

915PD 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 federation of 38 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. 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 38 Affiliate Organizations and through social media in 14 languages.

Results

1,983 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 50% disclosed them to their healthcare team. Of the 70% of patients who 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'.

Conclusions

This exploratory research sheds light on the unmet needs in the RCC patient experience and warrants further analysis. 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.

Legal entity responsible for the study

The International Kidney Cancer Coalition.

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Disclosure

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