# 524262: Emotional Concerns Due to Kidney Cancer (KC) and Disparities in Patient Support Across North America (NA): Results from the International Kidney Cancer Coalition (IKCC) Global Patient Survey (GPS)

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## Background

- Patient support services are an important component of care for people with KC, which can lead to better outcomes, improved emotional wellbeing, and a higher quality of life[1]
- The IKCC and its network have conducted a biennial GPS since 2018 to assess patient/caregiver experiences on KC burden, diagnosis, and management, to identify unmet needs and country variances, and guide recommendations and actions to close gaps
- We present 2025 GPS data on emotional wellbeing and patient support across NA compared to global resources

## Methods

**Survey development**
- IKCC conducted a biennial survey of KC patients, and carers
- It was developed by the IKCC steering committee, including patient advocates, medical experts, and the Picker Institute (UK)
- The survey was cognitively tested and offered 16 languages

**Survey availability and promotion**
- The survey was available online and in hardcopy (for countries with limited internet access) from September 23, 2024, to November 15, 2024
- It was hosted on Qualtrics via an open link and distributed by the IKCC and Partner Organizations to KC patients, those with a kidney cancer, and their carers
- Promotion occurred through IKCC Partner Organizations, healthcare professionals, social media and websites

**Respondents**
- Before starting the survey, respondents were informed of the survey's purpose, voluntary nature, confidentiality, and intended use of results
- No identifiable data were collected
- Aside from required demographics, questions could be skipped
- Routing logic ensured only relevant questions were shown

**Analysis and review**
- After the survey closed, data were analyzed in aggregate and via cross-tabulations. Responses not meeting inclusion criteria were removed
- Data were analyzed for duplicate responses through the open link and Bot Detection

## Results

**Patient characteristics**
- Between September 23, 2024, and November 15, 2024, the survey collected 2,677 responses from 46 countries (2,049 patients; 628 carers)
  - Overall, 54% were male, and 80% were aged 46–80. Clear cell RCC was the most common diagnosis (62%); 19% were diagnosed at stage 4, and 52% within the past four years **(Table 1)**
  - Notably, 10% of respondents did not know or were not informed of their KC sub-type

Table 1: Global Participant Characteristics

| Characteristic | | |
|---|---|---|
| Gender, % n=2677 | Male | 54 |
| | Female | 45 |
| Age group, % n=2655 | <18 years | <1 |
| | 18-29 years | 2 |
| | 30-45 years | 13 |
| | 46-65 years | 54 |
| | 66-80 years | 26 |
| | >80 years | 4 |
| Stage at diagnosis, % n=2438 | 1A | 24 |
| | 1B or 2 | 38 |
| | 3 | 19 |
| | 4 | 19 |

Table 1: Global Participant Characteristics (continued)

| Characteristic | | |
|---|---|---|
| Current stage, % n=2157 | No evidence or cured | 51 |
| | 1 or 2 | 8 |
| | 3 | 6 |
| | 4 | 36 |
| Year of Diagnosis, % n=2655 | Prior to 2011 | 15 |
| | 2011-2013 | 6 |
| | 2014-2016 | 10 |
| | 2017-2019 | 17 |
| | 2020-2022 | 27 |
| | 2023-Present | 25 |
| Kidney cancer sub-types, % n=2677 | Clear cell renal carcinoma | 62 |
| | Papillary renal cell carcinoma | 6 |
| | Chromophobe renal cell carcinoma | 5 |
| | Unclassified renal cell carcinoma | 2 |
| | Xp11 translocation type | 1 |
| | VHL (Von Hippel-Lindau syndrome) | 2 |
| | Renal medullary carcinoma | 1 |
| | Collecting duct renal cell carcinoma (Bellini Duct) | <1 |
| | Transitional cell carcinoma (urothelial carcinoma) | 1 |
| | Renal sarcoma (NOT renal cell carcinoma with sarcomatoid appearance) | 1 |
| | Wilms Tumor | 1 |
| | Benign growth | 2 |
| | Other | 5 |
| | I did not receive this information | 4 |
| | Don't know / can't remember | 6 |

**Impact on Emotional Wellbeing**
- Globally, 85% of patients reported being emotionally impacted because of KC, with variations observed across countries in NA **(Figure 1)**
  - Overall, the most common emotional concerns were disease-related anxiety (50%), fear of recurrence (49%), sadness/depression (36%), fear of dying (35%), and difficulty in daily living, on the job or in school (23%)
  - Emotional concerns were observed across all stages of disease

**Patient Concerns Discussed with an HCP**
- Among respondents who experienced emotional concerns globally, only 40%–66% of respondents discussed their concerns with an HCP **(Figure 2)**
  - Respondents from Mexico discussed the concerns they had more frequently with an HCP (68%–94%) than respondents from Canada (20%–70%), and the USA (30%–72%)
  - Emotional concerns most commonly discussed by country:
    - Canada: difficulty navigating the healthcare system (70%), fear of recurrence (60%), disease-related anxiety (57%), general anxiety (57%)
    - Mexico: difficulty navigating the healthcare system (94%), disease-related anxiety (92%), general anxiety (92%), fear of dying (90%)
    - USA: disease-related anxiety (72%), fear of recurrence (71%), sadness/depression (69%), general anxiety (66%)
- Overall, 12%–33% of conversations with HCPs were not considered helpful **(Figure 2)**
  - Notably, among respondents who had difficulty navigating the healthcare system, 27% from Canada, 22% from the USA, and 40% from Mexico reported their discussions regarding these difficulties was not helpful

