



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

INTEGRATIVE REVIEW ARTICLE

CARING THE FAMILIES OF CHILDREN WITH RENAL FAILURE: INTEGRATIVE REVIEW

ATENÇÃO ÀS FAMÍLIAS DE CRIANÇAS COM INSUFICIÊNCIA RENAL: REVISÃO INTEGRATIVA ATENCIÓN A LAS FAMILIAS DE LOS NIÑOS CON INSUFICIENCIA RENAL: REVISIÓN INTEGRATIVA

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ABSTRACT

Objective: to analyze the scientific production on relevant aspects of caring for the families of children with renal insufficiency. **Method:** an integrative review that aimed to answer the question: What scientific evidence is available on the issues identified as relevant in the care of families of children with renal failure? The survey occurred in May of 2014, in four electronic databases (CINAHL, PubMed/MEDLINE, PSYCINFO and WILEY), using the keywords "renal failure", "family" and "child". After thematic analysis, the data were grouped and categorized. **Results:** ten studies met the inclusion criteria. Eight articles were qualitative and two were quantitative, and were related to the care of families who have experienced chronic renal failure in childhood, the knowledge and social support network of families. **Conclusion:** family members consider this experience to be a negative event. They need support and adjustments to the new demands imposed by the chronic condition. **Descriptors:** Niños; Enfermería; Familia; Insuficiencia Renal.

RESUMO

Objetivo: analisar a produção científica sobre os aspectos relevantes na atenção às famílias das crianças com insuficiência renal. **Método:** revisão integrativa que buscou responder à questão << Quais as evidências científicas sobre os aspectos apontados como relevantes na atenção às famílias das crianças com insuficiência renal? >> A pesquisa ocorreu no mês de maio de 2014 em quatro bases de dados eletrônicas (CINAHL, PubMed/MEDLINE, PSYCINFO e WILEY), utilizando-se as palavras-chave "Insuficiência Renal", "Família" e "Criança". Após análise temática, os dados foram agrupados e categorizados. **Resultados:** atenderam os critérios de inclusão, dez estudos. Constatou-se que oito artigos eram qualitativos e dois quantitativos, estes abordaram a atenção às famílias que vivenciaram a insuficiência renal crônica na infância, o conhecimento e a rede de apoio social das famílias. **Conclusão:** a família considera essa experiência como um evento negativo. Necessita de apoio e ajustes com as novas demandas imposta pela condição crônica. **Descritores:** Criança; Enfermagem; Família; Insuficiência Renal.

RESUMEN

Objetivo: analizar la producción científica sobre los aspectos relevantes en la atención a las familias de los niños con insuficiencia renal. **Método:** revisión integrativa que busco responder a la pregunta - ¿Cual es la evidencia científica sobre los aspectos considerados relevantes en la atención a las familias de los niños con insuficiencia renal? - La investigación se realizó en el mes de mayo de 2014 en cuatro bases de datos electrónicas (CINAHL, PubMed/MEDLINE, PSYCINFO e WILEY), utilizando las palabras clave "Insuficiencia renal", "Familia" y "Niño". Después de analizar la temática, los datos fueron agrupados y clasificados. **Resultados:** diez estudios respondieron a los criterios de inclusión. Se constato que ocho artículos eran cualitativos y dos cuantitativos, y estaban relacionados con el cuidado de las familias que han experimentado la insuficiencia renal crónica en la infancia, la red de conocimientos y el apoyo social de las familias. **Conclusión:** los familiares consideran que esta experiencia es un evento negativo. Necesitan apoyo y adaptaciones a las nuevas exigencias impuestas por la condición crónica. **Descritores:** Niños; Enfermería; Familia; Insuficiencia Renal.

