








SUPPORT NETWORKS TO USER WITH CHRONIC KIDNEY DISEASE IN THE ECOSYSTEMIC PERSPECTIVE

REDES DE APOIO AO USUÁRIO COM DOENÇA RENAL CRÔNICA NA PERSPECTIVA ECOSISTÊMICA

REDES DE APOYO AL USUARIO CON ENFERMEDAD RENAL CRÓNICA DESDE LA PERSPECTIVA ECOSISTÊMICA

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ABSTRACT

Objective: identify and analyze the support networks used by the chronic renal user and family, from the ecosystemic perspective. **Method:** qualitative study developed at the household of three users with chronic kidney disease in two municipalities in southern *Rio Grande do Sul*. Data collection took place in the period from May to June 2016, through a semi-structured interview. Data analysis was performed using the thematic analysis method. **Results:** it was possible to identify several support networks for patients with chronic kidney disease and family, which constitute an important strategy for the actions of care, stimulating the coping of the disease. The interactive relational bonds established among the components of the household ecosystem exert influences in the health-disease-care process of the user with chronic kidney disease when exercised with confidence, reciprocity and affection. **Conclusion:** this relationship of interdependence and interconnection between the elements, constituents of the household ecosystem, provides information exchange, cooperation, partnership and sharing of experiences and configures itself in the family, social and support network to health professionals. **Keywords:** Renal Insufficiency, Chronic; Social Networking; Nursing; Family Relations; Ecosystem.

RESUMO

Objetivo: identificar e analisar as redes de apoio utilizadas pelo usuário renal crônico e família, a partir da perspectiva ecossistêmica. **Método:** estudo qualitativo desenvolvido no domicílio de três usuários com doença renal crônica em dois municípios do sul do Rio Grande do Sul. A coleta de dados ocorreu no período de maio a junho de 2016, por meio de entrevista semiestruturada. A análise de dados foi realizada pelo método da análise temática. **Resultados:** foi possível identificar várias redes de apoio ao portador de doença renal crônica e família, que se constituem em uma importante estratégia para as ações do cuidado, estimulando o enfrentamento da doença. Os vínculos relacionais interativos que se estabelecem entre os componentes do ecossistema domiciliar exercem influências no processo saúde-doença-cuidado do usuário com doença renal crônica quando exercidos com confiança, reciprocidade e afeto. **Conclusão:** essa relação de interdependência e interconexão entre os elementos, constituintes do ecossistema domiciliar, proporciona intercâmbio de informações, cooperação, parceria e compartilhamento de vivências e configura-se na rede de apoio familiar, social e de suporte aos profissionais de saúde.

Palavras-chave: Insuficiência Renal Crônica; Rede Social; Enfermagem; Relações Familiares; Ecossistema.

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RESUMEN

Objetivo: identificar y analizar las redes de apoyo utilizadas por el usuario renal crónico y su familia desde la perspectiva ecosistémica. **Método:** estudio cualitativo llevado a cabo en el domicilio de tres usuarios con enfermedad renal crónica en dos municipios del sur del estado de Rio Grande do Sul. La recogida de datos se efectuó entre mayo y junio de 2016 por medio de entrevistas semiestructuradas. El análisis de datos se realizó según el método del análisis temático. **Resultados:** se identificaron varias redes de apoyo que fomentan el afrontamiento de la enfermedad. Los vínculos de confianza, reciprocidad y afecto que se establecen en las relaciones interactivas entre los componentes del ecosistema familiar influyen en el proceso salud-enfermedad-cuidados del usuario con enfermedad renal crónica. **Conclusión:** la relación de interdependencia e interconexión entre los elementos que constituyen el ecosistema domiciliario proporciona intercambio de información, cooperación, alianza, posibilidad de compartir experiencias y se configura en red de apoyo familiar, social y de respaldo a los profesionales de salud. **Palabras clave:** Insuficiencia Renal Crónica; Red Social; Enfermería; Relaciones Familiares; Ecosistema.

