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## Learning prospects in the consultation for renal patients and caregivers: a phenomenological study

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### ABSTRACT

**Aim:** Understanding the repercussions of the educational actions of the nursing consultation on the life of chronic kidney patients and their caregivers. **Methods:** Qualitative research, using the Social Phenomenology reference. Open-ended interviews with 12 patients and their 12 caregivers were conducted in a public hospital outpatient clinic in Rio de Janeiro, Brazil, in 2016. **Results:** The analysis of the participants' testimonies allowed the elaboration of two concrete categories of the experience lived concerning the reasons "why": Sum of learning lived by the sick and those who care also learn. **Conclusion:** The importance of the perspectives of chronic kidney patients and their caregivers for the design of educational actions stands out in the face-to-face interaction, in the shared approach and the approximation of the nurse.

**Descriptors:** Office Nursing; Renal Insufficiency, Chronic; Health education; Qualitative Research.

## INTRODUCTION

The Clinical Guidelines for the Care of Patients with Chronic Kidney Disease (CKD) of the Unified Health System (*Sistema Único de Saúde* – SUS) have argued that these patients must be accompanied by a multiprofessional team in the basic health units and, in the progression of the disease, should be referred to care in CKD specialized care units, for guidelines and health education<sup>(1)</sup>.

Currently, CKD is considered a public health problem and has been described as one of the main determinants of risk for cardiovascular events, with high cardiovascular morbidity and mortality among patients with CKD. CKD adverse results, such as end-stage renal disease, cardiovascular disease (CVD) and premature death, can be avoided or delayed when treatment is started in the early stages of the disease<sup>(1-2)</sup>.

Thus, once diagnosed with CKD, chronic renal patients should be treated as early as possible, regardless of being a conservative or dialytic treatment. The news of the loss of renal capacity, as well as the need for specialized treatment, can be characterized as a difficult and arduous experience, but it becomes essential for the maintenance of the life of the person with CKD<sup>(3)</sup>.

Therefore, it is important to incorporate strategies that can contribute to the person suffering from CKD to become increasingly participatory and active in their treatment, allowing the means to manifest their autonomy, in order to stimulate self-care as a possibility for better adherence to therapy<sup>(4)</sup>.

In addition, the individuals who participate in this process with the chronic renal patient, that is, their caregivers, need attention and voice in order to understand this new way

of life to which they will be subject with the therapeutic plan of their loved one.

Thus, nursing consultation represents one of the main health strategies with a primary focus on the risk factors that influence the control of CKD. Likewise, the consultation allows the follow-up, the educational process, which through a method and strategy of scientific work, performs the identification of health/disease situations, supporting the prescription and implementation of nursing actions<sup>(5)</sup>.

This proposal provides for consultation not only as a work tool to be used within SUS, but as a moment of perception and understanding of the daily life of this subject, which increasingly becomes dependent on care and educational strategies to provide them with quality of life.

In this sense, the way the subjective senses express themselves in the individual life depends on the totality of the experience that the subject constructs in the course of its concrete existence. This experience adds a wealth of knowledge that is available and accessible, according to the biographical situation of the subject. Such interpretations of social contexts are relevant for the conditioning of treatment, regarding adherence and control, in view of the non-progression of CKD.

Studies show that nursing performance has improved blood pressure control and is configured as a support system for education. This leads to the enhancement of health care skills and, during the course of the nurse-led intervention, there is a better control of the accepted risk factors for progression of CKD, combined with empowerment<sup>(6-8)</sup>.

However, studies on clinical aspects and drug treatment prevail, with no emphasis on

preventive programs, prevention in terms of complications, and slowing down renal disease, for which many sociodemographic aspects, such as educational level, are associated with health disparities, including kidney disease<sup>(9,10)</sup>.

Assuming that the nursing consultation allows the identification of health/illness situations and supports the prescription and implementation of the Nursing actions, it is justified to understand the perspectives of educational actions of the nursing consultation in the world of life of the renal patient and their caregivers.

Considering the broader perspective of care for chronic kidney patients, the presence of a caregiver is necessary. This person may be from the family and/or community, with the proper support and guidance of a health professional, whose role goes beyond the simple monitoring of individuals' daily activities. They should be prepared to experience the care process of their loved one, especially within their homes, since many of them do not have this experience and are afraid to experience it.

Faced with this, it is fundamental to establish educational strategies that can contribute to the lives of these individuals to reach satisfactory results. Thus, the following research question emerged: What are the repercussions of the educational actions of the nursing consultation for the chronic renal patient and their caregivers?

