Unspoken Perspectives: Patient Sentiments Toward Clinical Trials in Kidney Transplantation

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INTRODUCTION

- Patients with end-stage kidney disease (ESKD) face substantial medical and emotional burdens.[1]
- Following kidney transplantation, patients may experience side effects associated with standard-of-care immunosuppression, including nephrotoxicity, neurotoxicity, and new-onset diabetes after transplantation, which could negatively impact patient experience.[2,3]
- Clinical trials testing novel immunosuppressants after kidney transplantation can offer hope to patients that an alternative therapy will aid recovery; however, patients may also experience concerns regarding the safety and unknown effects of the therapy, as well as struggle to trust the healthcare professionals who are providing the therapy.[4–6]
- The importance of capturing and understanding experiences associated with diseases and treatment directly from patients and caregivers, and how this can influence participation in clinical studies, is now well established.[6–8]
- However, there has been little research into how these sentiments affect the willingness of patients with ESKD to participate in clinical trials.

OBJECTIVES

- This study sought to understand the perspectives and experiences of patients and their caregivers in relation to kidney disease and kidney transplantation clinical trials, with the aim to inform a more patient-centered trial design.

METHODS

- Adult patients with ESKD and caregivers for patients with ESKD were recruited from across Europe (Germany, Netherlands, Norway, Portugal, Spain, UK) and the USA to participate in two half-day qualitative patient advisory groups.
- Prior to the in-person sessions, participants received a pre-meeting survey and pre-read materials (study brochures).
- Discussions were recorded, summarized, and analyzed to identify shared and region-specific themes.
- Topics explored during the facilitated sessions included: what matters most to patients and their lived experience with kidney disease; perspectives on clinical trial participation, including fears and barriers; and the role of caregivers.
- Responses were collated either from patients or caregivers specifically, or from all the participants grouped together.

RESULTS

- In total, 24 participants attended the sessions (**Figure 1**).
  - 17 were patients with ESKD and 7 were caregivers.
  - Of the patients with ESKD, 10 were receiving dialysis and/or waiting to receive a kidney transplant (3 in Europe and 7 in USA) and 14 had already received a kidney transplant (5 in Europe and 9 in USA).

Experience of living with kidney disease

- Participants reported impacts on their daily lives, as well as their experiences associated with waiting for a transplant and the quality of care received (**Table 1**).

Figure 1. Participants recruited in the study

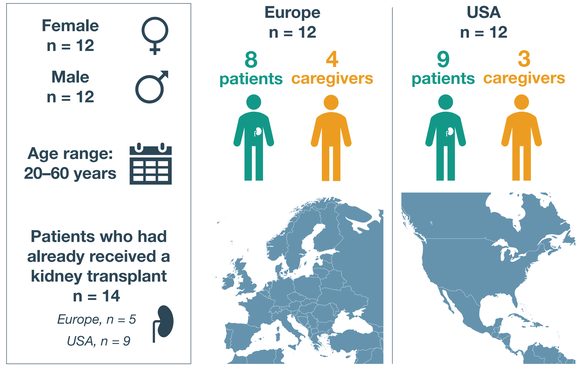


Table 1. Participant input related to their experiences of living with kidney disease

Category	Reported experiences	Participant quotations[a]
Impact on daily lives	• Difficulty attending work/school • Difficulty maintaining social lives • Live without energy • Burdensome condition	**"You lose your professional character"**
Emotional burden	• Strong emotional and psychological impacts of the disease and transplantation • Experience feelings of being a burden to others, as well as fears, including of transplant failure	**"I don't feel like myself"** **"My body healed faster than my mind"**
Impact of waiting for a transplant	• A stressful experience associated with emotional and time-associated challenges that are related to having a donor who is living or deceased	**"Dialysis can feel like a death sentence"**
Quality of care received	• Variability in quality of care received • Clinical support was typically stronger than psychological support • Support was typically generic, rather than personalized to the individual • Experienced mixed knowledge and understanding of the assistance available through support groups	**"Doctors don't know Kidney Care UK exists"**

[a]All quotations are from patients with ESKD. ESKD, end-stage kidney disease.

