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“We never truly regained a new life”: Social isolation among kidney transplant recipients: A Qualitative Study

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Abstract

Social isolation (SI) has been increasingly recognised as a critical psychosocial outcome undermining long-term well-being and social reintegration among kidney transplant recipients (KTRs). This descriptive qualitative study aimed to explore these experiences through semi-structured in-depth interviews with 18 KTRs recruited from a tertiary hospital in China, with data analysed using reflexive thematic analysis guided by Link and Phelan's stigma framework. The study was conducted from March to June 2025. Interviews revealed four major themes and ten sub-themes: iatrogenic isolation (frequent medical surveillance, physical fatigue, and fear of infection), defensive isolation (stigma-driven withdrawal and emotional self-silencing), relational isolation (kin-and-friend alienation, impaired binary relationships, and workplace discrimination), and core needs (yearning for support and self-expectations). This study identifies critical facilitators and barriers affecting KTRs' social participation and highlights the emotional, relational, and structural challenges they face. The findings advocate for integrated, multi-level interventions that combine psychosocial screening, family engagement, multidisciplinary care, and anti-stigma campaigns, and underscore the urgent need to address the hidden psychosocial predicaments of KTRs within both clinical and societal contexts.

1. Introduction

With the growing number of patients with end-stage renal disease, replacement therapy has become essential to sustain their lives (Li et al., 2025). Kidney transplantation (KTx) is one of the most effective replacement therapies for end-stage renal disease (Hariharan, Israni, & Danovitch, 2021). As surgical techniques and drug development have advanced, kidney transplant survival rates have steadily increased over the years (Lentine et al., 2025). However, successful transplantation signifies biological survival rather than full social recovery. Although organ function is restored, KTRs continue to face profound long-term constraints in daily and social life. Existing studies have documented postoperative challenges including anxiety, depression, fatigue, and treatment-related distress (Bossola et al., 2021; Sung, Hershberger, & Lockwood, 2023). Besides these psychological burdens, the overall level of social adjustment among kidney transplant recipients remains poor (Lorenz et al., 2019). Psychosocial adaptation therefore represents a critical challenge in the post-transplant period.

SI is a complex, multidimensional phenomenon characterized by a reduction or absence of social connections with others, manifesting as social avoidance in behavior and negative emotional experiences (Liang, Hao, Wu, & Hou, 2022). Beyond the behavioral and emotional manifestations, SI also involves the loss of meaningful social roles and the breakdown of reciprocal social support networks, which are essential for maintaining mental health and adaptive coping in chronic illness. SI is associated with various adverse health outcomes, including accelerated disease progression and increased mortality risk (Christiansen et al., 2021). It reflects not only individual feelings but also the loss of social roles and erosion of support networks that are critical to well-being in chronic illness.

To maintain graft function, KTRs require lifelong immunosuppressant therapy, strict monitoring of physiological parameters, and long-term rigorous self-management, including the adherence to a healthy lifestyle such as dietary control, moderate physical activity and regular work-rest schedules (Knobbe et al., 2023). This long-term medical management regimen not only imposes a persistent daily burden on patients but also restricts their flexibility in daily life and social activities, as any deviation from the regimen may increase the risk of adverse clinical outcomes, such as immune rejection, infection, cardiovascular complications, and graft failure. These risks represent acute threats in the short term after transplantation, and simultaneously serve as latent chronic hazards that persist throughout the entire post-transplant period, keeping KTRs in a state of persistent psychological anxiety and vigilance. Furthermore, long-term use of immunosuppressants may lead to a range of adverse reactions, including changes in physical appearance, osteoporosis, neurotoxicity, and metabolic disorders (Josephson et al., 2023; Secondulfo et al., 2025). The dual burden of physical symptoms and pharmacotherapy erodes patients' physical resilience and depletes their psychological resources, leaving them with limited energy for social interactions and interpersonal communication. These compounded impairments in physical, psychological, and social functioning ultimately render KTRs a high-risk population for SI. For KTRs specifically, this risk is particularly concerning, as SI can further reduce medication adherence and self-management compliance, creating a vicious cycle between poor psychosocial health and adverse clinical outcomes.

Many studies have investigated psychological morbidities among KTRs, and some have addressed related phenomena such as social adaptation and life experiences (Hu, Yang, & Wang, 2024; Zhang, Wang, Sun, & Wu, 2025). However, little attention has been paid to the lived experiences of SI among KTRs, specifically how SI is subjectively perceived, manifested in daily life, and shaped by multiple social and structural forces. Understanding these lived experiences is essential because SI is not merely an objective lack of social contacts but a deeply subjective state that influences medication adherence, psychological well-being, and long-term social reintegration. Stigma, defined as a process involving labeling, stereotyping, separation, status loss, and discrimination (Brewis et al., 2018; Link & Phelan, 2001), is a key driver of SI in chronic illness. Yet, the role of stigma in generating and perpetuating SI among KTRs remains largely unexplored. Furthermore, social exclusion is a multidimensional process through which individuals are denied access to social resources, relationships, and participation. It often operates in tandem with stigma to reinforce isolation, but its specific manifestations in the post-transplant context have not been systematically examined. Therefore, drawing on Link and Phelan's (2001) conceptualization of stigma and the literature on social exclusion, this study employs a descriptive qualitative approach to explore how stigma and social exclusion shape the lived experiences of SI among KTRs. Specifically, we examine how these processes manifest in their daily social interactions, medical encounters, and intimate relationships. This approach extends stigma theory to the field of organ transplantation and provides evidence to support equitable social integration for KTRs.

