

Peritoneal dialysis: family care for chronic kidney disease patients in home-based treatment

Diálise peritoneal: cuidado familiar ao cliente renal crônico em tratamento no domicílio
Diálisis peritoneal: cuidado familiar al paciente renal crónico en tratamiento domiciliario

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ABSTRACT

Objective: to propose a family care model for patients with chronic kidney disease in peritoneal dialysis based on evidence indicated by family members. **Method:** this was a qualitative descriptive study that used the Convergent Care Research method. It was conducted at a state hospital in Rio de Janeiro, including techniques for recording individual interviews and consisted of a group of 19 study participants. Data were analyzed according to the stages proposed by the method, generating a category that used a cultural question as the basis for patient care resulting in a proposal for home-based family care. **Results:** the patient care model proposed includes dialogue and reflection in sharing the knowledge of “professional” and “popular” systems, aiming to improve the patient’s quality of life. **Conclusion:** family members were able to promote care based on cultural preservation, accommodation and repatterning, as proposed by Leininger’s Sunrise Model.

Descriptors: Nursing; Nephrology; Peritoneal Dialysis; Family; Family Care.

RESUMO

Objetivo: propor um modelo de cuidado familiar ao cliente renal crônico em tratamento com a Diálise Peritoneal a partir das evidências apontadas pelos familiares. **Método:** estudo descritivo com abordagem qualitativa, tendo como método a Pesquisa Convergente Assistencial. O cenário foi um hospital estadual do Rio de Janeiro, onde foram realizadas as técnicas de entrevista individual gravada e de um grupo de encontro com 19 participantes da pesquisa. Os dados foram analisados de acordo com as etapas propostas pelo método, emergindo uma categoria sobre a questão cultural como base para o cuidado: uma proposta de cuidado familiar no domicílio. **Resultados:** o modelo de cuidado proposto contempla o diálogo e a reflexão, no sentido de compartilhar os saberes dos sistemas “profissional” e “popular”, visando à melhoria da qualidade de vida dos clientes. **Conclusão:** os familiares conseguiram realizar a preservação, acomodação e repadronização cultural do cuidado propostas pelo modelo Sunrise de Leininger.

Descritores: Enfermagem; Nefrologia; Diálise Peritoneal; Família; Cuidado de Parentes.

RESUMEN

Objetivo: proponer un modelo de cuidado familiar al paciente renal crónico en tratamiento con Diálisis Peritoneal partiendo de las evidencias informadas por familiares. **Método:** estudio descriptivo, con abordaje cualitativo, usando como método la Investigación Convergente Asistencial, realizado en hospital estatal de Rio de Janeiro, donde fueron realizadas las técnicas de entrevista individual grabada y un grupo de encuentro con 19 participantes de la investigación. Datos analizados según las etapas propuestas por el método, emergiendo una categoría sobre la cuestión cultural como base para el cuidado: una propuesta de cuidado familiar domiciliario.

Resultados: el modelo de cuidado propuesto contempla el diálogo y la reflexión, apuntando a compartir los saberes de los sistemas

“profesional” y “popular”, con objetivo de mejorar la calidad de vida del paciente. **Conclusión:** los familiares consiguieron realizar la preservación, acomodación y reestandarización cultural del cuidado propuestas por el modelo Sunrise de Leininger.

Descriptores: Enfermería; Nefrología; Diálisis Peritoneal; Familia; Cuidado por Familiares.

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INTRODUCTION

Chronic kidney disease and its treatment by dialysis lead to circumstances that affect the physical and psychological aspects of patients' lives, which may impact their personal, family and social spheres. These circumstances force patients to change their lifestyle to fulfill the demands of a routine full of medical procedures, doctor's visits and exams. The experience of living with a patient with a chronic disease changes the attitudes and practices of their families, creating new meanings and causing those involved with the patient to change their habits and expectations because of the new reality⁽¹⁾.

These changes do not always occur because the family members want them, but they occur because of the situation. For this reason, the chances are very high of the families experiencing physical, emotional, social and financial overload. However, regardless of the reason which causes a family member to assume the responsibility of providing care for a patient with chronic kidney disease, the level of participation between them can vary. When there is a high level of participation, the family member remains present in the patient's life with love and loyalty, giving of him/herself to the patient, being present. However, when the family member assumes this role only because of the situation, there may be very little participation, with a lack of sensitivity on both sides⁽²⁾.

