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Social support network after kidney transplantation: a qualitative study from the perspective of patients, professionals and managers

Rede de apoio social após o transplante renal: estudo qualitativo na perspectiva dos pacientes, profissionais e gestores

Red de apoyo social después de trasplante de riñon: estudio cualitativo en la perspectiva de pacientes, profesionales y gerentes

ABSTRACT

Objective: To describe the perspectives of kidney transplant recipients, health professionals and managers on the social support network. **Method:** A qualitative study conducted with kidney transplant recipients, professionals and managers. The data collected was audio-recorded individual interviews from two instruments that composed questions using the Assessment for Chronic Illness Care (ACIC) and Patient Assessment of Chronic Illness Care (PACIC) scales, adapted for the Brazilian culture. **Results:** The data revealed the participation of non-governmental entities and health professionals and the link that they establish with kidney transplant recipients, especially with the medical and nursing professionals, in addition to other professional categories. Also, other data brought up was the opinion of health professionals about the bond that they establish with the family of the person. **Conclusion:** The established bond remains strong even after kidney transplantation, which demonstrates the success in establishing emotional bonds by the multi-professional team, including nursing.

Descriptors: Chronic Kidney Failure; Kidney Transplantation; Social Support; Qualitative Research; Nursing.

RESUMO

Objetivo: Descrever as perspectivas de receptores de transplante renal, profissionais da saúde e gestores sobre a rede de apoio social. **Método:** Estudo qualitativo realizado com transplantados renais, profissionais e gestores. Os dados coletados foram entrevistas individuais gravadas em áudio a partir de dois instrumentos que compuseram perguntas por meio das escalas Assessment for Chronic Illness Care (ACIC) e Patient Assessment of Chronic Illness Care (PACIC), adaptadas para a cultura brasileira. **Resultados:** Os dados revelaram a participação das entidades não-governamentais e dos profissionais de saúde e o vínculo que estabelecem com os receptores de transplante renal, sobretudo, com o profissional médico, com a enfermagem, além de outras categoriais profissionais. Também, outros dados trazidos foi o parecer dos profissionais de saúde sobre o vínculo que estabelecem com a família da pessoa. **Conclusão:** O vínculo estabelecido continua forte mesmo após o transplante renal, o que demonstra o sucesso no estabelecimento de vínculos emocionais pela equipe multiprofissional, incluindo a enfermagem.

Descritores: Insuficiência Renal Crônica; Transplante de Rim; Apoio Social; Pesquisa Qualitativa; Enfermagem.

RESUMEN

Objetivo: Describir las perspectivas de los receptores de trasplantes de riñón, profesionales sanitarios y gestores acerca de la red de apoyo social. **Método:** Estudio cualitativo realizado con trasplantados renales, profesionales y gestores. Los datos recolectados fueron entrevistas individuales grabadas en audio a partir de dos instrumentos que componían preguntas adaptadas a través de escalas Assessment for Chronic Illness Care (ACIC) y Patient Assessment of Chronic Illness Care (PACIC), adaptadas a la cultura brasileña. **Resultados:** Los datos revelaron la participación de entidades no gubernamentales y profesionales de salud y el vínculo que establecen con el receptores de trasplante de riñón, especialmente con el profesional médico, con la enfermería, además de otras categorías profesionales. Asimismo, otro dato aportado fue la opinión de profesionales de salud sobre el vínculo que establecen con la familia de la persona. **Conclusión:** El vínculo establecido mantiene fuerte incluso después del trasplante renal, lo que demuestra el éxito en el establecimiento de vínculos emocionales por parte del equipo multiprofesional, incluida la enfermería.

Descriptores: Insuficiencia Renal Crónica; Trasplante de Riñón; Apoyo Social; Investigación Cualitativa; Enfermería.

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INTRODUCTION

Chronic kidney disease (CKF) is considered an emerging public health problem⁽¹⁾. When a person is affected by this disease, treatment is initiated for the replacement of kidney function. In this context, the person is submitted to one of the forms of renal replacement therapy (RRT), which are hemodialysis (HD), peritoneal dialysis (PD), and kidney transplantation (KT)⁽²⁻³⁾. About the KT, despite not promoting a cure, it increases the autonomy and provides improvement in the quality of life of the person, by reestablishing the kidney function from the transplantation process of a renal graft from a living donor or a cadaver⁽³⁾.