INTRODUCTION

Chronic Non-Communicable Disease (CNCD) are multifactorial and develop throughout life, for long periods of latency and prolonged course. Its occurrence is very influenced by the living conditions, by social inequalities, not being only a result of lifestyles.^{1,2} Among the CNCDs, chronic kidney disease (CKD) stands out, which has been increasing significantly in the last two decades, as a consequence of population aging and the high prevalence of diabetes *mellitus* and systemic arterial hypertension.³

The definition and classification of CKD evolved over time, but current international guidelines define this condition as diminished renal function, demonstrated by the glomerular filtration rate (GFR) lower than 60 mL/min by 1,73m² or markers of renal damage, or of at least three months of duration, irrespective of the underlying cause.⁴ Consequently of impaired renal excretion, the substances normally eliminated in the urine accumulate in the body fluids, leading to metabolic and endocrine dysfunctions. However, in order to maintain life, renal impairment needs to be adequately treated by means of renal replacement therapy (RRT).

The modalities of RRT are classified as renal transplantation (RT) and dialytic therapies. Among these, hemodialysis (HD) and peritoneal dialysis (PD) are cited. The complexity of renal substitutive therapy makes hemodialysis costs higher than the costs of peritoneal dialysis, whether manual or automated.⁵ In Brazil, data show that more than 120,000 people are dependent on dialysis therapies, with 30% being over 65 years old.

According to a survey conducted by the *Sociedade Brasileira de Nefrologia* (SBN) in July 2016, data indicate that the es-

timated total number of dialysis users was 122,825. It is also worth noting that, of the prevalent users, 92% were on hemodialysis, 8% on peritoneal dialysis and 29,268 (24%) were waiting for transplantation;⁶ 85% of this treatment is financed by the Brazilian *Sistema Único de Saúde* (SUS), with estimated annual expenditure of \$ 2.2 billion Brazilian reals.⁷ Thus, early detection of CKD and appropriate therapies to delay progression of the clinical picture may minimize the emotional impact to users, family, and financial costs associated with the disease.

The hemodialysis treatment results in several changes, bringing in addition to physical limitations, a variety of feelings that significantly affects psychological and emotional aspects. Chronicity and the effects of disease and treatment greatly affect the performance of daily life activities and consequently, have a serious impairment in the quality of life of users.⁸ This condition promotes changes in the lives of individuals affected by the disease and, because of this; the RRT affects the user's living process in their household ecosystem.

The ecosystem is understood as the space/environment that, in the theme of the present research, characterizes the locus of the user with CKD, formed by the set of biotic/physical and abiotic/social elements in mutual interaction, constituting the home ecosystem.⁹ This space/environment highlights the exchange of matter, energy and mutual influences between the biotic elements: parents, children, family and other living beings that relate to them, influence and provoke transformations in their way of being, acting and living. In addition, as part of this ecosystem are the neighbors, the people participating in associations, clubs and local institutions to which they belong and with which they interrelate.

Influences and possible changes, based on the ecosystem perspective, among themselves go beyond personal, individual and group characteristics and behaviors, because the physical space itself in which they live, work and develop fulfill important function in the experience of human being. Thus, the experimentation of the disease results in a disorder that can affect several levels of the organism, as well as its interaction with the other systems that surround it, influencing and being influenced by the relations that are established between the components that compose this space/ecosystem, forming true networks.⁹ Therefore, the networks are constituted of inter-relations and interconnections present in this household ecosystem.

The network is a basic standard of organizing living systems, it is necessary to comprehend it in order to understand the functioning as a whole, and the same occurs with the social network, formed by knots and filaments. While the nodes represent the points that form the network: family, neighbors, relatives, associations, clubs, church, among others, filaments are conceived as the bonds that bind and unite the nodes expressed through dialogue, communication, understanding be-

tween the various services who share the attention, care with the CKD patient.^{9,10} To the extent that there is interrelationship between the physical and social elements that form the network, there is a capacity to self-organize, presenting adaptations and continuous changes. In this sense, the components of the network have the function of transforming the elements because they relate and influence, enabling transformations.

In light of the above, this study aims to identify and analyze the support networks used by users with CKD and their family, from an ecosystem perspective.

