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Reasons referred by individuals who were not on kidney transplantation waiting lists

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Motivos referidos pelos indivíduos que não estavam em lista de espera para o transplante renal

Razones referidas por individuos que no estaban en lista de espera de trasplante renal

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ABSTRACT

Objective: To describe the reasons reported by individuals in hemodialysis that were not registered on kidney transplantation waiting lists.

Methods: Cross-sectional study conducted in six renal replacement therapy services in Rio Grande do Sul, Brazil with 214 individuals undergoing hemodialysis who reported the reasons for not being registered on kidney transplantation waiting lists. The data collection was carried out through a questionnaire from March 2016 to March 2017. The Stata software was used to the statistical analysis and independence test.

Results: The main reasons reported by the 214 individuals who were not registered on kidney transplantation waiting lists were due to the lack of information of the individuals, not wanting to be on list, due to morbidities and age.

Conclusions: The lack of information was associated with the variables low education, male, ≤ 5 years of time since diagnosis and ≤ 5 years in renal replacement therapy. The reason for not wanting to be on the list was associated with the variables illiteracy and age.

Keywords: Kidney transplantation. Waiting lists. Dialysis.

RESUMO

Objetivo: Descrever os motivos referidos pelos indivíduos em hemodiálise que não estavam cadastrados em lista de espera para o transplante renal.

Métodos: Estudo transversal realizado no Rio Grande do Sul, Brasil em seis serviços de terapia de substituição renal com 214 indivíduos em hemodiálise que referiram os motivos de não estarem cadastrados em lista de espera para o transplante renal. A coleta de dados foi realizada por meio de questionário entre março de 2016 e março de 2017. Para a análise estatística descritiva e do teste de independência, utilizou-se o software Stata.

Resultados: Os principais motivos referidos pelos 214 indivíduos que não estavam cadastrados em lista de espera para o transplante renal foram: a falta de informação dos indivíduos, não desejar estar em lista, o impedimento por multimorbidade e a idade.

Conclusões: A falta de informação apresentou associação com as variáveis baixa escolaridade, sexo masculino, ≤ 5 anos de tempo de diagnóstico e ≤ 5 anos em terapia de substituição renal. O motivo não desejar estar em lista esteve associado com as variáveis não saber ler e idade.

Palavras-chave: Transplante de rim. Listas de espera. Diálise.

RESUMEN

Objetivo: Describir las razones informadas por personas en hemodiálisis que no estaban registradas en lista de espera para trasplante renal.

Métodos: Estudio transversal realizado en Rio Grande do Sul, Brasil en seis servicios de terapia sustitutiva renal con 214 individuos en hemodiálisis que informaron los motivos de no estar registrados en listade espera para trasplante renal. La recolección de datos se realizó mediante un cuestionario entre marzo de 2016 y marzo de 2017. Para el análisis estadístico descriptivo y test de independencia se utilizó el software Stata.

Resultados: Las principales razones reportadas por las 214 personas que no estaban inscritas en listade espera para trasplante renal fueron la falta de información de las personas, no querer estar en lista, impedimento por multimorbilidad y edad.

Conclusiones: La falta de información se asoció con las variables baja escolaridad, género masculino, ≤ 5 años de tiempo desde el diagnóstico y ≤ 5 años en terapia de reemplazo renal. El motivo de no querer estar en la lista estuvo asociado a las variables no saber leer y edad.

Palabras clave: Trasplante de riñón. Listas de espera. Diálisis.

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INTRODUCTION

Chronic Kidney Disease (CKD) is associated with high mortality risks, low quality of life and highcosts to the Public Healthcare System(1–2). It is estimated that global mortality from CKD could reach 5 million people per year, becoming the fifth leading cause of death in the world by 2040. CKD is also strongly linked to cardiovascular disease and diabetes(3). Although most individuals with end-stage CKD undergo dialysis, kidney transplantation is recognized as the best therapy option, as it leads to improved clinical outcomes and better quality of life(4–7).

