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Crianças e adolescentes renais crônicos em espaço educativo-terapêutico: subsídios para o cuidado
cultural de enfermagem

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Children and adolescents with chronic kidney disease in an educational-therapeutic environment: support for cultural nursing care*

CRIANÇAS E ADOLESCENTES RENAI CRÔNICOS EM ESPAÇO EDUCATIVO-TERAPÊUTICO: SUBSÍDIOS PARA O CUIDADO CULTURAL DE ENFERMAGEM

NIÑOS Y ADOLESCENTES RENALES CRÓNICOS EN ESPACIO EDUCATIVO-TERAPÉUTICO: AYUDAS PARA EL CUIDADO CULTURAL DE ENFERMERÍA

Viviane Peixoto dos Santos Pennafort¹, Maria Veraci Oliveira Queiroz², Maria Salete Bessa Jorge³

ABSTRACT

This qualitative study was performed using an ethnographic approach, with the objective to understand how children and adolescents with chronic kidney disease experience their disease and treatment, and describe the educational-therapeutic care from the perspective of transcultural nursing. Participants were eleven subjects undergoing dialysis treatment. The study phases followed the observation-participation-reflection model, complemented by interviews. The analysis was guided by the four phases of the ethnonursing guide, revealing the following categories: living with kidney failure and changes in daily life; and the hospital environment and educational-therapeutic activities, which show the discomforts and difficulties that impact several dimensions of life, somewhat compensated by the therapeutic environment and the opportunity for leisure. Culturally consistent care was understood as an intentional intervention constructed by the interaction between scientific knowledge and the valorization of the cultural knowledge of children and adolescents and their families.

DESCRIPTORS

Child
Adolescent
Renal insufficiency, chronic
Transcultural nursing
Nursing care

RESUMO

Trata-se de estudo qualitativo na abordagem etnográfica, cujos objetivos foram compreender como crianças e adolescentes com doença renal crônica vivenciam o adoecimento e a terapêutica e descrever o cuidado educativo-terapêutico no enfoque da enfermagem transcultural. Participaram onze sujeitos em tratamento dialítico. As fases da pesquisa seguiram o modelo observação-participação-reflexão complementado com a entrevista. A análise foi orientada pelas quatro fases do guia da etnoenfermagem, emergindo as categorias: convivência com a insuficiência renal e mudanças no cotidiano; ambiente hospitalar e atividades educativo-terapêuticas, as quais mostram desconfortos e dificuldades em várias dimensões da vida de certa forma compensados pelo ambiente terapêutico e oferta de lazer. O cuidar culturalmente congruente foi entendido como uma ação intencional construída pela interação entre os saberes científicos e a valorização dos saberes culturais das crianças e adolescentes e de suas famílias

DESCRIPTORES

Criança
Adolescente
Insuficiência renal crônica
Enfermagem transcultural
Cuidados de enfermagem

RESUMEN

Estudio cualitativo de abordaje etnográfico que objetivó comprender el modo en que niños y adolescentes con enfermedad renal crónica experimentan el padecimiento y la terapéutica, y describir el cuidado educativo-terapéutico en el enfoque de enfermería transcultural. Participaron 11 sujetos en tratamiento dialítico. Las fases de la investigación siguieron el modelo observación-participación-reflexión, complementado con entrevista. El análisis se orientó por las cuatro fases guía de la etnoenfermería, emergiendo las categorías: convivencia con la insuficiencia renal y cambios en el cotidiano; ambiente hospitalario y actividades educativo-terapéuticas, las cuales mostraron incomodidades y dificultades en varias dimensiones de la vida, en cierto grado compensadas por el ambiente terapéutico y la oferta de recreación. El cuidado culturalmente congruente se interpretó como acción intencional construida por la interacción entre los conocimientos científicos y la valorización de los conocimientos culturales de los niños y adolescentes y de sus familias.