METHOD

The present study was a descriptive, exploratory study with a qualitative approach, developed in the household context of patients with CKD on RRT by hemodialysis, living in two municipalities in the southern region of *Rio Grande do Sul* (RS)/Brazil, *Pelotas* and *Pedro Osório*. Participants were three users with CKD and three caregiver families, selected from a substitutive renal therapy service of a mid-sized university hospital in south region of the country (RS). The choice of this space for the participants' selection is justified by being the researchers work environment.

Selection of the participants were observed the inclusion criteria: to be a carrier of CKD in hemodialysis treatment; being a user and attending the *Serviço de Terapia Renal Substitutiva* of said university hospital; being in the dialysis program for more than 90 days; be at least 18 years old; be domiciled in the urban zone in one of the two municipalities of the southern region of state. The selected participants complied with the convenience criterion, based on the ease of verbal expression and the requirement to reside in the municipality in which the researcher resides and/or exercises their work activities. There was no refusal or loss of any selected participant.

The data collection was carried out in May and June of 2016, through a semi-structured interview using an instrument with open and closed questions, prepared for this purpose, duly tested with an experimental test before applying it in the research. In addition, the participants signed a two-way informed consent form (ICF). In order to preserve the anonymity of the research participants, they were identified with the letter U (user) followed by an Arabic number, starting with the number one and, subsequently, with the others, according to the order of the interviews. The family participant was identified by the first letter of the kinship level, e.g.: F-Child, M-mother, followed by the identification of the user with CKD: FU1, FU2 and FU3.

The interviews were carried out at the home of five selected CKD users, of whom two were used as pilot tests and after adjustments in the order of questions of the interview form, were discarded. With the other three users, the re-

searcher herself carried out three interviews with a duration of one and a half hours.

After the data collection, the data were transcribed and submitted to the thematic¹¹ analysis steps, firstly the floating reading of the data, organizing them after the resumption of the initial objective of the study and the research question. Then, the data were explored through exhaustive readings, and the most significant words of the texts were selected, and from there proceeded to the grouping of the similar data, constituting the recording units, and then a regrouping, forming the subcategories and finally the categories. The category under analysis is the support networks and places frequented by the user with CKD and family.

An ecomap was elaborated for each family. The Ecomap is a useful tool to assess the relationship of an individual or family with the social environment, serving to evaluate the resources and needs of that individual and/or family. The symbolism adopted in the construction of the ecomaps, present in this work, is based on the didactic material, contained in the basic care booklet No. 39 of 2014, elaborated by the Brazilian Ministério da Saúde (BR).¹²

The ethical principles, as foreseen in Resolution 466 of December 12, 2012,¹³ were respected during this investigation, and the work was approved by the *Comitê de Ética da Área da Saúde* (CEPAS) da *Universidade Federal do Rio Grande* (FURG), RS, Brazil, under No. 182/2015.

RESULTS

Initially, it is present the ecomapas of the three families with a user with CKD, based on the data collected.

The family I consists of three people, the user (U1), the Wife (EU1) and the daughter (FU1). The ecomap shows that the greatest support comes from the family, the wife and the friends of the user.

Family II consists of five people, the user (U2), the companion, the daughter (FU2), the son-in-law (GU2) and the granddaughter (NU2). The ecomap shows that the main sources of support are family and religiosity.

The family III consists of three people, the user (U3), the mother (MU3) and the daughter (FU3). The ecomap demonstrates that the main support networks are family and spirituality.

It can be seen in the statements of those with CKD that everyone tries to attend spaces that help in coping with the disease through entertainment with family and friends, soccer games, dances, pizzerias. Meanwhile, only one mentions that it seeks strength / energy to face the disease, attending the spiritist center. On the other hand, the relatives of the users seek support both in the health service, in the church, residents association, not forgetting the spaces of fun.