In this context, it is important to note that Brazil ranks second in the world in the number of KT⁽⁴⁾. For this procedure, the support network is evaluated by the multi-professional team before the surgery, due to its important role in maintaining the patient's health⁽⁵⁾. In view of this, new health care needs to be adopted by the person, with the need for information and support from the formal network, formed by the health services, in addition to support from the informal network, composed of the family and the community, so that there is success in the adopted therapy and guarantee of greater survival of the transplanted organ. Thus, the social support network is essential to avoid complications, given the fragility of the patient due to this procedure⁽⁶⁾.

It should be noted that the social network refers to the relationships established by kidney patients, which include family, friends, health professionals, among others. The social support is related to the roles assumed by people and/or groups that make up the social network, which are sources of help and collaboration in obtaining information and care practices, and can be classified as emotional support, instrumental, informative and evaluation, achieved by the social connection with the network members. Thus, the social support network is a set of systems and significant people, which make up the received and perceived relationship links of the individual⁽⁷⁾.

A study conducted with the theme support network, especially the social one, made it possible to explain its diverse terminology, related to: instrumental and emotional support, feedback, counseling, positive interaction, guidance, trust, socialization, feeling of belonging, information, material assistance, among others. Thus, social support is conceptualized based on the existence, quantity, and property of the relationships that people maintain⁽⁸⁾.

When searching the literature for scientific productions on the theme of this study, it was observed that some investigations are developed from the kidney disease in dialysis modalities (hemodialysis and peritoneal dialysis)⁽⁹⁻¹²⁾. In the context of kidney transplantation, the contact with the health services can be difficult for patients living in distant locations from the transplant center, due to the need of family support and/or social service support to make the transport to the health services feasible.

Thus, this study was developed due to the need to survey the perspectives of patients, health professionals and managers about the bond established by the transplanted person with the formal support network. Therefore, the objective was to describe the perspectives of kidney transplant recipients, health professionals and managers about the social support network.

METHODS

This is a qualitative study in which used as a conceptual framework, the Chronic Care Model (CCM), in which in the transplantation process has been proposed to improve long-term outcomes after surgery. Thus, the CCM has been based on the principles of chronic disease management and responded to the needs of solid organ transplant recipients regarding continuity of care and support for self-management of transplanted persons⁽³⁾.

Three municipalities of the State of Rio Grande do Sul were involved in the study, i.e., Pelotas, Rio Grande, and São Lourenço do Sul. The number of participants occurred from an intentional sample, consisting of 30 people, being 15 kidney transplant recipients, 11 professionals of the renal replacement therapy services and four managers, who met the inclusion criteria: for kidney transplant recipients, to be 18 years old or older, to have at least six months of kidney transplantation and to have performed hemodialysis or peritoneal dialysis before kidney transplantation; for professionals of renal replacement therapy services, to have higher education and to work at least one year at the site; and for managers, to hold the position of superintendent of the sector responsible for transplants and to work at least one year at the site.

Regarding the exclusion criteria for the selection of participants, those who were excluded from the study were: among kidney transplant recipients, those who lived in rural areas were excluded due to the difficulty of access and the available means of transportation; among professionals, those who were away from their functions in nephrology services for any reason (vacation, health leave, maternity leave); and for managers, those who did not perform activities focused on attention to chronic diseases were excluded.

For data collection, the instruments used for a semi-structured interview were scripts with questions from the international scales Assessment for Chronic Illness Care (ACIC) and Patient Assessment of Chronic Illness Care (PACIC), with the version translated and adapted to Brazil⁽¹³⁾. For this section of the study, the questions were related to what was most important for the treatment and how the association occurs between health services and community organizations that can provide complementary care to the person undergoing kidney transplantation.

The data was audio recorded and then transcribed digitally. For the management and organization of the information that was obtained, specific software was used for data analysis. Thus, for the generation of codes in order to proceed with the directed content analysis⁽¹⁴⁾, In the first

moment, the data was read in their entirety, and in the second moment, they were read line by line. After that, the categories related to the elements that compose the CCM were identified, which for this study was about the composition of the social support network of the kidney transplant recipient.

