

# PERSONAL SENSE OF ROLE IN MAIN CAREGIVERS OF HEMODIALYSIS PATIENTS IN CUBA

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— *Abstract*—

The research developed offers the characterization of the personal meaning of the role in primary caregivers of patients undergoing hemodialysis treatment at the "Arnaldo Milián Castro" Hospital in the city of Santa Clara, given the importance of knowing the senses that the caregiver attributes to their role and therefore to the activity of care. It presents a characterization of the personal sense from four indicators of analysis (meaning in the patient-caregiver relationship, sense of care, sense formations and sense attribution).

Multiple-case study was used as a research design and a system of qualitative tools was used to drill down from the selected sample. It is evidenced that the personal sense of the role is based on the personal, family and social commitment of the caregivers as well as source of satisfaction and well-being.

**Keywords**

*Personal sense, main caregivers, hemodialysis.*

In the last decades it is recognized worldwide the increase of non-transferred pathologies and among them the Chronic Kidney Failure (hereinafter CKF) which is characterized by the kidneys' progressive and global inability to discard the toxins of the organism compromising the renal function in almost 90% of its totality.

According to the World Health Organization (WHO, 2014), a significant increase in non-transferred diseases as a leading cause of death has been reported in the last decade. For a mortality rate of every 100,000 inhabitants, the regions of Africa, South-East Asia and the Eastern Mediterranean have numbers between 652 and 656 people who die due to non-transferred diseases, which differs in the Americas and Europe to 437 and 496 inhabitants respectively (WHO, 2014).

The main risk factors contributing to the increase in this problem are advanced age, family history of the disease, diabetes, high blood pressure, obesity, self-medication, exposure to toxic substances, inadequate fluid intake habits, unhealthy diet, smoking and alcohol abuse (WHO, 2014).

In Latin America, countries such as Colombia report a disease prevalence rate of 0.87%, which has centered the attention of the health authorities due to its chronic course and in relation to the high economic and human cost of the care of these patients (Rivas *et al.*, 2013).

In the United States, the disease is an incidence of 4.3% and 7.6% as a prevalence rate, with a higher rate with adults over 65 years of age. These data are closely related to the prevalence of chronic diseases in this type of patients (González, Vargas, Echeverri, Díaz y Mena, 2013).

The number of patients receiving dialysis treatment by the end of 2014 in Cuba reached 2982 people, which by the end of the year was estimated to have been exceeded (Fariñas, 2015). For its part, the Provincial Health Center of Villa Clara province reported in the year 2014 a total of 143 new cases of patients with CRI with an annual prevalence of 1224. Only for the municipality of Santa Clara the incidence reached 104 patients per thousand inhabitants, for a total of 180 patients in renal replacement therapy, 159 of them went to the Hemodialysis service.

Guerra, Díaz and Vidal (2010) report that on receiving hemodialysis treatment the patient experiences changes in diet, fluid consumption, social, labor, family

and personal. The changes made for this new stage are fundamentally associated with lifestyle, medical recommendations and caregiver assistance.

The person in charge of providing these informal supports or care is recognized as the main caregiver, a role that is mostly assumed by a family member on whom rests the greatest responsibility for care. The caregiver is the resource, instrument and means through which specific and specialized care is provided, based on the commitment to preserve the patient's life (Cruz and Ostiguín, 2011).

The assumption of the role carries with it implications in the social, physical and psychological order manifesting itself in the abandonment or restriction of social activities, the lack of self-care skills, the overload and the experience of negative emotional states such as fatigue, depressive symptoms or proper depression (Arechabala, Catoni, Palma and Barrios, 2011).

The actions that derive from the caregiver role acquire meaning for the person who performs the role, however, the exercise of the role is not reduced to it, the complexity is that assuming it, this person restructures his / her life situation according to his family and the needs of the same. Hence, meanings, although frequently representing meanings in themselves, do not express a direct, linear, or intentional relationship with the senses (González, 2010)

The sense constitutes, then, a new type of psychic unit susceptible to the language and consequent to the culture, like organized psychic unit appears in the present moment of relations of the person (González, 2013). According to Vergara (2011) through the social relations established by the subject with the environment, personal sense is constituted as an element that grants internal congruence and a notion of oneness.

The caregiver attributes a personal sense to the activity that he/she performs in function of the multiple conditions that particularize this process. This allows us to understand that the formation of personal senses centered on an activity such as care appears mediated not only by the action itself but by the system of experiences that are derived as executors in the attribution of meanings.

The relevance acquired by the present study is supported by the insufficient approach of research that places the caregiver as the center of attention and the personal sense that acquires the role as a regulatory dimension of the relationship system and its behavioral expression.

Taking into consideration the proposed research objective: To characterize the personal meaning of the caregivers' role in their patients in Hemodialysis of the Hospital "Arnaldo Milian Castro" of the city of Santa Clara.