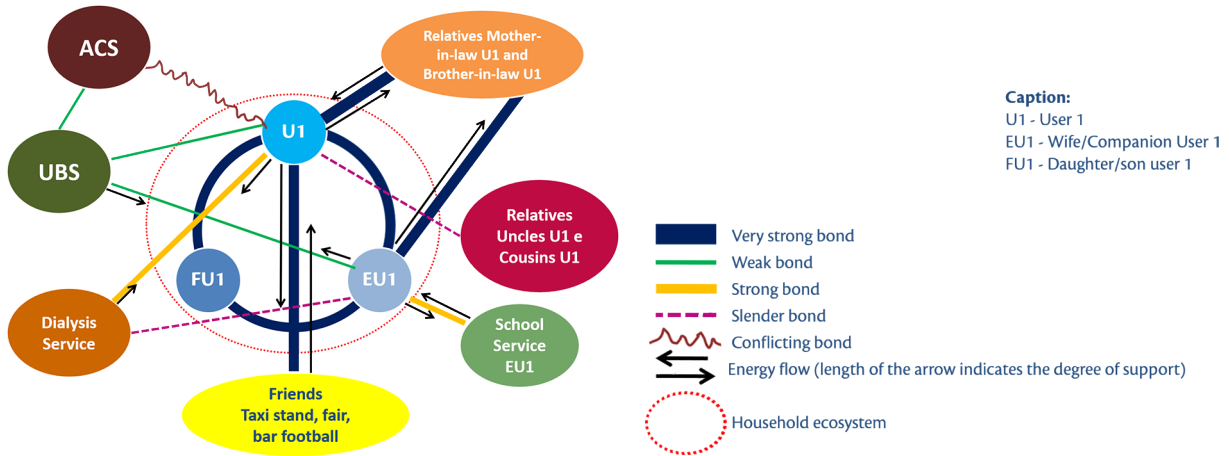


Figure 1 - Ecomap of Family I – Pelotas – June 2016.
 Source: research data organized by the researchers.

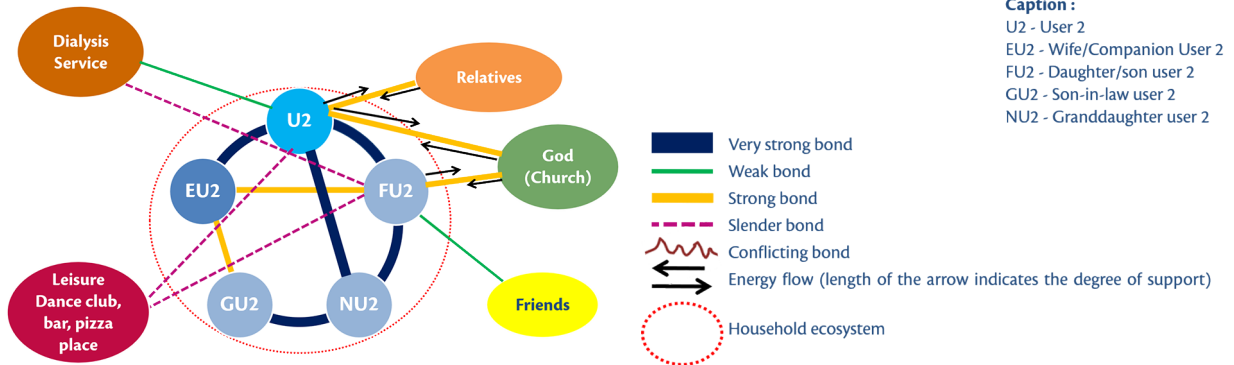


Figure 2 - Ecomap of Family II – Pelotas – June 2016.
 Source: research data organized by the researchers.

