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Meanings of the body experiences of people on peritoneal dialysis*

Significados das experiencias corporais de pessoas em diálise peritoneal

Significados de las experiencias corporales de personas en diálisis peritoneal

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The aim of the study was to understand the meaning of the physical experiences of people with kidney disease when living on continuous ambulatory peritoneal dialysis at home in relation to the body. Qualitative, ethnographic study, from a critical interpretative perspective and from Medical Anthropology carried out in a hospital in the state of Rio Grande do Sul, Brazil. Twenty people participated in continuous ambulatory peritoneal dialysis, with data obtained between April 2013 and June 2014 through open, semi-structured interviews and participant observation. Conventional content analysis was used, and six categories were constructed: *Marked body*, *Threatened body*, *Extended body*, *Imprisoned body*, *Limited body* and *Reflective body*. People use the body as reference for themselves, by valuing physical experiences, and the meaning they give to them, to make choices, make decisions and keep life on dialysis. Such a process is built and transformed by dialysis, which is incorporated into the body, over time and environment.

Descriptors: Life change events; Renal insufficiency, Chronic; Dialysis.

O objetivo do estudo foi compreender o significado das experiências corporais de pessoas com doença renal ao viverem em diálise peritoneal ambulatorial contínua no domicílio em relação ao corpo. Estudo qualitativo, etnográfico, a partir de uma perspectiva crítica interpretativa e da Antropologia Médica realizado em um hospital do Rio Grande do Sul, Brasil. Participaram 20 pessoas em diálise peritoneal ambulatorial contínua, sendo os dados obtidos, entre abril de 2013 a junho de 2014 mediante entrevistas abertas, semiestruturadas e observação participante. Foi utilizada a análise de conteúdo convencional, sendo construídas seis categorias: *Corpo marcado, Corpo ameaçado, Corpo estendido, Corpo aprisionado, Corpo limitado* e *Corpo reflexivo*. As pessoas utilizam o corpo como referência de si próprias, mediante valorização das experiências corporais, e significado que dão a elas, para fazer escolhas, tomar decisões e manter a vida em diálise. Tal processo é construído e transformado pela diálise, a qual é incorporada ao corpo, ao longo do tempo e ambiente.

Descritores: Acontecimentos que mudam a vida; Insuficiência renal crônica; Diálise.

El objetivo del estudio fue comprender el significado de las experiencias corporales de personas con enfermedad renal cuando viven en diálisis peritoneal ambulatoria continua en casa en relación con el cuerpo. Estudio cualitativo, etnográfico, desde una perspectiva interpretativa crítica y de Antropología Médica realizado en un hospital de Rio Grande do Sul, Brasil. Participaron 20 personas en diálisis peritoneal ambulatoria continua, y los datos fueron obtenidos entre abril de 2013 y junio de 2014, mediante entrevistas abiertas, semiestructuradas y observación participante. Se utilizó un análisis de contenido convencional y se construyeron seis categorías: *Cuerpo marcado, Cuerpo amenazado, Cuerpo extendido, Cuerpo atrapado, Cuerpo limitado* y *Cuerpo reflexivo.* Las personas utilizan el cuerpo como referencia de sí mismas, valorando las experiencias corporales, y el significado que les dan, para hacer elecciones, tomar decisiones y mantener la vida en diálisis. Este proceso se construye y se transforma mediante la diálisis, que se incorpora al cuerpo con el tiempo y el entorno.

Descriptores: Acontecimientos que cambian la vida; Insuficiencia renal crónica; Diálisis.

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INTRODUCTION

The growing advances in the field of biomedicine have provided distinct discoveries and development of medical technologies, in addition to treatments that extend the lives of people with chronic diseases. Therefore, the body came to be understood as an object-body and, thus, as something that can be modified and reformulated[1]. Chronic renal failure is one of the chronic diseases with a sudden onset, and it has an impact on the daily lives of people and families, generating physical, emotional, relational and social transformations[2], in addition to costly financial expenses to them[3,4] and to the health systems[5].

In its most advanced stage, an increasing number of people need renal function replacement therapy to survive, including continuous ambulatory peritoneal dialysis. This therapy is performed at home, by the patient and/or their family. Such dialysis is continuous, as it is in the abdominal cavity twenty-four hours a day, and the frequency of edialysis solution change depends on the patient's clinical condition[6,7]. It is a complex therapeutic regimen that influences daily living[6-10] and ends up causing biographical disruptions.

The emphasis of works carried out is on the biological, anatomical, physiological and biochemical aspects of kidney disease and dialysis. From the point of view of the biomedical paradigm, the disease is located in the body as a physical object or physiological state[11]. This focuses on seeing the disease isolated from the experience itself, minimizing or ignoring the subjective reality of those who experience it[12]. However, contrary of what this paradigm considers, the disease is not simply an interruption of biological functions. In the process of illness and suffering that accompanies people, the body is configured as a means of privileged access to the dimensions of experience[11].

When dealing with the experience of illness, the anthropologist Byron Good[11] says that it is essential to focus on how the dimensions of the perceived world are destructed, torn apart, interrupted, as a result of a chronic disease. Still, the experience of illness has meaning for those who live it, and the way this meaning is attributed has to do with the individual and social identity of being ill[12].

