

## Hemodialysis: patient's adaptation and life style\*

*Hemodiálise: estilo de vida e a adaptação do paciente*

*Hemodiálisis: el estilo de vida y la adaptación del paciente*

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### ABSTRACT

**Objective:** To identify and describe how patients on hemodialysis cope with their disease regarding changes in attitudes, behaviors, and practices of activities of daily life. **Methods:** This qualitative study, guided by grounded theory, was conducted among patients attending the association of renal transplant of Rio de Janeiro. The sample comprised 10 patients. **Results:** The analysis suggested that the patients went through denial, negative thoughts, and social adjustment to achieve adaptation by constructing a new life style. **Conclusion:** Nursing interventions must go beyond the physical and biological patients' needs to include social and psychological approaches that might be effective in improving the quality of life of patients on hemodialysis.

**Keywords:** Hemodialysis/psychology; Adaptation, psychological; Patient-centre care; Nursing care

### RESUMO

**Objetivo:** Identificar como o paciente dependente de hemodiálise enfrenta no dia-a-dia o processo saúde-doença, considerando atitudes, comportamentos e práticas. **Métodos:** Estudo de abordagem qualitativa baseado nos princípios da Teoria Fundamentada nos Dados e realizado na Associação de Doentes Renais e Transplantados do Estado do Rio de Janeiro. Participaram do estudo dez sujeitos dependentes de hemodiálise. **Resultados:** A análise apontou para a adaptação, a negação, o ajuste social e a luta contra maus sentimentos que desvelaram a categoria (Re)Construindo um novo estilo de vida: a adaptação. **Conclusão:** As ações do enfermeiro devem seguir para além das necessidades físicas e biológicas atingindo os campos social e psicológico, onde estratégias para a melhoria da qualidade de vida destes indivíduos devem ser consideradas, orientadas e estimuladas.

**Descritores:** Hemodiálise/psicologia; Adaptação psicológica; Assistência centrada no paciente; Cuidados de enfermagem

### RESUMEN

**Objetivo:** Identificar cómo enfrenta, en el día a día, el proceso salud-enfermedad el paciente dependiente de hemodiálisis, considerando actitudes, comportamientos y prácticas. **Métodos:** Estudio de abordaje cualitativo basado en los principios de la Teoría Fundamentada en los Datos y realizado en la Asociación de Enfermos Renales y con Transplantes del Estado de Rio de Janeiro. Participaron en el estudio diez sujetos dependientes de hemodiálisis. **Resultados:** El análisis apuntó hacia la adaptación, la negación, el ajuste social y la lucha contra los malos sentimientos que develaron la categoría (Re) Construyendo un nuevo estilo de vida: la adaptación. **Conclusión:** Las acciones del enfermero deben ir más allá de las necesidades físicas y biológicas alcanzando los campos social y psicológico, donde las estrategias para mejorar la calidad de vida de estas personas deben ser consideradas, orientadas y estimuladas.

**Descritores:** Hemodiálisis/ psicología; Adaptación psicológica, Atención dirigida al paciente; Atención de enfermería

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## INTRODUCTION

In the present study, we tried to understand how patients coped with hemodialysis. The interest in this issue started from questions we had after observing these patients in supervised training in the Nephrology sector during nursing undergraduation course.

Having a chronic disease is a major challenge since individuals have to change their lifestyle regarding diet and physical activities, with continuous use of medications and dependence on people and machines to adapt themselves to a new way of living<sup>(1-2)</sup>.

Within this perspective, chronic diseases are seen as stressful events and their impact can occur at any time and become permanent, changing the process of being healthy of individuals and groups<sup>(3)</sup>. Hemodialysis-dependant-individuals experience a sudden change in their routine and the way they cope with it is unique but relevant to Nursing since it sees individuals as total human beings.

To that end, we must encourage individuals' capacity to adjust positively to a new lifestyle and to take control of their treatment, approaching health and disease not as opposite elements but rather as part of a unique process. The disease experience should work as a process integrating body, mind and physiological entity, inserting this process in a sociocultural context<sup>(2)</sup>.

The focus of disease as a continuous process is part of a systemic approach of individuals, opposed to the current biomedical model with Cartesian characteristics. The focus is no longer smaller units but rather the whole matter, the life and mind which influence and determine each other. A Holistic conception of health occurs when care meets these aspects<sup>(4)</sup>.

To face the challenges of the specificity of working with hemodialysis-dependent-individuals physical and mental availability are necessary in the care offered<sup>(5)</sup>. The study points out the interdependence between knowledge and sensitivity, aiming at ensuring care based on a systemic view of individuals<sup>(6)</sup>.

With the ideas presented, this study aimed to identify how dialysis patients cope every day with the health-disease process, considering their attitudes, behavior and practices. We should highlight that individuals face an important change in their routine when they have to receive hemodialysis. Thus, studying the way individuals cope with hemodialysis was the objective of the present study.

## METHODS

Qualitative study performed at the Association of Renal and Transplanted Individuals from the State of Rio de Janeiro after the project had been approved by the Research Ethics Committee at Anna Nery Nursing School/Hospital Escola São Francisco de Assis. The principles

of Grounded theory were adopted to understand, after in-depth analysis, the process leading to the phenomena investigated<sup>(7-8)</sup>. Thus, we have used vertical distribution of the discourse, open coding, axial coding and selective coding to delineate the phenomenon investigated.

Participants' systematic observation and semi-structured interview was used through a script approaching the experience in the health-disease process of these patients, considering the experience in hemodialysis to propose an in-depth interaction. The sample was formed by ten adults, seven were women and three were men from the city of Rio de Janeiro, they were at different age groups and underwent replacement renal therapy with time receiving hemodialysis ranging from 2 to 25 years.

