

Impact of peritoneal dialysis on the family life of children with chronic kidney disease: integrative literature review

Impacto da diálise peritoneal na família da criança com doença renal crônica: revisão integrativa da literatura

El impacto de la diálisis peritoneal en la vida familiar de los niños con enfermedad renal crónica: revisión integradora de la literatura

Lurdes Lomba*; Alexandra Lameirinhas**; Ana Margarida Silva***; Juliana Brito****

Abstract

Background: Living with a child with Chronic Kidney Disease (CKD) on Peritoneal Dialysis (PD) has a significant impact on the family.

Aims: To identify the difficulties experienced by the parents and the strategies adopted by the nurses to minimize the impact of PD on the family life of children with CKD.

Methodology: A literature review was conducted using different search engines and databases with predefined inclusion criteria and descriptors. After critical appraisal of the results, 7 articles were obtained: 5 from MEDLINE and 2 from CINAHL.

Results: Changes in family daily lives are consequence of the disease. The results showed that parents, particularly the mothers, are the main caregivers of these children. They mentioned difficulties related to maintaining a steady job, financial constraints and increased medical costs.

Conclusion: The changes imposed by the CKD adversely affect the family dynamics. Thus, the nurses' interventions should focus on identifying the difficulties experienced during the adaptation process, sharing care and promoting the family's well-being. Future studies on the nurses' interventions with these families of children on PD are recommended.

Keywords: peritoneal dialysis; renal insufficiency, chronic; child; adolescent; family; nursing.

Resumo

Contexto: Conviver com uma criança com Doença Renal Crônica (DRC) em Diálise Peritoneal (DP) tem um impacto significativo na família.

Objetivos: Identificar dificuldades parentais e estratégias utilizadas pelos enfermeiros na minimização do impacto familiar da DP na criança com DRC.

Metodologia: Realizou-se uma revisão da literatura recorrendo a motores de busca e bases de dados informáticas com critérios de inclusão e descritores predefinidos. Obteve-se, após avaliação crítica dos resultados, sete artigos científicos: cinco da MEDLINE e dois da CINAHL.

Resultados: A alteração do quotidiano familiar é uma das consequências da doença. Os pais e, particularmente, as mães são os principais cuidadores destas crianças, sendo referidas como dificuldades a manutenção do emprego, limitações financeiras e custos elevados dos cuidados.

Conclusão: As mudanças exigidas pela doença têm efeitos adversos na dinâmica familiar e as intervenções do enfermeiro deverão centrar-se na identificação das dificuldades, no processo de adaptação, partilha de cuidados e promoção do bem-estar familiar. Sugerem-se estudos futuros, centrados na avaliação dos resultados de intervenções de Enfermagem nas famílias de crianças em DP.

Palavras-chave: diálise peritoneal; insuficiência renal crônica; criança; adolescente; família; Enfermagem.

Resumen

Contexto: Convivir con un niño con enfermedad renal crónica (DRC, por sus siglas en portugués) en Diálisis Peritoneal (DP) tiene un impacto significativo en la familia.

Objetivos: Identificar las dificultades parentales y estrategias utilizadas por los enfermeros para reducir el impacto familiar de la DP en el niño con DRC.

Metodología: Se realizó una revisión de la literatura. Para ello, se recurrió a los motores de búsqueda y bases de datos informáticas, y se utilizaron criterios de inclusión y descriptores predefinidos. Se obtuvieron, tras una evaluación crítica de los resultados, 7 artículos científicos: 5 de MEDLINE y 2 de CINAHL.

Resultados: La alteración de la rutina familiar es una de las consecuencias de la enfermedad. Los padres y, particularmente, las madres son los principales cuidadores de estos niños. Las principales dificultades que se mencionaron fueron el mantenimiento del empleo, las limitaciones financieras y los elevados costes de los cuidados.

Conclusión: Los cambios que la propia enfermedad exige tienen efectos adversos en la dinámica familiar. Las intervenciones del enfermero deben centrarse en la identificación de las dificultades, el proceso de adaptación, el intercambio de cuidados y la promoción del bienestar familiar. A este respecto, se sugiere realizar futuros estudios centrados en la evaluación de los resultados de las intervenciones de enfermería en las familias de los niños en DP.

Palabras clave: diálisis peritoneal; enfermedad renal crónica; Niño; Adolescente; Familia; Enfermería.

