

Applicability of the uncertainty in illness theory on patients on kidney transplant waiting lists

Aplicabilidade da teoria da incerteza da doença na lista de espera de transplante renal

Aplicabilidad de la teoría de la incertidumbre de la enfermedad en la lista de espera de trasplante renal

ABSTRACT

Purpose: To understand the daily experiences of people on a kidney transplant waiting list and to verify the applicability of the Uncertainty in Illness Theory in this context. **Method:** An exploratory, descriptive, and qualitative research, based on Merle Mishel's Theory of Uncertainty in Illness. **Results:** From the analysis of interviews with eight patients, two significant axes emerged: a) Internal aspects of adjustment to the condition of the disease; and b) External aspects of adjustment to the condition of the disease. These axes cover the categories "adaptation", "coping", "structure providers", "stimulus board" and "new life perspectives". **Conclusion:** The study made it possible to understand the predominant feelings of people on a transplant waiting list, in addition to learning about their interpersonal relationships with family members and the health team, their coping with the disease, and their hope for a compatible organ. It was also possible to understand the applicability of the Theory in the context of a kidney transplant.

Descriptors: Kidney Transplant; Uncertainty; Hope; Nursing Theory.

RESUMO

Objetivo: Aprender as experiências da vida cotidiana de pessoas em lista de espera de transplante renal e verificar a aplicabilidade da Teoria da Incerteza da Doença nesse contexto. **Método:** Pesquisa exploratória, descritiva de abordagem qualitativa, interpretada à luz da Teoria da Incerteza da Doença, de Merle Mishel. **Resultados:** Emergiram, da análise do conteúdo das entrevistas de oito pacientes, dois eixos significativos, denominados Aspectos internos do ajustamento à condição da doença e Aspectos externos do ajustamento à condição da doença que abrangem as categorias nomeadas de adaptação, enfrentamento, fornecedores de estrutura, quadro de estímulos e nova perspectiva de vida. **Conclusão:** O estudo possibilitou aprender os sentimentos preponderantes nas vivências das pessoas em lista de espera de transplante, as relações interpessoais com os familiares e equipe de saúde, o enfrentamento da doença e a esperança de um órgão compatível, assim como a aplicabilidade da Teoria no contexto do transplante renal.

Descritores: Transplante de Rim; Incerteza; Esperança; Teoria de Enfermagem.

RESUMEN

Objetivo: Conocer las vivencias de la vida diaria de las personas en lista de espera de trasplante renal y verificar la aplicabilidad de la Teoría de la Incertidumbre de la Enfermedad en este contexto. **Método:** Investigación cualitativa descriptiva exploratoria, interpretada a la luz de la Teoría de la Incertidumbre de la Enfermedad de Merle Mishel. **Resultados:** Del análisis del contenido de las entrevistas de ocho pacientes surgieron dos ejes significativos denominados Aspectos internos de ajuste a la condición de la enfermedad y Aspectos externos de ajuste a la condición de la enfermedad, que abarcan las categorías denominadas adaptación, afrontamiento, proveedores de estructura, relación de estímulos y nueva perspectiva de vida. **Conclusión:** El estudio permitió conocer los sentimientos predominantes en las vivencias de las personas en lista de espera de trasplante, las relaciones interpersonales con los familiares y el equipo médico, el afrontamiento de la enfermedad y la esperanza de un órgano compatible, así como la aplicabilidad de la Teoría en el contexto del trasplante de riñón.

Descritores: Trasplante de Riñón; Incertidumbre; Esperanza; Teoría de Enfermería.

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INTRODUCTION

Kidney transplantation is seen as one of the great advances in modern medicine, enabling quality of life and longevity for patients with Chronic Kidney Disease (CKD)⁽¹⁾. On the world stage, Brazil is the second country, in absolute numbers, with the highest number of kidney transplants performed. In 2020, 4,805 transplants were performed, 441 with living donors and 4,364 with deceased donors. However, despite the high number of transplants, there are still barriers to its performance, such as the insufficient number of donors to meet the growing demand of patients who need the procedure, which, in 2020, was 26,862 people. The new Coronavirus pandemic, declared by the World Health Organization (WHO) in March 2020, significantly affected the number of transplants in Brazil. Kidney transplantation with a living donor was classified as elective surgery, which caused its suspension for different periods in most states, with a consequent drop of 24.5% in its rate. In 2020, the waiting list for kidney transplants grew 6.2%, while admission to the list dropped 32% and mortality on the list increased 27%, which may be related to the higher risk of exposure to Coronavirus due to the performance of the hemodialysis⁽²⁾.

