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Estratégias de (re)organização da família que convive com familiar em diálise peritoneal no domicílio

(Re)organization strategies of the family that lives with a family member in peritoneal dialysis at home

Estrategias de (re)organización de la familia que convive con familiar en diálisis peritoneal en domicilio

Arlete Maria Brentano Timm¹; Margrid Beuter²; Nara Marilene Oliveira Girardon-Perlini³; Macilene Regina Pauletto⁴; Naiana Oliveira dos Santos⁵; Carolina Backes⁶

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ABSTRACT

Objective: To describe the family's (re)organization strategies while living together with a member that makes peritoneal dialysis at home. **Methods:** Qualitative study conducted through interviews with seven families that had a member in peritoneal dialysis, linked to a renal clinic in the south of Brazil, from March to May, 2012. The data were submitted to thematic analysis. **Results:** The strategies adopted by families were: to adapt the treatment schedule with other activities; to acquire knowledge and develop abilities to make peritoneal dialysis; to adequate the physical environment of the residence; and to adapt the family routine to face the sickness and the treatment of familial member. **Conclusion:** The (re)organization of the family has occurred to make treatment and daily activities possible. Once the nurse acknowledges the individuality of the families, when they ask him/her to help, he/she can help them, and try to attend the expectations of each one with sensibility.

Descriptors: Family relation, Peritoneal Dialysis, Nursing, Chronic Disease, Home Nursing.

¹ Nurse. Master degree in Nursing by the Federal University of Santa Maria (UFMS). Nurse at the University Hospital of Santa Maria. E-mail: ambtimm@yahoo.com.br.

² PhD in Nursing. Associate Professor at the Department of Nursing, and at the PPGEnf/UFMS. Associate Professor at the Master's Course in Gerontology/UFMS. Rio Grande do Sul, Brazil. E-mail: margridbeuter@gmail.com.

³ PhD in Nursing. Adjunct Professor at the Department of Nursing, and at the PPGEnf/UFMS. Rio Grande do Sul, Brazil. E-mail: nara.girardon@gmail.com.

⁴ Nurse. Master degree in Nursing, by the Federal University of Santa Maria (UFMS). Nurse at the University Hospital of Santa Maria. E-mail: macipauletto@gmail.com.

⁵ Nurse. PhD in Nursing, by the Federal University of Rio Grande do Sul (UFRGS). Rio Grande do Sul, Brazil. E-mail: naiaoliveira07@gmail.com.

⁶ Academic student from the Nursing Undergraduate Course at the Federal University of Santa Maria UFMS. Scholarship holder FIPE-UFMS. Rio Grande do Sul, Brazil. E-mail: karolbackes@hotmail.com.

RESUMO

Objetivo: Descrever as estratégias de (re)organização da família ao conviver com um dos membros realizando diálise peritoneal domiciliar.

Métodos: Estudo qualitativo, feito por meio de entrevistas realizadas nas residências de sete famílias que tinham um familiar em diálise peritoneal, vinculados a uma clínica renal do sul do Brasil, de março a maio de 2012. Os dados foram submetidos à análise temática. **Resultados:** As estratégias adotadas pelas famílias foram: conciliar os horários do tratamento com a realização de outras atividades; adquirir conhecimento e desenvolver habilidades para realizar a diálise peritoneal domiciliar; adequar o ambiente físico do domicílio; e adaptar o cotidiano da família diante da doença e do tratamento do familiar. **Conclusão:** A (re)organização familiar ocorreu para viabilizar o tratamento e a continuação de atividades cotidianas. O enfermeiro, ao conhecer a individualidade das famílias, pode auxiliá-las no enfrentamento e atender as expectativas de cada uma com sensibilidade.

Descritores: Relações Familiares, Diálise Peritoneal, Enfermagem, Doença Crônica, Assistência Domiciliar.

RESUMEN

Objetivo: Describir las estrategias de (re)organización de la familia al convivir con un familiar realizando diálisis peritoneal en domicilio.

