Beyond Coordination: A Case Study of Social Work Practice in Kidney Transplantation Services

Dona Maria Kuriakose*
Research Scholar, Loyola College of Social Sciences
Jasmine Sarah Alexander
Assistant Professor, Loyola College of Social Sciences
**Corresponding Author Email: dmaria541@gmail.com*

Abstract: *This qualitative single case study explores the various roles and functions of social workers as kidney transplant coordinators in Kerala's organ transplantation ecosystem. Drawing on an in-depth interview with a Master of Social Work graduate employed as a kidney transplant coordinator in a tertiary care hospital in Kerala, this study examines how they navigate both living and deceased donor transplantation pathways. The findings of the study reveal that the role of the coordinator extends far beyond administrative duties to include grief counselling, pre- and post-surgical counselling, crisis intervention, legal navigation, ethical adherence, and prolonged psychosocial care. This study situates these practices within the regulatory frameworks of The Transplantation of Human Organs and Tissues Act, National Organ and Tissue Transplant Organisation, State Organ and Tissue Transplant Organisation, and Kerala's Mrithasanjeevani programme, highlighting various social work competencies that are foundational to successful organ donation outcomes. The findings argue for the central role of social workers in advancing the organ donation ecosystem in India.*

Keywords: Social Work, Kidney Transplant, Transplant Coordinator, Grief Counselling, Organ Donation

1.INTRODUCTION

Chronic Kidney Disease (CKD) represents a growing public health burden in India, with recent data showing a prevalence of 13.2% among adults aged 15 and above (Wiley et al., 2025). The Global Burden of Disease Study estimates that CKD affects 788 million people worldwide, with India accounting for a majority of this burden due to its large population, high prevalence of NCDs, and limited treatment modalities for this large population (Bikbov et al., 2020). In India, the Indian Council of Medical Research (ICMR) reported a prevalence of 9.4% of CKD patients in urban populations across seven major cities (Lok Sabha, 2025). Despite its advanced healthcare settings, Kerala faces a disproportionate burden, with a recent study indicating a CKD prevalence of 22.6% in the state (Jeemon et al., 2025).

End-stage renal disease (ESRD) is the terminal phase of CKD, characterised by irreversible loss of kidney function, requiring either dialysis or renal transplantation for survival. Renal replacement therapy is of two forms: dialysis, which includes peritoneal dialysis and haemodialysis, and the second option is kidney transplantation. While dialysis can sustain life for many more years, it is often associated with poor quality of life, financial loss, significant morbidity, and an average estimated survival of 10–15 years depending on age and comorbidities (Lam et al., 2018). However, kidney transplantation restores near-normal renal function and improves the quality of life of the patient, reduces long-term treatment expenditures, and increases life expectancy compared with dialysis (Tonelli et al., 2011). The World Health Organization (WHO) reports that transplantation meets less than 10% of the global need, creating a widening gap between the supply and demand of organs worldwide (World Health Organization, 2010).

1.1 BACKGROUND OF LEGISLATIVE FRAME WORK GOVERNING ORGAN TRANSPLANTATION IN INDIA

1.1.1 The Transplantation of Human Organs and Tissues Act

The Transplantation of Human Organs Act (THOA) was enacted in 1994 in India to regulate the matters regarding organ transplantation and prevent commercial dealings in organs. The Act was amended in 2011 to include tissues within its scope, thereby changing its title to the Transplantation of Human Organs and Tissues Act (THOTA). The act was further amended in 2014 to include the definition of direct relatives who could donate organs without governmental authorisation. The amendment also established NOTTO as the apex national body to govern

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all aspects of transplantation in the country (Ministry of Health and Family Welfare, 2014). The THOTTA, 2014, prescribed a list of standardised forms for various transplantation procedures, including Form 8 for declaration cum consent, Form 10 for brain-stem death certification, Form 11 for approval of living donor transplantation, and various other forms to evaluate the living donor, family member approval, and bank statements to ensure transparency in the financial motives of living donor transplantation (NOTTO, 2019).

