

Exploring the Life Experiences of Adult Renal Transplant Recipients at Selected Multi-Speciality Hospitals in Northern Kerala: A Holistic Qualitative Approach

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ABSTRACT

Background: Renal transplantation is the treatment of choice for end-stage renal disease (ESRD), yet the recipient's journey extends far beyond the restoration of biochemical function. In Kerala—a state with one of the highest ESRD burdens in India—the subjective, holistic experience of transplant recipients remains under-explored. **Objective:** To explore and describe the lived experiences of adult renal transplant recipients attending selected multi-speciality hospitals in Northern Kerala, encompassing physical, psychological, social and spiritual dimensions. **Methods:** A descriptive phenomenological qualitative design was adopted. Ten adult recipients (6–60 months post-transplant) were recruited through purposive sampling until data saturation. Data were gathered via in-depth, semi-structured face-to-face interviews, audio-recorded, transcribed verbatim and analysed using Colaizzi's seven-step method. Trustworthiness was ensured through member checking, peer debriefing and an audit trail (COREQ-compliant reporting). **Results:** Five themes emerged: (1) Rebirth and the gift of borrowed time; (2) Living under the shadow of uncertainty; (3) The burden of lifelong vigilance; (4) Redefining self, family and social roles; and (5) Spirituality, gratitude and indebtedness to the donor. Recipients described profound relief from dialysis alongside persistent fear of graft rejection, heavy financial and pharmacological demands, and a re-negotiation of identity mediated by faith and family. **Conclusion:** Renal transplantation is experienced as a paradox of liberation and lifelong vulnerability. Nursing and transplant services in Kerala should integrate structured psychological counselling, financial navigation support and culturally sensitive spiritual care into routine post-transplant follow-up.

Keywords: Renal transplantation; Lived experience; Phenomenology; Qualitative research; End-stage renal disease; Kerala; Holistic nursing care.

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1. Introduction

End-stage renal disease (ESRD) represents the terminal, irreversible stage of chronic kidney disease and constitutes a growing global public-health challenge.^{1,12} For most patients, renal transplantation offers superior survival, better quality of life and lower long-term cost than maintenance dialysis, and it is therefore widely regarded as the optimal renal-replacement modality.^{2,3} India carries a disproportionate share of the global kidney-disease burden, and the southern state of Kerala—despite its relatively advanced health indicators—reports one of the highest prevalence rates of chronic kidney disease and diabetic nephropathy in the country.⁴

The clinical success of a transplant is conventionally measured through graft survival, serum creatinine and the absence of rejection episodes. Yet a graft that functions biochemically does not automatically confer a life that feels whole. Recipients must adapt to lifelong

immunosuppression, recurrent surveillance, dietary restriction, financial strain and an ever-present fear that the transplanted organ may fail. These realities generate a distinctive lived experience that is physical, psychological, social and spiritual in equal measure—an experience that biomedical outcome measures are poorly equipped to capture.

A substantial body of quantitative research has documented health-related quality of life after transplantation, but numeric scales cannot fully articulate what it means to receive, live with and steward a donated kidney. Qualitative inquiry—and phenomenology in particular—is uniquely suited to illuminating the meaning that recipients themselves assign to their transformed lives.^{9,11,13} In the cultural context of Kerala, where family solidarity, religiosity and community identity are especially salient, the recipient experience is likely to be shaped by forces that are invisible in standardised instruments.

Despite the region's high transplant activity, few studies have explored the holistic, first-person experience of adult renal transplant recipients in Northern Kerala. This gap has direct clinical relevance: nurses and transplant coordinators who understand the recipient's inner world are better positioned to deliver anticipatory, person-centred care. The present study was therefore undertaken to explore and describe these lived experiences using a rigorous qualitative approach.

1.1. Aim and Research Question

The overarching aim was to explore the holistic life experiences of adult renal transplant recipients attending selected multi-speciality hospitals in Northern Kerala. The guiding research question was: *"What are the lived physical, psychological, social and spiritual experiences of adult renal transplant recipients following successful transplantation?"*

2. Materials and Methods

2.1. Study Design

A qualitative research approach using a descriptive phenomenological design, informed by Husserlian philosophy, was adopted to capture the essence of the recipients' experiences as they were consciously lived. Descriptive phenomenology was selected because the study sought to describe—rather than interpret against a pre-existing theory—the shared meaning structures of the transplant experience. Reporting adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist.⁷

2.2. Setting and Participants

The study was conducted in the nephrology and transplant out-patient departments of two selected multi-speciality hospitals in Northern Kerala with established renal-transplant programmes. Participants were recruited through purposive sampling to obtain information-rich cases.