Métodos: Estudio cualitativo, entrevista en las residencias de siete familias de pacientes vinculados a una clínica renal del Sur de Brasil, de marzo a mayo de 2012. Los datos fueron sometidos a análisis temático.

Resultados: Las estrategias adoptadas por las familias fueron: coincidir los horarios de tratamiento con la realización de las demás actividades; obtener conocimiento y desarrollar habilidades para realizar la diálisis peritoneal en su domicilio; adecuar el ambiente físico del domicilio; adaptar el cotidiano de la familia frente la enfermedad y el tratamiento del familiar. **Conclusión:** La (re)organización familiar ocurrió para lograr el tratamiento y la continuidad de las actividades cotidianas. El enfermero, al conocer la especificidad de las familias, puede auxiliarlas en el afrontamiento, con sensibilidad intentar atender expectativas de cada una.

Descriptor: Relaciones familiares, Diálisis Peritoneal, Enfermería, Enfermedad Crónica, Atención Domiciliar de Salud.

INTRODUCTION

The family can be understood as a complex system, in which each element is in reciprocal interaction, and each member is an individual part that composes the whole.¹ Regardless of the context or type of family constitution, the family is formed by each of its members or components, as a social group constituted by a set of people.² In order for this set to work in a stable way, the family must be in constant movement and adaptation, and any change, in only one part, may cause the family imbalance.¹

The illness of one family member is an imbalance factor that can cause changes in the family structure. In this situation, every family system must reorganize itself to assimilate the new condition, and learn how to live with it. The tendency is the family to rebalance or stabilize, but in a different way from the original organization before the disease have appeared.¹ At the beginning of the disease, the family fragments itself to face the patient's care, but in the

face of the daily difficulties and needs, the family reorganizes itself in an integrated way, to a lesser or greater degree to care for its relative.³

Some families, after the beginning of the disease, find it difficult to restructure, others reorganize themselves by excluding or including new members, who may be neighbors, and friends.⁴ Under the conditions imposed by a chronic illness, each family produces its way to take care of the sick family member, according to their reality and needs.⁵

The effects of chronic disease affect all family members, with greater or lesser intensity. In this sense, the health team needs to be attentive to the needs of care, emotional and social support to the patients and each of the family members, since the chronic illness can trigger conflicts in family relationships and socioeconomic difficulties.⁶

Families, when facing chronic illness' situations, often adopt external interventions to solve problems related to the disease. Some families prefer that outsiders take care of the patient, because they have difficulty in caring for their sick members at home. While others prefer to solve their problems internally, considering the stressful foreign aid, even if necessary. This type of family can apply more fully its competences and leaderships in the domicile scope. Thus, it is necessary to recognize the families' characteristics, and to attend them according to the need of each one of them.⁷

This scenario includes chronic kidney disease, which in its last stage leads to the need for dialysis therapies to maintain life.⁸ Peritoneal dialysis is one of these therapies, which can be performed at home by the patient or another person. In most of the cases, only one of the family members is responsible for performing dialysis and caring for the sick family member.

In this sense, the knowledge of the strengths, resources and difficulties faced by the families that take care of their family member is an element that can direct and potentialize the proposals for the family's intervention and reorganization. Faced with the understanding of this family scenario, the nurse can help the family solving their problems, and stimulating the support among its members to use their own internal and external forces and resources. Support among family members can avoid overloading the family sickness situation, leading them to see that, even in the face of problems, there are possibilities for mobilizing sufficient forces to overcome them.¹

When working with patients who perform peritoneal dialysis at home, the need for the family's presence is verified empirically, either to provide direct care or to support the diverse needs of the sick person and his/her family. It is also observed that the families, in general, have difficulties to organize themselves in function of the complexity that involves the treatment, and the questions inherent to their daily life.

