

The social network and support of kidney transplantees

A rede e apoio social do transplantado renal

La red y apoyo social de transplante de riñón

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ABSTRACT

Objective: to know the social network and support of those who experience the process of kidney disease and transplantation.

Methods: a descriptive qualitative study, based on the concept of social network and social support from Sherbourne and Stewart. Semi-structured interviews were conducted from November 2013 to September 2014, with 12 kidney transplantees, which passed through content analysis. This study had the following selection criteria: the interviewee must have had a transplant five years ago, at most, be at least 16 years of age and have preserved cognitive and language skills.

Results: three categories were constructed from the analysis process that link the family as the main component of the social network, health service offers support in its various dimensions, even if it is occasionally disconnected; other interpersonal relationships are mentioned as vulnerable in this process; spirituality helps in coping.

Conclusions: despite the different forms of support for transplantees, weaknesses were observed in these networks and social supports.

Keywords: Chronic disease. Kidney transplant. Family nursing. Social support.

RESUMO

Objetivo: conhecer a rede e apoio social da pessoa que vivencia o processo de adoecimento e transplante renal.

Métodos: estudo descritivo com abordagem qualitativa, fundamentado nos conceitos de rede e apoio social de Sherbourne e Stewart. Foram realizadas entrevistas semiestruturadas no período de novembro de 2013 a setembro de 2014, com 12 transplantados renais, às quais passaram por análise de conteúdo. Teve como critérios de seleção: realização do transplante, há no máximo, cinco anos, ter idade maior de 16 anos, ter cognição e linguagem preservadas.

Resultados: do processo de análise, três categorias foram construídas que apontam a família como a principal componente da rede social, o serviço de saúde oferta apoio em suas várias dimensões, ainda que ocasionalmente desarticulado; demais relações interpessoais são mencionadas como fragilizadas neste processo; a espiritualidade auxilia no enfrentamento.

Conclusões: apesar das diferentes formas de apoio aos transplantados, foram observadas fragilidades nessas redes e apoios sociais.

Palavras-chave: Doença crônica. Transplante de rim. Enfermagem familiar. Apoio social.

RESUMEN

Objetivo: conocer la red y el apoyo social de la persona que vive la enfermedad y el trasplante renal.

Métodos: estudio cualitativo descriptivo, basado en los conceptos de red social y apoyo Sherbourne y Stewart. Se llevaron a cabo entrevistas semiestruturadas a partir de noviembre de 2013 hasta septiembre de 2014, con 12 trasplantes de riñón, que se analizaron mediante análisis de contenido. Tuvimos como criterios de selección: han llevado a cabo el trasplante, hay un máximo de cinco años, ser mayor de 16 años, han conservado la cognición y el lenguaje.

Resultados: del proceso de análisis, se construyeron tres categorías que unen a la familia como el principal componente de la red social, servicios de salud ofrecen apoyo en sus diversas dimensiones, aunque a veces inarticulado; otras relaciones interpersonales se mencionan como vulnerables en este proceso; espiritualidad ayuda a hacer frente.

Conclusiones: a pesar de las diferentes formas de apoyo para el trasplante, se observaron debilidades en estas redes y apoyo social.

Palabras clave: Enfermedad crónica. Trasplante de riñón. Enfermería de la familia. Apoyo social.

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■ INTRODUCTION

A total of 2,651 kidney transplants took place in Brazil in the first half of 2016, and the number of active patients on the waiting list for the same transplant was 19,700 in June of the same year⁽¹⁾. The data indicate a reduction in the number of kidney transplants, compared to the same period last year, and the goal of performing 6,000 kidney transplants per year is still far from being achieved⁽¹⁾.