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INTRODUCTION

Renal failure (RF) is a condition related to irreversible kidney damage that can occur regardless of age, and is a global public health problem. The early stage is a scarcely investigated event, and most of the information referred to is concentrated in epidemiological studies in adults. During childhood, only the final stages of the disease are studied, when replacement therapy (dialysis or transplantation) is required to sustain life, which reduces the possibility of treatment in the early stages. This is still a disease that, when it occurs in childhood, affects the entire family unit.¹

The prevalence of children affected by RF in the United States, during 2007, was 84.6 cases per million of the population of a compatible age (pmpca).² In 1998, the estimated incidence in Japan, was of four new pmpca cases, while in a survey involving 12 European countries between 1985 and 1990, the incidence was ten new pmpca cases.¹ These numbers represent a challenge for health services, since the RF is associated with high mortality and cardiovascular morbidity, as well as impaired growth, and the need for psychosocial adjustments that impact the children's quality of life.

Unfortunately, Brazil does not have exact data on the prevalence of RF in the childhood, regardless of the stage of the disease, which reinforces the need for epidemiological studies. Among the restrictions imposed by RF on the child, there are limitations to motor skills and autonomy in performing basic activities when compared to others of the same age, such as in eating, dressing, playing, and hygiene.³

From this perspective, it is essential to know how the family experiences caring for a child with RF at different stages, (1) at diagnosis, (2) progressive RF, and (3) end-stage renal disease, which includes a form of substitutive treatment: hemodialysis, peritoneal dialysis and/or kidney transplant). Professionals can develop care strategies to achieve better results in the medium and long term; preventing injuries from conservative renal treatment, given that RF entails a burden to the quality of life, affecting the daily activities of children and their families.³⁻⁴

OBJECTIVE

- To analyze scientific literature on relevant aspects of caring for families of children with renal failure.

METHOD

This was an integrative review, and for its completion, the steps followed were: 1) identification of the subject and selection of the research question; 2) establishment of the inclusion and exclusion criteria; 3) identification of pre-selected and selected studies; 4) categorization of the selected studies; 5) analysis and interpretation of the results; and 6) presentation of results.⁵⁻⁶

The survey was conducted in the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), American Psychological Association (PSYCINFO), John Wiley & Sons, Inc., an international publisher (Wiley), and the National Library of Medicine of the United States (PubMed/MEDLINE), during May of 2014. The studies that addressed the subject of "caring for the families of children with renal failure" and answered the research question, "what scientific evidence on the issues was identified as relevant in caring for families of children with renal failure?" were selected. The key words were "*renal failure*"; "*family*", "*child*"; "renal insufficiency"; family; child; "renal insufficiency"; "family"; "niño"; and linked by the Boolean operator *AND*.

Regarding the inclusion and exclusion criteria for studies, those initially included were: primary studies with qualitative or quantitative methodologies, published from 2004 to 2014, available in full text in English, Spanish or Portuguese, and those which answered the research question. Publications of conference abstracts, news, and letters to the editor, and studies that were not related to caring for the family of the child with RF were excluded.

Two reviewers performed the data collection and a third was consulted in case of doubts. A proper data collection instrument was developed, including the following information: authors, year of publication, design, level of evidence, population, and main results.

The levels of evidence were classified as: Level 1 - evidence from meta-analysis of controlled trials; Level 2 - evidence from experimental trial; Level 3 - evidence obtained from quasi-experimental controlled trials without randomization, pre-test/post-test control group design, time series or case-control; Level 4 - evidence from study with a non-experimental design, such as correlational and descriptive qualitative research or case studies; Level 5 - evidence systematically obtained, verifiable, program evaluation or case report data; Level 6 - evidence derived

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from a single descriptive or qualitative study; Level 7 - evidence from the opinion of respected authorities based on clinical competence or expert committees, including interpretations of information not based on research .⁶

Two reviewers read ten articles for the analysis, and a third was consulted in case of doubts. The results allowed the development of the categories for the following topics: "aspects identified by the family caring the child with renal failure" and "aspects identified by the staff caring for the child with renal failure".