Regarding this situation, coupled with gaps in scientific production regarding the families' perspective that have one of their members in peritoneal dialysis, it is considered

relevant to investigate the way these families organize themselves. In addition, it is expected, with the present study, to stimulate reflections and to provide subsidies that can contribute to raise awareness among health professionals who work with families living with peritoneal dialysis at home. Thus, the guiding question of the study is: what are the (re)organization strategies used by families to live with one of their members in peritoneal dialysis at home? The purpose of this study is to describe the strategies of (re)organization of the family when living with one of its members performing peritoneal dialysis at home.

METHODS

It is a field research with qualitative, descriptive and exploratory methodological design. Studies of this nature allow us to deepen questions regarding each family, in order to better understand how they are organized when having one of their members performing peritoneal dialysis at home. Seven families participated in this research, with a total of fifteen subjects. In all families, one family member (in six families) or two (in a family) participated in addition to the family member. Regarding the family bond with the patients, four were spouses, two were daughters, one mother and one son-in-law.

The collection of the families was done by consulting the medical records of patients who were on domiciliary dialysis peritoneal, linked to a renal clinic located in the interior of the state of Rio Grande do Sul, Brazil. It is a private institution, agreed to the Unified Health System (SUS), which provides services to renal patients who require renal replacement therapy. At the time of data collection, the service attended about 340 patients in renal replacement therapy (hemodialysis and peritoneal dialysis), of these 40, were on peritoneal dialysis program.

The criteria for inclusion of the families were: families with one of their members performing peritoneal dialysis at home (regardless of modality), patients on peritoneal dialysis over eighteen, and having at least two people present at the time of the interview, being one of them, the patient him/herself. Exclusion criteria were: patients on peritoneal dialysis who did not live in the municipality of the research and had some difficulty in communication or understanding. Of the 40 patients on peritoneal dialysis at home linked to the service, 20 met the inclusion/exclusion criteria.

By means of a telephone call from the nurse responsible for the peritoneal dialysis service, the patients/families were informed about the research and the consent was requested to provide the telephone data to which the researcher could contact later and invite them to participate in the study. There was no refusal among the families to provide telephone contact, to receive the information and invitation to participate in the study, which, in advance, allowed the identification of the probable availability and interest of the

people contacted in participating in the study. The criterion of selection of families for contact occurred randomly.

Data collection took place in the households, at dates and times pre-scheduled by means of telephone contact made by the researcher. As an instrument for data production, an interview was developed based on the construction of the genogram of the families. In the interviews, the questions were related to the way which the family organized in the presence of peritoneal dialysis at home.

The genogram represents the internal structure of the family, providing important data about the relationships among its members.¹ In this research, the genogram contributed to know the structure, life cycle and family relationships, and as a form of interaction between the participants and the researcher to conduct the interviews. In relation to the family organization, circular questions were asked in order to provide all members present during the interviews participation. Circular questions are based on the answers or information to the initial questions, constituting a cycle.¹

The data collection period was from March to May 2012, in a single visit to each family's home. The interviews were recorded in audio, transcribed in full in text editor and closed when the objective of the study was answered.

The data of the interviews were submitted to the thematic analysis procedure, a modality of content analysis. This analysis identifies the nuclei of meaning that constitute a communication whose presence or frequency means something to the intended analytical objective. The technique unfolds in three stages: pre-analysis, material exploration and treatment of the obtained results, and interpretation.⁹

Thus, in the pre-analysis, a systematic and thorough reading of the interviews was carried out, which was organized to establish the corpus of the study. For the material exploration stage from the raw data, similar and significant data were collected in the different fragments, classifying them for the themes' constitution. In the last step, the senses were searched in the speeches of the interviewees, to analyze and associate it with the theoretical referential.⁹

In all of the research stages, the requirements of Resolution n° 196/96 regarding ethics in research with human beings were met, focusing on the confidentiality of the information obtained and respect for the participants. Thus, the families were clarified about the purpose of the study, consent to record the interviews and signing the Term of Free and Informed Consent of all participants in two ways. The research was approved by the Ethics Committee in Research of the institution, under the Certificate of Presentation for Ethical Appreciation number 01158012.0.0000.5346. To preserve the identity of the research participants, the subjects were coded: "F" with the interview number followed, followed by the letters "D" of diseased, "C" of consort, "F" of children (in portuguese), "M" of mother and "G" of son-in-law (in portuguese).