It is important to emphasize that kidney transplantation represents the hope of returning to a normal life, with the possibility of regaining freedom and autonomy. From this perspective, transplantation, when faced with a hopeful disposition, allows patients to put their energy into the expectation of restoring health, well-being, and quality of life. However, the long stay on the waiting list has significant impacts on the patient's well-being. The unpredictability of the waiting time for lists increases uncertainties and prevents the planning of patients' lives, as well as those of their families⁽³⁾.

Uncertainty in illness arises when conditions are ambiguous, complex, unpredictable, and when information is not available or inconsistent with reality. It is defined as a cognitive state, in which the individual is unable to attribute meaning to events related to the disease, which may entail important risks, compromising the motivation to continue fighting the disease⁽⁴⁻⁵⁾.

In this scenario, considering that waiting on the transplant list can trigger feelings of uncertainty and hopelessness and that these feelings can harm the health of patients, as well as the few studies on the themes of uncertainty and

hope as factors that impact the health of patients on the transplant list, we understood that this study is important and justifiable.

Given the above, this study aimed to apprehend the experiences of the daily life of people on a waiting list for kidney transplantation and to verify the applicability of the Disease Uncertainty Theory in this context.

METHODOLOGY

This is exploratory, descriptive research, based on a qualitative approach based on the Disease Uncertainty Theory. The study was carried out at the Transplant Center of a public hospital in the Federal District of Brazil, with patients on a waiting list for kidney transplantation. The inclusion criteria were: people over 18 years old, of both genders, registered on the waiting list for kidney transplantation, who were being monitored at the aforementioned hospital. We excluded people with difficulties in verbal expression and cognitive organization of ideas.

For data collection, we used a sociodemographic questionnaire and a semi-structured interview script. The instruments were built by the researchers, mixing the concepts of the Disease Uncertainty Theory and the objectives of the study. The sociodemographic questionnaire was composed of 16 questions to identify the profile of the participants, comprising questions about age, gender, marital status, place of residence and whether they live alone or with family members, family composition, level of education, professional situation, religious/spiritual beliefs, comorbidities, time on the waiting list, if they were previously on the waiting list, kidney offer, during the waiting and participation in a support group. The interview script consisted of six guiding questions that addressed themes such as coping with the disease, waiting period for the transplant, plans, and support for handling difficulties. The two instruments were submitted to a test with three patients who were not included in the research, which enabled the assessment, language adequacy, and reformulation of the instrument to make them more objective and adjusted to the profile of the participants.

At the time of data collection, from October to December 2016, seventy people were active on the waiting list for kidney transplantation. Participants were approached in meetings held by the transplant sector and in outpatient

consultations. They were invited to participate in the research. Participants were included until reaching data saturation, which consists in the interruption of data collection when finding that new elements to support the research will no longer be found in the field, as there were repetitions and redundancies in the participants' statements. Eight patients on the kidney transplant waiting list participated in the study.

In the first contact, the researcher presented and explained the objective, procedures, risks, and benefits of the research, inviting them to participate. The possible risks from participation in the research were the emotional discomfort that could be manifested for talking about such a delicate period. If any discomfort was detected, it would be reported to the transplant team for psychological support. The benefits explained were the contribution of each one in helping to better understand the feelings of people on the transplant waiting list; better self-knowledge and; assistance to other people who experience a similar situation, as the information provided would allow a better understanding of the needs. After acceptance, the participants signed the Informed Consent Form and were asked about the best date and time for the interview, which, in general, took place within 1 week of the invitation. The interviews were carried out in a private room at the same hospital as the participants.

On the scheduled days, the sociodemographic questionnaire was completed, followed by the interview, which was recorded with the consent of the participants, with an average duration of 40 minutes.

The researcher transcribed the data, generating a corpus that was subjected to thematic content analysis, based on Bardin's theoretical reference, which consists of discovering the nuclei of the meaning of communication, whose presence or frequency mean something to the analytical object.

To help with this analysis, we used the software *Analyze Lexicale par Contexte d'un Ensemble de Segments de Texte (ALCESTE)*, version 2017. From the lexical analysis, ALCESTE groups the semantic roots of textual data (corpus) and, according to the occurrence and co-occurrence of the words and their textual function, the classes/categories are delimited. The use of this tool seeks to delimit the researcher's action and interference in the process of separating the categories/classes of analysis.

The analysis of the narratives was interpreted based on the main concepts of the Disease Uncertainty Theory, comprised of the three pillars: uncertainty antecedents, uncertainty assessment process, and coping strategies.

The research followed all ethical precepts of Resolution number 466, of December 12, 2012, of the National Health Council (CNS), ensuring the individuals involved in the research data preservation and confidentiality by participating in all moments of research. The study was approved by the Research Ethics Committee of the Faculty of Health Sciences, the University of Brasília, under opinion 1,734,604 and Certificate of Presentation of Ethical Appreciation (CAAE) 57667316.6.0000.0030.