RESULTS

The search performed in the PubMed/MEDLINE initially identified 186 articles; with the use of the search filters of

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language and publication period (2004-2014), 44 titles and abstracts were generated. After reading of the titles and abstracts, and following the inclusion and exclusion criteria, six articles were selected for analysis in full text. In the CINAHL® database, three studies were selected and one in the WILEY database. No study was found in the PSYCINFO database. Thus, ten studies were selected for analysis.^{3,4,7-14}

Figure I shows the characteristics obtained after reading the studies. Subsequently, the data were analyzed according to the survey question for this review. The categorizing and interpretation of results was then performed.⁵

Author (year)	Country	Method	Level of evidence	Population	Main findings
Setz VG, Pereira SR, Naganuma M. (2005).	Brazil	Qualitative, Semi structured interview.	VI	15 children on dialysis and hemodialysis; ages between six and 16 years old.	Children realized that kidney transplant provides the only possibility for returning to a life like that of any other child of their age who does not have renal failure.
Batte S, Watson AR, Amess K. (2006).	United Kingdom	Qualitative, semi structured interview.	VI	15 siblings: eight boys & seven girls, ages between eight and 12 years old, whose brother or sister was on dialysis or awaiting kidney transplantation	The psychosocial assessment of families should include evaluation of the siblings, considering the child's level of development in order to assess potential risk of emotional harm. The health team members should encourage parents to give siblings the opportunity to discuss their anxieties and concerns.
Paula ES, Nascimento LC, Rocha SMM. (2008).	Brazil	Qualitative, interview.	VI	Four families (14 participants) of children and adolescents receiving hospital care	The families of children with RF need to be included in the planning of care, as facilitators of the therapeutic child process, receiving guidance about the disease and treatment. Nurses need to identify and support the social networks that improve their use and strengthen the coping mechanisms for the disease. Inter-sectorial and multi-professional actions are necessary within a large social network.
Johnson S, Sidelinger DE, Blanco E, Palinkas LA,	United States of America	Qualitative, semi structured interview.	VI	28 families of children and adolescents	Emphasizing the importance of social support networks to treatment adherence.

MACdonald D, Reznick V. (2008). Paula ES, Brazil Nascimento LC, Rocha SMM. (2008).	Case study	VI	Four families (14 members) of children in peritoneal dialysis.	The assessment of family roles provides a current view of potential health problems, and assists in identifying the needs of families to the nurse and the families of children with RF on peritoneal dialysis. The mother is overloaded by childcare. The siblings feel excluded because they do not receive the same attention. Other members feel affected by the burden of care for the child.
Vieira SS, Brazil Dupas G, Ferreira NMLA. (2009).	Qualitative, semi structured interview.	VI	Eight children between seven and 14 years old.	Shows the importance of hearing the child to identify their potential and their needs. Adding value to socio-economic, cultural, educational aspects, social support and individual characteristics that influence the ways of coping. The nurse has an important role in facilitating the understanding of the situation, assisting with problem-solving.
Tong A, Australia Lowe A, Sansbury P, Craig JC. (2009).	Qualitative, in-depth interview.	VI	20 parents of children with RF.	Despite facing profound difficulties, parents strive to fulfill their responsibilities of provider, of both parents and health. Parents seem to need better support structures to help them cope with the difficulties found during all stages of their child's illness.
Wiedebusch S, Germany Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, et al. (2010).	Qualitative, cross sectional study.	VI	195 parents of children with RF	The parents of children on dialysis experienced a more limited quality of life than the parents of children with a kidney graft, and parents of children undergoing conservative renal treatment. The mothers of children had a lower quality of life than the fathers.
Waissman R. (2010).	Qualitative, semi structured interview.	VI	Patients, professional and families of children with RF	The patient and his family acquire a practical and theoretical knowledgebase on pathology and treatment, which empowers them to manage the care. Family members and professionals exchange views and evaluate what is best for the treatment and management of the child's care.
Canhestro MR, Brazil Oliveira EA, Soares CMB, Marciano RC, Assunção DC, Gazzinelli A. (2010).	Qualitative, interview.	VI	75 children and adolescents with their main caregiver	Among the respondents, 54.7% had insufficient knowledge. It highlights the need for reassessment of the strategies that have been used in educational activities, individualizing them for each patient, considering his ability to understand and accumulate experience.

