



Constitution of the caregiver subject at home care: psycho-affective, cognitive and moral dimensions

Constituição do sujeito cuidador na atenção domiciliar: dimensões psicoafetiva, cognitiva e moral

Constitución del sujeto cuidador en la asistencia domiciliar: dimensiones psicocativas, cognitivas y morales

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ABSTRACT

Objective: to analyze the subjectification process of caregiving persons in home care. **Method:** qualitative study, carried out in a home care service. Data were collected from February to June 2018, through observation, with 26 caregivers and six professionals followed by in-depth monitoring of four cases and interviews with six professionals and seven informal caregivers. Discourse analysis was used to interpret the data. **Results:** caregivers are predominantly women and have a parental bond with the user. The constitution of the caregiver is associated with the psycho-affective dimension, which refers to affectionate values, feelings of retribution, identity and aptitude. The cognitive dimension is related to the learning of care and administrative activities. In the moral dimension, assuming the role of caregiver is revealed in accordance with socially constructed norms. **Conclusion and implications for the practice:** the subjectification of the caregiver derives from a relationship of themselves, built by the way these subjects relate to the speeches, power relationships, care experiences and social norms. The findings can contribute to providing moments of reflection with caregivers, in times and movements by which they learn about themselves and about assistance in home care.

Keywords: Caregivers; Home Care Services; Home Care; Family.

RESUMO

Objetivo: analisar o processo de subjetivação dos sujeitos cuidadores na atenção domiciliar. **Método:** estudo qualitativo, realizado em um serviço de atenção domiciliar. Os dados foram coletados de fevereiro a junho de 2018, por meio de observação de 26 cuidadores e seis profissionais, seguida de acompanhamento aprofundado de quatro casos e entrevistas com seis profissionais e sete cuidadores informais. Utilizou-se a análise do discurso para a interpretação dos dados. **Resultados:** os cuidadores são predominantemente mulheres com vínculo parental com o usuário. A constituição do cuidador está associada à dimensão psicoafetiva, que se refere aos valores afetuosos, sentimentos de retribuição, identidade e aptidão. A dimensão cognitiva relaciona-se com a aprendizagem das atividades de cuidado e administrativas. Na dimensão moral, assumir a função de cuidador é revelada em concordância às normas socialmente construídas. **Conclusão e implicações para a prática:** a subjetivação do cuidador deriva de uma relação do próprio eu, construída pela forma como esses sujeitos se relacionam com os discursos, as relações de poder, as experiências de cuidado e as normas sociais. Os achados podem contribuir para oportunizar momentos de reflexão com os cuidadores, em tempos e movimentos pelos quais eles aprendam sobre si e sobre o cuidado na atenção domiciliar.

Palavras-chave: Cuidadores; Serviços de Assistência Domiciliar; Assistência Domiciliar; Família.

RESUMEN

Objetivo: analizar el proceso de subjetivación de cuidadores en la atención domiciliar. **Método:** estudio cualitativo, realizado en un servicio de atención domiciliar. Datos recopilados de febrero a junio de 2018, por medio de observación, con 26 cuidadores y seis profesionales, seguido de monitoreo en profundidad de cuatro casos y entrevistas con seis profesionales y siete cuidadores informales. Interpretación de datos por el análisis del discurso. **Resultados:** cuidadores son predominantemente mujeres y tienen vínculo parental con el usuario. La constitución del cuidador está asociada con la dimensión psicoafectiva, referente a valores afectivos, sentimientos de retribución, identidad y aptitud. La dimensión cognitiva está relacionada con el aprendizaje de la atención y las actividades administrativas. En la dimensión moral, asumir el papel de cuidador se revela de acuerdo con las normas socialmente construídas. **Conclusión e implicaciones para la práctica:** la subjetividad del cuidador deriva de una relación de su propio yo, construída por la forma en que estos sujetos se relacionan con discursos, relaciones de poder, experiencias de cuidado y normas sociales. Los hallazgos pueden contribuir a proporcionar momentos de reflexión con los cuidadores, en tiempos y movimientos mediante los cuales aprenden sobre sí mismos y sobre la atención domiciliar.

Palabras Clave: Cuidadores; Servicios de Atención Domiciliar; Atención Domiciliar de Salud; Familia.