In this study, the experience of illness was adopted as a starting point, in which the interest is in the subjective experience of living with and despite the illness in daily life from the perspective of the patient themself[12]. From the experience of illness, the body experience assumes important proportions for people who experience a chronic disease[11]. Thus, bodily experiences constituted the central concept of the study, as they include subjective processes, which must be addressed in health care practices, in addition to biological processes[13-15].

There is a growing interest in the study of the body, both in social and health sciences, using different theoretical concepts that make it possible to build a legacy in the field of a sociology and or anthropology of the body[16]. Anthropologists Nancy Shper-Huges and Margaret Lock[17] define and consider the relationship between three bodies: the individual body, the social body and the political body.

Individual body is understood as experiences of the self; social body is understood as the representation of the body as a natural symbol, and political body refers to regulation and control of the body. Studies that address the body and its representations, relationships, sensations and body image focus on the experience of falling ill[13-15,18,19].

Bodily experiences, in turn, point out that conceptions were important for decision making both for diagnosis and in the choice and continuity of therapy[13,14]. Another study investigated the bodily experiences of ventilator dependent patients with chronic alveolar hypoventilation, and pointed out that the use of technology built new meanings for the body and enabled them to manage and solve problems arising from illness and treatment[15].

The bodily experiences are placed in terms of the individual's direct verbal reference, how they saw themselves from the disease and treatment, and which events are more significant for them during the process of getting ill[13-15]. It is a matter of saying that bodies are not silent, and bodily experiences are mediated by the way people describe their perceptions[13].

There is a growing interest in investigating the experiences of people living with kidney disease and on peritoneal dialysis[20]. However, until now, the experience of illness of people with kidney disease when living on peritoneal dialysis has been little explored[6-10], and, still, the meaning of bodily experiences for these people[8], and of qualitative studies on peritoneal dialysis with an ethnographic focus[7-9] are almost unexploted dimensions.

Research with this theoretical basis is important in the discussion about construction of the disease beyond the biomedical paradigm, in view of the recognition of the individual experience, and of its collective construction in the construction of illness. Therefore, it is essential to consider the subjective dimension of people with kidney disease to understand and interpret the meanings of falling ill, based on body experiences and the impact it has on the life of the patient, their family and the health system. Thus, developing public policies and subsidized health actions in this perspective can have a positive impact on assistance, care and self-care for these people.

Thus, the present study aims to understand the meaning of bodily experiences of people with kidney disease when living on continuous ambulatory peritoneal dialysis at home in relation to their bodies

METHODS

This study was carried out in a nephrology service in a municipality in the state of Rio Grande do Sul. It is of a qualitative type, with ethnographic design, in the critical-interpretative [21] and Medical Anthropology perspectives. The theoretical constructions of Byron Good[11], Thomaz Csordas[22] and David Le Breton[1] were used to understand the phenomenon.

The fieldwork was carried out between April 2013 and June 2014. The selection criteria were: men or women registered in continuous ambulatory peritoneal dialysis for more than six months, who lived in urban and rural areas, and did not have communication issues.

People participated in the study by means of intentional and theoretical sampling from the consultation schedule of patients registered in the dialysis program. The sample size was determined by the information saturation criterion, allowing the construction of a theoretical scheme to answer questions and the research proposal.

Data collection techniques included participant observation, open and semi-structured interviews; in addition to the use of medical records. Guides were developed for observation and interviews techniques. The observation of the participants took place in the nephrology service, in the hospitalization unit and in the home of people on dialysis, as well as the ways in which they related to family members and health services, including the professionals who worked in it.

From observations, field notes provided contextual information to complement the analysis of the interviews, as well as documenting and describing the fieldwork.

For this study, the guiding question was considered: *What are the meanings attributed to the bodily experiences of people with kidney disease when living on continuous outpatient peritoneal dialysis at home?* The interviews were carried out individually, at times previously defined with the participants, with a duration of 60 to 180 minutes. The open interview, the first to be conducted, was guided by the question "*Can you tell me when the kidney disease started?*". In the subsequent interviews, themes that emerged during fieldwork and analysis in the previous interview were discussed in depth.

Most participants were interviewed in their homes, with the exception of four people, who were interviewed in a reserved room of the nephrology service, according to the participants' wishes. The interviews were recorded and transcribed in full by two trained transcribers, and subsequently revised by listening to the recorded audios and reading the written text.

The medical records were checked in order to identify sociodemographic, clinical and location information, in order to know the health condition to complement the other data collected.

For the organization and management of the data set, the Ethnograph V6 Program was used. This data set was analyzed by conventional content analysis[23]. The analysis consisted of a reading of data, for immersion and understanding of it as a whole. Then, the reading was carried out line by line, until the generation of codes, and then the codes were compared and text fragments selected to identify themes, which later were used to create categories. During this process, themes related to experiences of illness most relevant for the participants were identified.

We used a comparative system of data collection techniques, developed over a long period of time, in the contexts in which people on dialysis experienced the phenomenon. Thus, it was a question of understanding not only what they said and felt, but also what they did in their daily lives and in their treatment.

The research was approved by the Research Ethics Committee of a public university under Opinion No. 538,882. The ethical precepts of Resolution 466/12 of the National Ethics Council were followed. Participants signed the Informed Consent Form and pseudonyms were used to ensure anonymity.

RESULTS

Twenty people on dialysis participated in the study. Of these, 14 were women and six, men, aged 22 to 63 years. As for place of residence, five lived in rural areas and 15 in urban areas. Only one of the participants had a paid job, and the others were retired due to being on dialysis.