Inclusion criteria: adults aged 18–65 years; recipients of a first renal transplant; between 6 and 60 months post-transplantation; medically stable with functioning graft; able to communicate in Malayalam or English; and willing to provide written informed consent.

Exclusion criteria: recipients with graft failure or active rejection at the time of interview; those with documented cognitive impairment or severe concurrent psychiatric illness; and multi-organ transplant recipients.

Sample size was governed by the principle of data saturation.⁸ Recruitment continued until no new codes or themes emerged from successive interviews; saturation was judged to be reached at the eighth interview, and two further interviews were conducted to confirm it, yielding a final sample of ten recipients.

2.3. Data Collection

Data were collected over a four-month period through individual, in-depth, semi-structured, face-to-face interviews conducted in a private room within the hospital. An interview guide, developed from the literature and validated by three nursing and nephrology experts, opened with a broad grand-tour question—"Can you tell me what life has been like for you since your kidney transplant?"—followed by probes exploring physical health, emotions, relationships, work, finances and beliefs. Interviews lasted 40–65 minutes, were audio-recorded with consent, and were supplemented by field notes documenting non-verbal cues. Each participant was interviewed by a single trained female researcher with no prior therapeutic relationship to the recipient.

2.4. Data Analysis

Audio recordings were transcribed verbatim and, where applicable, translated from Malayalam to English with back-translation to preserve meaning. Transcripts were analysed manually using Colaizzi's (1978) seven-step method⁵: (1) reading all transcripts to acquire a global sense; (2) extracting significant statements; (3) formulating meanings; (4) clustering meanings into themes; (5) integrating findings into an exhaustive description; (6) reducing the description to a fundamental structure; and (7) validating the structure with participants through member checking.

2.5. Trustworthiness

Rigour was established according to Lincoln and Guba's criteria.⁶ Credibility was supported by member checking and peer debriefing; dependability and confirmability by an audit trail and reflexive journaling to bracket the researcher's preconceptions; and transferability by thick description of context and participants. Coding was independently cross-checked by a second researcher, and discrepancies were resolved through consensus.

2.6. Ethical Considerations

Ethical approval was obtained from the Institutional Ethics Committee (approval no. [IEC/XXX/2024]). Written informed consent was secured after explaining the purpose, voluntary nature and right to withdraw. Confidentiality was protected by replacing names with participant codes (P1–P10), and recordings were stored on password-protected devices. Given the emotionally sensitive nature of the topic, provision was made for referral to counselling services.

3. Results

3.1. Participant Characteristics

Ten adult renal transplant recipients participated. The sample comprised 7 men (70.0%) and 3 women (30.0%), with a mean age of 44.3 ± 10.4 years. The majority received a living-related graft, and most were between one and three years post-transplant. Socio-demographic and clinical characteristics are summarised in Table 1 and depicted in Figure 1.

Table 1: Socio-demographic and clinical characteristics of participants (N = 10)

Characteristic	Category	n	%
Gender	Male	7	70.0
	Female	3	30.0
Age group (years)	25–34	2	20.0
	35–44	3	30.0
	45–54	3	30.0
	55–64	2	20.0
Donor type	Living related	6	60.0
	Living unrelated	2	20.0
	Deceased donor	2	20.0
Time since transplant	6–12 months	3	30.0
	1–3 years	4	40.0
	3–5 years	2	20.0
	> 5 years	1	10.0
Employment status	Employed / self-employed	5	50.0
	Unemployed / on leave	3	30.0
	Homemaker / retired	2	20.0
Monthly household income	< ₹20,000	4	40.0
	₹20,000–50,000	4	40.0
	> ₹50,000	2	20.0

Note: Percentages are based on $N = 10$. ₹ = Indian Rupee.

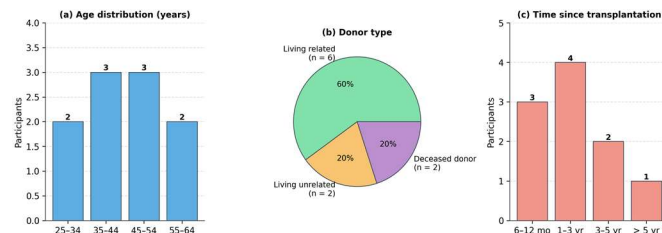


Figure 1: Socio-demographic profile of participants: (a) age distribution, (b) donor type, and (c) time elapsed since transplantation ($N = 10$).