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INTRODUCTION

The pattern of health and disease of the Brazilian and worldwide populations undergoes several transformations, among which the epidemiological transition stands out, which change the profile of society with new demands for the health system.¹ To deal with these changes, it is necessary to build public policies appropriate to social and life context that meet the needs of users. In this sense, home care presents itself as a possibility of care in a new assistance model, but in which gaps need to be identified and analyzed to enhance the provision of services.²

In Brazil, home care services provided by the Unified Health System (UHS) within the scope of the Programa Melhor em Casa (Better at Home Program, in free translation) are governed by the Ministry of Health Ordinance No. 825, of April 2016, playing an important role in the health system, in urgency and emergency network and in the interface with primary care.³

It is important to mention that home care services have experienced a strong expansion in recent years and this growth is related to health needs.⁴ However, some aspects still need to be improved to overcome the challenges of the field, especially with regard to the participation of the caregiver and the family in this type of assistance.⁵ To be linked to the Better at Home Program, the user needs to have a caregiver responsible for home care.³

The caregiver can be formal, when performing a professional job and receives financial resources to perform this function, or informal, when unpaid, sometimes performing non-professional care, in which case, a family member, friend, neighbor.⁶ Home caregivers are mostly linked to the informal system. They interpret care as a mission, strengthened by the feelings they have for their family and friends.⁷

The caregiver is an essential subject for care at home, especially for users with multiple conditions of illness and high demand for care.⁸ Becoming a caregiver is a complex process that involves subjective and subjectivizing experiences.⁸ In general, the literature has presented the challenges for the caregiver at home^{5,7} with few productions that investigate the constitution of this caregiver.⁹

To understand this process of constituting the caregiver in home care, the theoretical contributions of Michel Foucault were adopted in this study. For Foucault, modern men are constituted as such in processes of subjectification and objectification, insofar as they establish their daily relationships, in which they live, produce and express themselves.

In the dynamics of formation, objectification and subjectification are complementary processes that culminate the first in disciplined individuals and the second, in subjects attached to an identity that is attributed to them.¹⁰ Thus, objectification refers to the view of the individual as an object, limited by time and historical space.¹¹ In this process, there are forces that strain toward the subjection to the standard established by norms and rules, by legislation, political and moral discourses that produce a certain way of seeing life.

Through subjectification, the individual ceases to be seen among other objects to become the subject of him/herself, insofar

as he/she is known and recognized by his/her own body, by his/her desires and his/her speeches.¹¹ This way of constituting him/herself as a subject is permeated by relationships with him/herself and with others, in a historical plot that allows men to assume, as their own, a certain identity produced by the combination of different knowledge-power strategies.¹²

With regard to the caregiver in home care (HC), his/her constitution as the subject responsible for care is a *sine qua non* condition for linking to the Home Care Service (HCS). In this context, it is particularly interesting to understand the subjective components of the constitution process, expressed in the strategies, speeches and relationships that are established in home care.

Other studies have been dedicated to analyzing the forces that strain toward the subjection of the caregiver, reflected by the objectification process.^{5,8,13} However, there are gaps in the elements that make up the process of subjectification, justifying the focus of this research in this dimension of the subject's constitution. This understanding can contribute to qualify this type of care by indicating the development of government actions, support and care practices for caregivers that operate as subjectivation devices.

Based on these theoretical-conceptual considerations, the present study had as its object the constitution of the caregiver subject in home care, seeking to identify the aspects that interfere in the constitution of this subject. The objective was to analyze the subjectification process of the caregiver subjects in home care.

METHOD

It is a qualitative research, as it makes it possible to understand the studied phenomena and extract, from the everyday context, the relationships with individuals in their environment and work and life process.¹⁴

The study took place in one of the Home Care Services linked to the Better at Home Program, in a large city in the State of Minas Gerais, Brazil. Intentionally, a team was included in the study, the only one in the city that exclusively attends users who have diagnoses and profiles that require long-term care, such as chronic obstructive pulmonary disease (COPD), neurological and degenerative disease (NDD) in respiratory support, for example mechanical ventilation, oxygen therapy or for bronchial hygiene.

Participants were identified at the time of insertion in the field, during visits with the team. In this analysis, the data of informal caregivers, users and professionals that make up the HCS team were considered. These participants were chosen because they constitute social individuals that interfere in the constitution of the subject and his/her identity. It is important to note that individuals are constituted through the establishment of relationships with themselves and with others.