Six categories were built, namely: *Marked body*, *Threatened body*, *Extended body*, *Imprisoned body*, *Limited body* and *Reflective body*. The meaning of living on peritoneal dialysis was shown to be mediated by the bodily experiences built over time, giving the body a new meaning and identity. The body is an active agent of experience; a body transformed and constantly changing over time, due to its deterioration due to disease and peritoneal dialysis.

Marked body

Having a marked body means having visible physical marks, both in themselves and in other people. The marks mentioned were: enlarged abdomen, body weight, changes in skin pigmentation and texture, hair loss, tooth stains, generalized swelling, surgery scar and presence of the dialysis catheter. The appearance of these marks was progressive, as it altered the body image, resulting in a new identity, and, in some cases, it prevented patients from starting a romantic relationship and even leaving their home.

The enlarged abdomen, swelling and presence of the catheter were considered as the most significant marks, especially for women, which made them look pregnant, and this situation was the main reason why they had to explain and justify their treatment to other people. Among the terms and metaphors used by the participants, the following were found in the interviews: "*to become pot-bellied*", "*big belly*", "*the belly grows*" and "*to get fat everywhere*":

The only thing I was concerned about was appearance. I didn't have a belly, so I got it after going on dialysis, and it really changed... then I started getting fat like that, my belly got big [...] *I got fat everywhere. Because I thought I couldn't get with anyone* (man) *with this disease and this thing* [the catheter]. (Ana)

[...] *the belly changes, it looks like I'm pregnant. I even had to laugh, a woman asked me, she knew I already had a little girl: "And what's next, is it a little boy or a little girl coming?" I had to laugh at her, I said: "Nothing is coming, this is a treatment for my kidneys, that's why it looks like I'm pregnant, but nothing will come out of here. She didn't know: "I'm* *sorry, I didn't know, I thought you were really pregnant, with that big belly!" . I say: It is not a pregnancy! See if it is not almost the size of a child, two liters of water into the belly* [...]. (Julia)

Swelling of the feet, legs, face, sometimes on the whole body was present. The swelling caused them to have difficulty breathing, walking and performing activities at home. To improve this condition, excess fluid needed to be removed, as it was the main reason for malaise. This mark was interpreted as something wrong, and as a consequence of what they ingested and how they chose their dialysis bags. When swollen, the liquid gave the body a different shape, expressing itself as "*abnormal*"; they used expressions such as, feeling "*bloated*", "*big*", "*it was just liquid and I became thin*". The swelling was visible, and caused feelings of malaise and to describe it use metaphors such as "*tingling*" and "*exploding*":

I felt it at the time, when I had a lot of liquid in my body. It's hard to breathe, but bah! You are crazy! When I drank a lot of fluids, it already showed, for example, so, I was very well, I ate salty food, and drank a lot of water, my shins and feet swell up on the spot. There was a time when my feet looked like they were going to explode like that, they even tingled because they were so swollen; really swollen. (André)

The marks that included hair loss and stains on the teeth also altered body image, and the repercussions on the body were drastic, as they saw their body being marked, transforming themselves in such a way that it was impossible to recognize and interact with other people. They used metaphors, for example, the skin as "*spoiled skin*", "*dry and darkened skin*":

The presence of the catheter was described as a bothersome "*foreign body*", visible because it was hanging from the body, and disfigured it. Such a catheter sometimes needed to be hidden from other people, and hiding it proved to be difficult, especially during summer, when the heat was more intense, and people tended to wear lighter clothes, and/or with part of the body exposed, and keeping their abdomen exposed was no longer an option:

[...] *I got depressed because my hair started falling out, and that* [dialysis] *liquid darkened my teeth.* [...]. *My hair started falling out, it was well taken care of, always brushed, but I couldn't brush anymore because it was falling all over. So it was my hair, and my teeth* [...]. *The damaged skin, I took care of my skin, and then I was very depressed. I don't see myself as a woman, even because of this here in the belly* [catheter]*, there is this whole process like that.* [...] *I keep thinking, I don't know if it's fair to have someone in this process with me, because I can die suddenlyand leave the person alone here.* [...] *take away the sensuality of us as women with this here in the belly, there are women who do not lose it, but I lost it* [sensuality]. (Paula)

Threatened body

Living on dialysis meant having a threatened body. Such a body is under constantly threats from situations in the activities of daily living and interactions with other people and/or animals that, due to physical contact, could cause infection. Being in contact posed a danger to dialysis and to life itself.