2. Materials and methods

2.1 Design

A descriptive qualitative research approach was used. This approach facilitates an in-depth understanding of participants' lived experiences and subjective perceptions during their postoperative social activities. Guided by Link and Phelan's (2001) conceptualization of stigma, which posits that stigma arises from labeling, stereotyping, separation, status loss, and discrimination within power-laden contexts, this framework is particularly suited to exploring social isolation among kidney transplant recipients, as they are often ascribed devalued identities that subject them to exclusion across multiple life domains. Throughout the interviewing and analytic process, the research team maintained the view that knowledge is inherently subjective and emerges through the collaborative engagement of researchers and participants. The research design and reporting process strictly adhere to the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

2.2 Sampling and recruitment

Using purposive sampling, participants were selected based on the principle of maximum variation in terms of gender, age, marital status, occupation, education background, residence, time since KTx and complications, to capture the broadest possible range of SI experiences among KTRs. The study enrolled KTRs who attended follow-up visits at the organ transplantation department of a tertiary hospital in China from March to June 2025. The inclusion criteria were: (1) KTRs with a post-transplant period of ≥ 3 months; (2) Age ≥ 18 years; (3) Possessing adequate cognitive ability and communication skills to participate in an interview; (4) Awareness of their disease condition. The exclusion criteria were defined as follows: (1) History of re-transplantation; (2) Severe psychiatric disorders that might interfere with study participation; (3) Malignant tumors or other severe physical illnesses. The sample size was determined based on data saturation when no new themes emerged. A total of 18 participants were ultimately included in the study.

2.3 Data Collection

Prior to the formal interviews, two KTR participants were selected to take part in pilot interviews. After synthesizing feedback from the two participants and seeking guidance from four researchers specializing in qualitative research methods and the sociology of health, the research team discussed and revised the outline. The final interview guide is provided in Table 1. The data were independently collected through face-to-face semi-structured in-depth interviews. Prior to each interview, participants were provided with a clear oral explanation of the study purpose, procedures, confidentiality assurances, and their right to withdraw at any time without consequences. Oral informed consent was obtained from all participants at the beginning of the interview session. This approach was approved by the ethics committee given the low-risk nature of the qualitative interview study and to minimise unnecessary psychological burden or formality-related stress for patients already undergoing long-term medical management. All interviews were conducted in a private, quiet room to ensure confidentiality. Interviews were audio-recorded, and field notes were taken to document non-verbal expressions. To minimize bias,

interviewers encouraged participants to speak freely and avoided using leading questions or suggestive prompts. Each interview lasted approximately 20 to 60 minutes. Upon completion of each interview, the researcher meticulously organized the data and wrote reflective journals.

Table 1
Outline of the interview.

Questions
1. Could you please tell me a little about what your life has been like since your kidney transplant? 2. What are your genuine feelings about your transplant experience? Do you feel you belong to a distinct group now, separate from others?
3. What do you think others assume about you because of your transplant?
4. What changes have occurred in your social interactions since the kidney transplant? Are there any aspects of social interaction that you find particularly challenging? 5. How do you think your broader environment(home/workplace/community)has affected your current situation?

2.4 Data Analysis

Interviews were transcribed verbatim within 24 hours. Reflexive thematic analysis was conducted in line with the six-phase framework proposed by Braun and Clarke (2006). Data were analyzed with the support of NVivo 12.0 software. Analysis was carried out inductively and driven by the data. Transcripts and field notes were repeatedly read for familiarization, initial codes were generated across the dataset, candidate themes were constructed and reviewed against the full dataset, and thematic structures were defined and refined through systematic comparison. Final themes were confirmed through independent coding and cross-checking by two researchers, with any discrepancies resolved through group discussion. The research team held regular discussions to critically examine how their own perspectives and theoretical assumptions influenced their interpretation of participants' experiences of SI. Member checking was undertaken to ensure the credibility and authenticity of the thematic results.

2.5 Rigour and Reflexivity

This study followed the consolidated criteria for reporting qualitative research (COREQ) checklist (Supplementary Table S1) to guarantee methodological rigour. The two interviewers (x.x. and x.x.) conducted interviews during their internship in the Organ Transplantation Department and had no supervisory or clinical relationship with the participants. This insider perspective sensitized us to medical burdens but risked over-privileging biomedical narratives; we mitigated this through reflexive dialogues challenging each other to trace accounts to structural and relational contexts. Interviews were conducted in Mandarin Chinese, transcribed verbatim, and translated into English by an independent bilingual translator, with interviewers reviewing translations against original transcripts for equivalence. The data analysis process was completed by two researchers via independent coding and cross-checking, with disagreements resolved through collective discussion. Member checking validated the

thematic results. Reflective journals were maintained throughout the study to prioritize participants' lived experiences.

3. Findings

3.1 Participant Demographics

A total of 18 KTRs were interviewed. The study sample included 9 men and 9 women. The average age of patients was 42.44 ± 13.57 years old (ranged from 18 to 65); the average time since transplantation was 31.17 ± 24.19 months (ranged from 3 to 74). The basic characteristics of the respondents were detailed in Table 2.

