

SELF CARE DEFICITS IN CHILDREN AND ADOLESCENTS WITH CHRONIC KIDNEY DISEASE¹

Malueska Luacche Xavier Ferreira de Sousa², Kenya de Lima Silva³, Maria Miriam Lima da Nóbrega⁴, Neusa Collet⁵

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² Master's student of the Post-graduate Nursing Program of the UFPB. Registered Nurse of the Emergency Room of the Deoclécio Marques de Lucena Regional Hospital, Parnamirim-RN. Paraíba, Brazil. E-mail: malu_luacche@hotmail.com

³ Doctoral student of the Post-graduate Fundamental Nursing Program of the Ribeirão Preto College of Nursing. Professor of the Department of Public Health Nursing and Psychiatry (DESPP) of the UFPB. Registered Nurse of the Pediatric Clinic of the Lauro Wanderley University Hospital/UFPB. Paraíba, Brazil. E-mail: kenya_enf@hotmail.com

⁴ Ph.D in Nursing. Professor of the Post-graduate Nursing Program of the CCS/UFPB and of the DESPP/UFPB. Paraíba, Brazil. E-mail: miriamnobrega@uol.com.br

⁵ Ph.D in Nursing. Professor of the Post-graduate Nursing Program of the CCS/UFPB and of the DESPP/UFPB. Paraíba, Brazil. E-mail: neucollet@gmail.com

ABSTRACT: This descriptive-exploratory study aimed to investigate the requirements of self care in the health deviations associated with chronic kidney diseases in children and teenagers based on the theoretical framework of Orem; to identify nursing diagnoses in self care deficits with the support of the International Classification for Nursing Practice; and to develop interventions with the child/adolescent in order to identify deficits in the self care requirements. A semi-structured interview was applied with four children/adolescents, aged between 8-13 years, from October to December/2009. The deficits were found in the universal, development and health deviations self care requirements. Diagnoses were formulated, such as risk for nutritional deficit, ineffective management of therapeutic regimen and deficient health knowledge. The study showed that it is difficult for the child/adolescent to live with the alterations required by the disease. As the child/adolescent is not completely capable of responding to the healthcare process, their caregivers need to assume the condition of self care therapeutic agents.

DESCRIPTORS: Family. Chronic disease. Nursing. Self care.

DÉFICITS DE AUTOCUIDADO EM CRIANÇAS E ADOLESCENTES COM DOENÇA RENAL CRÔNICA

RESUMO: Pesquisa descritivo-exploratória que objetivou investigar os requisitos de autocuidado nos desvios de saúde associados às doenças renais crônicas em crianças e adolescentes, à luz do referencial teórico de Orem, identificar diagnósticos de enfermagem nos *déficits* de autocuidado com auxílio da Classificação Internacional para a Prática de Enfermagem e desenvolver intervenções junto à criança/adolescente, ao identificar *déficits* nos requisitos de autocuidado. Utilizou-se a entrevista semiestruturada com quatro crianças/adolescentes entre 8-13 anos, de outubro a dezembro/2009. Os *déficits* foram encontrados nos requisitos de autocuidado universal, desenvolvimento e desvios de saúde. Formularam-se diagnósticos como risco para alimentação comprometida, controle ineficaz da terapêutica e conhecimento de saúde diminuído. O estudo evidenciou ser difícil para a criança/adolescente conviver com as alterações requisitadas pela doença. Como a criança/adolescente não é completamente capaz de responder pelo processo assistencial, faz-se necessário que os responsáveis pelo seu cuidado assumam a condição de agente de autocuidado terapêutico.

DESCRIPTORIOS: Família. Doença crônica. Enfermagem. Autocuidado.

