TEENS IN HEMODIALYSIS: EFFECTS OF THE ILLNESS AND TREATMENT IN MENTAL HEALTH

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ABSTRACT

The research aimed at analyzing the impact of the disease and treatment in the mental health of adolescents on hemodialysis. This is a clinical qualitative study carried out in a dialysis clinic of the city of Fortaleza/Ceará from february to april 2013. Data were used as instruments of production to semi structured interviews and non-participant observation. The participants were eight teenagers diagnosed with chronic renal failure undergoing dialysis selected by intentional sampling. The analysis of thematic content of Bardin was used. As a result of the interviews, taking the corpus, two categories emerged; 1 - Perception of chronic renal hemodialysis teen about the condition experienced: feelings and expectations and 2 - Impact of hemodialysis on lifestyle and mental health of adolescents. The results show that, among the study participants, mental health is affected intensively because in includes a constant struggle to overcome the changes caused by the disease and the need to learn to deal with feelings that cause discomfort. It is conclude that the illness and particularly the hemodialysis affects the mental health, but it can be minimized by the provision of a humanized and comprehensive care.

Keywords: Adolescent. Renal dialysis. Mental health.

INTRODUCTION

The interest related to the context of adolescents in hemodialysis occurred due to the professional career, which provided a contact with patients with chronic renal failure in a dialysis clinic. The observation of the scene, behavior, habits and demands of adolescents on hemodialysis, led to the reflection upon the impact of the illness and hemodialysis in their lives.

Chronic kidney disease (CKD) is a progressive and irreversible deterioration of renal function, which generates an electrolyte and metabolic imbalance and requires treatment in the form of dialysis or kidney transplant⁽¹⁾.

In addition to the biological and subjective transformations, generators of conflicts that are characteristic of this period of life for being a transitional stage between childhood and adulthood, recognized as a critical moment of human existence⁽²⁾, adolescence may become even more confrontational if you add a disease such as CKD, which results in many restrictions and transformations. Thus, adolescents may have a greater chance of having affected their mental

health when compared to healthy adolescents.

A chronic disease in childhood and adolescence is generally taken as a risk factor for the onset of psychological problems before the natural vulnerability of this phase. The specific characteristics of these diseases and their treatments usually involve changes in lifestyle and painful experiences, since the individuals suffering from chronic diseases must adhere to complex medical procedures, prolonged treatment and dietary restrictions. All this may require significant changes in the adolescent's life and his family's, creating conditions for the existence of effects on mental health⁽³⁾.

The consequences of chronic diseases, especially the CKD, which entails an invasive treatment that involves changes, are perceived in many aspects of life and they go beyond the purely physical consequence. A chronic condition can deprive a person of several possibilities as it interferes with their daily lives, in their self-esteem, in the control of their own bodies and in their interpersonal relationships. It can also generate complex problems and long-term implications that will translate into losses in mental health^(4,5).

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As a result, it is important to study the effects of CKD on the mental health of adolescents on hemodialysis (HD); and when focusing their efforts on adolescents care, nurses must recognize their experiences to provide care planning in order to meet the demands related to this context. From this, they will develop and implement strategies for promoting mental health for these adolescents in order to offer them better conditions to cope with the disease, especially before a clinical situation in which the cure is not an achievable goal.

Given the above, this study aimed to analyze the effects of illness and treatment in terms of the mental health of adolescents on hemodialysis.

METHODOLOGY

This is a clinical-qualitative research carried out in a dialysis clinic that maintains an agreement with the Unified Health System (UHS), located in the city of Fortaleza/CE, in the period from February to April 2013.

The clinical-qualitative research is the and the construction of the study epistemological limits αf certain individualized qualitative method in health settings and it includes the discussion of a set of appropriate techniques and procedures aimed at describing and understanding the relationships of meaning and significance of the above human phenomena. These become relevant objects of study as they are confirmed by a critical remark, as they often create and/or exacerbate the complex-structured anguish⁽⁶⁾.

