



Conditional freedom: repercussions in the family living with a member on peritoneal dialysis

Liberdade condicionada: repercussões na família ao conviver com um membro em diálise peritoneal

Libertad condicional: repercusiones en la familia a vivir con un miembro en diálisis peritoneal

Arlete Maria Brentano Timm¹, Margrid Beuter², Nara Marilene Oliveira Girardon-Perlini², Macilene Regina Pauletto¹, Naiana Oliveira dos Santos³, Jamile Lais Bruinsma²

Objective: to describe the repercussions in the family living with a member on peritoneal dialysis at home. **Methods:** qualitative research conducted in a clinic for kidney dysfunctions in southern Brazil. Interviews were conducted with seven families. The data were submitted to thematic analysis. **Results:** two themes emerged: demands arising from dialysis: a prison in families' lives; and restrictions and family adjustments to treatment: the conditional freedom. It was found that the families coping with peritoneal dialysis at home lose their freedom, this being subject to treatment needs. **Conclusion:** living with a family member on peritoneal dialysis causes repercussions in various spheres in the families' routine. The nurse can help in these situations, by identifying problems and proposing alternative to meet the specific needs of each family.

Descriptors: Family Relations; Peritoneal Dialysis; Nursing.

Objetivo: descrever as repercussões na família em ter um membro em diálise peritoneal no domicílio. **Métodos:** pesquisa qualitativa realizada em uma clínica renal no sul do Brasil. Realizou-se entrevistas com sete famílias. Os dados foram submetidos à análise temática. **Resultados:** emergiram dois temas: exigências decorrentes da diálise: uma prisão na vida das famílias; e restrições e ajustes da família ao tratamento: a liberdade condicionada. Verificou-se que a família que convive com a diálise peritoneal no domicílio perde sua liberdade, ficando esta condicionada as necessidades do tratamento. **Conclusão:** conviver com um familiar em diálise peritoneal ocasiona repercussões em diversas esferas na rotina das famílias. O enfermeiro pode auxiliar nestas situações, ajudando a identificar problemas e propondo alternativas para atender as necessidades específicas de cada família.

Descritores: Relações Familiares; Diálise Peritoneal; Enfermagem.

Objetivo: describir las repercusiones en la familia en tener un miembro en diálisis peritoneal en casa. **Métodos:** investigación cualitativa, realizada en una clínica renal en el sur del Brasil. Se realizaron entrevistas con siete familias. Datos sometidos a análisis temático. **Resultados:** dos temas surgieron: requisitos derivados de diálisis: una prisión en la vida familiar; limitaciones, restricciones y ajustes de la familia al tratamiento: la libertad condicional. La familia que vivía con diálisis peritoneal en casa pierde la libertad, pues enfrentan varias privaciones frente al tratamiento. **Conclusión:** convivir con un pariente en diálisis peritoneal provoca repercusiones en diferentes ámbitos de la rutina de las familias. El enfermero puede auxiliar en estas situaciones, ayudando a identificar problemas y proponer alternativas para satisfacer necesidades específicas de cada familia.

Descriptores: Relaciones Familiares; Diálisis Peritoneal; Enfermería.

¹Hospital Universitário de Santa Maria. Santa Maria, RS, Brazil.

²Universidade Federal de Santa Maria. Santa Maria, RS, Brazil.

³Universidade Federal do Rio Grande do Sul. Porto Alegre, RS, Brazil.

Corresponding author: Arlete Maria Brentano Timm
Rua Felipe dos Santos – 385, Duque de Caxias. 97070-340 – Santa Maria, RS, Brazil. E-mail: ambtimm@yahoo.com.br

Introduction

In the scenario of socioeconomic transformations that have occurred over time, changes in the lifestyle of people cause also changes in the patterns of health and illness of population. Added to this, non-communicable chronic diseases have been emerging as a worldwide epidemic⁽¹⁾.

Chronic disease usually causes concern and changes in the family daily routine, changing the balance and the roles of family members. The person, when sick, must be understood as a family segment⁽²⁾. Therefore, the family needs to restructure so they can cope the best possible way with the disease and its implications.