Each participant was identified by a code: the kidney transplant recipients were specified by the PKT (Person Undergoing letters Transplantation), followed by the Arabic number, according to the sequence of interviews, plus age (for example, PKT1, 29 years old). The professionals of the nephrology services were mentioned by the letters NSP (Nephrology Service Professional), followed by the Arabic number, according to the sequence of interviews, plus the age (e.g., NSP1, 34 years old). The managers were called by the letters HDM (Health Department Manager), followed by the Arabic number, according to the sequence of interviews, plus age (for example, HDM1, 42 years old).

All participants signed the Free and Informed Consent Term in two copies. Moreover, the study project was registered in the *Plataforma Brasil* and forwarded to the Research Ethics Committee, receiving approval under opinion number 1,548,228, CAAE 55712616.3.0000.5337.

RESULTS AND DISCUSSION

On the composition of the social support network of kidney transplant recipients, the data of this study revealed the participation of non-governmental entities (transplanted patients' association) and health professionals (nutrition team, medical team and nursing team, both from the transplant center and nephrology service). This situation is present in the following statements:

"Only Association that has here in Pelotas. Now he [president of the non-governmental association] is in his house. [...] He is also transplanted. But then they closed there, put an office in another place and then he used to borrow the piece there [...]. If there is a lack of medicine or something like that, he manages. If the medicine doesn't come, if the government doesn't send it, then we look for him" (PKT2, 44 years old).

"This from the professionals were more, those helped me a lot. [...] From [the transplant center site] also, nutritionist. They were very important for me, nutrition in my recovery [...]. They supported me a lot. The doctor also [...]. The nurses there were very caring during the time I was there [in the nephrology service]" (PKT8, 48 years old).

The two statements presented have some important information that need to be highlighted. Initially, the participant transplanted PKT2 affirms the importance of the non-governmental entity in the supply of immunosuppressive drugs, when it is absent in the place responsible for distribution (Municipal/State Pharmacy), for whatever reason. The participant transplanted PKT8 addresses the support of health professionals both from the transplant center and the nephrology service.

For people with CKD undergoing treatment, knowing the types of support they have allows

health professionals to target actions to the strengths and difficulties of this support network⁽⁹⁾. In this sense, the functioning of an effective support network is presented by responses with significant reduction of psychopathological symptoms, such as depression and feelings of helplessness. In its absence, one can verify the increased vulnerability of people facing a situation of risk, compromising their health and the imposed treatment, such as kidney transplantation.

Health professionals of nephrology services described that for kidney transplant recipients it is essential to maintain the bond with the professionals of that service. This is mainly due to the time of dialysis treatment and consequent coexistence with their peers and professionals who assisted them. The speeches are as follows:

"When they are on the machine, this is an experience of the room that I am telling you about, they are in the room dialyzing 'Oh, because I don't want to be on this machine anymore, because I don't like to come here, because I have an obligation'. When they do the transplant, there is a void. They verbalize, many of them, not all: - 'I felt like this, without having that commitment to come in the morning. - 'But wasn't it an obligation for you?' - 'Yeah, but now, I sometimes miss it'. -Sometimes I miss it! Not that it's that frequent thing, you know? But they do, so much so that they come here [nephrology service]. There is a patient who is from Bagé, he comes to say hello to everyone and leaves. After a while, two, three months, he shows up again [...], says hello to whom he knows and leaves" (NSP1, 39 years old).

people "Sometimes old come [nephrology service] to visit. This time it didn't even happen on my shift when I was here, but it happened that a transplanted gentleman came. [...] He came, but he came just to say hello. [...] You can't not get involved. [...] Because as you say, the person comes three times a week, that schedule, especially for nurses, technicians, imagine spending four hours a day with a person, sometimes not even with your family, sometimes you end up spending this exclusive time there. So you are there with that person, that person is there helping you, assisting you, so there is no way you cannot create a bond" (NSP4, 32 years old).

It is observed in the statements of health professionals that the kidney transplant recipient establishes a bond with the nephrology service, which is already created at the time of hemodialysis, as treatment for CKD. Furthermore, nursing was cited in the formation of bond when the person is on hemodialysis treatment in the nephrology service, as mentioned by participant NSP4.

Given this situation, it is important the support of health professionals for the formation of a harmonious relationship, in order to promote guidelines on adherence to treatment, in addition to specific care that kidney transplant recipients need to obtain with their health to benefit from the outcome of the adopted therapy. Thus, the performance of the nursing team stands out, since it is the profession that is closest to the patient,

having as its work object the care, it can stimulate the exercise of autonomy and self-care in search of better quality of life $^{(2)}$.