The body is threatened when going to public places, at home and or work environment, outdoors walking the streets, as well as indoors, such as going to the supermarket, going to ballrooms, using public transportation and even walking home. Public places, because of crowding of people, were considered a threat, both for fear of losing the catheter, as well as for the acquisition of other diseases and/or infection by dust and/or other invisible microorganisms. The constant fear of being "*bumped*" and the catheter being "*pulled out*" from their body was experienced, and were terms present in the interviews. The expression "*bumped*" was used to explain the "*hitting*" between people, experienced mainly in public places, and even in health services. The constant fear of these threats were experiences that gave meaning to a new body and guided decisions about living on dialysis:

So I am afraid of going to where there are a lot of people on the street, as it happened before, on the sidewalk even [...] *because the biggest fear I have is tpeople bumping into me* [...]. (Aline)

You do not imagine, you do not even think, for example, on the bus you do not imagine that a bag will pass by you and pull the catheter right out [...]. (Luisa)

[...] *we used to dance, but we don't do it anymore because there are a lot of people in the room, how can I say it, there may be a disease and we may catch it, so we are kind of out, where there is a lot of crowd we don't mix* [. ..] *and there is dust* [...]. (Maria)

Water and animal hair also posed a threat to the body, since it could cause them to become infected due to contamination. Animal hair was mentioned, mainly by those who lived in the rural area, due to physical contact with dogs, cats, horses and others. Still, both the water used in the shower bath and the water in the beach could be contaminated by mold, chlorine and microorganisms, and the risk was even greater when in contact with the catheter site, which they considered to be the entrance door for "*threats*":

I do deal with the horses [...]. *They* [professionals] *thought that because it was created in the campaign for touching a cat, touch it* [shows the catheter], *touch a puppy, touch it* [shows the catheter]. *I already got the cat, I got the dog, but here* [the catheter] *can't touch it, you have to take care.* (Aline)

I wash myself like this in the basin, I use warm water like this, I go to the bedroom and wash myself. And there was a woman there, who took a shower, took everything off, but no one knows where this water comes from, although it comes from the city, but, it is water that has mold, or it may have bacteria, or it has this chlorine [...]. *So they dye their hair and take a shower, and that water flows here in the hole* [shows the catheter] [...]. *I don't, when I wash my head, I take a huge cloth like this and tie it here* [on the catheter to protect] *and wash my head.* (Maria)

We can't go to the beach, we who use this thing [catheter] *can't get water there in the orifice, water comes here, then it can contaminate it, cause peritonitis, then the person gets hurt.* (Luís)

The environment, both the one where the exchanges were carried out and the place of work, posed a threat from contamination. This threat occurred in the daily exchange, especially when they decided to change something in the dialysis process and/or did not follow the necessary precautions, such as keeping the "*piece's*" door closed, washing hands, among others. Having a catheter that "*connects*" the inside of the body to the outside was evidence that a barrier had been "*broken*". The constant fear of infection and it not being identified in time, because it was not always accompanied by pain, was the biggest concern. They were always "*running*" against time, if they waited, they could die; Thus, even if they were not sure, they went to the nephrology service to identify and treat it, if that was the case; according to the reports:

I had 14 days at home, got peritonitis, I had to go back to the hospital. I say: Bah!, is this really like this? Will it only give me an infection? Then I was a little scared. I wasn't like that, so I knew exactly how the exchange was. Do you know what I did? [speaks in a lower tone] *It gave me a stomachache and I had to go to the bathroom, I couldn't hold it and I left the pipe hanging there, so open, you know, it got bacteria, and it can't. If you go out, you have to discard that bag and get a new one, you can't just hang it up and use it.* (Elisa)

Limited body

The limited body consisted of the limitation and fragility of being unable to carry out activities of daily living, fulfilling the social role in front of themselves and other people, and expressing sexuality. It was a body limited by abandoning work and/or studies, by the inability to take care of their home, family and even themself, and in expressing sexuality. This is due to constant tiredness and loss of strength, sometimes due to pain and a feeling of weakness and impotence. In addition to the impossibility of maintaining social life as before the disease, due to the exchange regime, frequent use of health services and hospitalizations.

The disruption of activities in daily life resulted from a body that depended on rest, time to recover and recharge energies to move on. Thus, fatigue and sometimes pain forced them to leave work and made it impossible to contribute to the family's income. Thus, activities that required physical strength and endurance were no longer performed. Not being able to "*strain themselves*" and with the feeling that they "*lost*" their lives, especially those of men, it became meaningless:

Ah, after I started dialysis, I couldn't work properly. I used to work [as a mechanic] *in the past, now I can't work anymore, I can't afford it, it looks like I'm going to be able to do something, but I can't do it, I have to lie down a bit. I don't know, I get tired* [...] *I feel it. Sometimes I have to get something of my own, but then it is annoying. I can do it, but it takes me a week to fix it, and up to a month, depending on the thing, sometimes even a small thing. I get tired next.* (Daniel)

From the moment I started dialysis, I couldn't work anymore, I couldn't do it anymore, I totally lost my strength. I was like this, a person who had a lot of strength, I took a bag of cement from the floor and walked with it, but at the time I was doing dialysis I couldn't grab five kilos, I don't know how I lost all my strength. [...] *it is embarrassing at first, I thought ah !, I'm not going to do anything else, I'm disabled, I'm not going to be able to work anymore, I felt kind of invalid* [...] *Then the woodworkers said: "We have a little job there for you, we know that you cannot strain yourself, but go there to stay there talking to us "*[...]. (André)

These limitations were not only felt by the patient, but were also observed by their family members. For women, on the other hand, the limited body was felt as the one responsible for the reduction in domestic chores. Over time, "*tiredness*", "*lack of strength*" and "*pain*" were frequent and reduced the pace of activities to the point that some were not performed at all. Activities were abandoned, such as cleaning the house, taking care of clothes and cooking. Being "*idle*" was something that bothered them, made them angry, and made them feel useless.