After a family member is diagnosed with a chronic disease, it is important to know the stage of the family life cycle and the individual stage of development of all its members, not just the patient. This is because the illness of a family member can profoundly affect the life goals of other family members. The impact of chronic disease will depend on the type of pathology and the role each member played before illness⁽³⁾.

In this context, the chronic kidney disease often can progress to the need for renal replacement therapy. One of the therapies used is peritoneal dialysis, which is a treatment regimen of challenging compliance, that requires discipline and lifestyle changes involving the whole family.

The continuous ambulatory peritoneal dialysis is performed manually, on average four times a day. In automated peritoneal dialysis a cyclor machine is used for infusions and drainage of the dialysis solution in the peritoneum, lasting eight to twelve hours, usually during the night, while the patient sleeps. The therapy, that is manual or automated, can be performed at home by the patient him/herself or by another person, usually a family member⁽⁴⁾.

Peritoneal dialysis, despite the difficulties, is still a therapy that favors the return and the maintenance of patients with end-stage renal disease

in the labor market, due to greater autonomy for self-care, realization of treatment at home, with return to the clinic once a month or when complications arise⁽⁵⁾.

In experiencing a chronic disease, in general, the family is an important link for support and maintenance of the treatment to the sick family member, since chronic illness brings changes in lifestyle, reflecting on the whole family⁽⁶⁾. Understanding the needs of the family in the everyday care of the chronic patient can help professionals to offer support so that the family can deal with the repercussions arising from the disease, treatment, conflicts and dissatisfactions that can undermine family relationships⁽⁷⁾.

Nursing cannot ignore the problems experienced by families who have a family member in peritoneal dialysis. Many difficult situations faced by the family may be consequence of a nursing care that little meets their real needs, since the focus still remains mainly on the sick patient and on the technical aspects for carrying out peritoneal dialysis.

Despite the studies focusing on the family and their relationship with the context of peritoneal dialysis at home, it is understood that to comprehend how families cope with one of their members performing peritoneal dialysis, it is necessary to organize and investigate on this topic and then propose strategies to enhance the care provided and to achieve a better performance of nursing in this reality.

This statement results from the authors' professional experience with people who perform peritoneal dialysis at home, which allows observing, empirically, that family involvement is essential to enable the realization of this dialysis method. However, it turns out that families have difficulties to care for their members, both regarding the procedure and regarding the social, financial and emotional involvement.

Given the above, considering the importance to expand knowledge about families living with a family member that performs peritoneal dialysis at home, this study aimed at describing the repercussions for the family of having a member on peritoneal dialysis at home.

Method

It is a qualitative descriptive study, developed with patients on peritoneal dialysis and their families. Data were collected through interviews in the families' homes from March to May 2012.

The inclusion criteria of participants were: families with one member performing peritoneal dialysis at home (regardless of modality); peritoneal dialysis patients and family members over eighteen years old; families with at least two people present for the interview, being one of them the patient. Exclusion criteria were: families residing outside the municipality where the clinic for kidney diseases is located, due to the difficulty of access for researchers, and presenting speech impediment.

Families were found by consulting the medical records of patients linked to a renal clinic located in a city of Rio Grande do Sul State, Brazil. This is a private institution that offers treatment of hemodialysis and peritoneal dialysis and has agreement with the Unified Health System and other agreements. The clinic was chosen because it is a reference on dialysis in the region.

In the data collection period, 40 patients were on peritoneal dialysis, and 20 met the inclusion criteria. Randomly, the nurse firstly contacted the patients to inform them and their families about the research and the possibility of their participation. Later, one of the researchers conducted a new contact formalizing the invitation and giving information about the study. Upon acceptance, home visits were scheduled for data collection, according to availability.

Seven families were interviewed: in six families, two members participated and in the other family, there were three participants. Thus, the study had a total of 15 participants. The patient was present in all interviews, which were closed when it was possible to identify the impact on families of having a member on peritoneal dialysis at home.

