

## The body marked by the arteriovenous fistula: a phenomenological point of view

*O corpo marcado pela fístula arteriovenosa: um olhar fenomenológico*  
*El cuerpo marcado por la fístula arteriovenosa: una mirada fenomenológica*

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### How to cite this article:

Silva DM, Silva RMCRA, Pereira ER, Ferreira HC, Alcantara VCG, Oliveira FS. The body marked by the arteriovenous fistula: a phenomenological point of view. Rev Bras Enferm [Internet]. 2018;71(6):2869-75. DOI: <http://dx.doi.org/10.1590/0034-7167-2017-0898>

Submission: 12-21-2017

Approval: 02-07-2018

### ABSTRACT

**Objective:** To understand the experience of people with chronic kidney disease using arteriovenous fistula. **Method:** Qualitative and exploratory study based on Social Phenomenology, conducted on 30 adults undergoing hemodialysis by using the fistula, interviewed in 2017. The interviews were analyzed according to the empirical-comprehensive model proposed by Amedeo Giorgi. **Results:** We found the categories “The changed body aesthetics”; “The perception of the other about my body”; and “The fistula as an inseparable condition for life maintenance.” **Final considerations:** The experience of people using fistula showed that this venous access leaves marks that change the body aesthetics, making the body imperfect. Such changes cause low self-esteem and attract the look of the other, causing embarrassment in those who have the body changed. Thus, they react by camouflaging the fistula, without which there is no life. This perception arises from the fear that works as a catalyst for self-care. **Descriptors:** Chronic Kidney Disease; Fistula; Kidney Dialysis; Nursing; Body Image.

### RESUMO

**Objetivo:** Compreender a vivência de pessoas com doença renal crônica em uso de fístula arteriovenosa. **Método:** Estudo qualitativo e exploratório, fundamentado na fenomenologia social, realizado com 30 adultos em tratamento hemodialítico por meio de fístula, entrevistados em 2017. Os depoimentos foram analisados segundo o modelo empírico-compreensivo proposto por Amedeo Giorgi. **Resultados:** Foram desveladas as categorias: A estética corporal alterada; O olhar do outro sobre o meu corpo; e A fístula como condição indissociável à manutenção da vida. **Considerações finais:** A vivência de pessoas em uso de fístula revelou que esse acesso venoso deixa marcas no corpo que alteram a estética corporal, tornando o corpo imperfeito. Essas alterações provocam baixa autoestima, e atraem o olhar do outro, causando constrangimento naquele que tem o corpo marcado. Esse, por sua vez, reage camuflando a fístula, sem a qual não há vida. Dessa percepção surge o medo, que atua como catalisador para o autocuidado. **Descritores:** Insuficiência Renal Crônica; Fístula; Diálise Renal; Enfermagem; Imagem Corporal.

### RESUMEN

**Objetivo:** Comprender la vivencia de personas con enfermedad renal crónica en uso de fístula arteriovenosa. **Método:** Estudio cualitativo y exploratorio fundamentado en la fenomenología social, realizado con treinta adultos en tratamiento hemodialítico por medio de fístula, entrevistados en 2017. Los testimonios fueron analizados según el modelo empírico-compreensivo propuesto por Amedeo Giorgi. **Resultados:** Se desvelaron las categorías “La estética corporal alterada”; “La mirada del otro sobre mi cuerpo”; y “La fístula como condición indisociable al mantenimiento de la vida”. **Consideraciones finales:** La vivencia de personas en uso de fístula reveló que ese acceso venoso deja marcas que alteran la estética corporal, haciendo el cuerpo imperfecto. Esos cambios provocan baja autoestima y atraen la mirada del otro, causando constreñimiento en el que tiene el cuerpo marcado. Este, a su vez, reacciona camuflando la fístula, sin la cual no hay vida. De esa percepción surge el miedo, que actúa como catalizador para el autocuidado. **Descritores:** Insuficiencia Renal Crónica; Fístula; Diálisis Renal; Enfermería; Imagen Corporal.

