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HOME PERITONEAL DIALYSIS: INTERLOCATIONS BETWEEN USERS AND HEALTH CARE NETWORK SERVICES

Diálise peritoneal domiciliar: interlocuções entre usuários e serviços da rede de atenção à saúde

Diálisis peritoneal en casa: interlocaciones entre los usuarios y los servicios de red de atención médic

*Denise Rocha Raimundo Leone[1]; Beatriz Francisco Farah[2]; Edna Aparecida Barbosa de Castro[3]**

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ABSTRACT

Objective: To understand the interlocutions between users who perform peritoneal dialysis at home and the services of the Health Care Network. **Method:** qualitative research carried out with 19 people undergoing dialysis treatment distributed in three sample groups according to the Grounded Theory method. Analysis through open, axial and selective coding. **Result:** the care context studied exposes the discontinuity of dialysis care in the spheres of primary and hospital care, analyzed by the category "Performing Peritoneal Dialysis at home, being inserted in the Health Care Network". **Conclusion:** from the interviewees' point of view, the main dialogue is with the renal replacement therapy service, the main reference for care and complications with home dialysis. The interlocutions with the other assistance points of the Network aim to obtain support services, not involved with the peritoneal dialysis procedure at home.

Descriptors: Peritoneal dialysis, Health care, Health services, Integrality in health, Nephrology.

[1] Nurse. Specialist in nephrology from the State University of *Rio de Janeiro*. Master in Nursing from the Federal University of *Juiz de Fora*. PhD student in Collective Health at the Federal University of *Juiz de Fora*.

[2] Nurse. Master in Nursing from the Federal University of *Rio de Janeiro*. PhD in Collective Health from the State University of *Rio de Janeiro*. Associate Professor at the School of Nursing and at the Stricto Sensu Postgraduate Nursing Program at the Federal University of *Juiz de Fora*.

[3] Nurse. Master in Education from the Federal University of *Juiz de Fora*. PhD in Collective Health from the State University of *Rio de Janeiro*. Professor and researcher of the Stricto Sensu Post-Graduation Program in Nursing at the Federal University of *Juiz de Fora*.

RESUMO

Objetivo: Compreender as interlocuções entre os usuários que realizam a diálise peritoneal domiciliar e os serviços da Rede de Atenção à Saúde. **Método:** pesquisa qualitativa realizada com 19 pessoas em tratamento dialítico distribuídas em três grupos amostrais conforme o método da *Grounded Theory*. Análise através da codificação aberta, axial e seletiva. **Resultado:** o contexto assistencial expõe a descontinuidade do cuidado dialítico nas esferas da atenção primária e hospitalar, analisada pela categoria "Realizando a Diálise Peritoneal no domicílio, estando inserido na Rede de Atenção à Saúde". **Conclusão:** na ótica dos entrevistados a principal interlocução é com o serviço de terapia renal substitutiva, principal referência para o cuidado e intercorrências com a dialise domiciliar. As interlocuções com os outros pontos assistenciais da Rede visam obter serviços de apoio, não implicados com o procedimento de dialise peritoneal domiciliar.

Descritores: Diálise peritoneal, Atenção à saúde, Serviços de saúde, Integralidade em saúde, Nefrologia.

RESUMEN

Objetivo: Comprender las interlocuciones entre usuarios que realizan diálisis peritoneal en el hogar y los servicios de Health Care Network. **Método:** investigación cualitativa realizada con 19 personas sometidas a tratamiento de diálisis distribuidas en tres grupos de muestra según el método de la teoría fundamentada. Análisis mediante codificación abierta, axial y selectiva. **Resultado:** el contexto de atención estudiado expone la discontinuidad de la atención de diálisis en las esferas de atención primaria y hospitalaria, analizada por la categoría "Realización de diálisis peritoneal en el hogar, que se inserta en la red de atención médica". **Conclusión:** Para los entrevistados, la interlocución principal es con el servicio de terapia de reemplazo renal, la principal referencia para la atención y las complicaciones con la diálisis en el hogar. Las interlocuciones con los otros puntos de asistencia de la Red apuntan a obtener servicios de apoyo, no involucrados en el procedimiento de diálisi.

Descriptores: Diálisis peritoneal, Cuidado de la salud, Servicios de salud, Integralidad en salud, Nefrología.