* Adjunct Professor, Ph.D., MSc, RN, Escola Superior de Enfermagem de Coimbra, 3046-851, Coimbra, Portugal [mlomba@esenfc.pt]. Address for Correspondence: Rua Quinta da Portela, nº 91. 2.º Esq. 3030-481 Coimbra, Portugal.

** RN, Frimley Park Hospital, GU167UJ, Frimley, Surrey, UK [xanilah91@hotmail.com].

*** RN [titacs_91@hotmail.com].

**** RN [julianalh@hotmai.com].

Received for publication: 22.01.14

Accepted for publication: 27.05.14

Introduction

Chronic Kidney Disease (CKD) is a progressive loss in kidney function, and is characterized by the permanence of disability and irreversible change, with expected long periods of care. The optimal definitive treatment, kidney transplantation, involves a lengthy process, and until it is performed, the alternative lies in dialysis (Martins, França, & Kimura, 1996; Frota, Machado, Martins, Vasconcelos, & Landin, 2010).

Dialysis, as a renal replacement therapy, is intended to improve the patient's quality of life. However, this treatment causes changes in the personal, family and social dynamics, thus patients and families may experience difficulties adapting to the disease and its consequences and be uncertain about the future. Technological advances have brought about a significant improvement in the treatment of CKD, but some risks increase the rates of physical morbidity and associated emotional issues, in particular due to the abrupt changes imposed by the treatment (Frota et al., 2010).

Both children with CKD and their families have to deal with various medical procedures on a daily basis. The renal replacement therapy, in particular the use of PD at home, is complex and requires family members to adopt the role of main caregivers with significant impact on their well-being and quality of life (Tong, Lowe, Sainsbury, & Craig, 2008). Indeed, as according to Santos (1998), taking care of a child

with CKD has a significant impact on the family's dynamics and functioning, and it is generally agreed that these children's parents experience more stress than the parents of healthy children. The family is confronted with new demands, changes and constant readjustments. However, these difficulties can be alleviated by the support of health care professionals, particularly nurses (Tong et al., 2008). These professionals should develop strategies to minimize the impact on the family, *i.e.* interventions facilitating the family's adaptive process to the health care needs of the child on PD and promoting their well-being.

Recognizing that the family dynamics changes due to prolonged treatment and that care brings with it difficulties, an integrative literature review was conducted to answer the following research question: *What are the difficulties experienced by the family in caring for the child on PD and what are the strategies used by nurses to minimize these difficulties?* This review aimed to describe the state-of-the-art in this field.

Methodological Procedures of the Integrative Review

In June 2013, a systematic review of published scientific literature was performed on the search engines SciELO, B-Online and EBSCO, using the following databases: MEDLINE with Full Text, CINAHL Plus with Full Text, MedicLatina and Psychology and Behavioral Sciences Collection. The studies were selected based on the criteria in Table 1.

Table 1
Criteria for inclusion of studies

PICOD	Criteria for Inclusion of quantitative studies
Participants	Families of paediatric patients with kidney disease on PD. Nurses responsible for the provision of care to children on PD.
Interventions	Studies that allow the identification of the difficulties experienced by the families of children on PD and descriptive studies of the nurses' interventions, with a view to alleviating these difficulties.
Research Outcomes	Various difficulties experienced by the families and the nurses' intervention strategies inherent in each of them.
Study Design	Empirical studies conducted with quantitative methodology at any level of evidence.
PICo	Criteria for Inclusion of qualitative studies
Participants	Families of paediatric patients with kidney disease on PD. Nurses responsible for providing care to children on PD.
Phenomenon of interest	Difficulties experienced by the families of children on PD and the nurses' interventions to alleviate these difficulties.
Context	Medical services (Hospitals and providers of care to children on PD) and their homes.

The following exclusion criteria were also defined: studies that did not address the impact on the family; studies relating to the technical procedures of PD; systematic literature reviews; studies with no full-text version; studies in a language other than Portuguese, Spanish or English; and studies which had not been carried out in between 2000 and 2013. The search expressions used were the following:

- In b-on: (Child* OR adolescen* OR youth* OR young* OR teen*) AND (peritoneal dialysis OR chronic kidney disease) AND (famil* OR nurs*), in the field “assunto”;
- In EBESCO: AB (Child* OR adolescen* OR youth* OR young* OR teen*) AND AB (peritoneal dialysis OR chronic kidney disease) AND AB(famil* OR nurs*);
- In SciELO: (Child* OR adolescen* OR youth* OR

young* OR teen*) AND (peritoneal dialysis OR chronic kidney disease) AND (famil* OR nurs*), in the fields *all indexes* and *regional*.