Figure 1. Characteristics of studies addressing the care of families of children with renal failure.

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Initially, the description of the studies was analyzed and then, the results were presented. Among the ten studies analyzed, six were performed by nurses^{3,7-11} and four by physicians;^{4,12-14} five studies were conducted in Brazil,^{3,8-11} one in Germany,⁴ one in Australia,¹² one in the USA,¹³ one in France,⁷ and one in the UK.¹⁴

Eight studies used qualitative designs,^{7-10,12-14} and two were quantitative.^{4,11} All of them showed a level of evidence of VI and among those, the center of the investigations were the families in five studies,^{4,8,9,12,13} children and adolescents in three studies,^{3,10,14} adolescents were the major caregiver in one,¹¹ and one studied adolescent children, families and professionals.⁶ Only one study was about children in conservative renal treatment¹¹ and in nine the children were on dialysis treatment,^{3-4,7-10,12-14} demonstrating lack of studies approaching children in renal conservative treatment and their families. About 70% of these publications were conducted after 2008.^{3-4,7-9,11-13}

DISCUSSION

◆ Aspects identified by the family caring for the child with renal failure

The aspects presented and discussed in this category are those considered important for family caring for the child with RF. The experience of being a mother or father of a child with a chronic illness is reported, by parents, as a profoundly negative event in their lives, permeated by moments of uncertainty regarding their ability to deal with the new condition.¹²

One study demonstrated that parents of children receiving hemodialysis treatment have a lower quality of life compared to those in conservative renal treatment,⁹ with the mother as the primary caretaker of the child with RF.¹¹ Therefore; mothers have a lower quality of life compared to that of the father.^{4,9} These family members feel overburdened with caring of the child's new condition; in addition, they must meet daily and health needs of parents.^{8,11}

There is the reference that family dynamics (the home and employment environment, finance and recreation) is disrupted with the diagnosis, as the primary caregiver, which in most cases is the mother, needs to be present in the hospital with her child and manage the care at home. For others, the decision to donate a kidney brought uncertainty and pressure from an obligation to donate.¹²

Parents need to be prepared for the role and emotional adjustments they may

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experience, being aware of the new conditions they will face, as renal disease is a lifelong condition, regardless of the type of treatment adopted. Knowing the experiences and perspectives of parents is needed to improve their quality of life, and that of their children.¹⁵

Children, in turn, refer to the realization that their lives change with every treatment modality, since this requires adaptation, which causes pain and fear. In addition to renal disease, some children experience other limitations, such as in motor, hearing and growth, which in themselves lead them to feel differently. So, they face mockery and exclusion by other children, and even adults.³

Communication is an important factor among family members, since children can be aware of this difficult time but do not understand what is happening, feeling guilty about the circumstances that the family is experiencing.⁸ In some cases reported in the studies, parents provided alternative care for siblings, for example, with relatives. Thus, they had to re-establish relationships with the siblings who felt excluded, abandoned and neglected because they did not receive the same attention.^{9,12}

Another aspect evidenced in the studies^{8,9} was the need for a social support network for the family. The social network refers to a structural or institutional dimension connected to an individual. The social support network, from the personal perspective, consists of members of the social network that is really important for families.¹⁶ This necessity is due to the new demands resulting from the child's chronic condition, as some families have difficulty coping with the child's illness during all its stages.^{7,12} Some parents referred to the need for better support structures that help them to cope with the peculiarities found, and stated that emotional support was mostly found in the family and from other parents of children with RF.^{8,12}

The support for parents to learn and to provide support for other parents facing similar situation is important, enabling efficient communication, allowing them to face problems in a healthy way.^{8,13,15}

A Brazilian study showed that the scope of support is related to the way that the families access the available resources for child care, promoting family health directly and indirectly. These families reported using day care services, special schools, companies where they worked, city resources, medicines, and housing as support.⁸

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However, the child's daily routine and family dynamics are changed after the disease, becoming more restricted; he is not allowed to do various activities as he used to do before, depriving the family of leisure activity, generating social isolation.³