The data production instruments used were the semi structured interviews composed of the following guiding questions: "What does it mean to be a teenager with chronic renal failure?" and "What happened in your life when you began to dialyze?"; and the nonparticipant observation, with a structured script based on three points: observation of the clinic adolescents in prior hemodialysis session, during the session and after dialysis. We conducted a visit for a week during one month, and recorded them in a diary as a pre-established script. Eight adolescents diagnosed with CKD undergoing

dialysis and selected by purposeful, intentional or deliberate sampling participated in the interview.

In this type of sample there is a deliberate choice of respondents, subjects or environments that can, in the researcher's view, bring heartier information on the subject investigated⁽⁶⁾.

The observation of the setting is a key part of the field research for the property that has to capture a variety of phenomena that cannot be achieved solely through interviews⁽⁶⁾.

The inclusion criteria are: to be between the ages of adolescence defined by WHO (10-19 years); to perform hemodialysis for more than six months, to allow them to have experiences regarding the dialysis process; to be authorized by parents or guardians to participate in the study; and to undergo dialysis on Mondays, Wednesdays and Fridays in the 2nd hemodialysis shift (from 11 am to 3 pm). Teenagers are chosen to perform treatment during this period because these are the days and times when they have the highest number of subjects who meet the inclusion criteria by treatment group. Data collection was performed during the dialysis session to take advantage of the permanence of teenagers in the service (average of four hours/session).

During the study period a total of 29 teenagers undergoing hemodialysis were treated at the clinic which is a benchmark in the care of children and adolescents with CKD in Ceará, delivering services in all dialysis modalities.

The interviews were recorded and were treated with the thematic content analysis of Bardin, aiming at the units of meaning that make up communication, whose frequency made sense for the analytical subject in question. The analysis allowed greater understanding of the object, bringing out the categories and subcategories of thought, their correlation and the way in which they manifest themselves. The subjects were identified with the initial of Adolescent and numerically.

As a result of the interviews, considering the corpus, two categories emerged: Perception of the chronic kidney teenager in hemodialysis on the condition experienced: feelings and expectations; and Effects of hemodialysis in the lifestyle and mental health of adolescents.

In accordance with Resolution 466/12 of the National Health Council, the teenagers who signed the Consent Term, which informed about the research objectives and guaranteed them anonymity, participated in the investigation. The Informed Consent (IC) was signed by parents or legal guardians.

The research project was submitted for evaluation of the Ethics Committee of the Federal University of Ceará, and was approved under Opinion No. 226/11.

RESULTS AND DISCUSSION OF THE DATA

Through the observation of hemodialysis adolescent treatment scenario it was possible to learn that several structural and organizational elements reflect in terms of the way it fits into the hemodialysis treatment setting and the repercussions due to the demands/peculiar vulnerability to this phenomenon, described as follows.

First the research site was observed before the hemodialysis session, to understand how teens are inserted in this context and their relationships. Patients routinely remained in the cafeteria or in the waiting room waiting for the beginning of treatment, where everyone, regardless of age, stayed together, but few engaged in dialogues. They basically watched TV and had their meals.

To enter the room where they underwent dialysis, all of them checked their weight on a scale in order to sit beside the machine reserved for them. Most of them remained quiet, silent, just wondering who would puncture them; however, the two younger teens (10 years) were tense, tearful, scared of the puncture and complained about their medical condition, requiring the presence of their companions. For the other teens, these were basically technical procedures.

The routine **during treatment** primarily valued the hard and soft-hard technology, that is, related only to procedures, machinery and instruments (7), as the dynamic was restricted to verify their weight, perform the puncture or access the central venous catheter, operate the dialysis machine, check blood pressure, administer medications and, in the event of

complaints, proceed as clinical protocol; therefore, it was noticeable the little demonstration of concern in terms of the psychological aspects.

Nursing technicians followed a standard routine, trying not to waste time at the beginning of the dialysis session. They focused on the puncturing technique of the arteriovenous fistula or on accessing the dialysis catheter to start the session of the hemodialysis patients under their responsibility as soon as possible, which resulted in a faster session.

