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Significance of the disease and live transplantation for kidney recipients

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ABSTRACT

Introduction: In living donor kidney transplantation, the personal experience of the disease situation significantly influences the emotional adaptation and coping of the individual.

Objective: This study aims to uncover the personal significance attributed by individuals with living donor kidney transplants to their disease and its treatment and to identify any changes in this perception before and after transplantation.

Material and Method: Qualitative phenomenological study. Seven people with kidney disease who received a preventive living donor kidney transplant participated. Data were obtained through semi-structured interviews and qualitative observation.

Results: Three themes emerged from the thematic analysis of the interviews: no feeling of illness (they did not feel ill either physically or psychologically); no need for transplantation (the disease did not alter their lives, but they trusted the professionals and accepted the surgery); and transplantation to maintain the same way of life (to avoid dialysis and recover activities).

Conclusions: The meaning of the disease and renal transplantation change according to the stage (pre- or post-transplant) in which the patient is: identification of the disease is related to the presence of symptomatology, to physical symptomatology and to routines of taking daily medication and follow-up visits; and renal transplantation, means avoiding dialysis, doing the same way of life, overcoming a challenge and recovering physical condition.

Keywords: kidney failure; qualitative research; narrative medicine; kidney transplantation.

RESUMEN

Significado de la enfermedad y el trasplante de vivo para las personas receptoras de riñón

Introducción: En el trasplante renal de donante vivo, la percepción de la situación de enfermedad y la vivencia personal influyen de forma significativa en la adaptación emocional y el afrontamiento de la persona.

Objetivo: Conocer el significado que atribuyen las personas con trasplante renal de donante vivo a su enfermedad y a su tratamiento, y detectar si existen cambios antes y después trasplante.

Material y Método: Estudio cualitativo fenomenológico. Participaron 7 personas con enfermedad renal que recibieron un trasplante renal de donante vivo preventivo. Se obtuvieron los datos mediante entrevistas semiestructuradas y observación cualitativa.

Resultados: Del análisis temático de las entrevistas emergieron tres temas: sin sentimiento de enfermedad (no se sentían enfermos ni a nivel físico ni psicológico); sin necesidad de trasplantarse (la enfermedad no les alteró su vida, pero confiaron en los profesionales y aceptaron la cirugía); y trasplantarse para mantener el mismo modo de vida (para evitar la diálisis y recuperar actividades).

Conclusiones: El significado de la enfermedad y del trasplante renal cambian según la etapa (pre o post trasplante) en la que esté el paciente: la identificación de la enfermedad está relacionada con la presencia de sintomatología, con la sintomatología física y con las rutinas de toma de medicación diarias y visitas de seguimiento; y el trasplante renal, significa evitar la diálisis, hacer la misma vida, superar un reto y recuperar la condición física.

Palabras clave: insuficiencia renal; investigación cualitativa; medicina narrativa; trasplante de riñón.

INTRODUCTION

A person who opts for a living donor kidney transplant (LDKT) will experience major physiological and psychosocial changes throughout the process, beginning a phase of individual and family decision-making, searching for a compatible donor, undergoing suitability testing, and scheduling surgery. Post-operatively, there is a period of recovery and adaptation for both the donor and the recipient. By understanding the lived experience of the person moving through these stages—viewed as transitions[1]—nurses can help facilitate a healthy transition through LDKT. Guerrero et al.[2] state that the meaning of Chronic Kidney Disease (CKD) varies according to the stage the person is in. Other studies, such as that by Boaz and Morgan[3], report that the experience of kidney transplantation (KT) involves a range of negative and positive emotions, notably guilt, gratitude, and fear. De Pasquale et al.[4] conclude that the KT process can pose a potential risk to a patient's psychological equilibrium. After KT, recipients who hold a positive view of the healthcare team and of coping with the disease have a better quality of life[5].

The relationship between emotional health outcomes and a person's perception of kidney disease has been studied from a psychological perspective. A recent Spanish study of people with advanced kidney disease[6] linked perceived disease threat with anxiety symptoms and depression, especially among women. Other research in people on haemodialysis programmes has related illness perception to quality of life[7], depression[8], and mortality[9]. In this regard, Rees et al.[10] argue that emotional consequences and impacts on quality of life may stem from how the disease is perceived or understood. Illness perception differs by renal replacement therapy modality. Griva et al.[7] found that kidney transplant recipients believed less strongly that their condition was chronic, had fewer symptoms, and perceived greater control and fewer disruptions due to their illness and/or treatment than people on dialysis.