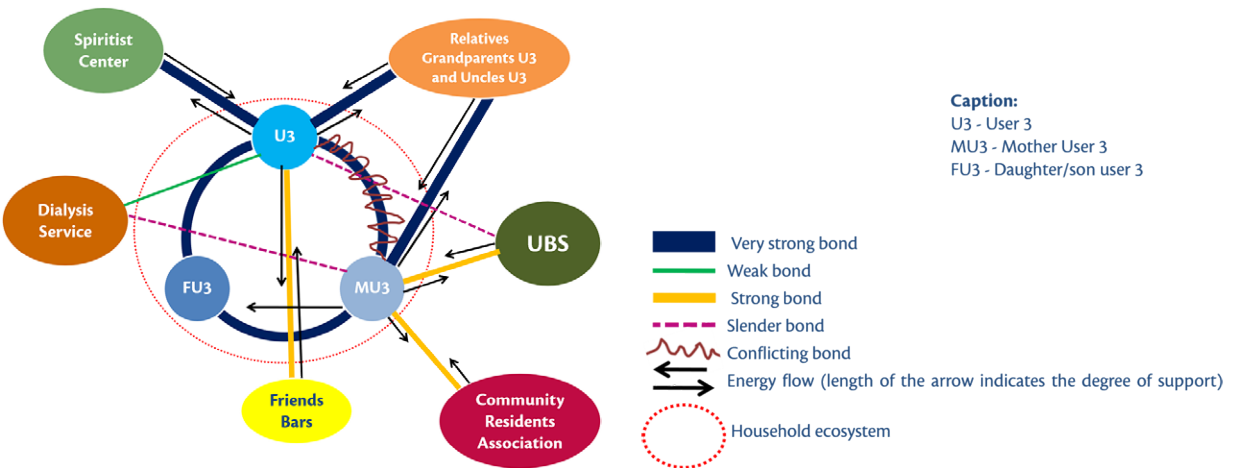


Figure 3 - Ecomap of Family III – Pelotas – June 2016.
 Source: research data organized by the researchers.

As for the activities developed by users and family members in these places, leisure, socialization, health maintenance, community and religious actions are mentioned, as they are mentioned in some of the statements:

[...] Chat with friends, take a chimarrão drink, exchange ideas, always be renewing, learning [...] (U1).

[...] we talk, talk about everything, laugh, spend time [...] (U2).

In the Spiritist center, I course a course, I make evangelization [...] bar is socializing with friends[...] (U3).

[...] to take the ticket to get the medicine (FU1).

In the church, [...] I ask God every day, I pray, I talk to God to give me strength, to help me [...] (FU2).

Continuing the interview, it sought to know what the participants usually do in these places and in which the people of these places help them, to which they replied:

[...] In the soccer game [...] you are not thinking about dialysis [...] helps not to sink(U1).

[...] to forget about my problem, we talk, we speak. [...] (U2).

[...] The Spiritist center [...] is there where I calm my heart, I understand and I renew [...] Helps in my mental equilibrium (U3).

[...] in school, they help me a lot, they let me come home, came to see how my husband is [...] At the health center [...] I do not have much help and collaboration [...] they even help by talking [...] The community agent does not cooperate (FU1).

Regarding her illness [...] we have the doctor at home [...] The family is always available, both to stay with me and to stay with the granddaughter, to take her to the hospital, as to stay in the hospital [...] (MU3).

When asked about the support they received in the spaces they attend, it is possible to detect that the majority of patients with CKD express that the support in fact are the moments in which they stop thinking about the treatment, forgetting the problem by dialoguing, talking or still, as manifested by one of the interviewees, who manages to calm down and find the mental balance in the Spiritist center.

On the part of the family members, there is a widespread regret about the support that should be granted by the health center, the community agent, but rely on their work colleagues, family members and one family member rely on the doctor at home.

DISCUSSION

Events such as illness in the family cause significant changes and mobilize the members in caring for the sick family member. In view of this, there is a need for a reorganization and adaptation

of its functions in order to confront the misfortunes and limitations caused by CKD. This reorganization moves the entire family unit, the space in which they live and attend and which they seek support/assistance to contribute to the treatment of many different forms. The family union, generally, is accentuating, providing strengthened relationships, making the family relationship fundamental in the process of overcoming the disease.¹⁴

This strengthening in family relationships meets the ecosystem principles that perceive the human being as a system in search of dynamic balance, with biological, social, spiritual, psychological and cultural patterns, interdependent, integrated and inserted in a wider context and in a geographic area delimited.¹⁰ Thus, the ecosystem considers that a community of organisms that compose a reality interacts with each other, if it influences, cooperates and maintains relationship with the environment in which it lives, works and develops.⁹

Considering the above, the elements that compose the space/environment of the user with CKD, when relating, construct networks capable of providing what is necessary to strengthen the bearer, through a continuous exchange of matter and energy between themselves and the environment, assisting him in coping with the disease. This interaction becomes necessary because the human being, when being affected by a disease like the CKD faces structural alteration of his life and it is indispensable to gather strength and energy from the other elements that form his network of relations to potentialize his attitudes and behavior in front to cope with disease and therapy.