DÉFICITS DE AUTOCUIDADO EN NIÑOS Y ADOLESCENTES CON ENFERMEDAD RENAL CRÓNICA

RESUMEN: Investigación descriptivo-exploratoria objetivó investigar los requisitos de autocuidado en desvíos de salud asociados a las enfermedades renales crónicas en niños/adolescentes bajo la óptica del referencial teórico de Orem; identificar diagnósticos de enfermería en los *déficits* de autocuidado con auxilio de la Clasificación Internacional para Práctica de Enfermería y desarrollar intervenciones tras dicha constatación. Se utilizó entrevista semiestruturada con cuatro niños/adolescentes entre 8-13 años de octubre al diciembre/2009. Los *déficits* fueron encontrados en los requisitos de autocuidado universal, desarrollo y desvíos de salud y formulados diagnósticos como riesgo para alimentación comprometida; control ineficaz de la terapêutica y conocimiento de salud disminuído. El estudio evidenció ser difícil al niño/adolescente convivir con las alteraciones provocadas por la enfermedad. No siendo el niño/adolescente capaz de responder por el proceso asistencial, hace falta sus responsables asumir la condición de agente de autocuidado terapêutico.

DESCRIPTORIOS: Familia. Enfermedad. Enfermería. Autocuidado.

INTRODUCTION

The chronic diseases are a theme of extra relevance for reflection on the human living process, considering that, even with the advances in science and technology in the sphere of early diagnosis of diseases and their appropriate therapeutics, which often allow the control of their evolution and cure, this group of diseases promotes organic, emotional and social changes that require constant care and adaptation.¹

The chronic condition can be defined as health disorders that have a long course, of more than three months, impose limitations on the functions of the individual in their daily activities, and can cause hospitalization of at least one month per year.²

The aim of the management or control of these diseases is to reduce suffering and improve the quality of life of the individuals, however, in the majority of cases, the patients are not completely cured. In this process, extensive hospitalizations, even during the diagnosis period, are also frequent.³

In infancy, children and adolescents with chronic conditions generally need to undergo aversive medical procedures, hospitalizations, and worsening of their physical condition, and may have their physical and emotional development affected. This may lead to the presentation of psychological maladjustments arising from the disease and from the treatment.⁴ Thus, hospitalization permeates their processes of growth and development, modifying, to a greater or lesser degree, the quotidian, separating them from their families and environment.¹

These diseases present high indices of morbidity and mortality and have gained a prominent position in the changes happening in the global epidemiological profile. These changes arise from alterations in habits and lifestyle, increased life expectancy, reduced infant mortality, effective treatment of infectious diseases, expansion of vaccination programs, improved prenatal care, and oral rehydration therapy for acute diarrhea.⁵⁻⁶

Ministry of Health data show that, in 2004, 74.7% of the causes of death were due to non-transmissible chronic diseases. In Brazil, these diseases have started, in recent decades, to determine the most frequent causes of premature death and premature disability, overtaking the rates of mortality for infectious and parasitic diseases. In

2005, deaths from non-transmissible diseases came to represent two thirds of the total of the known causes.⁷ In this sense, the chronic diseases currently constitute a subject of great concern for healthcare professionals, due to their limiting aspects and the consequences of their treatment, even being outpatient treatment, causing distress and suffering for the affected person,⁸ as well as their family.

Children and adolescents with chronic conditions often have alterations triggered in their growth and development process, mainly due to the aggressiveness of the established therapeutic model. Children and adolescents with chronic kidney disease, in addition to these aspects, have the associated risk of disease progression and failure of their kidney function, leading to even more serious complications.

Therefore, it was asked whether the knowledge that the children and adolescents with chronic kidney disease have about their illness, and self care requirements related to it, gives them a foundation for the continuation of the therapy in a way that is appropriate and prevents relapses. Therefore, it is necessary that healthcare professionals be aware of the need for the investigation of the necessity for self care of adolescents and children in order to implement interventions that address the singularity of each specific moment. For the individuals with chronic diseases, when they assume an active role in the health-disease process, they contribute to the reduction of recurrent hospitalizations and of suffering resulting from these.⁹ Thus, it may be comprehended that in order to promote a better quality of life in their process of adaptation and the course of disease, the guidance of the child/adolescent and their family is of great value for the improvement of their clinical condition and control of the disease. Given this situation, it is essential to investigate the self care necessity in children and adolescents with chronic kidney disease as a basis for the implementation of measures that promote self care within the human necessities of these individuals.