Table 2
Demographic Characteristics of Respondents (n = 18)

Characteristic	Frequency (n)
Gender	
Male	9
Female	9
Age	
18–24 years	1
25–34 years	2
35–44 years	9
45–54 years	1
55–64 years	3
≥ 65 years	2
Marital Status	
Married	12
Unmarried	4
Divorced	2
Employment	
Yes	8
No	3
Not-in-labor force	7
Educational Background	
Primary School Graduate	1
Junior High School Graduate	8
Senior High School Graduate	2
Associate Degree Graduate	2
Bachelor's Graduate	4
Master's Graduate	1
Residence	

Characteristic	Frequency (n)
Gender	
Urban	14
Rural	4
Time Since Kidney Transplant	
3–12 months	6
13–36 months	6
37–60 months	4
> 60 months	2
Complications	
Present	14
Absent	4

3.2 Themes

In this study, the average interview duration with the 18 KTRs was 30.8 minutes, resulting in the transcription of 112,000 words of textual data. Four themes and 10 sub-themes were extracted, encompassing iatrogenic isolation, defensive isolation, relational isolation, and core needs. These themes and sub-themes were presented in Fig. 1.

3.3 Theme 1: Iatrogenic Isolation

KTRs faced multiple physical and mental challenges and encountered intersecting structural and medical constraints that restricted social participation. Lifelong immunosuppressive treatment and ongoing hospital surveillance were required to maintain graft function, creating a sustained regimen of medical governance. Compromised immunity further heightened infection vulnerability, while persistent physical fatigue depleted capacity for engagement.

3.3.1 Frequent medical surveillance

Some participants reported that frequent follow-up visits, long-term, strict medication regimens, and monitoring for complications created substantial time and structural burdens, which took up a significant amount of their personal time and energy. They were repeatedly required to prioritize medical schedules over social activities, disrupting established social rhythms and leading to involuntary withdrawal from daily social networks.

N1: It was only a few days after returning home before I had to come back to the hospital. You have no idea how difficult each round trip is!

N8: I feel a bit lonely. I haven't gone back home yet, and I am renting a place near the hospital for medical treatment. There is hardly any social interaction.

N11: Because of the KTx, I have no other choice. I have to take medication every day and get regular checkups. It definitely leaves me a bit disconnected from society. (sigh)

3.3.2 Physical Fatigue

Following KTx, patients often experience a decline in physical strength due to surgical discomfort, numerous side effects from immunosuppressive medications, and postoperative complications. Many participants reported that their physical condition was inadequate for the physical demands of social engagement. Consequently, they deliberately chose to reduce or avoid social engagements. This pattern represented not only physical exhaustion but also eroded motivation and structural limits to social participation.

N2: I hardly interact with the outside world anymore. I'm just like an elderly person now, because I don't have the energy to go out.

N14: Making friends takes a lot of energy. I'd rather spend my time doing things I enjoy.

N16: I've lost much interest in socializing now. I feel somewhat reluctant to go out. It leaves me feeling tired, unenthusiastic, and mentally drained.

3.3.3 Fear of Infection

Almost all KTRs experienced infections of varying severity. As a result, they were highly sensitive to the risk of infection and felt a deep sense of fear. To minimize exposure to potential pathogens and protect themselves, some reported deliberately restricting their social circles, reducing interpersonal contact, and even avoiding important social occasions such as family gatherings.

N4: I'm worried about my health. When I go out, I meet different people, but I don't know where they're from or if they have any illnesses.

N8: We KTRs have no choice but to stay isolated, so we rarely go out. Even if we're interested in going somewhere, we don't dare to, mainly because we're afraid of getting infected.

N11: I don't even attend important family members' birthdays or big gatherings during the Spring Festival... Because the doctor emphasized avoiding crowded places, I generally avoid any activities with more than two or three people.

3.4 Theme 2: Defensive Isolation

Most KTRs were not passively isolated by others but actively employed a series of strategies to cope with disease-related psychological stress, negative emotions, as well as avoid potential social risks. Therefore, to protect themselves and those around them, they deliberately employed defense mechanisms, forming a self-protective form of SI.

3.4.1 Stigma-Driven Withdrawal

Participants reported profound stigma, shame, and feelings of inferiority linked to the identity of being a transplant recipient. To avoid negative judgment or preserve self-esteem, KTRs chose to reduce social interactions, resorting to self-isolation as a protective strategy against potential harm.

N6: After the transplant, I was afraid people would look down on me. I started buying disposable cups for guests because I feared they'd think my household items were dirty. I realized it was better to just reduce social interactions altogether.

N15: Friends invite me to gatherings, but I don't want to go. I feel like I look different from others now.

N16: Some relatives just think someone can't survive without normal kidneys. They say girls like me are useless… I don't want to socialize because I lack confidence. I'm terrified people will say hurtful things, like calling me a worthless piece of trash. It would really hurt me. (sob)

N18: I don't socialize much. Actually, I feel really insecure. I worry people will think, 'Why did you end up like this?' and laugh at me.

3.4.2 Emotional Self-Silencing

Participants often actively suppressed their emotions and concealed discomfort out of concerns about burdening relatives and friends, which marked the onset of self-isolation. When they attempted to confide in others, they frequently encountered inadequate understanding or unsupportive responses, thereby shifting them from active emotional suppression to passive self-isolation. Prolonged emotional suppression and social withdrawal fostered a profound sense of meaninglessness, which further dampened their desire to engage in social interactions.

3.4.2.1 Self-Perceived Burden

Some participants reported engaging in emotional suppression behaviors, such as deliberately inhibiting their emotional expression or concealing physical discomfort, due to concerns that their condition would impose psychological stress, caregiving responsibilities, or financial burdens on others.

N12: I basically keep everything to myself. I rarely confide in others or even talk to my parents. I bear most things on my own because I don't want to impose unnecessary burdens on my family... They have already spent a lot of money on me.