At the dialysis time, care actions were restricted to hard and soft-hard technologies, since they were only related to technical aspects; therefore, it was more common for the nursing professionals selected for this work to dialogue with their co-workers, who were part of their team, than with the teenagers in treatment.

Caring involves interactive action, which must be grounded in the ethical dimension between caregiver and patient. In particular, hemodialysis requires specialized nursing care, but which is not restricted to technical aspects. Thus, it is evident that nursing professionals need to be trained and must be aware of their importance of achieving a comprehensive care and promoting the mental health of individuals suffering from CKD⁽⁴⁾.

In the study setting, nurses performed the first punches, complex punctures, checked the fittings of the machine programming, supervised the team and remained in the room until patients started dialysis and, where necessary, provided support and talked to teenagers, but only about technical matters, basically following the biomedical model.

In the hemodialysis room environment, there was no concern in terms of hosting. Most of the time people told stories of suffering due to disease socioeconomic problems. and Professionals tended to move away when patients requested and questioned in an attempt to avoid complaints -fact perceived in the attitudes of professionals and conversations between them. It was a place with few colors, excessive hard technology, with little room for movement, intense noise of the equipment and technical routines. Teenagers usually watched TV and/or slept during treatment, and only a few played or talked on the phone.

After the hemodialysis session teenagers take not to leave. They talked little and only said goodbye. As they left the session, it was unusual to receive any kind of guidance, just reminders when there was some procedure to be performed or HD shift exchange. Professionals basically followed the biomedical model, paying little attention to the educational components and health promotion.

When you think about the technological issue of nursing care in health facilities, the first impregnated idea is that this technology comes down to machinery/equipment. Therefore, it is necessary to incorporate other values that will make a difference in care in the daily work, such as improving interpersonal relationships and aspects related to health education, since the assistance that prioritizes the hard and soft-hard technologies remains reflected in patient care in hemodialysis.

In complex units such as hemodialysis clinics, the machines used in patient care are hard technologies or dead labor, as they are material resources obtained through the use of equipment such as work instrument. As a complement, there are light-hard technologies, expressed in the handling of technological equipment and knowledge for its use; and the light ones, identified in relations, which are characterized by live work in action, in the direct relationship between users and professionals⁽⁸⁾.

In addition to the machines and technical expertise, there is something nuclear in health work, which is the relationship between the subjects and their daily routine. It is, above all, the recognition and that the space that produces health is a place where you can also make the wishes and inter-subjectivity that structures the action of subjects come true⁽⁹⁾.

Although the technological evolution has contributed to prolonging the lives of people with CKD in recent years, little has helped in minimizing the problems in their everyday lives and aspects related to mental health. In this context the technical care actions still prevail, making it necessary to adopt health promotion practices and light technologies involving dimensions of care that seek to improve the health status of individuals and communities⁽¹⁰⁾.

It is necessary to train professionals in the hemodialysis units to avoid transforming the contact with these people into an automatic routine, settling in turning the catheter of the dialyzing infusion on and off, for the care given by them is important as a strategy to help these users in fighting their problems and demands⁽¹¹⁾.

The nursing care provided to adolescents with chronic diseases such as CKD demand of health professionals a broad knowledge to perform technical and scientific skills together with humanization and integrity, in order to apprehending them in their subjectivity.

After the observation period, the interview was conducted with the teenagers. The group had the following characteristics: Eight subjects of the study were between 10 and 17 years, six female and two male; the level of education varied, but all were literate. Of these adolescents, only two remained enrolled at school; the justification of others for not being studying was that the hemodialysis treatment requires a long time. In relation to disease duration, the average was 3.1 years.

The interviews revealed the following categories:

Category 1 - Perception of the teenagers suffering from chronic kidney disease on hemodialysis in terms of the condition experienced

In analyzing the data related to the meaning of the condition experienced by teenagers, two subcategories emerged: feelings related to the condition of having a chronic kidney disease and expectations related to coping and adapting to the disease.