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## INTRODUCTION

In the context of each country, the chronic kidney disease (CKD) is a serious public health problem, considering its high incidence in the population. Currently, it is considered a pandemic by the World Health Organization<sup>(1)</sup>. In Brazil, it has been estimated that in 2013 there were more than 100,000 patients undergoing some alternative renal therapy, of whom 90% corresponded to hemodialysis<sup>(2)</sup>.

Hemodialysis corresponds to the extraction of toxic nitrogenous substances from the blood and excess of water through the vascular access, which can be obtained by the central vein catheterization with double-lumen catheter or through surgical operation for implementing the arteriovenous fistula (AVF)<sup>(3)</sup>. In Brazil, the AVF cannulation is traditionally carried out by the rope-ladder technique, characterized by the use of sharp needles to puncture sites, which are constantly alternated in an attempt to avoid vascular trauma<sup>(4)</sup>.

However, after some time using this technique, there is the emergence of bruises, aneurysms, scars, and thrombi areas that alter the body perception, that is, the self-image of subjects in dialysis treatment<sup>(5)</sup>, causing, in addition to physical damage, sensations and psychosocial processes that may generate difficulties in accepting the disease and its therapeutic processes<sup>(6)</sup>.

In the CKD context, the AVF, understood as the best access route for hemodialysis, outstands as the first physical mark that the disease has been established in the body, and subjects start perceiving themselves as a different body from that which is healthy<sup>(7)</sup>.

According to the phenomenology of perception, the body is a reflection element, because it works as a receptacle of the existence and the experience of being in the world. Therefore, it is not only a biological matter: it is a social construct, whose existential relationships are assimilated by the contact with each other and with the world, and is also a constituent element of individuality<sup>(8)</sup>. Hence, the illness process causes a natural process of rupture between individuals and their body, since the subjectivity and the perception of being-in-the-world emerge from a practical engagement with the reality experienced by the body<sup>(9)</sup>.

Accordingly, the complexity of CKD and its treatment go beyond the physiological objectivity, requiring a perspective of psychosocial-cultural conditions enhancing the individual's experience and perception as a *sick being*, considering the holistic care and the improvement of quality of life.

To do so, it is essential that health professionals, in particular the nephrology nurse, work as closely as possible to these patients, performing a therapeutic listening in a process of dialogic care, which embrace the perceptions before the limitations imposed by the disease and the dialysis treatment<sup>(10)</sup>.

We aim to contribute to the professional practice by researching subjective elements, supporting new ways of care that value the completeness and, consequently, promote the well-being and quality of life of CKD patients using fistula in their body.

## OBJECTIVE

Our study aims to understand the experience of people with CKD using AVF.

## METHOD

### Ethical aspects

Since this is a research involving human beings, the project was submitted to the Research Ethics Committee of the Medical School of Universidade Federal Fluminense, and it was approved in June 2016. All recommendations of Resolution 466/2012 from the National Health Council (from Portuguese, *Conselho Nacional de Saúde* – CNS) were followed. Participants signed an informed consent form and were informed about the existing risks of the research.

### Type of study

This is a qualitative and exploratory study, based on Social Phenomenology, which seeks to understand human phenomena from the perspective of subjects' experience.

### Methodological procedures

We used a semi-structured questionnaire comprising data regarding the characterization of participants as for sex, age, time of diagnosis, time with vascular access for dialysis, and underlying disease that triggered the kidney disease; in addition to and a script containing a triggering question for the phenomenological interview.

### Study scenario

The research was conducted in a private dialysis clinic, which has a partnership with the Brazilian Unified Health System, specialized in patients with CKD at a high complexity level, located in the metropolitan region of Rio de Janeiro state.

### Sample

The study population comprised 163 users undergoing hemodialysis at the clinic in March 2017. For determining the sample, we considered those undergoing hemodialysis with the use of the traditional AVF puncture technique (rope-ladder) for at least two years and aging 18 years or over. The exclusion criteria were: cognitive deficit that precludes participation in the study; non-adherence to treatment, i.e., users with recurring absences and/or who do not undergo 12 hours of weekly dialysis, and those forwarded to other hemodialysis service during the period of data collection.