Choosing LDKT as a treatment option means accepting a kidney from a donor—most often from within the family. Concern for the donor's health and fear that the relationship might change can lead to initial reluctance among recipients to accept the kidney offer[11,12] and may even lead to refusal[13]. Typically, the decision to donate a kidney arises from an offer by the prospective donor[14]. Reasons such as concern for the recipient's health and the desire to improve their quality of life—along with preventing complications or even death—have been cited in several studies[11,14-16]. Personal factors (e.g., love and responsibility towards an ill relative) and spiritual factors have also been highlighted as important motives for kidney donation[15]. A meta-analysis shows that the closer the relationship between people, the greater the tendency to donate[17]. However, the wish to donate a kidney is tightly interwoven within a web of complex family dynamics[18] and may be a source of family tension.16 In intrafamilial donation, notions of mutual obligation take concrete form within family roles[19].

According to Franklin and Crombie[20], LDKT creates a particular relationship between donor and recipient characterised by mutual emotional support, which helps them cope with this exceptional situation. A range of benefits for donors and recipients are associated with transplantation, including quality of life, satisfaction, and wellbeing[21-23].

The experience of kidney donation among donors has been a major focus of qualitative research, and several reviews have explored donor motivations, expectations, and the consequences of donation[24-26].

By contrast, the recipient's experience of LDKT has received less attention. A qualitative meta-synthesis[17] found only one study reporting recipients' experiences. In the review by Hanson et al.[27] on decision-making around living donor transplantation, more studies on the experiences of people with kidney disease appear, and the review by Ralph et al.[28] addresses the donor–recipient relationship in the context of kidney donation.

In this study, we explore the less-studied experiences of people receiving a kidney from a living donor to understand the meaning they attribute to their disease and treatment throughout the transplant process.

MATERIAL AND METHOD

We conducted a qualitative study using a hermeneutic phenomenological approach following Heidegger's principles.

Participants were living-donor kidney transplant recipients. Inclusion criteria were individuals with CKD awaiting pre-dialysis LDKT who were seen at the Renal Transplant Units of *Hospital Clínic de Barcelona*, *Hospital Germans Trias i Pujol*, or *Hospital del Mar.* Individuals awaiting LDKT were enrolled and followed for up to 6 months post-transplant. People who commenced dialysis during the study were excluded. The study was conducted from January 2019 to July 2021. An intentional (purposive) sampling strategy was used until data saturation was reached.

Data were obtained through semi-structured interviews conducted in participants' homes and audio-recorded after informed consent. To address the study objectives—understanding the meaning of illness and treatment before and after living-donor transplantation—each participant was interviewed multiple times. All participants were interviewed both before and after transplantation; in some cases where the pre-transplant phase was prolonged, an additional interview was conducted. This methodological decision allowed accompaniment of the person through their illness and treatment journey, capturing their experience and exploring whether changes occurred before and after transplantation. Data saturation was achieved at 17 interviews from 7 participants.

We conducted a thematic analysis to understand meanings within participants' narratives. First, interviews were transcribed verbatim. Transcripts were read repeatedly and initial notes made. Initial codes were then generated and inductively grouped into themes and subthemes. We verified that themes were relevant to the research objectives and, in the final analytic phase, findings were checked against the entire text. Two team members reviewed the data analysis, and Atlas.ti v.9 was used to support coding.

Participants received verbal and written information from the lead researcher regarding the study purpose and objectives and were informed that participation was voluntary and that confidentiality would be ensured by anonymising personal data. All participants provided written informed consent. The study received favourable ethics approval from *Consorci Hospitalari de Vic*, *Hospital Clínic de Barcelona*, and *Hospital Germans Trias i Pujol* Research Ethics Committee.

RESULTS

A total of 7 recipients took part in this study. Their characteristics are shown in **table 1**.

The thematic analysis of the interviews with recipients yielded 3 themes: not feeling ill; no need for a transplant; and undergoing transplantation to maintain the same life.

Theme 1: Not feeling ill

The recipients involved in the study did not experience a sense of illness. They were diagnosed with chronic kidney disease, underwent a living-donor kidney transplant, and stated that they had not felt ill throughout the process and treatment.

Experiencing (or not) a sense of illness was linked to having (or not) physical symptoms. They reported that kidney disease did not cause notable physical symptoms and therefore they did not feel ill. If anything, they noticed some tiredness just before the operation.