Subcategoria 1.1 - Sentimentos dos adolescentes renais crônicos sobre a doença

Having quality of life involves overcoming and controlling the specific conditions and feelings that are brought by the experience of the kidney disease. Feelings such as fear of complications and death, the shame of what others will think of them and the difficulty in accepting the disease were expressed by members of the research:

I feel sad because nobody wants to live attached to a machine. There are days when I'm worse. It is worrisome. (A2 - 14 years)

Sometimes I feel very angry to live like that. We lose a lot [...] there are days when it is hard and we're sad. (A4 - 17 years)

It's good for our health, because we get better, but it's bad for the head. We think nonsense, get ashamed and sometimes have to be hospitalized [...] I'm afraid of dying, afraid of suffering without access to dialysis, because I have seen many people like that. (A7-13 years)

The diagnosis of a child or adolescent with CKD has negative consequences in his life; insecurity and fear often accompany people with chronic diseases because they feel that the condition causes repercussions, mainly because it is a prolonged treatment and they cannot keep control of the situation⁽¹²⁾.

A chronic health condition causes changes in social, psychological and physical levels. It is a reality in which the teenager with a kidney disease is inserted and is obliged to get adapted to it, thus learning to deal with the unknown, the new⁽¹³⁾.

Thus, the changes that come with the disease process and consequently the treatment favor the exacerbation of feelings such as anger, denial, shame, fear, among others.

The occurrence of chronic renal diseases in adolescence brings successive loss of independence and control, feelings of anxiety, sadness, anger and fear. Moreover, they are also required to deal with changes in social relations⁽¹⁴⁾.

In this context, it is important that the professionals who are close provide an environment/moment so that the patients can show their doubts and anxieties, as these manifestations may help alleviate feelings of discouragement and uncertainty, thereby contributing to their mental health.

Subcategory 1.2 - Expectations of adolescents related to coping and adapting to the illness

When it comes to expectations; teenagers reported desire with regard to overcoming the limitations imposed by the illness, especially hemodialysis:

It is not easy to live with this kind of disease, but I believe I cannot be discouraged nor give in, because things will get better and I will be able to be transplanted and then I will no longer need to dialyze, but in the mean time I have to accept it. (A2 - 14 years)

There are days when I get sad, but then it's over, because I still want to study hard and have a good job, because I dream of better days. (A4 - 17 years)

I think the worst thing is getting stuck in this machine, so I really want to be transplanted and want everything to go well so I can go back to doing things without much concern. I hope to face this issue despite being so bad (A5 - 13 years)

The CKD brings many changes that may reflect in disturbing ways on mental health because hemodialysis promotes the improvement of some clinical symptoms, but at the same time it causes some emotional disorders⁽¹⁵⁾. However, through the reports, it was found that teens have many expectations for overcoming difficulties, which promotes mental health, helping them to cope with the changes. By recognizing these demands, they can learn to cope and adapt to the experienced condition.

Despite the restrictions and changes in lifestyle, teenagers with CKD learn to live with a stress permeated condition. This adaptation is important in order to promote their quality of life⁽¹²⁾.

Category 2 - Impact of hemodialysis in the lifestyle and mental health of adolescents

Subcategory 2.1 - Changes in the lifestyle of the adolescents on hemodialysis

Other aspects reported by participants were the changes in lifestyle caused by dialysis, as the following statements:

The disease itself is not so bad, because you only have to go to the consultation and take the medication. The worst is that over time I had to start dialyzing. Then things got really worse. But eventually we got used to it. (A1-10)

I stopped studying, I stopped eating many things [...] 'you can't do this, you can't do that, be careful with it.' I know all this is protect me from getting sicker, but it's boring. I am different from most of my friends. (A2 - 14 years)

I had to quit school [...] You have to stop doing many things or have to do many things that you didn't have to before. (A4 - 17 years)

The difficulty that teenagers have shown was related to the change in lifestyle, and especially the limits posed by the disease, or more specifically, by hemodialysis. When in need of hemodialysis, the patient is faced with real situations that will be present throughout the treatment.

