

Research Article

Perception on Health and Disease, Patient in Treatment on Hemodialysis - Can Feeling Healthy Be Enough?

Dandara Novakowski Spigolon^{1*}, Jéssica Poliana de Souza², Carlos Augusto da Silva², Dheboraluiza Zollner Sary², and Ana Paula Modesto²

¹Department of Nursing, Universidade Estadual, Brazil

²School of Medicine, Pontifícia Universidade Católica, Brazil

***Corresponding author**

Dandara Novakowski Spigolon, Department of Nursing, Universidade Estadual do Paraná, Av. Gabriel Esperidião, 87703-000, Paranavai, PR, Brazil, Tel: 55-44-3424-0100; Email: dandaraspigolon@gmail.com

Submitted: 01 April 2016

Accepted: 05 September 2016

Published: 07 September 2016

ISSN: 2379-9501

Copyright

© 2016 Spigolon et al.

Keywords

- Hemodialysis
- Health
- Disease

Abstract

Hemodialysis is a treatment that requires from the patient a level of commitment certain to impose daily difficulties and limitations that may interfere with his biological, mental, social and spiritual balance. The study herein intended to assess the perception of health and illness of the individual on hemodialysis. It is a qualitative research with interview questions, which used the Collective Subject Discourse Methodology (CSD), carried out in a hemodialysis clinic in Curitiba, Brazil. Sixty-three patients were interviewed and six main discourses were obtained: "Health is the absence of pain"; "Health is physical and mental well-being"; "I'm always healthy"; "The disease is something that weakens and prevents you from living a normal life"; "Disease is having to do hemodialysis"; and "I always feel like a sick person." Physical and mental well-being may or may not be present in the routine of those on hemodialysis, but it can determine the way this individual copes with the obstacles presented to him.

ABBREVIATIONS

CSD: Collective Subject Discourse

INTRODUCTION

Chronic kidney disease results in kidney damage and progressive and irreversible loss of kidney function (glomerular, tubular and endocrine). In later stages, the kidneys can no longer maintain homeostasis; it becomes necessary the use of renal replacement therapy [1,2] Renal therapies available today are peritoneal dialysis, hemodialysis and kidney transplant; hemodialysis being the most commonly used, with over 400,000 patients currently under treatment in the United States [3].

The hemodialysis treatment can impose limitations and adjustments to the lifestyle of an individual, since it requires long stays in dialysis centers, which sometimes lead to or may lead to changes, e.g., contribute to the abandonment of daily activities like work, studies, physical exercises and nutritional restrictions [4]. These factors ultimately alter the patient's perception of health and disease.

Health can be defined as a "state of complete well-being, physical, mental and social, and not simply the absence of disease

or infirmity" [5]. As common sense, health is still considered the absence of disease, and disease, in turn, the absence of health and defined as a set of specific signs and symptoms that affect an individual, modifying his normal state [5].

The perception of health and disease acquired by chronic kidney disease patients after the beginning of dialytic treatment stands out in this study. Health and disease have different meanings for these individuals, i.e., perceptions are often subjective and sometimes objective, but always connected to the reality they experience. This perception of the individual on hemodialysis offered the questions that guided this study: "Is it possible to feel healthy being dependent on a machine?" or "Is it odd to feel sick"? This work aspires to contribute to the scientific community; considered the relevance of the subject to health professionals; allowing the knowledge of these different perceptions to provide a better understanding of the implications and changes that hemodialysis brings to the everyday life of these patients, thus enabling better support to the assistance provided by nurses, and consequently improving the expected results. To that end, this study intended to evaluate the perception of health and disease of individuals on hemodialysis.

MATERIALS AND METHODS

This is a descriptive study, using the Collective Subject Discourse (CSD), through interviews and recordings. This study is part of the research project QUALITATE-HD - The Impact of Life-quality Indices on Adherence to Treatment of the Patient on Hemodialysis, approved by the Ethics Committee in Research of the Pontifical Universidade Católica do Paraná, Brazil, NO. 449.828.