DESCRIPTORES

Niño
Adolescente
Insuficiencia renal crónica
Enfermería transcultural
Atención de enfermería

* Extracted from the thesis "Vivências de crianças e adolescentes com doença renal crônica: aproximações com o cuidado cultural", State University of Ceará, 2010. ¹ RN. Doctoral student, Graduate Program in Clinical Care in Health and Nursing, State University of Ceará. Fortaleza, CE, Brazil. vivipsf@yahoo.com.br ² RN. PhD in Nursing. Professor, Academic Master's Program in Clinical Care in Health and Professional Master's Program in Child and Adolescent Health, State University of Ceará. CNPq Fellowship. Fortaleza, CE, Brazil. veracioq@hotmail.com ³ RN. PhD in Nursing. Coordinator, Doctoral Program in Collective Health, State University of Ceará and Federal University of Ceará. CNPq Fellowship. Fortaleza, CE, Brazil. masabejo@uece

INTRODUCTION

Chronic Renal Failure (CRF) generally develops after a renal injury followed by a slow, progressive and irreversible loss of kidney function. The diagnosis is based on the identification of risk groups, the presence of microalbuminuria, proteinuria, hematuria, and a reduced glomerular filtration rate, assessed through a laboratory test called creatinine clearance⁽¹⁾.

The first records concerning renal failure during childhood date from the 19th century with the Henoch-Schönlein purpura, bladder exstrophy, and nephritis. Pediatric Nephrology, as a specialty, was developed and established in the 20th century⁽²⁾.

In this context, a cohort study conducted in 2003 observed that the incidence of Terminal Chronic Renal Failure (TCRF) among children and adolescents under dialysis was of 15 patients per one million of inhabitants, similar to the incidence (15.5) observed in European countries⁽²⁾.

About 1.2 million people worldwide live with hemodialysis. There are approximately 70,872 patients in Brazil, 90.7% of which are under hemodialysis while 9.3% are under peritoneal dialysis; 1.5% of these are patients younger than 18 years of age. The etiology and incidence of CRF vary according to age. The most frequent causes among children younger than five years old are malformations (congenital) of the urinary tract, while acquired and hereditary kidney diseases predominate among individuals five to 15 years old⁽³⁾.

Despite the apparently low incidence and prevalence of the disease among this population, extensive care and materials, are required by these patients, in addition to medication that is expensive to the State, especially when under dialysis or after renal transplantation⁽⁴⁾.

Chronic kidney disease has a dimension permeated by meanings in the lives of children and adolescents that is manifested in the course of hospitalization and other stages of treatment. The child perceives the severity of the chronic disease and knows the procedures performed and side effects of some medication and tries to understand and justify them⁽⁵⁾.

It is essential in the context of hospital care that the nursing staff understand that rigid routines and extremely painful procedures isolate and terrify children and adolescents in different ways because these events may harm their active participation in the therapeutic process. Therefore, nurses should share knowledge that enables care through affective and cognitive activities that recog-

nize the patients' subjectivity through therapeutic educational practices and professional-patient interaction.

Health education is a strategy that enables such an approach and implies educational principles that facilitate understanding the daily lives of patients, that is, understanding the human being in his/her various dimensions and not only in the biological aspect, the aspect most commonly valued in one's professional practice⁽⁶⁾.

Educational practices are assumed to be an innovative way to encourage conscious and intentional attitudes of those involved, in addition to encouraging the valorization and recognition of one's rights and citizenship⁽¹⁸⁾. For that, the knowledge held by individuals should be taken into account in the learning process⁽⁷⁾.

Offering opportunities for children to express themselves so that suffering is bearable is a duty of nurses⁽⁸⁾. In this sense, it is essential to establish a connection between the individual's history and his/her subjective constitution as a being of language. Thus, nursing interventions go beyond their instrumental nature and permeate a connection between professional expertise and patients' lay knowledge through attentive listening and the active participation of those involved.

The cultural approach in nursing presents the Theory of Cultural Care Diversity and Universality, which assumes that health is understood in either a subjective or objective conception of the perception of body and its interaction with the context experienced, which influences individuals or groups in decision-making concerning care. The development of the theory makes it apparent that health care is enacted through two systems, the lay (folk) and professional. The local system, the system of traditions, is considered to be the lay system in which the family and community are included. The professional system

of cure and care is developed in specialized services provided by health workers in health facilities. Health in these systems is a perceived or cognitive state of well being, which qualifies the individual or group to perform activities according to standards desired in a given culture⁽⁹⁾.