3.4.2.2 Ineffective External Responses

When expressing the physical and emotional distress caused by their illness, some KTRs frequently encountered a lack of understanding. This led them to feel that communication was inadequate and their needs were unmet. Such invalidating responses diminished their willingness to confide, prompting them to adopt a withdrawal behavior where they bore their burdens alone.

N7: I faced so many problems that no one understood. Not even my parents could grasp it because they just couldn't comprehend. No one shared that burden with me. I cried constantly... People simply couldn't empathize with how utterly frustrated we felt.

N13: No matter how close a friend is, I always feel we're not on the same level. People in different circumstances just can't understand how we feel.

N17: They don't understand anything, so it's definitely not easy for them to empathize with me. When I'm feeling really low and I try to explain how I'm doing, others just can't relate. They can't help me at all.

3.4.2.3 Heightened Meaninglessness

KTRs experienced long-term emotional suppression and social withdrawal, coupled with social maladjustment phenomena such as occupational interruption, changes in social roles and lifestyle disruptions. These factors led to a profound sense of worthlessness and meaninglessness. KTRs began to devalue their self-worth, lose their sense of life purpose, and progressively eroded their motivation to engage in social activities, constituting a deep-seated factor underlying self-isolation.

N6: In the past, I could tolerate unpleasant remarks from others. But now, if someone says something I don't like, I will stay awake all night, dwelling on it, and end up feeling like a worthless person.

N13: Staying at home makes me feel utterly worthless, leaving me with nothing but a sense of loss. Unintentionally, my social circle has shrunk, interacting only with family members... now I have a strong sense that life is meaningless.

N18: I was supposed to work until the age of 65, but due to KTx, I had to retire early, which left me with a sense of loss. I feel that my life has lost its value. I once had a successful career, but now I can no longer accomplish anything, and it seems that I am no longer needed in many aspects.

3.5 Theme 3: Relational Isolation

KTRs often faced workplace discrimination, societal misunderstanding, restrictions on marriage and childbearing, and interpersonal alienation. These challenges led to the gradual weakening, fraying, or even complete severing of the KTRs' connections with their external social networks, which in turn created a state of SI marked by eroded interpersonal bonds.

3.5.1 Kin-and-Friend Alienation

From their perspective, KTRs required long-term social distancing after surgery to manage physical recovery and prevent infection risks, resulting in a gradual decline in their willingness and ability to socialize under prolonged suppression, ultimately leading to the formation of solitary habits and decreasing interactions with relatives and friends.

N15: After transplantation, I feel like my personality changed. Like, when there are too many people around, hearing them argue makes me feel a bit dizzy. I don't even know what to talk about with them anymore. I just don't enjoy interacting with people much anymore.

N16: I don't think I'm cut out for socializing anymore. I've gotten used to it, and I guess my social circle is just what it is. I haven't really given it much thought.

From the perspective of relatives and friends, they reduced or even severed contact with the patient out of fear of being implicated or after their repeated invitations were declined. Consequently, previously close family relationships, friendships, and other external social ties gradually deteriorated.

N1: After I got sick, relatives gradually drifted apart. They didn't want to offend me, but they gradually pulled away. People are afraid I'll ask for money or drag them down.

N6: Even among siblings, if you keep rejecting well-meaning visitors over time, misunderstandings are inevitable. After being turned down several times, they'll eventually grow distant.

3.5.2 Impaired Binary Relationships

Many participants reported that their intimate partner relationships, such as marriages and romantic partnerships, were often strained or even ruptured due to practical pressures associated with the disease. These pressures included the burden of treatment, the risk of transplanted kidney injury, and restrictions on fertility.

N3: I had a girlfriend before, but I didn't dare tell her about my condition. After I finally told her, we didn't stay together. She's very realistic.

N5: We were supposed to get married six years ago, but after I was diagnosed with renal failure and told I needed a kidney transplant, I honestly told her because I didn't want to burden her. Even a dutiful child may not stay with a parent's sickbed forever, let alone a partner.

N16: I really desire to get married, but given the societal pressures, I feel it's better to give up on the idea. Even if he agreed, his family would surely be against it. Besides, if my kidney disease flared up after we got married, I'd feel terribly guilty toward him.

3.5.3 Workplace Discrimination

In the workplace, many participants concealed their medical history or suspended employment to avoid discrimination, bias, or questioning. Treatment requirements further hindered engagement in regular

work, creating substantial barriers to occupational and social reintegration. Consequently, they faced significant challenges in reintegrating into society through their occupational roles.

N3: Colleagues have a negative view of us. A coworker noticed that I was always taking medicine, so I had to pretend I had stomach discomfort, but he still told the boss. Bosses generally don't hire KTRs, thinking we're useless.

N16: Colleagues often see me taking medication, so I hide it by saying I have chronic gastritis. I've switched two or three companies over the years, always using this excuse. When I first started working, I'd even sneak into the bathroom to take my pills, worried about people giving me strange looks and questioning my abilities.

3.6 Theme 4: Core Needs

Despite experiencing multi-dimensional SI, KTRs did not passively resign themselves to this state. Instead, they held two interrelated core needs: a strong yearning for targeted external support and clear self-expectations for social reintegration. These dual needs served as key internal motivations for them to actively cope with SI and strive to rebuild social connections.

3.6.1 Yearning for Support

Rather than living in complete isolation, KTRs demonstrated a nuanced reliance on external support systems. They actively sought assistance from healthcare providers, peers, and family members. These needs encompassed both practical support and emotional recognition and understanding.