This study was carried out in Brazil, between October 2013 and January 2014, in a nephrology clinic that assists people on an outpatient hemodialysis program. Sixty-three patients were approached, among men and women, over 18 years old, who use the clinic either through the Brazilian Unified Health System, or private health insurance plans.

Data collection

A questionnaire was devised and used for data collection with the objective of analyzing the perception of health and disease of patients on hemodialysis. Subsequently, an interview with four open-ended questions was conducted:

1. What is health in your opinion?
2. When do you feel healthy?
3. What is a disease in your opinion?
4. When do you feel sick?

The questionnaire was applied during a hemodialysis session, a decision that eliminated the cost of setting up individual interviews. However, patients could not be moved to a more private secondary location, due to the impossibility of moving the equipment.

Data analysis

The CSD methodology, the tabulation of technical and organizational data, based on the Theory of Social Representations, was employed for data analysis. The goal of the Theory of Social Representations is to explain the human phenomena from a collective perspective, without losing sight of individuality. The challenge that the CSD is seeking to solve in this study is the self-expression of thought or collective opinion [6,7].

Once the answers were transcribed, each of these statements main ideas and their corresponding key expressions, which make up one or more discourses, were extracted, thus designating the CSD. The answer clusters were in put to Microsoft Word table, enabling the association of each subject with its respective main idea.

Finally, the subcategorized answers were merged using the CSD technique, based on the analysis of the verbal material collected, which presents the testimonials as raw material.

RESULTS AND DISCUSSION

Sixty-three patients were interviewed and six main discourses were obtained: "Health is the absence of pain"; "Health is physical and mental well-being"; "I'm always healthy"; "The disease is something that weakens and prevents you from living a normal life"; "Disease is having to do hemodialysis"; and "I always feel like a sick person."

Main Idea

Health is the absence of pain.

The patients described pain as a source of suffering, which, in addition to the manifestation of signs and symptoms, leads to concern and commitment to medication and treatment; being healthy is being pain-free:

CSD: "Health is not feeling pain and fatigue, not having to take medication, not having any kind of illness to worry about and not needing to treat a disease continuously, as is hemodialysis."

The discourse contradicts a survey of elderly patients in a hemodialysis clinic, which showed that in the dialysis treatment, pain was reported only at the time of puncturing the arteriovenous fistula [4]. This might pose further questions, for example, can pain also be emotional? It may be subjective to define painlessness for these patients, moreover, we must consider their comorbidities, medication, age and therapy time, which can also influence their perception of pain. As a result, pain may not be related only to the event of puncturing the arteriovenous fistula, as the aforementioned survey describes.

Another study showed that one hundred and three patients (50%) reported a problem with pain. Patients with pain had been on HD therapy longer (52.2 months) than those without pain (37.7 months). Causes of pain were diverse, and 18.4% of patients had more than a single cause for their pain. Musculoskeletal pain was the most common (50.5%) and equal in severity to pain associated with peripheral neuropathy and peripheral vascular disease. It can be concluded that pain is a significant problem in more than 50% of HD patients and that it is not being effectively managed. The development of effective pain management strategies, underpinned by appropriate training and education, is necessary to improve the quality of life for dialysis patients [8].

Main Idea: Health is physical and mental well-being.

Patients describe health as a whole, mutual body and mind welfare condition, where routine and leisure activities can be carried out.

CSD: "Health is all the best! It is being emotionally and physically well; sleeping and waking up well, with all your body functions in order; having quality of life; practicing physical exercises, taking walks and feeling happy; carrying out your usual activities; doing what you want and eating what you want. It is not being let down by problems and living well, having the strength and being able to do your job, enjoying yourself. We need health to be able to help our family, and feel part of the community; it is living life to the fullest. It is the most important thing in life, if you do not have health, then you have nothing."