"I know my kidneys don't work, but I feel fine, I don't feel ill." (Participant 6, 60 years).
"I live a completely normal life; it's just that now I get tired a bit more." (Participant 4, 41 years).

The disease and the transplant did not negatively affect them psychologically. Going through this illness–care process was not a source of major concern: they were not constantly preoccupied with or reminded of having a disease, and they approached surgery with optimism. Once transplanted, participants described a feeling of having accepted and integrated the new organ as their own without generating confusing emotions.

"It's so integrated that you don't think about it much. It's like… I don't know… honestly, it's as if I'd had it all my life. You don't notice a before-and-after difference." (Participant 2, 73 years).

Future health and graft rejection did not appear to worry the living-donor transplant recipients excessively. If anything, they were concerned about the donor's health.

"Not for me, but for her. If it went badly, I'd say, 'Blimey, she has to go through all this… and then you reject it [the kidney]…" (Participant 3, 43 years).

Table 1. Characteristics of participants: kidney transplant recipients.

Participant	Sex	Age (y)	Type of KT	Relationship to Donor	Interviews Pre-KT	Interviews Post-KT
R1	Male	39	Paired Exchange	Son	2	2
R2	Male	73	Direct	Husband	1	2
R3	Female	43	Paired Exchange	Daughter	1	0
R4	Male	41	Direct	Son	1	2
R5	Male	74	Paired Exchange	Husband	1	2
R6	Male	60	Direct	Husband	1	1
R7	Male	71	Direct	Husband	1	0

KT: kidney transplant.

Recipients reported feeling ill only in the immediate postoperative period—within the first 2 or 3 months after surgery—while resuming usual activities, seeing the new scar, and being physically aware of the new kidney. These were the factors that reminded them they had gone through an illness process.

From 3 to 5 months onward, taking regular medication and frequent follow-up visits were the situations that reminded them they had undergone a kidney transplant.

"I never think I've been transplanted, only when I take my medication." (Participant 7, 71 years).

Theme 2: No need for a transplant

Participants did not feel a need to receive a kidney transplant. Their minimally affected physical condition and the fact that their lives had not been constrained by the disease were, in their view, the reasons for this experience.

"Of course, I don't 'need' to have it [a transplant]. Biologically speaking I do need it. Physiologically. But as I don't feel anything… For me it's a step I could completely do without. It feels… very strange. I don't feel ill; I don't feel anything." (Participant 1, 39 years).

Chronic kidney disease progresses slowly, and recipients did not experience abrupt physical changes that would have altered their personal, social, or work lives.

"My doctor says, 'You've got used to living like this.' I'm fine now because I've got used to it. It's been 15 years [laughs]. It didn't happen suddenly; it was progressive. And I feel fine." (Participant 7, 71 years).

Many testimonies conveyed a degree of hope about not having to undergo transplantation, related to their experience of "not being ill". Nevertheless, the surgical phase was seen as a process they had to go through, and they expressed a desire to proceed with it promptly.

"What I'd like now is to have already been through the transplant, that it's gone well, and that I'm… already starting to recover and get back to normal life." (Participant 1, 39 years).

Recipients' narratives showed acceptance of biomedicine as the reference medical system. Trust in test results and in the nephrology professionals caring for them was essential to proceed.

"Because the blood tests say so; otherwise, I'd say, 'Do I have to be transplanted? No. What for? I'm not unwell" (Participant 2, 73 years).

Theme 3: Undergoing transplantation to maintain the same life

Kidney recipients perceived transplantation as a way to continue with the same life they had before the operation. In their accounts, the possibility of avoiding dialysis offered by transplantation was one of the strongest meanings.

"I'm fully aware that this has allowed me not to do dialysis." (Participant 3, 43 years).

Having a transplant to keep 'feeling just as well' recurred frequently in pre-operative interviews. The desire not to get worse (which would occur with starting dialysis) was reaffirmed after surgery, as their accounts stated they 'felt the same as before'.

"I don't feel that I'm better or worse now. I feel the same—in terms of the energy I might have and life in general." (Participant 6, 60 years).

Undergoing kidney transplantation meant having completed 'something that had to be done' to carry on with their lives, which kidney disease had not markedly changed. One element that had been slightly affected was the ability to make plans—arranging trips, etc.—which was curtailed by uncertainty around the surgery date.

For some recipients—those who noticed more pre-operative tiredness—transplantation allowed them to regain their physical condition.