The research was carried out in three distinct phases. In the first, the objective was to understand the performance and relationship of the team in the process of constituting the caregiver. To this end, home visits were carried out with the professionals to capture, through observations, the team's work with caregivers and users. This procedure lasted five months, followed 30 visits to 21 users, who were cared for by 26 informal caregivers.

Although the presence of formal caregivers was identified in this manuscript, the analysis was restricted to activities performed only by informal care. It is noteworthy that some users were accompanied by more than one caregiver. Attracting, admission, routine, discharge and post-death visits were observed.

Regarding caregivers, 20 were female and six were male, 20 were in the age group of 20 to 59 years old and six caregivers were elderly who provide care to other elderly users dependent on care for the Activities of Daily Living (ADL). The classification of users followed the model adopted in the service that employs Katz Index of Independence in Activities of Daily Living.¹⁵ This Index stratifies patients according to the level of dependence into independent, partially dependent or totally dependent. For the purposes of the study, the user's classification was considered as a criterion for the second and third phases allowing the inclusion of users with different degrees of dependence.

The data from this stage resulted in a total of 60 hours of field work, which were recorded in the Field Diary (FD) and are identified in this text with the code "field note", FD and date on which the visit took place, type visit and listed user. In this process, the focus of the observation record was the caregiver's relationship with the team, especially the way the caregivers received the guidance, participated in the actions during the visit and answered the professionals' demands.

The second phase of the research comprised the deepening of observations on the routine of caregivers at home. For this stage, four cases were chosen from those who received the highest number of visits in the first phase. We sought to include cases with different demands regarding the degree of dependence, as it is a factor that interferes in the intensity of care with implications for the caregiver.¹⁶ Thus, we included: a case of independent user diagnosed with hypoventilation due to chronic obstructive pulmonary disease (COPD); a case of partially dependent user diagnosed with COPD and Diabetes; two cases of dependent users with a diagnosis of amyotrophic lateral sclerosis and neurological disease (central pontine myelinolysis). Each user was assisted by two caregivers, totaling eight caregivers at this stage. Three home visits were made to each of the four users and their respective caregivers, totaling 36 hours of field work. The second phase visits were carried out by the researcher without the presence of the team. The data for this stage were identified by the Code: Observation note, FD and date when the visit took place; observed user and caregivers.

In the third phase, interviews were carried out with the six professionals followed in the first phase (a doctor, two nurses, a physical therapist, a speech therapist and an occupational therapist) and with seven of the eight caregivers included in the second phase, as there was a refusal by a caregiver. The interview was guided by a separate semi-structured script for professionals and caregivers. The questions to the professionals were aimed at understanding the relationship with the caregiver, also seeking to capture the perception about the caregiver constitution process in home care. The questions for caregivers inquired about what it means to be a caregiver, the processes and motivations to

assume the role, the time of experience, the types and form of learning of the activities performed and the support networks.

The interviews lasted an average of 11 minutes, totaling 138 minutes and 30 seconds. The time of each interview varied between the participants, being more productive among the caregivers who computed a time between 16 to 25 minutes of recording. The interview with the professionals was shorter and focused on the perception about the caregiver, with a variation between 06 and 22 minutes of recording.

The interviews were recorded in order to enable the formal capture of the discourse narrated on the theme, transcribed in full in a judicious manner, with the codification of meanings contained in the text to capture the oral language. In the transcriptions, the symbols were used: [...] to indicate partial transcription or elimination of content;::: to indicate lengthening of the speech and (+) to indicate every 0.5 second of pause or silence. The data for this stage are identified by the code "Interview" and the code of the interviewed professional or caregiver.

To ensure anonymity, when presenting the results, the study participants were coded. The professionals were given the letter I followed by a number, the caregivers were identified with the letter C followed by a number and the patients/users were coded with the letter U followed by a number. The researcher received the R coding.

Data analysis was guided from the perspective of the discourse presented in the studies of Michel Foucault. Foucault does not present a specific analysis technique, but establishes "clues" for discursive analytics, expressed through the guiding principles of discourse analysis: inversion, discontinuity, specificity and externality.¹⁷ The researcher's work aims to show how certain statements appear and are distributed within a certain discourse.¹⁸

It is important to mention that the discourse, for Foucault, must be interpreted seeking to reveal the historical-social perspective that involves the subject, the perspective of the things said, the appearances, the regularity, the events, as well as the unsaid, the excluded, the ignored, what was meant, the behind.¹⁷ The author also reminds that statements position subjects, whether those who produce them or those towards whom these statements are addressed.¹⁷

Based on the conceptual contributions and analytical principles proposed by Foucault, the data treatment process followed the organization of the material for the interpretation of the speeches. In this process, each corpus (from the reports of the observations and interviews) was read, seeking to identify the statements that referred to the central questions of the study.