Thus, it was asked: what are the deficits in the self care requirements in children and adolescents with chronic kidney disease? Is it possible to develop interventions that minimize these deficits? Given these questions, this study aimed to: investigate the self care requirements in the health deviations associated with chronic kidney disease, in children and adolescents, in light of the theoretical framework of Orem, to identify nursing diagnoses

in the self care deficits with assistance from the International Classification for Nursing Practice (ICNP®), and to develop interventions, with the child/adolescent, at the moment of the identification of the deficits in the self care requirements.

METHODOLOGY

In order to investigate the self care deficits in children and adolescents with chronic kidney disease a qualitative approach was used of the exploratory-descriptive type. This method was chosen because it allows the revelation of little known social processes relating to particular groups,¹⁰ as well as providing greater familiarity with the object of study in order to make it explicit or to constitute hypotheses.¹¹

The study was conducted at the Pediatric Outpatient Clinic of a teaching hospital, located in the municipality of João Pessoa-PB, in the period between October and December 2009. The service was chosen because it is a reference in the state for the care of children and adolescents with chronic kidney disease, as well as due to the existence of academic and/or employment links between the researchers and the institution.

The universe considered for this study was, children and/or adolescents diagnosed with chronic kidney disease treated at the unit in question. For the selection of the participants, the following criteria were considered: to be present for consultation during the period of data collection, to have a history of chronic kidney disease for more than one year, aged between seven and 18 years and accompanied by the caregiver.

The study was conducted taking into consideration the ethical aspects of research involving human beings, as recommended by Resolution No. 196/96 of the National Health Counsel.¹² The research project was evaluated by the Ethics Committee of the Hospital, which the outpatient clinic is linked to, and approved according to protocol No. 223/09. In addition to the ethical and legal guarantees recommended in the Resolution, the participation of each child/adolescent was conditional upon the signing of the Terms of Free Prior Informed Consent by their legal representative, after the agreement and acceptance of it, releasing the child to participate in the study.

Data collection was conducted through means of semi-structured interviews with the child/adolescent and their companion, it is rel-

evant to mention that during the interview the companion was asked to confirm the data related to the time of diagnosis and the family income. The data collection instrument was based on the General Theory of Nursing,¹³ since it aimed to investigate the self care requirements in the health deviations associated with chronic kidney disease in children and adolescents, in light of the theoretical framework of Orem. The data were recorded on electronic media (MP3), with the aid of a field diary to avoid forgetfulness, considering recording criteria such as clarity, reliability and legibility.

Before the data collection began, the researcher was present at the Pediatric Outpatient Clinic, at the moment that preceded the consultation with the nephrologist of the service, which was used to initiate contact with the child/adolescent and companion. This contact was intended for the introduction of the researcher and presentation of the Term of Free Prior Informed Consent of the study.

Even before the consultation with the nephrologist the interview was started with those who had agreed to participate in the investigation. At the same time as the interviews were conducted and the self care deficits of children/adolescents with chronic kidney disease identified, nursing interventions were implemented, which were directed toward the children and, consequently, their companions, since some interventions needed the involvement and the comprehension of the caregivers in order to be performed.

The interviews were transcribed and, using the notes in the field diary, the history of the child was constructed, which was used in an attempt to deepen the discussions regarding the self care requirements identified during the interview, associated with the chronic kidney diseases. Next, the nursing diagnoses related to each *deficit* were identified, with the aid of the ICNP®. After the identification of the diagnoses more interventions were formulated, in order to contribute to the care of other children, since the publication of the study also has this purpose.