3.6.1.1 Healthcare providers Support

The professional attitude and compassionate care provided by healthcare providers alleviated the psychological burden on recipients and enhanced their confidence in coping with the disease, serving as a crucial factor in mitigating feelings of SI.

N1: The healthcare providers did not treat me as a patient, and I did not perceive myself as a hospital patient either. This prevented me from developing that kind of fear and made me feel completely normal.

N9: The doctors and nurses were like siblings, and I could consult them about anything. They understood our concerns and never made us feel like we were causing trouble.

N8: During that period when I was disinclined to speak, my nurse consistently came to talk with me. That period was very important.

3.6.1.2 Peer Support

For some KTRs, peers who shared similar disease experiences offered unique understanding and encouragement. This emotional bond rooted in shared circumstances served as a vital outlet for

processing inner emotions, mitigating the SI often stemming from illness. Participants noted that when confronting potential discrimination or misunderstanding from others, peers could offer mutual empathy and solace, drawing strength through mutual encouragement.

N1: Patients like us face discrimination in society. Only when we are together can we empathize with and support each other, offering mutual encouragement and understanding.

N7: We have a support group for KTRs, where we often share our experiences. Because we've been through similar situations, we can truly understand one another.

N10: People outside only know that I am suffering, but they cannot truly grasp my experience. When I talk with peers who have undergone the same surgery, they understand exactly how it feels. Through these conversations, the distress gradually lessens.

3.6.1.3 Family Support

Some participants indicated that KTRs craved understanding and emotional comfort from family members when coping with the physical and psychological distress of their illness and potential social challenges. Such familial support helped them better regulate their psychological state and engage more positively with life.

N7: My husband always takes me out shopping. I used to resist, afraid of catching viruses, but being out with him eases my worries.

N13: When I was sick last time, my husband stayed by my side the whole time. He lost over ten pounds. He said, 'If you can't sleep at night, just wake me up anytime you want to talk.'

3.6.2 Self-Expectations

Beyond seeking external assistance, KTRs also sought self-worth. When facing social dilemmas, they held clear expectations and goals for themselves. These expectations served not only as an internal driving force for coping with SI but also profoundly reflected their longing for a normal life. This aspiration motivated them to strive to overcome the negative impacts of their illness and reintegrate into society as equal and valued members.

3.6.2.1 Return to Work

Return to work was regarded by many KTRs as a crucial pathway for social integration and achieving a sense of accomplishment. Most KTRs expressed a strong desire to return to work, aiming to overcome the stigma of being 'useless'. They indicated that work represented not only a potential source of income but also an important means of demonstrating their capabilities and maintaining connections with society.

N13: I genuinely wish to return to work, and I still strongly desire to reintegrate into society. Employment provides a sense of accomplishment and allows me to realize my personal value, which I find more meaningful than merely performing household chores.

N16: I feel that the sense of achievement I get from work surpasses that from any other source… Striving for further career advancement may help prevent others from looking down on me or viewing me with prejudice.

3.6.2.2 Independent Living

Some KTRs reported experiencing excessive attention from others and a loss of autonomy following surgery. In fact, they aspire to participate fully in society with autonomy and equality, maintaining normal social interactions and daily routines, rather than being overprotected.

N5: I specifically told my family that I can live alone. I need to engage in some activities and can't always be taken care of by others. Actually, it is better for me to have things to do.

N13: For the first two to three years, I basically did nothing except breathe. I attempted to tidy up the dishes, but my hands would tremble, so my family members would stop me. However, greater physical engagement would have been more beneficial than such overprotection.

N17: I just want to live like anyone else, without excessive attention... Every time I catch a cold, my family bombards me with warnings. But I really think this overprotectiveness is unnecessary.

4. Discussion

SI among KTRs is a significant yet often overlooked issue, characterized by different manifestations and influenced by many factors. While KTRs share some commonalities with individuals suffering from other chronic disorders, their experiences are shaped by unique challenges, including the constant risk of graft rejection, the side effects of immunosuppressive agents, and ongoing graft function uncertainty. These challenges embed KTRs within a system of long-term medical governance, producing a form of SI that is not merely individual psychological distress but a structurally conditioned phenomenon shaped by overlapping medical, cultural, and social factors. This study reveals that frequent medical surveillance, physical fatigue, and fear of infection collectively form the core drivers of iatrogenic isolation. This phenomenon fundamentally stems from the dual pressures of mandatory medical requirements for transplant treatment and the need to avoid health risks. As documented in previous research, the one-year readmission rate for kidney transplant recipients approaches 43.2% (Sharma, Bhardwaj, & Mathur, 2021). Consequently, KTRs are structurally constrained to disrupt their usual social routines by the demands of ongoing follow-up care and lifelong immunosuppressive therapy. Persistent postoperative fatigue and fear of infection may further exacerbate experiences of social alienation (Ju et al., 2019). Indeed, research indicates that 33% of KTRs still report severe fatigue one year post-transplant, and such persistent exhaustion can lead to deliberate withdrawal from social encounters (Van Sandwijk et al., 2019). Furthermore, the infection risk induced by immunosuppression

creates a form of self-protective social restriction. Yang et al. (2020) described this as a "dark period" marked by profound infection-related anxiety and heightened vigilance. The resulting physical and psychological fatigue drives KTRs to transition from being unable to socialize to unwilling to socialize, thereby intensifying the experience of SI.