1.1.2 Regulatory Bodies: NOTTO, ROTTO, SOTTO, KSOTTO

The National Organ and Tissue Transplant Organisation (NOTTO) functions as a national-level nodal agency for regulating organ and tissue transplantation in India under the Ministry of Health and Family Welfare. It mainly functions to coordinate organ allocation, maintain a registry of donors and recipients, formulate policies, and provide an overview of lower-tier bodies (NOTTO, 2019).

Regional Organ and Tissue Transplant Organizations (ROTTO) function at the zonal level across five geographic regions in the country. There are five regional ROTTOs located in Chandigarh, Mumbai, Chennai, Kolkata, and Guwahati. These centres coordinate interstate organ sharing, provide technical support to state-level bodies, and manage regional matters (Ministry of Health and Family Welfare 2014).

The State Organ and Tissue Transplant Organization (SOTTO) functions at the state level. In Kerala, the SOTTO is the Kerala State Organ and Tissue Transplant Organisation (KSOTTO). It functions under the Health and Family Welfare Department of the Government of Kerala to coordinate deceased donor activities, live donor transplantations, maintain a state-level checklist, oversee the brain stem death certification process in hospitals in Kerala, and administer the Mrithasanjeevani programme of the state (KSOTTO, 2022).

1.1.3 Mrithasanjeevani

The term 'Mrithasanjeevani' means 'the life-giving herb', as mentioned in Indian mythology. It is the flagship deceased-donor organ donation programme in Kerala. It operates under KSOTTO and is designed to systematically assess and locate potential deceased donors and recipients. The program is managed through an online platform accessible to registered hospitals and enables timely reporting of brainstem death patients and facilitates the allocation of recipients sorted by blood group and clinical priority. The program also focuses on building public awareness, professional training, and transparency in organ allocation matters (Kerala State Organ and Tissue Transplant Organisation, 2022).

2. METHODOLOGY

This study employed a qualitative case study design to explore the professional role within its real-world institutional and regulatory context (Yin, 2018). A key informant interview was conducted with a kidney transplant coordinator with seven years of experience in a tertiary care hospital in central Kerala. The participant was purposively selected based on his professional experience and accessibility.

Data were collected through semi-structured interview to explore the details in depth. The interview lasted 45-60 minutes and was audio recorded with the participant's consent. The interviews was later transcribed verbatim.

3.CASE NARRATIVE

The participant was a Master of Social Work (MSW) holder with seven years of work experience in the field of kidney transplantation. The position of the kidney transplant coordinator operates under the nephrology department of the hospital, reflecting the organisational integration of transplant services within renal care pathways. The coordinator's role included navigating both living donor and deceased transplantation pathways, each presenting distinct legal, clinical, and psychosocial complexities.

3.1 DECEASED DONOR (CADAVERIC) TRANSPLANTATION PATHWAY

When a patient with severe neurological injury enters the ICU, the treating medical team institutes standard critical care management. Upon determining that "there is no hope", doctors break the bad news to the relatives of the patient, presenting two options: withdrawal of life-sustaining treatment or organ donation consideration. The role of the transplant coordinator only commences when the family expresses interest in organ donation.

Brainstem death declaration: Following the family's willingness, the formal brain death certification process is initiated. Two apnoea tests conducted six hours apart for adults are required to confirm the absence of any spontaneous respiration. Brain death is confirmed when both tests are positive. Four mandated doctors must witness both tests, one of whom is a representative medical practitioner from a government hospital. After confirming brain death, it is formally declared to the family. Four medical doctors should sign Form 10 of kidney transplantation procedures, and this form is a declared official document for brain death confirmation. Both apnoea tests were video-recorded to ensure transparency.

Family Consent and Counselling: Following brainstem death certification, the coordinator obtained the family's consent for organ donation using form number 8 (Declaration cum consent) after explaining the details of the procedures. This stage is crucial, as it demands the coordinator's role as a grief counsellor. Families may find it difficult to accept the reality of the sudden loss of a loved one. Here, the coordinator engages family members to communicate clinical details and obtain legally valid consent, along with managing their grief stages through sensitive communication, cultural awareness, and crisis counselling.