The hemodialysis treatment causes significant changes in the daily lives of teenagers, as they have to adjust to the treatment routine. Being subjected to dialysis takes time, since it is a therapy which requires visits to the clinic three times a week for four hours for undergoing dialysis.

These events change the relationships of adolescents with their social environment, impair their routine life and distance them from living with friends and even family⁽¹⁶⁾.

Because it is a stressful condition, the chronic disease has an impact that can arise at any time and remain, thus changing the process of being healthy individuals or groups. The hemodialysis-dependents experience a sudden change in their daily lives and the way they face the situation is personal⁽¹⁷⁾.

Researchers point to the lack of ability of nursing professionals in dealing with patients' needs, noting that a critical and reflective behavior in terms of the performance of care actions should be encouraged⁽¹⁸⁾.

Thus, it is necessary to stimulate adolescents with CKD on dialysis the ability to adapt positively to the new lifestyle through a health care that improves the quality of life⁽¹⁰⁾.

Subcategory 2.2 - Impact of the routine treatment in the mental health of adolescents

The chronic kidney disease causes changes in lifestyle and it also affects the mental health of these people. This may be a reflection mainly of the routine treatment imposed by hemodialysis, as can be identified in the following statements:

I complain a lot, but I have to try to get used to it, but it is bad to worry about what will eat during the dialysis treatment. So I just want to undergo the transplant so I no longer have to worry and feel different from others. It wears me out. (A1-10)

There's not much to do during the treatment. [...] It's always the same thing, we treat the body and forget the soul and it makes us confused, just thinking about bad things. (A4 - 17 years)

Hemodialysis is boring and tiring. [...] Those who make this treatment are always anxious and worried,

willing to know if something will happen, because we so many sad things. (A5-13 years)

Hemodialysis requires a lot of patience. I suffer a lot because it makes me sad and tired with all this stuff. (A7-13 years)

The CKD and hemodialysis cause significant changes in the lives of adolescents. The impact of the disease and treatment entails, in addition to the physical wear, a great emotional stress. The individuals are forced to live with the fact of having an incurable disease that leads to dependence on painful treatment. a unpredictable duration and uncertain consequences for their lives and the lives of those who make up their social network.

Such treatment becomes indispensable, making the routine of chronic kidney disease patients complicated. This can lead to a psychological dysfunction, since emotional disorders resulting from the process of adaptation to the new reality may be generated in situations of chronic diseases that require complex treatments^(16,19).

The requirements resulting from the treatment encourage the reflection on the difficulty that young individuals with CKD face in dealing with this disease and the risk of depression. Depression is associated with a reference of loss, and patients on dialysis have multiple losses⁽¹⁵⁾.

It is noticed that teenagers have trouble getting along with limits and learning to deal with situations, especially fear of complications. This requires an adaptation to the conditions experienced on the repercussions in their lives.

It is necessary to consider that each person has an answer to the same stressful situation; therefore, the planning of nursing actions should occur from the recognition of demonstrations to confront the situation experienced by the patient⁽²⁰⁾.

Thus, in order to contribute to mental health, an important aspect to be considered in the care of these adolescents is to be sensitive to the changes experienced and provide care that is not restricted to hard technology (dialysis machine, punches) and soft-hard technology (protocols, care routines), because these people have many demands. Thus, it is increasingly necessary to include humanization and valuing interpersonal relationships in the nursing care, in order to

assist them in coping with experienced stressful situations.

Nursing care is mediated by interaction and communication in its daily exercise, establishing itself as an essentially human inter-subjective process. The care dimension, producer of lightweight relational technologies, becomes important for increasing the ability of workers to cope with the health needs of users⁽²¹⁾.

Therefore, in addition to technical tools and knowledge, that is, the more structured technologies; there is another knowledge that has been designed as critical to the production of care for patients with chronic renal failure on dialysis: knowledge in terms of relationships.

