Patient-Reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas: Results from a Global Patient Survey in 43 countries

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Abstract

Background: The International Kidney Cancer Coalition (IKCC) is a collaboration of 45 affiliated patient organizations representing 1.2 million patients worldwide that is committed to reduce the global burden of kidney cancer. A large-scale global survey of RCC patients to capture real world experiences (RWE) has never been undertaken. Methods: The 35-question survey was designed to identify geographic variations in patient education, experience and awareness, access to care, best practices, quality of life, involvement in clinical trials and to highlight unmet needs. Goals were to identify opportunities to improve care and develop programs to better meet the needs of patients. The survey was conducted in Sept-Oct 2018 and completed online or in paper form by kidney cancer patients and/or their caregivers identified by IKCC’s Affiliate Organizations and through social media in 14 languages. Results: 1983 responses were recorded from 43 countries. Analysis revealed that at diagnosis, 43% of all respondents had no understanding of their RCC sub-type; patients with clear cell carcinoma (64%) had a notably poorer understanding of their RCC subtype than did patients with rarer RCC subtypes. While 96% of respondents reported psychosocial impacts, surprisingly, only 56% disclosed them to their healthcare team. Of the 70% of patients who reported that they were never asked to participate in a clinical trial, 89% responded they would have “fairly likely” done so if asked. RCC patients <45 years old reported nearly twice as many barriers to treatment as patients >45 at diagnosis. Females reported longer delays to diagnosis than males. Shared decision making remains aspirational across major cancer centers and community hospitals: globally 29% of all patients reported no involvement in their treatment decision, responding “my doctor decided for me”.

RESULTS

Clinical Trials

70% of patients were not asked to participate in a clinical trial.

30% not asked

70% asked

Of those asked it was fairly likely they would have participated if asked.

Psychosocial Issues

96% of patients are impacted by psychosocial issues. Most common:

60% Disease-related anxiety

50% Fear of recurrence

44% Fear of dying

31% General anxiety

50% are not talking about their psychosocial issues with their healthcare professionals.

Physical Conditions

92% of patients said their physical well-being was impacted since the initial diagnosis. Most common conditions included:

Hair loss

Nausea

Weight change

Diabetes

Fatigue

CONCLUSIONS

•The survey identified several unmet needs to be further addressed.

•This first-ever global survey serves as a benchmark for longitudinal data collection.

•RWE indicates opportunities to improve communication about diagnosis, psychosocial impacts, and clinical trials.

Conflict of Interest

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