In this research, the participants identified several places and people with whom they interact and that constitute aid in various domains of their lives. The institutions attended and people cited were: health institutions (basic units); residence of relatives; religious environments (church, Spiritist center), home of friends, school and social environments (bars, football courts, pizza places, dance clubs, beach, fair and taxi stand). These data corroborate the results obtained by a study carried out with 30 people living in chronic kidney conditions in a hemodialysis unit in Northeast Brazil, since they cite as found sources of support family, health and religious institutions.¹⁵

In relation to the activities carried out by users and their families in the institutions or with the people who compose their network of relationships, leisure, socialization, religious, community and health maintenance activities were mentioned. Thus, anchored in the ecosystem inter-relationships, these opportunities for coexistence and support provided by the linkage and interactions between users with CKD, other individuals and institutions provide energy exchanges and information capable of stimulating optimistic attitudes towards life, maintaining a dynamic balance in their way of living.¹⁰

Observing the support provided to users and their families, the research evidenced several forms of assistance: needs

regarding the maintenance and repair of the user's health, emotional support, logistical support in family activities, support for changing working hours and spiritual support. These results converge with those found in the literature¹⁴ when evidencing that the social network for people with chronic disease constitutes an effective strategy of support in search of improvement in the quality of life.

Considering the results obtained in the elaboration of the ecomaps, data obtained through the interviews, it is perceived that the family, in the present research, constitutes the fundamental element in the support to the user. It is present in all the participants' statements, emphasizing the very strong attachment with the closest caregivers. However, one of the statements - F1 - shows that family support presents fragilities in relationships with distant relatives. It is possible, finally, to infer that the family forms a support network for the users and that the most distant relatives can be supporters in order to contribute in the treatment and the attendance to the necessities derived from the user's health.

The family still provides emotional / psychological support, as evidenced by participants' statements - U2 and U3, providing mental balance and the possibility of forgetting the disease through recreational and distraction activities. Pay attention to the aspects in which these users are inserted in relation to their chronic health condition, their family and social relations becomes fundamental for the provision of safe, effective and quality care.⁸

In this perspective, it was evidenced that family relationships enable the human being to learn to think, act and react through ethical, moral, religious and social principles that interrelate and influence their way of being in the world. This network of relationships, interactions and cooperation - with their beliefs, values, feelings, among others - are able to respond to internal and external changes, establish connections and thus adapt to new situations in the way of living of user's with DRC.

Faced with the changes caused by the CKD, there is a destabilization of the individual's biological, social, spiritual and psychological dimensions and family modifications, which require the sharing of activities and support of other interconnected networks that comprise the ecosystem of users with CKD and family members. Therefore, from the ecosystem perspective, this web of connections and interconnections, through relationships of reciprocal interactions, is capable of providing an exchange of information that can positively contribute to the health-disease-care process.⁹

In relation to the support network, FU1's testimony identifies the assistance provided by the school in which she carries out her work activities, authorizing her departure during the working period, in order to take care of her husband with CKD. This attitude indicates that there is a solidary support network

capable of enabling the interrelationships and, indirectly, establishing bonds that subsidize care actions in the home ecosystem.

One of the elements configured as spiritual support, present in the testimonies of some of the participants - U2, U3, FU2 - identify the support offered by religious institutions and spirituality, an inherent dimension to the human being. In order to alleviate and/or minimize situations of instability and inconsistency involving diseases characterized as serious, the search for spirituality and practices related to beliefs, faith, values and religion have been presented as coping strategies in the health-disease-care process.¹⁶

From this perspective, the positive energy emanated by faith, belief and/or other aspects that transcend the physical and biopsychic aspect may contribute to improve the condition of living, feeling and reacting of the user with CKD.¹⁶ Thus, for better results in health and quality of life, it is understood that spirituality is multidimensional, relational and encompasses meanings, purposes, self-reflection, hope, faith and beliefs in coping with the disease and treatment.