Other data related to the social support network composed of health professionals also emphasized the existing positive bond. Especially with the medical professional responsible for monitoring the kidney transplant, being highlighted in the statements of NSP1, NSP1, NSP4, NSP10, and NSP13, especially in the monitoring and adjustment of immunosuppressive drugs prescribed for treatment success.

"They [physicians] also pass to adjust the dose, because many times because of immunosuppressants they have to adjust the doses and they end up adjusting everything because the pressure [blood pressure] later may return to normal because he [person with kidney transplant] is already urinating. The function of the kidney is back, so they maintain this direct contact with the physician there [at the transplant center] to adjust these medications" (NSP1, 39 years old).

"The doctor in nephrology is the one who attends. So now she is the one who attends me. [...] When she is not there, another one is, but there are several nephrologists there [at the transplantation center]. So I think that they put a little bit of patient for each one. But as I am a patient that doesn't give problems, thank God, I go there, do my exams and come back and everything is ready. I am staying within the same weight, understand, she said I didn't gain weight, but then I lost a little weight and stayed within the same weight. Every time I go, she controls the weight. She says: - 'At least you don't increase, but you don't lose'" (NSP1, 58 years old).

"I only started with my doctor after I left [discharge-hospital from the transplant center]. Doctor [name of medical professional] who was my Resident forwarded everything with Doctor [name of medical professional], all the steps that had been done. I had the medical report that had been done so that he could continue to accompany me. [...] I do all the exams. [...] Exactly everything is with him" (NSP4, 61 years old).

"That's the most important thing, now, the support of the doctors, of course, is essential because they have, let's say, they have a patience to explain you. Myself, I am very curious, so I change a lot of explanations or I feel something and I already go there [at the transplant center] and make a list at home of questions. It gets to be boring, but I have this habit of asking and they answer everything with patience, explaining everything in detail. I think that this is also important" (NSP10, 26 years old).

"The doctor, I asked her everything. Until today, when I go there [at the transplant center], I visit her on the fifth floor, I take a chocolate, I understand, for the service" (NSP13, 63 years old).

In these speeches presented, it was observed that the kidney transplant recipients show satisfaction for having received the kidney by donation and transplantation and the gratitude they have for the support received from the medical professionals who assist them. They reinforce the care they receive for the therapeutic follow-up of the kidney transplant.

When looking at the link with the medical professional, one study observed that medical professionals were cited in greater numbers in relation to providing support to the person when they are linked in various types of health services, such as rehabilitation centers, public and private hospitals, private clinics and health centers in primary care⁽¹⁵⁾. Also, another study found favorable results with positive impact on the good doctorpatient relationship⁽¹⁶⁾. This is similar to what was found in this study.

Curiously, regarding the doctor-patient relationship, historically, the patient has always been subordinated, since the doctor's performance, supposedly, would aim at the patient's good. Since the end of the 20th century, the idea of autonomy has been strongly introduced as an argument to equalize the relationship between doctor and patient⁽¹⁷⁾.

In the following statement, interviewee NSP6 refers to loss of medical bond, especially, feeling a lack of greater contact with the professional responsible for performing the kidney transplantation. Furthermore, there was no closer contact with the other physicians who attended him during the post-transplant review visits.

"Actually, I think that it is more this affective issue that we feel, because you end up trusting the doctor who did your surgery and who gave you all the initial support and who treated you for a long time as a brother, as a partner, and suddenly time goes by and he starts to have more work with other patients and then he dismisses you. So, I think this is something that is kind of complicated. [...] It's worse, because the other [doctors] you don't get to create a bond because you go in one month it's one, then when you come back the next month it's another one who sees you [...]. So there are always different people, you don't get to create that bonding thing" (NSP6, 58 years old).

Although there was not the creation of a bond that could compose a social support network for the kidney transplant recipient, as mentioned by NSP6, it is noteworthy that health professionals, in general, can develop an important supporting role. Especially when facing the disease and treatment process, as occurs in CKD.

In this way, the professionals inserted in the institutions, besides providing instrumental and informational support, can provide emotional support⁽⁹⁾. Thus, favorable communication, accompanied by a positive therapeutic bond and the sensibility of the professional in perceiving the context experienced, is an efficient driver of health care for the person⁽¹⁸⁾.