The findings demonstrate that KTRs engage in proactive, self-protective behaviours to avert perceived social and psychological harm, which together constitute a distinct pattern of defensive isolation. This suggests that stigma operates across structural, interpersonal, and intrapsychic levels simultaneously in the transplant population. In essence, this represents a state of withdrawal that KTRs actively choose to cope with psychological pressures and social risks. At the level of stigma, they feel ashamed and avoid social interactions due to changes in body image, such as surgical scars, or weight gain and hair loss caused by long-term use of immunosuppressants (Leblond, Achille, Clermont, & Blydt-Hansen, 2020). In addition, many KTRs also resist being identified as a vulnerable or chronically unwell group, leading them to actively conceal their transplant history. This concealment reinforces a self-reinforcing cycle of stigma, social withdrawal, and social withdrawal, which in turn deepens experiences of SI (Sluiter et al., 2024). Our findings extend Link and Phelan's (2001) stigma framework by demonstrating that for KTRs, stigma is not solely an interpersonal labeling process but is also structurally embedded in the medical regimen and internalized as defensive self-silencing. This study found that KTRs simultaneously exhibit both active and passive forms of emotional suppression. On one hand, influenced by the Chinese cultural norm of "spread only the good news and cover the bad," KTRs tend to conceal their negative feelings to avoid burdening their families (Tucker et al., 2019). On the other hand, due to a widespread lack of understanding among family, friends, and society regarding treatment methods of KTx, when KTRs attempt to share their experiences, they frequently face unsupportive or uncomprehending responses (Jones et al., 2020). This dual dilemma of emotional communication exacerbates SI. A sense of meaninglessness represents a deeper manifestation of defensive isolation. Many KTRs report a profound erosion of self-worth, stemming from disrupted employment, lost social roles, and diminished sense of life purpose. This study demonstrates that such experiences gradually erode the very motivation for social engagement. The employment rate after KTx is only 38.2%, significantly lower than that of the general population (Kirkeskov, Carlsen, Lund, & Buus, 2021). When an individual fails to perceive their own social value and sense of purpose, the fundamental motivation for engaging in social interaction dissolves, leading to a state of entrenched SI.

Relational isolation reflects the erosion of social connections and the breakdown of social support networks among KTRs. This is mainly reflected in three aspects: alienation from relatives and friends, impaired intimate relationships, and workplace discrimination. This is a pattern shaped by interpersonal misunderstanding, structural exclusion, and the ongoing demands of post-transplant care. This isolation manifests in three interrelated dimensions: alienation from relatives and friends, impaired intimate relationships, and workplace discrimination. Within family and friendship networks, the need for long-term rest and infection prevention following transplantation compels KTRs to limit interactions with them, gradually weakening emotional ties over time. Compounding this, family members and friends frequently demonstrate limited understanding of transplantation and its long-term management, and in

some cases, hold negative or dismissive attitudes (De Beir et al., 2024). Within intimate relationships, persistent uncertainty around graft survival, the enduring burden of long-term treatment, and concerns related to fertility have emerged as key factors undermining relationship stability. Several participants described how their partners expressed anxiety about disease recurrence and the long-term implications for their shared life, which often led to recurring conflict and, in some cases, the breakdown of the relationship. In addition, Some KTRs experience sexual dysfunction, impacting marital relationships and further exacerbating anxieties regarding marriage and partnership (Miron, Nistor, Morosanu, Siriteanu, & Covic, 2023; Raggi et al., 2012). As the most fundamental social unit, the instability or absence of binary relationships deprives patients of a crucial emotional connection point (Zhao et al., 2025). In the workplace, KTRs often face hidden discrimination. Due to the need for regular follow-up visits and the risk of infection, they are unable to fully adapt to the work rhythm, and some employers are reluctant to hire or retain them due to misconceptions about their physical condition and perceived “vulnerability.” Consistent with the findings of Akıncı et al. (2024), we observed that KTRs encountered exclusion in the workplace, reflecting the presence of stereotypes toward KTRs in occupational settings. This reinforces the finding that recipients face systemic barriers to workplace reintegration and full social inclusion, rather than mere individual challenges. Negative attention directed at KTRs in the workplace may lead them to anticipate potential discrimination from employers if their medical condition is disclosed, thereby raising concerns about employment discrimination and involuntary interruption of their career progression. This not only makes it difficult for KTRs to obtain economic income but also deprives them of the opportunity to realize their self-worth through work, which further aggravates their sense of social exclusion. As one of the most critical platforms for adults, workplace discrimination may hinder patients’ ability to rebuild their social roles and gain recognition of their value.

Identity conflict lies at the heart of stigma processes among KTRs. While recipients actively strive to resume a normal healthy life, they remain structurally constrained by the enduring identity of being a transplant patient, which carries with it expectations of vulnerability, dependency, and ongoing medical need. These experiences trap recipients in a long-term state of liminality, where they are neither fully "healthy" nor overtly "sick", but confined to an ambiguous space between these two social categories. KTRs experience a paradoxical existence, they desire social integration yet avoid interactions due to infection concerns; they wish to participate in activities but often lack sufficient energy; and they feel reborn through transplantation yet perceive themselves as different from others due to surgical scars and medication side effects. Ultimately, many come to perceive themselves not simply as patients, but as ‘special patients’, a self-identification that reinforces their sense of being distinct from both healthy individuals and other chronic illness populations (Knobbe et al., 2023).