The ICNP® version 1.0 is presented in a classification structure comprised of seven axis, through which the nursing diagnoses, interventions, and outcomes can be constructed. The ICNP® is a system of unified nursing language, instrumental terminology for the nursing practice that facilitates cross-combination of local terms with the existing terminology.¹⁴⁻¹⁵ In the Seven-Axis Model, for the construction of statements of the

nursing diagnoses and outcomes, a term of the Focus Axis is used, with one of the Judgment Axis and, if necessary, additional terms of the Focus, Judgment or other Axes.¹⁴

RESULTS AND DISCUSSION

The study was conducted with four female children, with ages ranging between eight and 13 years; all residents of the state of Paraíba. The subjects arrived at the study hospital to define the diagnosis or to continue treatment and, from then, continued going there to perform monthly or semi-monthly outpatient consultations; the schedule established due to the progression or control of the disease. The children/adolescents had a confirmed diagnosis of Chronic Kidney Disease, Glomerulonephritis and two had a diagnosis of Nephrotic Syndrome. The length of treatment and monitoring of the children/adolescents was from a minimum of four years to a maximum of 10 years. Furthermore, they were from low income families.

Considering the described self care requirements, to assess the history of the children/adolescents, it can be inferred that the self care requirements of these subjects are not found in isolation, on the contrary, they are interlinked, since the children experience a pathological process in a period of life where they go through physical and psychological changes, in addition to expanding their relational bonds.

Universal self care requirement

Through the analysis of the histories of the children and adolescents the nursing diagnoses in the following universal self care requirements were identified: demand/maintenance of a sufficient intake of food (risk for nutritional deficit), alteration in the promotion of the functioning and development of the human being/potential and in the limitations and desires to be normal (negative self-image).

The universal self care requirements are essential for all human beings and are present at all the phases of the life cycle, considering that they are associated with maintaining the integrity and functioning of the human body and general well-being. These requirements correspond to: sufficient inhalation of air and ingestion of food and water, provision of care associated with the processes of elimination and excretion; maintaining a balance between activity and rest and

between solitude and social integration; prevention of damage to life, to the functioning and to the well-being; promotion of human functioning and development in social groups according to the potential, known limitations and the desire to be normal.¹³⁻¹⁶

Food intake is one of the factors responsible for adequate growth and development during infancy. For this reason, the risk for nutritional deficit is a nursing diagnosis that should be monitored, in order to minimize the risks of complication. The need for feeding involves restrictions and re-adaptations to the lifestyle of a child/adolescent affected by chronic kidney disease, which can compromise the nutritional status of the child. Furthermore, rapid intervention in nutritional support can minimize the impact, leading to clinical benefits, even in the absence of an effective treatment for the underlying condition.¹⁷

By analyzing the histories it can be perceived that the children/adolescents and their caregivers were aware of the need to follow a differentiated diet. However, this adaptation in the lifestyle was not always adopted. Therefore, it is important that these children/adolescents and their family members have accurate information regarding the importance of following the diet indicated, with the need for dietary restrictions and the problems arising from failure to follow this guidance being made clear. Given the above, nursing interventions are needed, such as dietary guidance for the children/adolescents with chronic kidney disease and their caregivers, using clear and easy to comprehend language, encouraging the development and practice of self care, in order to make them active members in the health-disease process.

The self-image is the view that each individual has of himself, including the shape, size, body proportions, the feelings in relation to it and its parts according to their individual judgment. The self-image emerges in the interaction of people with their social context, stemming from established relationships with others and oneself, being regarded as the knowledge and recognition that we have of ourselves, how we sense our potentials, feelings, attitudes and ideals, the most realistic possible image, finally, what we make of ourselves.¹⁸

Children/adolescents affected by chronic kidney disease experience many limitations in the quotidian and constant adaptations, beyond the necessity of submission to pharmacological

therapy. Therapeutics that, in the majority of cases, causes reactions reflected in the bodily image.¹ In this way, the self-image may be compromised and reflected in the feelings of difference in relation to others, especially in adolescents.