With regard to the doctor-patient relationship, it is fundamental to achieve good therapeutic results and strengthen the bonds of respect and solidarity⁽¹⁷⁾. In fact, it is a mutual relationship of expectations and hopes, in which the patient expects relief and comfort, and if possible, a cure. In this sense, promoting the listening to the patient's life story, in parallel to the formal anamnesis that is usually performed, becomes a link to seek differentiation in the doctor-patient

interlocution, through the development of creativity and sensibility used as working tools⁽¹⁹⁾.

As seen in the statements that specify the bond established with the nursing team and the medical team, being important social support networks for kidney transplant recipients, in this study, there were also reports that demonstrated the professional attention transmitted. This situation involved other professional categories, such as social work and psychology, both from the nephrology service and the transplant center.

"He [the person with the kidney transplant] has the service available to him. With the Social Service if he needs something. We also do emergency medical care when they need it, but there is no predetermined regular activity" (NSP3, 36 years old).

"The doubts I have, I am guided. What I need, I ask, they [health professionals] tell me. No one has ever refused. There are social workers that if I need them, I go to them. That I never needed, thank God. I have always been well resolved, I have not needed support from anyone, but if I need it, I get there and I have it" (PKT1, 58 years old),

"I go there to visit the gurias [health professionals]. Sometimes there is medicine left over, I go there to give it to them. The kids are still the same. I go there to visit the girls. Until now it has been a while since I went there" (PKT5, 43 years old).

"The service of [name of transplant center] has a social assistance service, the service of the nurse, the psychologist and the doctor, and this service is very well done like this. They [people with the kidney transplant] already come with all the orientations. But when they have doubts, they come to talk to us, and we manage to orient and reinforce this as much as possible. But it is not very common for them to come and ask. They usually come already well oriented" (NSP8, 31 years old).

"Nowadays I go there [nephrology service] more. [...] I don't do hemodialysis anymore, but I left friends there. The nurses also, I get along very well with them. So I look for them more, but they are always asking when they see a family member or something, they always ask about me" (PKT10, 26 years old).

"I used to call there [nephrology service], now I haven't called. Sometimes I would call them and talk to the girls. I was even supposed to go there now. [...] I called from the hospital when I got out, then I was there. Now I am there to visit them, take some snacks for them, that they treated me very well" (PKT11, 62 years old).

"Doctor [name of medical professional] always contacted us. He is a very good doctor. [...] He called to see how we were doing and he is very playful. The doctor with us wants us to stay away, that in the clinic, the hemodialysis clinic, after the transplantation, the [name of the transplant center] team of doctors advises that we should not go there too often because our immunity is low, so it is dangerous. So, after a while, I was there [in the Hemodialysis Clinic], visiting them and talked with the doctor [name of the medical professional] and

also with the nurse [name of the professional]" (PKT12, 51 years old).

"The staff, the employees call. Even after I transplanted, I appeared there [nephrology service] to visit, that after a certain time, so much time on hemodialysis, they already get to know each other. So I go there to visit the staff" (PKT15, 30 years old).

Regardless of the types of bonds that people establish with each other, it was observed the existence of affective interpersonal relationships that over time are strengthened by interactions. In this sense, such relationships can help in biopsychosocial health and in coping with the demands caused by the chronicity of kidney disease.

The opinion of health professionals for the discussion about the bond that they also establish with the person's family were the result of statements brought in the speeches of NSP6 and NSP7:

"Normally these are patients that we are already used to. They are hemodialysis patients, so you already know that every month we have a consultation and this patient who had the transplant is a patient who is always in contact with us. Normally, we already know the family member. [...] They visit. It is difficult for those who do not come. Of course, there are some that have an easier bond and there are others that come once and then don't even want to know, because this brings back memories, so they try to stay away. [...] But most of them come, bring something for the girls [health professionals], bring a candy" (NSP6, 48 years old).

"We have an affective contact. As our dialysis is a small dialysis, the patients are chronic patients; we have a very affectionate relationship with the patients. So, generally, immediately after the transplant they come here. We celebrate, we commemorate, we give them a friendly support. But as the first year of transplantation is more difficult, because the consultations are weekly, then fortnightly, and as it is so difficult to obtain transplantation, if there is any intercurrence, we always refer them to the reference service for transplantation in order not to lose the graft [...], but we follow up because they [people] return to the service because they are our friends, we have created a relationship of affection, but the intercurrences are all treated by the transplantation team" (NSP7, 54 years old).

