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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IKCC International Kidney Cancer Coalition

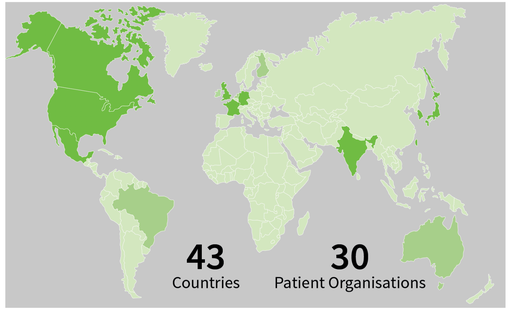
Abstract

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:**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 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

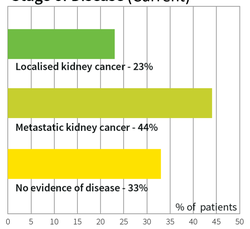
Patient Characteristics

Total Global Participants:
1983

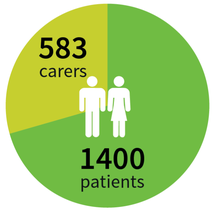


The Global Patient Survey included respondents from Canada (12%), France (12%), the United States (12%), South Korea (12%), Japan (10%), the United Kingdom (9%), Mexico (7%), India (7%), Germany (6%), Brazil (3%), The Netherlands (2%), Australia (2%), Finland (2%), Other (4%).

Stage of Disease (Current)



Participants



Knowledge and Understanding of Diagnosis

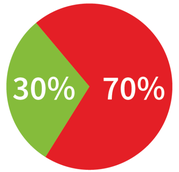
43% did not understand their subtype

38% were not told their subtype at diagnosis

11% still did not know their subtype at time of survey

RESULTS

Clinical Trials



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

Of those, **89%** said 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

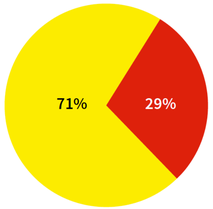
50% Fear of recurrence

44% Fear of dying

31% General anxiety

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

Shared Decision Making



29% of patients were not engaged in their treatment decisions at all.

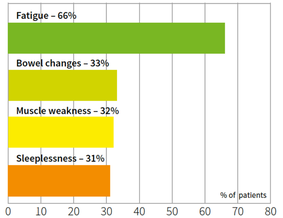
Where were they treated?
Of patients who reported "my doctor decided for me" **34%** were treated in a community or local hospital and **45%** in a major cancer centre.

What stage was the cancer?
Patients of all stages were not involved in their treatment decisions:
– **25%** were stage 1 or 2
– **20%** were stage 3 and
– **30%** were stage 4.

Physical Conditions

92% of patients said their physical well-being was impacted since the initial diagnosis.

Most common conditions included:



SCAN ME

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

This project was funded with sponsorship from the following companies in full compliance with the IKCC Code of Conduct: BMS, Ipsen, Novartis, Pfizer, Roche. Data was independently analyzed by Perception Insight.

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