Preferences for certain procedures differ according to the particular experiences of children. Some of them state they prefer hemodialysis because they can eat and drink while being dialyzed, others affirm that home peritoneal dialysis is more comfortable and they do not need to travel to the hospital, which offers greater freedom.³

The family knowledge about pathology and treatment phases of the child's disease as noted in the studies are insufficient.¹¹ Others studies stated this knowledge was empowering, as the medical team provides theoretical knowledge and are constantly updated by their work experience, while the patient and his family acquire a practical and theoretical knowledge base (formal and informal) on pathology and treatment, which empowers them to manage the care.^{7,10} However, other families show that information related to the disease is needed, as well as on medications, procedures to be performed, treatments (dialysis or transplantation), dietary advice, complications, information on how to access financial assistance, and psychological care for the child.¹¹⁻¹²

In a study that evaluated the knowledge of children, adolescents and the primary caregiver¹⁰ for the disease, most of them had knowledge about kidney function and knew that the treatment would last a lifetime. However, many of them believed that the treatment can cause a complete cure of the kidney, and others did not recognize hypertension and diabetes as triggering factors for renal problems.¹¹

Another study that was analyzed addressed the barrier to acquiring knowledge about the disease¹³, the low sensitivity and understanding of health professionals about family communication, as some of them avoid giving further explanation about the treatment, assuming that the parents are not sufficiently able to understand the therapeutic plan.⁸ However, the family needs information about the health/disease of the child, since they are responsible for his care, and when space for communication is allowed, reflective questions about care demands emerge, as well as strategies for coping with the situation.¹⁸

The data from these studies highlight the importance of understanding by health

professionals to reduce the disparity between the perceptions of parents and children about the stages of kidney disease.¹⁴ Furthermore, the professionals must be educated regarding cultural dimensions of the disease and the access to care.¹³

♦ Aspects identified by the staff caring for the child with renal failure

The aspects that the health team considers important in the care of children with renal failure are presented and discussed in this category. The families of children with renal failure require several adjustments to their routine, including a prescribed diet for the child at the beginning of the disease, which may be a factor of conflict among family members, since it is not easy to get the child to accept, and even more difficult for family members to meet the dietary restrictions.⁷ These issues involve changing of habits and are directly related to the cultural aspects of each family, which can make the process of adaptation more difficult.

Therefore, the need for support and information about depression and aggression in children with RF is reported, which is referred to by the parents as a need greater than the disease itself, since they believe psychological problems are related to the medication and its side effects.¹²

The study highlights that nurses implement programs to prepare families for the challenges of long-term child-care management, reducing stress from parents, increasing their confidence, and reducing family neglect, related to non-adherence and/or treatment dropout. This manner of continued care should enable guidelines (on the disease, treatment, lifestyle changes, support services, dietary advice) and opportunities for parents to express their concerns and feelings. Thus, parents should be equipped and trained to provide home-based care.^{8,15}

In this sense, there is an organization that studies renal care in Europe, which found that most call centers had a multidisciplinary team to meet the families, and that they are actively involved in the care management.¹⁶ Thus, they exchange views and evaluate what is best for treatment and for child care management.⁷

It is clear that nursing, when caring for families and children with renal disease, forms outstanding bonds, because children perceive the relationship with the health team and other patients as a positive aspect in their treatment, which makes them feel

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important.³ Therefore, the qualification of professionals involved in care is necessary.

According to a study that evaluated the renal care in Europe, most professionals possess expertise in pediatric and/or renal nursing.¹⁷ However, some studies showed that the nursing care was perceived as being of poor quality by the children's parents, emphasizing that nurses demonstrate being inattentive, aggressive and impatient with the child.^{8,12}

This type of care does not correspond with what families and children should receive. Thus, when nurses are promoting dialogue, listening to family members, they can identify their skills and potential health problems, to then share this information with other professionals who provide child care, such as psychologists, social workers, nutritionists and physicians. Thus, communication becomes fluent, both between family and staff, and among health team members.⁸⁻⁹

