RESEARCH

BODY PERCEPTION AMONG INDIVIDUALS WITH CHRONIC KIDNEY DISEASE: A PHENOMENOLOGICAL STUDY

A PERCEPÇÃO DE CORPO POR PESSOAS COM DOENÇA RENAL CRÔNICA: UM ESTUDO FENOMENOLÓGICO

PERCEPCIÓN DEL CUERPO POR PERSONAS CON ENFERMEDAD RENAL CRÓNICA: UN ESTUDIO FENOMENOI ÓGICO

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ABSTRACT

Objective: to understand the experience of patients whose body has been invaded by chronic kidney disease (CKD). Methods: exploratory and qualitative study based on the social phenomenology of Amedeo Giorgi. A total of 30 patients attending a hemodialysis clinic in the state of Rio de Janeiro, Brazil took part in the study. Phenomenological interviews were held in March 2017. Results: The invasion of one's body by CKD is characterized by incapacitation in performing daily tasks, as well as something triggering biological and physical-aesthetic body changes, while some participants consider it not to belong to the pathological sphere, whether because they are resilient or because they deny this new condition that causes changes in their way of life. Conclusion: the CKD imposes the re-signification of one's body and a new way of life. Thus, it is essential to understand the complexity of this occurrence in its subjective sense, in order to provide care that is appropriate to the needs of patients. Keywords: Renal Insufficiency, Chronic; Perception; Renal Dialysis; Human Body; Nursing.

RESUMO

Objetivo: compreender a vivência do paciente como corpo invadido pela doença renal crônica (DRC). Métodos: estudo exploratório, qualitativo, alicerçado na fenomenologia social de Amedeo Giorgi. Participaram 30 pacientes de uma clínica de hemodiálise do estado do Rio de Janeiro. Realizaram-se entrevistas fenomenológicas aplicadas em março de 2017. Resultados: Desvelou-se que a invasão do corpo pela DRC se caracteriza como incapacitante para a realização das tarefas cotidianas; como provocadora de alterações biológicas e físico-estéticas corporais; e, para alguns, não pertencente ao patológico, quer seja por desenvolverem resiliência ou por não aceitarem a nova condição que acarretará mudanças no seu modo de viver. Conclusão: a DRC impõe a ressignificação do corpo e um novo modo de viver. É imprescindível compreender a complexidade dessa afecção no seu sentido subjetivo, para, então, promover adequado cuidado às necessidades do sujeito.

Palavras-chave: Insuficiência Renal Crônica; Percepção; Diálise Renal; Corpo Humano; Enfermagem.

RESUMEN

Objetivo: comprender la experiencia del paciente como un cuerpo invadido por la enfermedad renal crónica (CKD). Métodos: estudio exploratorio y cualitativo basado en la fenomenología social de Amedeo Giorgi. Participaron 30 pacientes de una clínica de hemodiálisis del estado de Río de Janeiro. Se realizaron entrevistas fenomenológicas en marzo de 2017. Resultados: se observó que la invasión del cuerpo por CKD se caracteriza porque impide que la persona realice tareas diarias; provoca alteraciones biológicas y físico-estéticas del cuerpo y, para algunos, no pertenece a lo patológico ya sea por la resiliencia o porque no aceptan la nueva condición que traerá cambios en su modo de vida. Conclusión: la CKD impone la re-significación del cuerpo y una nueva forma de vida. Es esencial comprender la complejidad de esta enfermedad en su sentido subjetivo para después promover los cuidados adecuados a las necesidades del sujeto.

Palabras clave: Insuficiencia Renal Crónica; Percepción; Diálisis Renal; Cuerpo Humano; Enfermería.

