

Researchers in Asia develop tool to help patients after kidney transplantation

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To measure the ability of people to engage with their lives after kidney transplantation

A global team of researchers from Australia, US, UK, France, Korea, and George Institute India have collaborated to develop a tool (SONG – LP) to assess life participation, or the ability to engage in daily life activities of people who have had kidney transplants.

In a global consensus process involving more than 1100 patients, caregivers, and health professionals from over 70 countries, life participation was established as a critically important outcome for kidney transplant recipients. The ability to consistently measure this outcome is valuable to inform routine care, clinical audit, and research.

Recognising the importance of life participation among kidney transplant patients, researchers collaborated in a global initiative involving 249 adult kidney transplant recipients from 20 countries to develop a tool to measure this important parameter for transplant recipients.

This was done through a consensus workshop with inputs from all relevant stakeholder groups (patients, caregivers, and health professionals) on developing content for the SONG-LP (Standardised Outcomes in Nephrology life participation), a core patient-reported outcome measure for life participation in kidney transplant recipients.

The tool is in the form of a questionnaire called SONG-LP for adults who had kidney transplants. The questionnaire asks about four aspects of their life: leisure, family, work, and social activities. The participants answer each question on a scale from 0 (never) to 4 (always). The total score is the average of all four answers.

The SONG-LP instrument assesses the well-being of individuals with kidney transplants. It evaluates their capability to actively participate in daily life activities, covering various aspects such as leisure, family, work, and social interactions.

The team aims to conduct future research to include a more diverse group of kidney transplant recipients, ranging from those facing health issues to those in good health. This will help determine whether the observed high levels of life participation are consistent across the entire kidney transplant recipient community or if they apply more to specific.