## DEVELOPMENT

### *1. Equipment and method*

A qualitative methodology was used in the research, given the flexibility and openness that it offers for the study of the psychological phenomena. The data were obtained in natural environments of the studied subjects. According to Hernández, Fernández and Baptista (2010) the natural conditions for the investigation allow to evaluate the development of events without manipulation or stimulation with respect to reality, guaranteeing a greater reliability of the results.

The case study is used, specifically the study of multiple cases with the objective of approaching in depth and detailed the identified problem.

#### *1.1 Sample*

The Hospital "Arnaldo Milián Castro's" Hemodialysis Room of the Villa Clara city is chosen as the unit of study, being the only institution that offers this health service at the provincial level. A total of 5 daily shifts with a duration of 4 hours and in alternate frequencies for Monday, Wednesday and Friday, as well as Tuesday, Thursday and Saturday are identified. The selection of the sample was intentional according to: the operational capacity of collection and analysis; the understanding of the phenomenon and the nature of the same as factors for sampling in qualitative research. The sample of cases-type is used for the richness, depth and quality of the information that allows obtaining and from inclusion, exclusion and exit criteria.

#### *Inclusion criteria*

- Main caretakers of patients with CFK in hemodialysis treatment for less than six months.
- Main caretakers of patients with CFK in hemodialysis treatment who wish to participate in the research.

#### *Exclusion criteria*

- Main caretakers of patients with CFK in hemodialysis treatment for less than six months.
- Caretakers that are not available to participate in the research.
- Caretakers that only fulfill the function of accompaniment during the treatment schedule.

#### *Departure Criteria*

- Caretakers who during the process decide to abandon the research.
- Caretakers that during the investigation his/her relative dies.
- Caretaker that during the investigation his / her relative receives a transplant.

The sample consisted of 8 primary caregivers of hemodialysis patients who met the defined criteria for selection.

#### *1.2 Equipment used*

In accordance with the research objective, a system of techniques is used:

- **Semi-structured interview:** it is oriented to the data collection through the verbal interaction and according to the degree of structuring there is a level of premeditation in the questions or the topics to be deepened. (Appendix 1)
- **Interview in Depth:** it is directed to the obtaining of information that is desired to probe in depth with the interviewee establishing core analysis thematic. (Annex 2 and 3)
- **Observation:** allows direct and immediate information on the phenomenon or object of investigation.
- **Technique of the 10 desires:** according to González (2008) studies the diversity and hierarchy of needs in their expression through activity, desires and imagination. It consists on the direct method, indirect method and the activity record. For the purposes of the investigation only the direct method is used which allows the expression of the subject's conscious desires from the actual situation that he experiences. (Annex 4)
- **Phrase Completion Test:** projective technique composed of incomplete phrases that act as inductors on the subject and allow to explore psychological contents such as motives, needs, conflicts, concerns and interests. (Annex 5)

- **Composition:** open non-standardized technique based on the subject's experiences in relation to the content that needs to be known. According to González and Mitjás (1989) the composition is an important way to determine the integration of a psychological content in a psychological formation of the personality. (Annex 6)

### 1.3 Ethical Considerations

The respect for individuality and the confidentiality of the data obtained were considered as ethical principles of the research. Voluntary participation and informed consent of the participants were established as ethical requirements to proceed in the study. The study objectives were explained and the schedules and conditions of realization were negotiated.

### 1.4 Procedure for analysis results

For the data qualitative analysis, two phases were integrated. Initially, an individual analysis was carried out per case and then a generalization of results by techniques through content analysis where indicators of analysis were established as: (1) Patient-caregiver relationship meaning; (2) Care meaning, (3) Meaning of formation and (4) Attribution of meaning.

## RESULTS

A predominance of the female gender in the role of primary caregiver is identified for the sample studied, being a total of 6 women and 2 men. The ages of the participating caregivers fluctuate in the 41-60 age range, with a period of experience in the role as caregiver between 2 and 6 years. In relation to the employment relationship of the caregivers, it was found that 3 caregivers perform domestic duties as housewives and the rest are active labor.

For those caregivers who are linked to work, it is complex to maintain both tasks due to the systematic treatment, as well as the duration of treatment, which interrupts the traditional working day.

In this regard, they say: *«I have continued to work because at work I am considered enough if not, I'd have to leave it», «my sister and I share the care and accompaniment to the room so that each one can keep working», «my work is a lot of responsibility and because of my situation I have thought about retirement to take care of my wife, but thanks to my boss that has not happened, he considers takes me in consideration».* The work and family adjustments are

the main mechanism that guarantees the employment relationship for these caregivers, as well as the type of activity that they develop.