In Brazil, hemodialysis is also the predominant renal replacement therapy (RRT) method used, about 92% of the 133,464 individuals on dialysis in 2018(4), among which 45% were eligible for kidney transplantation. In addition, each year it is estimated that 40,000 new individuals will be undergoing dialysis treatment, with 160,000 Brazilians expected to be undergoing treatment in 2022. On the other hand,28,000 individuals stop dialysis for the following reasons:22,000 die and 6,000 undergo kidney transplantation. The average time a patient spends on the waiting list for kidney transplantation is six years(8,9).

According to the legislation on kidney transplantation, the Unique Technical Registry is made at the Center of Notification, Procurement and Distribution of Organs (CNCDO) by the healthcare establishment and/or the team responsible for patient assistance. The National Transplant System, responsible for the entire process, is fullyfunded by the Unified Health System (SUS). This process includes two steps, the first is the registration on the waiting list and the second is the allocation of an organ, and as of September 2021 there were 26,413 Brazilians on this waiting list(9), which represents 20% of the individuals in dialysis.

In addition, there are numerous individuals eligible for the waiting list, though not registered. Several factors can explain this behavior, including demographic, socioeconomic and clinical variables that impact registration on the waiting list(11–12). It is known that CKD is related to socially defined factors such as population with low socioeconomic status, in social vulnerability and ethnic minorities. These groups face the coexistence of communicable and noncommunicable diseases, as well as the difficulty of initiating treatment in one of the RRTs(13–16).

Studies show(3–7) that despite the availability of a universal healthcare system, inequality in access to the waiting list for kidney transplantation(7) is evident, including in the different regions of the country(6–7,11–16) . Therefore, regional studies on the reasons why individuals are not registered on the waiting list for kidney transplantation are needed. In this regard, the present study was motivated by the importance of elucidating the reasons mentioned by individuals who are not on the waiting list for kidney transplantation in the Southern Half of Rio Grande do Sul.

Therefore, this study aimed to describe the reasons mentioned by individuals on hemodialysis who were not registered on the transplant waiting list.

METHOD

Cross-sectional study of non-probabilistic convenience sampling originated from the research "Health care in renal replacement therapy services in the Southern Half of Rio Grande do Sul" and "Empowerment and autonomy for people in renal therapy services in the Southern Half of the State of Rio Grande do Sul".

Data was collected between March 2016 and March 2017 in six renal replacement therapy services (RRTS located in five municipalities (Pelotas, Rio Grande, Uruguaiana, Alegrete and São Lourenço do Sul) of the Southern Half of Rio Grande do Sul, Brazil. None of these RRTSs had a transplant center. All individuals on hemodialysis are referred to transplant centers in other municipalities, mainly to the capital, Porto Alegre.

The non-probability convenience sampling consisted of all individuals who were on hemodialysis treatment in the six RRTSs aged ≥18 years, preserved cognitive ability and verbal communication and legally able to be on the waiting list. Individuals who were not included in the RRTS, such as cases of emergency dialysis, in transit, in an acute condition or hospitalization and without cognitive and communication conditions, were excluded.

The pilot test was applied before the beginning of data collection for this study. The application of the test resulted in meetings with researchers and statistical advice, revision and alteration of the questionnaire, standardization of collection procedures and training of the collection team. Pilot test data did not make up the database.

The interviews were carried out during the hemodialysis sessions, with the use of a questionnaire applied by six trained collectors (undergraduate and graduate nursing students) and the information was complemented with the analysis of the medical records. The interviews lasted about

20 minutes. Participants' right to privacy and to confidentiality of their information were ensured and they agreed to participate in the study by signing the Free and Informed Consent Term (FICT).