RESULTS

Among the 15 participants, there was a predominance of females (ten participants), aged between 31 and 79 years old, and education level from complete primary education to higher education. Regarding the peritoneal dialysis modality, six patients underwent Automated Peritoneal Dialysis (APD) and one patient underwent Continuous Ambulatory Peritoneal Dialysis (CAPD). The period patients undergoing peritoneal dialysis treatment ranged from three months to six years.

From the analysis of the data, it was identified that the strategies adopted by the families that live with one of their members in peritoneal dialysis at home are based on: conciliating the schedules of the treatment with the accomplishment of other activities; acquiring knowledge and develop skills to perform peritoneal dialysis at home; adjusting the physical environment of the home; and adapting the daily life of the family in the face of illness and the treatment of the family member.

The strategy to reconcile treatment schedules with other activities was adopted by the families participating in the study, who try to adapt the treatment to daily, professional and social activities, and to coexist with other family members. The adjustment in the activities of the social life of the family is limited to the rigidity of the schedules of accomplishment of the treatment. Therapy often requires the cooperation of colleagues, family, and friends.

“When we go to the movies or go out to dinner, we try to go back earlier. On the other hand, if we want to stay longer, we can combine with someone to stay here [...] my cousin, she is practically family. She comes, she does not care, she sleeps here if it is necessary, there is always someone here [...] this was the main change that we had. I did not have this concern before.” (F2 F)

“We leave, but we’ll be back earlier to turn it on (dialysis) if it’s not too late and he’s late for work the other day. For example, the other day we went out at night and arrived at nine, and at nine-thirty I was already turning it on. Another thing, to receive friends here at home, we invite and say: nine or ten hours is the limit. It’s only allowed with time.” (F3 C)

“I went to the spiritist center at night, but then when I had this problem, I went through the day, so now I go in the afternoon.” (F2 D)

Regarding the need to reconcile professional activities and peritoneal dialysis treatment, the participants demonstrated that they make constant adjustments to ensure the follow-up of professional life and to enable treatment, especially when related to the control of schedules.

“At the time I get home I go straight to the machine. The other day I was late in the service because I started dialysis very late at night. So I’m always running, running home to do the dialysis and running to the service to not be late”. (F3 D)

On the other hand, due to the impossibility of reconciling the treatment with previous work activities, the participants’ option was to dedicate themselves to the care of the sick family member, in face of the treatment requirements.

“I had time to retire, but I kept working, but then I stopped when she needed to start dialysis. I worked in two services.” (F6 M)

In relation to the coexistence with other members of the family, the desire and the pleasure of being together with other relatives, was an aspect pointed out by the participants. This is demonstrated by the arrangements and efforts made in the search for (re)adequacy in the accomplishment of the treatment according to the reality and possibility of each family.

“To get out [...] we go only to her parents’ house (sick), from here it’s about 50 Km. I distribute the bags in the car, get settled for two or three days, and we stay out these days, because it is a lot of material.” (F1 C)

Another strategy adopted by the families was to acquire knowledge, and to develop skills to perform peritoneal dialysis at home, pointed out by the participants as necessary to initiate and follow the treatment. Emphasis is given to the efforts of families to understand the meanings of chronic kidney disease associated with learning in relation to treatment.

The search for knowledge about chronic kidney disease has proved to be a challenge for families that face the need to perform dialysis treatment in their family member at home. Finding alternatives to understand and adapt themselves as best as possible to a new reality represented a demand for families.