INTRODUCTION

Chronic Renal Disease (CKD) is considered a global public health problem. The burden of this disease is increasing worldwide due to the increase in its incidence, prevalence and the number of deaths attributable to it. Its treatment generates high cost and complexity, which implies investments in state-of-the-art technology and professional qualification.[1-2]

In its V stage, the most advanced stage of the disease, the use of a renal replacement therapy (RRT) is necessary, which can be hemodialysis (HD), peritoneal dialysis (PD) or renal transplantation.[3]

The prevalence of individuals on dialysis continues to increase, configuring a rising curve.[4] In Brazil, it is estimated that there are 126,583 people on dialysis treatment, of these, 93.1% were on HD as treatment and 6.9% on PD.[1] In Latin America, the prevalence of PD use as treatment for CKD is higher when compared to HD, in only three countries: El Salvador, Guatemala and Costa Rica.[5]

PD uses the membrane of the peritoneum and can be performed at home after training the person and/or his/her caregiver to perform the technique and adequacy of the residence to perform the procedure.[6-8]

However, people who perform this treatment have to administer multiple and complex factors that involve the care with disease, beyond the dialysis procedure. These can be considered obstacles to treatment and, to minimize them, attention to the PD person requires a multidisciplinary approach plus collaborative efforts between the dialysis services and the other health services serving this population.[9]

In Brazil, the users of the dialysis service demand other services offered by the Rede de Atenção à Saúde (RAS), which act orderly to meet the health needs of the The nephrology service has been pointed out as the only reference for the patient in PD, however it permeates the RAS services and needs to be welcomed and feel secure in meeting their demands. It is known that the nephrology service is highly specialized and, therefore, it is essential that the professionals who work in the other points of the RAS receive training, which enables them to care for people with CKD who perform PD at home according to the technological density demanded in the continuum of a line of care.

Challenge, since universal access to dialysis does not only imply public financing, but also the guarantee of integrated and adequate measures to address all barriers related to treatment.[10-11]

Based on these analyses, an assumption is made that in order to achieve the completeness of the assistance to the person with CKD, it is relevant to establish interlocutions between the assistance points in RAS, of different technological densities, bringing up the following question: how do the interlocutions between users who perform peritoneal dialysis at home and the services of the SUS Health Care Network occur?

Therefore, studies of this nature are justified, which by assuming the magnitude of CKD as a public health problem, invest in the search for understanding of issues extracted from the list of care performed by the user and family at home. The benefits fall within the scope of the assessments on the importance of SAN and on the essential increments in the management of all aspects, from the most basic to the most complex, that involve the treatment of CKD. Therefore, the objective was to understand the interlocutions between users who perform peritoneal dialysis at home and the existing services in the SUS RAS.

METHODS

A qualitative study anchored in Grounded Theory was conducted. This is a field methodology that appropriates the collected data, without any preconceived hypothesis, to

found a theory.[12]

The scenario was the home of people in PD registered in a dialysis service of a public hospital in Minas Gerais, with capacity to care for 50 people, which provided assistance to 37 during the period of this study. The data were collected at home from June 2015 to June 2016, through open interview, participant observation, field journal entries and preparation of memos. 19 individuals participated in this study.

Inclusion criteria were: to be over 18 years old, capable of expressing oneself through verbal language; to perform home PD and to accept to participate voluntarily in the research, rectifying one's agreement with the signing of the Free and Informed Consent Term. Those who were unable to answer for themselves were excluded.

The participants were distributed in three sample groups. The first group included ten people, and because of the need to use new research questions, a second sample group was formed, with four people. The third sample group, which aimed to validate the theoretical substantive model, consisted of nine people, four of whom also participated in the first group. From this, a total of 23 interviews were conducted.

The sample size followed the theoretical saturation criterion and this corresponds to the good development of the categories with respect to their properties and dimensions, the non-emergence of any new and relevant data related to the categories and also that these are well established and related.[12]