A systematic for this analysis was built, using the text transcribed in Word, and pointing, in a side column, the elements of the discursive formation: object, space and relations. As for the discursive object, the representations and meanings attributed to the statements emerged. In relation to space, the social place occupied by the caregiver was identified and, in the relationships, the standardized conventions and networks for exchanging of feelings, affections and conflicts stood out. At the end, the

aggregation and segregation that the set of these elements pointed out was sought, forming the categories of this study.

The investigation respected the ethical precepts for research involving human beings, according to Resolution No. 466, of December 12, 2012, of the National Research Ethics Commission, with the participants signing the Free and Informed Consent Term. The project was approved by the Research Ethics Committee under process number CAAE 67123317.0.0000.5149 and opinion number 2.422.020.

RESULTS

Participated in the study caregivers who had the following degrees of kinship with the user: nine daughters, four wives, three mothers, three sons, two granddaughters, a nephew, a grandfather, a sister, a niece and a husband. Male caregivers (children, husband, grandfather and nephew) were responsible for independent users or were secondary caregivers. It was also observed that the caregivers lived in the same home as the users or very closely (sometimes, in the same lot). They were caregivers predominantly from middle, lower middle-class neighborhoods and who had an educational level up to high school. Only one caregiver had a college degree.

The findings showed that the constitution of the caregiver subject in home care is related to three different dimensions: psycho-affective, cognitive and moral.

Psycho-affective dimension: feelings in the constitution of the caregiver

The psycho-affective dimension in the constitution of the caregiver subject in home care is marked by values and expressions of fondness and affection, by the feelings of retribution, love, zeal, compassion, commitment and allegiance. Subjective experience, the parental/family, religious and social relationships are strongly associated with the psycho-affective dimension of caregivers and are present in statements that demonstrate the discursive object of care permeated by affection.

During the care, the caregiver shows affection: caresses the patient, praises, expresses concern for his/her well-being and his/her happiness (R on a routine visit with the team to U6).

Wow! I accompany him in everything, I help to take care of him [...] I became a minister, I went to the church after he was born with the disease. I have to thank and ask God. People seek the church for love or pain. In my case, it was due to pain (C18).

I love my dad so much, I keep kissing him all the time [...]. He was an excellent father, he lived to take care of the family, now we have to take care of him (C6).

During the visits, it was possible to witness disagreements between caregivers and users regarding the fulfillment of the

team's requests regarding care assistance or regarding the purchase of supplies and medicines for care.

Before entering the residence, I2 expresses that caregiver C17 does not agree with the patient's behavior. He expresses dissatisfaction with the habits of smoking and drinking. E2 reports that there is wear and tear in the family relationship and that the caregiver does not perform the oriented care, being more absent. During the visit, E5 explains: You need to go to the clinic to get the drugs. E2 asks: who gets the medicine for you? U17 answers: a 'child of God' or when I have about 20 reais I pay someone (R on a routine visit with the team to U15 and Caregiver C17 absent).

The team organizes the medications, surveys the consumed quantity and the need to obtain other medications that are getting to the end or that have ended. The nurse identifies the lack of an antihypertensive drug. The doctor asks the patient if anyone can go to the health center that day to pick it up. Someone needs to get this medicine today! If you don't have it at the health center, you need to go to the popular pharmacy, because there they also have it. Patient U4 says she will see if she can get someone to pick it up (R on a routine visit with the team to U4 and caregiver C4 absent).

In the team's representations, it is clear that the process of constituting the caregiver is related to their involvement with the user. When the caregiver does not have an affective relationship or when the act of caring is associated with the obligation, the training process can become painful and have implications for user assistance.

Many times, they become the main caregiver, despite how hard it is ... (I2).

The lack of a caregiver is an obstacle, a hindrance in the care process or even when the caregiver is there not by choice, but by necessity and doesn't have much of a care profile (I4).