INTRODUCTION

Chronic kidney disease (CKD) is considered a severe national public health problem in Brazil, the epidemiological data of which reveal the existence of approximately 112,000 patients on dyalisis.¹ Given the irreversible nature of the disease, palliative and continuous care is required to prolong life. In addition to the biological aspects and pain, this condition leads to biopsychosocial repercussions and changes in lifestyle that interfere in one's identity, worsening quality of life.²

Living with a chronic disease forces people to organize their lives around the disease and treatment. Nevertheless, each individual experiences the disease in his/her own way, as subjectivity is conceived as a being in the time and space in which one lives. That is, one's perception of being in the world is fundamentally a practical involvement with the reality that is experienced, a process that takes place through one's body.³

In the phenomenology of perception, the body is configured as an object of reflection, understanding that it is, at the same time, the source of existence and place of perceptual experience and involvement of the person with the world. Therefore, in addition to the biological being, the body is a social construction that works as a mark of values and meanings socially imposed and as an element that is indispensable to one's individuality.

When one experiences disease, one experiences a rupture with his/her body, which affects one's body image and aesthetic sense, which in turn activates diverse sensations and feelings that need to be embraced by health workers, to avoid difficulties accepting the disease and its therapeutic process for patients.⁶

In keeping with the previous discussion, greater attention has been given to the relationship between psycho-cultural conditions and kidney disease, as foreseen by an acknowledged researcher. According to this researcher, much has been learned about the disease's physiological aspects, which in turn have presented a new challenge to the community of scientists in the association and impact of psychosocial factors on how the disease progresses among those affected.⁷

The relevance of this subject is based on this understanding. Thus, it is essential to understand the complexity of this disease in its subjective meaning, which can only take place

based on the perception of an individual of his/her own body and the individual's experience in the context of a chronic disease, then to provide care that is appropriate to a patient's needs. Thus, this study's objective is to understand the experience of patients whose body is invaded by CKD.

METHOD

This is an exploratory study with a qualitative approach, using the phenomenological method, because it allows understanding what one wants to study as a human phenomenon, experienced by an individual, who when asked, reveals him/herself in all his/her subjective dimensions, revealing meanings concerning his/her experience of life.

This study was developed in a dialysis facility located in the metropolitan region of Rio de Janeiro, RJ, Brazil. It is a high complexity private facility linked to the Brazilian public health system, specializing in the care of patients with CKD.

The study's population was composed of the 163 registered patients receiving treatment in this facility in March 2017. The following inclusion criteria were used to compose the sample: being under hemodialysis using the traditional technique of puncturing an arteriovenous fistula (rope-ladder cannulation), for at least two years and being at least 18 years old. Exclusion criteria were: presenting cognitive deficit that impeded participation, non-adherence to treatment, that is, those who repeatedly miss treatment and/or do not have 12 hours of dialysis weekly, or those referred to another hemodialysis service during the data collection period.

The participants were chosen according to convenience, characterized in this study by the presence of the patient in the clinic during data collection, a time when the researcher checked eligibility criteria by consulting medical files. Those who met the criteria were individually invited to participate and received clarification regarding the study's objectives. Sample size was determined by theoretical saturation of data – the inclusion of new subjects ceased when data became redundant and the researcher considered that new data would not change the understanding of the phenomenon under study.

Thus, the sample was composed of 30 individuals, without sample loss.

Data were collected in March 2017 through phenomenological interviews with the following guiding question: "how do you perceive the kidney disease in your body?", which aimed to gather the meanings individuals assign to the experience lived as a sick body. No additional questions were necessary during the interviews, though the researcher adopted a listener's posture, while at the same time encouraging participants to talk: whenever there was a need to obtain further information, he asked the interviewee to talk more about the subject.

According to the participants' preferences, the individual interviews took place during dialysis, with complete privacy and free from interruptions. Interviews were recorded and transcribed verbatim to preserve the characteristics of the reports.

Data concerning the characterization of the participants were obtained through their medical files using a form that addressed sex, age, duration of diagnosis, duration of vascular access for dialysis, and primary disease that triggered the kidney disease. These data were analyzed by means of descriptive statistics using Microsoft Excel® 2010.