Thus, the present study was elaborated with the following objective: to understand the repercussions of the educational actions of the nursing consultation for the chronic renal patient and their caregivers.

## METHODS

This is a qualitative study, guided by the social phenomenology of Alfred Schutz. Such an approach makes it possible to reveal the phenomenon lived by the subject in his daily life, seeking the understanding of reality to describe the phenomenon, in this case, the lived experience and how people perceive themselves in it<sup>(11)</sup>.

Thus, social phenomenology is given in order to explain the meaningful structure of the social world, that is, the set of subjective meanings that make up this world of life, on the basis that every action that subjects develop has an intentional sense and seeks to meet their expectations<sup>(12)</sup>.

The world of life is conceptualized as the whole of everyday experience; are the directions and actions by which individuals deal with their interests, manipulating objects and dealing with people, conceiving and realizing plans, that is, it is not a private world of a single individual, but an intersubjective world, common to all of us, in which there is no theoretical but eminently practical interest<sup>(11)</sup>.

These actions are interpreted from their existential motives. The motifs that relate to the projects of the future are called "reasons for" and those based on the collection of knowledge and experience lived in the biopsychosocial scope of the subject are called "reasons why"<sup>(13)</sup>.

The set of reasons "for" and "why" translate the flow of action into agenda, that is, the baggage of contextualized and translated knowledge, since such subjects are inserted in a subjective world in which the concrete categories of the lived are formed. This world is nothing more than the theoretical organization of the characteristics of the concrete

existence of typical subjects inserted in the social world<sup>(11)</sup>. In this study, the reasons “why” are presented, and these are explained based on the background, the knowledge pool, the environment, and the psychic predisposition of the actor<sup>(11)</sup>.

The survey area was the daily life world of chronic kidney patients and their caregivers, who participate in the nursing consultation in a nephrology outpatient clinic of a university hospital, located in the city of Rio de Janeiro, Brazil.

The nursing consultation at the outpatient clinic is held on Wednesdays and Fridays by three nurses who are included in the clinical staff of the specialty in the service, including the principal investigator. Initially, the physician meets and evaluates the CKD patients and then forwards them and their caregivers to nursing consultation. Both are received by the nurse who, in possession of the medical record, initiates the nurse-patient and caregiver dialogue, inquiring about the health and well-being of the patient with renal disease, thus, carrying out the process of educational actions based on the main doubts and complaints of chronic kidney disease. Currently, scheduling is focused on chronic kidney patients at various stages of CKD and those with treatment adherence difficulties.

Twelve chronic kidney patients, aged 18 years and older, attended the program of conservative treatment of CKD in advanced stages of the disease, and their 12 family caregivers, older than 18 years old, who accompany their family member, thus forming the inclusion criteria. The reason for inserting chronic renal disease patients into advanced stages of CKD is because their experience is permeated by a clinical profile that influences health needs. In this way, the chronic renal patient is a constant presence in the

consultations, and can already be prepared for a dialytic therapy.

For a better structuring of the treatment of chronic kidney patients, as well as for prognostic estimation, all patients must be classified according to the stages after diagnosis: conservative treatment, when the stages are from 1 to 3; pre-dialysis, when they are 4 and 5-ND (non-dialytic); and renal replacement therapy, when they are 5-D (dialytic). Conservative treatment consists of controlling the risk factors for the progression of CKD, as well as for cardiovascular events and mortality, in order to maintain the glomerular filtration rate for the longest possible evolution<sup>(5)</sup>. Chronic renal patients who attended the consultation alone, as well as those who participated in the consultation for the first time, were excluded because they did not ‘live’ the consultation.

In the period from November 2015 to April 2016, in the treatment rooms, phenomenological interviews were conducted to obtain the testimonies, which were recorded by the principal researcher through a media device, with an average duration of 25 minutes. The following question was presented to the chronically ill: What do you expect when you come to the nursing office in the nephrology clinic? And for caregivers, the question was: What do you expect from the nursing consultation at the nephrology clinic and what educational guidelines did you receive during the nursing consultation to take care of your loved one during the treatment?

The participants of this study were contacted in advance, so that the date and time for the interviews were scheduled. Participants signed the Free and Informed Consent Term and, to ensure their anonymity, the entries were identified by the terms “CKD Patient” and “Caregiver”, and the Arabic numeral

corresponding to the order of the interviews: CKD Patient 01 to CKD Patient 12; Caregiver 01 to Caregiver 12. The number of participants for the interviews was not predefined, since in the phenomenological interview the quantitative can be closed when there is a significant repetition of the information in the speech, that is, when there is no evidence of new meanings, since it is sought to reach in depth and not in quantity<sup>(14-15)</sup>.