When the relationship is based on more distant bonds or in a worn-out relationship, there is not necessarily an abdication of the performance of the function, but a distancing of the caregiver in the assistance is perceived.

Cognitive dimension: learning to be and becoming a caregiver

Becoming a caregiver is also associated with a cognitive dimension, related to learning the activities to be developed. Some attributions that were, until then, unknown, became part of the caregiver's daily routine at home. Therefore, it is necessary to adapt to this new reality, both on the part of the user and the relative caregiver.

The statements reveal that caregivers predominantly perform assisting care activities, which include changing wound dressings, checking vital data, aspirations, breathing maneuvers with the ambu mask, stimulating communicative skills, functional stimulation of swallowing, hygiene, user support in activities of daily living. In many situations, caregivers become responsible for daily activities, previously performed by the users themselves.

The caregiver would bathe the patient, but did not start, as the team arrived to make the visit. To perform the bath, the help of another person is necessary: a neighbor (R on a routine visit with the team to U5).

C26 takes a cup of coffee and takes the comb from the room. She comes back, combs the user's hair and makes a braid (R on a routine visit with the team to U1).

(+) she cut her nails, yeah::: she cut her hair, shaved, and I helped her in the bath, we put her on the chair, she would carry him to put on the chair and::: so, we went on. Every day I bathed him, changed everything appropriately (C6).

For some users, especially those with high physical, mental and technological dependence, as in the case of users using mechanical ventilation and continuous oxygen therapy, the demand for care is uninterrupted. The time of dedication, associated with the intensity of care, requires the appropriation by caregivers of care techniques and technologies, both in terms of language incorporation and operational performing. In this sense, informal caregivers learn to prepare and administer medications, perform dressings, proceed with endotracheal aspiration, requiring support and guidance from the team in the activities to be carried out.

I5: the fan is missing the memory card. I5 puts the card in the device: Will the device read what happened when it was missing the card? U8: I don't think it will read, it will only read what happened after inserting the card. C9: I think there should be no problem, as the parameters were changed in the previous week. In the evaluation of the card, you can see that the problem is not during the day, it is during the night, because there is volume during the day and it is bad at night. (R on a routine visit with the team to U8).

The nurse prepares the patient for the enema application, but the caregiver identifies that the patient needs to be aspirated. The nurse signals that she is going to proceed to aspiration, but C26 leaves the room and returns with two probes stating that she is able to aspirate herself. C26 performs the aspiration and the nurse asks if she is able to use the ambu mask. The caregiver says yes. (R on a complication visit with the team to U21).

Caregivers also perform a set of activities called indirect, as they are related to bills payment, ordering and withdrawing of medicines, equipment and materials, requests for assistance

and social services. These activities require time, organization and persistence on the part of the caregiver, as there is often an ignorance of the flow to be followed in order to be able to go through the health care network and social services. In this trajectory, the empowerment of caregivers who start to claim and fight for users' rights can occur, adding knowledge to themselves about the health and social assistance system. This finding is portrayed in the statements that follow, demonstrating the subject's position.

I go after the devices, the best ones for him. I seek medicine at the Health Secretariat,::: I seek medicine at the health center... what is really necessary... (C14)

As I said, it's not just him that I take care of. There are also other boys that I need to take to the doctors:::, tax, health secretariat; I'm running after the fan. I always have these breaks that I need to leave (C24)

Caregivers' learning and knowledge come from a constant process of transformation. Daily practice and team guidelines make it possible to discover new ways of conducting care and awareness of the user's conditions and needs. However, caregivers represent this process as arduous, and sometimes abrupt, thus accelerating the need to understand themselves as a subject in HC and to develop to assist the other.

So, there was no facility, every day is a new learning, a new way of working, of seeing how he will be, I think that is it (C19).

Look, because he was becoming incapacitated::: more and more incapacitated, because he had ALS, Amyotrophic Lateral Sclerosis. And he did so, missing the games, little by little. Before, he sat down, after he couldn't stand sitting anymore [...] he::: stopped::: taking a diet and::: it was like that, a process. And we learned, because he started to use the fan::: It was like this successively. Oxygen 24 hours, we had to know the right amount, we had to learn, just like we learn to move. [...] So, we will be::: learning, forcibly. And, after he was bedridden, there are those processes involving diapers, clothes, bathing and not letting the wound hurt (C7).