The names of the participants were replaced by fictitious first names to preserve the identity in the discussion of study results.

RESULTS

Eight participants on the kidney transplant waiting list composed the study, whose characterization is shown in Table 1. Regarding gender, six (75%) participants were male, the age ranged between 29 and 78 years and the mean age was 47.6 years, with more participants in the range of 41 to 60 years, considered an adult population. Regarding their professional status, six (75%) had no occupation, either due to retirement, unemployment, or not working.

Table 1 - Characterization of participants regarding gender, age, marital status, professional status and religious beliefs. Brasilia, Brazil, 2016

Variables		Women	Men	Total
Gender		2	6	8
Age	20-40 years old	1	2	3
	41-60 years old	1	3	4
	More than 61 years old	-	1	1
Marital status	Single	1	2	3
	Common-law Marriage	-	2	2
	Married	-	2	2
Professional situation	Divorced	1	-	1
	Employed	-	2	2
	retired by age	-	1	1
	Retired on disability	1	2	3
	Unemployed	1	-	1
Religious beliefs	Not working	-	1	1
	Catholic	2	5	7
	Evangelical	-	1	1

Source: Dados da Pesquisa (2021).

The length of stay on the list ranged from 1 month to 10 years, with an average time of three years and six months. Four (50%) of the participants did

not receive a kidney offer during the wait and 8 (100%) did not participate in support groups (Table 2).

Table 2 - Characterization of participants regarding gender, age, time on the waiting list, kidney offer, and support groups. Brasilia, Brazil, 2016

Variables		Women	Men	Total
Waiting list time	Less than a month	-	1	1
	1-12 months	-	2	2
	1-4 years	1	2	3
	4-8 years	-	-	-
	8-10 years	1	1	2
Offer kidney while waiting	No	-	4	4
	1 offer	1	1	2
	2 offers	-	1	1
	3 offers	1	-	1
Attend support group	Yes	-	-	0
	No	2	6	8

Source: Research Data (2021).

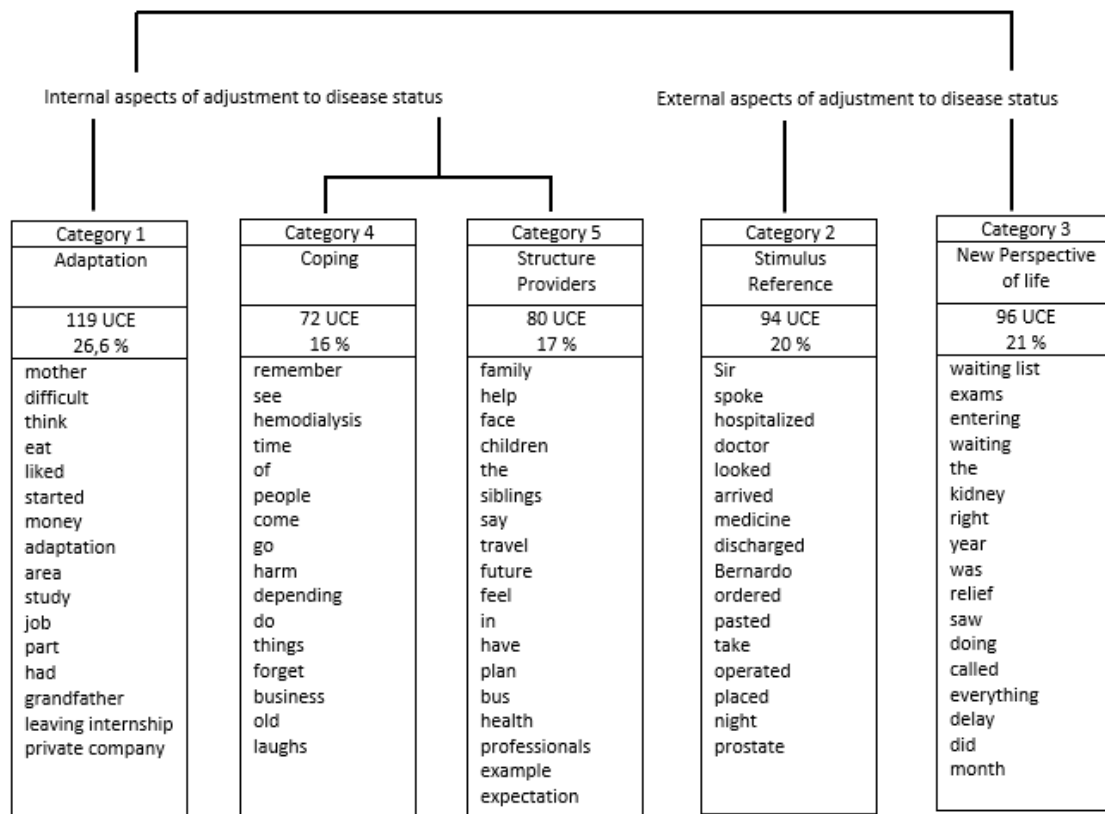
Even with the offer of a kidney during the waiting period, the transplant will not always be carried out, due to the incompatibility of the recipient-donor.