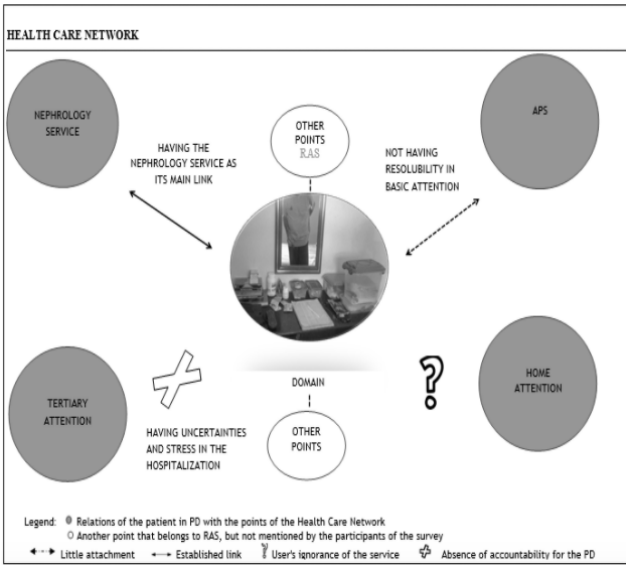
The analysis was performed concomitantly with the collection and occurred according to three types of coding: open, axial and selective. The first consisted in the identification of the concepts expressed in the data and was performed through the microanalysis technique of the interview transcriptions. Axial coding sought to establish a relationship between categories and their subcategories and, through selective coding, a substantive theory on the phenomenon researched was integrated and refined, presented in the form of a diagram, in which the relationship between the central category and subcategories was identified using in-depth analysis.[12] For the organization of the empirical database, textual editing and coding support, OpenLogos software was used.

The research observed the ethical aspects, according to Resolution n. 466/2012 13 and was approved by an Ethics Committee under the opinion: 1,004,325. In order to guarantee the anonymity the participants were designated in the quotations of this text by flower names.

RESULTS

Of the participants, 16 (84.2%) were women. Age ranged from 32 to 74 years, with an average of 52.9 years. PD time varied between five and 108 months, with an average of 34 months. Through the data analysis process, the category "Performing Peritoneal Dialysis at home, being inserted in the Health Care Network" was reached, which is constituted from three subcategories: "Not having resolution in Primary Care and not being attended by Home Care", "Having the nephrology service as the main link" and "Having uncertainties and stress in hospitalization". Diagram 1 visually represents the relationship between the category and subcategories.

Diagram 1 - Performing peritoneal dialysis at home and being part of the SUS Health Care Network. Juiz de Fora, MG, Brazil, 2016



Not having resolubility in Primary Care

The users who performed PD at home presented health needs whose solubility is found in the interface between the specialized service in nephrology and other points of the network, among which Primary Health Care (PHC) stands out. The analysis of the data identified that the professionals who work in this point of the RAS include in their work process the follow-up to the users in PD. However, not specifically with regard to aspects related to dialysis procedure. It was understood that home visits to these people are not included as a routine, as reported by Azaléia:

> *When I go there [Basic Health Unit], they ask me if everything is okay. When I'm in need of something, they attend me very well, but to come here they never came. (Azaleia)*

However, when they occur, they are not intended for continuity of treatment. It is understood that among the competencies and skills that could be related to this point of the network would be the clarification of doubts; the verification of whether the environment in which the individual performs PD is adequate for the performance of the therapy; the evolution of the PD process in a shared way with the specialized services.

> *There are those girls who walk on the street, the health*

agent. They don't solve anything, they just come for us to sign and that's it. (Carnation)

The weaknesses in the interlocution between users and the health service pointed out by the interviewees, related to PHC, may be anchored in the lack of knowledge of health professionals about the technical procedures demanded by PD and the pertinent competencies for primary care.

We arrive at the station and the staff doesn't know it, they know hemodialysis, you speak dialysis and the staff doesn't know what it is, then you have to explain. (Gérbera)

I even talk to them about me on dialysis, but it's no use me wanting to know something or asking questions, they don't know. (Amarilis)

It is understood that there is a lack of knowledge on the part of the professionals who work in the PHC about PD and this can prevent proper guidance and conduct for these users.

Having the nephrology service as its main link

In the conception of the patient, the nephrology service is his main reference, being resolutive for him in the attendance to the care needs related to the treatment. From the reports obtained, it is consolidated the understanding that the aspects related to the treatment and its complications were attended, exclusively, by the dialysis service.

The XXX [nephrology service] is my reference when I need it. Because at the [UBS] Post, it does not answer. The other day, the girl claimed the following: that they don't have the capacity to attend a person who does dialysis. (Astromelia)

However, these users find themselves helpless when they have intercurrences in the dialysis procedure, which usually occurs during the night, when the dialysis service is closed.

If there is a problem with the machine, I turn the machine off and go to sleep, then, the next day, I call and go [nephrology service], because it doesn't work there at night. (Amarilis)

However, aiming at the realization of PD, the interviewees seek strategies to solve the problems that arose in order to enable the continuity of treatment. One, for example, was to call the Serviço de Atendimento ao Consumidor (SAC) of the company that supplies the material of dialysis.