The difficulties for those with chronic renal disease are not limited to the waiting list and the organs available for transplantation. The literature shows⁽²⁾ that, beginning with the detection of the chronic disease, including the dialysis treatment until the completion of the transplant, these people suffer considerable upheavals in their lives caused by physical discomfort and the considerable changes in daily life and eating habits, and that suffering often continues after transplantation. A study reinforces the need to offer support to patients with chronic kidney disease (CKD), who can often overestimate the transplant and, after the procedure, still have to face comorbidities, medication side effects, rejection, infection and numerous other processes that may reduce the quality of life⁽³⁾.

Taking these facts into account, the difficulties and the concern with the increase in survival and recovery of quality of life of these patients, it is very important to know the factors that influence coping and provide a more favorable and less painful path. A study shows that the social network and support play a crucial role to coping with CKD, including interfering in improving the quality of life of these patients⁽⁴⁾. Social support is important to help the patient adhere to treatment⁽⁵⁾ and to ensure the patient has a more positive outlook for the future and the difficulties resulting from chronic disease⁽²⁾.

A social network is the group of people you one keeps in touch with, people who are close and significant others, relating to family, friends, community and institutions, among others. In turn, social support refers to direct resources that individuals make available to others who are in need. Sherbourne and Stewart⁽⁶⁾, when developing these concepts, subdivided social support in five dimensions: *instrumental support*, that is a material aid or practice, also called tangible aid; *emotional support* refers to empathic relationships, listening, understanding, expressing trust and care; *information support*, that is the guidelines, warnings, suggestions and advice; *affective support* that involves physical demonstrations of love and affection; and *positive social interaction* that are the leisure and recreation activities that involve fun and relaxation⁽⁶⁾.

From these concepts and motivated by a few existing studies, mainly with a qualitative approach on the social

network and the types of social support of patients with CKD⁽⁷⁾, this study was conducted meeting the health research priorities in Brazil, regarding the evaluation of networks and social support and the dynamics of life of people with chronic conditions⁽⁸⁾. Knowing the social network and the types of support that patients with CKD have enables health professionals to direct actions to the strengths and weaknesses of this support network.

To achieve this result, the following research question was made: "What is the social network and the types of social support available to the patient who experiences the kidney disease and transplantation?". This study aimed to know the social network and support of those who experience the process of kidney disease and transplantation.

■ METHODOLOGY

This is a descriptive study with a qualitative approach to the data, which were analyzed from the conceptual perspective of social network and support⁽⁶⁾, and originated from a master's dissertation⁽⁹⁾. The study participants were 12 people who underwent kidney transplantation, whose data were collected in the Service Branch of the High Cost Pharmacy, in a municipality of the state of São Paulo. This research was done through the registration of people receiving post-transplant medications.

Data were collected from November 2013 to September 2014, and the selection criteria were: the interviewee must have had a transplant five years ago, at most, be at least 16 years of age and have preserved cognitive and language skills. The number of participants in the survey was defined according to the data saturation criterion⁽¹⁰⁾, used to determine the final sampling and interrupt the recruitment of new members, which occurs when data collected are redundant or repetitive in the perception of researcher.

The study was approved by the Ethics Committee of the Federal University of São Carlos, in Opinion No. 358.059, CAAE No. 18505313.9.0000.5504. After a detailed explanation of the study and its objectives, participants were invited to participate and, upon express and voluntary agreement, signed the Free and Informed Consent Form (FICF). When the interviewee was a teenager, participation occurred through verbal consent of the participant and signature of free and informed consent forms by their legal guardian. All aspects contained in Resolution No. 466/2012 have been respected⁽¹¹⁾.

Semistructured audio recorded interviews were used for data collection, conducted by the lead author at the participant's residence, except for one that occurred in the Basic Health Unit at the participant's request. The interviews

were scheduled through telephone contact and lasted an hour and a half on average. The interviews focused on the experience of illness and transplantation, as well as major support elements evoked by transplantees. Its content was transcribed in full with complete reliability to the original audio, having been endorsed by the participants.

