



## THE PERITONEAL DIALYSIS IN THE EXPERIENCE OF FAMILY CAREGIVERS\*

*A DIÁLISE PERITONEAL NA VIVÊNCIA DE FAMILIARES CUIDADORES*

*LA DIÁLISIS PERITONEAL EN LA VIVENCIA DE FAMILIARES CUIDADORES*

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This study aims to know the experience of family caregivers responsible for the peritoneal dialysis procedure at home. Qualitative search conducted with eight family caregivers of patients who had peritoneal dialysis at home, linked to a clinic in Rio Grande do Sul. The data collection happened through a semi-structured interview between April and May 2009. The data was submitted to thematic analysis from which three categories emerged: conditions that impose the responsibility with peritoneal dialysis; the complexity of care; and the changes in the routine of family caregivers. The responsibility in the peritoneal dialysis procedure modifies meaningfully the life of family caregivers. It is up to the health professionals to seek strategies to work according to the patient's and the caregiver's reality with the purpose of minimizing the impact on these people's lives.

**Descriptors:** Nursing; Chronic Renal Insufficiency; Peritoneal Dialysis; Caregivers.

Este estudo tem como objetivo conhecer a vivência de familiares cuidadores na condição de responsáveis pela realização da diálise peritoneal domiciliar. Pesquisa qualitativa realizada com oito familiares cuidadores de pacientes que estavam em diálise peritoneal domiciliar, vinculados a uma clínica, no interior do Rio Grande do Sul. A coleta dos dados ocorreu por meio de entrevista semiestruturada nos meses de abril e maio 2009. Os dados foram submetidos à análise temática da qual emergiram três categorias: as condições que impõem a responsabilidade com a diálise peritoneal; a complexidade do cuidado; e, as mudanças no cotidiano de familiares cuidadores. A responsabilidade na realização da diálise peritoneal altera significativamente a vida dos familiares cuidadores. Cabe aos profissionais de saúde buscar estratégias para trabalhar de acordo com a realidade do cuidador e do paciente com intuito de minimizar o impacto na vida dessas pessoas.

**Descritores:** Enfermagem; Insuficiência Renal Crônica; Diálise Peritoneal; Cuidadores.

El objetivo fue conocer la vivencia de familiares cuidadores como responsables por la realización de la diálisis peritoneal domiciliar. Investigación cualitativa con ocho familiares cuidadores de pacientes que estaban en diálisis peritoneal domiciliar, vinculados a una clínica, en el interior de Río Grande del Sur, Brasil. La recolección de datos fue por entrevista semiestructurada entre abril y mayo de 2009. Los datos fueron sometidos a análisis temático que reveló tres categorías: condiciones que imponen la responsabilidad con la diálisis peritoneal; complejidad del cuidado; y cambios en el cotidiano de los familiares cuidadores. La responsabilidad en la realización de la diálisis peritoneal modifica significativamente la vida de familiares cuidadores. Cabe a los profesionales de salud buscar estrategias para trabajar según la realidad del cuidador y paciente, para minimizar el impacto en la vida de esas personas.

**Descriptorios:** Enfermería; Insuficiencia Renal Crónica; Diálisis Peritoneal; Cuidadores.

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## INTRODUCTION

In the group of chronic diseases there is the chronic kidney disease, with high morbidity and mortality, and consequent economic and social implications<sup>(1)</sup>. The chronic renal failure is the final result of multiple signs and symptoms resulting from the kidney's failure to maintain the internal homeostasis of the organism. Thus, a treatment is necessary to replace the kidney's function. Currently the available treatments are: hemodialysis, peritoneal dialysis and kidney transplantation<sup>(2)</sup>.

Peritoneal dialysis consists of the infusion, retention and drainage of solution (dialysis bath) in the peritoneal cavity, by means of a flexible catheter implanted in the abdomen. This process promotes the removal of excess body fluid and toxic substances which would normally be eliminated by urine<sup>(1,3)</sup>. Peritoneal dialysis is performed in specialized hospitals or in the patients' homes. It can be continuous or intermittent, and manually or automated. When one uses a machine called cycler, it is the automated peritoneal dialysis (APD). The machine is programmed according to the medical prescription, and the dialysis is usually performed during the night while the patient sleeps. The manual mode is called continuous ambulatory peritoneal dialysis (CAPD). In this modality four daily exchanges are held with infusion, permanence, and drain of a dialysis fluid in the abdominal cavity<sup>(3)</sup>.

To perform peritoneal dialysis at home it is necessary for family members and, if possible the patient, to take a training given by nurses. The training consists of theoretical and practical classes, which aim to qualify the patient and their family to conduct the technical procedure safely at home<sup>(1)</sup>.