“From peritoneal dialysis we did not know [...] the doctor said that she had chronic renal failure, and that she needed dialysis, it was a surprise that we went searching on the internet, we did not know.” (F2 F)

“When he had to put the catheter in, we stayed in the hospital for eight days, and then the doctor would say, you just go away the day you learn to move the machine, so that pressured me a lot, I learned, but not for sure. I came home, read everything on the polygraph.” (F3 C)

Another aspect mentioned was the need to learn the techniques for conducting the peritoneal dialysis treatment. Participants pointed out the initial difficulties in handling the dialysis equipment, and it is necessary to acquire skills that were developed and assimilated during the course of home treatment.

“With that thread locked, she screamed [machine]. So look! There were many things until we got to know the machine well [...] there are a lot of tricks that we get later. Things happen and we learn.” (F2D)

“I still fight with the machine, but now I already know how to deal with it. At first, I cried day and night. Now it’s better [cried].” (F3C)

“The most difficult thing was [to learn] the order of things in the machine. So I went looking in the manual, accompanying in the manual, now I do it automatically.” (F7 D)

Even in the presence of possible problems and interurrences related to chronic kidney disease and peritoneal dialysis treatment at home, participants reported using some personal skills acquired with knowledge and experience.

“She already has medication, when she is in pain she takes paracetamol, and when the machine has a problem, we take it to the clinic.” (F1 D)

“If something happens, she has to disconnect from time to time, she already knows how to do it, she knows how to stop the machine, she puts the lid on, she knows how to do it.” (F2 F)

Adapting the physical environment of the home was also identified as one of the reorganization strategies used by the participants, considered as essential for performing peritoneal dialysis with safety and comfort, taking into account the hygiene and the necessary care to perform the technique, according to the possibilities for each family.

“You’re going to see her in her room. It has a pedal sink, so you do not put your hand on the tap when it sanitizes your hand, it has paper picked up and soap. Her room was in a hospital environment, so she would not get bacteria or anything. Everyone got involved to clean the room.” (F2 F)

“I made an extension of the telephone to the dialysis room. Then when I’m on dialysis and I’m alone, the

phone rings, if my hands are free, I pick it up, I get it and I solve it.” (F5 D)

Another strategy includes the possibility of adapting the family’s daily life in the face of illness and the treatment of the family member, in the situation of illness and all the implications of the peritoneal dialysis treatment. This refers to the cooperation among the members as a fundamental aspect to the maintenance of care for the sick family member. Regarding the need to adapt to the new situation, some participants pointed out that faced with a lack of choice or alternative, they adopt the idea that treatment becomes part of daily life as something that needs to be accepted and incorporated into their lives.

“For me it’s normal, I’ll pretend I am not connected to the machine. I get up in the morning and I think that I am going to live my life, so I leave all my stuff and I say: that is enough. Now only at night. If all people were like this, living a normal life would be better.” (F2D)

“There’s no way. We’ve already adjusted, because it’s been six years on dialysis. But we think it’s something that has moved us.” (F5D)

“This becomes routine, after a while. So it’s something that is a task, that we have to do every day, it’s automatic. We can organize ourselves.” (F4 F)

Cooperation among family members was pointed out as one of the factors that minimize the implications of the disease and treatment requirements. In this sense, the participants reported that there is the collaboration of the family members in the follow-up of the patient in the consultations, the peritoneal dialysis technique or even financial support for the acquisition of medications, when necessary.

“She [daughter] is always together, helping, she goes to the doctor, since she was little, of course, the first few times we went with her mother, because she was weak.” (F2 F)

“He [husband] helps me, he cleans the table, sterilizes the bag, the clips, the cap, and hangs the bag, and I wash myself, I pick it up and do it. So, we do everything like this, helping each other.” (F5 D)

“They [nephews] help when we need a medicine. They always call and ask what do we need, and then they send some money or what we need, they are very attached to us.” (F6 M)

Regarding collaboration among family members, participants expressed that family involvement enables responsibilities to be divided and planning for their activities. Thus, strengthening the union and the family's commitment to the disease and the need for home treatment has a positive effect regarding the conduct of this process, including in leisure activities.