Nursing by the family was studied in this context, which is defined as a group of actions aimed at improving the patient's quality of life, and promoting, strengthening and keeping the family's well-being intact⁽³⁾. Based on this study, it was possible to get to know the families and see how they behave in new situations and how they solve problems. Nurses will then start to understand the family as a system, with values, practices, rituals, strengths and roles.

Nursing professionals need to recognize that a patient's family also require scare, hence it is necessary to identify the biopsychological, social and spiritual dimensions of this unit and develop punctual interventions to improve the quality of life of its members⁽⁴⁾.

A family has and transmits common beliefs, values and knowledge which is influenced by their culture and socioeconomic standards. To analyze the cultural questions that are present in the family context, the interrelations between the concepts from the Cultural Care Diversity and Universality, as developed by Madeleine Leininger, were applied. The Sunrise Model was used, which is based on the belief that people from different cultures are able to inform and guide professionals in receiving the care they want or need and thus attain culturally congruent care⁽⁵⁾.

This study aimed to propose a family care model for chronic kidney disease patients who receive peritoneal dialysis based on evidence indicated by their family members.

METHOD

Theoretical and methodological reference and study design

This was a qualitative descriptive study that used the Convergent Care Research (CCR) method. It was a type of study which is used in areas of care provision where a practice is developed with active participation of the studied subjects. It is focused on resolving or minimizing problems in practice or on introducing changes and innovation in healthcare practices which may then lead to theoretical constructions⁽⁷⁾.

Study scenario

The study scenario was a State University Hospital located in Rio de Janeiro that has a Nephrology division subdivided into Peritoneal Dialysis, Hemodialysis and Kidney Transplantation. The study was conducted in the Peritoneal Dialysis (PD) subdivision, which had, in the study period, 30 patients; of these, 29 were in Automated Peritoneal Dialysis (APD) and one was in Continuous Ambulatory Peritoneal Dialysis (CAPD). This service had a multidisciplinary team comprised of a head nurse, nursing and medical residents, a physician, a nutritionist and a psychologist.

Data source

The study participants consisted of 19 family members of chronic kidney disease patients in PD at the health institution mentioned above. Of these, 15 belonged to a nuclear or primary family and four to the nuclear family in its declining phase, that is, when adult children leave to create their own core or secondary families. Regarding the division of these participants by family, seven families had two family members in the study and five families had one family member, totaling 12 families.

The inclusion criteria used in participant selection were: family members of patients in PD, either in its manual (CAPD) or automated form (APD); family members of patients conducting the treatment independently, that is, by themselves, or with the help of a family member who had received treatment training; family members of both sexes; family members who lived or did not live in the same household as the patient in CAPD/APD, without necessarily considering their degree of kinship (primary or secondary) and family members of patients in CAPD/APD treatment for more than three months. This was considered as the minimum time required for method adaptation and evaluation of the treatment training process.

The family members who were able to participate in the group activity and interview were curious about these activities, as they were considered a new experience in their routine lives. They also saw this as an opportunity to receive support, get incentivized, clarify issues and obtain guidance and direct contact with the research nurse and other family members of patients in PD.

Data collection and organization

At first, an identification form was filled out to characterize the study participants; then, an individual interview was conducted, using a semi-structured questionnaire, previously developed and tested, with 11 questions related to the central theme of the study. The interviews were conducted between December 15, 2011 and January 17, 2012. They were recorded in a digital format (MP3), with the participant's prior authorization, and then they were fully transcribed. Later, to complement and more thoroughly detail the individual interviews, whose information would not be verified only through this technique, a convergence group was created in the hospital. This was as a result of a limitation in the study, characterized by issues of financial problems or an incompatible agenda due to the working hours of family members.

Six participants, two from one family and four from four different families, were able to organize a group activity with the researcher, which, although it was conducted only once a week, did not compromise the technique and data production.

These six subjects had participated in the individual interview before the group activity, answering question 11, which referred to themes that they would like to be seen addressed in the group. Later, these themes were screened to select the ones most similar and appropriate to the central study theme.

The convergence group activity was called "family meeting". It lasted 01h30min, and the conversation was digitally recorded (MP3) and then fully transcribed by the researcher. The other remaining 13 subjects that were not able to take part in the group activity had participated in the individual interview and they answered 10 questions, excluding question 11 about the group activity.