The search resulted in an initial sample of 94 references to scientific studies. Of these, 11 were excluded due to repetition, 65 based on title, one on language, and seven on abstract, resulting in a final sample of 10 articles. After the full-text reading of the 10 studies, three were also excluded for not meeting the inclusion/exclusion criteria. This process of composition of the corpus was carried out jointly by three authors and, in a consensus meeting, extended to the four authors. From this process, a consensus on seven articles was reached. The selection process is represented in the form of a Diagram in Figure 1.

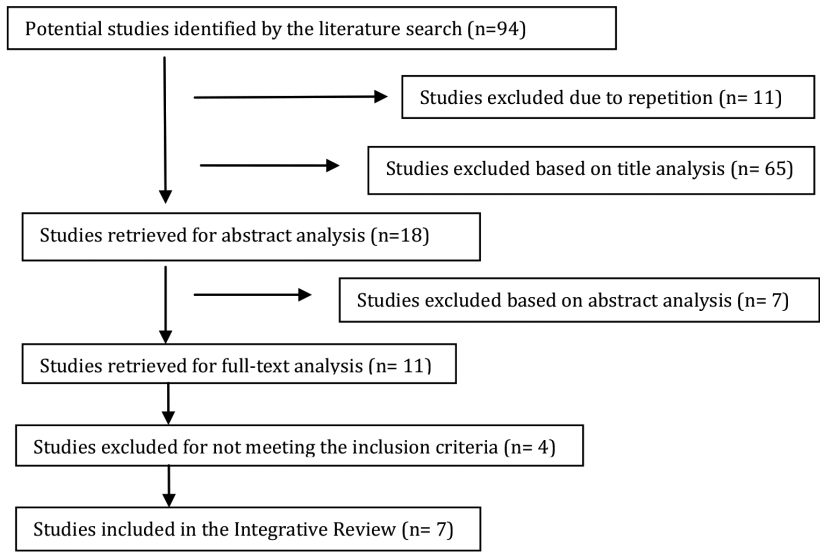


Figure 1. Diagram of study selection process.

Table 2 shows the list of articles selected for the integrative literature review, identifying their authors, date and title.

Table 2
Identification of the Studies

No.	Authors	Year	Title
E1	Paula, Nascimento, and Rocha	2008	A influência do apoio social para fortalecimento de famílias com insuficiência renal crônica.
E2	Abrahão et al.,	2010	Dificuldades vivenciadas pela família e pela criança/adolescente com doença renal crônica.
E3	Heaton, Noyes, and Shah	2005	Families' experiences of caring for technology-dependent children: a temporal perspective.
E4	Paula, Nascimento, and Rocha	2009	Religião e espiritualidade: experiência de famílias de crianças com insuficiência renal crônica.
E5	Paula, Nascimento, and Rocha	2008	Roles assessment in families of children with chronic renal failure on peritoneal dialysis.
E6	Abrahão et al.,	2010	Estudo descritivo sobre a prática da diálise peritoneal em domicílio.
E7	Tsai, Liu, Tsai, and Chou	2006	Psychosocial effects on caregivers for children on chronic peritoneal dialysis.

The selected articles were analysed to provide an answer to the research questions of this study. Data were extracted from the articles so as to gather information about the country and context where the study took place, the period in which it was carried out, its objectives and design, the number and type of participants, the phenomena of interest studied, the results obtained and the conclusions drawn.

Results and Interpretation

For a better structural organization of the extracted results, the qualitative studies were first analysed, followed by the quantitative studies. A description of the seven studies and the results obtained in each of them are schematically shown in the following tables.