The organization and categorization of the research material were carried out according to steps taken by researchers of social phenomenology<sup>(13,16)</sup>. Initially, careful reading of each testimony was carried out in order to identify and apprehend the meaning of the educational action in the nursing consultation for the client and the caregiver in the nephrology outpatient clinic. Next, the unstructured material emanating from the convergence of meanings regarding learning in the nursing consultation was organized. This organization aimed to obtain concrete categories, considered as objective constructs elaborated by the researcher, based on the experience explained by the participants. The discussion of the data had as its guiding axis the theoretical reference of the social phenomenology of Alfred Schutz and literature related to the theme of the study.

This research was approved by the Research Ethics Committees of the proposing and co-participating institution, through the reports numbered 1,045,709 and 1,067,955, respectively, according to Resolution 466 of December 12, 2012, of the National Council of Health, Ministry of Health, Brazil.

## RESULTS

Of the chronic kidney patients participating, seven are men and five are women, aged 21 to 81, six of whom are married. All have systemic arterial hypertension; seven have a diagnosis of diabetes, and eight have stage 4 CKD. Only one participant has physical limitation. The average age of the caregivers is 31 to 72 years old, ten females and two males. The bond is given by the wife and husband relationship, children, mothers and a chronic kidney patient has a friend as primary caregiver.

The analysis of the participants' testimonies allowed the elaboration of two concrete categories of the experience lived concerning the reasons "why": sum of learning lived by the patients and those who care also learn.

### *Sum of lived learning*

When chronic kidney patients learn in the nursing consultation they bring constructs that have been added during their personal experience and participation in the consultation. By being involved in their self-care, these patients rely on their stocks of lived experiences to change their current situation.

My son can go. They told me about the machine, but the nurse and you said it all depends on me. (CKD Patient 02)

I control myself a lot. I can't have another option; It's kill or cure (laughs). With the hospitalizations I had and the treatments, I got my act together and thought about taking care of myself. (CKD Patient 03)

Oh, it's been normal. I've been careful as far as possible not to get too bad. But let's see how it's going to be from now on [...] and not let it get worse. (CKD Patient 05)

Oh, it's gotta work. I drink more water as you told me to; I try to eat well and avoid much junk food. If there is something different in the pee I get worried [...] (CKD Patient 10)

When we came to talk to you, it was cool, because you talked about matters relating to our life. So, I think I've already managed to think about having a quiet, normal life as anyone [...] (CKD Patient 11)

It should be noted that all the participants presented, through their testimonies, are in an advanced stage of CKD, and that they participate actively in the outpatient clinic in order to think and rethink their actions with the intention of understanding a future treatment.

### *Those who care also learn*

Caregivers showed to be active in educational actions when they understood and put into practice such actions. Caregivers have become people who promote awareness for patients in daily activities to maintain the health of their sick loved ones.

[...] We talk, talk and talk and sometimes we don't even eat, just so he can feel it. And I think it's going to be his way. But here we see that it's cool to always be with him, because sometimes he understands us. (Caregiver 01)

So all the guidance that the professionals and I give are important and I'm always with her so she can do everything right, taking the pills, going to physical therapy, walking with her, these things. (Caregiver 06)

[...] Everyone at home makes food and it is important to help them have a balanced meal. (Caregiver 08)

Putting it into practice is cool. My mother is "super polite" with her things. After she was here, she became much more attentive to her things. (Caregiver 09)

Once we have discovered all this, at home, we have tried to sort things out calmly. My husband and I give the necessary support, including the right food, studies and good conditions. But it depends much more on them than on us [...]. (Caregiver 11)

## **DISCUSSION**

The participants of this study demonstrate that what they learned in the nursing consultation was based on the relationships established by their peers and the approach of the nurse, thus demonstrating their baggage of knowledge. The baggage of knowledge acquired comes from their life process and participation in health services. Throughout life, this knowledge is restructured from concrete experiences and serves as the basis for subsequent actions<sup>(11)</sup>.

The first category demonstrates that, in their daily experience, renal patients have

already witnessed or lived socially with someone who underwent hemodialysis. This is expressed in the lines: *"they told me about the machine"* and *"I cannot have another option"*. Those who did not physically witness it did so in their imagery, when presented by the doctor about this possibility as the only form of treatment and survival.

It is perceived that the knowledge related to the treatment is fragmented, disconnected and deficient, and that it is related not only to the causes, but also to the complications and the treatment.

In this sense, it should be pointed out that due to the close and continuous contact with patients and their responsibilities for care, nurses should position themselves from their constitution of actions, focusing on integral care and health education, allowing involving both the team of professionals and the caregivers<sup>(17)</sup>.