After dedicating their lives taking care of children and the household, some women had difficulties to take care of their personal hygiene and, most of the time, they had to rest and give their body the time it needed to recover, and start again what they had to do. The illness made it impossible for them to take care of the house, family and themselves, as in personal hygiene:

[...] *I get sick of being idle, or having things to do and not being able to do them, it makes me irritable, nervous, because I've always done things* [...] *I feel useless, totally useless.* [...] *The only thing I can no longer do is take care of the children, because I have to walk behind them* [...]*, but, otherwise, fold a blanket, make a bed,* [...] *do the dishes, I get tired a lot of standing, then I sit, rest a little, go, wash again, then sit down, that's how I go. I don't like being idle, so I do it slowly* [...] *take a shower, now I bought a plastic stool, because I can't stand for very long, because it hurts, and then I sit under the shower and take a shower , it is the only way I can do it* [...]. (Angela)

When we are on dialysis, there are days when we are kind of incapacitated, there are days when we are not feeling well enough to do the housework, there are days when we cannot do it. I miss it, how am I going to say it, I lack strength, there are days I don't feel like doing things. (Ana)

Social life activities, which were carried out before getting sick, such as traveling, going to parties and talking with friends, became severely restricted or no longer possible over time. In addition to these activities, others abandoned their studies due to constant hospitalizations due to complications from the disease and dialysis:

I went to rodeos when I didn't have this kidney problem. We participated, I rode those black horses, I participated in the lasso, then I couldn't participate anymore. [...] *But now I'm just going as a spectator. I don't go out much with them anymore, due to my problem, but we still get along, only they did their activities.* (André)

The limited body also involved difficulty in expressing sexuality, especially for women, who revealed difficult moments with their partners, and some were "*abandoned*", as "*they were no longer valuable*", this expression being present in some interviews. Others reported decreased self-esteem and concerns about sexual intercourse, as it became limited, and even interrupted by fear of causing complications to the treatment. Changes in body image due to the presence of the catheter and the amount of fluid in the belly, associated with tiredness, restriction in physical effort, and threat of complications were decisive for couples to stop "*having sex*" or (re)adapt, once that the life of the person in treatment was more important:

And sex, let's stop it. I asked the doctor, he said: "Look, it can be bad, it can't, I can't guarantee it". I said, if you're not sure, let's just let it go. It's tough, it's hard! (Maria)

[...] *of course it has to be slower, it's not that thing, it can't be rough sex, you have to be careful* [...] *With the catheter, because there is a way, there is always one that we adapt to better, it's not just one way. It was good for me, it improved a lot, my self-esteem improved a lot, something that before I thought I couldn't have anyone* [due to illness and dialysis], *then there was this possibility, and it improved my way of thinking a lot.* (Ana)

There were other limitations of the body, such as "*hearing loss*" and poor memory, as they easily forgot conversations and memories. Some depended on family members to do and/or assist in dialysis changes, administer medications; others, to accompany medical consultations and exams, and to go to places, such as supermarkets and/or for leisure.

Extended body

The extended body consisted of the extension not limited to the biological body, extending to other spaces, objects and substances. In the incorporation of substances, equipment, devices to the body, technology starts to replace an "*essential organ*", the kidney, becoming indispensable for survival. The incorporation of something into the body broke the sense of normality, and led them to reflect on this new body, seeking to give meaning to it and its behaviors experienced by illness.

Metaphors were used using expressions for the dialysis catheter, such as: "*flash drive*", "*tweety*", "*my thing*", "*pingolin*", "*little pipe*". Expressions such as "*connecting*" and "*linking*" to perform dialysis were still frequent in the reports and, at times, they recognized themselves as non-human when defining themselves, for example, as "*bionic woman*":

I call it a flash drive [catheter]*. Because mine is different, but it's so bad to say catheter, so I call it a flash drive, mine is fancy, mine is a flash drive, because it has the shape of a flash drive. Because I used to joke about it, I mean, but this looks like a flash drive, and like everyone else at the hospital, it calls "Tweety", "my thing". So everyone knows that mine is a flash drive, because it has the shape of a flash drive* [...]. *I call mine a flash drive, because at the time of the exchange you have to connect too. Then I connect it, as I call myself the bionic woman, because it has to be all connected, then I call it a flash drive. I call myself a bionic woman because of the things you need to connect* [...]. (Alice)

The incorporation of substances from dialysis bags into the body was felt as something beyond biological. These substances that remained in the abdomen for 24 hours to keep them alive, described as substances that "*cleanse the blood*" and "*catch*" impurities that do not belong to the body and need to be "*eliminated*". Sensations such as "*getting full*" have the sense that something is being put into the body and needs time to settle, to put in order what was wrong, to adjust:

Always with liquid in it, the belly is never free of liquid, because the liquid is where the blood passes in the peritoneum , and it captures the impurities, I change it again six in the afternoon, then again at midnight. I don't feel any pain. Of course, you feel that it goes into the belly, it gives you a feeling of fullness, of getting full, then it passes, it seems that it settles in the cavities and becomes normal. (André)

The extended body also incorporated necessary and indispensable materials for the treatment, such as dialysis bags, equipment, clamps and facial masks, indispensable for the daily ritual that, over time, became a "*natural*" part of daily life, when the technology was being incorporated:

At the end of those two pipes there is a donut that screwed in here [raises her shirt and shows the catheter], *I can't open it now because it can't be opened. So here* [shows the catheter] *I turn on, and the top clamp is locked so the belly fluid comes out first, then I clamp the bottom one when I empty the belly, then I close the bottom one and open the top one to enter the belly. Yes, then when you are ready to close the catheter, then I sanitize my hands with alcohol again and close it and keep it here* [shows the cloth belt he made]. (Elisa)