The choice of peritoneal dialysis can be a joint decision, from the patient, his family and the health team, or in some cases, it is determined by the patient's

clinical condition<sup>(2)</sup>. This type of treatment could be suitable for most patients in need of therapy for replacement of the renal function. However, in most cases its indication is limited to patients who have difficulties in having venous access for hemodialysis, to patients with heart disease in advanced stages or those who live long distances away from the hemodialysis center<sup>(1)</sup>.

In the report of the Brazilian dialysis census of 2010, the estimated number of individuals with chronic kidney disease on dialysis in Brazil was of 92,091. Out of these, 90.6% were in hemodialysis and 9.4% in peritoneal dialysis<sup>(4)</sup>. According to these data, the peritoneal dialysis is performed by a small proportion of the population undergoing dialysis treatment but it must be considered for its relevance, because the disease and the treatment have implications not only in the individual's daily life, but also in the family dynamics.

In this context, most of the times, the caregiver's role is played by only one family member, without help from other family members or hired professionals<sup>(5)</sup>. The technical care and availability to fulfill the schedules involved in the peritoneal dialysis at home, impact the lives of people who live with this reality. Among the consequences there is the caregivers' unemployment, often due to the incompatibility of a work schedule with the completion of dialysis exchanges<sup>(6)</sup>.

Given the above about peritoneal dialysis treatment and the involvement that it requires, it is necessary to deepen the knowledge about the everyday life of family caregivers in performing peritoneal dialysis at home.

Thus, one has as the guiding question of this study: What is the experience of family caregivers who perform peritoneal dialysis at home? And one established as the objective to know the experience of

family caregivers in the condition of responsible for performing peritoneal dialysis at home.

## METHOD

This is a qualitative study with descriptive and exploratory character. The study was conducted in a renal clinic located in the state of Rio Grande do Sul. It is a private institution linked to the Unified Health System and other health insurances that provide dialysis treatment in the modalities of hemodialysis and peritoneal dialysis.

Out of the 37 patients in peritoneal dialysis linked to this clinic, one interviewed eight family caregivers of people who were undergoing treatment for peritoneal dialysis at home, and two of these relatives were caring for the same patient.

Inclusion criteria for the subjects were: being a family caregiver responsible for performing peritoneal dialysis at home and being over eighteen years old.

The selection of subjects happened according to their schedule of monthly visits during the period of data collection. These consultations consist of medical and nursing assessment of the patient, who usually comes to the clinic accompanied by a caregiver. At this time one checked whether the person accompanying the consultation met the inclusion criteria. Those who met the criteria were invited to participate in the study randomly.

For data collection one used a semi-structured interview consisting of two themes: living with peritoneal dialysis at home and the changes generated in the caregiver's life due to the development of the activity of peritoneal dialysis. The interviews took place in a private room at the clinic. All interviews were audio recorded and transcribed, upon authorization of the respondent. The duration of each interview was on average 30 minutes. The period of data collection occurred in the months of April and May 2009.

Data were analyzed using content analysis in the thematic modality<sup>(7)</sup>, which consists of discovering the core meaning of a communication and counting the frequency of the units of meaning, as defining of the character of speech. Operationally the analysis followed the steps of pre-analysis, material exploration and treatment of the information obtained and data interpretation. To preserve the anonymity of the participants, one identified the speeches by the letters FC, family caregiver, respectively, followed by arabic numerals referring to the order in which the interviews were conducted.

To develop the research the ethical principles in research with humans were respected, according to Resolution 196/96 of the National Health Council<sup>(8)</sup>. The research began only after authorization from the clinic and the approval by the Ethics in Research Committee under protocol number 0303.0.243.000-08 and signing of the Free and Clarified Consent Form.

From the reports and methodological reference used, the following categories emerged: conditions that impose responsibility with peritoneal dialysis, the complexity of care and changes in the daily life of family caregivers who composed the *corpus* for discussion of this study.

## RESULTS AND DISCUSSION

The study subjects were between 31 and 67 years old, all female, five married and three unmarried. Regarding family relations, four of them were daughters, two mothers, a wife and a sister of the person cared for. As to the origin, half of the subjects lived outside the city where the clinic was located. The educational level ranged from incomplete elementary school to university degree. The family income of the subjects was between two to 11 minimum wages, and six had an income of two minimum wages.

Regarding the type of dialysis performed at home, seven of the family caregivers performed the APD, and one performed the CAPD. This result is in agreement with the dialysis census data, showing the prevalence of patients in APD<sup>(4)</sup>.

The time period in which the relatives were responsible for performing peritoneal dialysis ranged from 35 days to three years. It is observed by professional practice that, over the years, this daily and repetitive activity can generate fatigue and exhaustion to caregivers.