Nine of the interviews had the participation of a family member at the insistence of transplanted and/or their family, though the focus of analysis was the manifestation of the transplantee. At all times of the interview, there was care and respect in dealing with the memories and emotions that accompanied the participants throughout their statement. Some clarification of legal rights and rights of access to health services were held at the end of the interviews. To preserve anonymity, the participants were identified with the initial E representing the word interviewee, followed by a number corresponding to the entry order in the study.

The method used was content analysis⁽¹²⁾ consisting of three stages: pre-analysis, a detailed description of the data set and the interpretation of various aspects of the theme. The first step, pre-analysis, consisted of a comprehensive reading of material, organization of data and hypothesizing. In the second step, the raw data was coded, meaning the exploration of the material. In the last stage, the data were interpreted and, the themes were defined in parallel based on the established understanding of meanings.

■ RESULTS AND DISCUSSION

Of the study participants, only one (8.4%) was a teenager, and adults had a mean age of 44.4 years. Most were male (58.3%), married or in Common-law marriage (58.3%) and had a family *per capita* income above 1.2 minimum wage (75%). Less than half had completed high school (41.6%), and 50% of them lived with two people in the same household. Most had the organ transplanted from a cadaveric donor (75%), and although most reside in the municipality where they underwent hemodialysis (91.6%), none of the participants lived in the municipality where the transplant was performed. Participants received some financial help from the city (75%) and transport (25%) to go to routine consultations at the health facility where they performed the transplant.

We observed that the profile of the participants in this research is in accordance with the national scenario of chronic/renal transplant patients. A literature survey shows that 57.7% of chronic kidney patients in Brazil are male⁽¹³⁾. According to the Brazilian Association of Organ Transplantation (ABTO), 88.1% of transplant patients are adults, and 78.31% of total transplants performed in 2016 were from cadaveric donors, with the same profile in previous years⁽¹⁾.

With regard to financial support, the study shows that driving to health facilities is a resource widely used by those who experience a chronic condition⁽¹⁴⁾ and perform monitoring in remote health services in their municipality of origin. This patient profile is also found in other studies with chronic renal failure patients^(13,15).

From the analysis of the interviews, in the light of the guiding concepts of social network and support, three categories were built: 1. Family: main component of the social network; 2. Health service: articulating to meet the dimensions of support; and 3. God, the transplantees pairs, friends and employer: an important support to the transplantee.

Family: main component of the social network

The family was singled out as the main component of the social network that helped the transplantee prevail through hemodialysis and transplantation. There were several times when the family expressed support, and emotional support and positive social interaction, the most significant and valued support types.

Oh, I liked it when my daughter stayed with me, it encouraged me (laughs). I would talk to her, we would watch a movie, we drank tea, we made popcorn. (E 8)

My family supported me and was always at my house, talking with me; That was how they helped me. I was always with them at their house, too. It helped a lot because I didn't feel alone. (E 11)

The welfare of dialysis and transplant patients is closely related to the support provided by family members. A study that addressed the adherence to treatment in the first year after renal transplantation has identified a strong family social support compared with full adherence to immunosuppressive treatment⁽¹⁶⁾. Another study with hypertensive patients with CKD also corroborated these findings, since the family was an important emotional support provider⁽¹⁷⁾ with love, affection and gratitude.

In our study, the family also showed support when the diagnosis of chronic renal failure was revealed and when the organ was donated to the family member that much needed it.

Family is everything when you need them, because you can not stand that "thump". When the doctor says: "You lost your kidney!" Or "You lost an organ!" You can not take it if your family does not support you. (E 3)

Family to me is everything. It was my sister who gave me (the kidney). It's like she says: 'I have a bit of her in me, in my body and in my heart.' (E 11)

Family, besides provided affection, was fully involved in care, helping transplantees deal with the changes and restrictions arising from the disease. Offering the individual affection, transportation, care, help in house activities and adapting to food and social restrictions were recognized as forms of family support.