Interviews were guided by the thematic axis:

the family living with peritoneal dialysis at home, and were audio-recorded and transcribed in a text editor. As a strategy to encourage interaction between people present in the interviews, circular questions were held, based on the answers given to the initial questions, covering a round of questions and answers⁽⁸⁾.

Data from the interviews were subjected to thematic analysis, which consists of pre-analysis, material exploration, treatment and interpretation of results⁽⁹⁾. In the first stage, the interviews were read thoroughly and organized to obtain the study data. Following, similar and significant information were gathered, from which the following themes emerged: demands arising from dialysis: a prison in the families' lives and restrictions and family adjustments to treatment: the conditional freedom. In the last step, authors sought to interpret meanings contained in the interviews, to analyze and discuss with the theoretical framework⁽⁹⁾.

This study met the requirements relating to ethics in research involving human. All participants signed an Informed Consent Form. The research was approved by the Ethics Research Committee of the institution under protocol No. 8937/12. To preserve participants' identity, the following codes were used: "F" for family, followed by the interview number, and the letters "P" for patient, "S" for spouse, "C" for child, "M" for mother and "L" for son-in-law to identify the family member.

Results

The age of respondents ranged from 31 to 79 years old, and ten were females and five, males. As for the type of peritoneal dialysis, six patients performed automated peritoneal dialysis and one performed continuous ambulatory peritoneal dialysis. The time of performance of peritoneal dialysis at home ranged from three months to six years.

The main repercussions in the family having one member on peritoneal dialysis at home are presented

in two themes: demands arising from dialysis: a prison in the families' lives and family restrictions and adjustments to treatment: the conditioned freedom.

Demands arising from dialysis: a prison in families' lives

Families relate changes in their lives in face of the hours scheduled to perform peritoneal dialysis and time-consuming due to the treatment. These issues resonate negatively in the family system because they limit the planning and carrying out other activities in addition to dialysis.

It can be seen by this that the family system is conditioned to a new routine due to the situation of having a family performing peritoneal dialysis at home. Thus, family members have their freedom impaired. Carrying out activities of personal interest is often conditioned on the dialysis treatment, which maintains life imprisoned. *Everything has time, there is dialysis time, you cannot say, I'll do this or that, because there is the dialysis (F1 S). There is a time, especially in summer, when it is hotter, that we have the habit to stay longer out there, so she has to go to the machine (F2 C). We lose a lot of time with it (dialysis) (F3 S). It was not like this, now everything depends on the dialysis. She (patient) does not find it easy, she wakes up around five in the morning, so she gets a bit upset (F5 S).*

The changes that occur as a result of performing peritoneal dialysis in a family, as mentioned by the participants, are configured as a "prison" in the families' lives. The term "prison" is related to changes in everyday life, when they fail to leave the house or go out only due to the treatment, which causes them to live in conditional freedom. *A prison! I have an opinion on this dialysis and he has another, which is not the same. For him, it is good. For me, it is not! (F3 S). I'm imprisoned! I'm even thinking that I'm stressed. Because I do not go out anymore, except to go to the bank to receive money, to go to the hospital to visit the doctor, to take blood tests, nothing more! (F5 P). Our life has changed a lot, we became a little imprisoned. Now that I'm retired I could go out, but I can't because of dialysis (F7 P).*

The idea that dialysis is a kind of prison is also

related with the time that patients are connected to the machine, which limits interaction with family members and impairs connection with other relatives and friends. In addition, it causes losses in meeting the physiological needs of the patient. *Getting stuck for ten hours inside her room, it is not easy! (F2 C). Sometimes I feel like evacuating, because I'm stuck to the machine from midnight until ten o'clock in the morning, so I keep controlling myself, so it's a prison. Yesterday I was off so we went out, but at nine o'clock we were already at home to be early on the machine, not to delay the service today, so it is a prison (F3 P).*