Study with patients carriers of pulmonary, cardiac and renal advanced disease, and their family caregivers discusses that these caregivers need careful attention in the care process of the family, as there may be an overload of activities, depending on the psychological aspects and comorbidities that affect the patients<sup>(9)</sup> with chronic diseases.

This fact points to the need for health professionals to understand this reality and act together with the family, in order to prevent that this activity becomes a factor which causes illness and demotivation of caregivers. One also notices that the implications for the caregiver may reflect directly in the patient's treatment and in the family relations.

### **Conditions that impose responsibility with peritoneal dialysis**

Assuming the role of family caregiver can occur naturally before the outbreak of the disease in a relationship between mother and daughter: *Among all children, she chose me to take care of her. Soon after she came to live with me, this problem started to emerge in the kidney. She had to do it (dialysis), so I automatically took responsibility for this part ...* (FC 1).

The family living together allows the identification of care needs of one of its members in the different stages of life. The beginning of the disease in the family requires that a member becomes responsible for care.

In most situations this role is developed by only one family member, called the main caregiver. This care conducted by the family is becoming usual, due to the expansion of chronic diseases<sup>(10-11)</sup>. *...because I accompanied her in the hospital, so I took the training, my husband and I went, in this case ... but it is more me.* (FC 3). *Because it is like ... When he (the son) was taken to hospital, I was the one together with him. Then at home I have more time than his father. Right now, I'm doing it (dialysis)* (FC 6). *It is because I have more free time and thought I was more able to do it (dialysis), because it needs so much (capacity) .... it is very thorough* (FC 8).

Besides the availability of time for care with peritoneal dialysis, the family member often considers himself more suitable for the activity, defining himself as a caregiver. For this, the responsible family member needs to take a training to give satisfactory care. *... the doctor, explained to us, me and my sister, that a family member should take the training, that it was something universal. So the two of us, I took and she (the sister) also took the training* (CF 2).

A study that examined the quality of life of caregivers and patients on peritoneal dialysis concluded that the selection of caregivers should be cautious, considering that this responsibility can lead to social implications. Despite these effects, the presence of the caregiver increases the patient's confidence to perform the treatment at home<sup>(12)</sup>.

In this context, it is up to the health professional to clarify and inform the family about the treatment and the need for a responsible person to perform peritoneal dialysis when the patient is unable to assume this role. Thus, it is necessary that the responsible person receives training for the application of the technique of peritoneal dialysis in a safe way without risks for the patient. In addition, the moment of training is important to strengthen the bond of the patient and the family with the service and the health team involved<sup>(13)</sup>.

Accepting this task will depend on each one. Initially there may be resistance to accepting the position of the caregiver responsible for peritoneal dialysis, by feeling unprepared for this activity: *... my*

*sister-in-law at first said: No, I will not do it (dialysis), I will not do it! ...and nowadays she does it in a very calm way ... (FC 7).*

A strategy to assist caregivers in the task of taking care is to try to involve the family in this process through educational activities with an encouraging perspective that can minimize their difficulties, helping families plan and provide the necessary resources for the care of the chronically ill patient. The process of adapting to certain situations or not, depends on several factors that include cultural and emotional issues, previous experiences and personal characteristics<sup>(5)</sup>.

### **The complexity of care**

A very common concern of caregivers when they are responsible for peritoneal dialysis at home is to follow strictly the technical procedures to avoid risk of infection and complications for their family members: *For me, the main concern was the issue of hygiene of the hands, the table, the bags. And then not being familiar with gloves, gauze, bandages, do you understand? All those care measures they (health team) suggest, with the room, so that there are no infection problems (FC 5). I used to wash my hands three times ... Now I wash them the first time to clean the material and then the three minutes (FC 8). ... the care we have to take to prevent peritonitis, we have to take special care! (FC 6).*

Among the several aspects involving peritoneal dialysis, one of them is learning a complex and unknown technique by the family member. Despite the training and guidance received from the nurse, the caregiver notices the need to perform this procedure which is so complex and extremely important for the patient's health<sup>(6)</sup>.

The written guidelines on how to install dialysis are important to reduce uncertainty, help the learning and facilitate the conduction of the procedure. *... the nurse who taught us ... gave it written. So that made it much easier for us, because of it we felt safer. We took it home and we stuck it next to the machine (FC 7). ...sometimes some doubts emerged,, but my sister had it in writing, an outline step by step that she typed on the computer, so we relied on that... (FC 2).*

The support to the dialysis technique through educational material can minimize the caregivers' doubts during the procedure. In this study one verified the involvement and initiative of the caregivers and health professionals in preparing explanatory material to assist in home care.