The hemodialysis treatment includes factors that reflect in the quality of life, leading to psychosocial conflicts, such as changes in appearance, addictions, realization of potential death, dietary and hydric restrictions, and changes in the socialization of the patient and his family [9].

Another study conducted over 12 months with 93 patients in a hemodialysis center, concluded that, after the course of a year, there was an improvement in mental and emotional levels, contrasting with the fact that the dialysis treatment influences the psychological balance of the patient negatively, and supports the idea that it results in harmful physical effects [10]. Over time, a psychological adaptation takes place, and the chronic disease patient resorts to rational strategies to deal with it [11].

Main idea: I am always healthy.

The subject can embrace the obligations, duties and responsibilities of the treatment, facing chronic kidney disease rather naturally, as mentioned in the CSD:

CSD: "I always feel healthy. As long as you are not sick, you're healthy. With all the little problems that can sometimes be disturbing, I am happy with the kind of life I lead. All my life I've been healthy, I feel well every day! I have health, which is good enough for me, thanks to God, I'm fine! I am still working and supporting my family; my only problem is my kidney."

As time passes, patients undergoing renal replacement therapy become familiar with the treatment. The hemodialysis room becomes a pleasant environment, offering distraction and leisure, such as reading and TV viewing, besides allowing for an environment where friendships might start [4].

We see that "health is understood as a state of non-sickness, non-discomfort and no pain when the individual can carry on with his life without major changes or uncertainties" [4]. A study refers to coping strategies, which are positive emotional reactions that could mask a condition of distress or a threat to one's well-being; in order to maintain or to create self-control before a situation he must face [12]. According to the CSD, being a chronic kidney disease patient on hemodialysis becomes something acceptable, through the creation of a "coping strategy" that helps him meet his challenges successfully.

Main idea: The disease is something that weakens and prevents you from living a normal life.

The patient correlates the disease with the inability to perform the daily duties or the activities that would please him, either because of the time devoted weekly to his treatment or because of the signs and symptoms caused by chronic kidney disease, as mentioned below:

CSD: "It's not being able to walk, being unable to do anything, standing still, not being able to do what you want, and notating what you feel like! After all, because of this problem of ours, we have to control the food, eat what is not fat or salty. Overall, being sick is not doing the things you're used to doing every day, it is putting a limit to life, it is wanting to do things and not being able to, it is depending on others, preventing you from living normally. It is when you lose the conditions to perform your chores that make you feel powerless."

The anemia, weakness, back pains, ankle edemas, bone pains, discomfort at the joints, and periarticular calcification with calcium deposits are some factors that lead to the limitations reported by patients [13].

A study conducted in São Paulo, whose objective was to analyze the meaning of health and disease in the perception of children between 7 and 12 years old, demonstrated that for a considerable part of the interviewed population, the disease is related to impediments and limitations [14]. This discourse shows us that regardless of age, having a disease becomes acceptable, provided that it does not interfere with one's daily activities.

An analysis performed to evaluate the quality of life of 113 hypertensive patients in Brazil, used the SF-36 tool (Medical Outcomes Study 36 - Item Short Form Health Survey) in which descriptive measurements of data are taken through eight domains. Among them are "functional capacity" and "physical

performance"; indices for these domains showed that individuals define disease as the inability to walk and to work [15].

Another author opposes this concept, addressing the disease as "thing", which is manifested by symptoms that are treated by medication and surgical intervention [16].

The patient in this CSD also refers to imposed dietary restrictions, as well as the lack or excess of components that may influence the evolution of the disease. These individuals should restrain potassium, salt, protein, iron and high-calorie food intake.

From the moment he cannot perform his tasks or something else he likes to do, the patient ceases doing them or requests help from someone, creating a dependency that definitely shatters his ego.

Main Idea: Disease has to do hemodialysis.