"Everyone gets involved. When we went to the beach for a week, my sister stayed here with her mother one night. That's because my cousin had also traveled to enjoy the carnival holiday." (F2 F)

"My sisters live here in the front of us, they help us when we need it, they are always around, they give us help." (F6 M)

DISCUSSION

The family reorganization in the sense of reconciling the schedules of the peritoneal dialysis treatment at home with other activities was one of the strategies used by the participants. With the adoption of such strategies, it was identified that families adjust themselves to provide the patient with safety and viability in the treatment.

Families make arrangements between members to follow-up the care given to the family member as well as the peritoneal dialysis treatment. However, the rigid schedules and the family involvement that this treatment requires, can make the adjustment of the family's social life more difficult. The study points out that the peritoneal dialysis by the patient and his/her relatives gives them different implications with losses and changes in their lives,¹⁰ because the routine often revolves around the disease and the exhaustive treatment, which can lead to social isolation.¹⁰⁻¹¹

Each family has its challenges to face in the presence of chronic illness in the family environment, often need to be willing to share responsibilities in order to maintain relationships with each other.⁶ When the family is participative, the difficulties to perform peritoneal dialysis at home are minimized, the patient feels safer, more confident, and more stable emotionally. The participation of other people in the care of the patient in the home environment, such as family members, friends, among others, makes caring easier, and may reduce the burden of the person responsible for the patient.¹² In this study, the collaboration occurred among the members themselves.

It could be verified that families adjust their schedules and modify their work routine in order to reconcile the accomplishment of the treatment and the professional life. On the other hand, there are situations in which this is not possible, requiring the interruption of professional activities to take care of the sick family member. These aspects may reflect negatively on the family, both for the possible impairment of

family income, and for the emotional repercussions on the family member who needs to leave work.

A study done about the experience of patients in peritoneal dialysis at home indicates that work is abandoned due to the forced changes in peritoneal dialysis patients' lives, since much of the time is absorbed by the treatment. Regarding this, people's lives become radically qualitative and quantitative, failing to do many things that they valued and enjoyed before becoming ill.¹⁰ The fact that he/she can not work outside home worries the sick person very much, especially those who have always been directly responsible for supporting their families.¹²

In this study, it was shown that families use strategies that helps to maintain ties to minimize the changes caused by the needs of peritoneal dialysis at home, which does not always prevent some patients from considering their selves as a "weight" for the family. In this sense, actions that favor, empower and encourage families to identify and use their own available resources, with the support of other members, can be relevant initiatives in order to solve their problems or issues in their lives in an effective way.¹

Another strategy mentioned by the participants was to acquire knowledge and skills development to perform the treatment at home. Participating families sought to provide knowledge and information beyond those provided by health professionals. This points out to the importance of health professionals providing information grounded in the reality of families that face a family member's illness. In these interventions it is necessary to consider the singularity of each family, for this it is necessary to adapt the interventions and the domains according to reality and necessity, in the attempt to solve the problems of each one of the families. Given this, nurses can interfere with a focus on cognitive, affective and behavioral domains.¹

The difficulties encountered in the initial process to learn the technique and handle the machine mentioned by the participants of this study were also highlighted in another research, in which patients describe peritoneal dialysis as "awful" at the first moments, due to the changes that occur in their daily life and also by the need to learn the technique which is permeated by fear in the face of the complexity and constraints of the method.¹¹ The level of information that is passed on to the technique, access to referral health services and the relationship between patient, family and professionals seem to play an important role in the proper accomplishment and success of peritoneal dialysis. Study suggests that nurses perform theoretical and practical evaluations through a home visit, to provide information based on the real situation that the family is at home.¹³

The circumstances that occur in the families' daily lives facing one of their members' illness require skills to overcome the difficulties they find. In these situations, the family uses their knowledge based on their experiences, and worldview, together develop the necessary care to maintain their physical and emotional integrity. The experiences acquired by family

members in the care of their members translate into the ability of families to react positively, to be resilient in the face of the critical situations, promoting their adaptation in a productive way to the well-being of their members.¹⁴