The variables for this article, as well as the way in which the data were treated, were determined based on recent studies on renal replacement therapy(16–19). The variables age (≥18-39, 40-59, 60-79, ≥ 80 years) were selected; skin color (white, black, brown and yellow); family income, corresponding to the value of the Brazilian minimum wage in 2016 (≤BRL880.00; BRL880.01-BRL2640.00;≥BRL2640.01); marital status (married or stable union, single, separated/divorced and widowed); years of schooling (0, 1-4, 5-9, 10-12, ≥ 13 years); time elapsed since diagnosis of chronic kidney disease and time elapsed since the beginning of therapy, which were divided (≤ 60 months or ≥ 61 months); the dichotomous variables: reading ability, having multimorbidities, having spending on chronic kidney disease, having had a transplant, hospitalization, being enrolled on the waiting list, living alone, having children, gender and area of residence. The reasons spontaneously mentioned by individuals who were not on a waiting listfor kidney transplant were as follows: not wanting to be on the waiting list, lack of information, multimorbidity, fear, recent diagnosis, dropped out, others. The reasons were mentioned by the individuals (open-ended question) and later, grouped and coded. Thus, the phrases "does not know about the possibility of transplantation", "(the professionals) did not speak" and "waiting for someone to talk about the treatment" were grouped together in lack of information, and "does not want to be on the waiting list", "doesn't want to be on the list" and "has no interest in being on the list" were grouped into not wanting to be on the list. The reason "others" refers to the following situations: the individual has no family, difficulty traveling in the capital (where the transplant center is located), the child is on the list, has already undergone the transplant and was not successful, and is a foreigner.

Data were stored in the EpiData software with double data entry and checking for inconsistencies and later transferred to the Stata Software, version 13 format. Descriptive statistical analysis was performed with distribution of relative and absolute frequencies. The relationship between the categorical variables was analyzed using the independence test (Pearson's chi-square), considering a 95% confidence interval and assuming for statistical significance the value of $p \leq 0.05$.

The procedures adopted in this study followed the provisions of Resolution No.466, of December 12, 2012, of the National Health Council. The original research was approved by the Research Ethics Committee under opinion protocol no 1.386385, with Certificate of Presentation of Ethical Appreciation CAAE 51678615300005316.

RESULTS

Of the 314 hemodialysis patients who met the eligibility criteria, 72.6% (n=228) were not registered on the kidney transplantation waiting list. Of the 228 questionnaires completed by these 228 patients, 14 questionnaires were excluded because they did not inform the reasons. Therefore, this study describes the reasons reported by the 214 individuals on hemodialysis who were not on the waiting list for kidney transplantation.

Regarding the stratified distribution of socioeconomic and clinical variables of respondents not registered on the waiting list for kidney transplantation, there is a predominance of the age group from 60 to 79 years old, male, with self-reported white skin color and family income ≤ BRL880.00 (minimum salary in 2016). As for the residential location, the individuals who were not registered reported living with other people, in the urban area, having children and being divorced. In addition, most unregistered individuals cannot read, have not studied, have no expenses with the disease, are undergoing therapy and were diagnosed with kidney disease within a period of up to 5 years, did not undergo transplantation, were not hospitalized in a unit hospital and have morbidities. The shortest time elapsed since subjects were diagnosed with chronic kidney disease and started hemodialysis treatment was one month.

Table 1 shows the relationship between the reasons mentioned and the socioeconomic and clinical characteristics that showed statistical significance in the independence test were age ($p<0.001$), gender ($p<0.001$), ability to read ($p<0.021$) years of education ($p<0.010$), time elapsed since diagnosis ($p<0.001$) and timein therapy ($p<0.003$).

Table 1 – Socioeconomic and clinical characteristics and reasons mentioned by individuals on hemodialysis who were not registered on the waiting list for kidney transplantation (n=214). Rio Grande do Sul, Brazil, 2021