Researchers interviewed the participants to adapt to Portuguese standards and adapted to the requirements of the software used. As for the analysis performed by the ALCESTE software, 36,706 words were identified. The program split the corpus into 817 elementary context units (ECUs), which are extracts from the interviewees' statements. Of these, 461 (57%) were included in the five categories, as shown in the dendrogram below. A minimum number of 41 ECUs is necessary to constitute a category. The naming of the categories generated by the software was

performed based on the main concepts of the Disease Uncertainty Theory, comprised of three pillars: uncertainty antecedents, uncertainty assessment process, and coping strategies.

From the content analysis of the interviews, two significant axes emerged. The first axis, called "Internal aspects of adjustment to the condition of the disease" was composed of three categories: adaptation, coping, and structure providers. The second axis, named "External aspects of adjustment to the disease condition", was formed by two categories: stimulus reference and a new perspective of life (Figure 1).

Figure 1 - Dendrogram of the corpus of interviews organized into two axes and five categories. Brasilia, Brazil, 2016



Source: Research Data (2021).

Adaptation

The most prominent words were *mother*, *difficult*, *a lot*, *money*, and *adaptation*, and the verbs were *I think*, *eat*, *liked*, *started*, and *was*, which were related to the aspects and the way the patient adapted or was adapting to the new condition of life.

According to the Disease Uncertainty Theory, adaptation is multiple and complex and encompasses different segments of life, such as biological, psychological, and social, and occurs within an interval defined by the individual. This perception is in line with a study subject, pointing out that the adaptive responses of the patient to CKD are experienced individually and are influenced by several factors, such as personality, way of coping, history of previous life, process cognitive and meaning of the disease process and treatment⁽⁵⁾. The difficulty of accepting the diagnosis of the disease and the need for transplantation was observed:

"(...) Because, I think so, I thought, I couldn't accept the disease". (Lucia, 8 years on the waiting list).

Adaptation to the disease had an impact on loss of working activity status. Through extracts from the speeches, the meaning of the work for the participants was apprehended. The lack of work, to occupy the mind, to feel useful, or even the need for personal support or independence, represented a great challenge.

"Staying at home, I never liked staying at home, I've always been a very active person. So not working for me is bad, it's just a matter of working, having my money and doing what I want (...) you are useful, you have your money, you don't have to ask anyone for anything- you don't have to satisfy anything." (Viviane, 3 years on the waiting list).

During the adaptation process, the feeling of guilt and the feeling of being a burden on family members was also found:

"She lives for me. I think it's beautiful because she's a mother, but like this, I wanted her to live her life more, she knows how to enjoy it, go out. She gets so worried she can't, poor thing. I feel sorry for her because I don't know what it's like for a mother to have a sick daughter, as it's always been us, I think she's afraid of losing me." (Viviane, 3 years on the waiting list).

Feelings of weight and burden can generate sadness and guilt in the participant. This perceives the importance of support and values it, however, feels suffocated and uncomfortable with the situation. This moment of the interview was permeated by a mixture of emotions: gratitude, concern, complicity, empathy, sadness, guilt, burden and non-acceptance of the disease, feelings that need to be shared and understood so that the adaptation process can be positive.

Coping

The most prominent words were *hemodialysis, time, people, harm, and depending*, and the verbs were *remember, see, come, do and forget*, explaining the emotional state of patients waiting for the organ, their relationship with hemodialysis, and ways of coping their condition.

According to the Theory, uncertainty can be assessed as a danger or as an opportunity and, depending on how it is assessed by the individual, different strategies will be used. When assessed as a danger, coping strategies are aimed at reducing uncertainty, if possible, and managing the feelings generated. To this end, two types of coping are pointed out: mobilization strategies, consisting of the set of attitudes and behaviors assumed by the person to solve the problems generated by the disease, in an attempt to obtain information related to the disease, for the resolution of problems and/or regulation of emotions; and strategies related to managing emotions, which can be cited as faith and cognitive planning, which consists of creating new meanings about the problem and new ways of facing it⁽⁵⁾.

In evaluating uncertainty as an opportunity, we used amortization strategies, including avoidance, selective ignorance, reordering of priorities, and neutralization. We suggested that one of the explanations for patients to remain uncertain would be to facilitate hope⁽⁵⁾.

We noticed that one of the ways of coping used by patients was amortization, characterized by the avoidance of the current condition and escape from reality:

“When I wake up and remember that I have to come here like this, I only come because I know that if I don't come it won't last long, but that's all, otherwise I wouldn't come. (...) When I leave here, forget it again, it's always like that, I'm like that, when I leave, forget it, when you remember.” (Vinícius, 2 months on the waiting list).

