providers by phone to ensure that they are not missing critical information about patients’ hospital stays.

Patient education is an important part of treating renal cell carcinoma patients. While Fox Chase does not have tools specific to renal cancer yet, they have developed patient decision-making tools for other disease sites and use universal principles from these to help patients navigate resources or make informed clinical decisions.

Dr. Smaldone said that the ideal patient decision-making tool “should be simple, direct, understandable, and primarily focused on patient concerns rather than practitioner concerns regarding treatment and the subsequent impact on quality of life.”
DEDICATED GU RESEARCH STAFF ENSURE PATIENT ACCESS TO CLINICAL TRIALS

Norton Cancer Institute
Louisville, Kentucky

Norton Cancer Institute, part of Norton Healthcare, provides cancer care at several locations in the greater Louisville area, with their patient catchment area extending into Southern Indiana. The network hospital system includes four adult hospitals, seven medical oncology offices, three radiation therapy centers, seven chemotherapy infusion centers, three general infusion center locations, and three Cancer Resource Centers. In 2014, Norton Cancer Institute diagnosed 84 patients and treated 109 patients with RCC. Norton Cancer Institute staff includes providers who sub-specialize in genitourinary cancers, including RCC.

Dedicated Multidisciplinary Providers
The dedicated genitourinary team at Norton Cancer Institute includes medical oncologists, urologists, nurses, and research staff. Multidisciplinary care is the standard even prior to treatment. The medical oncologists work on-site with the urologists to provide collaborative care planning and treatment review, enabling the patient to discuss treatment options regarding surgery, radiation therapy, and systemic therapy with multiple providers prior to the initiation of treatment. This care model saves the patients from having to make multiple appointments and “providers are able to have real-time discussions with the patients regarding treatment options,” said Arash Rezazadeh, MD, Research Program director, Urologic Oncology, at Norton Cancer Institute.

Clinicians also present RCC patients at tumor board to further multidisciplinary discussion on diagnosis and treatment. (Tumor boards are offered throughout the Norton Healthcare system). Tumor board participants include surgeons, radiologists, pathologists, medical oncologists, radiation oncologists, nurses, navigators, and psycho-social staff. Care is coordinated via nurse navigators from the initial visit through the continuum of care.

Clinical Trials
A group of clinical research staff that focuses specifically on GU oncology screens all patients to identify needs—both for internal clinical trial participation and outside referrals to other programs. Research staff stays updated on current RCC developments by reviewing new data, investigational treatment options, and associated clinical trials. Norton Cancer Institute also has affiliation agreements with the University of Kentucky and Moffitt Cancer Center regarding clinical trial participation.

The physicians work closely with this subset of oncology-dedicated clinical research staff to identify patients and populations that could benefit from clinical trial participation. “Our goal is to provide patients with the latest and most advanced treatment options that otherwise may not be available to them. Research staff is integrated into the Norton Cancer Institute clinical areas and work alongside clinic staff daily to ensure continuity of care for patients participating in clinical trials within our program,” said Dr. Rezazadeh.

In addition to education and support from clinic nurses and staff, patients also receive extensive education from research nurses on the investigational aspects of clinical trials treatment.

Oral Therapies & Managing Toxicity
Oral therapies are widely used to treat RCC. Between December 2005 and January 2012, the U.S. Food and Drug Administration (FDA) approved five such oral medications. To optimize patient care and access to these new agents, in January 2009, Norton Cancer Institute opened an oncology specialty retail pharmacy.

“Oftentimes these expensive medications are sent to outside mail-order specialty pharmacies. Having knowledgeable pharmacy staff on-site leads to quicker turnaround time to prescription receipt and a more personal experience,” said Stacy Bloecker, PharmD, pharmacy director at Norton Cancer Institute.

RCC patients prescribed an oral therapy are provided with printed education material that outlines the most common side effects of their therapies, as well as information on how to access the physician’s office both during and after hours. Patients are instructed to contact their physician’s office if they experience any changes from their
baseline normal health status. A healthcare provider then triages the symptom or side effect and provides direction to the patient.

Many factors can influence patient compliance to medication regimens and follow-up care. “Multidisciplinary care that provides resources to address barriers and to empower the patient to access care and participate in decision making is essential,” said Cheretha Hall, RN, OCN, patient navigator at Norton Cancer Institute.

To help improve treatment adherence, Norton Cancer Institute employs a dedicated nurse navigator who works with patients prescribed oral targeted therapies to assess for adherence, side effect management, required monitoring, and additional labs or follow-up appointments. To learn more about oral chemotherapy navigation and specialty pharmacy at Norton Cancer Institute, read the ACCC publication Effective Practices in Myelofibrosis Programs (accc-cancer.org/resources/pdf/Myelofibrosis-Effective-Practices-in-Myelofibrosis-Programs.pdf).