Organ Allocation: Completed details of Forms 8 and 10 were entered into the official portals of KSOTTO and Mrithasanjeevani. The government then allocates organs to the required individuals based on priority and medical urgency. The interviewee mentioned that the sole responsibility of allocating organs is vested in the government, and hospitals have no role in this process. If a registered recipient within the same hospital has the highest priority on the list, that person may receive the required organs, but it was determined by KSOTTO.

Medico-legal case handling: For cases involving legal formalities, such as accidental deaths or crime victims, the coordinator obtains an NOC from the deputy superintendent of police at the concerned station before organs can be retrieved.

Organ retrieval and Green Corridor: Once the allocation of organs is confirmed, the coordinator manages the entire process. Medical teams from recipient hospitals are guided by the coordinator and serve as the primary point of contact for all incoming retrieval teams. The coordinator also manages the logistical and administrative aspects of retrieval and ensures that copies of the required forms accompany each retrieval team and organ. The duration between organ retrieval and transplantation is recorded cold ischaemia time, referring to the period during which organs are preserved outside the body under cold conditions. Prolonged ischaemia time may adversely affect the transplant outcomes. In cases of heart and liver retrieval, a 'green corridor' is established to ensure an unobstructed road passage or air transport route for fast organ transfer.

Post-retrieval procedures: After organ retrieval is completed, the coordinator arranges for the respectful transfer of the donor's body to the hospital's mortuary. A formal 'guard of honour' ceremony is conducted before the body is released. In MLC cases, police clearance must be obtained before the body can be released to the family. All aspects of the final procedures were overseen by the coordinator. Families of deceased donors bear no costs for procedures occurring after organ donation is confirmed, as it is borne by the recipient.

3.2 LIVING DONOR TRANSPLANTATION

Living donor transplantation involves a donor who voluntarily donates a kidney to a recipient while living. When a patient with kidney failure visits the nephrology department, the doctor advises them in case kidney transplantation is needed, and the patient is then referred to the kidney transplant coordinator.

Initial counselling: When a potential donor and recipient come to the coordinator, a joint counselling session is initiated. It addresses all possible effects of kidney transplantation procedures, thereby ensuring informed decision-making. The coordinator explains surgical risks, long-term implications for the donor, treatment adherence requirements, lifestyle modification, and post-transplantation medication regimens in detail.

Medical Evaluation: Following the initial counselling session, the coordinator refers both parties for comprehensive medical testing. The nephrologist then verified the test reports. After clearance from the nephrologist, the coordinator proceeds with the legal formalities required for live donor transplantation.

Relationship verification: Under the THOTA Act, 'direct relatives' of the patient can donate without government body approval, including parents, siblings, grandparents, grandchildren, spouses, and children. Clearance from a hospital-based authorisation committee is only required for cases with direct relatives as donors. The coordinator verifies the relationship and prepares legal documents, including proof of the relationship, and submits them to the hospital committee. When the donor is not a direct relative, authorisation must be obtained from a state-level authorisation committee, typically located at the government medical college in that area. In certain cases, the committee might deny approval if financial motives or irregularities are suspected.

Post-committee approval: After obtaining approval from committees, the coordinator fixes a date for transplantation, coordinates with surgical teams, arranges preoperative counselling for both parties, and establishes protocols for post-transplant follow-up for donors and recipients.

4.DISCUSSION

The case narrative presented in this study highlights the role of the kidney transplant coordinator in a tertiary care hospital. The functions extended beyond administrative tasks to include clinical documentation, legal verification, and crisis counselling. This discussion situates these findings within the broader framework of the existing literature on transplant coordinators, organ donation governance in India, and medical social workers to triangulate the participants' narratives.

The case study demonstrates how a Master of Social Work (MSW) graduate functions as a kidney transplant coordinator by navigating both the living and deceased donor pathways. The participant's seven years of practice revealed the multifaceted roles of a social worker as a grief counsellor, administrator, family crisis supporter, and ethical mediator.

