Background and Rationale

- Chronic kidney disease (CKD) affects >700 million people globally.
- However, the daily personal impact of the disease on individuals diagnosed with CKD (and their families) has not been determined—either qualitatively or quantitatively.

A global CKD-Personal Impact Index (PII) uncovering the direct and indirect impact of living with CKD on patients’ activities of daily living and overall quality of life (QoL) is described here, which provides unique insights into the patient experience that other studies do not traditionally report.

Methods

- We outline a multisource, collective analysis of aggregate data from a geographically diverse cohort of patients living with CKD (Figure 1A).
- As part of the research recruitment criteria, patients whose activities of daily living (or overall QoL) were impacted by their diagnosis of CKD were included. Any patients who reported no impact were excluded.
- Online social media landscape analyses (>200 million internet sources), qualitative telephone interviews (N=15), and an online quantitative patient survey (N=443) determined the personal impact attributes (PIA) and quantified the extent of patients’ experience of FIA (Figure 1B).
- The PIA that were assessed as part of this study are outlined in Figure 1C.

Conclusions

- The research highlights the most burdensome PIA, potentially facilitating the development of tangible and realistic solutions for managing the burden of living with CKD and could help identify patient cohorts whose activities of daily living and QoL may be severely impacted.
- To manage the negative impact of CKD on activities of daily living that are impacted profoundly and rapidly post-diagnosis, it is important to establish a multidisciplinary team comprising nephrologists, renal dieticians, nurses, and primary care physicians early in the CKD patient journey.
- The research highlights the most burdensome PIA, potentially facilitating the development of tangible and realistic solutions for both patients and healthcare providers.

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References


Figure 1A. CKD-PPI Development

A. Outline of Methodology

The index content was developed through a phased approach.

C. Personal Impact Attributes (PIA) assessed in patients with CKD

- Impact on Activities of Daily Living
- Impact on Overall QoL
- Impact on Sleep Schedule
- Impact on Meal Management
- Impact on Mental Well-being
- Impact on Exercise Schedule
- Impact on Time Management
- Impact on Employment Status
- Impact on Personal Mobility
- Impact on Household Responsibilities
- Impact on Finances
- Impact on Travel
- Impact on Social Media

Figure 2. Impact on Overall Quality of Life

Figure 3. Timeline of Impact on Overall Quality of Life

Figure 4. Impact on Activities of Daily Living

Figure 5. Timeline of Impact on Activities of Daily Living

Figure 6. Personal Impact Attributes

Figure 7. Prioritization of Attributes

Figure 8. Patient Perspectives Describing the Impact of Living With CKD

Figure 9. Impact on Specific Activities

Figure 10. Timeline of Impact on Specific Activities

Figure 11. Burden of PIA:

- Extremely impacted (%)
- Somewhat impacted (%)
- Not impacted (%)

- Brazil
- China
- Sweden
- United Kingdom
- United States

Sample size: N=(Total Global, Brazil, China, Sweden, UK, US)


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