Aptitude is linked to the ability to care. In this condition, the speeches are made giving centrality to the I-caregiver subject who is the central character in everyday decisions. Caregivers define what they will do based on the knowledge acquired during the time of assistance and relational care for the user. This knowledge makes it possible to identify which actions generate pain, discomfort and acceptance by the user and which are decisive in their point of view.

From the perspective of the professionals, the learning process to become a home caregiver is revealed as a complex discourse object and established by a spiral relationship that

passes from anxiety and anguish, through the adaptation of the routine, culminating in the resignification of their doing and of the subjects themselves in the act of caring.

In fact, the time it ... takes away the anxiety of the new. For example, [...] the patient was sometimes at home, he was not careful, and when he comes back home, he is careful, he has ostomies, he has drains, he has stopped talking, he does not take a bath alone, he needs giving medicines. This new anguishes the family a lot, especially the family that has a bond [...]. But this, in the first, second week, is no longer new. Then, what remains is a heavy routine, the care routine... (15).

Technical accuracy, in a way of putting it, what has to be done, the person has more security to perform. Now, for sure, it brings tiredness, wear and tear, the situation is getting more and more prolonged. In general, we perceive these caregivers to be more worn-out, more tired (16).

I think it works as a curve: in the beginning it is very difficult, because it is a moment when the caregiver has to learn many things, many procedures, learn to personalize the house (14).

Moral dimension: the values and rules imposed by the historical and social context

The speeches express a feeling of social and moral obligation of caregivers due to the role played in home care. This moral dimension runs through the caregiver's constitution and conditions them to occupy a position that they accept, to return something that they consider obligated as a family member, especially wife and daughter.

The consequences of life, it puts things, every day::: I had to assume it, I had no way to run (C14).

For me it was so, magnificent! First because he was my father. So, it's rewarding. And::: it was very good, it is an experience, a great learning experience (C6).

Because, well, we always lived together. Everyone has always been together at home, everyone has had a rough time and everyone in the family was always together. I think even more now. It's the same thing. Now it's a problem that is happening to him, I think the whole family is supporting him (C19).

The role played by wives, daughters, grandfather, granddaughters, is added to a new relationship and position: that of caregiver. The wife and daughter play this role through the contractual relationship, the fulfilled promise to stay together, to take care of each other.

He is my father, he always worked to take care of the family, and today it is the family that helps him. So, for me

it was so, magnificent, first because he was my father, you know. So it's rewarding, and::: it was very good, it's an experience, a great learning experience (C7).

It is because like this, we have always lived together, everyone has always been united at home, everyone has had a hard time and everyone in the family was always together. I think nothing else now, is the same, right, now it's a problem that is happening to him, I think the whole family is supporting him (C19).

The moral dimension is permeated by explicit and latent disputes and conflicts in the face of moral codes. Taking on the role of caregiver results from a natural and subjective feeling, through the relationship with oneself, which determines how the individual is constituted as the subject of his/her own actions. In this process, he/she carries a moral code that is expressed in the socially constructed obligation to be a caregiver imposed by the responsibility to care for the relative's illness.

R: And::: what motivated you to take on this care? C14: (+) Wanting to see him well, always improving (+), with all the treatment he has today, good medicines, good devices (C14).

For being a wife, right ... For me, it's easy, it's a way like this::: to::: help him, so that he doesn't get too depressed, that he doesn't feel alone (C7).

The constitution of the caregiver's identity is marked by his/her mode of existence and the ability to care. The caregiver is represented as a central agent and guide for the production of care, leaving its mark in the enunciation mode. In this process, the caregiver incorporates and appropriates his/her function and position, assuming the identity of the being and the possibilities of metamorphoses, of the becoming a caregiver.

I took care, helped to take care of my mother. In fact, it was me alone who took care of my mother, from being her private driver, from hand feeding, changing diapers, until she got better (C25).

Because I already take care of special children::: that I take care of at home [...]. So, I sometimes call someone to be with the boys that I take care of to have a little bit of time and space. And, I take care of him, because I prefer to take care of him myself (C24).

The caregiver's identity can be provoked by the conviction built by family experiences and the family's social value. The position assumed in the family, in this case, by wife or daughter, has as a consequence a responsibility for the care of family members. Thus, there is a discursive relation of acclimation in the process of being a caregiver that follows the moralization of the way of being.