The actions and care provided to individuals with kidney disease and their families, as well as the studies addressing the experiences of these individuals in the face of a chronic disease, are still scarce in the context of Nephrology nursing. Nurses perhaps ignore the fact that beliefs emerge from meanings developed by the patients and their families concerning chronic disease. These beliefs influence decision-making, actions and behavior, which result in health workers constantly imposing care procedures that are disconnected from the care in which families believe and adopt⁽¹⁰⁾.

It is essential in the context of hospital care that the nursing staff understand that rigid routines and extremely painful procedures isolate and terrify children and adolescents in different ways because these events may harm their active participation in the therapeutic process.

Therefore, it is worth keeping in mind that the health-disease continuum of individuals, families and groups is culture-bound. Thus, nurses should analyze the individuals' cultural context and verify whether professional care is similar to care provided by the family, taking into account the patient's culture while providing care⁽⁹⁾.

It is believed that studies addressing the experiences of patients with the disease and hospitalization can support cultural care. In this context, the theoretical-philosophical assumptions, described in the Theory of Cultural Care Diversity and Universality based on Cultural Anthropology provide important fundamentals for the investigation of these experiences, supporting nursing care provided to children and adolescents with chronic renal failure.

Given the previous discussion, this study sought to reveal the routines of children and adolescents with CRF undergoing dialysis from a cultural perspective. This approach is relevant in the fields of care and education and can support actions appropriate to the needs of this clientele.

The following objectives were pursued in the development of this study: to understand how children and adolescents with chronic renal disease experience the disease and the treatment and describe actions within educational and/or therapeutic care with a focus on cross-cultural nursing.

METHOD

This is a qualitative study with an ethnographic approach, based on the assumptions of the Theory of Cultural Care Diversity and Universality, the method of which is called ethnonursing. Ethnonursing has played an important role in modern nursing when the objective is to acquire a cultural perspective of the phenomenon⁽⁹⁾.

The field research was developed from July to October 2009 by the primary researcher in the study's setting. The first contact was established with the Nephrology clinic where the patients were undergoing dialysis. Then, the primary researcher visited the households of some children and adolescents to collect complementary information. The studied clinic is a private facility located in Fortaleza, CE, Brazil, linked to the Brazilian Single Health System (SUS), which specializes in the diagnosis and treatment of chronic renal failure in children and adolescents. A total of 205 chronic renal patients were enrolled in the clinic at the time of data collection. Of these, 33 were children and adolescents undergoing dialysis in different modalities of renal replacement therapy.

Subjective information was captured through participant observation and interviews with subjective questions, held with 11 individuals intentionally chosen who met the inclusion criteria: children seven years old or older and adolescents between 12 and 18 years⁽¹¹⁾ old with a diagnosis of CRF undergoing dialysis for at least one month.

A direct search of children and adolescents only included those informants who showed full interest and the conditions necessary to participate, after receiving clarification of the study's objectives, purpose and how they would participate. A free and informed consent form was read, seen to be understood and signed by the participants and their legal guardians.

The observation-participation-reflection model was used in data collection. This technique favored various phases of observation, that is, from general observation to the time of observation-participation and, finally, observation with reflection. In addition to observation, the researcher participated in the informants' activities and daily situations, favoring interaction and communication. Thus, the researcher could capture information that was not clear in the informant's verbal report⁽⁹⁾.

During the observation-participation phase, a semi-structured interview was conducted based on the following: *Please describe your daily life considering the disease and treatment; What do you need to do to comply with your treatment and prescribed care when you are at home?; What do you like to do at home and at the hospital?; and What activities are provided at the hospital that help you with self-care?*

The interviews were recorded with an MP4 player due to the facility to store and reproduce interviews on computer, which facilitated listening and transcription. All the interviews were held in a private room in the dialysis unit, in accordance with the decision of the participants or their families, and took an average of 40 minutes each.

A guide was used to analyze qualitative information, which was composed of the following phases: transcription, description, and documentation of information; identification, categorization, and codification of meaning units; grouping of categories and contextual analysis; identification of themes and description of actions and nursing decisions for cultural care⁽⁹⁾.

A theme emerged from the analytical procedures previously described: *children and adolescents with CRF and the educational-therapeutic space: actions and decisions for nursing cultural care* and two categories: *living with CRF and changes in daily life* and *the hospital environment as health promoter*.