The discomfort with the current situation, whether caused by the multiple restrictions of daily life or the long weekly hours in hemodialysis sessions, is evidenced by the desire to forget, despite knowing about the importance of treatment and the possible consequences in the case of abandonment, that is, death. The lack of hemodialysis sessions allowed inferring discomfort in dealing with the situation, seeking to avoid it.

Linked to the desire to forget, the patients' despondency was also evident due to physical changes, such as bodily changes resulting from hemodialysis, such as the creation of a fistula, thinness, bruises, scars, and changes in skin color. In addition to feelings of shame, fear of prejudice/stigma and non-acceptance were perceived throughout the speeches.

“If I remember it's worse. Even my boys, don't know that much. They see the thing in my arm like this and I say I'm going to the hospital to draw blood, that kind of thing. (...) There are a lot of people, even today my neighbors, almost no one where I live knows that I do hemodialysis, few people know that. On the street, no one, because I'm really ashamed, on the street, walking like that normally, people ask: what's that there (fistula)?” (Vinícius, 2 months on the waiting list).

“No, not from the people on the street, but there are some who have a lot of questions, that's what kills people with anger, they keep asking, asking.” (Lucas, 1 year and 6 months on the waiting list).

In certain extracts of speech, feelings of guilt/punishment for the current situation were apprehended. Participants associated the disease as a result of previous bad behaviors:

“(…) It's just like I told you, if I had looked for Him (God) earlier, I wouldn't have these things (disease).” (Lucas, 1 year and 6 months on the waiting list).

“I feel (guilty) because, for example, the accident I had at the time, if I hadn't been drinking, I don't think it would have happened. I was drunk, riding my motorcycle drunk, I wasn't conscious. So, if I hadn't been riding my motorcycle drunk at that time, I don't think it would have happened.” (Cícero, 1 year on the waiting list)

Structure Suppliers

The most prominent terms were *family, help, children, siblings, and future* and the verbs were *to face, say, travel, feel and have*, referring to the role of support, whether social or coming from professionals, family, institutional and religious /spiritual, during the patient's adaptation to the new condition of life.

The Disease Uncertainty Theory defines structure providers as the resources available to assist the person⁽⁵⁾. In the following statements, the support of family members, the health team, and the religious/spiritual team was observed:

“Look, my family, what matters to my family is the support I receive. I get a lot of support from my wife as well as my children. Because they, my children, I can't complain about a pain they're already on top of, my wife is on top to help me, you know? (...) Sometimes I'm a little slow, my children come and give me advice, my wife gives me advice: lift your head, go, move on, it can't be like that. (...) I have the doctors, I have the nurses, I have all these health professionals who are good people who help us to fight, right.” (Bernardo, 8 months on the waiting list).

“I ask God that everything goes well with this transplant. I ask every day, all night, see, that everything works out, and that it works, I can only thank you. Hey man, that helps a lot, I face things, every single thing in life just with faith.” (John, 1 week on the waiting list).

Support from family, friends, and people with similar experiences, directly and indirectly, reduces uncertainty. It directly influences the modification of three types of uncertainty: ambiguity about the state of the disease, complexity of treatment, and unpredictability about the future. Indirectly, social support reinforces the clarity of the pattern of symptoms that the person is experiencing⁽⁵⁾.

A recurrent complaint in the patients' statements was about the difficulty of finding vacancies in hemodialysis clinics across Brazil, creating impediments for eventual travels, evidencing the lack of logistical support for the treatment:

“Because sometimes you go to a place that doesn't have treatment, then you have to (...), it's a responsibility. Sometimes you want to go to the countryside and you can't, because you don't have it there.” (Cicero, 1 year on the waiting list).

“We transplanted don't stop being chronic renal, right. I'm there...we feel limited, you can't travel, it's difficult. Power can even be arranged if you arrange it if you have a small town that has a hemodialysis clinic. Because many don't, then I feel a little limited.” (Mateus, 10 years on the waiting list).

Stimulus Board

The most prominent words were *sir*, *hospitalized*, *doctor*, *medicine*, and *discharge*, and the verbs were *to speak*, *arrive*, *look and send*, which can be related to the signs and symptoms of

CKD, also denotes the mode of communication used in the diagnosis.

In the disease uncertainty theory, the stimuli reference is defined as the form, composition, and structure of stimuli related to the disease and treatment. This reference is divided into three components: the pattern of symptoms, familiarity of the event, and congruence of the event. These three components provide the stimuli that are structured by people in the cognitive scheme and are inversely proportional to uncertainty, with the clearer the less the uncertainty⁽⁵⁾.