Therefore, KTRs desire a support system comprising family support, healthcare providers support and peer support. This aligns closely with the buffer model of social support, emphasizing the crucial role of diverse support systems in mitigating the negative impact of stress on social participation (Cohen & Wills, 1985). Family support can provide recipients with practical financial assistance and emotional validation that help mitigate post-transplant stress (Roberts & Zelikovsky, 2024), yet overprotective family behaviors, despite good intentions, may instead heighten social alienation by reinforcing

recipients' sense of being different or vulnerable (Slominska, Loban, Kinsella, Ho, & Sandal, 2024; Zhang et al., 2025). Although such overprotection stems from care and concern, it actually accentuates the perceived differences between KTRs and healthy individuals. This suggests that family support should strike a balance between protection and autonomy. Regarding healthcare providers support, KTRs expressed a strong desire for psychological support from healthcare providers. However, healthcare providers predominantly focus on physiological indicators while rarely proactively addressing or assessing recipients' psychosocial distress or identity conflicts (Been-Dahmen et al., 2018). This oversight leads to the long-term accumulation of psychological issues. Peer support from individuals who share the lived experience of transplantation emerges as a particularly powerful form of support, enhancing KTRs' self-efficacy and overall quality of life (Ghahramani, Chinchilli, Kraschnewski, Lengerich, & Sciamanna, 2021). Communication among peers with shared experiences effectively breaks SI, with this effect being more pronounced among individuals facing common health challenges (Theurer et al., 2021). KTRs with different characteristics face varying realistic pressures and exhibit significant differences in social needs. Pomey et al. (Pomey, Gallego, Affdal, & Fortin, 2021) noted that younger female recipients focus on issues such as pregnancy, sexual activity, and career development, whereas elderly recipients are more concerned with long-term post-transplant care and the management of chronic comorbidities. KTRs within three months after surgery require rehabilitation experience sharing, while those beyond one-year post-surgery need greater support for long-term social adaptation. Adult patients, due to concerns about becoming a family burden and enduring financial stress, often experience a loss of meaning (Yang et al., 2020), their social needs tend to focus on gentle communication with family members and sharing coping experiences, such as work-related challenges with fellow patients. Adolescent patients, who may avoid activities like swimming due to scarring or hair loss, are prone to a state of alienation characterized by superficial conformity but internal isolation (Leblond et al., 2020), their social needs lean more toward peer acceptance and body image affirmation.

Slominska et al. (2024) noted that returning to work or school is a core need for KTRs, as it helps rebuild social roles and promotes social integration. Current research confirms that a multidisciplinary team can provide recipients with comprehensive, personalized care that extends beyond clinical management to include psychosocial support. This directly addresses the stigma-related psychosocial distress that undermines prognosis and quality of life (Taberna et al., 2020). By integrating the professional expertise of multiple disciplines, including clinical transplant diagnosis and management, rehabilitation medicine, clinical psychology, and nutritional medicine, targeted recommendations can be offered to KTRs across multiple dimensions, including physiology, psychology, and functional adaptation. This holistic approach lays a solid foundation for their successful reintegration into mainstream social contexts, helping them navigate the stigma and social exclusion that often hinder their return to normal social roles. The efficacy of cognitive behavioral therapy interventions has been clearly established through empirical research. Through psychological education, cognitive restructuring, exposure training, and social skills training, it helps patients better cope with social situations and enhance their social adaptation abilities (Creswell et al., 2021). Acceptance and commitment therapy has also been shown to help patients cope with stigma-related disease shame, learn safe emotional expression techniques, and alleviate

psychological concerns when returning to work or school (Pakenham, Mawdsley, Brown, & Burton, 2018). Existing care models emphasize the importance of family members accurately understanding the key aspects of postoperative care and providing supportive companionship rather than excessive protection, which serves as a critical foundation for patients' social recovery after surgery. The effectiveness of peer support has been validated by research, with peer guidance models tailored to different stages and groups demonstrated to precisely match patients' evolving needs (Pomey et al., 2021). Additionally, the establishment of online social platforms for KTRs can overcome geographical barriers, enabling patients to share experiences and seek assistance anytime. This is particularly beneficial for individuals in remote areas, providing them with convenient avenues for social interaction (Malo et al., 2024). Societal-level interventions focus on raising public awareness and addressing widespread social misconceptions, which are core strategies for reducing structural stigma (Link & Phelan, 2001). Anti-stigma campaigns centered on transplant knowledge dissemination can effectively increase public acceptance of recipients, directly challenging the negative stereotypes and labeling that perpetuate social exclusion (Van Der Stigchel, 2023). Promoting institutions such as businesses and schools to implement recipient-friendly policies, including flexible work hours, academic support, and privacy protection is a crucial approach to helping recipients smoothly reintegrate into their social roles.

5. Implications and limitations

By illuminating the structural, interpersonal, and intrapsychic drivers of isolation, our findings enable healthcare professionals to identify at-risk patients and address their underlying psychological distress. These insights advocate for the adoption of holistic nursing practices that incorporate routine psychosocial screening, family engagement, and multidisciplinary collaboration, thereby shifting post-transplant care from a purely biomedical focus toward comprehensive, person-centered support. Several limitations should be acknowledged. First, as a single-center study conducted at a tertiary hospital in China, it has geographical and cultural constraints: the underrepresentation of rural participants precludes in-depth analysis of urban-rural differences in SI experiences, and the Chinese cultural context limits the generalizability of findings to KTRs from other cultural backgrounds. Second, participants with malignant tumors or other severe physical illnesses were excluded to eliminate confounding effects of these conditions on SI, which restricts the applicability of the findings to KTRs with such comorbidities. Third, the study only adopted the perspective of KTRs without incorporating those of family members, healthcare providers or employers, hindering a comprehensive understanding of KTRs’ social interaction systems. Future research should include longitudinal and quantitative studies with larger, representative samples to track changes in SI and examine its associations with a range of psychosocial, clinical, and demographic variables. Comparative studies across diverse cultural and healthcare settings are also needed to understand the causes of SI among kidney transplant recipients and to provide a basis for developing tailored interventions.