Extended body incorporates a place/part/environment for dialysis. There were those who incorporated dialysis in their own room, inside the house; there were those who used different areas of the house to perform treatment (living room, kitchen, bathroom); and those who built an exchange-only environment. An environment that brings together furniture such as a table, sink and support for bags, microwaves, dialysis boxes, medicine boxes, gauze, among others. Each environment had a function, and was created and personalized by the participants, building their identity:

Heat the bag in the kitchen, because I have nowhere to put it, how am I going to put the microwave in the room, you know. Then I thought of leaving it in the kitchen. Everything is close together, everything is tiny, the bathroom for washing hands, in the kitchen there is a microwave to heat the bags, [...] *and the exchange in the bedroom, and the boxes are in the living room.* (Luisa)

Imprisoned body

An imprisoned body is a body linked to dependence on dialysis to survive, use of equipment, the need for an environment and a daily regimen of continuous care. In addition to the dependence on the health system and other people, such as family members and health professionals. The body trapped on dialysis was one that could not get away from the environment (house/room/piece), from the daily "*commitment*" to the exchanges, established times, with four daily exchanges, recognizing that they needed them and, because of this, led to the feeling of being trapped:

It was the need for this dialysis, there is no longer freedom that it once brought, that discourages me. I feel trapped, not that I can't walk, but I feel trapped. Because in Pelotas you can even come here, anything you get here [dialysis service] *and do the change, but in another city you cannot* [...]. *You have to do dialysis, you have to do seven-thirty, eight hours, then half an hour, one hour, five, five-thirty, six hours and then it's eleven at nigh* (João)

Being in a circle of friends, watching a movie, paying a bill, going to the supermarket, these were situations that must be planned regarding time and even considering distance from the home, because, in most cases, there was a need to interrupt them because of dialysis, causing them to suspend and/or (re)schedule changes. Daily and continuous dialysis gave participants the feeling of being in prison. Expressions such as "*every day there is dialysis*", and "*all day*" dialysis, "*24 hours*" were verbalized frequently in the interviews. Being tied to monthly routine appointments and periodic exams prevented some participants from traveling, and following it implied having the time to fulfill the demands of the treatment:

We get really stuck like that. [...] *You leave, for example, one o'clock and you have to run, because you need to be back at four o'clock, so the hours are very tight. And if you have to go to the bank, and then the bank works late and you are haven't been serviced yet, what do you do?* (Luisa)

It's kind of complicated, I can't go out for a whole day, stay in the street for a whole day, like in the day to pay the bills, things like that, I can't spend the whole day out, shopping and stuff, I don't have to think about the bag, this is my time like this. Then I already feel like staying at home, because it bothers me to do it, it's four, five times a day [...] *you're watching a movie, eleven o'clock at night, you have to stop and change the last bag* [...]. (Ana)

The feeling of "*obligation*" that led to them to stay "*locked up*" in the bedroom, four times a day, and the need for a place to dispose of the materials for changing the bags was also mentioned. Some participants used the expression "*I lock up*" give meaning to the imprisonment. Thus, staying in an enclosed place reinforces this feeling, even if temporarily:

When the time comes, I lock myself up in my room, which I have to do and do, so it's a commitment [...]. *I do it at seven in the morning, then at noon, then at five in the afternoon and at 11 at night, always like that* [...]. (Julia)

For some, peritoneal dialysis was the only survival therapeutic option, so they were stuck with it. The clinical condition left them with no alternative to choose another therapy, so they surrendered their body to the doctors for them to decide what to do. In addition, others felt trapped by the family due to the excessive care their family had with them. Starting dialysis was like going back to the past, receiving care that they only received when they were children, and that bothered them, intensifying the feeling of being trapped:

I didn't choose, it was the last alternative I had. The doctor said: "There is no other, because there is no fistula." The catheter here [shows the neck] *was blocked because of the veins, so I either did it* [PD] *or I died.* (Angela)

Reflective body

Considered as the one in which participants "*saw*", "*heard*", and "*recognized*" the need for their body, as they believed that assessments based on their body experiences were a reference for making decisions about what they should do, which bag to use, for how long, what and how to do it. Such assessments guided them to decide which type of bag to use, thus, they could "*give the body what it asked for*". They experimented, tested different concentrations of dialysis bags based on personal knowledge, resulting from body signs, symptoms and sensations, and found which bag was best to use, such as the "strong bag", which resulted in the disappearance of swelling and a sensation of well-being:

If I use only the weak bag, I feel bloated, and the strong bag makes me feel like that even more, of course, as he said that I had lost a lot of weight, I said: Doctor, it is not that I lost weight and deflated. I was very swollen, now the swelling is gone. I use the strong bag, the swelling is gone, and not the weak ones. That is why people get so swollen, I have observed this here, with people who have come for consultations only do weak dialysis, and get cheeks, people get very swollen. (Luisa)