The doubt of the condition evidenced by the lack of clarity in the pattern of symptoms can generate an increase in uncertainty, as shown in the following extract:

“I took medicine in the vein, but there was no way out and I had to be hospitalized, I was hospitalized for 3 days, just like I told you. They put a catheter in the neck, it didn't work, then it was in the groin, this one could stay for a while”. (Lucas, 1 year and 6 months on the waiting list).

We could learn that the greater the lack of clarity in the information provided, the greater the uncertainty factor:

“I called my wife, she talked to Dr. Pedro and told me to come. I came, I arrived and he looked at the exam he said just to me like this: you'll probably have to undergo dialysis, these kidneys are here, we're going to do some more exams so we can see. (...) I was hospitalized for about five days; I did the exams and it was detected that my kidneys were paralyzed. He (doctor) hospitalized me for five days, when I left, she (nurse) said: stop by for hemodialysis and talk to Dr. Saulo and he will explain to you what you have to do”. (Bernardo, 57 years old, 8 months on the waiting list).

“But at that time, as I didn't know, they put a catheter right in the neck and I said: my dear Lady, they said I was going to have hemodialysis and they're killing me!” (Mateus, 57 years old, 10 years on the waiting list).

In the extract from the two statements, we can see the lack of clarity in the communication between the team and the patient, as the patient was not informed about the procedure/exams, did not receive an explanation about what hemodialysis was, and they also did not check with him if there were doubts about his current condition.

Feelings such as fear related to the treatment and the possibility of death, sadness, uncertainty about the condition and the future, hopelessness, and anxiety are present at the time of diagnosis and throughout the treatment:

"I have no access, we are sad to say, but I have no access in this case. I already had my groin, they did it here, they fixed this fistula here, if I lose this one, there's no way to dialyze it". (Mateus, 57 years old, 10 years on the waiting list)

The extract above refers to feelings of concern and sadness regarding the waiting situation and access conditions for hemodialysis. It denotes the hopelessness for the long time and failure to wait for the transplant and the imminent impossibility of performing hemodialysis. The longer the treatment, the greater the uncertainty of getting a kidney, due to both the waiting time and the complications of therapy, such as the loss of fistulas. Losing access means the possibility of dying, since the fistula, in this case, is the real connection between the patient and the hemodialysis machine, that is, between life and death.

New Perspective of Life

The most prominent words were *waiting list, exams, kidney, relieved, and years* and the verbs were *enter, wait, do, call and delay*, relating the experiences of patients before and after joining the kidney transplant waiting list.

According to the theory, the new perspective on life is the formulation of a new sense of order. It is the result of the continuous integration of uncertainty in the patient's self-structuring, and uncertainty is accepted as a natural rhythm of life⁽⁵⁾. Relating to the pace of life of the patient on the waiting list, after the news of the need for a transplant, the uncertainty of organ donation becomes integrated into daily life.

Among the most present expressions in this category, the terms "exams" and "enter" were evidenced, which refer to the pre-list experiences:

"I was relieved, right? I tried... I almost passed it, now the other time I spent almost a year taking the exam because I couldn't do it, a struggle to do it, it costs more to do the exam than it seems to transplant. Just like this time now, this time I almost couldn't, I was giving up almost again, nine to ten months doing an exam, a little exam. Once I got it, it was a relief. Every time I scheduled an exam, I arrived here and there was no way to do it, I came back again, feeling discouraged." (Vinícius, 2 months on the waiting list).

The delay in carrying out the exams by the Unified Health System (Sistema Único de Saúde – SUS) meant an impediment to join the waiting list. Delays in care, long lines for exams, few devices, and broken devices represent wasted time delaying the insertion of patients on the waiting

list, which contributes to increased uncertainty. Thus, access to the list was perceived with joy, relief, and hope.

"I said all the time: as soon as I left again I went in again. Because if you need me, I'll go in ten times. Anyway, you're fighting over there, undergoing hemodialysis, it's the fight in the same way, better try to take a risk right away and do it right?" (Vinícius, 2 months on the waiting list).

Despite several negative feelings and experiences that the patient goes throughout the diagnosis, the hope of a transplant makes waiting more acceptable, even when there is the rejection of the new organ and the need for retransplantation. The feeling of hope of getting a new compatible organ reinforces the commitment to the treatment, even if it means entering the waiting list ten times, in search of a better life.

In the search for a better life, an aspect that can contribute to the reduction of hope is the frustration when you receive a communication from a possible compatible organ and the news of not being chosen for transplantation:

"I was very sad, like, I didn't say anything to anyone like that, but I got inside, right? Inside I was sad. But then, the second time came, I said: oh, I won't even be happy, I'll wait and see what happens. And the third as well." (Lucia, 8 years on the waiting list).