Norton Healthcare also has a dedicated oncology ICU, which is used by patients requiring treatment with high-dose interleukin-2 (IL-2). According to the Kidney Cancer Association, “The term ‘high-dose or IV bolus’ refers to the relatively large dose of a drug given intravenously as a 15-minute infusion every 8 hours for a maximum of 14 infusions to hasten or magnify a therapeutic response. When administered in this fashion, patients are admitted to the hospital for the duration of the treatment cycle to be closely monitored. Recent statistics on long-term survival in patients treated with high-dose IL-2 continue to demonstrate that this therapy is effective for selected patients with metastatic renal cell carcinoma who can tolerate these large doses.”

Toxicities associated with IL-2 treatment include nausea, vomiting, hypotension, cardiac arrhythmias, diarrhea, loss of appetite, gastrointestinal bleeding, rashes, disorientation, hallucinations, fever, and chills. While most of these side effects are reversible on discontinuation of drug administration, they can be severe for patients.

Support Services Help Alleviate Barriers to Care

All of the supportive care services at Norton Cancer Institute are offered at no cost to patients. Financial counselors, as well as social workers, are available to patients and families, including a financial counselor dedicated solely to oral medication authorizations and financial support. Two dietitians work specifically with the cancer program to assist patients with nutritional evaluations. If patients are eligible for nutritional supplements, a dietitian will facilitate orders and deliveries for patients.

Nurse navigators and social workers screen RCC patients for eligibility for community patient assistance programs, pharmaceutical co-pay and patient assistance programs, and grant-funded programs. “Knowing the totality of available resources is critical to finding the right help that each patient needs,” said Judy Fisher, RN, OCN, director of Community Resources and Support Services at Norton Cancer Institute.

As the first line of screening for RCC patients, the nurse navigators handle both patient education at presentation and assessment for any potential barriers. These navigators prepare basic education packets for patients, which include a disease-specific resource guide that has information on:

- Medical terminology that will be used
- The types of available treatments
- A clinical trials overview
- Information on supportive care services
- Contact information for the navigators and oncology support services.

“We try to walk the fine line of providing patients with information but not overloading them,” said Fisher.

Navigators perform 6-month and 12-month follow-up calls with RCC patients to touch base—even if they have transitioned to another care setting—to ensure that no issues go unaddressed. Norton Cancer Institute uses a software program that prompts navigators to follow-up with patients.

A common barrier for the cancer program’s patient population in rural Kentucky is transportation. Social workers and navigators work in tandem to secure either internal funding or to access community resources. The American Cancer Society’s Road to Recovery program can help with rides to and from appointments; a medical public transportation system in the community is also available for patients with a cancer diagnosis.

While Norton Cancer Institute does not currently have a support group specific to renal cell carcinoma patients, providers work with Friend for Life, a Cancer Support Network (friend4life.org) that matches trained volunteers with patients based on disease site for one-on-one support. “We work as a whole to build our resource pool and resource library for patients,” said Fisher.

References
Checklist for Documentation of Oral Chemotherapy Adherence and Toxicity

Provided courtesy of Arizona Oncology

Patient Name/MRN: ____________________________ Date: ____________________________

Medication: ____________________________
Frequency of office visits: ____________________________

Provider/Clinician Reviewing Checklist with Patient: ____________________________

- Inquire if all questions and concerns about oral chemotherapy have been addressed.
- Verify that the patient understands how to take the prescribed oral chemotherapy (e.g., frequency, with or without food, whole or crushed, etc). Oral chemotherapy medications should not be touched. Handle using a disposable paper cup or gloves and wash hands before and after handling. Women who are pregnant or breastfeeding should avoid handling these medications. Medication should be stored away from children and pets.
- Confirm that the patient filled and/or refilled the prescription as written and has reviewed prescription label for correct patient name and drug information and directions.
- Ask the patient if he or she has any concerns about treatment costs.
- Ask patient if he or she has missed any doses.
  Number of doses missed per week or month: ____________________________
  Reason for missing dose(s): ____________________________
    - Side effects (list): ____________________________
    - Patient forgot: ____________________________
    - Lifestyle and dosing schedule not compatible: ____________________________
    - Cost of medication: ____________________________
    - Provider and/or nurse recommended that patient skip dose: ____________________________
    - Other reason(s): ____________________________
- Verify that the patient understands what to do in case of missed doses.
- Assess for potential toxicity, by asking the patient if he or she has experienced any of the following:
  - Nausea/vomiting: ____________________________
  - Diarrhea: ____________________________
  - Fatigue: ____________________________
  - Mouth sores: ____________________________
  - Aches on muscles/joints/bone: ____________________________
  - Rash: ____________________________
  - Other: ____________________________
- Nurse/staff/non-physician practitioner/physician discussed side effects with patient and recommended:
  ____________________________
  ____________________________
- Shared suggestions for improved adherence with patient:
  - Keep a journal of side effects, including timing around medication.
  - Keep track of when you need a refill and plan ahead before you run out.
  - Adjust time of taking medication to better fit into daily schedule.
About The Association of Community Cancer Centers

The Association of Community Cancer Centers (ACCC) is the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 20,000 cancer care professionals from 2,000 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. Not a member? Join today at accc-cancer.org/membership or email: membership@accc-cancer.org. For more information, visit the ACCC website at accc-cancer.org.

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