Because of financial problems or an incompatible agenda due to working hours, of a total of 19 participants, it was necessary to visit the homes of 11 of them to conduct the interview. Two participants who came to the hospital received financial support from the researcher to go back to their homes, as they claimed they had no resources to come to the hospital at times other than for patient visits.

At the moment of the interview, each participant received an informed consent form (two copies – one for the researcher and one for the participant). This document outlined in detail the ethical aspects of the study, explaining its content, benefits and possible risks. This study had the approval from the Research Ethics Committee, as required by Resolution 466/12 of the Brazilian Health Council. The process of data production started with the application of instruments previously authorized by the participants voluntarily involved in the study. To preserve participant anonymity, they were assigned names of precious stones plus "F" for female or "M" for male participants.

The principles of the model were respected, maintaining a close relation with the healthcare practice for social situations, emphasizing the participation of subjects in the research process and the researcher as a subject immersed in the professional team.

Data analysis

The model, proposed by Madeleine Leininger's Cultural Care Diversity and Universality Theory, was used as a

strategy to analyze data from both the convergence group and the individual interviews.

This analysis was conducted according to the phases proposed by the CCR. In data collection, transcribed data were organized for easy coding, which involved the recognition of words, phrases, paragraphs or key words frequently repeated in the participants' interviews.

After this coding process, an empirical category was created, which is a group of expressions with similar characteristics or with a close complementary relationship, according to specific criteria. This was to provide, by condensation, a simplified representation of raw data, followed by the application of content analysis⁽⁶⁾. The material generated from the individual interviews and convergence group discussions were submitted to content analysis techniques, aimed at keeping congruence across the process.

In this initial phase of data analysis, the material produced in the individual interviews and convergence group was analyzed separately to prevent false results, because at certain times, the subjects answered the questions individually, and at others, they discussed their opinions collectively.

The content analysis technique allowed for the identification of similarities and divergences in participant speeches in both data production techniques with the same theme. This way the content from individual interviews and from the convergence group could be addressed collectively, as they did not depend on another variable that would determine any significant change between them.

Therefore, when analyzing data collectively, a theme matrix was generated, based on the questions from the semi-structured questionnaire used in the individual interviews and from themes addressed in the convergence group. This matrix generated a category that used the cultural question as the basis for patient care and for a proposal for home-based family care.

RESULTS

With regard to the Sunrise Model, this study identified in participant interviews, the components of social structures and world view factors that influence patient care and health. Among these were political, economic and educational factors.

The technological factors proposed in the model are directly related to the question of home-based PD treatment. Home experience with PD equipment (called cyclor) at the beginning of treatment, caused fear, concern and anguish in some family members. Regardless of the treatment training they had received, they had an uneasy feeling.

The peritoneal dialysis machine made me a little anguished in the beginning [...], I was afraid of doing something wrong, of using it incorrectly. But I talked to the nurses and they helped me, providing support and explaining, and then I changed my way of seeing things and today I manage it calmly. (Jasper M)

Regarding religious factors, the search for sense and meaning is one of the essential needs of a human being, who is a Being to himself, his peers, the nature and religion.

Today, I thank God and all of you from the hospital, because everything happened in the right moment! I had to be balanced between a daughter that had no problem and a daughter with a problem, but God managed it right and I only have to thank. (Diamond F)

Kinship and social factors are directly related to how family members interact among themselves and with the social aspects involved. The variability or singularity of the organizational structure of the family takes into account its processes of living according to the sociocultural and environmental context where it is situated.

Look, with the disease, we try to keep a healthy environment at home, with tranquility, to help my mother! We're very close to each other and she is a great mother, so we get along very well! (Onyx M).

The values and lifestyles are directly linked with culture, with its conceptual systems which allows for experience acquired by individuals to be selected and organized. It should be considered that everyone has a background, and through it, builds and conveys the knowledge he/she has acquired.

It's interesting to talk about that, because for me, what I experience in my daily life is a reflection of culture. Because every day I learn a little more about life with the experiences I have and I learn from others. I think it's an exchange, you exchange knowledge and experience and always learn a little. (Opal M)

The political factors emerged subtly during the convergence group meeting. Two family members reported delayed receipt of government benefits granted to patients with CKD, especially the free pass. When asked by the researcher about the possibility of obtaining more information about what was happening in the appropriate governmental bodies, these family members answered they preferred to say nothing about it and wait for the natural conclusion of the free pass request process.