3.2. Overview of Themes

Analysis of the ten transcripts yielded 236 significant statements, condensed into 41 formulated meanings, 12 sub-

themes and 5 major themes. The thematic structure and its relationship to the central phenomenon are presented in Figure 2, while the distribution of theme endorsement across participants is shown in Figure 3 and Table 2.

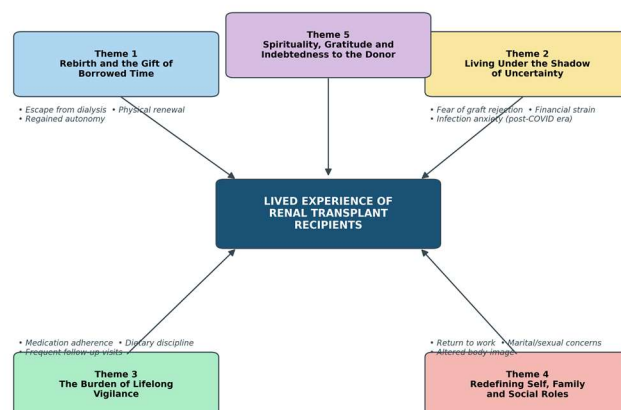


Figure 2: Thematic map of the lived experience of adult renal transplant recipients, showing five interrelated themes converging on the central phenomenon.

Table 2: Themes, sub-themes and representative significant statements

Theme	Sub-themes	Representative statement (participant)
1. Rebirth and the gift of borrowed time	Escape from dialysis; physical renewal; regained autonomy	“I feel I was born a second time” (P3)
2. Living under the shadow of uncertainty	Fear of rejection; financial strain; infection anxiety	“Every fever makes me think the kidney is failing” (P8)
3. The burden of lifelong vigilance	Medication adherence; dietary discipline; frequent follow-up	“My life now runs by the tablet clock” (P2)
4. Redefining self, family and social roles	Return to work; marital concerns; altered body image	“I am a husband again, not just a patient” (P6)
5. Spirituality, gratitude and indebtedness	Faith; gratitude to donor; sense of purpose	“This kidney is God’s gift through my brother” (P5)

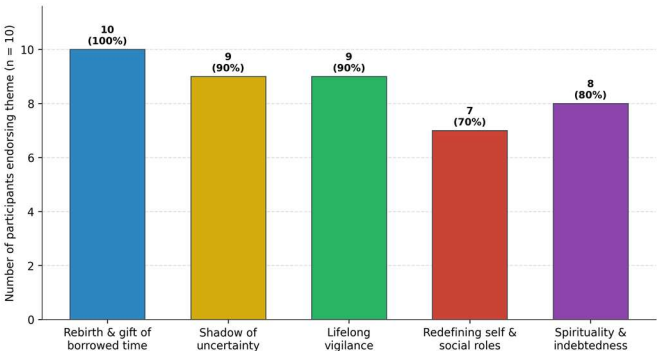


Figure 3: Number and proportion of participants endorsing each of the five major themes (N = 10).

3.3. Theme 1: Rebirth and the Gift of Borrowed Time

Almost universally, recipients framed transplantation as a second beginning. Liberation from the relentless schedule of haemodialysis was the single most transformative change. Participants described the return of energy, appetite, urine output and the freedom to travel and eat with fewer restrictions as nothing short of a resurrection.

“Before the transplant, three days a week belonged to the dialysis machine. Now those days belong to me again. I feel I was born a second time.” (P3, male, 38 years)

This renewed vitality was accompanied by a restored sense of control over one’s own body and future, which many contrasted sharply with the dependency of their dialysis years.

3.4. Theme 2: Living Under the Shadow of Uncertainty

Relief coexisted with a persistent, low-grade dread. The possibility of graft rejection loomed over ordinary life, so that minor symptoms—a fever, fatigue, a change in urine—were interpreted as potential catastrophe. Financial anxiety compounded this fear, as the recurring cost of immunosuppressants strained household budgets, and several participants reported heightened infection-related vigilance carried over from the COVID-19 pandemic.

“Every time I get a fever, my heart sinks. I immediately think the kidney is failing. The medicines are also very costly—I worry how long I can afford them.” (P8, female, 52 years)

3.5. Theme 3: The Burden of Lifelong Vigilance

Recipients described a life reorganised around adherence. Immunosuppressive medication had to be taken at fixed times without fail, dietary and fluid discipline maintained, and follow-up appointments and laboratory tests attended regularly. While participants accepted these demands as the price of survival, many experienced them as a form of continuous labour.