Table 3
A influência do apoio social para o fortalecimento de famílias com crianças com insuficiência renal crônica

Study code: E1	
Country	Brazil.
Objectives	To identify the social support available for families of children with chronic kidney disease on PD with a view to promoting health.
Study design	Qualitative study.
Number and type of participants	14 Participants (4 families of children with chronic kidney disease on PD, including 4 mothers, 4 siblings, 1 grandmother, 1 uncle and 4 children).
Duration of study	5 months.
Phenomenon of interest	Support and social networks that strengthen interventions with a view to promoting the families' health.
Context	Hospital and at home.
Results	Emotional support: by the extended family, reassuring the parents that they could rely on help. Informative support: the family considered the information provided by the professionals to be scarce, Instrumental support: provision of material and operational resources and collaboration in child care by the extended family. Reinforcement support: positive statements of family members regarding the care provided and the results obtained. Institutional support: support that facilitates child care and access to resources available from hospital, religious, educational and business institutions.
Conclusions	The families of children with CKD should be included in the care plan as facilitators of the therapeutic process. The nurse should assess their knowledge to promote adaptation to disease. The identification of social support allows for a better use and strengthening of defence mechanisms.

Table 4

Dificuldades vivenciadas pela família e pela criança/adolescente com DRC

Study code: E2	
Country	Brazil.
Objectives	To describe and discuss the reports of caregivers on the reactions and difficulties experienced by the family and children/adolescents with CKD regarding the use of PD.
Study design	Descriptive study.
Number and type of participants	30 children and adolescents.
Duration of study	2 years and 2 months.
Phenomenon of interest	Difficulties experienced by the family and the child/adolescent with CKD in using PD.
Context	At home.
Results	The caregivers mentioned fears about PD-related health complications (infection and peritonitis); concern about the technical procedures that they have to perform; feeling of over-responsibility and inadequate conditions for performing PD. The negative repercussions on the family and social life (need of constant presence and inability to perform other activities), increased costs/expenses and decrease or lack of financial autonomy were also mentioned.
Conclusions	PD brings about several difficulties for the family and child with CKD. The description of these difficulties should be used to assess the adherence to treatment in order to improve the users' quality of life and the well-being of those involved.

Table 5

Families' experiences of caring for technology-dependent children: a temporal perspective

Study code: E3	
Country	United Kingdom.
Objectives	To explore the long-term consequences of therapeutic regimens in technology-dependent children and their families.
Study design	Qualitative study.
Number and type of participants	36 families, in a total of 75 members, including 46 parents, 13 technology-dependent children, 15 siblings and 1 grandmother.
Duration of study	Undefined.
Phenomenon of Interest	Changes in the routines and experiences of technology-dependent children and family members.
Context	Undefined.
Results	Technical care were mainly provided by the parents, particularly the mothers, with support from other family members or specialized professionals. Changes in the siblings' childhood by imposition of responsibilities such as household chores, caring for the ill child and the younger siblings, with limitations in the social and school spheres, were underlined. Some of them mentioned <i>tension</i> at home and the need for a break. The parents reported difficulties in the provision of care, maintenance of a steady job, high health care costs and limitations in social activities for not having someone to replace them. Reference was made to disorders and periods of sleep disruption. Some mentioned adverse consequences for the relationship, while others mentioned a stronger relationship as a result of daily experiences.
Conclusions	The technical routines of child care are complex and the inherent demands lead to limitations in family life. The need for interventions to reduce the impact of the necessary techniques was underlined.

Table 6

Religião e espiritualidade: experiências de famílias de crianças com Insuficiência Renal Crônica

Study code: E4	
Country	Brazil.
Objectives	To describe the manifestations of religiosity and spirituality in families of children with Chronic Kidney Failure undergoing peritoneal dialysis.
Study design	Qualitative study.
Number and type of participants	14 participants (4 families of children with chronic kidney failure undergoing peritoneal dialysis, including 4 mothers, 4 siblings, 1 grandmother, 1 uncle and 4 children).
Duration of study	6 months.
Phenomena of interest	The experience of children undergoing PD and their families and the care provided to promote health.
Context	Undefined.
Results	God was considered a source of hope to cure the disease and protect from clinical complications. In the relationship with God, the families mentioned gratitude and help to fight for the child's recovery. They considered that a lack of belief in God can cause despair. The disease brought them new values and a different way of thinking about life. They appreciated the involvement of the church with prayers for the child's recovery.
Conclusions	Religion and spirituality are sources of comfort and hope for the caregivers, making them stronger and promoting their well-being. The identification of the family's religious practices may help the nurse understand their attitudes towards the disease and therapeutic process, helping them to maintain health promotion practices. The nurse should conduct interventions to improve the quality of life, strengthen the defence mechanisms, and promote the family members' health and well-being.