In the relationship between the nurse and the family caregiver it is essential an area of education, organized by knowledge and techniques, where there is physical proximity, creativity and respect for the customs and cultures of the family, to take the dialysis care at home<sup>(14)</sup>. To provide individualized care at home it is necessary to know the history of life and the social and cultural context in which the individual is<sup>(15)</sup>. Thus, it is necessary for nurses to develop a joint work with the family, as the patient's health and well-being depend on the responsibility and commitment of the one who takes care of him<sup>(16)</sup>.

### **Changes in family caregivers' lives**

Family members who live with a patient on peritoneal dialysis experience many changes in their day to day. These are related to the habits of the family, social activities, the physical structure of the home and work activity. *...with this situation of our mother, many things have changed for us. It isn't something simple and easy. I say there have been changes in our lives, several (FC 2). ... what changed? ... It was the question of reorganizing the time. So in that specific time (dialysis) I tried not to have another appointment... at lunch there was a change of schedules ... this period of manual dialysis required this reorganization, do you understand? (FC 5). Oh, there are days I think ... there are four exchanges per day and we ... Look, it's not easy, to go out! You have that schedule, you have to get home and make dialysis...(FC 4).*

The dialysis treatment at home requires changes in the organization of the family who needs to adapt to this new reality. In this direction, a study on home care dispensed to children with chronic kidney disease, reported that the moments of distress experienced by family members at home are connected to the non-

acceptance of the disease and the changes brought about in the routine<sup>(17)</sup>. The conduction of the dialysis at home causes changes in the family routine, because the process of care requires that the caregiver devotes himself entirely, leading him to redefine his routine<sup>(6)</sup>. ... *in manual dialysis we need ... at those schedules to be at home. Then of course after he started dialysis, there were no trips, to spend a night out* (FC 5).

The peculiarities of the treatment of peritoneal dialysis, such as the pre-arranged time for change of bags, cause changes in the social life of the caregiver. The daily and continuous care of peritoneal dialysis may not be delegated to someone who was not qualified for the procedure. This situation generates overload hindering the social life of the caregiver. In this sense, the caregiver has the tendency to a bigger social isolation<sup>(18)</sup>.

The physical structure of the home also needs to be adapted according to the dialysis treatment. ... *even our house changed, ... my house is full of boxes filled with liquid (dialysis), the house got cramped, the room, I had a living room, now I don't, because there is the place where we do dialysis, it is dedicated only for that...* (FC 6).

To perform dialysis at home it is necessary to adapt the environment, offering a place for the bags, hand washing, to prepare the material and conduct the procedure of peritoneal dialysis.

From the moment that caregivers are responsible for the care of dialysis, labor activities are affected. *I used to work ... I worked with sales. Then, when she chose me, I could not work anymore, because I had to take the responsibility. So I stopped working* (FC 1). *I used to work ... But I don't work anymore ... We cannot adapt the schedule. At first I tried... Then I stopped working...* (FC 3).

Caring for a family member in peritoneal dialysis may lead the caregiver to quit his job because of the big involvement this therapy requires. The difficulty of the caregiver in maintaining his job may not only be related to the schedules of the therapy, but also to the degree of dependence of that individual. Besides the changes observed in this investigation, another study suggests

that the emotional turmoil caused by the experience of illness and other issues may impact on health problems of family caregivers<sup>(19)</sup>.

### FINAL CONSIDERATIONS

The study showed that family caregivers take the responsibility of dialysis for being the closest people to the patient. Thus, this function is performed naturally as they feel more qualified and because they have more time.

The concern of family caregivers is related mainly to the accuracy of the dialysis technique, and its consequences for the patient. The exercise of that activity causes losses in the personal, social and economic spheres. These losses are related to deprivation in the activities of social life, changes of habits, need of time reorganization, need of adjustments in the physical structure of the house and the impossibility of continuing to work.

By knowing the experience of these family caregivers one can infer that the responsibility for the conduction of peritoneal dialysis changes significantly the lives of those who take this role.

In this sense, one highlights the important educational role that nurses develop, as they teach the caregiver and/or the patient to become able and prepared to perform peritoneal dialysis at home. One believes that it is essential to extend attention to the caregiver, to value him, making him realize he is not alone in this process, in which he will receive orientation to adapt more calmly and to minimize the implications that may occur while taking this function.

It is imperative to stimulate research into the experiences of family caregivers in peritoneal dialysis, since there are gaps in the literature on this topic. Thus, the knowledge produced is relevant to qualify the assistance developed by health professionals involved with patients and families who experience the

conduction of peritoneal dialysis at home. However, this study may have limitations due to the subjectivity of the theme and the individuality of family caregivers.

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