In order to take care of someone, it is necessary to understand the person being cared of, be authentic and true to the family and the child. This will strengthen the relationship; since you cannot look at the facts as if that they were as they should be. Therefore, you must present yourself exactly in a manner that you are able to be fully present with one other. This is to be consistent between what one says and does and what one says and feels.¹⁰ Furthermore, the health professionals should make home visits to promote a transition from hospital to home care, to monitor the parents' quality of life, and to design coping strategies and interventions when needed.^{4,15}

CONCLUSION

Among the aspects identified as relevant for the care of families of children with RF, the experience of RF in childhood is considered by the family to be a complex event that affects all members, triggering changes in family dynamics, leading to deficiencies in the quality of life, affecting mothers more frequently and with more intensity, as they are generally the main caregivers of their children, requiring, therefore, adjustments and support for the new demands.

The child and the family should be encouraged to participate in decisions, allowing them to feel involved and important. Although the health professionals may know the ideal diet, what medication to use, who is better able to perform certain care for the child, the people who will really decide,

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however, and will have to adapt to such care are the child and his family. Therefore, the meaning and significance of these "prescriptions" will determine whether or not they will adhere to these or not.

In this context, there must be support for the family routine to be reorganized. Thus, the emotional bond established by nurses is considered important, maintaining sensitivity and respect for these individuals in order to develop healthy ways of coping with the new conditions imposed by the disease.

Among the shortcomings noted is that during the initial phase of RF, only one study addressed the primary caregiver of children and adolescents in conservative renal treatment, demonstrating a clear lack of research. Moreover, despite the aim to understand pre-dialysis treatment in childhood, most studies focus attention on the family of children with RF who are on dialysis and hemodialysis. It is necessary to perform studies assessing the social support network, for its influence on treatment adherence and coping with the disease. Thus, it is expected that nursing can contribute to the performance of studies that seek to understand how the care of children with renal failure is occurring.

ACKNOWLEDGMENTS

To the Research Support Foundation of Rio Grande do Sul (Fundação de Apoio à Pesquisa do Rio Grande do Sul - FAPERGS) for scholarship research awarded to the first author.

REFERENCES

1. Waradi BA, Chadha V. Chronic kidney disease in children: the global perspective. *Pediatr nephrol* [Internet]. 2007 [cited 2014 May 21];22:1999-2009. Available from:<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2064944/>
2. Collins A, Foley R, Herzog C, Chavers B, Gilbertson D, Ishani A, et al. Excerpts from the US Renal Data System 2009 Annual Data Report. *Am j kidney dis* [Internet]. 2010 [cited 2014 May 29];55(1Suppl1):S1-420-7. Available from:<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2829836/>
3. Vieira SS, Dupas G, Ferreira NMLA. Doença renal crônica: conhecendo a experiência da criança. *Esc Anna Nery* [Internet]. 2009 [cited 2014 May 21];13(1):74-83. Available from:http://www.scielo.br/scielo.php?pid=S0080-62342014000400602&script=sci_arttext&tlng=pt