Such knowledge and experiences constitute the world of the life of chronic renal patients in conservative treatment, since they arrive at the nursing consultation full of their own conceptions and beliefs and that need to receive broader and clearer explanations on their real health condition.

In this context, it is perceived that, in order for the consultation to reach its final goal, which is health education, that is, the patient's behavior change for effective control of the risk factors for the progression of CKD, attention must be paid to the way that these individuals present themselves in the nursing consultation.

The presentation is the stage of the first contact, that is, an initial moment for exchanging glances, presentation of simple questions and mistrust. Sometimes this is the stage of escape or denial of the disease, in which patients are not aware or do not

accept the knowledge of their illness. At this moment, nurses, patients and caregivers do not know each other.

As they approach, little by little, the nurse deepens his questions during the anamnesis, in search of better knowledge of the patient and his life experiences. At this moment it is important to look at the interactions between body and environment so that the dialogue is efficient and to bring concrete answers that facilitate the learning of new discoveries for the patient. It is the moment in which the phenomenological understanding of the world of the life of patients and caregivers is an essential part for effective communication, since knowing their life, their experiences, what they do and how they do it in their daily life, which brought them to the ambulatory specialized in nephrology, and what their expectations are.

And, finally, the interaction, as this is the bonding and trusting phase during the nursing consultation. Without this moment the educational actions do not happen in a profitable way, and would be only information to be passed on to the listeners. At this stage, patients express their doubts, "open part or all" of their world of life so that nurses can know, since they have acquired confidence in their knowledge and will correspond to their guidelines. Here, nurses, already familiar with the everyday lives of patients, carry out educational actions in an individualized and holistic way.

Nursing consultation, in light of the phenomenological reduction, unlike the usual consultation, does not happen in a simplified manner, without interactions or mechanized perceptions. It goes through these steps to really achieve its purpose; thus, without this understanding, there is no effectiveness, motives and concrete results, and the essence of

the query is lost. The experience with which patients start the process of following the guidelines given is observed, but after a period, they stop following them, they miss their consultations and, when they return, they have a clinical condition in an advanced stage.

The phases of the nursing consultation can occur in a day, in days or even months, because they depend on the level of approximation between nurses and patients; the greater the approximation, the better the interaction.

The interaction established through the listening and reception between the health team and the family is a preponderant factor to assist the coping of the disease and acceptance of the treatment, providing more security and emotional stability for the chronic renal patients and their family system<sup>(18)</sup>.

Afterwards, the success of the educational actions in the speeches is observed: "they said that everything depends on me", "thinking about taking care of myself", "I have taken care of myself", "it has worked", and "you have talked about our life's affairs". The approach allowed knowing the world of the patients' life, since they have become open to conversation and interaction and can dialogue on various subjects. Thus, the elaboration of educational actions, according to what is possible for them to carry out, turns into empowerment. That is, patients realized that the quality of life and their health depend on themselves and their choices.

It can be said that people who are more informed, involved and accountable, that is, empowered, interact effectively with health professionals, trying to perform actions that produce health outcomes. From this perspective it is possible to sensitize people so that they learn, in the various stages of the living process, to face the chronic diseases that affect health<sup>(19)</sup>.

The second category reflects the learning of the active participation after the educational actions are carried out, that is, it is not enough for patients to follow recommendations, the family support is important for the planning of joint actions, because they collaborate so that care happens. Caregivers also learn and end up adopting healthier lifestyle measures, so that interaction and resolve take place within the family.

The educational actions and the prescription of nurses change as an advance occurs and the improvement of the parameters evaluated in each consultation is detected. Patients also become aware of their clinical parameters such as, for example, levels of urea, creatinine, cholesterol, blood sugar, potassium, parathyroid hormone, hemoglobin, weight, and blood pressure. Then, at each visit, the parametric levels are discussed together and thus the strategies are elaborated with a view to maintaining or improving the results of the exams, as is explicit in the speech: "*After she was here, she became much more attentive to her things*".

Thus, it is demonstrated that the patient-caregiver relationship is valid when it is observed that, when a close person can understand and explain the changes that can be imposed to the individual by the diagnosis or treatment, with a more proper language, the coping becomes better administered<sup>(20)</sup>.

This discussion brings health care to the world of life, where CKD patients and their caregivers are constantly in a dynamic relationship, whether social, personal, clinical, and/or cultural. It is a world in which the person is "fully awakened," and which imposes itself as the "main reality" of their life<sup>(11)</sup>. This world provides its construction throughout our experiences and, therefore, is subject to transformations.