We chose the subjects for convenience, and such choice was qualified in this study by the presence of the subject at the clinic during the data collection period, at which point the researcher consulted the medical records to verify eligibility criteria and, once granted, the user was invited to join the study.

### Data collection and organization

Data were collected in March 2017 by phenomenological interview operationalized by the following triggering question: "How does it feel to live with a fistula in your body?", which sought to understand the meanings that subjects give to their experience as a body marked by AVF.

The collection of statements ended because of theoretical saturation, i.e., the inclusion of new subjects was suspended when the researcher assumed that new data would not change the understanding of the phenomenon. Thus, 30 individuals

constituted the sample, who were identified in this study by the "Con" acronym (standing for "contributor"), followed by a number.

By choice of the subjects, individual interviews occurred during the time when they were undergoing dialysis; such were recorded on digital equipment and transcribed in full.

### Data analysis

The characterization data of participants were analyzed by descriptive statistics by the Microsoft Excel® 2010 software. The statements, on their turn, were considered and analyzed according to the empirical-comprehensive model proposed by Amedeo Giorgi, by employing the following steps: (1) thorough reading of descriptions expressed by the research subjects, aiming at grasping the complete meaning of the phenomenon; (2) identification of the units of meaning (UI); (3) transformation of the language of the interviewee (UI) into scientific language (articulated assertions), still focusing on such phenomenon; (4) synthesis and integration of articulated assertions into analytical categories, which are: "The changed body aesthetics"; "The perception of the other about my body"; and "The fistula as an inseparable condition for life maintenance".

## RESULTS

Our research comprised 30 individuals with CKD using AVF for hemodialysis, being 15 men and 15 women, with an average age of 48.2 years. The time of CKD diagnosis ranged between 2.1 and 26 years, and the time undergoing hemodialysis using AVF ranged between 2.1 and 6 years. The most prevalent underlying disease was the systemic arterial hypertension (SAH), diagnosed in 26 (86.7%) patients.

### The changed body aesthetics

According to the statements, the recurrence of units of meaning related to aesthetic consequences due to the fistula was correlated with the following articulated assertions: *the fistula leaves marks on the body* (19 UI); *the fistula changes the body aesthetics* (11 UI); *the fistula makes the body imperfect* (6 UI); and *physical changes due to the fistula cause low self-esteem* (4 UI).

We perceive that the CKD marks the body aesthetics in a scathing way, either by the signs of the disease, or invasive accesses, such as the fistula, which enables therapies to maintain life. In this respect, the corporality of the *being someone* and the way subjects perceive their body are impaired, and may generate psychosocial implications such as low self-esteem and feeling of imperfection.

*I feel like the Bionic Woman. It's like that movie in which you have something strange in your body, and it bugs you. My looks bugs me... My looks as a woman... the looks of the arm, which is ugly, those changes in the arteries.* (Con. 1)

*My arm has really become awful. It's horrible! And I don't like to look at myself in the mirror.* (Con. 20)

*It marks me; a scar. I look at it and think that something is missing in me. The fistula brings me the memory that something is missing.* (Con. 21)

*It's really awful because our veins become dilated, one arm is thicker than the other, and that bugs me a lot because of these lumps in my arm.* (Con. 22)

*It's obnoxious 'cause it creates these huge lumps in our arms.* (Con. 26)

### The perception of the other about my body

This category of comprehensive analysis derived from units of meaning that culminated in the following assertions: *the other reacts against the body modified by the fistula* (57 UI); *the embarrassment of the marked body that is perceived by the other* (28 UI); *the body marked by the fistula is camouflaged* (9 UI).

Aesthetic consequences are closely related to the way subjects perceive themselves and are perceived in the world. Considering the physical changes due to the use of the fistula, the perception of the other over the marked body, which is based on the curiosity about the different *being*, is significant and troubles those who are suffering, triggering feelings of rejection and discrimination. In this scenario, the subjects hide themselves or the indiscretion object of the other, in this case, the fistula, which is hidden by their clothing.