When something unexpected happens related to peritoneal dialysis, it was observed in this study that the families solve their problems by the knowledge acquired in living with the treatment, they use internal or external resources of the family. The ability of the family to solve their problems effectively may be due to the conviction that it has in solving it and by previous experiences or successes.¹

It is considered fundamental that the family can effectively count on the technical support of professionals sensitive to their needs, with scientific knowledge about the area of nephrology and skills in interpersonal relationship, to take care not only of the chronic kidney patients in peritoneal dialysis, but of their families as well. In addition, it is imperative to know and understand their reference system, regarding the family as a whole, without annulling the individuality of each of its members and so little dissociating them from the time and context where they are inserted.¹⁴

Adequacy and changes in the physical home environment, in general, are necessary requirements for performing peritoneal dialysis at home, making it feasible with prospects of greater dialysis effectiveness. The adequate and sanitized environment is one of the aspects to be observed and essential in the execution of peritoneal dialysis technique. In this study, the modification of the environment was performed in the sense of providing safety and comfort to the patient.

For the participants of this study, dialysis is necessary, and becomes over time an integral activity of their routine. The families' daily life, faced with the need for one of the family members to perform dialysis at home, undergoes changes, in which they need to be readjusted and deal with the best possible way. However, it is observed that this routine is seen differently among families. Some of them can adapt and live well with dialysis, while others have no choices. In this sense, a study corroborates, over time, the families adapt to living with the disease and the treatment, but the care based on dedication, commitment and affectivity, is in charge of each family.¹⁵

Families take care of their sick family member of their own free will or obligation, in situations where there is no other person who is responsible for such care. Thus, the non-involvement of some family members, care can be provided either by a voluntary or taxing act. In the process of care provided by relatives, they may sometimes experience feelings of suffering and anguish, when they see their patient in situations inherent to chronic kidney disease and treatment with peritoneal dialysis.¹⁴

The way families shape or adapt themselves to the illness is related to their beliefs and behavior, and these in turn are strongly intertwined with the family context. Regarding this, the intensity that the disease affects each family member is

related to the type of involvement that he/she has with the sick family member, what role this family member will take with the patient, what changes after illness, and also the life cycle of the sick family member, and family development.¹

In this study, it was reported that there was participation of several forms among its members in the peritoneal dialysis at home, providing the family reorganization. Families form ties, and there is a strengthening of the union between the members, in order to follow up the care given to the sick family member. A study shows that the family tries to make adjustments when faces one of its members with a chronic illness. Adaptations and changes of roles are restructured due to the continuity of treatment.⁶ In the context of the care, supporting networks become necessary for the distribution of tasks, these are made feasible and accessed when the caregiver is heard.¹⁶

The alliance and the union between the family members are factors that can facilitate the reorganization and the conviviality in the occurrence of new facts in the family, as for example the disease. For this, it is important that nurses might evaluate the flexibility of the family and how the members adjust themselves to the new situations that occur in the family system.¹ In this study, it could be verified that the members cooperation makes the family organization possible in relation to the leisure activity, promoting an approximation between them.

Peritoneal dialysis at home can be an unfeasible therapy when there is no family support. In Brazil, due to the social and cultural characteristics, patients on peritoneal dialysis are generally cared by their families.¹⁷ A study about the quality of life of the caregiver of patients with renal insufficiency, shows that the social well-being of the caregivers is affected, mainly in the physical and psychological questions. To that end, they suggest interventions aimed at improving the quality of life of caregivers and caregivers.¹⁸

Patients feel more secure, confident, and emotionally stable to perform self-care at home when the family is involved in treatment. When the opposite occurs, regardless of the reason for the lack of cooperation, they feel alone, discouraged and helpless.¹² As families overcome the impact of the diagnosis of chronic kidney disease and the peritoneal dialysis treatment of their relative, they seek the necessary resources to readapt the new life condition.¹⁴