The health professional participants, NSP6 and NSP7, stated about the professional bond created with the kidney transplant recipient and the family, which started during their time at the nephrology service and continued after the kidney transplant. This fact makes health professionals an important support network for the follow-up of the care required by the treatment. When it comes to health care, the CCM alludes that a team composed of proactive and prepared professionals acts effectively in the interaction with people, with support and with the necessary resources to provide quality care⁽¹³⁾.

Thus, strengthening the bond between health professionals and kidney transplant recipients is essential. Thus, the respectful educational activity

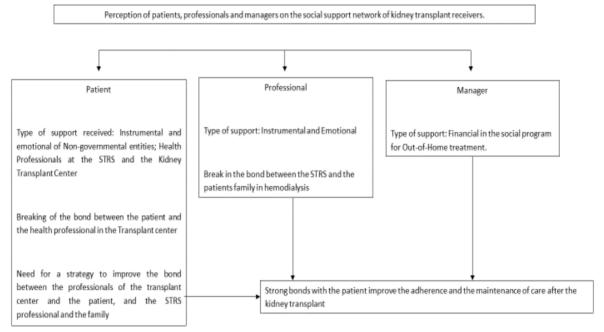
carried out and the understanding by the team, the subjectivity and individuality of each human being, associated with a professional practice that includes the person as a whole, having him/her and his/her family as the focus of care, are evidenced as strategies that cooperate to the coping, adherence, and adaptation of the health-disease process regarding the chronicity of the condition, as well as the extensive and complex treatment in all the limitations generated by it⁽²⁰⁾.

Although in the interviews with managers the social support network was not addressed, in an informal conversation with a manager, he reported the importance of the financial and logistical support of the Out-of-Home Treatment (OHT) social program. The OHT is responsible for paying for

travel, lodging, and meals for the patient and the accompanying person, who are users of the Unified Health System (UHS), for pre-transplant consultations and follow-up consultations after the kidney transplant. This form of assistance geared to economic conditions is especially important for users who lack financial resources due to their inability to maintain their work activities and who live far from the large centers where transplants are performed⁽⁵⁾.

Finally, it is important to highlight the data found in this study, a scheme represented by Figure 1 on the perception of patients, professionals and managers about the social support network of kidney transplant recipients.

Figure 1 - Perception of patients, professionals and managers about the social support network of kidney transplant recipients.



Source: Own authorship.

CONCLUSION

perspective From the of patients. professionals and managers, it was possible to describe the social support network of kidney transplant recipients and to realize that, for the patients, the professionals of the renal replacement therapy services and the transplant center, as well as non-governmental organizations, were an important source of support in this process. Furthermore, it was evidenced that for both patients and professionals of the renal replacement therapy services, the bond established while they were under hemodialysis treatment remains strong, kidney transplantation, after demonstrates the success in building emotional bonds by the multi-professional team.

The support of social assistance professionals, nursing, medicine and nutrition were mentioned by the kidney transplant recipients as sources of support, as well as the economic support to users with compromised professional life and working capacity, highlighted by a manager. These situations were important to understand the social support network of people after kidney transplantation.

The limitations of this study are related to the little information obtained on the subject by the

managers and professionals of the transplant center, which leads to the need of further studies with professionals connected to the transplant service and management so that they can contribute to the understanding of the meaning of the social support network after kidney transplantation. Furthermore, in view of the results, it can be stated that there is a need to further study the economic support and the expenses of patients with the treatment after kidney transplantation.

From the perceptions about the social support network after kidney transplantation, it is expected that health professionals will appropriate this knowledge to create strategies to approach the patient and the family when there is a rupture of the bond, as well as to appropriate the established link and use it as a strategy to improve adherence maintenance kidnev and of care after transplantation; especially, in the renal replacement performed therapy services, where they hemodialysis, with which the patient has a strong bond with the health professionals.

By using the CCM to describe the composition of the social support network of the kidney transplant recipient, in this study, it was essential to know the way of life and history of the participants. Also, it was important to know how the

interpersonal affective relationships happen that can help in biopsychosocial health and in coping with the demands caused by the chronicity of kidney disease. Based on the data found and in agreement with the literature, the professional can improve the support to the transplanted patient through instrumental and emotional support, feedback, counseling, positive interaction, guidance, trust, socialization, feeling of belonging, information, among others.

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