A couple of times, at night, I called XXX [the company that supplies materials for dialysis], but it didn't work, they couldn't solve the problem, so I turned off the machine and the next day I took it there [nephrology service]. (Orchid)

Another strategy reported, and more frequently, was to call the dialysis nurse, even though he was outside of his working hours.

At night, I'd call XXX [nurse], right?! I always called, sometimes the machine gave me a problem there and I didn't understand, then I said XXX [nurse], for God's sake, I'm terrified. (Azaleia)

Among the professionals in the nephrology service, the nurse was pointed out by the interviewees as being the one who stands out in the care needs related to the dialysis procedure, since his availability to assist them, even outside the work shift, gives him satisfaction and security to perform the dialysis practice at home.

However, they understand that this service is on a personal level and is a reason for concern, because if there is a change of professionals in the service, the service changes due to the inexistence of a protocol that guarantees them support at home during the night.

Having uncertainties and stress in hospitalization

When the individual who performs PD demands a hospital admission, it causes him stress and anxiety. The participants reported that these reactions occur not only because of the hospitalization itself, but also because of the need to continue the treatment in the hospital context.

When they needed to be hospitalized, three options were extracted from the analysis: the first was the performance of HD to the detriment of PD during hospitalization.

I was hospitalized because it filled the pericardium. At that time, I was already on dialysis [peritoneal], but there it was done here [showed the fistula to HD], not peritoneal dialysis. (Balsam)

The second alternative during hospitalization was to go to the institution where the patient is hospitalized to have PD performed by a relative or a person close to the patient.

I stayed in the hospital last year and what I did to avoid hemodialysis, I took the machine, I set a table [...] my wife and my sister, who they made for me, nobody knew, seemed to be a seven-headed animal. (Chrysanthemum)

And the third was not to perform the dialysis, even knowing the risks that this attitude generates. However, it was the only alternative for an interviewee hospitalized in an emergency room.

When I was admitted to XXX [Emergency and Emergency Services], they wouldn't accept it because of infection, so I didn't do it for three days. Then I was transferred to YYY [Dialysis Service Hospital] and there I stayed one night without doing it, then the other day in the morning I went there to XXX [Dialysis Service] and I did there and then I came back. (Tulip)

The lack of knowledge of professionals who work in tertiary care recurs in the testimonies of the participants, exposing what can be the cause of discontinuity and insecurity in the care of these patients.

In hospitals, they have no knowledge, so you have to explain what it is and how it works. (Lisianto)

The vulnerability of the user who performs PD at home arises allied to the lack of knowledge of professionals and weakens the fulfillment of the service competencies in the line of care of RAS.

By bringing up the problem of lack of knowledge about PD by professionals, the need for policies that invest in the accomplishment of permanent education by health professionals, of the different points of the RAS on the subject of DRC, its treatments and implications is exposed.

DISCUSSION

The success of PD in the home requires the accompaniment of the user and family in primary care actions, which demands the training of professionals on the skills and competencies expected from this point in RAS.[14] The lack of trained professionals in PD in Bangladesh is considered a reason for a smaller number of people to perform this therapy as a treatment for CKD.[15]

There is evidence, as this research also identifies, that the VDs performed by Community Health Agents (CSAs) sometimes aim at collecting signatures to meet management goals at the expense of the care provided.[16-17]

However, the RV performed by the CSAs are considered fundamental for the promotion of the health of the chronic renal patient, constituting a link between the user and family in their most emerging doubts and needs and the professionals of the family health strategy. Restricting the performance to the collection of signatures, however, shows the need for training on the functions of this professional and the direct supervision of his actions, in order to achieve not only the management goals, but the resolubility and effectiveness of the care that fits this level of attention.

VD, when performed according to the surveillance and health promotion purposes, becomes an important instrument in the health-disease process, directing the planning and implementation of interventions to the professionals, since it provides the understanding of the reality, considering the subjects' and their relatives' life context.[17]

In the case of patients in PD, RV provides support, support, construction of links, exchange of experiences, adaptation of the environment and extends the subject's autonomy through an educational process. [8,18-20] Therefore, professionals can and should include in educational strategies real elements of the patient's environment.[21] As far as Home Care is concerned, the participants in Home Care were unaware of the existence of the Home Care Service, were not admitted by it and did not receive a visit from the Equipe Multiprofissional de Atenção Domiciliar (EMAD), nor from Equipe de Apoio da Atenção Domiciliar (EMAP).

It should be noted that people registered in this service need to present difficulty or physical impossibility of locomotion to a Health Unit.[22] And since the participants in this research did not present restrictions to health services, they were not in the eligibility criteria to participate in the service.