**Patient Support Groups**
- Globally, half of respondents (50%) reported they have used a patient support group, either in person or online, with ≈50% indicating the groups were helpful or somewhat helpful **(Figure 3)**
  - Respondents from the USA used patient support groups more frequently than respondents from Canada or Mexico and found them more helpful **(Figure 3)**
- In general, respondents from Mexico preferred support services that involved personal interactions **(Table 2)**

Figure 1: Patients Emotionally Impacted by Kidney Cancer Diagnosis (%)

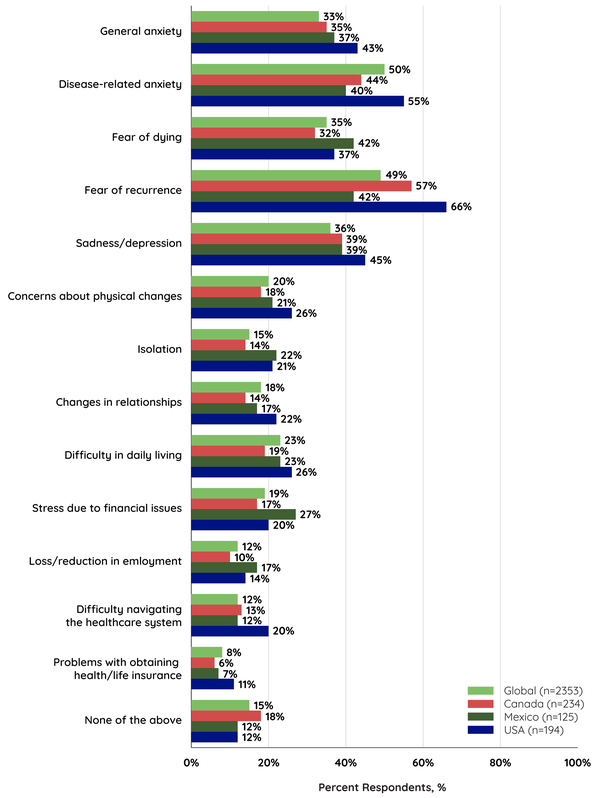
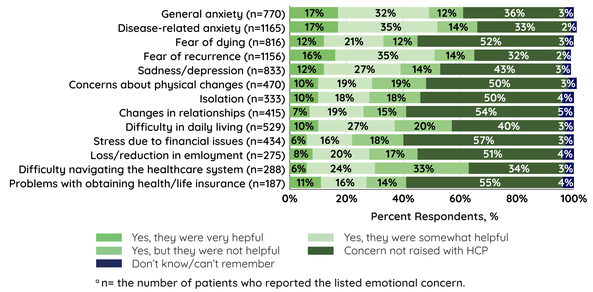



Figure 2: Patient–HCP Discussions About Concerns and Reported Helpfulness: Global Responses (%)[a]




[a] n= the number of patients who reported the listed emotional concern.

Figure 3: Patient Use of Support Groups and Perceived Helpfulness (%)

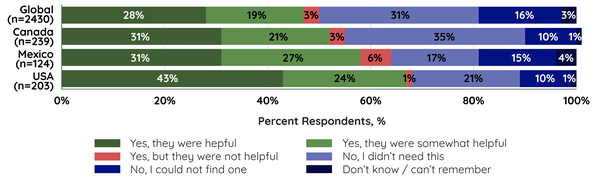



Table 2: Patient Support Resources

| | Resources Considered the Most Helpful | | | |
|---|---|---|---|---|
| | Global (n=2390) | Canada (n=238) | Mexico (n=125) | USA (n=202) |
| 1 | Patient organization website (28%) | Online support groups (39%) | In-person support groups (39%) | Online support groups (58%) |
| 2 | Online support group (27%) | Printed patient information (33%) | Peer-to-peer support group (34%) | Patient organization website (31%) |
| 3 | Printed information (22%) | Online education events (29%) | Counselling and/or psychological support (34%) | Online education events (29%) |
| | **Support Services/Resources Respondents Wanted More Access To** | | | |
| | Global (n=2353) | Canada (n=234) | Mexico (n=125) | USA (n=194) |
| 1 | In-person support groups (26%) | Counselling and/or psychological support (26%) | In-person support group (34%) | Online support group (26%) |
| 2 | Counselling and/or psychological support (26%) | Online support group (24%) | Counselling and/or psychological support (31%) | Peer-to-peer support (26%) |
| 3 | Online support group (21%) | In-person support group (21%) | Peer-to-peer support (30%) | Online education events (25%) |

## Conclusions

- Most respondents in NA experienced an impact to their emotional wellbeing due to KC; however, many did not use a patient support group or discuss their emotional concerns with an HCP
  - More respondents from Canada and the USA than Mexico did not discuss their concerns with an HCP
  - Of respondents who used a patient support group, most found them helpful
- Improved communication is needed between patients/carers and HCPs to address emotional concerns
- Referrals to patient organizations can reduce existing gaps in emotional support services
  - Notably, many respondents desire more in-person support programs and counselling/ psychological support

**References**
1. Chakraborty R, et al. Psychosocial and patient support services in comprehensive cancer centers. In Aljurf M, et al (Eds.) *The Comprehensive Cancer Center: Development, Integration, and Implementation [Internet]. Springer, 2022. Available at: https://www.ncbi.nlm.nih.gov/books/NBK584188/*

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