*When you arrive anywhere, people's eyes invade your body... The facial expression of people when they look at you bothers you! [...] People make this adverse reaction to our appearance grow... Almost 100% react against the imperfection and you realize they think it is disgusting, ugly.* (Con. 1)

*The issue is people's observation. But since I wear long-sleeve blouses, it's stopped.* (Con. 2)

*The fistula in the arm is something that draws attention, especially my aneurysms, which are too big. Then everyone asks: "is it contagious?".* (Con. 6)

*It bothers, aesthetically speaking, because people notice it a lot. It's the first thing people notice... one day I was having a barbecue and a woman demanded for me to cover it.* (Con. 7)

*I feel a little ashamed, because sometimes there is this big lump and people are staring and questioning... you sit on the bus and the person [beside you] sits a little further away, wondering you have something serious.* (Con. 10)

*Everyone looks at my arm. It's my reference point! Everyone looks: "it's the girl with that thing in the arm." Sometimes some people say: "oh, I saw that girl with that thing in the arm!". That's how people refer to me. I used to be the chubby girl, now I'm the girl with that thing in the arm.* (Con. 12)

*The feeling is horrible. That's where people look and you see they get scared! [...] I don't go out showing my arm. I feel ashamed... they look at you with pity. I think this is lack of knowledge and discrimination too.* (Con. 16)

*It bothers me because people notice it, they think it's awkward... some people look with discrimination, they think it's a serious disease, they are even afraid to come near me... I've broken off a relationship because of that.* (Con. 18)

### The fistula as an inseparable condition for life maintenance

Despite the physical and psychosocial implications of living with the fistula, the interviewees perceive it as the mechanism that allows the maintenance of life, that is, there is no life without the fistula. In this sense, for them, the world acquires a new meaning: feelings of gratitude for staying alive coexist with those of extreme caution due to the fear of losing the fistula, which is their source of existence. Such feelings were unveiled in the statements from the recurrence of units of meaning associated with the following connective assertions: *the fistula represents life* (24 UI); *the care with the fistula due to fear* (18 UI).

*It's as if at some point the fistula will stop and you will no longer live... I fear it won't work anymore.* (Con. 1)

*It's what keeps me alive. If it wasn't for it, I wouldn't be here... my greatest fear is losing the fistula... I'm very careful with it. We need to be careful when sleeping... I clean it, I do all I have to do very carefully* (Con. 3)

*I'm very careful not to lose it, for no one to hit my arm, I avoid sweeping my home, but to me it's a precious thing! It's my life.* (Con. 5)

*I take care of it [the fistula] as it was my child.* (Con. 7)

*My greatest concern with the fistula is if it stops working.* (Con. 17)

*I'm aware that I have to keep it working, I must be very careful with it.* (Con. 21)

## DISCUSSION

CKD is a morbidity with repercussions on the individual behavior that often call into question the existence of the subject in the context of the family and social interactions. The reality set in the perception of subjects undergoing hemodialysis using AVF enables the possibility to reconceptualize this new condition of health/disease. However, many times these subjects are part of a world of impossibilities and, when faced with the marks imposed by the disease on their body, they perceive themselves and are perceived as different beings in the life-world.

In this sense, and considering the assumptions of the healthcare integrality, the care towards subjects with CKD must consider not only biological elements, but also psychosocial aspects. To do so, there must be a dialogue between practical scientific evidence related to the disease, its symptoms, and its therapeutic techniques with the subjects' experiences, connecting clinical reasoning with subjectivity<sup>(11)</sup>.

Understanding the experience of people undergoing hemodialysis using AVF refers to the sense of social phenomenology that every action is socially constructed and is based on the existential context, in which are interwoven the understanding of corporality-mediated experience, temporality, concerns, and meanings assigned to experiences<sup>(11)</sup>.

In our study, our focus – the use of AVF – demonstrated that people with this vascular access have a context marked by the imminence of death. Hence, the fistula emerges as a possibility

of life maintenance; nevertheless, the context of meanings reveals a body that perceives and is perceived as flawed, marked by aesthetic changes.