Patient and caregiver views and understanding of clinical trial participation

- When discussing clinical trials, participants reported a limited understanding of the processes and opportunities associated with clinical trial participation. Participants also talked about negative emotions and fears associated with being invited to participate in a clinical trial, which could act as potential barriers to patient participation (**Table 2**).
- However, participants also mentioned that involvement in clinical trials represents a small amount of risk in comparison with the risk of dying, and that clinical studies would bring much-needed innovation.

Proposed methods to improve clinical trial involvement for patients and caregivers

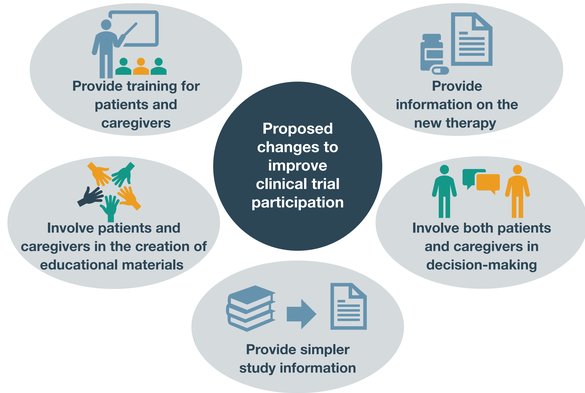
- Participants mentioned ways in which their experiences could be improved when participating in clinical trials (**Figure 2**).
- A primary concern expressed by patients and caregivers was that they wanted to be more informed so they could understand why the treatment is an option and the associated risks and benefits of the treatment, alongside other general information on the investigational therapy.

Table 2. Participant input related to their views/understanding of clinical trial participation

Category	Reported views/understanding	Participant quotations[a]
Limited understanding of clinical trials	• Limited awareness of clinical trial processes and opportunities • Lack of understanding of how the research would benefit themselves, their children (in the case of genetic disease), or patients in the future • Thought clinical trials were only for the elite, used as a last resort, and/or would cost them money	**"I know nothing about clinical trials"**
Emotional impact	• Highly stressful for patients and caregivers when they are asked to participate in a clinical trial at the point when transplantation is required, particularly because of the additional time pressure	***"It's hard to not be overprotective"***
Fear of proposed therapy	• Experience fear that the transplant will go wrong or be rejected, resulting in a return to dialysis • Uncertainty regarding the safety, efficacy, and long-term effects of the treatment being tested • Caregivers expressed concern regarding the burden, guilt, and sense of responsibility when making decisions on behalf of young patients	**"Switching drugs is scary"**

[a]Quotations are from patients with ESKD or caregivers; the quotation from a caregiver is in italics. ESKD, end-stage kidney disease.

Figure 2. Proposed methods to improve participation in clinical trials for patients and caregivers



Differences between participants in Europe and the USA

- During the sessions, participants in Europe and the USA displayed differences in how they reported their experiences:
  - **European participants** described more practical and stoical coping styles, emphasized quality-of-life disruptions, and noted substantial differences in patient pathways across countries and between adult and pediatric care.
  - **US participants** commonly voiced a mistrust of biopharma, financial concerns related to drug costs and insurance, and more intense emotional reactions to disease burden.

CONCLUSIONS

- Engaging patients and caregivers early in clinical trial planning provides essential insights into motivations, fears, and unmet needs.
- Gaining patient and caregiver perspectives can help strengthen trust, improve recruitment and retention, and ensure that patient-reported outcomes reflect meaningful lived experiences.
- Future studies on clinical trial design should expand engagement with patients and caregivers to additional regions, languages, and age groups to help integrate patient partnership into ongoing trial development.

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