Caring for patients with less common cancers, such as renal cell carcinoma, presents unique challenges for community–based cancer care providers who may be challenged to keep up with evolving treatments and the availability of clinical trials.

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.)

Renal cell carcinoma (RCC) is the most common type of kidney cancer, accounting for around 90% of all kidney cancers. Early stage renal cancers tend to have a better prognosis, while advanced (metastatic) cancers have a worse prognosis. At diagnosis, approximately 20 percent of patients present with metastatic renal cell carcinoma (mRCC).

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.

PROJECT OBJECTIVES AND OVERVIEW

SURVEY OVERVIEW
Who Took Our Survey?

- 58% Physicians
- 17% RNs
- 12% Social workers
- 8% Pharmacists
- 2% Physician assistants
- 2% Nurse practitioners
- 1% Dietitians

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%

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%
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

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.

The Association of Community Centers (ACCC) is the leading advocacy and education organization in multidisciplinary cancer care, with an estimated 60 percent of the nation’s cancer patients being treated by a member of ACCC. Approximately 20,000 professionals from 2,000 hospitals and practices nationwide are affiliated with ACCC. Not a member? Join today at accc-cancer.org/membership.

ACCC is pleased to partner on this project with the Kidney Cancer Association.

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