Marks on the patients' body do not emerge on the arms only, but also on the whole body structure through perception. They take shapes and sizes that trigger feelings of frustration and low self-esteem in the patients when facing the world in which they live. The perception of subjects experiencing the AVF is a reality etched on their body: seen and spoken, felt and perceived. This is because subjects are not an absolute presence by themselves, with no interposed body and history – they are the continuous and visible construction<sup>(12)</sup>.

Rethinking the body separated from the arm that experience the AVF is not a phenomenon merely triggered by the mark on the body as a result of the treatment. The act of hiding the arm with the fistula through clothing, in addition to initiating a process of non-recognition of themselves, represents a tension between this body – understood as damaged – and the socially constructed idea that the body needs to be healthy, perfect, similar to the others. Thus, there is a body-patient that expresses pain beyond the biological body, which is perceived by others and which produces and incorporates new meanings<sup>(13)</sup>.

Marks due to AVF arouse curiosity and, often, discrimination. Before the perception of the other, subjects produce representations about the changed body that make them feel weird and, in this movement, emerge feelings of embarrassment and anxiety which, for their turn, intensify the suffering and have great impact on self-image<sup>(6,14-15)</sup>.

Studies on the issue have pointed out that the change in the perception of self-image affects the identity of the subjects as social beings, causes emotional imbalance and feelings of inferiority, weakens the sense of living<sup>(16-18)</sup>, and is associated with depressive symptoms in CKD patients<sup>(19)</sup>.

This perspective is highlighted in the speech of one of the interviewees, who claims to feel like the *Bionic Woman*. This is a character created in the 1970s who, after an accident that seriously injured her body parts, receives bionic implants, among them a new arm with extraordinary strength. However, the implants are rejected and the character is in extreme pain and has psychiatric problems, which determine the removal of implants in a procedure during which the character dies. Then, she is revived by experimental procedures, but she loses her identity and memory<sup>(20)</sup>.

Drawing a parallel between this plot and the subjects addressed in our study, we may assume the accident as the CKD diagnose, i.e., the loss of the kidney functionality; the bionic arm as the arm with AVF, understood as an implant, something introduced in the body and that, although keeping it alive, is an external device to the original body; and the implant removal surgery followed by death represents the possibility of losing the AVF and consequently their lives. All this context comprises new representations of the body and the sense of being, which cause a disorganization in the sense of identity.

It means that, before being a body with this disease, the marks imposed by the treatment had no meaning in their existence. But the new way to position themselves in the world reconceptualizes the subjects' perception about the body structure

and, in some cases, their speech attempts to deny such effects by “conformity,” frequently, in the halls of hemodialysis clinics and in the life-world, as evidenced by other studies<sup>(21-22)</sup>.

Conformity is generally characterized by passivity and resignation before the disease and the treatment. Therefore, it features a false adaptation to the experienced situation concealing fear, resulting or aggravating the suffering. We must promote resilience, which, unlike conformity, indicates the positive adaptation and active acceptance of the disease condition, enabling the development of inner coping capabilities<sup>(23-24)</sup>.

Active acceptance of the disease itself and of aspects inherent to the treatment is a positive factor that can stimulate subjects to adapt to this new way of living. Subjects encouraged with positive attitudes are more inclined to adhere to the treatment and to take care of themselves<sup>(25)</sup>. In this sense, nurses, as the specialized professionals in the AVF care, should enable the development of resilience and self-care. Not a self-care due to the fear of losing the fistula and consequently life, since it limits subjects in different ways; but a reflexive self-care based on knowledge and the recognition of themselves as active beings and in permanent construction.

Nurses, when perceiving the fear of losing the AVF, which is considered by the subjects as a vital organ, must empower themselves of health education as a nursing care tool, eliminating doubts about the care that must be provided with the vascular access and stimulating subjects to understand this feeling, dismissing it as a limiting factor.

Sensitivity of nurses makes a difference in the care towards subjects in their new life condition. Thus, the technical understanding of the CKD should not counteract the human understanding within hemodialysis; welcoming is part of the sensitive care. Sensibly working is a required construction of nurses; perceiving the other, in their complexity, is an essential step for the effectiveness of the practice-care. This is because it is well known that self-awareness regarding the disease is an ally for the maintenance of the treatment, and the nursing staff can work as a catalyst in this process.