The compromised self-image in the children/adolescents, accompanied in this study, was identified in the statements of discomfort with their own bodies, when they feel fat and are considered as such, or perceive themselves as having a smaller stature than others of the same age group. This perception of self can be reflected in the quality of life and in the self-esteem of these children, since they are at the stage of psychological development and in the process of formulation of this perception.

Aiming to reduce the losses originating from the perception of the self-image, the nurse can inform the child/adolescent and the parent about the effects that the disease and the pharmacological treatment can cause in the life of the child, especially those that are visible to their eyes and the eyes of others, such as bodily changes. Furthermore, it is important to encourage the child/adolescent to share their fears, their anxieties and dissatisfactions about their image with their caregiver and with the professionals responsible for their monitoring.

Requirement of developmental self care

Deficits in the requirements of developmental self care were confirmed, with the identification of the nursing diagnosis of inadequate growth, in the children/adolescents involved in this study.

The requirements of developmental self care correspond to the demands that occur during the adaptations related to normal situations or to crises during the life cycle, such as infancy, adulthood and aging, pregnancy and childbirth, situations of marriage, divorce or separation, and situations of changes in the life course¹³.

Infant growth constitutes a continuous process with specific characteristics in each phase of life which are influenced by various factors, among which are included the endogenous, which relate to biological, genetic and ethnic determinants; and the exogenous, related to the nutritional, cultural, environmental and social conditions.¹⁹

Among the problems triggered by these factors, chronic disease is highlighted, because it provokes significant changes in the renal structure and in the production of substances that

help the growth spurt, such as growth factor, or the hematologic function, such as erythropoietin, which stimulates the formation of erythrocytes and with this improves cellular oxygenation and, consequently, provides adequate nutrition for the cell. Because of this, the earlier the children present renal alterations, the greater the alterations in their rhythm of growth, weight/height ratio and neurological development.²⁰

Chronic kidney disease affects the growth of children and adolescents compromising the organs directly and indirectly involved with the disease, due to inadequate nutrition, malabsorption, increased catabolism, the associated complications and infections, and the effects of the treatment of the disease.²¹

An important aspect to direct the nursing actions toward the children with chronic kidney disease is aimed at preventing inadequate growth. Accordingly, the guidance for these families should emphasize treatment and nutrition and requires the professionals to involve themselves in the process, so that they feel co-responsible for the evolution of the growth of the children, with minimal compromise.

Self care in the health deviations

During this study, it was realized that the effective control of the prescribed therapy is not always achieved, as exemplified in the statements of some children, where they related that they do not properly follow the suggested diet and do not observe the effects of treatment.

The requirements of health deviations relate to functional and genetic problems as well as to the medical diagnosis and means of treatment.²² These occur when individuals find themselves in situations where they do not react to an event of loss of sensation or where they do not control their functions and potentials of self care, for example: when they are sick, have accidents, are incapacitated or are under medical diagnosis or medical treatment.¹⁸ Considering these statements, the following nursing diagnoses were identified: Ineffective management of therapeutic regimen related to not following the recommended diet and deficient health knowledge related to not understanding the precise diagnosis.

The ineffective management of the therapeutic regimen occurs when the individual, affected by a particular acute or chronic disease, is subjected to treatments that require alterations in functioning,

or in the previous lifestyle, and cannot integrate these adjustments into their routine, in addition to not staying attentive to the results and/or discomfort presented. These changes arise from the use of medication, alterations in eating habits, and inclusion of exercises in daily life, among others.⁷

Children/adolescents with a chronic disease should be aware of the need to follow the treatment plans that are being submitted avoiding, in this way, some harm that may arise, such as an exacerbation of the disease and difficulties to achieve a cure or to stabilize it. For this to be achieved, the child/adolescent must have the support and guidance of the parent/guardian, who should also receive support from the healthcare professionals through educational activities. Health education is fundamental to nursing care, as it may determine how individuals and families are able to perform the behavior that leads to self care.²³

Healthcare professionals, by identifying the factors that cause or contribute to the impairment of the efficacy of this control, can collaborate by providing simple and direct instructions to the child/adolescent and caregiver on how to control the therapeutic regimen, making them actively participate in the care. Deficient health knowledge was another nursing diagnosis identified in the self care requirement in the health deviations. It can be said that this relationship arises from the lack of control of the disease and the absence of the family members in the decision-making processes regarding the disease and the treatment.