These data coincide with the studies of Gil *et al.* (2013) and Aguilera *et al.* (2016) by identifying characteristics that coincide with the caregiver's profile around the female gender, age and absence of employment relationship as conditions prone to assuming the role.

Regarding the patient-caregiver relationship degree, three groups are distinguished: friendship, sisters, daughters and spouses, which are recognized as the main support system among caregivers and coinciding with previous studies (Santos Lima *et al.*, 2013).

- Indicator 1: Patient-caregiver relationship meaning

Caregivers recognize that the emotional management of their family member stands out as the most complex function, characterized by affective changes and states such as aggressiveness, irritability, depression, anxiety, sadness and uncertainty. The experience of these emotional states in the patient mediate the relationship with the caregiver which hinders the care process or facilitates care, while some may be undisciplined, irritable and aggressive or otherwise disciplined and docile.

Before the emotional manifestations of their relatives, the caregivers express: «*the has his days and his moments*», «*sometimes I do not know what to say to not bother him*», «*when he is like that, we have to let him be*», «*There are times when he/she doesn't even want to look at me*», this generates sadness and impotence in the caregivers due to the affective relationship they maintain with their family member and the concern that causes them both their physical and psychological health.

On the other hand, the quality of the interpersonal bond and the personality characteristics of the relative act as elements flattering to the relationship. In this respect they express: «*she surprises me with her optimism, the way she faces the disease*», «*she has a desire to live*», «*she has faced very difficult things that I do not think I could have endured*», «*she infects us with her optimism*», «*she prevails over adversities*»; these verbalizations show in the patients psychological formations such as self-esteem and resilience that intervene as factors in the process of therapeutic adherence.

- Indicator 2: Care meaning



It is evident among the study's caregivers signs of physical and emotional exhaustion that are identified by expressions such as: «*there are times when I can't anymore*», «*I feel very stressed*», «*I am tired because of the rhythm of life I lead*», «*we live the same situation day by day*», «*I feel super tired*». These phrases express the overload role experienced by caregivers based on the responsibility involved in the care of a patient with hemodialysis, which in many cases is exacerbated by inefficient support networks that contribute to these tasks.

The family financial aid or the stay of some of its members when the patient is hospitalized are the main types of help that in many cases the caregivers receive from their family. In this respect they refer: «*this is a long illness, of resistance, at the first the all begin, but t some do not make it all the way*»; the caregiver refers to the duration of treatment and the involvement of the rest of the family in the process. Time, family and social networks are elements that modulate not only the patient-caregiver relationship but also the care experience (Chaparro, 2011).

As a result, the caregivers recognize that from the tasks and responsibilities multiplicity associated not only with the care of their relative but with domestic or work activities their own health is affected and they point out: «*I do not sleep as I did before*», «*I neglect myself to attend to him*», «*I always look out for him*», «*there is always concern*», «*one looks after them and forgets oneself*», which denotes for some cases inefficient self-care skills. On the other hand, the concern for "others" appears as a nucleus of meaning when the person is meaningful to the caregiver (Santos Lima *et al.*, 2013).

- Indicator 3: Personal meaning formation

The main needs identified in caregivers relate to the family member's health, the family, adverse effects to treatment, emotional stability, self-care actions, as well as economic and labor problems.

The health status of the relative is recognized as a regulatory motive that is constituted as a mediator of emotional state in caregivers. The patient's hemodynamic stability results in the caregiver's own emotional stability, which is characterized by states of expectation and marked concern. On the other hand, insufficient family support generates overload for the caregiver, which in turn limits the satisfaction of their personal needs, which implies that a restructuring of projects necessarily occurs when caring for others (Santos Lima *et al.*, 2013)

They are evidenced as psychological units that reach meaning in the configuration of sense for the subjects' family illness, psychological content of a personal nature, family support, the experience of negative emotional states, concern about death, needs for affection, acceptance and self-care.

The personal psychological contents are expressed in relation to the personal and professional improvement, the family and work area as spaces of socialization and generators of well-being. It is expressed in some cases the configuration of psychological formations such as self-assessment, future projects and conception of the world.

The concern about death is expressed in only two of the caregivers, this is contradictory in that the characteristics of the treatment to which the patients are exposed are characterized not only by their complexity but also by the commitment that life generates.

The unfavorable clinical condition of the family relative to the rest of the patients in the room constitutes in one of the cases the reason for reflection towards death. On the other hand, the attitude assumed regarding the disease itself, the posthumous legal or familiar dispositions in one of the patients is of concern for its caregiver. This allows us to note that for the rest of the caregivers an uncritical attitude is manifested around the situation, due to conditions such as the systematically, frequency and duration of treatment, hemodynamic stability of the patient or favorable clinical conditions and the patient's attitude towards the illness.