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4. Wiedebusch S, Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, et al. Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. *Pediatr nephrol* [Internet]. 2010 [cited 2014 May 20];25:1477-8. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1779073/>
5. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem integrative literature. *Texto & contexto enferm* [Internet]. 2008 [cited 2014 May 03];17(4):758-64. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-7072008000400018
6. Melnyk BM, Fineout-Overholt E. Making the case for evidence-based practice. In: Melnyk BM, Fineout-Overholt E. *Evidence-based practice in nursing & healthcare: a guide to best practice*. Philadelphia: Lippincott Williams & Wilkins; 2005 [Internet]. 2006 [cited 2013 Aug 3];3-24. Available from: http://download.lww.com/wolterskluwer_vitalstream.com/PermaLink/NCNJ/A/NCNJ_546_156_2010_08_23_SADFJO_165_SDC216.pdf
7. Waissman R. Social experience among vulnerable populations: conflicts and negotiations between chronic patients and their doctors seen as a challenge to medical practice. *Clin nephrol* [Internet]. 2010 [cited 2014 May 21];74(Suppl.1):S134-7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20979979>
8. Paula ES, Nascimento LC, Rocha SMM. A influência do apoio social para o fortalecimento de famílias com crianças com insuficiência renal crônica. *Rev latino-am enfermagem* [Internet]. 2008 [cited 2014 May 21];16(4):[about 8 p]. Available from: http://www.scielo.br/scielo.php?pid=S010411692008000400007&script=sci_abstract&tlng=pt
9. Paula ES, Nascimento LC, Rocha SMM. Roles assessment in families of children with chronic renal failure on peritoneal dialysis. *International journal of nursing practice* [Internet]. 2008 [cited 2014 May 21];14:215-20. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18460062>
10. Setz VG, Pereira SR, Naganuma M. O transplante renal sob a ótica de crianças portadoras de insuficiência renal crônica em tratamento dialítico - estudo de caso. *Rev acta paul enferm* [Internet]. 2005 [cited 2014 May 21];18(3):294-300. Available from: <http://www.scielo.br/pdf/apv/v18n3/a10v18n3>
11. Canhestro MR, Oliveira EA, Soares CMB, Marciano RC, Assunção DC, Gazzinelli A. Conhecimentos de pacientes e familiares sobre a doença renal crônica e seu tratamento conservador. *Reme, rev min enferm* [Internet]. 2010 [cited 2014 May 22];14(3):335-44. Available from: <http://www.reme.org.br/artigo/detalhes/124>
12. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child care health dev* [Internet]. 2010 [cited 2014 May 22];36(4):549-57. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2214.2010.01067.x/abstract>
13. Johnson S, Sidelinger DE, Blanco E, Palinkas LA, Macdonald D, Reznic V. Ethnic differences and treatment trajectories in chronic kidney disease. *J health care poor underserved* [Internet]. 2008 [cited 2014 May 22];19(1):90-102. Available from: [https://muse.jhu.edu/login?auth=0&type=sum mary&url=/journals/journal_of_health_care_f or_the_poor_and_underserved/v019/19.1john son.html](https://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal_of_health_care_for_the_poor_and_underserved/v019/19.1johnson.html)
14. Batte S, Watson AR, Amess K. The effects of chronic renal failure on siblings. *Pediatr Nephrol* [Internet]. 2006 [cited 2014 May 18];(21):246-50. Available from: <http://link.springer.com/article/10.1007%2Fs00467-005-2064-9>
15. Tong A, Lowe A, Sansbury P, Craig JC. Systematic Review of Qualitative Studies Experiences of Parents Who Have Children With Chronic Kidney Disease: A Systematic Review of Qualitative Studies. *Pediatrics* [Internet]. 2009 [cited 2014 May 21];121:349-60. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18245427>
16. Pedro ICS, Rocha SMM, Nascimento LC. Apoio e rede social em Enfermagem familiar: Revendo conceitos. *Rev latino-am enfermagem*. 2008 [cited 2014 Dec 17];(16):2. Available from: http://www.scielo.br/pdf/rlae/v16n2/pt_24.pdf
17. Knoll J, Demol A, Elseviers M, Harrington M, DE VOS JY, Zampieron A, Ormandy P, Kafkaia T. The organization of pediatric renal care in different European countries: results of the PAC project. *EDTNA ERCA J* [Internet]. 2006 [cited 2014 May 28];23:51-6. Available from: [http://www.unboundmedicine.com/medline/cita tion/16700170/The_organisation_of_paediatric](http://www.unboundmedicine.com/medline/citation/16700170/The_organisation_of_paediatric)

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18. Rodrigues PF, Amador DD, Silva KL, Reichert APS, Collet N. Interação entre equipe de enfermagem e família na percepção dos familiares de crianças com doenças crônicas. Esc Anna Nery [Internet]. 2013 [cited 2014 Dec 17];(17):4. Available from:http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452013000400781.

Submission: 2015/02/03

Accepted: 2016/03/02

Published: 2016/04/15

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