My family has adapted to me. The food here at home is based on my food, because I have this problem, we removed salt from our meals "[...]" (E 10)

"[...]" they [family] would come see me every week, talk to the doctor and see how I was. Then they were happy! They would come, sit down and give me water to drink, they brought me things to eat "[...]" (E 2)

"[...]" he [husband] takes care of everything: he washes, cleans and dusts. I can't because I have not been released to do these things. (E 3)

Chronic disease leads to changes in the patient and family's daily life, leading the family unit to a change in roles and functions for the welfare and care of the sick member⁽¹⁸⁾. The instrumental support is highlighted in the reports, when referring to the family's help with transportation, care and daily life activities, from the moment the transplantee fell ill until after the transplant. Family occupies a central position in the activities of this type of support to chronic patients, and extend to financial, operational, health care related, and household activity support⁽⁵⁾.

There were participants who reported lack of support from family, which brought feelings of abandonment, grief and suffering. Improper intervention in the decision making process of the patient and the distancing of people from the extended family, for fear of being approached and asked to take the kidney donation compatibility tests, were examples of situations that cause distress in this study.

I really missed my family "[...]" That's what makes us kind of angry. "[...]" I did not want to retire on disability. I was crying until the last moment. I want to work, can't you [father] understand that? He said: 'honey, at the moment, you have to do it, because we are going through difficult times.' "[...]" I've retired because I am disabled and it hurt me a lot because I did not want to be retired, I wanted to work. (E 9)
When my brothers, nephews, family, knew I needed a kidney, a transplant, they turned away, afraid that I would ask

for there organ. "[...]" Not one of my brother asked my wife: 'How can I visit him?' (E5)

Although the family has been a prominent figure in the social network of renal transplantees, there were cases where support was weakened mainly by the difficulties arising from treatment. The family's refusal to take the kidney donation compatibility test can cause feelings of sadness and frustration on the part of the patient with CKD⁽¹³⁾.

Health service: seeking to meet the dimensions of support

During the course of the disease and transplantation, there were several health professionals who attended the person with CKD. Professionals who stood out in this tour were the hemodialysis nursing staff, psychologist, nutritionist and medical staff of the specialized assistance service (SAE), where the transplant is performed. These professionals supported the person with CKD, in the various dimensions of social support, such as instrumental, emotional, informational and positive social interaction dimension. It was also reported that these supports are intensified during the transplantation period.

In hemodialysis, we had a little party every 15 days or 1 month. Nurses would make hot dogs, "[...]" birthday parties, Children's Day, Christmas. They alleviate our suffering as much as possible. (E 10)

They [health professionals] guide us a lot, everything they can do and even what seems impossible. They make it clear that the transplant is not a cure, it is a treatment. That's why we have a balanced diet, nice and controlled. (E 9)

When you get the transplant, that's when you're assisted by everyone. You see the psychologist, nutritionist. You go through several interviews when you enter the list, they prepare you in everything. (E 12)

In other studies, the support that professionals offer through recreational activities and guidelines is also evident⁽¹⁹⁻²⁰⁾. The family is supported in order to strengthen itself and have an information apparatus that enables it to provide quality care and lower physical and emotional distress⁽¹⁹⁾. The emotional support provided humanizes the care⁽¹⁸⁾, makes the nurse a supporter⁽²⁰⁾, and contributes to overcoming limitations in adapting to a new lifestyle⁽²⁾.

Families that are supported by health professionals are more engaged in offering help to chronic renal disease.

Study on the social support of families of cancer patients in poverty showed the need for support from the multidisciplinary team to face the disease in its diagnosis phase, assisting in the lack of information about the disease and care⁽¹⁹⁾.

The instrumental support offered by public services in this study through the free medicine and transport to the dialysis unit and SAE was a facilitator for access and continuity of care, as well as considerable financial savings.

