The Chronic Kidney Disease-Personal Impact Index: Analysis of the Global Day-to-Day Personal Impact on Patients With Chronic Kidney Disease



OBJECTIVE



Develop a global Chronic Kidney Disease-Personal Impact Index uncovering the **direct and indirect impact** of living with chronic kidney disease

METHODS



Online social media landscape analysis, qualitative telephone interviews, and an online quantitative patient survey determined the personal impact attributes (PIA) and quantified the extent of patients' experience of PIA





Social Media Landscape



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Quantitative Patient Survey

Data from all phases culminated in the development of the Chronic Kidney Disease-Personal Impact Index

Patients included from 5 countries: Brazil, China, Sweden, UK, and US



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KEY INSIGHTS

Overall Quality of Life



38%

of respondents reported an impact immediately/within first 3 months post diagnosis



Globally, 56% of patients reported their overall quality of life was extremely impacted by living with chronic kidney disease

Activities of Daily Living



43%

of respondents reported an impact immediately/within first 3 months post diagnosis



Globally, 50% of patients reported their activities of daily living were extremely impacted by living with chronic kidney disease

Personal Impact Attributes

Globally, mental well-being (39%), sleep schedule (35%), and diet/meal management (27%) emerged as the top three most burdensome on patients' personal lives as a result of living with chronic kidney disease and associated comorbidities.



well-being





schedule

Management of meals/dieting

Globally, managing insurance and professional time, personal relationships, and managing family were the least burdensome on patients' personal lives.









PATIENT PERSPECTIVES

The research could help identify patients cohorts, with moderate or moderate to severe chronic kidney disease, whose activities of daily living and quality of life may be severely impacted.

My emotional health is impaired.
You start thinking that you're giving everybody else a hard time, you feel weak and powerless.



I always think about my illness and feel depressed.



The constant pain affects me mentally a lot.



Knowing my kidneys have failed makes me somewhat depressed a lot of the time.



I do not sleep well... it makes it hard to be productive when I am always tired.



CONCLUSIONS



The results of the Chronic Kidney Disease-Personal Impact Index analysis raise awareness regarding the burden of living with chronic kidney disease for patients with moderate or moderate to severe chronic kidney disease.

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DISCLAIMER: As noted above, the objectives of this index is to highlight the day to day and overall quality of life impact of living with CKD for patients. It is recognized that patients with mild CKD and only mildly impaired renal function, as evidenced by their e-GFR, may actually be asymptomatic with no immediate impact on their day to day living and overall quality of life. This actual CKD Personal Impact Index analysis did not state whether the patients evaluated had mild, moderate, or moderate to severe CKD. This index therefore has limitations because it does not examine how or at what stage of CKD said impact changes in robust detail but instead examines those quality of life impacts arising for all patients, using an aggregated analysis of all patients who participated in the research. Furthermore, the findings contained within the index herein are developed solely based on several bodies of data that represents patient reported outcomes. The findings are not based on a literature review or what we know to be true on the medical landscape of chronic kidney disease.

James M, Windett C, Guiglotto J. The Chronic Kidney Disease-Personal Impact Index (CKD-PII): Analysis of the Global Day-to-Day Personal Impact of Disease on Patients with CKD. Abstract PO#0637 presented at: Virtual Congress of Nephrology (WCN); 15-19 April 2021.