“My whole day is planned around my tablets. I set three alarms. My life now runs by the tablet clock.” (P2, male, 45 years)

3.6. Theme 4: Redefining Self, Family and Social Roles

Transplantation prompted a renegotiation of identity. Many recipients were able to resume employment and reclaim their roles as breadwinners, spouses and parents, which restored dignity and self-worth. However, some grappled with altered body image from steroid-related changes, and a few voiced concern about marital and sexual relationships. Family members—often the very donors—were central to this reconstructed self.

“When I went back to work and could take care of my children again, I felt like a husband and father again, not just a patient.” (P6, male, 41 years)

3.7. Theme 5: Spirituality, Gratitude and Indebtedness to the Donor

Faith and gratitude permeated the recipients’ accounts. Many interpreted their survival through a religious lens and expressed profound, sometimes overwhelming, indebtedness toward their donor—living or deceased. This gratitude frequently translated into a renewed sense of purpose and a moral obligation to “live well” on the donor’s behalf.

“This kidney is God’s gift, given to me through my brother. I must take care of it well—it is not only mine now.” (P5, female, 34 years)

4. Discussion

This study explored the holistic lived experiences of adult renal transplant recipients in Northern Kerala and revealed a fundamental paradox at the heart of post-transplant life: transplantation simultaneously liberates and constrains. Recipients experienced profound physical and existential renewal—captured in the recurring metaphor of rebirth—while remaining tethered to lifelong vigilance and an ever-present fear of loss. This tension resonates with the wider international literature on organ recipients,^{9,11,13} yet the present findings foreground culturally specific features of the Keralan context.

4.1. The Paradox of Liberation and Vulnerability

The dominance of the rebirth metaphor (Theme 1) alongside the shadow of uncertainty (Theme 2) illustrates that quality of life after transplantation cannot be reduced to graft function. Recipients who were biochemically stable nonetheless carried substantial psychological burden. This finding reinforces calls to integrate routine psychological screening into transplant follow-up rather than treating distress as an exceptional complication.¹⁰

4.2. Financial Toxicity as a Lived Reality

The salience of medication cost and financial strain—woven through Themes 2 and 3—reflects the out-of-pocket nature of much long-term transplant care in India. For recipients from lower-income households, the price of immunosuppression is not merely an economic inconvenience but a persistent source of existential threat to the graft itself. Structured financial navigation and subsidised medication schemes therefore emerge as clinical, not merely administrative, priorities.

4.3. Family, Faith and the Cultural Shaping of Gratitude

The prominence of family donors and the religious framing of survival (Themes 4 and 5) are consistent with the collectivist and deeply religious character of Keralan society. Gratitude toward living related donors was intense and, for some, tinged with a sense of indebtedness that shaped their commitment to adherence. Culturally sensitive spiritual care

and structured donor–recipient counselling may help recipients process these complex emotions constructively.¹⁴

4.4. Implications for Nursing Practice and Policy

- **Psychosocial care:** Embed structured psychological counselling and periodic distress screening within routine post-transplant clinics.
- **Financial support:** Establish financial navigation services and expand subsidised immunosuppressant access for low-income recipients.
- **Spiritual care:** Incorporate culturally and religiously sensitive spiritual care and donor-acknowledgement rituals into holistic nursing.
- **Adherence education:** Develop recipient- and family-centred adherence education that acknowledges the lived burden of the “tablet clock”.

4.5. Strengths and Limitations

Strengths include a rigorous phenomenological design, COREQ-compliant reporting, data saturation, member checking and an audit trail.¹⁵ Limitations include a small sample recruited from only two hospitals in a single region, which—while appropriate for transferability rather than statistical generalisation—may not capture the full diversity of the Indian transplant population. Recipients with graft failure were excluded by design, so the experiences reported here reflect those of medically stable recipients. Social-desirability bias in a hospital setting cannot be entirely excluded.

5. Conclusion

For adult renal transplant recipients in Northern Kerala, transplantation is lived as a profound paradox of liberation and lifelong vulnerability. It restores vitality, autonomy and social identity while imposing continuous vigilance, financial strain and an abiding fear of loss—experiences mediated powerfully by family and faith. These findings underscore that successful transplantation must be defined not only by graft survival but by the recipient’s holistic flourishing. Transplant and nursing services should move beyond a purely biomedical model to embrace integrated psychological, financial and spiritual support as core components of post-transplant care.

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Conflict of Interest

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