FINAL CONSIDERATIONS

Data analysis allowed the foundation of the theoretical and practical knowledge related to the demands of the patient who depends on hemodialysis from a systemic perspective. It has been possible to identify behaviors, attitudes and practices experienced in the treatment of everyday life in hemodialysis sessions and its impact on mental health.

It was observed that there is a gap in terms of care concerning the psychological dimension that affects the mental health of those involved, requiring the redirection of the care model for patients with CKD for the recognition of this demand, thus allowing the construction of new practices sustained on full care.

This study may reaffirm the need to strengthen professional nursing practices that go beyond traditional models of management and health care. Moreover, it may contribute to the construction/reconstruction of theoretical and methodological frameworks that provide grounds for a care practice aimed at the promotion of mental health.

ADOLESCENTES EM HEMODIÁLISE: REPERCUSSÕES DO ADOECIMENTO E TRATAMENTO NA SAÚDE MENTAL

RESUMO

A pesquisa teve como objetivo analisar as repercussões do adoecimento e tratamento na saúde mental dos adolescentes em hemodiálise. Estudo clínico-qualitativo, realizado em uma clínica de diálise do município de Fortaleza/CE de fevereiro a abril de 2013. Foram utilizados como instrumentos de produção de dados a entrevista semiestruturada e a observação não participante. Participaram da pesquisa oito adolescentes com diagnóstico de insuficiência renal crônica, submetidos ao programa de diálise e selecionados por amostragem intencional. Foi utilizada a análise de conteúdo temática de Bardin. Como resultado das entrevistas, tomando o *corpus*, emergiram duas categorias: *Percepção do adolescente renal crônico em hemodiálise sobre a condição vivenciada: sentimentos e expectativas e Repercussões do tratamento hemodiálitico no estilo de vida e saúde mental dos adolescentes*. Os resultados evidenciaram que, para os participantes do estudo, a saúde mental é afetada de forma intensa, pois inclui uma luta constante para superar as transformações ocasionadas pela doença e a necessidade de aprender a lidar com sentimentos que provocam desconforto. Conclui-se que o adoecimento e o tratamento hemodialítico repercutem na saúde mental, mas os efeitos negativos podem ser minimizados com a prestação de um cuidado humanizado e integral.

Palavras-chave: Adolescente. Diálise Renal. Saúde Mental.

ADOLESCENTES EN HEMODIÁLISIS: EFECTOS DE LA ENFERMEDAD Y DEL TRATAMIENTO EN LA SALUD MENTAL

RESUMEN

La investigación tuvo como objetivo analizar los efectos de la enfermedad y del tratamiento en la salud mental de los adolescentes en hemodiálisis. Estudio clínico-cualitativo, realizado en una clínica de diálisis del municipio de Fortaleza/CE de febrero a abril de 2013. Fueron utilizados como instrumentos de producción de datos la entrevista semiestructurada y la observación no participante. Hicieron parte de investigación ocho adolescentes con diagnóstico de insuficiencia renal crónica, sometidos al programa de diálisis y seleccionados por muestreo intencional. Fue utilizado el análisis de contenido temático de Bardin. Como resultado de las entrevistas, considerando al *corpus*, emergieron dos categorías: *Percepción del adolescente renal crónico en hemodiálisis sobre la condición vivida: sentimientos y expectativas*; y *Efectos del tratamiento hemodialítico en el estilo de vida y salud mental de los adolescentes*. Los resultados evidenciaron que, para los participantes del estudio, la salud mental es afectada de forma intensa, pues incluye una lucha constante para superar las transformaciones ocasionadas por la enfermedad y la necesidad de aprender a lidiar con los sentimientos que causan malestar. Se

concluye que la enfermedad y el tratamiento hemodialítico afectan la salud mental, sin embargo los efectos negativos pueden ser minimizados con la prestación de un cuidado humanizado e integral.

Palabras clave: Adolescente. Diálisis renal. Salud mental.

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