The study rigorously followed the requirements of Resolution No. 196/96, which define the guidelines and regulate standards for research involving human subjects⁽¹²⁾. The study was submitted to the Ethics Research Committee at the State University of Ceará and to the Board of Directors of the facility where the study was conducted. Data collection was initiated only after the Ethics Committee approved the study (protocol 08670492-3) and authorization was obtained from the facility's legal representative. The participants were identified by the letter I (Interviewee) followed by a number according to the sequence of interview I1...I11.

RESULTS

Characterization of the study's participants

Among the 11 participants undergoing dialysis, three were children aged 10 or 11 years and eight were adolescents aged from 13 to 18 years old; thus, most participants were adolescents. Three participants were male and eight were female.

In regard to their origin, six were from cities in the state of Ceará and five were from the capital Fortaleza, CE, Brazil. Self-reported family income ranged from one to two times the minimum wage. Only one adolescent cohabitated with a partner and lived with her mother; all the remaining were single and lived either with parents or relatives. One child lived in a hospital for one year because she was awaiting the construction of one bedroom and one bathroom to perform dialysis at home.

Chronic renal patients who were children and adolescents in the therapeutic-educational space: actions and decision for cultural care in nursing was expressed by two categories that emerged from the analyzed testimonies: "Living with renal failure and changes in daily life" and "Hospital environment and educational-therapeutic activities".

Living with renal failure and changes in daily life

The first category that emerged from the observation-participation-reflection phases expressed the experience of the individuals with kidney disease, the changes that had occurred in daily life since the onset of the disease, and the repercussions for the various dimensions of life. These were visions of the world constructed in the social-family and professional interactions were manifested in the units of meanings: transformed body; life habits; being distant from school routine; experiencing leisure; difficulties faced; family support; beliefs in the search for a cure.

The children and adolescents re-signified the transformed body due to the presence of scars caused by the various invasive procedures they had already experienced. The participants reported the people's prejudice and how people become annoyed by the presence of visible catheters, fistulas and bandages.

I have several scars on my body because of the treatment and also because I already had a kidney removed; I already had a catheter in my tummy and the doctor put another in my neck when I underwent hemodialysis; it was pretty bad, hurt a lot, bled, and the bandage the nurses applied would get stuck in my hair, now the fistula is better (...) I no longer like to go to the beach because of them (I6).

This fistula, many people ask what it is and some had already asked me if it was a tumor, I've said no, that it was a vein for hemodialysis, people are afraid of getting the disease, I become embarrassed when people stare (I8).

Habits of life were another unit of meaning present in the participants' reports concerning the daily changes involving diet and the restriction of fluids, personal hygiene and sleep patterns.

I eat rice, string beans, pasta, I just can't drink too much water or juice, this is the worse, having to bear thirst, I can't drink too much water otherwise I get sick (I3).

When I realized I'd stopped urinating... I no longer urinate, it is weird, I haven't got used to it yet (I7).

Taking a shower by myself is still hard; I'm still afraid of pulling the catheter or not drying it properly, and of getting an infection (I2).

I always slept on a hammock, but when I had to do hemodialysis my mother bought a bed for me so I'd not sleep over this arm with the fistula (I1).

Being removed from the school routine was apparent in all the individuals who considered it to be a loss not only of formal education but also a loss of other opportunities to learn, such as making friends and moments of distraction.

I'm not attending school this year, I study at home and sometimes my friend brings homework for me and I do it at home, but it is not the same as going to school or hanging out with friends (I4).

In experiencing leisure, the individuals listed the essential requirements for their social-educational development, and emphasized contact with friends, boyfriends, girlfriends, neighbors and with religious groups as meaningful moments for recreation and leisure.

My boyfriend is a very nice person, we go to the park near my house, we go to the church with our friends, but we don't go to places where there are too many people; I'd rather stay in calmer places, I feel better (I7).

I go to church every week, I sing in the church choir, together with the girls; when I'm home, I go out onto the porch and talk to my neighbors (I1).

Another unit of meaning present in the category *living with the disease* was difficulties faced by the patients and their families and refers to commuting to the dialysis clinic or hospital. Financial and living conditions were also reported as aspects that hampered treatment and continuous follow-up in the dialysis clinic.

I need to wake up at 3am to get to the clinic at 6am and sometimes I still arrive late; it takes a lot of time to get back home, too, and on the days I don't do dialysis, I need to get back here (Fortaleza) to have the tests required for transplantation, it tires me out but I have to come (I4).