The patient relates hemodialysis with disease. His life becomes dependent on a machine, sections become a part of his routine, and he must follow them to the letter to ensure survival, as described in the report:

CSD: "I have a chronic disease, I have to do hemodialysis, and it's something that makes me very tired, anyway, I have health problems and I think no one would want to be like this... It's hard, but we live on, after all, we do hemodialysis to live on. Even so, this kidney problem is tough, it is not very serious, but it will never heal! So, disease is this, do hemodialysis, kidney problems, these things."

A survey referring to data from the BRAZPD (Brazilian Peritoneal Dialysis Multicenter Study) with the help of the Karnofsky index (assessment of quality of life) and SF-36, scored low in quality of life and in all aspects of the SF-36, but, based on the Karnofsky evaluation, scores for quality of life were high [17]. The author justifies that patients with chronic kidney disease may have their quality of life reduced because of the various restrictions they are submitted to, however, elderly and diabetic patients showed higher physical, mental and social compromise [17].

Another study showed that patients with higher education levels assimilate their health conditions more easily, positively influencing their psychological state and preventing hemodialysis from disrupting the emotional state of those people [18].

Main Idea: I always feel like a sick person.

The CSD shows that care must be part of the daily routine of the patient, regardless of the place, and yet, when convinced that all is well, a physical reaction due to the chronic kidney disease reminds him it is there:

CSD: "I always feel sick, because I really am. The situation I am in here is routine. I feel sick all the time and while I am alive, I will feel sick. I am fighting a physical and mental battle, because mentally I say I'm fine, but the body does not show it."

Authors report that restrictions and obligations arising from chronic kidney disease, reflect in a psychological impact, causing patients to evaluate the opportunities they had and their current limitations, which creates uncertainty and insecurity about what is to come, resulting in a feeling of powerlessness before life, making them see themselves as eternally sick [19].

In contrast, a study of 20 individuals who were in hemodialysis, showed that the psychological domain is the least affected, and the physical domain (pain, discomfort, lack of energy, fatigue and drowsiness) interferes significantly with the quality of life of those people, and, because it is a chronic disease, this factor becomes common on a day-to-day basis [20]. A survey with chronic disease patients, observed that the loss of autonomy to carry out some activities, result in a feeling of being terminally ill [21].GHG

CONCLUSION

From the six main ideas taken from the responses of the subjects, we can conclude that despite the similarity of their situations, with regard to disease treatment, life expectancy, constraints, dependencies, etc., their ways of undertaking adversity are totally different.

So much variety depends on many factors, ranging from their religious beliefs, their accomplishments, their living arrangements - with family or not, their sense of worthlessness, their dependence, not only on people, but also on a machine that begins to exert a function that was natural until then. All that involves the human being as part of the environment where he is inserted, playing his role in his community, and to himself. Details, these small things accumulate, disrupting the patient's life. It becomes important to point out that the dialysis treatment presents not only psychological problems, but it also affects the body, what is impossible to hide.

Nevertheless, this study presents limitations. It is important to highlight that not all dialysis patients are the same; they have different ages, may or may not present comorbid conditions or risk factors, differ in dialysis time etc., thus being a diverse population, who has the treatment of hemodialysis in common. This can alter the perception of their health-disease process, but the main ideas are relevant and deserve to be addressed in future studies, perhaps considering the socio demographic characteristics of this population.