Data obtained during the interviews were collected, treated and analyzed according to the empirical-comprehensive model proposed by Amedeo Giorgi and is composed of four main steps: a) focused reading of descriptions expressed by the participants; b) identification of units of meanings; c) transformation of the participants' language into scientific language, while keeping an emphasis on the phenomenon; d) synthesis and integration of units of meaning.⁸

In accordance with ethical principles, the study project was submitted to and approved by the Institutional Review Board at the Medical School, Universidade Federal Fluminense, (No. 1.589.579) in June 2016. Confidentiality was ensured by identifying the participants by the abbreviation Col (collaborator) followed by a number.

RESULTS

A total of 15 men and 15 women, aged 48.2 years old on average, took part in the study. The duration of CKD ranged from 2.1 to 26 years, while duration of dialysis (arteriovenous fistula) ranged from 2.1 to six years. The most prevalent primary disease was hypertension, which was diagnosed in 26 (86.7%) patients.

The phenomenological interviews resulted in a *corpus* of analysis, the most frequent units of meanings of which were: disease (n=36); dialysis (n=32); life (n=29); I feel (n=21); I perceive (n=24); body (n=20); and changes (n=16).

A comprehensive analysis of the reports enabled capturing the essence of the individuals' perceptions regarding their bodies being invaded by CKD, revealing that this invasion is characterized by being incapacitated, causing bodily biological change, and some individuals did not feel it belonged in the pathological sphere.

INCAPACITATED BODY

When the participants reported how they felt and perceived the kidney disease in their bodies, their incapacity to perform daily tasks was frequently mentioned. The most frequently reported action restricted by the disease was work.

"I realize my incapacity to perform tasks I used to perform in the past" (Col. 1).

"I'm currently doing nothing, I can't have a boyfriend, I can't do anything" (Col. 6).

"A feeling that you don't want to have it. It's bothersome! It's restrictive! It limits the time you have to do things!" (Col. 9).

"I feel sluggish, my body doesn't allow me to do much. Everything's changed. I want to clean, tidy up the house really well but I just can't" (Col. 16).

BODY BIOLOGICALLY CHANGED

The disclosure of the diagnosis is marked by negative feelings and difficulty understanding what the disease is, bodily changes, treatment, and changes in lifestyle. Even though knowledge concerning the disease can be socially acquired, through common sense, professional guidance, or individual research, it is the experience that gives meaning to it. In this sense, invasion by the disease causes these individuals to experience biological and physical aesthetic changes, especially in regard to swelling (a term that appeared 25 times) caused by generalized edema and weight, a term that represents the perception *I was fat and lost weight*.

It changes all your physique, your appearance. You notice your physiognomy changes, your body aches, your belly seems swollen (Col. 1).

Skin changes over time, your hair, even the way you walk (Col. 2).

I lost a lot of weight and my skin is really flabby (Col. 8).

The body gets heavy, you becomes sluggish, you feel your body burning, something you cannot rub off or

touch, I got pretty swollen and didn't know what it was (Col. 12).

I had a much larger body and even felt better with this body, but then I became very weak (Col. 15).

Degenerative. A disease that is slowly destroying you (Col. 20).

BODY DOES NOT BELONG TO THE PATHOLOGICAL SPHERE

Kidney disease often sets in suddenly and quietly, not showing signs or symptoms, which for many are factors that configure the existence of a disease in their bodies. In the absence of signs or symptoms, many individuals do not perceive themselves as being sick.

Other people, either because they are more resilient or because they do not accept an invader that triggers changes in their way of life, do not assume the condition of "being a sick body". If, for the former, resilience stands out as a coping strategy and psychological adaptation to changes in daily life that are caused by the CKD treatment, for the latter, denial constitutes suffering and may negatively influence treatment adherence.9

To be honest, I feel nothing, for me it's a normal disease (Col. 15).

I only feel sick during the three days I have hemodialysis! I only feel sick on Mondays, Wednesdays, and Fridays. On the days I'm not here, I live my life normally; I don't think I'm sick. This is my conception! (Col. 13).