Participants also reported that dialysis is a prison, when comparing the automated peritoneal dialysis with continuous ambulatory peritoneal dialysis, preferring automated peritoneal dialysis. Even though they need be connected to the machine for a long time, they consider that this method also provides greater freedom. *Performing it on the machine is better, but the only thing is that she gets stuck in there (room), because she stays connected to the machine for ten hours, but it's better than the manual dialysis, in which the person needs to do it four times a day, then they get really stuck! (F4 C).*

The need to be close to the sick family member due to peritoneal dialysis or dependence was also cited as a family repercussion, since this type of treatment at home restricts the freedom of the family. Reported changes occur both in the patient's life and in the life of the family member who looks after the sick person, also reaching the other family members. Participants mention the removal from work and domestic activities due to illness and the need for performing peritoneal dialysis at home, which cause guilt in the sick relative. *Because the machine beeps, wakes me up and wakes her up too. So I feel like I'm a weight on her back. Before it, she stayed two or three days in her daughter's house with her grandson, and now she can't go, she has to stay with me (F3 P). He depends on me for everything, even to pee. We have no bathroom in the room. So I have to take the bedpan (F3 S). Since I started to get sick and do dialysis, I stopped doing the things I did for her (wife). And then I broke my hips (fracture), she does everything alone. She carries the bags. She cleans everything alone. There is a patio out there, she cleans it (F7 P).*

It was also reported concern about being close to the sick family member while performing the peritoneal dialysis procedure, due to the possibility of complications. In this sense, families come together and look for alternatives to be present whenever they can. This causes the family to be organized to provide safety and support to the patient and to their own members. *We try not to leave her alone overnight. So when she connects to the machine, at ten o'clock at night, we do not let her alone, because the telephone may ring, somebody may knock at the door, or she may need something, and she connected (F2 C). Sometimes she (patient) has problems, low glucose, then she cannot do the dialysis, so we help her (F5 S).*

Restrictions and family adjustments to treatment: the conditional freedom

The clinical changes as well as the water and food restrictions faced by the patient bring repercussions to the family unit. This is because the physical changes related to pathology and treatment of the patient impact the family system as they affect other members and these need to adjust to assist the sick relative in the face of situations that arise, thus remaining vigilant. *At first I was trembling, I had profound anemia, so I could not do anything, not even dialysis. My daughters, my sister-in-law and my niece used to do my service and dialysis (F2 P). I feel very weak. I'm always tired, but I walk normally. I get tired to climb the stairs. In my service, the locker room is two floors under, so, I get very tired to go up. The machine sometimes gets me exhaust, and then I feel a stomachache and weakness (F3 P). I feel pain in the legs too, because diabetes is tough with me. So I hardly go out. So if he wants to meet his friends, I do not stop him. Because his life goes on. I cannot prevent him from having dinner with friends, but then she stays with me (a sister who lives with them) (F5 P).*

Families show concern about health condition and treatment of the sick family member, relating to stories from others who have experienced situations similar to theirs and that the family member died. So the family seems to live afraid and on alert, fearing that the same will happen with their family member.

Her life is always in danger. When she used to do hemodialysis, I did not know whether I would find her alive after it (sighed). A few of her friends had already died. I had a neighbor here who had undergone dialysis for 30 days and had a heart attack and died! We're always concerned. She knows that as soon as she is well, she is not (F1 S).

Food and water restrictions also affect the family system as the other members follow the guidance provided by health professionals and sympathize with the patient's effort, who seeks to follow a proper dietary intake on a daily basis. *He eats and drinks what his doctor and the nurse there in the clinic say he can. He is very obedient (F3 S). It is upsetting that you cannot eat this, you cannot eat that. One day I got anger with the doctor and the nurse. I said, stop talking! You cannot eat this! You cannot eat that! So tell me what I can! (F3 P). In the beginning, his food had to be almost saltless. So I did the same for everyone. Then I would put the salt and condiment on the table and each tempered as they pleased. There are a lot of foods that have potassium and we do not even know. And he had high potassium levels in the beginning. The doctor cut this, cut that. At first he lost a lot of weight (F7 S).*