A situation highlighted especially by younger recipients was concern that others might suspect they had undergone transplantation. Worries about whether the operation would leave visible marks that revealed they had gone through this process arose in pre-operative interviews and dissipated afterwards. This relates to 'not feeling ill' and, above all, to not being labelled as ill. Consequently, they often chose not to disclose their disease and subsequent transplant to others. *"It doesn't matter if my dentist or the pharmacist knows. My closest circle won't see any change in me. But what I really couldn't be bothered with was telling people I see day to day and then having things change. You know… being treated as an ill person. And that's not what I want."* (Participant 1, 39 years).

Maintaining the same life also entailed hoping the relationship with the donor would not change—and post-transplant interviews confirmed this. Recipients expressed gratitude towards the person who had given them the kidney.

"I'm very grateful, of course. I don't tell her all the time, but I suppose she already knows." (Participant 5, 74 years).

DISCUSSION

Participants in our study did not hold a negative perception of their disease, unlike other studies in which anxiety, depression, or even a perception of threat to the patient appeared[6,8]. They construct their perception and identification with the disease through physical symptoms and changes in therapeutic habits, depending on the stage of their illness. Identification with illness has been shown to change over time[29]. Our findings are consistent with Rees's qualitative study[10], which showed that identifying oneself as 'ill' was constructed in relation to the physical symptoms experienced by people with CKD—the more symptoms perceived, the stronger the identification as 'ill'. However, that study differs from ours in showing that transplant recipients who had previously undergone dialysis accepted that they would always be people with kidney disease. We were unable to compare our findings on illness identification among recipients with similar studies because our study population is very specific: people who underwent pre-dialysis living-donor kidney transplantation.

As noted above, for our recipients transplantation meant avoiding dialysis. At the same time, it allowed them to maintain or preserve the same life—echoing the qualitative semantic-network study by Guerrero and Gallardo[2]. In that study, transplant recipients linked concepts such as 'normality in activities' with 'kidney transplantation', whereas people on dialysis linked it with 'improving health' or a 'second chance'. In Lonning et al.[30] the expectation of receiving a kidney among wait-listed patients on dialysis related to 'getting life back' and 'seizing the opportunity'; in Da Silva et al.[31], to 'starting a new life' and 'freeing oneself from limitations'. A comprehensive review of qualitative studies[32] found that people on dialysis hoped transplantation would lead to a 'more normal life' and reduce restrictions on work, travel, planning, and diet. Thus, the meaning of transplantation differs considerably by renal replacement therapy modality.

After transplantation, recipients' cultural construction of their illness related to medical follow-up activities and medication-taking—contexts in which the social category of 'being ill' addresses them directly.

Across recipients' narratives we can identify elements of the kidney disease and transplantation process that involve biological perspective, cultural construction, and social definition of illness. On the one hand, participants know and accept the diagnosis and treatment proposed by the biomedical system—a scientific–medical model accepted and shared within the same sociocultural context. At the same time, the lived meaning of their illness and treatment is constructed and evolves throughout the transplant process. Notably, although prior to transplantation there was a mismatch between subjective experience and biomedical parameters—showing significant physical impairment at this advanced disease stage—no problems with therapeutic adherence were perceived among interviewees. In Kleinman's terms[33], recipients and the professionals caring for them share similar explanatory models, and the therapeutic procedure—in this case living-donor kidney transplantation—is accepted with little conflict. Nevertheless, they display ambivalence towards transplantation as 'not necessary' and even express some hope of not needing it. One study[34] notes that denying or minimising the severity of illness delays the possibility of living-donor transplantation. Regarding the social dimension[35], we see that interviewees aimed not to be seen or labelled as 'ill people' throughout the process—so much so that behaviours related to appearance and communication were influenced.

Using a qualitative methodology allowed us to delve deeper into the living-donor transplant process and how it is constructed through recipients' voices and experiences.

However, the study has limitations. All recipients who participated underwent kidney transplantation without significant complications and with a functioning graft; therefore, people who experienced rejection or severe complications fall outside our results. Finally, the sample size does not allow generalisation—although this is not the aim of qualitative methodology, which seeks instead to explore and deepen recipients' narratives to understand the experience of living-donor kidney transplantation.

We conclude that the meaning of illness and of transplantation changes according to the stage (pre- or post-transplant) the kidney recipient is in: identification with illness is related to the presence of symptoms, to physical symptomatology, and to routines of daily medication and follow-up visits; and kidney transplantation means avoiding dialysis, living the same life, overcoming a challenge, and regaining physical condition and certain previously limited activities.

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Conflicts of interest

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