"(...) It was one more disappointment, right, it wasn't my turn yet, it wasn't my turn." (Mateus, 10 years on the waiting list).

We perceived two antagonistic feelings: the happiness and optimism of being called for a transplant, followed by the disappointment of not being chosen. In the second line, the word "yet" portrays a lingering hope, with a vision of the future that the transplant will happen, sooner or later.

Another reason that can cause a decrease in hope is the discovery of distorted information, generating discredit in health professionals:

"Except for those people who undergo transplants from relatives, which is another case, but I didn't know anyone who was on the waiting list for 1 year. Everyone stays much longer than the 1 year the doctors talk about." (Viviane, 3 years on the waiting list).

DISCUSSION

According to the study results, six (75%) of the participants did not work. This data is confirmed by other investigations⁽⁶⁻⁷⁾. The job plays a central role in people's lives. In addition to representing a component of the constructed and reproduced social reality, it interacts with different personal and social variables and influences people's actions. It is also the center of individual and collective concerns and investments, a source of income, structures time, brings self-fulfillment, social status, and is a mechanism for social integration, expressing great relevance in adult life, making it more significant. Disability, whether due to physical limitations and/or due to the time invested in the machine, affects the job, causing feelings that depress the quality of existence⁽⁶⁻⁷⁾. Among the participants, the inability to work, as well as the need for help to attend hemodialysis sessions, caused feelings of burden and discomfort about dependence on their families, referring to lack of freedom and feelings of uselessness. These feelings can cause emotional problems, making them feel a burden on their families⁽⁸⁾.

Based on Merle Mishel's Uncertainty of Disease Theory, one of the interpretations of uncertainty is associated with opportunity, using amortization strategies, such as avoidance to face and minimize the suffering caused by the disease, and to keep hope⁽⁵⁾. We observed that, after the hemodialysis sessions, there was an attempt to disconnect from the treatment, as well as an effort to change the focus of life. We also detected the attitude of trying to live in the present moment, taking the focus off the future from waiting, silencing feelings of doubt, and trying to live one day after another. The absence from hemodialysis sessions was a strategy verified in the study, being corroborated in the literature, in which the participants also used denial and escape from the experienced condition⁽⁹⁻¹⁰⁾. Attention is drawn to the monitoring of these patients by the health team, as strategies involving escape are related to suffering and low quality of life rates⁽⁹⁻¹¹⁾.

Attitudes or feelings of inferiority, discomfort, shame and prejudice generated negative feelings, leading patients to isolation, harming their social relationships, and reducing the support network, which is a fundamental element in the treatment⁽¹²⁻¹³⁾. Many reported embarrassment about the fistula, so they chose clothes very carefully, for example, avoiding light clothes, especially in summer. They reported that,

when the fistula was accidentally exposed, there was a concern to quickly hide it⁽¹⁴⁾.

Social support is of paramount importance for patients on the waiting list, having a specific definition in theory, as structure providers⁽⁵⁾. Among them, we highlight the support of family members, the health team, religious groups, and support in general⁽¹⁵⁾. Support can cause positive results in short- and long-term psychological problems⁽¹⁶⁾. Patients felt grateful for their family members to be present in the search to resolve problems, uncertainties, difficulties, suffering, and all kinds of restrictions in their daily lives while waiting for a kidney transplant. Family support had a protective effect, not only in crises but also in transition periods that occur throughout life. The perception of adequate family support is related to the increased sense of security in people with chronic diseases⁽¹⁷⁻¹⁹⁾.

During the stay on the waiting list, the support of the health team is crucial. The team must be attentive to the daily events of patients and their needs during the waiting process. The bond of trust between patients and staff needs to be constantly renewed so that they do not give up on the transplant and remain hopeful and on the waiting list^(15,18-19). Based on the disease theory, the health team is defined as a credible authority, with the ability to reduce uncertainty, by providing information and promoting confidence in its judgment and clinical performance. Confidence in the ability of health professionals to determine the diagnosis, control the disease, and promote adequate treatment can reduce the uncertainty of patients with chronic diseases⁽⁵⁾.

We found that none of the participants were part of support groups. An effective method for reducing patient uncertainty is to encourage communication between patients who have successfully managed their uncertainty. A study with patients on a waiting list showed that respondents perceived the importance of talking to other people in the same condition, as this would help them to withstand the waiting situation. The exchange of experiences, conversations with people who have already lived the experience of waiting for a transplant, reinforce the hope and relief of feeling understood and accompanied during the waiting period^(4-5,19).

Therefore, the role of the support group is fundamental and represents a facilitating strategy in the process of coping with the disease, as it has the function of helping individuals, during periods of adjustment to change, in the treatment of crises,

in the maintenance and/or adaptation to a new situation and the structuring of the stimuli around it. Group care with participants who experience the same situation facilitates the exchange of confidences, particularities, and intimacies between members, promotes support, raises self-esteem and self-confidence, and enables the health team to know the real needs and concerns of the participants^(4-5,16,19).