6. Recommendations for policy and practice

Addressing social isolation among kidney transplant recipients requires coordinated, multi-stakeholder interventions aimed at reducing stigma, enhancing social support, and fostering an inclusive environment. These efforts are essential to promote psychosocial adaptation, facilitate social reintegration, and improve long-term health outcomes for this vulnerable population.

7. Conclusion

This study reveals that SI among KTRs is a structurally conditioned phenomenon shaped by medical surveillance, stigma, and relational breakdown. By integrating the perspectives of KTRs, we go beyond documenting individual distress to expose deeper structural challenges, including the need to integrate psychosocial assessment into follow-up care, balance family protection with patient autonomy, establish peer networks stratified by transplant stage and age, combat workplace discrimination, and embed psychosocial rehabilitation into multidisciplinary care protocols. The findings also highlight the emotional and ethical burdens on families, shaped by cultural norms of caregiving and systemic gaps in support. Addressing these challenges is critical to advancing more equitable and person-centered post-transplant care.

Declarations

8. Competing interests

The authors declare no competing interests.

9. Data availability

The data presented in this study are available from the corresponding author upon reasonable request, but are not publicly accessible due to privacy and ethical constraints.

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Figures

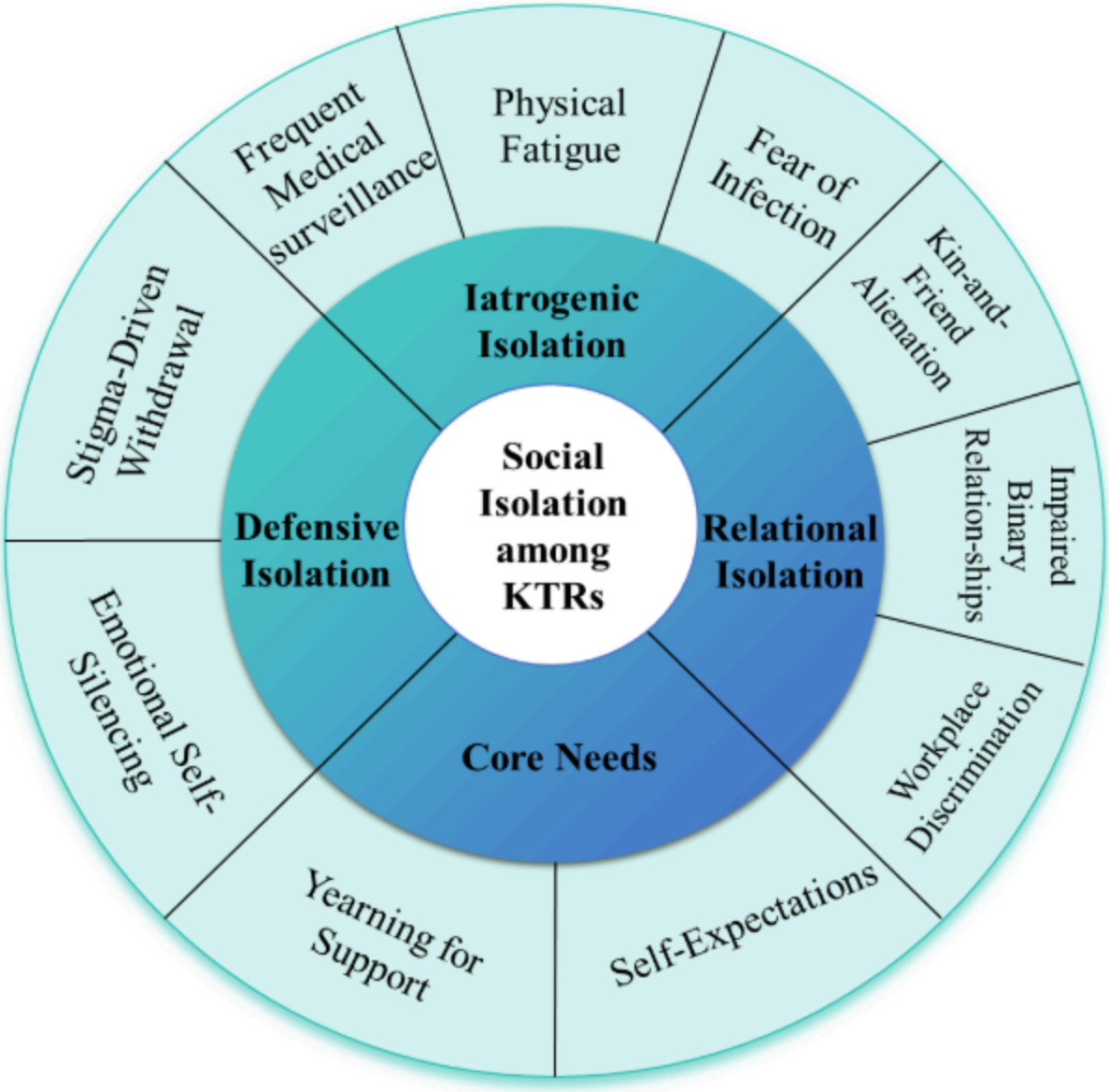


Figure 1

Major themes and sub-themes from the data.

Supplementary Files

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