I had problems getting my wife's pass, I was so upset with the delay that I ended up taking no action about it. When I needed, I paid for the transport, I didn't want to get nervous, I already had a lot to decide, we had no time, then, I put it aside [...]. (Jasper M).

The economic factors, when addressed by the group, showed a direct relation with absence from work of family caregivers. When asked about it, these family members said this situation was due to the fact that they were indirectly responsible for providing care to the CKD patient, resulting in times of financial problems.

As I said before, I produce manual works, different types of craftwork, such as furniture and small items. As the situation was complicated, I started to sell these manual works I produce. And the best thing is that, besides making money, this change of attitude allowed some distraction. Then, this change was good for me. (Jasper M).

The question of the training process before starting the PD at home was also addressed by the group activity, demonstrating that the educational process in this context was linked with educational factors proposed in the Sunrise Model.

All family members who participated in the group activity were trained in both manual and automated PD technique; however, all interviews showed that, at first, all of them were afraid and uncertain about their learning. These feelings disappeared with time, as they became more confident that everything would get better.

In the beginning of the training, I was afraid. First, I learned the manual technique, then, when our daughter got the machine, I was trained on it. I had doubts and I didn't know if I could operate it correctly, alone at home. I was really afraid in the beginning. But with time, and operating it at home, you start to remember what was taught and you start to think about it, then you feel more confident. (Diamond F)

DISCUSSION

The cultural question as the basis for patient care: a proposal for home-based family care

Cultural care involves standardized values, beliefs and expressions that are cognitively known. They help, support or train other individuals or a group in preserving well-being, improving the human condition or when facing death and deficiency⁽⁹⁾.

The Convergent Care Research method served as an intervention in the area investigated because, combined with Madeleine Leininger's Sunrise Model, it allowed for the generation of knowledge which influenced the provision of healthcare by family members for patients in PD, and was aimed at reaching culturally congruent care.

The technological factors demonstrated that, despite the challenges they faced at the beginning of the treatment, in the process of getting familiar with the PD equipment, the family members were able to overcome such challenges, either supported by their own resources or with the help of nursing professionals. It shows the existence of cultural care negotiation or accommodation, which refers to the decisions and actions of supporting staff, facilitators or enablers, who help people adapt and negotiate with others, aiming to achieve a beneficial or satisfactory health result⁽¹⁰⁾.

The religious factors showed that the family directs its members towards an intimate relation with God by incorporating into their daily life the practice of faith and prayer and guiding them according to their religious convictions. This relation with religion is part of human nature, the contact with the sacred world allows human beings to have a soft experience towards their existence as life is considered a path that ends with death⁽¹¹⁾.

The multidisciplinary team that provides care to these patients has to respect their freedom to express their spirituality which is aimed at preserving their quality of life. This attitude shows the presence of cultural care preservation and encouragement for the maintenance of family beliefs. The cultural care preservation respects the decisions and actions of supporting staff, facilitators or enablers, who help people retain

and/or preserve relevant values of care to ensure their well-being, recover from the disease or face deficiencies⁽⁹⁾.

The kinship and social factors showed that, despite the challenges they faced, the family members who participated in the study seek for unity and for the promotion of healthy family relationships. In this context, the social factors, as revealed in the interviews, were related to the question of collective habits, that is, social life with the family or friends.

The family members reported that, despite having direct or indirect responsibility for patient treatment, they try to maintain normal personal lives as far as possible, including the patient in their reality. The family relations are maintained, in both the aspects of interaction and social dynamics. Therefore, the families were encouraged in this preservation and maintenance of cultural care.

The cultural values and lifestyles were considered a form of knowledge by the participants. They understood knowledge as everything acquired in life; the ability to feel, act and think in ways that express the relation of people with nature, space, time, religion and with each other. In this sense, cultural knowledge is incorporated into the daily life of families. Therefore, culture is not a rigid pattern, because it continuously receives new elements, making people change every day. Culture is part of everyone's background, and everyone has a little of his/her culture to transmit⁽¹²⁾, based on the values, beliefs, patterns and lifestyles that have been learned, shared and transmitted. It belongs to a specific group that guides their thoughts, decisions and actions in a patterned manner⁽¹⁰⁾.

In this study, the cultural question was characterized by the difference between popular and scientific knowledge from different cultures. The health professional systems refer to: teaching, learning, the formal transmission of professional health care, disease, well-being, relative knowledge and practice abilities that predominate in professional institutions, usually with a multidisciplinary staff to provide care. On the other hand, the generic or folk system refers to how people tend to see the world and create an image or assume an evaluative position about life or the surrounding world⁽¹⁰⁾.