Socioeconomic and clinical Characteristics	Lack of information	Notwanting	Multi-morbidities	Age	Recent diagnosis	Fear	Quit	Others	p
	74 (34.5)	44 (20.5)	32 (14.9)	25 (11.6)	10 (4.6)	9 (4.2)	8 (3.7)	12 (5.6)	
Age									**< 0.001**
18-39 years	6 (33.3)	2 (11.1)	2 (11.1)	0 (0)	2 (11.1)	1 (5.56)	2 (11.1)	3 (16.6)	
40-59 years	24 (34.7)	10 (14.4)	18 (26.0)	0 (0)	5 (7.2)	4 (5.8)	1 (1.4)	7 (10.1)	
60-79 years	38 (35.8)	27 (25.4)	12 (11.3)	16 (15.0)	3 (2.8)	4 (3.7)	4 (3.7)	2 (1.8)	
80 years or older	6 (28.57)	5 (23.8)	0 (0)	9 (42.8)	0 (0)	0 (0)	1 (4.7)	0 (0)	
Gender									**<0.001**
Male	52 (40.6)	24 (18.7)	11 (8.5)	18 (14.0)	4 (3,1)	7 (5.4)	8 (6.2)	4 (3.1)	
Female	22 (25.5)	20 (23.2)	21 (24.4)	7 (8.1)	6 (6.9)	2 (2.3)	0 (0)	8 (9.3)	
Color									0.847
White	50 (32.8)	27 (17.7)	25 (16.4)	19 (12.5)	8 (5.6)	6 (3.9)	6 (3.9)	11 (7.2)	
Black	13 (35.1)	11 (29.7)	4 (10.8)	3 (8.1)	2 (5.4)	1 (2.7)	2 (5.4)	1 (2.7)	
Brown	11 (45.8)	5 (20.8)	3 (12.5)	3 (12.5)	0 (0)	2 (8.3)	0 (0)	0 (0)	
Yellow	0 (0)	1(100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	
Family income[a]									0.605
≤ BRL880.00	14 (37.8)	6 (16.2)	10 (27.0)	2 (5.4)	0 (0)	2 (5.4)	1 (2.7)	2 (5.4)	
≥ BRL880.01 ≤ BRL2640.00	52 (33.9)	34 (22.2)	19 (12.4)	20 (13.0)	7 (4.5)	6 (3.9)	6 (3.9)	9 (5.8)	

Table 1 – Cont.

Socioeconomic and clinical Characteristics	Lack of information	Notwanting	Multi-morbidities	Age	Recent diagnosis	Fear	Quit	Others	p
≥ BRL2640.01	8 (33.3)	4 (16.6)	3 (12.5)	3 (12.5)	3 (12.5)	1 (4.1)	1 (4.1)	1 (4.1)	
Leaves alone									0.564
No	62 (34.6)	38 (21.2)	28 (15.6)	20 (11.1)	6 (3,3)	7 (3.9)	7 (3.9)	11 (6.1)	
Yes	12 (34.2)	6 (17.1)	4 (11.4)	5 (14.2)	4 (11.4)	2 (5.7)	1 (2.8)	1 (2.8)	
Residential location									0.38
Rural area	8 (40.0)	1 (5.0)	5 (25.0)	4 (20.0)	0 (0)	1 (5.0)	0 (0)	1 (5.0)	
Urban area	66 (34.0)	43 (22.1)	27 (13.9)	21 (10.8)	10 (5.1)	8 (4.1)	8 (4.1)	11 (5.6)	
Has children									0.379
No	14 (50.0)	4 (14.2)	2 (7.1)	2 (7.1)	3 (10.7)	1 (3.5)	1 (3.5)	1 (3.5)	
Yes	60 (32.2)	40 (21.5)	30 (16.1)	23 (12.3)	7 (3.7)	8 (4.3)	7 (3.7)	11 (5.9)	
Marital Status									0.255
Married/Stable union	43 (37.7)	23 (20.1)	15 (13.1)	14 (12.2)	5 (4.3)	7 (6.1)	2 (1.7)	5 (4.3)	
Single	14 (29.1)	11 (22.9)	8 (16.6)	2 (4.1)	4 (8.3)	2 (4.1)	3 (6.2)	4 (8.3)	
Divorced	10 (45.4)	2 (9.0)	4 (18.1)	2 (9.0)	0 (0)	0 (0)	1 (4.5)	3 (13.6)	
Widowed	7 (23.3)	8 (26.6)	5 (16.6)	7 (23.3)	1 (3.3)	0 (0)	2 (6.6)	0 (0)	
Can read									**0.021**
No	5 (19.2)	12 (46.1)	1 (3.8)	4 (15.3)	2 (7.6)	1 (3.8)	1 (3.8)	0 (0)	

Table 1 – Cont.