In this sense, it is a broad intersubjective world and a social reproduction of ideologies, where the relation with the discursive construction of subjects' experiences is given by a set of meanings that bring together values, beliefs, and typifications, that is, the cognitive framework that guides the action of subjects in the world of life<sup>(11)</sup>.

The "reasons why" brought by the categories refer to the knowledge stock of these subjects, that is, it is a sphere that is heterogeneous and that is built in the history of experiences, and is a knowledge "about" and a knowledge "for" familiarity<sup>(11)</sup>. The value given to these experiences has repercussions on the care of patients with themselves, caregivers with patients or nurses with patients and caregivers. Each of them brings the individual wealth relative to the clinical and behavioral conditions of the therapeutic trajectory. These conditions, in turn, constitute singular experiences that reserve peculiar and individual characteristics<sup>(21)</sup>.

*This study was performed with renal patients on hemodialysis. The study showed that, when discovering an incurable disease, the person goes through a series of feelings that provoke conflicts. The most obvious feelings, in general, are denial, anger, bargaining, depression, isolation, and acceptance. What is important is to know that each one goes through these transformations individually, with their own intervals and sequences<sup>(3)</sup>.*

*Thus, it is relevant that the nurse practitioner must, initially, perform care from the perspective of phenomenological reduction, which happens when beliefs are left behind and opinions suspended to hear what the other has to say, without judging it<sup>(11)</sup>.*

In this way, nurses must give meaning to the experiences of others, which cannot be exactly the same meaning given by the

people themselves when interpreting them, for "if I could be aware of the whole experience of the other, he and I would be the same person"<sup>(11)</sup>. Thus, nurses in the nursing consultation recognize the limitations of self-concept and self-perception and the social role of chronic kidney patients with a view to proposing educational actions that cover human uniqueness.

Through the testimonies of the participants, it was verified that the educational actions in the nursing consultation give rise to questions of self-care, perceived by the chronic renal patients and encouraged by the caregivers on a daily basis. A study shows that chronic kidney patients on conservative treatment enjoy a certain degree of autonomy because it makes it possible to perform health benefits such as "feeling useful". Educational actions may allow autonomy for self-care in order to meet physical, mental and spiritual needs in the search for (re) establishment of the body's internal harmony<sup>(22)</sup>.

In this way, the educational actions in the nursing consultation allow growth to reach the critical sense of the patients and their caregivers. Their social relation makes it possible to achieve exchanges, to set up health strategies in daily life, to socialize, and to be individuals responsible for their attitudes.

Social life is life between subjects, intersubjective life and the meaning that is experienced in the singularity is at the same time experienced with others. Thus, it is relevant for nurses to rely on the experience of their neighbor, "because if I were in his place I would have the same experiences as he had; I could do the same thing he did and have the same odds or risks in the same situation". With this, the actual experience of the CKD patients is, for nurses, a possible experience<sup>(11)</sup>.

To do so, recognizing nursing consultation and its stages as directed towards caring in an integral and non-isolated way leads to the participation of CKD patients and their caregivers in the health-disease process as people-beings guided by their worldview. As it is known, CKD has no cure; however, there are ways that allow individuals to reflect on their actions and act properly in their treatment with the health team that is encouraged to do so.

Finally, it is understood that educational actions in the nursing consultation for CKD patients and their caregivers have an impact on coping with the disease, adherence to treatment and, consequently, on improving the quality of life, since it relies on a detailed and focused planning on the human needs of those involved. Thus, the awareness and mobilization of nurses in the claim of good conditions for the accomplishment of this activity reflect on the return to the health of the population.

## CONCLUSION

In this research it was possible to know how the impact of educational actions on the life of chronic kidney patients and their caregivers is perceived through sensitive listening, since it is configured as a care tool that favors the development of health education actions seen as a strategy to strengthen the link between the professional and the user.

This study shows the importance of the perspectives of chronic kidney patients and their close caregivers for the delineation of educational actions offered in the nursing consultation, highlighting the face-to-face interaction, the shared approach, the nurse approximation in this context, and the po-

tential support regarding the integral health of the chronic renal patient.

The findings of this study should not be generalized; however, they may be compared to other similar contexts. It is suggested to carry out new studies with other references, adding the perspective of professionals about the interdisciplinary actions of health in Nephrology, as well as other approaches and techniques for collecting and analyzing information about these actions, to deepen this understanding.

Although it has achieved its objective, this study has limitations provided by its realization in only one context, with a low number of subjects and the presence of a certain degree of social normativity, that is, the data were collected in a context that may have influenced them.

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