I'm living in the hospital in Banabuiú (a city close to the capital) because my father still doesn't have money to finish my bedroom so I can do the dialysis at home, and he also needs to build a bathroom (I11).

Adolescent I1 reported in the visit to her home that collective transportation, considered to be of poor quality, was the only means of transportation used by her family. The adolescent and her mother took two hours on average to get to the dialysis unit due the lack of public transportation.

Family support was the unit of meaning in which the individuals expressed the importance of their family getting involved and helping with the dialysis treatment.

My mother leaves everything to take care of me; she takes me to dialysis, to the exams; I like her very much and appreciate every effort she makes for me; she's my best friend, the only person who really supports me; I count on her for everything, I trust her a lot (I10).

My family became very concerned with me; my mother stays with me all the time, my father is preparing the room where I'll have dialysis when I get back home (I2).

The testimony of I6, an adolescent, drew attention. She reported having no support from her brothers, as her father lived in another city in Ceará and her mother had already passed away. She voiced contempt and sadness for not having a relative with whom to share her concerns and burden from the treatment.

So I don't have the support of my father anymore because he is in the country taking care of his things (...) I no longer have my mother; it is very sad not having their support at this time, I currently need my brothers a lot, but they don't care about me (...) I have two brothers who don't help me with anything, they don't understand my treatment; they are even violent with me, they've already beat me when I started dating, they are ignorant, you know how people from the country are. I feel so lonely having to take care of everything by myself (I6).

In regard to belief in the search for a cure, the participants highlighted faith and superstitions such as a possibility of improvement or even cure.

I was thinking today that God is in everything... today I'm in the church, I keep praying and wish everyone would do the same, go to the church, pray and ask God for cure, because it may not be today or even tomorrow, but in each prayer, Jesus has already scheduled an hour and day that will be the day of our miracle (I1).

They could not find out what I had, then my father and my mother took me to a prayer to see if he could see what I had and cure me; he's like a macumbeiro^(a). To see whether I had some evil spirit, you know? Only that it wasn't it, I kept swelling, I'm evangelical now because I know Jesus can do anything, I was almost dying, I stayed in the ICU for 15 days, I'm ok now but want to get better (I6).

^(a) A member of a religious cult of African origin.

Hospital environment and educational-therapeutic activities

The second category comprised the units of meanings in which the individuals expressed pleasure, satisfaction and social rights promoted within the hospital environment, which were represented by playful-pedagogical and recreational activities, and social benefits.

The participants reported participating in playful-pedagogical and recreational activities developed by the *Education and Health in Discovering Learning* project carried out during dialysis sessions or in the waiting room before attending medical consultations or peritoneal dialysis training provided by nurses.

The activities promoted here (the dialysis unit) by the people from UNIFOR are also very good; they help a lot when we are sad, they come and cheer everybody up; they talk to us, bring a drawing to color, ask to write a message about some subject, I've already wrote about disability, about kidney disease, about our lives; I even forget I'm doing dialysis when they come here (I10).

The children and adolescents highlighted the moments of relaxation promoted by the facility, spoke about the excursions, parties, and gifts they received.

Every year X organizes Easter parties, children's day, Christmas, it's very good; I've also went to the ballet presented at UNIFOR also; it was beautiful, I'd never saw it before, I loved it. Last year we went to the beach, rode in a tram, it was really fun (I1).

I like it here a lot; you saw our children's day party in the mall, didn't you? Every year the personnel from the clinic prepare a party for us, we get gifts, take a ride, it is a very good opportunity because I don't have money to go out, to go to these places they take us (I4).

The participants acknowledged the social benefits as being essential; they mentioned that the facility provided dialysis patients with a food basket every month and also with what is called the Continuous Cash Benefit, which amounts to one times the minimum wage.

I don't know how my life and that of my family would be if I didn't have the benefit and the food basket because my mother can't work, she has to accompany me (I1).

With the money I get every month, it's not much, but I can buy the most important things such as medication and food to help with the expenses at my uncle's house and I can also send a little bit to my father in the country; I know he also needs it (I6).