In the network that is formed, the configuration of the ecomaps - families I, II and III, represented by very strong, strong and weak bound, respectively, are connected to the support of friends. In family I, the user reports partnerships in leisure activities, emphasizing emotional support, encouraging him not to sink in the face of difficulties. In family II, there are companies for distraction activities and in family III, friendships that provide mental/emotional balance. Studies¹⁴⁻¹⁵ confirm the bonds of friendship as an important support force, minimizing the social isolation resulting from the disease and as strategies for coping with the disease, expanding the mood and maintaining the psych emotional balance.

Among the support networks evidenced in the FU1 and FU3 statements are the basic health units and, from the ecomap, and even the bonds established with the dialysis service are also observed. The formal support network formed by the renal replacement therapy service was mentioned in some studies,^{17,18} highlighting the lack of understanding on the part of the professionals responsible for dialysis, as well as a non-effective communication, which is responsible for compromising the care and treatment success for CKD. The data from this research identify that the bond with the hemodialysis service was only strong in the relationship of U1; in the other users did not represent significant results.

Regarding the BHU, the testimonies considered as a source of support the provision of prescription drugs and the provision of medical services, with a strong to weak bond. In family I, living in an inner city, there is animosity between the community health agent and the family members, evidenced in the user's complaint statements, which reports the lack of support by the health agent.

In meantime, there is a relational gap between the health services, users and family, with weak bond that may interfere and compromise adherence to treatment and self-care. These results are opposed to the guidelines of care for chronic disease¹, from which health services need to organize person- and family-centered care in order to strengthen bonds and intervene effectively in the health-disease-care process.

Thus, knowledge and understanding of the social network configuration of users with CKD is an important strategy for how they experience therapeutics in the course of the illness process. Therefore, knowing the interrelations that configure the social networks of users with CKD is capable of generating new knowledge in order to qualify the actions of Nursing/health care directed to the real needs of this population, contributing prevention and promotion of health.

CONCLUSION

The analysis of the data of this research allowed to identify that the networks serve as support to the user with CKD and family and that constitute an important strategy in the actions of the care, since its members form supporting bonds that help in the conduction of necessary care practices, minimizing the family burden and providing stimuli to cope with the disease.

It is noticed that the relational and interactive bonds that are established among the components of the home ecosystem play a fundamental role in the development of the user with CKD when exercised with confidence, reciprocity and affection. This relationship of interdependence, interrelationship and cooperation between the biotic and abiotic elements, constituents of the household ecosystem, provides information exchange, partnerships, sharing of experiences and thus, configures the family support network, social and support for chronic kidney users.

These interrelationships are capable of generating positive feelings, energizing and dynamic equilibrium, favoring the strengthening of the bonds between users, family member and health professionals, helping to overcoming the difficulties generated by CKD. In this sense, the insertion of nurses in this support network can contribute positively, creating subsidies for user empowerment in the health-disease-care process, through self-care practices.

By adding knowledge to this thematic area, the limitations of the present research stand out the small number of participants and the period of interviews, with no possibility of generalizations. However, it is possible to observe that the objective of the research was achieved and that new studies could subsidize new knowledge and implications for professional practice in the production of care for users with CKD.