Socioeconomic and clinical Characteristics	Lack of information	Notwanting	Multi-morbidities	Age	Recent diagnosis	Fear	Quit	Others	p
Yes	69 (36.7)	32 (17.0)	31 (16.4)	21 (11.1)	8 (4.2)	8 (4.2)	7 (3.7)	12 (6.3)	
Years of schooling									**0.01**
No schooling	5 (17.7)	9 (50.0)	1 (5.5)	3 (16.6)	0 (0)	0 (0)	0 (0)	0 (0)	
Up to 4 years	28 (42.4)	11 (16.6)	6 (9.0)	10 (15.1)	2 (3.0)	4 (6.0)	3 (4.5)	2 (3.0)	
Between 5 and 9 years	22 (27.1)	19 (23.4)	15 (18.5)	10 (12.3)	4 (4.4)	4 (4.4)	4 (4.9)	3 (3.7)	
Between 10 and 12 years	4 (23.5)	3 (17.6)	2 (11.7)	0 (0)	3 (17.6)	1 (5.8)	1 (5.8)	3 (17.6)	
More than 13 years	4 (23.5)	3 (17.6)	2 (11.7)	0 (0)	3 (17.6)	1 (5.8)	1 (5.8)	3 (17.6)	
Expenses with the disease									0.08
No	19 (34.5)	12 (21.8)	3 (5.4)	10 (18.1)	4 (7.2)	2 (3.6)	4 (7.4)	1 (1.8)	
Yes	55 (34.5)	32 (20.1)	29 (18.2)	15 (9.4)	6 (3.7)	7 (4.4)	4 (2.5)	11 (6.9)	
Time since diagnosis									**<0.001**
≤ 5 years	54 (42.1)	26 (20.3)	15 (11.7)	18 (14.0)	7 (5.4)	4 (3.1)	1 (0.7)	3 (2.3)	
> 5 years	20 (23.2)	18 (20.9)	17 (19.7)	7 (8.1)	3 (3.4)	5 (5.8)	7 (8.1)	9 (10.4)	
Time in therapy									**0.003**
≤ 5 years	58 (42.3)	29 (21.1)	18 (13.1)	17 (12.4)	6 (4.3)	3 (2.9)	2 (1.4)	4 (2.9)	
> 5 years	16 (20.7)	15 (19.4)	14 (18.1)	8 (10.3)	4 (5.1)	6 (7.7)	6 (7.7)	8 (10.3)	

Table 1 – Cont.

Socioeconomic and clinical Characteristics	Lack of information	Notwanting	Multi-morbidities	Age	Recent diagnosis	Fear	Quit	Others	p
Had a transplant									0.112
No	71 (35.3)	42 (20.9)	29 (14.4)	25 (12.4)	9 (4.4)	8 (3.9)	8 (3.9)	9 (4.4)	
Yes	3 (23.0)	2 (15.3)	3 (23.0)	0 (0)	1 (7.6)	1 (7.6)	0 (0)	3 (23.0)	
Hospital admission									0.285
No	9 (64.2)	3 (21.4)	1 (7.1)	0 (0)	1 (7.1)	0 (0)	0 (0)	0 (0)	
Yes	65 (32.5)	41 (20.5)	31 (15.5)	24 (12.0)	10 (5.0)	9 (4.5)	8 (4.0)	12 (6.0)	
Has multimorbidities									0.992
No	22 (40.0)	11 (20.0)	7 (12.7)	6 (10.9)	2 (3.6)	2 (3.6)	2 (3.6)	3 (5.4)	
Yes	52 (32.7)	33 (20.7)	25 (15.7)	19 (11.9)	8 (5.0)	7 (4.4)	6 (3.7)	9 (5.6)	

Source: Database, 2021.

DISCUSSION

This study is a pioneer in Brazil in describing the reasons reported by individuals on hemodialysis, who were not on the waiting list for kidney transplantation, using the quantitative method. As the rates of Brazilian individuals with CKD on RRT increase annually, it is of utmost importance to identify the variables that explain the reasons for non-registration of these individuals on the waiting list, in order to support decision-making that minimizes such behavior.