Due to the need to adjust to the demands of treatment, the family loses the freedom to decide on social and leisure activities they would like to participate, as they are conditioned upon strict compliance with the dialysis treatment with schedule that often coincides with the desired activities. This reality reflects in family life, and the patient and other family members stop, in most cases, visiting others, sightseeing and attending social events. *The difficulty is in everyday life, not only to travel, it is the everyday, immobility is a difficulty. It's not that we used to go out a lot, but now it's all over. First she had Tuesdays, Thursdays and Saturdays to go to dialysis appointment, it was sacred, we could not do anything at that time. And now it is every night, without fail, it only fails when there is no power, but then we have to do it manually. It's ten hours, every night (F1 S). We have no social life, there isn't. At first we would go to our daughter's house, now we can't anymore. Our daughter complains, but we can't (F3 P). We do not go out at night because I have to do dialysis. At first, we would go to the Traditions Center of our community; we would have dinner there and see our grandson dancing. Now it's not possible (F4 P). At first, we used to go out, we used to go to a bathing place almost every day. But how can*

he do it (dialysis) in there? There's no way to heat the bag and do in the bathroom, how can we? (F7 S).

The family difficulties to travel are also related to the clinical status of the patient and to the inconvenience of the great volume of material that they need to carry to perform the treatment outside the home. This affects the family leisure quality as they stop visiting relatives and stay more limited to their own houses, living a new reality in reclusion. *We used to travel a lot, we used to go to our nephew's house, but not anymore. It's not that we can't go out, but sometimes she is not feeling well. Besides, if I leave I have to take all the medication, and this is difficult. I have to take a lot of boxes. If I take little medication, there's no use in going today and having to come back tomorrow. So it's not worth it. So we stay here (F6 M).*

Families experience new routines in their lives due to the time consumption resulting from the completion of peritoneal dialysis at home and the need to be near the sick family member, with repercussions for the whole family unit. As a result, the impacts arising from the demands of peritoneal dialysis lead families to feel imprisoned and live in conditional freedom.

Discussion

The experiences reported by families living with a family member on peritoneal dialysis at home demonstrate that the treatment brings many changes in their lives. The families need to plan their activities according to the time of treatment and care for the sick relatives. This situation affects the family system and is configured as a "prison" and it can be said that they experience a freedom conditioned to the demands of dialysis therapy.

From this perspective, study on the experience of patients on peritoneal dialysis at home addresses the changes that this therapy imposes on people, highlighting the time devoted to its realization and care for the procedure⁽¹⁰⁾, which can also be seen in the results obtained in this study. Families when

confronted with health problems need to make adjustments that enable the proper functioning of the family system, since the illness of a member, often makes the instrumental activities of daily living increase⁽⁸⁾.

Because of the inflexibility of hours to perform dialysis, the family life becomes limited in several respects and that this requires that its members are or become flexible by working together to find alternatives to cope with this situation, preserving their relationships and keeping the family balance.

In situations where the patient requires dialysis, families come together and focus intensively in the care for the family member to provide both technical and emotional support. These arrangements also happen with families facing other chronic diseases⁽¹¹⁾. They have to adapt to routine changes both in the relationship among the members for a good living and by depriving themselves of some activities to take care of the sick family member.

However, lack of freedom of family due to the realization of dialysis can make the patient and closest relatives feel prisoners in the situation because of the time the patient remains connected to the machine. This perception of imprisonment was also found in another study, in which participants mentioned that peritoneal dialysis ruled their existence and it was not possible to accomplish the same things that were valued and appreciated prior to the disease⁽¹⁰⁾. The restrictions resulting from the disease and treatment compromise the autonomy and freedom of the family as a whole, and cause difficulties in performing daily, leisure and labor activities, which impacts on quality of life⁽⁵⁾.

Automated peritoneal dialysis was the modality that prevailed among the study participants, being considered by families as the method that still offers greater freedom. This, however, does not eliminate the sense of deprivation of freedom in face of the burden of performing the procedure. Research on the quality of life of people in treatment of chronic kidney

diseases shows that the automated peritoneal dialysis at home provides more benefits compared to other methods of renal replacement because it allows the daytime is free for other activities⁽¹²⁾.