In this sense, the nurse can be a communication link between family members or between families, and other health professionals.¹ Nursing needs to focus its actions on the experiences of family members, aiming the well-being of the patient and his/her family. The overcoming of a new reality is built upon a network of relationships and experiences lived throughout the life cycle, stimulating the family to react, in a positive way, to the situations that might cause mismatches, leading it to overcome difficulties and to promote their adaptation productively to their own well-being.¹⁴ It is the duty of the health professional, attention to the family, that contemplates the biological, psychological

and social dimensions, since the chronic illness in the family brings changes in the family relationship.¹⁵

The family support to renal patients is a positive factor to the good prognosis in the therapeutics. The actions of nurses in relation to the process of caring and care extended to the family nucleus should be considered in their professional practice, and it is necessary to constantly seek new technical, educational and organizational strategies with a view to promoting integral, safe and efficient care.¹⁹ It is understood as a fundamental strategy for the reorganization of the family that lives with a family member in peritoneal dialysis at home, support between family members and the health team.

CONCLUSION

It could be verified in this study that the families that live with one of their members in peritoneal dialysis at home need to adapt and organize themselves in the face of the family's illness situation, thus developing strategies that can enable care and assistance to the family member according to their possibilities.

In this way, the search for reconciling the rigidity of treatment schedules and the accomplishment of daily activities, professional, social, and living with other family members was a strategy pointed out by the families. In this perspective, some families may rely on other people collaboration to follow up on these activities or seek constant adjustments between the performance of the activities and the treatment, while others, given the impossibility of reconciling work activities especially, devote themselves to family care.

Acquiring knowledge and developing skills to perform peritoneal dialysis, in addition to the need for home adjustments, proved to be a challenge and a requirement for families in view of the need to perform dialysis treatment in their family member at home. This can be observed in this study, when the efforts employed by these patients, from the need to understand the disease, to the learning of peritoneal dialysis techniques.

It can be inferred that the daily life of the families is altered by peritoneal dialysis at home, since there is a need to devote much of the time to the treatment and the issues that involve it. In this sense, it was verified that, faced with the need to adapt to the new situation, some participants, faced with a lack of choice or alternative, adopt the idea that treatment becomes part of daily life as something that needs to be accepted and incorporated into their lives.

However, it was perceived in this study that the collaboration and involvement among the family members in relation to the disease and the peritoneal dialysis treatment at home, seems to allow the responsibilities to be divided and some planning exists, allowing to infer that the strengthening of the union and the commitment of the family to the disease and the need for treatment, has a positive impact on the conduct of this process.

However, it is perceived that the strategies adopted are mostly individual and require the personal dedication of the family member more directly involved in care. However, cooperation among family members is an important factor that can minimize the disease implications and the treatment requirements as pointed out by the participants of this study. In this sense, it is necessary for families to be understood and respected, since they, each one with its characteristics, can organize themselves so that the treatment can occur safely, guaranteeing the well-being of their sick family member, and live in harmony with the other members.

As limiting factors of this study, although it is not a new question, the thematic of the families that live with the family member in peritoneal dialysis in the home is still little discussed. Thus, it is believed that the development of this research can bring reflection to the professionals, to understand the needs of the patient and his/her family, and also to assist them in their difficulties and to sensibly perceive the presence of a human being who wishes to be understood in their expectations.

It is understood that these results should not be taken as absolutes, but rather open up possibilities for new paths that deserve to be investigated. It is recommended to expand the discussions presented here, in an attempt to promote their understanding and the searches for alternatives to face this reality.

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Author responsible for correspondence:

Arlete Maria Brentano Timm

Rua Felipe dos Santos, nº 385

Bairro Duque de Caxias

Santa Maria/RS, Brazil

ZIP-code: 97070-340

E-mail: ambtimm@yahoo.com.br