The holistic care of nurses through sensitive listening needs to be resumed, as well as the perception that this care is perceived by patients in all their strength to fight and also in their complaints. The past once lived without needing hemodialysis is resumed in their speech, in the changing of moods. Thus, there must be an understanding of the nurse that works within the CKD reality, whose challenges are not only related to expertise, but transcend: the changing body these professionals take care of is right in front of them, demanding a dialectic subject-nurse relationship.

The thinking/doing of nurses when welcoming subjects using AVF must be therapeutic, valuing not only the biological care, but also the pulsating bond that promotes the development of professional skills for the aesthetic care as enabler of reconceptualizing the existence of these subjects in the biopsychosocial context.

The constant punctures of AVF for hemodialysis performed by nephrology nurses are presented to patients and ensure them life, but also suffering. In physiological terms, the complication of AVF that has generated negative feelings the most

in hemodialysis subjects, including those of our research, is the emergence of pseudoaneurysms resulting from inadequate hemostasis and blood extravasation after removal of dialysis needles<sup>(26)</sup>. This complication has been shown as the greatest aesthetic change caused by nursing procedures when using the traditional technique of AVF puncture (rope-ladder), hindering the reinsertion of subjects into their professional and social lives due to the stigma.

Considering the chronicity of the CKD and the complications caused by the rope-ladder technique<sup>(25)</sup>, another technique for AVF puncture has been highlighted in Brazil: the buttonhole. Although little used in the country, the buttonhole is already preferred among those undergoing hemodialysis through AVF<sup>(27)</sup>. Studies indicate that this technique, when compared with the traditional one, is related to lower rates of complications such as hematomas, infiltration, and aneurysms, and thus offers small probability of changes in the body image<sup>(27-29)</sup>.

Therefore, one way to minimize the suffering of patients in the direct care of AVF is using other techniques, such as the buttonhole, which already has shown to be useful and efficient, in addition to enabling self-cannulation during therapy, giving even more protagonism and autonomy to subjects in their self-care process<sup>(27)</sup>.

In the context of the illness process, it is noteworthy that the perception of subjects is called into question. Hence, nurses need to realize that patients present an imbalance regarding their basic human needs, and creating skills to the development of care actions towards the subjects includes all physiological and therapeutic aspects – emotions, limitations, pains, and frustrations experienced in the context of health/disease caused by changes in the AVF.

### Study limitations

The limitation of our study was the adopted design, represented by the phenomenological interview, since it depends on the comprehensive interpretation of the researchers based on provided statements. Analyses performed with the statements may have been influenced by perceptions of researchers themselves, which we tried to repress through dialogue with inferences from other studies and by thoroughly studying theoretical references. Lack of literature considering the perception of patients regarding the use of AVF for hemodialysis may also have harmed the depth of the discussion.

### Contributions to the fields of nursing, health, or public policy

Our results contribute to the prospect of clinical intervention with people undergoing hemodialysis through AVF which is not limited to biophysiological aspects, researching new possibilities to provide care considering the perception of sick individuals regarding their body and body aesthetics as producers of representations able to trigger psychosocial complications.

### FINAL CONSIDERATIONS

The comprehensive analysis of the statements of subjects with CKD and in use of AVF showed that this venous access leaves marks that change the body aesthetics, making the body

imperfect. Such physical changes cause low self-esteem and attract the look of the other, causing embarrassment to those who have a marked body. Thus, they react by camouflaging the fistula, without which there is no life. This perception emerges from the fear that works as a catalyst for self-care.

Although the technological advancement in the field of health concerning the treatment of CKD patients has satisfactorily progressed, with innovative materials and products, there is still need

to rethink about the nursing care from the perceptions of those who experience the illness process and treatments that impose aesthetic changes and, consequently, psychosocial complications.

This involves the training of nurses with a perception that goes beyond the idea of assistance solely based on procedures that improve the biological condition: it is necessary to develop a dialogic care, which also considers the subjects' perception about their body as a being-in-the-world undergoing hemodialysis.

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