The 2011 and 2014 amendments of THOTTA, 1994, made the post of transplant coordinators mandatory in all registered hospitals, and the National Course Curriculum for Transplant Coordinators developed by NOTTO recognised social workers with postgraduation as a qualifying discipline, acknowledging that organ transplantations are not merely clinical but social and emotional too (NOTTO, 2021). Kumar (2013) documented the role of social workers as cadaver organ donation coordinators at AIIMS New Delhi and pointed out prominent functions in public education, staff training, and coordinating the process of donor identification and organ retrieval. The present study adds to this understanding by providing details of living donor transplantation and regulatory frameworks in the context of Kerala.

In the deceased donor pathway, the transplant coordinator's role commences only after the family approves organ donation. As THOTA mandates brain death certification using two apnoea tests six hours apart in the presence of four medical practitioners, hospitals most often avoid the possibility of organ donation, as it is a complicated, legally compliant, and time-consuming process. The participants' mention of 'sensitive communication, cultural awareness, and crisis counselling' while consulting the family of the deceased to obtain form 8 approval reflects the core role of a social worker as a grief counsellor and consent facilitator.

The participants' description of managing the 'entire process' of organ retrieval, including coordinating retrieval teams, documenting, and arranging a guard of honour ceremony before releasing the body, reveals how the practice of social work extends beyond traditional boundaries to include logistical coordination and dignity preservation.

Although ceremonial procedures are not legally mandated, they serve a psychosocial function by validating family loss and framing organ donation as an honourable act (PMC, 2025). The additional procedures in medico-legal cases to inform the police in charge and obtain a no-objection certificate from them further extend the job boundary of social workers in this post. Rajesh et al. (2024) identified that delays caused by such medico-legal issues constitute a major structural issue in organ donation. Tarabeih and Bokek-Cohen (2021), in their article, mentioned the "emotional labour of transplant coordinators" to simultaneously manage legal issues, clinical matters, and psychological and emotional stability of families.

In the living donor pathway, the social worker's role shifted from grief counselling to psychosocial assessment and relationship verification. In this context, patient rights were upheld through informed decision-making by both parties and their families. International guidelines recommend conducting a detailed psychosocial evaluation of living donors by assessing their psychological status, motivations, and potential for undue pressure (GIN, 2021). The verification of 'direct relatives' by the participant for living donor transplantation and navigation of state-level authorisation committees for cases of 'non-relatives' places the social worker in an ethical gatekeeping position demanding both vigilance against commercial exploitation and legal literacy.

Another phase of social work intervention was seen in the post-committee coordination role of confirming dates for transplantation, seeking convenience from all involved parties, coordinating with medical teams, providing presurgical counselling to the donor and receiver, and establishing protocols for follow-up. This demonstrates a longitudinal engagement model for social workers. Research suggests that in certain cases, factors such as persistent pain, medical adherence, prolonged hospitalisation, or poor recipient reciprocation may lead to poor psychosocial outcomes in the donor (Transplantation Proceedings, 2005). In such cases, the coordinator's follow-up protocols function to prevent the psychosocial breakdown of the donor, extending the traditional case management role of social workers to post-transplant care.

5. CONCLUSION

This case study demonstrates the role of a kidney transplant coordinator as practiced by a social worker. It extended beyond administration to include crisis intervention, grief counselling, ethical management, legal navigation, and longitudinal psychosocial care. Several social work competencies were also highlighted in the study, such as sensitive communication, family systems undertaking, cultural awareness, and strength-based engagement, which are not merely complementary but foundational to effective organ donation outcomes. The study also places the findings within the Mrithasanjeevani programme of Keral and NOTTO-SOTTO regulatory frameworks, highlighting both structures that enable the transplantation process and those which constrain it.

The findings suggest that the social work foundation in the field of kidney transplant coordination is not peripheral but central to addressing the psychosocial complexities that determine donation outcomes. As the country strives for self-sufficiency in organ donation and transplantation, professionalising this role through specialised social work curricula, ethical guidelines, and supervisory structures is a strategic imperative.

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