DISCUSSION

In regard to the first category, Living with renal failure and changes in daily life, body change was reported as one of the difficulties faced by those undergoing hemodialysis

due to the need to implement an arteriovenous fistula or insert a double lumen catheter⁽¹³⁾. Changed self-image is also observed among patients who undergo peritoneal dialysis because of the presence of a Teckhoff catheter. These procedures become an aggravating factor against treatment acceptance.

The participants' testimonies show that the consequences of these alterations for body image caused curiosity in people and were also motives for discrimination, which in turn caused suffering, discomfort, distress, shame and embarrassment, leading to social isolation and low self-esteem.

One study shows that chronic renal patients experience many limitations; a restricted diet is an additional burden among such limitations. Nutritional restrictions and recommendations are probably the most difficult part of treatment because they may alter one's life style and contradict one's preferences, food habits and also cultural aspects. Long-term adherence to a diet is a challenge for chronic renal patients, though counseling could optimize the process⁽¹⁾.

In addition to constraints, some characteristic symptoms of CRF such as urine output (oliguria and anuria) were considered to be strange and patients were trying to get used to them. The way personal hygiene is performed also changed due to the presence of means of access for dialysis.

In regard to sleep, the need to replace the hammock with a bed so the patient would not lie on his fistula or catheter revealed that this individual had to abandon a very common manner of sleeping in the state of Ceará to adapt to the treatment requirements.

School stood out among the daily activities of children with CRF in this age range, which means that changes are more intensively experienced. Social relationships take place in the school environment and these patients miss them⁽¹⁴⁾. The participants expressed the desire to keep studying and the difficulties they had to face due to the therapy.

A study performed with children and adolescents with chronic disease verified that the disease has repercussions for the lives of patients in changes to their routines, since the treatment requires frequent visits to the hospital for ambulatory return visits, exams and hospitalizations. These transformations imposed by the disease and treatment directly interfere in school adaptation and socialization, compromising school attendance, self-esteem, and, consequently, relationships with classmates and teachers⁽⁵⁾.

The testimonies show that the centralization of services in large urban centers limits access to dialysis units due to the distance and conditions of transportation, directly contradicting the principle of constant integrality provided for in the current Brazilian Constitution. Difficult access to the health system is frequently observed and depends on complex political cooperation at the city, state and federal levels.

The studied individuals attributed meanings to affective relationships because they value friendship and show satisfaction and joy when they have the presence of significant people in their lives; social interaction provides them some moments of leisure. It is noteworthy that reports reveal that recreation, conversations and distractions occurred naturally when these individuals were together with groups to which they belonged.

Family support was perceived through the attention and dedication to and involvement of family caregivers with the children and adolescents undergoing dialysis. Such attention is essential to the treatment and recovery of these individuals because care should not be restricted to diet, medication and dialysis. Care should comprise a larger dimension in which a relationship of friendship, understanding and interaction is established⁽¹⁵⁾.

The adolescents represented the family as an entity that protects and helps through the singular care provided by each family. The demands of care, as well as the need to have a caregiver supporting the child or adolescent during clinical follow-up was permeated by affective interactions, which are culturally constituted among the family members. The absence of such relationships of care and affection considerably hinders the therapy and family harmony.

The studied children and adolescents showed faith in God because their testimonies and manners were full of emotion, hope, and sensitivity to a belief in a superior Being. At the time they talked as if through prayer the temporality of the chronic disease seemed not to exist; they said that one day they would wake up and would not suffer anymore, no more artificial kidney or dialysis machine. Churches were mentioned as spaces they attend in the search of a miracle. The presence of a *prayer* or a *macumbeiro* also appears as an interesting option in one of the testimonies; spiritual beliefs are common in Brazilian culture.

Believing in spiritual forces gives one comfort. Scientific knowledge is not the only source of explanation for reasons and justifications of what is happening with a patient who is a child. While science causes uncertainties, particularly when the prognosis is threatening, spirituality encourages the family and gives hope or helps one to acknowledge the condition imposed by the disease. By identifying the family's religious and spiritual practices, nurses can understand its attitudes in the face of the disease and therapy, helping it to maintain health-promoting practices⁽¹⁶⁾.

The perception that the cultural context influences one's way of being and acting while providing care has been explored in the nursing field in the search for holistic care, a culturally defined, standardized and expressed care⁽⁹⁾. This type of care is more coherent and gratifying since it is adapted to the person's way of life.