Table 7

Roles assessment in families of children with chronic renal failure on peritoneal dialysis

Study code: E5		
Country	Brazil.	
Objectives	To describe the implications of role changes in families of children with chronic renal disease on peritoneal dialysis.	
Study design	Exploratory study, using a case study.	
Number and type of participants	14 participants (4 families of children on peritoneal dialysis, including 4 mothers, 4 siblings, 1 grandmother, 1 uncle and 4 ill children).	
Duration of study	5 months.	
Phenomenon of Interest	Feelings experienced by the families and their interpretations about living with a chronic patient.	
Context	Hospital and clinics where the children were being followed.	
Results	Mothers	Their role is burdened and intensified by their children's disease, with consequences in their daily life and family circle. They mentioned the lack of time for self-care, the need to be constantly with the ill child and the difficulty in getting help from and dividing tasks with other family members.
	Siblings	They demonstrated feelings of jealousy/envy for the care and attention given to the ill child. The intensification of the brotherly role in the responsibility for the care provided to the healthy siblings was also highlighted.
	Other relatives	The need to assume the role of caregiver, quit the job or start working again for financial support were underlined.
Conclusions	The intensification of roles and adjustments between the family members was demonstrated. Nurses should develop strategies to alleviate the family burden, with a view to improving the quality of life, strengthen the coping mechanisms and preserve the family's well-being.	

Table 8
Estudo descritivo sobre a prática da diálise peritoneal em domicílio

Study code: E6	
Country	Brazil.
Objectives	To describe the caregiver's level of information on the PD technique and the general conditions of the location to perform the PD, as well as find associations with the inadequate performance of this technique.
Study design	Quantitative descriptive study.
Number and type of participants	30 children and adolescents with CKD.
Duration of study	2 years and 2 months.
Outcomes	Knowledge of family members about the PD technique.
Intervention	The answers were classified as satisfactory or unsatisfactory, according to the researchers' criteria.
Results	For the performance of PD, the rooms had the necessary conditions for caregivers to wash their hands. They washed them for an adequate amount of time and frequency. The quality of the PD technique was considered inadequate in 60% of patients. All odds ratios indicated positive associations between the variables low education, low income, lack of basin in the room for PD, poor hand hygiene and inadequate levels of information on the PD and the variable inadequate technical quality, although no statistically significant differences were found.
Conclusions	Results show that the studied variables do not imply an inadequate performance of the PD technique.

Table 9
Psychosocial effects on caregivers for children on chronic peritoneal dialysis

Study code: E7	
Country	Taiwan.
Objectives	To explore the psychological effects of peritoneal dialysis on caregivers of children in Taiwan.
Study design	Quantitative case-control study.
Number and type of participants	187 caregivers.
Duration of study	Undefined.
Outcomes	Depression and quality of life of the caregivers.
Intervention	Two instruments were used: the <i>Taiwanese Depression Questionnaire</i> (TDQ) to explore the presence of depression and the <i>World Health Organization</i> QOL BRIEF-Taiwan version to assess the caregivers' quality of life.
Results	The prevalence of depression was significantly higher in the experimental group than in the control group, with 9 caregivers in the experimental group with depression, of whom 5 were aware of their tendency toward depression. As for quality of life, the scores of the domains assessed in the WHOQOL (physical, psychological, social and environmental) were lower in the experimental group than in the control group.
Conclusions	Caring for children on PD has psychological adverse effects on their caregivers and their quality of life, thus the high likelihood of depression and the need for appropriate treatment, when necessary, should be taken into account. The importance of preventing the caregivers' fatigue/burnout was also highlighted.

Therefore, and analysing first the families' experiences reported in the selected articles, it should be highlighted that the the main caregivers of children on PD are their parents, in particular their mothers. Studies E2 and E5 highlighted that the role of the mother, as the main responsible for performing PD,

is overburdened, with consequences in their daily life and the family environment. Other authors such as Simpionato (2005) and Marques et al. (2012) underlined the role of the mother as the primary caregiver and their lack of time as a result of taking care of their children.

The changes inherent to the situation of CKD in children affect the entire family circle in a negative way, as it was previously referred to by Santos (1998) and Vieira and Lima (2002). As major difficulties experienced by the caregivers, the maintenance of a steady job and the financial constraints imposed by high care costs should be underlined. The time demands for the provision of care and the lack of caregivers to replace the parents restrict the social life of many couples. Some parents mentioned adverse consequences in previous relationships, while others pointed out a stronger relationship resulting from the disease experience. However, Simpionato (2005) focused on the family imbalances, in particular the relationship of the parents, who suffer the greatest change in their role as they take on the role of caregivers.