In Brazil, it is estimated that 77.9% of individuals on dialysis are not registered on the waiting list(4). Thus, apparently, there is a small difference between the individuals registered on the waiting list when compared to the six RRTS located in the southern half of Rio Grande do Sul. This finding corroborates international studies that emphasize that registration on the waiting list varies between regions and also between the RRTS(6–7,11,16).

In this context, it is important to point out that the Unique Technical Registry is made at the Center of Notification, Procurement and Distribution of Organs (CNDO) by the healthcare establishment and/or the team responsible for patient care. Moreover, specialized kidney transplant teams will be able to delegate the registration of potential recipients and the updating of registration data in the Unique Technical Registry to the dialysis units under their supervision. Potential recipients diagnosed with chronic renal failure, who are undergoing any of the RRT modalities, have endogenous creatinine clearance values less than 10 ml/min/m^2, age < 18 years and with endogenous creatinine clearance < 15 mL/min/m^2, and who are diabetic with endogenous creatinine clearance < 15 mL/min/m^2(10). In Brazil, it is estimated that 45% of individuals undergoing renal replacement therapy are eligible for transplantation(8).

Therefore, in this study, the main reasons mentioned by individuals on hemodialysis for not being registered on the waiting list were highlighted, namely: lack of information followed by not wanting to be on the list, multimorbidity and age. Table 1 also shows that, among the reasons mentioned above, lack of information has a statistically significant association with sociodemographic and clinical variables low education, male gender, ≤ 5 years of diagnosis and ≤ 5 years undergoing RRT. On the other hand, the reason for not wanting to be on the list is associated with the variables unable to read and age (the older the individual, the greater the association).

These findings she light on the need for health services and their professionals to inform individuals on hemodialysis and their families about the possibility of transplantation, since lack of information is the main reason mentioned by individuals for not being registered on a waiting list and is present in all demographic, socioeconomic and clinical characteristics. This finding may reflect the fragility in the training of health professionals, as well as regarding the involvement of individuals and their families in health education(16–20).

Age is considered a limiting characteristic, since it is less likely that elderly individuals are willing to undergo a transplant, because, due to their physiological conditions, the procedure carries a higher risk of death. On the other hand, elderly individuals are less likely to be on a waiting list for kidney transplantation, but more likely to be transplanted after being on the list, possibly due to donor compatibility(18–20). However, substantial differences should be considered, such as legislation and the countries' different health systems regarding access to waiting lists for transplants(10).

For men, the lack of information about the possibility of transplantation was the main reason mentioned; on the other hand, for women, there seems to be little variation between lack of information, multimorbidities and not wanting to be on the list. It is known that males have a more passive approach to care and information about their health. On the other hand, it is understood that although women have professional occupations, they are also in charge of caring for children, spouses and running the household. Thus, the marital relationship can be a protective factor in the access to information and in the health care of men. In addition, with the event of the transplant, families face the impact of the entire process, including the fact that their members stop carrying out their professional activities, as well as the children's school dropout, which directly impacts the routine and family organization(12–15,20).

The reason for not wanting to be on the waiting list, mentioned by the individuals, was highlighted as the main reason for those who cannot read and for those who are illiterate, which expresses the relationship with illiteracy. Therefore, illiterate or functionally illiterate individuals are often excluded because they do not master reading, writing and calculation, activities considered essential for the insertion of individuals in the modern world, such as filling out forms and signing documents(14,15,20). These individuals may have a cumulative disadvantage, and due to their difficulty in communication and understanding, they are not informed of the possibility of having a transplant, and because they feel embarrassed, they do not seek relevant information.

Additionally, the reason for not wanting to be on the waiting list may be related to the geographic factor(11–13,16), as the displacement to the transplant center (located in the state capital) can be very expensive or partially covered by the Unified Health System, in addition to the difficulties of traveling in large centers such as reading signs and using means of transport. It is also necessary to keep in mind that the SUS has finite resources, and direct expenditures on dialysis exceeded BRL1.4 billion in 2020 alone(8). Furthermore, this value does not include personal expenses and the effects on incapacity for work and the need for family support, which substantially increases the social cost.