I've tried to understand what a patient with chronic kidney disease is. I'm a patient who's studied my treatment. I've got a book with the head nurse and studied it [...] I didn't make it difficult, I've tried to survive with the treatment. I've tried to learn what hemodialysis is (Col. 4).

Many people say that I don't look like someone who does hemodialysis, but I know I do, I only pretend that I don't (Col. 12).

You have an adverse reaction to the disease. You don't accept the fact you have a chronic disease. [...] I acted like I had nothing, that I was well, that was my way of acting and showing that it was part of my body. I guess I didn't care, but when I withdrew myself from my world, that frustrated me (Col. 1).

DISCUSSION

The study revealed the experience of individuals with CKD and its meanings expressed by the body that perceives, feels, and suffers bodily changes accruing from the disease. These changes express the quality of life of the being-in-the-world receiving hemodialysis and restricting the performance of daily tasks.

According to the literature, the main aesthetic changes arising from CKD involve the fistula (edema, hematoma) and changes in weight.⁶ These changes lead to psychosocial complications, especially low self-esteem and a feeling of inferiority, which, associated with a perception that people in general are curious about and prejudiced toward physical changes, are important factors for social isolation and distress.¹⁰⁻¹²

In this context, the health-disease continuum is painful and very personal. Each individual experiences it differently because health and disease are clinical and sociological phenomena culturally experienced by people. People experience the condition according to the meaning each assigns to the path taken during the experience of becoming sick.¹³

These phenomena become real for those with CKD receiving hemodialysis, especially when they perceive impairment that is established during the course of the disease and that presents itself as limitations regarding the performance of daily living activities such as working. In regard to this aspect, data from the Brazilian Society of Nephrology indicate that more than 66% of those receiving dialysis are of an economically active age¹; however, the percentage of patients who remain working after initiating the treatment is low. In the supplementary of the supplementary

In this sense, hemodialysis marks the presence of the disease, when these individuals, whose bodies experience aesthetic changes and become different, have to acknowledge that their bodies no longer favor their existence. These individuals lose their autonomy, no longer perceive themselves as the ones controlling their time due to the need to attend an appointment for hemodialysis three times a week.¹⁷ These beings live one day after another, without the prospect they will be able to control or determine their time/existence in this world.

The chronic nature of the disease, the fear of dying, and changes in body image trigger a series of stressors during the waiting period, which may significantly influence the success of their ongoing treatment.¹³

When the disease appears, it becomes a barrier in the process of living, changing lifestyle and social life. The unknown is formed by symbolic points of a society and may threaten the individual and his/her relationship with the world. The perceptible physical changes accruing from the disease associated with the clinical condition and treatment routine contribute to discomfort and distress that these individuals experience.¹⁸

The invasion of the disease is perceived in an awareness that the body—one's point of view regarding one's own body,

as a means of knowing oneself—is linked to a result of how relationships are established with the objective world. The perception one has of oneself is fragmented; the idea of control over one's body is diluted to the extent which one experiences CKD and related therapy.

According to Moreira, "the human being does not learn with his/her intelligence only, but with his/her body and "guts", sensibility and imagination". From this perspective, the relationship with the world can be learned through speech, the expression of each individual, his/her singularities and experiences. 19:140

This new identity, assumed with the emergence of kidney disease, is revealed as if the individual were invaded by a second person in his/her own body. A new sensible interpretation of this body, which assumes a new physiological condition, is necessary, for this phenomenological body is transcendent in the understanding that this new event in the vital process is inherent to our existence.