Oh, I know everything about that and when you have to stop too, otherwise it gives you back pain, then it takes away too much of what is good, it takes away what is bad and what is good, and then it gets bad. It's hard to. There is the same thing as an old man walking. When I'm fine, I can do it weak, when I'm not swollen and there is no pain anywhere, it's all *right. Then it starts to swell, I already go for the strong bag. I know myself, because to get to know the person, you have to be the person.* [...] *The body vitamin, the strong one takes out what is good and takes out what is bad, all together, then the person becomes weak. And keep the strong bag until there's nothing left on the body* (Daniel)

The exchanges of the bags were continuously tested based on body experiences, such as, the body feeling "*heavy*" because of tiredness, skin that "*tingled*" because of swelling and shortness of breath that decreased or stopped; feeling of "*stuffing*" by the amount of liquid in the abdomen, energy "*weakened*" by lowering blood pressure; condition of the skin, hair and teeth. Thus, it was possible to change the times and interval between one change and another, according to daily activities. When they felt or visualized something present in the body that they interpreted as a complication of the disease and dialysis, they adjusted the number of changes and concentration of the bags.

Bodily experiences supported assessment, influencing decisions and combination of practices. Over time, they combined practices, first based on knowledge, their experiences, and second on shared medical knowledge, as side effects of strong bags and, checking blood pressure before changes, to decide which bag to use, seeking to rescue a rebalancing of the body. Sensations such as "*having an ox across the abdomen*" reinforced the sense she attributed that it was time to remove the excess liquid, promoted by the strong bag:

When I feel heavy, with shortness of breath, then I make a strong bag, because then I eliminate it, because sometimes it is when I abuse it too much, in this case, I make a strong bag that is to pull more. It's [the feeling of the strong bag] *that it weighs on the belly, it's a weight that looks like an ox is crossed, it's that it pulls all the excess, it's much stronger, but also, when it comes out, it pops out, the bag comes out all over liquid you have.* (Angela)

I decided it myself, it's not the [nephrology department's] *decision, I'm doing it at four, and then I do it at nine and then go to sleep, there's no need to get up, I do it like this and I'm going to sleep. It is a very long period, but my body does not complain, I leave it like that, that I give a little out of control in the night. It's according to the service* [of the house] *I have* [...]. (Aline)

DISCUSSION

Illness happens as a living experience and as a change in the world of life. Thus, the body is both a physical object and an agent of experience[11,22]. The body is an important place in the construction of the individual's identity throughout history. When changing the body, people change their life, their identity, the look on themselves, and the look of others[1].

In this study, the meanings attributed to bodily experiences of people with kidney disease living on peritoneal dialysis corresponded to the construction of a body that is an active agent of subjective experience and culture. A body that is in constant process of embodiment, a body transformed and constantly changing over time and space in the face of its deterioration due to the disease and the incorporation of dialysis.

A study developed in Sweden[15] sought to understand the meaning of bodily experiences of people who need a mechanical ventilator to survive, based on interpretive phenomenology, which identified four configurations of bodily experiences: the body extended by the use of the ventilator to survive; the body marked by the effects of illness and treatment; the imprisoned body, both spiritually and physically; and the reflective body, in which they perceive flaws oresented by technology, so they have to be creative and act to manage care and improve breathing equipment.

Another study of ethnographic design from a critical interpretive perspective developed in Mexico with young people of both sexes on peritoneal dialysis identified multiple changes in the body, both in terms of the condition and the modality of treatment, resulting in seven configurations of bodily experiences. These bodily experiences correspond to being a marked body, extended body, vulnerable body, imprisoned body, limited body, unpredictable body and reflective body[8].

In the present investigation, the marks on the body broke with the standard of normality dictated by society and resulted in changes in body image, loss of self-esteem, loss of identity, construction of stigmas and social isolation. Having a marked body implied, in addition to physical changes, emotional, relational and social changes that led them to adapt and manage the sensations, signs and symptoms of this new body; as well as changes in habits and behaviors, including how to dress.

Other studies also found marks on the body, the most significant of which were anenlarged abdomen and a dialysis catheter, which led to changes in body appearance, producing a distorted image and the feeling of being different[7-10,24]. This body became responsible for the loss of identity, low self-esteem, loneliness, and barriers in relating to people[6,8,24].

The experience of a chronic condition systematically threatens to subvert, deconstruct or reconstruct the vital world in search of meaning[11]. Anthropology shows us that the body "*is the condition of man, the place of his identity, what is taken away from him or what is added to him changes his relationship with the world*"[1-399]. In Corporeality, the duality between body and mind is broken; the body is dynamic, as it is always experiencing, it is a body as an active and not a passive agent, which changes over time, relationships, emotions and situations of daily life[22]. Thus, social discourses and practices constitute the body[22].

Living on peritoneal dialysis means feeling constantly threatened by the environment they frequent, by situations present in the activities of daily living, and in social relationships. For this reason, they fear losing control over the body, because everything that comes may cost them the failure of treatment and life. Studies indicate that the fear of contracting infection, peritonitis, is the most frequent and feared threat by people on dialysis[7-8,25]. They live in fear of a serious complication, which could lead them to hemodialysis, and even to death, thus, they spend their daily lives trying to prevent such events from happening. For them, the future is uncertain, associated with the lack of control over the body[6-8].