All individuals were aware of the objectives of the study and gave their written consent to take part in it, according to Resolution # 196/96 of the National Health Council<sup>(9)</sup> with their confidentiality assured.

## RESULTS

We could notice that patients often denied their reality with feelings or actions of being rebellious regarding the treatment or were discouraged. In this context, patients start to see the treatment as a torture and a waste of time because they cannot see a cure.

*Imagine to waste three times a week to stay here, attached to a machine because your body no longer does what it should do. It is very boring.* Rubi

*I am hypertensive and I have diabetes that is why I started the dialysis, but I have been undergoing the treatment for a long time, I am under control. My health is good. But I am sick and tired of so many things, of this routine.* Cristal

Acceptance was observed when individuals acknowledged the role of treatment and the relevance of adjusting to the health situation and adopted behaviors, attitudes and practices that met the demands imposed by the chronic condition. They started the process of acceptance by abandoning the view of dialysis as a torture and adopting the view of it as a life-saver.

*[...] I accept it well.* Ametista

*It has not been that bad. Now it's been a while that I receive dialysis, it's not that bad. We get used to this sad routine [...] you are not the only one; there are people in worse situations.* Turmalina

We could see the adoption of similar practices to those they had before starting the treatment. Some individuals, from the adjustment experienced, considered themselves normal individuals, they continued to make friends, carrying out social and leisure activities at the same time

they fit treatment demands to their routine.

*I try to have my social activities, get information, know everything there is to know about dialysis, I know everything, I have learned to live with it without feeling a slave [...] I don't see it as slavery but rather as a help.* Esmeralda

Another characteristic observed was the constant exercise to gather strength and continue with the routine without being let down or discouraged by the several problems that may occur during therapy.

*I try to do everything I can not to think about the disease [...] so as not to be discouraged.* Quartzo Fumê

Thus, codes generated were grouped into subcategories: Experiencing adjustment: denial; Experiencing adjustment: acceptance; Adopting new and old practices: social living and Fighting bad feelings which, in turn, determined the category (Re) Building a new lifestyle: adjustment.

**Picture 1** – Category (Re) Building a new lifestyle: adjustment

Category	Subcategories
(Re) Building a new lifestyle: adjustment	I. Experiencing adjustment: denial
	II. Experiencing adjustment: acceptance
	III. Adopting new and old practices: social living
	IV. Fighting bad feelings

**DISCUSSION**

The way different individuals experience the same stressful situation is unique and developing a cognitive ability to cope is a singular mental process, where each individual has different levels of capacity to cope or respond to these stressors<sup>(1,10)</sup>.

Living with this new reality enables patients to give

their own meaning to disease and treatment<sup>(11)</sup>. In this sense, preconceived ideas on the chronic health state may influence the way each individual uses mechanisms to adjust to the health condition currently experienced.

Limits imposed by hemodialysis treatment, at times, lead patients to see the treatment routine with a negative perspective since it leads to impairment in the performance of everyday activities with impact especially in work and domestic activities<sup>(12-13)</sup>.

We must stress that although stages are designed through the subcategories, they do not define a linear path for coping with the situation thus individuals adjusted to the routine of hemodialysis may be in denial at times, rebellious at other times and supportive of patients coping with the situation at other times. Despite the great number of stressors experienced, many patients adjust well to the treatment routine experiencing negative symptoms temporarily in the beginning of adjustment<sup>(13)</sup>.

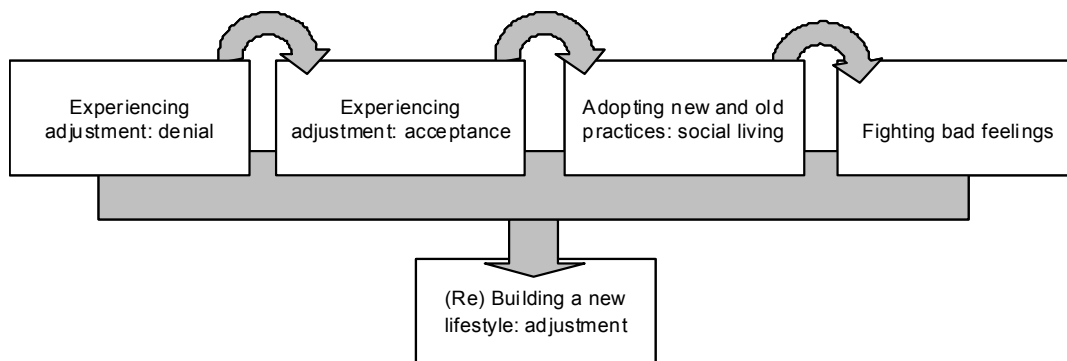
The idea of adjustment as a continuous and dynamic process is demonstrated through the constant chart in Picture 2.

**CONCLUSION**

Careful analysis of the data obtained enabled to base theoretical and practical knowledge on coping in hemodialysis-dependant patients under a systemic view thus, enabling the identification of behaviors, attitudes and practices experienced in the everyday changes imposed by hemodialysis.

We must consider that each person responds in a way to a stressful situation, therefore planning of nursing actions must occur from acknowledging how patients cope with these situations.

Thus, an important aspect that should be considered by nurses is patients' education concerning the demands imposed by treatment, since greater knowledge on the disease, its treatment and rehabilitation possibilities can help patients cope with stressful situations experienced in their routine.



**Picture 2** – Chart showing the category: (Re) Building a new lifestyle: adjustment

As a tool to help nurses, education actions will help patients regain control of their lives which was changed by the routine imposed by the chronic disease and loss of the associated autonomy.

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