The nephrology service has been pointed out as the only reference for the patient in PD, however it permeates the RAS services and needs to be welcomed and feel secure in meeting their demands. It is known that the nephrology service is highly specialized and, therefore, it is essential that the professionals who work in the other points of the RAS receive training, which enables them to care for people with CRT who perform PD at home according to the technological density demanded in the continuum of a line of care.

To this end, the Specialized Unit in CKD with RRT-Dialysis is responsible for the matriculation and training of PHC teams on topics related to renal diseases. Matricial support should be part of the work process of the specialized care teams and is considered an essential tool that provides an approach between the different points of SAR and the professionals, in order to favor an integral care.[11] The nephrologist can contribute with the clinical professionals by helping the individual on dialysis and his/her family to make individualized decisions that reflect the best evidence, besides his/her values and preferences.[14]

However, the lack of communication between professionals from different health care points has been reported as a constant concern, and many times the patient himself in PD becomes the channel of information among professionals.[23]

Matrix support to other health services is present in Thailand, there are three main services there that are considered to support other health network services. These are by area of location and are supported by academic and nephrologist physicians and nurses.[24]

With regard to the attention of the nurse outside their working hours to clear up doubts and attend to intercurrences of users related to dialysis, it is noted that in the United States, it is up to the nursing team, among other duties, to maintain availability of 24 hours a day to attend

calls. These should be answered as soon as possible, being a responsibility of the dialysis programs to their users.[25]

As for the need for hospitalization, there is evidence that hospitalization requires the individual to be able to adapt to the changes that have occurred in their way of living. When hospitalized, the individual follows the routines established by the institution, thus decreasing his/her autonomy and even depersonalizing the individual, depending on the length of hospitalization. These changes generate feelings such as fear, anxiety and discomfort.[26-27]

Autonomy implies decision making, in order to preserve the integrality and individuality of the person, according to his/her aspirations, values, beliefs and objectives.[28] However, decision making during hospitalization is surrounded by administrative and bureaucratic issues that are inherent to the hospital institution, and in the case of those interviewed, these have sometimes made dialysis therapy impossible.

In this study, there was a loss of autonomy of patients during hospitalization, including with respect to the performance of PD as an option for treatment of CKD. Choosing the RRT to be performed is a right for people who present this disease as a diagnosis.[11] It is considered that, since they need hospitalization and cannot perform PD during this period, they neglect a right.

Associated to the loss of autonomy during hospitalization, it was observed the restriction in performing self-care activities, causing greater dependence on family members for the effectiveness of therapy in this period. The lack of preparation is apprehended of the institutions that perform hospitalizations for the people who perform PD. It is worth mentioning that this unpreparedness contemplates public and private hospitals of the reality of the research, since these admissions occurred both in public and private institutions.

In Thailand, there is an incentive policy for home-based PD, which guarantees health training for professionals in health centers, hospitals, as well as secondary and primary care, aiming at serving this clientele. This training uses the concept of a chronic care model that favors the performance of therapy at home and aims to improve results.[24]

In Brazil, the search for coordination and maintenance of communication with the multiprofessional teams of the other RAS components are considered the attributions of the nephrology service.11 It is believed that the lack of sharing of the care demanded by DP with other RAS professionals leads to the centralization and overload of specialized services, with users stagnating at this point in RAS, omitting to take advantage of other support modalities. It reinforces the state of ignorance and culture that the responsibility for the care of the user with CKD in PD is exclusive to the services of nephrology.

CONCLUSIONS

The integrality and resolubility expected in health care are not expressed in the reality experienced by people who do PD, because the existence of fragmentations with Primary Care and insecurities in the care of hospitalization units were identified. The only link is the nephrology service, which does not work full time.

With this, the principle of integrity of the SUS is compromised and, consequently, those who perform the PD are exposed to fragilities in the assistential context. As for home care, the data presented in this report have made this unenforceable discussion, as there was no interviewee attended by this service, which was considered a limitation of this investigation.

It is believed that the permanent education provided by the specialized service for other RAS professionals reduces the vulnerability of patients. The nephrology service should be a reference for the other points of the Network regarding the care related to CKD and its treatment. It is anticipated that new researches will be carried out to make this discussion possible.

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***Corresponding Author:**
Edna Aparecida Barbosa de Castro
Rua José Lourenço Kelmer, s/n
São Pedro, Juiz de Fora, Minas Gerais, Brasil
E-mail address: ednabdecastro@aol.com
Zip Code: 36.036-900

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