Nurses need to be attentive to human existence and individuals' perceptions in order to intervene with actions that value the vital process, not only the physiological maintenance of the anatomical and biological body. It is necessary to implement strategies that will lead these individuals to reflect upon their context to seek and devise new paths.^{20,21}

The essence of nurses' work is to provide care, a process that involves close contact with patients and their health needs, denoting assisting human beings in their needs, involving acts, behaviors and attitudes that depend on the context and relationship established between patients and professionals. Additionally, nursing work is an action that comprehends care attitudes towards one's body, an attitude of looking in the eyes of patients and perceiving their feelings.²²

The body changes produced by the CKD are the patients' experiences of life. Therefore, even though bonds are established between health workers and patients during hemodialysis and the routine of care delivery, the perception of these changes has a singular, authentic meaning that is influenced by the objective relationships established with the world. Thus, before being an object, the body is our way of being in the world and enables the person to be in the world when it puts him/her in the situation of being. When this body bears marks, which are recognized by the individual who cares for them and by others, as anti-aesthetical and immutable marks, the perception the individual has of him/herself changes that individual's way of existing and being in the world.²³

Nurses have the opportunity to identify the expressions of bodily changes in patients and apply their knowledge through interventions, using mild, mild-hard or hard care technologies to promote comprehensive processes concerning life with CKD.²² Exchanges among people and between the psychological and physiological spheres of a human being allows the individual to develop other bodily significations.

In summary, the care provided to the body, to its functionality, to the physiological, is often valued at the expense of the aesthetic care. The latter is translated in well-being, even under adverse conditions. The body scheme is no longer the result of associations established in the course of the experience with CKD, but rather is established when a global awareness is acquired of the patient's intersensorial posture in the world.²³

Our relationships with the world are mediated by the body that occupies a space, as our body is not primarily in the space, it is and always will be its own occupied space.²³ Therefore, a person's own point of view is imbricated with the point of view that others have about the person. Since the CKD is not somebody else's experience, its coexistence with another is denied, and the patient is not ahead of his/her body; one is in one's body, or, one is his/her body. Sensorial perceptions regarding one's own body disqualify the individual when s/he makes decisions regarding him/herself.

Hence, nurses have to practice listening, in addition to seeing and observing the body. The nurse-being needs to exercise care and bring the patient into a unity to jointly comparing ways to "live" with CKD and hemodialysis. One cannot provide care without establishing bonds, without exchanging energy, or without reifying human care.

The perception of not belonging to the disease that invades the body on the part of some patients may be that these individuals are denying awareness of the meaning of the whole, which makes it imperative to produce studies that go beyond the clinical sphere addressing the psychological and aesthetical care, considering that human beings typify the "ill being".

Patients also need to recover their self-esteem so they can understand this phenomenological body that feels, perceives and is affected by social interaction, because the body is an expressive unit. When this is assumed, patients can learn to know their bodies. It is this structure that will communicate with the sensitive world, re-signifying their existence with CKD.

When nurses promote aesthetic care, they contribute to and help patients to learn to construct another point of view of their bodies' involvement with CKD, another use of one's own body, another reorganization of body scheme, another re-signification of a sensorial entity. To find oneself ill, without masking oneself, is an intrinsic movement, however of intra- and extra-relational dimensions that will favor the quality of life of individuals invaded by CKD. It is from this perspective that this study can contribute, not only to the patient as an invaded body and professionals, as beings attentive to the subjective aspect of the ones to whom they provide care, but also to Science. This study provides subjective aspects that need to be deeply addressed in further studies, with new analyses, addressing new possibilities of providing care, considering the individual needs of each patient, who are more than a sick body; a patient is a being who

experiences, perceives and produces affections, whom can not always be cared for through the physical body.

CONCLUSIONS

The theoretical-methodological approach of social phenomenology enabled understanding the *being-body invaded* by CKD, from a perspective that values the subjective and the context experienced.

The study reveals that the body is perceived as impaired, as biologically and aesthetically changed circumscription; while for others, it is viewed as something that does not belong to the pathological sphere. One's perception is singular and nontransferable, though it is amenable to comprehensive nursing care. In this sense, those with CKD need to receive care from professionals who are prepared to meet perceptive needs, among which are the bodily changes caused by the disease.

It is, therefore, necessary to contemplate and promote nursing care that is not dissociated from thinking/doing toward the bodies of these patients, that is, to devise nursing actions that transcend the physical body promoting the right to life, to citizenship, so patients can resume their interpersonal relationships as a way to minimize their pain and distress from living as a being-in-the-world with CKD.

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