REFERENCES

- National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney Disease: evaluation, classification, and stratification. *Am J Kidney Dis.* 2002; 39: 1-266.
- Verónica Guerra-Guerrero; Olivia Sanhueza-Alvarado; Mirtha Cáceres-Espina. Quality of life in people with chronic hemodialysis: association with socio demographic, medical-clinical and laboratory variables. *Rev Lat Am Enfermagem.* 2012; 20: 838-846.
- National Kidney Foundation. KDOQI Clinical Practice Guideline for Hemodialysis Adequacy: 2015 update. *Am J KidneyDis.* 2015; 66: 884-930.
- Modesto AP. O cuidado cultural de enfermagem com o idoso renal crônico em tratamento hemodialítico [tese]. Curitiba: Universidade Federal do Paraná, 2006.
- World Health Organization. Constitution of the World Health Organization. 1946. Basic documents. 47th ed. Switzerland: Geneva; 2009.
- Marília ZA Figueiredo, Brasília M. Chiari, Barbara NG Goulart. Discurso do sujeito coletivo: uma breve introdução à ferramenta de pesquisa qualitativa. *Rev Distúrb Comum.* 2013; 25: 129-132.
- Höijer B. Social Representations Theory: a new theory for media research. *Nordicom Review.* 2011; 32: 3-16.
- Davison SN. Pain in hemodialysis patients: prevalence, cause, severity, and management. *Am J Kidney Dis.* 2003; 42: 1239-47.
- Takemoto AY, Okubo P, Bedendo J, Carreira L Evaluation of quality of life in elderly undergoing hemodialysis. *RevGauchaEnferm.* 2011; 32: 256-262.
- Santos, Paulo Roberto, BRIDGES, Ligia Regina Sansigolo Kerr Mudança do nível de qualidade de vida em portadores de insuficiência renal terminal durante seguimento de 12 meses. *RevAssocMed Bras.* 2007; 53: 329-334.
- Paula DA, Marques IR. Estudos sobre a qualidade de vida de pacientes que realizam a hemodiálise. *RevEnferm UNISA.* 2010; 11: 108-114.
- Coletto M, Câmara S. Estratégia de coping e percepção da doença em pais de crianças com doença crônica: o contexto do cuidador. *Revista Diversitas Perspectivas em Psicologia.* 2009; 05: 97-110.
- Frazão CMFQ, Ramos VP, Lira ALBC. Qualidade de vida de pacientes submetidos à hemodiálise. *RevEnferm UERJ.* 2011; 19: 577-582.
- Moreira PL, Dupas G. Significado de saúde e de doença na percepção da criança. *RevLatAm Enfermagem.* 2006; 11: 757-762.
- Brito DMS, Araújo TL, Galvão MTG. Qualidade de vida e percepção de doença entre portadores de hipertensão arterial. *CadSaudePublica.* 2008; 24: 933-940.
- Camargo Jr, K. As armadilhas da concepção positiva de saúde. *Physis.* 2007; 76: 63-76.
- Grincenkov FRS, Fernandes N, Chaubach A, Bastos K, Quresh AR, Filho RP, et al. Fatores associados à qualidade de vida em pacientes incidentes em diálise peritoneal do Brasil (BRAZPD). *J Bras de Nefrol.* 2011; 33: 38-44.
- Castro M, Caiuby AVS, Braibe AS, Canziani MEF. Qualidade de vida de pacientes com insuficiência renal em hemodiálise avaliada através do instrumento genérico SF-36. *RevAssocMed Bras.* 2003; 49: 245-249.
- Lima AFC, Gualda, Dulce Maria Rosa. História oral de vida: significado de la hemodialisis para el paciente crónico renal. *RevEscEnferm USP.* 2001; 85: 235-241.
- Higa K, Kost MT, Soares DM, Moraes MC, Polins BRG. Quality of life of patients with chronic renal insufficiency undergoing dialysis treatment. *Acta Paul Enferm.* 2008; 21: 203-206.
- Costa VT, Alves PC, Lunardi VL. Vivendo uma doença crônica e falando sobre o cuidado. *RevEnferm UERJ.* 2006; 14: 27-31.

Cite this article

Spigolon DN, de Souza JP, da Silva CA, Zollner Sary DL, Modesto AP (2016) Perception on Health and Disease, Patient in Treatment on Hemodialysis - Can Feeling Healthy Be Enough? *Ann Nurs Pract* 3(6): 1063.