The need for dialysis affects family life in a way they start to prioritize the completion of treatment, to the detriment of social, recreational, and some daily tasks⁽¹³⁾, which enhances the sense of deprivation of freedom and consequently, has negative repercussions on the quality of life for the whole family unit.

Results show that the feeling of imprisonment is manifested mainly by family members who take direct care with the completion of dialysis, being closely linked with tiredness and limitations for carrying out other activities. In this regard, the study evidences that the demand for care in chronic disease in general impacts the lives of those who assume the responsibility for the care and may even lead to social isolation⁽¹⁴⁾ and illness⁽¹⁵⁾. This reinforces the need for cooperation and division of activities between family members, avoiding that only one person stay with full responsibility for patient care, minimizing fatigue and repercussions in the relational context of the family.

Faced with the repercussions caused by dialysis in the family, the sick person perceives him/herself as a burden that brings loss and hardship to the family. In this sense, study with patients on peritoneal dialysis found that they recognize their difficulties and aid dependency of family members and of health professionals, as well as the lack of perspective and the wait for an uncertain future⁽¹⁰⁾.

Feelings related to impotence and inability to take care of themselves because the patients frustration and guilt over the loss of freedom and need for help of family members, whether to perform the dialysis or other issues related to the treatment⁽¹⁶⁾. Uncertainties related to the evolution of the disease and the possibility of complications are present in the context lived by the sick person and their family members, which can be reinforced by shared stories

that resulted in the patient's death, leading the family to stay in constant vigilance.

With regard to dietary and water restrictions identified as dialysis repercussions on families of this study, it is stressed that these measures are indicated in the set of therapeutic actions to patients; however, they cause changes in eating habits adopted in the family culture. Compliance with these restrictions may not be an easy task as they require, also from the family, collaborative sense, sensitivity, flexibility and commitment to enable the completion of therapy⁽¹³⁾.

The context surrounding the realization of peritoneal dialysis at home intensely affects the lives of people who are part of the family, and it is a situation that can bring implications for the family system, whether regarding socioeconomic aspects, interpersonal relationships or skills and expertise to care. In this sense, it is necessary to provide emotional, social and technical support so that the family can learn new ways to play its role⁽¹⁴⁾.

For this purpose, awareness of the multidisciplinary health team about the challenges faced by the family that performs peritoneal dialysis at home is important for a qualified service, that must be available and able to provide help at any time, thus providing safety and well-being for the families.

Final Considerations

The family repercussions of having a member performing peritoneal dialysis at home comprise the routine of the unit as a whole. The requirement to conduct daily dialysis and the need to have someone present with the family member during the procedure is presented as a prison in family life.

The family begins to organize their activities from the care they need to pay to the sick person. In meeting the sick person's needs, some changes occur in interpersonal relationships, at work and in leisure of the family, who starts to have less time to relate to

others. The family life is restricted and there is the removal of work activities. Deprivation also occurs due to physical dietary restrictions to which the sick person is subjected. In this context of life, the family feels imprisoned, living in conditional freedom.

Living in conditional freedom relates to the restrictions and limitations to which family members need to observe to perform their personal activities while meeting the sick family member's needs. Thus, given the reality presented for the family, they chose to submit to live in conditional freedom in order to promote well-being and maintenance of the sick relative's life.

In this sense, the effective presence of nurses can help families, by identifying problem situations that require support, proposing alternative solutions, clearing doubts, strengthening capabilities and skills and intervening to meet specific demands of each family. By relieving anxieties, uncertainties and fears of families, as a dimension of care, and of the person undergoing peritoneal dialysis at home, who is limited to an experience of restrictions, renunciations and suffering, the nurse can alleviate the feeling of living imprisoned in conditional freedom.

Collaborations

Timm AMB, Beuter M and Girardon-Perlini NMO contributed to building design, collection, analysis and interpretation of data, drafting and preparation of the manuscript. Pauletto MR, Santos NO and Bruinsma JL contributed to the discussion of the data, preparation and drafting of the manuscript and final version to be published.

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