On the other hand, individuals who attended school reported lack of information regarding the possibility of being included on the waiting list for renal transplantation as the main reason. In this case, there seems to be a decreasing linearity, that is, the higher the individual's level of education, the better informed he or she appears to be. On this issue, studies that analyzed the fact that individuals with higher education are better informed, both in nephrology and in other pathologies, stand out. These individuals are more likely to report having been well or very well informed about the two categories of transplants (living or deceased donor) and, most importantly, they are more likely to seek information about the diseases and from healthcare professionals. In addition, there is evidence that low education contributes to a higher incidence of renal pathologies, a more frequent transition to end-stage renal disease, resulting in reduced access to registration on the kidney transplant waiting list(12–13,16–20).

The benefits for groups of individuals that attended school for a longer period of time are also known, as a higher level of education is considered one of the protective factors in the worsening of the effects of health problems(16–20). Thus, in the most advanced stage of CKD, when renal replacement is necessary, groups with a higher level of education benefit from access to the best available therapy, kidney transplantation. However, groups with a lower educational level are affected by cumulative disadvantages, as they do not adhere equally to dietary restrictions and a healthy lifestyle, which can accelerate the course of CKD. Furthermore, individuals with a lower level of education are more likely to suffer from diabetes, hypertension, obesity and malnutrition, pathologies considered to be at risk for kidney damage and more frequent in the socioeconomically vulnerable population(12–15,18–20).

The lack of information of individuals about registration on the waiting list was also the main reason for individuals who reported time elapsed since diagnosis of CKD ≤ 5 years and time ≤ 5 years since the beginning of RRT. However, for individuals with time elapsed since diagnosis ≥ 5 years, the reasons lack of information, not wanting to be on the list, and multimorbidity fluctuated little. The time elapsed until access to primary health services for the diagnosis of CKD is not adequate, especially in developing countries, and even the density of health professionals such as nephrologists is deficient(11–13,16,17). On the other hand, the time elapsed between diagnosis and the beginning of treatment in relation to access to the waiting list can be strategic. When the interval is longer, the individual has more time to learn and ask for information about the different RRTs available, in order to choose the therapy that best adapts to their pathology and life condition(12).

Regarding the decision made by individuals and their families: they do not wish to be on the waiting list, it must be respected. However, individuals must receive all necessary information about the possibilities of RRT. Based on this assumption, RRTS should invest in service infrastructure, training of health professionals and in-service continuing education(6,16,20).

In this scenario, nursing professionals of RRTS must be aware of the reasons mentioned by the individuals regarding registration on the waiting list for kidney transplantation. Thus, it is suggested that professionals develop health education strategies with the purpose of informing and communicating individuals and their families about kidney transplantation. These strategies can facilitate access to information to enable better decision-making by individuals, in order to overcome the factors that can be changed.

Some limitations must be considered when interpreting the results of this study. The first concerns the financial limitations of the study, which made it impossible for the team to travel to more distant RRTS. Because of this, the sample calculation was suppressed, which may have been insufficient as a result to represent the Southern Half of Rio Grande do Sul. Furthermore, although the team was trained to collect data, another limitation of this study may be related to the understanding of the questions by the study participants.

The benefits perceived in this study are supported by the visible gap in the knowledge of the subject. Thus, it is necessary to develop studies in other Brazilian regions, in order to clarify in depth the causes and effects of socioeconomic and clinical factors regarding registration on the waiting list for kidney transplantation, as well as to enable comparison between regions. Finally, based on the results presented in this study, RRTS can plan and develop interventions aimed at health education and access to information on the possibility of registration on a waiting list, in order to improve health care for the population with CKD in RRT.

CONCLUSION

This study described the reasons mentioned by individuals on hemodialysis who were not registered on the waiting list for kidney transplantation, showing that the most frequent reasons included lack of information, not wanting to be on the list and the presence of multimorbidities**.** Among the reasons, lack of information was the most recurrent and had a statistically significant association with the variables low education, male gender, time elapsed since diagnosis ≤ 5 years and time in RRT ≤ 5 years. The reason for not wanting to be on the list was associated with the variables not being able to read and age (elderly).

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