This study found that, regarding the political factors, under certain circumstances, family members and patients accommodate and do not seek to enforce their rights. Due to lack of time or passivity, they do not adjust their actions to claim a benefit that would certainly help the family structure.

From diagnosis to the start of treatment, the patients with chronic kidney disease are described as victims of the disease and considered invalid. They are "supported" by the State, which reproduces the technicality of biomedicine as it does not consider the quality of life of these people. It also does not properly and effectively ensure that the resources recommended for treatment, for the subjective arrangements that redefine the patient's identity and his/her social place and relations with other people are duly considered. Subjectivity is considered a historical network of beliefs and desires that cannot be represented, but described; that cannot be interpreted, but redefined⁽¹³⁾.

The economic factors were evident, particularly during the group activity, when the participants reported the

challenges they faced due to the absence of formal work that ensured a fixed monthly income. The family members explained the ways that they fulfilled their financial needs, such as doing alternative work, showing the presence of cultural care repatterning.

The educational factors were reinforced through information shared during the training provided by the nursing team. The family members were able to apply their knowledge and interact with the patient's reality, ensuring more autonomy and security and allowing for the development of cultural care accommodation and there patterning process.

After using the Sunrise Model to analyze the material produced in the convergence group and individual interviews, this study identified that family members were able to conduct, in their own time and ways, cultural care preservation, accommodation and repatterning. They did this by relying on the support of the nursing team as a link between the generic and professional systems of health, for future care decisions and actions that are congruent with everyone's culture.

In a different types of interaction, the link between the nursing team and the families is an encounter of different cultures. Although both may have common objectives, such as the production of knowledge to fulfill the needs and resolve the problems affecting the families, they have different reference systems with distinct backgrounds and knowledge.

For a family to reach level IV of the Sunrise Model, that is, a culturally congruent nursing care level, it should have an opportunity to speak up. It should have an opportunity for joint decision making, ensuring their right to decide their goals and the recognition that it has the knowledge and competence to resolve problems.

In the light of a shared care construct, a care model proposal was developed, based on the experiences of family members of patients in PD treatment, with the participation of the nursing team as facilitator. This care is possible, since the subjects involved in the care provision process (professionals, patient and accompanying person) are aware that they are a collective group and active producers of knowledge. Dialogue and a critical attitude to daily experiences should be encouraged⁽¹⁴⁾.

The practice of patient care in this study analyzed the experiences of family members who, when taking care of their patients, discovered their own solutions and methods to provide care at the family level. According to each family's particularities, everything is developed among easy and difficult aspects related to the specific care situation, congruent with the culture (beliefs, patterns, rites, myths, language, etc.). There was also a consideration of actual limits and possibilities that produced strategic arrangements in the care provided to patients.

The proposed care model involves dialog and reflection in sharing knowledge from the generic and professional systems. However, such care may have moments of crisis, when adversities may be found and discussed, indicating the provision of volitional or non-volitional care by family members. These discussions allow, through decisions and negotiations, there patterning of the care methods of these family members.

If the practices are beneficial or do not cause damage, they may be preserved; if they lead to risk, an agreement should be negotiated, suggesting or maintaining a more beneficial practice. Lastly, if potentially harmful, nurses may help explain the

risks, guiding the family from prior practice repatterning into a healthier practice, always respecting their autonomy and decision making power. Figure 1 refers to the proposed care model based on the Sunrise Model used by Leopardi.