When nurses seek to understand one's spirituality and other cultural aspects, they develop the ability to understand the patients' and their families' attitudes and practices, encouraging decision-making concerning therapy. It is possible for nurses to negotiate or keep health promoting practices when based on knowledge concerning the patient's culture.

In the category Hospital Environment and Educational-therapeutic activities, the participants highlighted the activities of the project *Education and Health in Discovering Learning*; an educational project directed to individuals with CRF, and was implemented after a patient undergoing hemodialysis asked for such a service. The clinical staff, sensitized by her request, contacted the Coordination of the Pedagogical and Psychology course of a university, which accepted the challenge and started the activities in April 2000. The project's participants teach patients how to read and write during hemodialysis treatment administering Portuguese classes, oral and written language and mathematical concepts with playful procedures⁽¹⁷⁾.

It was possible to observe these educational and playful activities implemented among the children and adolescents. The supervised trainees linked to the project developed these practices twice a week in the clinic on different shifts. These were times of distraction and great interaction among patients, professionals and students, with positive repercussions on the therapeutic project.

Another project *Arts Workshop* encouraged patients and family members to discover artistic talent in music, handcrafting and painting. In addition to these, the *Knowledge Project* offered guidance and counseling through lectures and roundtables to families of patients to facilitate coping. Based on cross-cultural theory, we describe the indicated nursing care in the first category, accommodating cultural care and negotiation, with the following actions and decisions: encourage children and adolescents, as well as their families to resume daily life, within abilities; discuss other forms of leisure according to each patient's and family's desire and ability, such as going to the beach, because those living in coastal cities did not abandon the beaches; instruct patients and their families about their rights, among them the possibility of undergoing renal replacement therapy in transit, providing information concerning the dialysis units available in the destination cities and encouraging trips and travels for pleasure, highlighting the right to interstate passage⁽¹⁸⁾; also, the professionals caring for these children and adolescents should, whenever possible, visit them at home to follow-up treatment and become familiar with their way of life and the difficulties faced by these individuals and their families, moving toward a culturally congruent care.

In regard to the second category, the indication of nursing care was: preserving cultural care and maintenance with the following actions and decisions: maintaining recreation, distraction and playful-pedagogical activities directed to children and adolescents; preserving proposals with a focus on autonomy and citizenship

through social projects already implemented for individuals and their families; disseminating the results of activities implemented in projects so new partnerships are established as a model for other facilities.

Care defined in the actions and decisions that valued culture was associated with dignified and respectful treatment that values the patient with a view to improve an individual's condition or life style⁽⁹⁾. In this context, nursing care can be seen as a set of actions and procedures implemented to favor, maintain or improve human life in the living or dying process. Caring is configured as an interactive process concerning development or growth that occurs continually and can enable transformation⁽¹⁹⁾. Even though a cure is not feasible for patients with CRF, the most important thing to consider is that providing care and promoting the well-being of individuals should be the core of health actions.

CONCLUSION

This study allowed us to become familiar with the studied children and adolescents, valuing their subjectivity, feelings, needs and learning about their culture. We believed that ethnonursing, as a research method, greatly contributes to the clinical practice as it supports cultural care, enabling the establishment of a connection between theory and practice and valuing new expressions for nursing care, which can qualify nursing care in nephrology.

Children, adolescents and family members face devastating situations when they learn about chronic renal disease and therapeutic interventions. Such situations are often incomprehensible and difficult to accept, deeply transforming these individuals' daily lives since special care is required for one's entire life. Therefore, nurses should be qualified to provide differentiated care using practices such as approximation, attentive listening, and understanding another's existence.

We highlight the valuable attempts to provide interdisciplinary and more humanized care to the studied children and adolescents in the study's setting. The studied dialysis facility went beyond hospital care and implemented for their patients playful-pedagogical projects, excursions, and social care that are capable of promoting joy and social inclusion.

Thus, providing care culturally congruent with the needs of children and adolescents with chronic renal diseases is an intentional care action established through the interaction of scientific knowledge and acknowledgment of these patients' cultural knowledge. Such care is developed through actions and decisions concerning care that emerged from the individuals' needs from the time the diagnosis is disclosed, to the recovery of their autonomy in the face of their dialysis.

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