The meaning of extended body made it possible to understand the incorporation of technology to the body and home. Over time, they adjusted and adapted, resulting in harmony between technology, person and environment. It consists of devices, equipment, medicines, materials, such as face masks, and it is through a foreign body, a catheter, that substances are introduced into the abdomen at certain times, in different spaces in the house. This is defined as an "*adapted house*", the "*home of someone on dialysis*", and becomes a reference to identify them where they live. A study showed similar findings, in which the use of devices hanging from the body, the connection to equipment, the introduction of fluids promoted a transformation in the body's configuration and a new meaning[8], and that dialysis extends inside and outside the home, and others environments are compromised[8,9].

To live on peritoneal dialysis is to live with the feeling of being trapped. Freedom is put to the "*test*", which is conditioned by the commitment to performing dialysis, which involves schedules, time, space, restrictions and frequent controls. Studies indicate that dialysis becomes the center of their lives, hence the idea of imprisonment, since it implies following a daily regime of care and restrictions[7,10]. Studies have described that people choose this modality, because it allows them to be at home and have greater freedom, however, later on, the home environment is adapted for treatment, and following the dialysis regime makes them feel restricted and controlled, with loss of autonomy and a sense of normality[6-10].

The meaning attributed to the body as limited consists of a body that is unable to perform certain activities, with limitations in daily activities, relationships, social life, work and sexuality. Studies have shown the limitations of a body that suffers from rupture and restrictions in life[8,10], the abandonment of a partner[10,24] leading to extreme comparisons between before and after becoming ill.

Limitations in daily and social activities, and work capacity are reduced[2,7,8,26,27], mainly due to chronic fatigue[7-8]. There are still other manifestations, such as inability to move, catheter trauma, restrictions on eating and sleep disorders[7-9].

As for sexuality, studies show that kidney disease and dialysis negatively affect both men and women[24,28,29]. There is a loss of sexual intimacy due to the body image being transformed by the disease and dialysis, decreased libido, erectile dysfunction, lack of pleasure in relationships, dissatisfaction with sexual life, in addition to the catheter being considered uncomfortable during sexual intercourse, associated with chronic fatigue and fear of being abandoned, constitutes the limited body in which it is unable to meet its own needs and those of the partner, being obstacles to starting and maintaining a relationship. Libido or sexual desire is important in the development and preservation of intimate relationships[24,29-30]. Given the above, there is a need for a comprehensive assessment of sexuality, both for men and women, including identification of gender and sexual orientation, as well as treatment[29].

The meaning of reflective body corresponds to a body that reflects, evaluates and values its experience, and that, therefore, has the ability to decide about itself and the treatment. It learns to know and recognize the body each day, through its own bodily experience, and gives it what it wants and needs, and acts when necessary.

For decision-making, it was necessary to reflect on it, and look for explanations to then reframe the situation and review behaviors and attitudes. Based on bodily experiences, they gave the body what it asked for, what it needed to be and feel good and, for them, no one knew it better than they did.

It was found that, over time on dialysis, they learned to listen and recognize the body better and better. Thus, they interpreted kidney disease as an illness that could be controlled by the use of dialysis, which is essential for survival, and that everything revolves around it and any activity requires reflecting on the decision to do it or not, attributing to the new body sense. Thus, they took responsibility for health care based on bodily experiences, therefore, they constantly evaluated the effects, as well as the risk that each intervention has on life, influencing self-care and treatment management.

Studies have shown that, over time, they acquired knowledge and skills based on bodily experiences with kidney disease and dialysis[6,8]. Similar findings have been described in studies with people with another chronic condition, such as cancer and chronic alveolar hypoventilation, that lay knowledge is built from body experiences[13-15]. So, patients can be perceived as specialists because they have knowledge about their bodies and experience[13-15]. In the present study, dialysis is understood as a embodied practice, and participants understand the need for dialysis, and also realize the implications that not using it can cause.

CONCLUSION

The bodily experiences of people on peritoneal dialysis have shown that the disease changes their lives and leaves marks on their bodies. It has physical, emotional, social and economic repercussions on daily life for patients and their families, requiring management of a complex treatment that implies facing difficulties and dealing with body responses, with resources available or not, and make adaptations in the context in which they live.

The people in the study used their bodies as reference for themselves by valuing their bodily experiences and the meaning they give to them, as being of vital importance for making choices and maintaining life on dialysis. This body questions its physical, biological, spatial and relational limits, regarding situations, environments and people. Such a process is built and transformed by dialysis, which is incorporated into it, over time and environment.

It is necessary for health professionals to recognize the way the body is felt and perceived by people with kidney disease on peritoneal dialysis. Equipment and materials must not only fullfil biological function of the body, but allow people to feel socially included, without fear of touching and being touched by others. "Threats" must be the subject of discussion in order to clarify that there are precautions that are sufficient, and that there are fears that can be overcome with greater mastery of technology.

The study points out the need to address topics that are little explored in health services, mainly in nephrology, such as sexuality and the difficulties that arise during illness, both in men and women, as it is not talked about. These issues need to be discussed, providing clarification and support during the incorporation of technology to the body and the home.

There is a need to develop studies that explore and deepen bodily experiences of people in chronic health conditions from the perspective of gender, socioeconomic status and stage of the family life cycle.

The study was limited by the fact that it was carried out in only one nephrology service located in a public hospital. However, it can shed light on aspects considered similar in the illness of people with kidney disease on peritoneal dialysis.

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Juliana Graciela Vestena Zillmer contributed to the conception, collection and analysis of data, writing and reviewing. **Denise Maria Guerreiro Vieira da Silva** participated in the design, writing and reviewing.

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