Study E2 mentioned the parents' dissatisfaction with the need to be constantly present. These difficulties may translate into a higher prevalence of depression and lower quality of life in the parents of children on peritoneal dialysis than in the group of parents of healthy children, as was confirmed in study E7.

Data from the selected studies also demonstrated the impact on the siblings. Studies E3 and E5 referred to a different childhood, since the focus of attention and the daily routines are oriented towards the ill child. The increased responsibilities in caring for the ill sibling and the other healthy ones when the parents are absent or busy were also highlighted. Simpionato (2005) combines the increased responsibility with the feelings of jealousy which were also mentioned in the analysed studies. The roles and responsibilities of the siblings intensify according to their age and the amount of time experiencing the disease situation. The limitations at the social, academic and well-being levels, as well as the experience of a distressing home environment were also described.

The studies also showed the occurrence of changes in the other family members' roles, namely their intervention as caregivers and/or as financial support. Thus, the extended family is highlighted as providing a major financial support.

As regards the performance of the PD technique, studies E5 and E6 showed that, despite the caregivers having adequate information, the PD was poorly performed. In addition to underlining the caregiver's concerns with the evolution of the child's health

condition, the main difficulties were related to the risk of complications and the often limited conditions to perform the technique. Simpionato (2005) and Tong et al. (2008) also mentioned the mothers' fear to perform the technique and the feeling of guilt if it was poorly performed, which is consistent with the results of the selected studies.

Study E1 showed that the family considers the information provided by the professionals to be an important, but insufficient, form of support. They also valued other forms of support such as the emotional support (mainly from the extended family), the positive reinforcement in relation to the care provided, and the support from hospital, education, political and religious institutions. After analysing the results that answer this review's second research question, we concluded that the selected studies suggest that nurses help the family reorganize the roles and adapt to the disease process, thus promoting the biological, emotional, physical and spiritual well-being of the family unity. Studies E1 and E5 complement each another by suggesting that the nurse should communicate in a clear and fluent way, and listen to the family members. The interventions should target all family members and address their experiences with the ill child and not only the implementation of the technical procedure. Study E4 points out the need for nurses to be familiar with the family's religious and spiritual practices, as a strategy for understanding their attitudes towards the disease process. Moreover, Marques et al. (2012), while conducting a study on CKD, concluded that it is essential for health professionals to study the family's experiences after the diagnosis, as well as the support provided to the family.

In summary, the results of the analysed articles showed that parents, particularly the mothers, are the primary caregivers of the child on PD. The main complaints relate to the fear of complications, the uncertainty about the child's future and the lack of time for personal activities and social relationships.

Other family members with particular importance are the siblings, with most of them having increased responsibilities and feelings of jealousy due to the attention given to the ill child.

Regarding the PD technique, and despite most of the caregiver's information being correct, the performance of the dialysis technique was inadequate. The information provided by health care professionals

is valued, although considered to be insufficient. The emotional support from the family and the instrumental support from various institutions were also significant.

As for the nurses' role in minimizing the families' difficulties, the analysed studies did not explore the use of interventions in the health care practice and their outcomes, only pointing out the nurses importance in the reorganization of roles within the family, the adaptation to the disease process and the promotion of partnership in care, with a view to promoting the biological, emotional, physical and spiritual well-being of the entire family unit.

Conclusion

The review of the selected studies underlined that caring for a child with CKD on PD has significant adverse effects on the family unit, particularly on the child's main caregivers, the parents. As for the identification of the difficulties, all studies point out changes in the family's dynamics, structure and functioning. The financial, professional, social and relational limitations arising from the demands of child care were presented as some of the major difficulties experienced by these families.

The Nursing interventions are referred to as essential to facilitate the family's adaptation process to the child's needs and promote the family members' well-being. The studies also highlighted the need for nurses to intervene with these families, aiming to improve their quality of life and the effectiveness of the coping strategies, as well as promote the physical, emotional and spiritual well-being of the entire family circle.