CONCLUSION

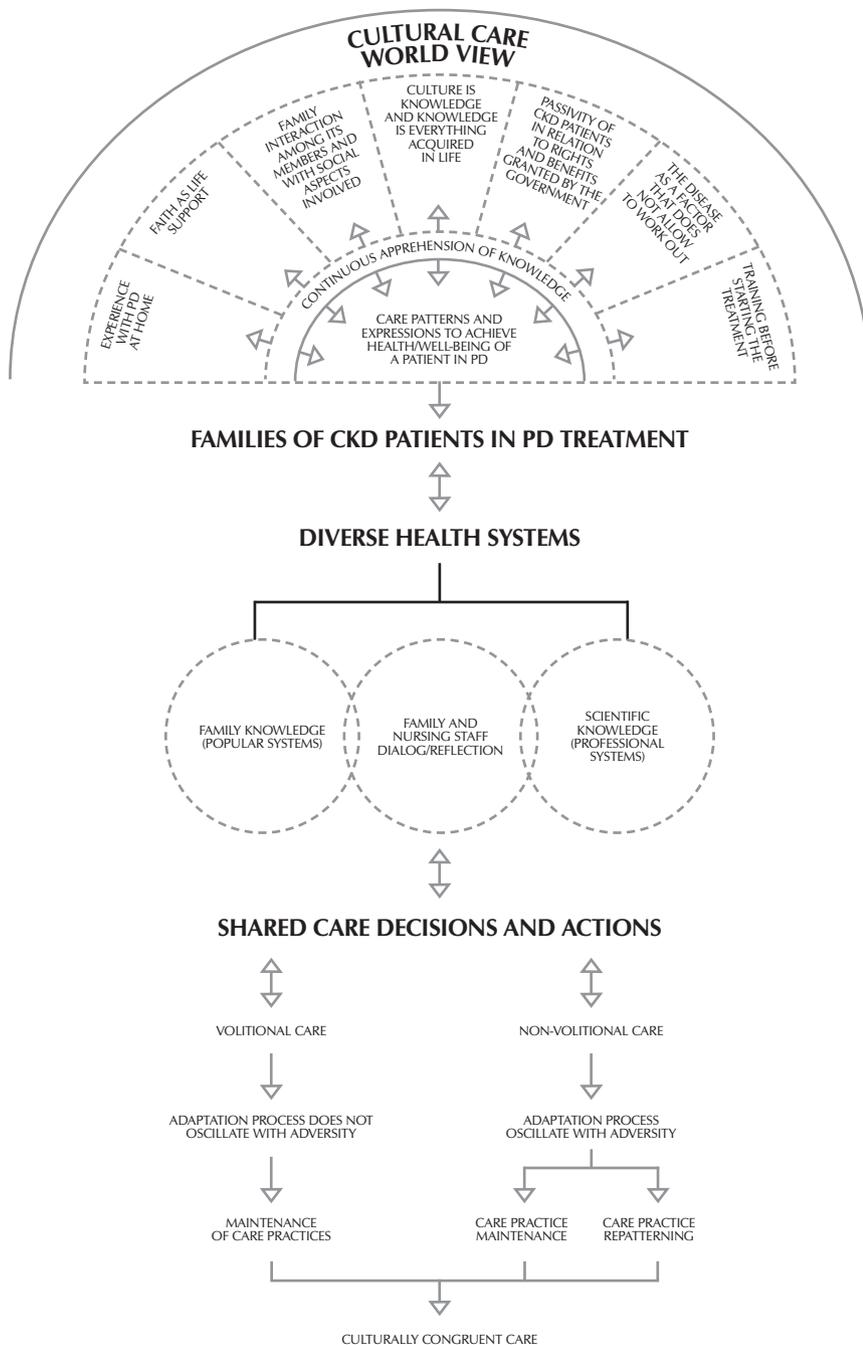
Patient care founded on a cultural basis will inform how family members of patients in home-based PD live and relate, explain their habits and daily activities and allow for care practices to be adequate and personalized according to the situations they experience.

The care provided by a family member is, to a large extent based on non-specialized knowledge. When the training is provided in the hospital on the PD technique, the scientific and professional knowledge justifies and exemplifies the actions, but the essence of home-based care is founded on common sense.

The Convergent Care Research method helped gather relevant information about this type of care, and it was essential for data production, especially during the group activity, because it provided a better integration of study participants and allowed them to objectively reveal their experiences.

The question of culture as the basis for care provided by a family member became evident when the Convergent Care Research was used, as this method acted as an intervention in the investigated reality. Combined with the Sunrise Model, it allowed for the development of a model that may influence the care provided by family members at home, based on the evidence indicated by them and on an analysis of the reach of the Cultural Care Diversity and Universality in the investigated reality.

When using the proposed family care model, the introduction of popular and professional knowledge will allow nursing staff and family members to analyze their knowledge collectively. This will facilitate the application of knowledge to diverse health systems, aimed at achieving patient care congruent with the culture of families involved in peritoneal dialysis treatment.



Source: Adapted from Leininger M, McFarland MR. *Transcultural nursing: concepts, theories, research and practice*. 3. ed. New York: McGraw-Hill; 2002.

Figure 1 – Family care model for chronic kidney disease patient in peritoneal dialysis treatment

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