Religious support, carried out through religious and spiritual groups, represents a sacred core that encompasses feelings, thoughts, and behaviors that emerge from a search for the transcendent, referred to as a divine being or as absolute truth, according to the perception individual of the individuals. According to the Theory, faith is one of the strategies used by individuals to manage their emotions when faced with the stimulus. Religion, spirituality, and faith in God and/or in the sacred help patients to adapt to the new reality of life, providing strength, trust, hope, and comfort, and this form of strategy is known as positive religious/spiritual coping.

However, the use of religiosity/spirituality as a coping strategy can also generate harmful or negative consequences for the individual (negative religious/spiritual coping), as can be seen in one of the participants' statements, who blamed their current condition on the postponement of communion with God. The use of this support in a negative way can impair treatment and quality of life and lead to uncertainty in individuals, requiring attention from professional care providers^(5,13,19-21).

The limitation regarding the fact of not being able to travel, whether due to the lack of hemodialysis clinics or the frequency of sessions, are identified as the main stressors in hemodialysis patients, confirmed by the study participants. According to the National Register of Health Establishments, there are 1,657 records of establishments specialized in DRC, and in Brazil there are 5,570 municipalities, demonstrating the lack of federal support, as some municipalities do not provide this service to their population. The reduced number of hemodialysis clinics enhances the patients' feeling of loss of freedom⁽²²⁻²³⁾.

The pattern of symptoms of patients generates a mixture of feelings, such as fear related to the treatment and the possibility of death, sadness, uncertainty about the condition and the future, hopelessness, and anxiety^(5,23-25).

The possibility of a transplant is symbolically related to a "light at the end of the tunnel", winning the lottery, as it motivates the patient to

go through the difficulties and focus on the hope of getting a compatible organ. Hope is a factor commonly evidenced in chronic patients, crucial for the adaptation of renal patients, and a source of support and strength, as it allows for the opening of new opportunities^(5,18,23). There was some doubt about the feeling of hope regarding the transplant, as they sometimes expressed hope and sometimes expressed feelings of uncertainty. This phenomenon can be enhanced during the waiting period, calling into question the real opportunity for a transplant⁽¹⁰⁾.

The health professional plays an important role in promoting hope. Perceived as a holder of knowledge, patients trust their information, however, if some situations do not happen according to the guidelines received, they feel deceived and may lose confidence in the health team. Participants expressed that, according to the professional's speech, the waiting time for the organ would be quick. However, this stipulated time arrived and the transplant did not occur. Insufficient or misleading information was identified as one of the stress factors for patients on the transplant waiting list, which characterizes communication difficulties between the health team and the patient^(10,18,25).

According to the theory, health professionals are a key point and influence the conception of a new perspective on life⁽⁵⁾. Information from health professionals promotes a probabilistic view of the world, encouraging the development of a new view of the patient's feelings. Therefore, the clarifications provided about CKD, the transplantation process, and hemodialysis treatment need to be personalized, individualized, and honest to favor the patients' understanding of their real situation^(5,10,18,25).

The activities of nurses in chronic diseases should promote probabilistic thinking to help the patient consider new options for carrying out activities, consider alternatives to adjust to the natural changes of the disease, and/or promote the notion that many factors influence the patient's response to treatment⁽⁴⁻⁵⁾.

CONCLUSION

The study enabled us to know the daily lives of patients on the waiting list, apprehend the most prevalent feelings, the difficulties to be included in the list, the relationship with family members and the health team, ways of coping with the reality of the disease and the role of hope, during the time on the list, aiming to get a compatible organ.

The Disease Uncertainty Theory made it possible to identify the impacts of uncertainty on the experiences of patients on the transplant waiting list. Reading the content of the interviewees' statements in the light of theory provided an understanding of the background to the uncertainty of these patients, the ways of coping with the disease, the ways of adapting, and the patients' assessments of their conditions at the time. The main concepts of the Disease Uncertainty Theory were clear, simple, precise, and general, attesting to its applicability to patients on the waiting list for kidney transplantation.

As a limitation of the study, one can mention that the study was carried out in a single institution, hindering the comparison of different services. Among the strengths, the variety of length of stay in the list of participants can be listed, which enabled to apprehend the different views of the different realities and allowed the use of a Nursing Theory to support the study. As a future agenda, a study with family members and patients on a waiting list inserted in support groups is recommended to verify coping measures against the condition and possible changes in feelings.

As a result of the study, we expected that professionals become aware of the emotional needs of patients on the waiting list, paying special attention to the impact of uncertainty and hope in the waiting process and encouraging the creation of support groups, as well as greater awareness by the population, about the importance of organ donation.

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