As highlighted in three of the analysed studies, the identification of the difficulties experienced by the family of the child on PD facilitates the nurse's role in maintaining the well-being and promoting the health of the family unit. However, the analysed studies only identified suggestions for Nursing care practice. No study was found to methodologically assess the outcomes of Nursing interventions aiming at family's difficulties resulting from the therapeutic process of PD and the specific care provided to children with CKD. Therefore, we recommend that Nursing interventions be implemented in the clinical practice aimed at the specific difficulties of the

relatives of children on PD which were identified in these studies, and that their effectiveness is assessed.

References

- Abrahão, S., Ricas, J., Andrade, D. F., Pompeu, F., Chamahum, L., Araújo, T. M., ... Lima, E. M. (2010). Dificuldades vivenciadas pela família e pela criança/adolescente com doença renal crônica. *Jornal Brasileiro de Nefrologia*, 32(1), 18-22. doi: 10.1590/S0101-28002010000100004
- Abrahão, S., Ricas, J., Andrade, D. F., Pompeu, F., Chamahum, L., Araújo, T. M., ... Lima, E. M. (2010). Estudo descritivo sobre a prática da diálise peritoneal em domicílio. *Jornal Brasileiro de Nefrologia*, 32(1), 45-50. doi: 10.1590/S0101-28002010000100009
- Frota, M., Machado, J., Martins, M., Vasconcelos, V., & Landin, F. (2010). Qualidade de vida da criança com insuficiência renal crônica. *Escola Ana Nery Revista de Enfermagem*, 14(3), 527-533. Retrieved from <http://www.scielo.br/pdf/ean/v14n3/v14n3a14.pdf>
- Heaton, J., Noyes, J., & Shah, R. (2005). Families' experiences of caring for technology-dependent children: A temporal perspective. *Health and Social Care in the Community*, 13(5), 441-450. doi: 10.1111/j.1365-2524.2005.00571.x
- Marques, D., Nascimento, E., Cruz, D., Lacerda, O., Souza, I., & Collet, N. (2012). Family's experience of living with a child's chronic renal disease. *Journal of Nursing*, 6(6), 1338-1345. Retrieved from http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/2513/pdf_1230
- Martins, L., França, A., & Kimura, M. (1996). Qualidade de vida de pessoas com doença crônica. *Revista Latino-Americana de Enfermagem*, 4(3), 5-18. Retrieved from <http://www.scielo.br/pdf/rlae/v4n3/v4n3a02>
- Paula, E., Nascimento, L., & Rocha, S. (2008). A influência do apoio social para o fortalecimento de famílias com crianças com insuficiência renal crônica. *Revista Latino-Americana de Enfermagem*, 16(4), 692-699. doi: 10.1590/S0104-11692008000400007
- Paula, E., Nascimento, L., & Rocha, S. (2008). Roles assessment in families of children with chronic renal failure on peritoneal dialysis. *International Journal of Nursing Practice*, 14(3), 215-220. doi: 10.1111/j.1440-172X.2008.00683.x
- Paula, E., Nascimento, L., & Rocha, S. (2009). Religião e espiritualidade: Experiência de famílias de crianças com insuficiência renal crônica. *Revista Brasileira de Enfermagem*, 62(1), 100-106. doi: 10.1590/S0034-71672009000100015
- Santos, S. (1998). A família da criança com doença crônica: Abordagem de algumas características. *Análise Psicológica*, 16(1), 65-75. Retrieved from <http://www.scielo.gpeari.mctes.pt/pdf/aps/v16n1/v16n1a07.pdf>

- Simpionato, E. (2005). *A enfermagem familiar na promoção da saúde da família com crianças com insuficiência renal crônica* (Dissertação de Mestrado não publicada). Escola de Enfermagem de Ribeirão Preto, Brasil.
- Tong, A., Lowe, A., Sainsbury, P., & Craig, J. (2008). Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. *Pediatrics*, *121*(2), 349-360. Retrieved from <http://pediatrics.aappublications.org/content/121/2/349.full.html>
- Tsai, T. C., Liu, S. I., Tsai, J. D., & Chou, L. H. (2006). Psychosocial effects on caregivers for children on chronic peritoneal dialysis. *Kidney International*, *70*(11), 1983-1987. doi: 10.1038/sj.ki.5001811
- Vieira, A., & Lima, R. (2002). Crianças e adolescentes com doença crônica: Convivendo com mudanças. *Revista Latino-Americana de Enfermagem*, *10*(4), 552-560. Retrieved from <http://www.scielo.br/pdf/rlae/v10n4/13368.pdf>