It is evident in the caregivers elaborations with a high emotional bond around the role they play and determined by positive affective expressions such as love, commitment, satisfaction and pride generated by the exercise of the role, which is constituted as a mediator of the personal sense that acquires the same within its motivational hierarchy. On the other hand, affective expressions such as fear, insecurity, and instability are identified; which have a negative evaluation based on personal experiences that also support the role's performance and are consistent with previous research (Santos Lima *et al.*, 2013).

- Indicator 4: Attribution of meaning

The elaborations and reflections as an expression of the role's personal meaning are based on a conceptual domain around the role's definition which have a generalizing level that transcends the common sense and the

social representation attributed to it. This favors that the reflections acquire an individualized and contextual sense starting from the referents of the caregiver.

The personal sense that the caregivers attribute to the role is based on the social, family and personal commitment that it acquires.

For some it is constituted as a constant process of self-improvement and generator of self-development, for others it becomes an opportunity to thank their family member and recognize it as a process of affective retribution. These results are compatible with those offered by Fernández-Lansac and Crespo (2011) when recognizing in the assumption of the role a state of well-being and satisfaction as benefits of care.

Caregiving actions appear as a means to compensate for and meet the needs for recognition, affection, acceptance, and appropriate self-worth. In all the cases studied and despite the individualities described, the role is recognized as an activity that generates satisfaction, pride and complacency. The results reflect coincidences with the statements of Chaparro (2011) when assessing the experience of care according to the meaning that the caregiver gives to their work.

## CONCLUSIONS

- The personal meaning that acquires the role is shaped from the personal, family and social commitment to the patient, which is based on the satisfaction and pride that generates its function.
- The role's personal meaning for caretakers is constituted in a process of self-development and self-improvement.
- Indicators such as the employment relationship, degree of relationship with the caregiver, years in the role, social support networks, the interpersonal patient-caregiver relationship and the personality characteristics of the relative are identified as variables that mediate the personal sense that the caregiver attributes to their role.

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## ANNEX

### Annex #1 Semi-structured interview

#### Objectives:

1. Obtain informed consent to proceed with the study.
2. Identify the participants' general data.
3. Explore conditions associated with the care process.
4. Analyze the emotional impact of the illness on the caregiver

#### Indicators

##### Caretaker general data:

- Name
- Age
- Gender
- Education level
- Marital status
- Employment relationship
- Kinship with the patient

##### Relative with hemodialysis general data:

- Name
- Age
- Gender
- Time of diagnosis of kidney disease
- Relative's time in treatment for hemodialysis
- Years in the role
- Patient's physical and emotional manifestations
- Emotional manifestations in the caregiver
- Overcharge or wear in the care process
- Self-care skills
- Social support perceived by the caregiver

### Annex #2 In-depth interview

#### Objectives

1. Clarify analysis' units particularized for each case study.
2. Triangulate the information obtained from the instruments applied.

### Annex #3 In-depth interview

#### Objectives

1. Explore the personal meaning attributed by caregivers to the role.
2. Identify the characteristics of the meaning that the role acquires for the caregiver.

### Annex #4 Ten wishes technique

#### Objective

Identify the hierarchy of needs in primary caregivers.

Name: \_\_\_\_\_ Age: \_\_\_\_\_

#### Instructions:

We need you to write down 10 wishes, it may be both what you want to happen and what you do not want to happen, you do not need to think hard to write, put whatever you can think of when reading the incomplete sentences that start each wish. It is important that you be sincere and manifest the desires you truly feel.

1. I wish \_\_\_\_\_
2. I wish \_\_\_\_\_
3. I wish \_\_\_\_\_
4. I wish \_\_\_\_\_
5. I wish \_\_\_\_\_
6. I wish \_\_\_\_\_
7. I wish \_\_\_\_\_
8. I wish \_\_\_\_\_
9. I wish \_\_\_\_\_
10. I wish \_\_\_\_\_

## Annex #5 Phrase completion test

### Objective

To explore the main motivations, conflicts, worries and frustrations in the main caregivers.

### Instructions

Complete or end these sentences that express your true feelings, ideas or opinions.

1. The happiest moment
2. Regret
3. My biggest fear
4. I can't
5. I suffer
6. I failed
7. My future
8. I'm better when
9. Sometimes
10. This place
11. The main worry
12. I wish
13. I
14. My biggest problem is
15. My main problem
16. Happiness
17. I think I can
18. I try hard every day for
19. I struggle
20. My biggest wish
21. I have always wanted
22. I struggle a lot
23. My aspirations are
24. My future life
25. I'll try to accomplish
26. My goal
27. Every time I can
28. I fight
29. The past
30. I feel



31. In the future
32. I need
33. I hate
34. When I'm alone
35. I feel depress when

### **Annex #6 Composition**

#### Objective

To analyze the personal meaning that acquires the role of caregiver.

#### Instruction

Write a composition with the title «*Being a caretaker is, for me...*».