The drugs I take, I get them all here at High Cost. The government gives me everything. This service is very good; it's great! (E 8)

When I started dialysis, I went back and forth in the city van. So I didn't need to spend on buses or depend on someone to pick me up. Because of the discomfort I felt after the session "[...]" now, I drive and the city reimburses me. (E 4)

In another study of patients with cancer, social support from the health service was also demonstrated with the supply of medicines and aid in transport to health services^(14,19), which ensured the completion of treatment, especially for patients with low income.

However, the fragility of the social support present in the health services exposes the person to difficult situations that impact them negatively. Among them, the one that upset the person with CKD the most was the little emotional support and information provided by health professionals.

One thing I did not like when I had the surgery [transplant] you're right there, suddenly several doctors and students enter "[...]" looking at you and talking among themselves. I thought: 'I'm going to die here, I don't know what's going on.' So I was afraid. (E 4)

In that place [hemodialysis] there were no psychologists, there were girls who are residents who are still learning. Some of them come over and stare at you, not asking questions, not talking, so we just stay quiet. So much so that I had to pay a psychologist for my daughter. (E 9)

The study participants also reported the lack of assistance from some health professionals.

I think the only thing that is missing here in hemodialysis is a doctor present full time during the session for so that people who aren't feeling well can be assisted. "[...]". This increased the fear of dying even more. Many people got sick there and there was no doctor to assist them. (E 3)

"[...] I knew she [professional nursing] would treat me badly and I was going to be sick. I wasn't able to lose weight and she was extremely impatient, so it was already difficult for us. (E 9)

Failure to meet the needs of patients with CKD by the public health services and professionals, and the absence of information, brings doubts and uncertainties about the surgical procedure and recovery. This was also observed in a survey conducted in the public service in the State of Mato Grosso, which aimed to understand the meanings of kidney transplantation, in view of the transplanted person⁽¹⁷⁾.

Another aspect mentioned was the shuttle service that despite being available for participants and often facilitating access to treatment, either in the dialysis unit or in SAE, exposes the person with CKD to uncomfortable situations. This is because there are long waiting periods, since transport can only return to the municipality of origin after all people are consulted, and also, because it carries people who are sick, there is fear of becoming infected.

What I found bad was this business of having to go to town X every month. "[...]". There's a van full of people, at ten o'clock I was released and had to wait until night to be able to return home. We go in the van with several people, I "caught" all sorts of diseases. (E 6)

Research points to gratitude of the people using the transport, because of financial difficulties and limited personal resources that hinder the follow-up treatment⁽¹⁴⁾. Increasing this service's supply and considering the special needs of patients with CKD could provide feelings of safety and support in the face of their physical and social vulnerability.

Interpersonal relationships with God and people: an important support for transplantees

Faith and belief in something bigger or more powerful has been identified as an important aspect when facing the process of transplantation and overcoming negative feelings. Closeness to God, the church and its members provided emotional support to individuals who received the transplant.

You have to have faith, if not, you won't 'pass' [crying]. It's difficult with Jesus, let alone without Him. So I say that He is everything! [crying] It was He who prepared, who gave me strength, if I was not here [crying]. He gave me this family

too [crying]. Without God I am nothing. God picked me up, brought me and said this: "Now I'll take care of you!" (E 2)

In the church, the biggest incentive for me to do the transplant was the priest, "[...]" He is a close friend, we are in each others lives, he visits my house. The whole time, always worried, calling. (E 12)

These things have changed a lot in my life, even the spiritual side, I began to seek God more. Before I didn't care too much. "[...]" I would tease people who were in search of religion. Today I take it more seriously. (E 11)

The person who's had a transplant seeks strength in their spirituality, and faith in God is a way to maintain physical and mental balance, in the process of becoming ill and searching for a cure. In an investigation that addressed the family context in the renal transplant process showed that spirituality is an essential factor when experiencing hardship and how faith is important for the expected improvement⁽¹⁵⁾. Strengthening actions of a spiritual and religious dimension act as therapeutic support, improving the health status in that it also improves the emotional state, resulting in hope, forgiveness, altruism and love⁽¹⁴⁾. Interest in religion is due to the fact that in the face of suffering, the individual seeks support to tackle the disease and can find support in the church, since positive attitudes and commitment to others are striking, favoring the formation of networks⁽⁹⁾.