REFERENCES

1. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Análise e Situação de Saúde. Plano de ações estratégicas para o enfrentamento das doenças crônicas não transmissíveis (DCNT) no Brasil, 2011-2022. Brasília: Ministério da Saúde; 2011.
2. World Health Organization. Mortality and burden of disease. Noncommunicable Diseases (NCD) Country Profiles, 2014: Brazil. Geneva: World Health Organization; 2014[cited 2018 Dec 19]. Available from: http://www.who.int/nmh/countries/bra_en.pdf?ua=1
3. Castro MCM. Conservative management for patients with chronic kidney disease refusing dialysis. *J Bras Nefrol.* Mar 2019[cited 2018 Dec 19]. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0101-28002019000100095&lng=en. Epub July 23, 2018. DOI: 10.1590/2175-8239-JBN-2018-0028
4. Webster AC, Nagler EV, Morton RL, Masson P. Chronic kidney disease. *Lancet.* 2017[cited 2018 Dec 20];389:1238-52. Available from: [https://doi.org/10.1016/S0140-6736\(16\)32064-5](https://doi.org/10.1016/S0140-6736(16)32064-5)
5. United States Renal Data System. 2013 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. 2013[cited 2018 Dec 20]. Available from: <https://www.usrds.org/atlas13.aspx>
6. Sesso RC, Lopes AA, Thomé FS, Lugon JR, Martins CT. Brazilian Chronic Dialysis Survey 2016. *Braz J Nephrol.* 2017[cited 2018 Dec 19];39(3):261-6. Available from: <https://doi.org/10.5935/0101-2800.20170049>
7. Gouveia DSS, Bignelli AT, Hokazono SR, Danucalov I, Siemens TA, Meyer F, et al. Analysis of economic impact among modalities of renal replacement therapy. *Braz J Nephrol.* 2017[cited 2018 Dec 19];39(2):162-71. Available from: <https://doi.org/10.5935/0101-2800.20170019>
8. Nogueira ILA, Tinôco JDS, Paiva MGMT, Trindade AOP, Lira ALBC, Enders BC. Sociodemographic and clinical aspects related to the quality of life of hemodialysis patients. *REME - Rev Min Enferm.* 2018[cited 2018 Dec 20];22:e-1080. Available from: <https://doi.org/10.5935/1415-2762.20180010>
9. Siqueira HCH, Thurow MRB, Paula SF, Zamberlan C, Medeiros AC, Cecagno D, Aurélia Sampaio A, et al. Health of human being in the ecosystem perspective. *Rev Enferm UFPE on line.* 2018[cited 2018 Dec 21]; 12(2):559-64. Available from: <https://doi.org/10.5205/1981-8963-v12i2a25069p559-564-2018>
10. Zamberlan C, Siqueira HCH. Household ecosystem of parents with heart disease and the way of living of sons: opportunities for health promotion by nursing/health knowledge. *Rev Enferm UFPE on line.* 2014[cited 2018 Dec 24];8(4):1098-100. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/9785/9935>
11. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 12ª ed. São Paulo: Huitec; 2014.
12. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Núcleo de Apoio à Saúde da Família: vol. 1: ferramentas para a gestão e para o trabalho cotidiano. *Cad Atenção Básica.* 2014[cited 2018 Dec 19];39. Available from: http://www.http://bvsms.saude.gov.br/bvs/publicacoes/nucleo_apoio_saude_familia_cab39.pdf
13. Ministério da Saúde (BR). Resolução n. 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas de pesquisas envolvendo seres humanos. Brasília: MS; 2012[cited 2018 Dec 19]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html
14. Schwartz E, Muniz RM, Burille A, Zillmer JGV, Silva DA, Feijó AM, et al. As redes de apoio no enfrentamento da doença renal crônica. *REME - Rev Min Enferm.* 2009[cited 2018 Dec 20];13(2):183-92. Available from: http://www.enf.ufmg.br/site_novo/modules/mastop_publish/files/_4c0e49f32d824.pdf
15. Silva RAR, Souza VL, Oliveira GJN, Silva BCO, Rocha CCT, Holanda JRR. Coping strategies used by chronic renal failure patients on hemodialysis.

- Esc Anna Nery Rev Enferm. 2016[cited 2018 Dec 20];20(1):147-54. Available from: 10.5935/1414-8145.20160020
16. Siqueira HCH, Cecagno D, Medeiros AC, Sampaio AD, Rangel RF. Spirituality in the health-illness-care of the oncological user process: nurse's outlook. Rev Enferm UFPE on line. 2017[cited 2018 Dec 20];11(8):2996-3004. Available from: 10.5205/reuol.11064-98681-4-ED.1108201702
17. Goff SL, Eneanya ND, Feinberg R, Germain MJ, Marr L, Berzoff J, *et al.* Advance care planning: a qualitative study of dialysis patients and families. Clin J Am Soc Nephrol. 2015[cited 2018 Dec 20];10(3):390-400. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25680737>
18. Bristowe K, Horsley HL, Shepherd K, Brown H, Carey I, Matthews B, *et al.* Thinking ahead- the need for early Advance Care Planning for people on haemodialysis: a qualitative interview study. Palliat Med. 2014[cited 2018 Dec 20];29(5):443-50. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25527527>
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