Knowledge about the health-disease process provides a feeling of greater control and responsibility regarding health, encouraging one to assume an active role in the management of their health. It is worth noting that it is necessary that healthcare professionals understand how the client interprets their illness, as it is the client who deals with it daily and learns the pattern of their symptoms.⁹

The child/adolescent with a chronic disease and their caregivers accumulate knowledge about the chronic disease and how to perform self care in diverse ways. This knowledge is constructed from popular beliefs, personal experiences or experiences of others who surround them, as well as from information obtained from healthcare professionals and the media.⁹ However, it is necessary to remember that their socioeconomic and education levels directly influence this process. Therefore, it is necessary for care actions to be performed with flexibility, through interactive dialogue that comprehends the process experienced by the family.²⁴

Considering that Orem's theory proposes the participation of the individual in the health-care process in a conscious and enlightened way, since, as the child does not yet completely have this capacity, it is the duty of those responsible for the care of the child to assume the condition of therapeutic self care agents. In this process, the agents have the function of providing the necessary self care for themselves or for another person, receiving ontogenetic, cultural and experimental support influences.¹² With the nursing actions being directed more towards guidance and clarification for the parents, children and adolescents, the interventions will be performed in the educational supportive system, which, according to Orem's theory, is applied when the client needs nursing assistance to acquire knowledge and skill.¹³

FINAL CONSIDERATIONS

Orem's Theory helps to identify that chronic kidney disease provokes significant modifications in the life of the child, the adolescent and their family members, often requiring from these people radical changes in their lifestyles. However, it is necessary that they possess adequate tools to deal with the situations provoked by the disease, which corresponds to access to information, guidance and materials to assist in the observation and control of the disease. Information regarding the conditions of health-disease is essential for the individual with chronic kidney disease and/or for their caregiver. Thus, they may become responsible for the care in the individual and social context, being able to make important decisions about health behavior that are more favorable, leading to a better quality of life.

The study showed that, among the modifications necessary in the quotidian of the child/adolescent, the differentiated diet is the most difficult to follow. It was perceived that alterations in the self-image and the growth of the child/adolescent are reasons for discomfort during the experience of the disease. Furthermore, it was identified that, although the information related to the diseases is easily accessible and provided by the healthcare professionals, there were still people who did not know the chronic condition of the child in its entirety, a situation that is perceived to be related to the level of literacy. It can be inferred that the way that this information is being transmitted by the professionals is inadequate for the comprehension of the families.

The guidance regarding self care dispensed by the nurse to children/adolescents and their family members must be in accessible language and be easily understandable, considering the totality and singularity of these individuals. In this way, it could be possible to encounter ways for the children/adolescents with chronic kidney disease to be co-responsible in their care process, able to cope, with the help of their caregivers, with changes in their quotidian for the pursuit of their well being.

To implement health education actions it is important that favorable environments are reserved for the exchange of information and that the nurse uses and develops sensitivity to meet the care needs. Thus, there are tools to identify the needs of each individual, allowing the choice of effective methods to reduce the cultural distance between children/adolescents, their caregiver and the nurse.

It is noteworthy that one of the limitations of this study was the number of participants. However, the findings open up a range of possibilities for the development of other studies that, whether targeted towards constructing educational strategies or towards developing horizontal educational programs, include the exchange of values in order to demonstrate an appropriate pathway in the care process.

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