The informational and emotional support from peers during hemodialysis sessions, was also mentioned by people with CKD in this study as being fundamental in this process.

What gave me 'a foundation' were the people I was getting to know there [hemodialysis], they were even worse than me. We exchanged experiences, learning with one another and giving strength. Sometimes, people who didn't even have food to eat and went to hemodialysis. There these families received food. (E 9)

One would play with each other. There were thirteen patients in a room, "[...]" I would distract myself a little, I could laugh, I had friendship there. I had a strong bond. "[...]" I helped too, I'd talk, tell stories. It was cool. (E 7)

Companionship and friendship among those who experience the same course of the disease and treatment impact coping with the illness condition⁽²⁰⁾. The exchange of experiences and "strengthening one's self" mutually and

constantly helped support periods of suffering. Similarly, it was the moments of relaxation that came as a relief to the hemodialysis patients of this study.

Employer support at work and friends also proves crucial to the successful treatment of patients with CKD. The withdrawal of friends and lack of employer support were cited in this study, and the stigma of "being sick" was the main reason. Discrimination was perceived by the person with CKD in the eyes of the people and has been linked to physical changes resulting from the disease. This brought feelings of sadness, as demonstrated in the speeches.

You start off by losing friends, right! They think that you will ask for money because you need medicine. The firm, when you start to bring in doctor's certificates, they start being "afraid" of you. Specially when you are sick. So then you have to be strong because it is not easy. (E 4)

I think what hurts the most is the way people look at you, sometimes it is not even the word that hurts, it's the way the person looks at you differently "[...]" As if I were an 'ealien with two antennas.' "[...]" People would say: "Wow, your "things" are looking crooked, you're shrinking." (E 2)

A research conducted in southern Brazil said that the changes in the daily lives of CKD patients also cover the workplace, which was highlighted as an important cause for satisfaction, when performing pleasurable activities. The withdrawal from industrial activities can cause feelings of inadequacy and limitations⁽¹⁸⁾.

■ FINAL CONSIDERATIONS

Data analysis allowed the scope of the study's objective to be reached and showed how the network and transplanted social support previously potentiated now seems weakened.

The family is referred to as the main component of the social network, being able to provide various types of support. In turn, the most emphasized support provided by the health services was the instrument that promoted expanded care and helped to adapt to difficult situations. The professionals involved in the institutions, in addition to providing instrumental and informational support, also promoted emotional support. The mutual reinforcement among peers during hemodialysis sessions and spiritual support were also highlights for confronting the disease and transplantation.

Despite the different forms of social support provided to transplant patients, in some cases weaknesses were observed in these social networks. The lack of emotional,

affective, instrumental and informational support was also found in the family, in health services, in friends and with the employer. This shows the social network with which the chronic kidney disease counts can't always meet their demands and can generate significant impacts during the transplant process.

The results of this study should be considered with its limitations, since in some of the interviews, family was present, which may have interfered in the evaluation of family support. The homogeneity of the results was due to the common environment of the research subjects, i.e., all the participants being from the same health services, offering a limited perspective through their social context. This work contributes to helping health professionals understand the context of network and social support and difficulties of people with CKD, supporting them in the needs of the patient, whether in as a reference or counter-reference.

A review of the network and social support elements available to transplantees and their families to make the trajectory of the disease and health recovery less painful and lonely is necessary. Studies with a family approach and using perspectives based on theoretical references about the culture and stigma may increase the understanding of the phenomenon and better understand the failure mechanisms of social support.

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