DISCUSSION

The act of being a caregiver is a process that is related to the psycho-affective, cognitive and moral dimension.

The **psycho-affective dimension** is represented by the feelings experienced by caregivers who change in the face of the care process. Physical proximity and affective condition are conditions that determine the fact of assuming the role of caregiver.¹⁹ The affection established between caregiver and user is represented by the gratification of the duty accomplished.²⁰

The feelings that were reported by the caregivers, such as compassion, happiness, solidarity, love and motivation are linked to the process of retribution in relation to the rewarding experiences of caring for someone from whom they have received care in previous moments of life.²¹ In this process, the feelings of love and involvement soften the care path, however, they did not eliminate the difficulties and interference related to it.

Physical proximity and degree of kinship are also factors that make up the psycho-affective dimension.²⁰ Women are responsible for playing the role of caregiver, meeting certain rules regarding the duty to maintain, protect and help the family.²²

The distance and omission in the assistance by the caregiver was verified. It is inferred that in these situations, the most distant bonds or the worn-out relationship are due to existing conflicts that could not be captured in depth during this study. Although there was disagreement in the opinions and conduct between caregivers and users, there was no evidence of abdication in the exercise of the care function.

The activities performed by caregivers have direct implications for user assistance. To this end, caregivers need support, both to help in the learning of assignments and to prevent and manage their own suffering and exhaustion.²³

It is reinforced the understanding that the subject suffers interference from the truth regimes to which he/she is exposed to, but also, it is a product of his/her own history.²⁴ Thus, although caregivers are influenced by socially determined constructions, these do not affect everyone in the same way. The actions and relationships established between caregivers and users are distinct and are linked to the construction established between them, in their families and in their daily relationships.

The **cognitive dimension** focuses on learning the caregiver's techniques and functions. The most common activities performed by caregivers are related to the administration of medication, hygiene, food, locomotion, therapies, meal preparation, cleaning the house, washing and ironing clothes, and even outside the home. Other studies corroborate this finding.^{17,25} Among the members of the HC team, the nurse's central position is emphasized, with a responsibility to promote health education for users, family and caregivers, including the training of these caregivers.²⁶

The caregiver's learning occurred in the middle of his/her constitution process, unexpectedly, abruptly or progressively. This made it possible to show anguish, fear and frustrations due to the lack of experience. The findings indicate that training is a

moment of modification of the subject, in an attempt to break with the feelings that generate insecurity when seeking to develop competence to assume this responsibility as a caregiver.^{6,20}

Most of the time, learning becomes difficult due to the inexperience of the caregiver to meet the demands that arise during the care process and that need to be learned in the coping with everyday life.²⁷ It is important to note that the majority of caregivers do not abdicate or withdraw their responsibility for the function of caring due to inexperience. However, the fact that they are "forced to act" without knowledge and help is stressful and frustrating, requiring support from the team to expand knowledge and reinforce the cognitive dimension linked to the constitution of the caregiver subject in HC.²⁰

The results indicate that the learning process to become caregiver at home is complex and established by a spiral relationship, due to its continuity and its possibility of reframing. The initial moment is permeated by anxiety and anguish, due to the new reality composed of routines and actions previously not performed or unknown. The new phase is related to adaptation to the routine, to the procedures. At this time, caregivers feel safer to perform care, although there is no reduction in physical and psychological overload. The third phase concerns a new reality constituted by the established transcendence of the overlapping and re-signification of the constructed moments, by means of the contraposition, the contradiction of conflicting elements and the new understanding of the role as caregiver.

The **moral dimension** also affects the caregiver's constitution. Morality makes it possible to understand the dynamics of social relations and the way the individual behaves in the face of rules and values, thus establishing judgment about their actions and behaviors.²⁸

Social constructions interfere with family behavior and practices. There is, on the one hand, the production of ideal behaviors and, on the other, the indication of a life of full freedom, without attachments or subjection to the norms that imply in life management and that tend to "[...] install a system of individualization that is designed to model each individual and manage their existence".^{29:30} In the overlapping of these two plans, the constitution of the subjects is a process that confronts the singular, individualizing experiences, with the collective social norms, being, therefore, a moral act in which the "behaviors are real attitudes of the individuals in face of the moral prescriptions that are imposed".^{30:618} In the relation with the other, this moral act is based on a contract model dictated by the moral codes that determine which acts are authorized or not and which have positive or negative value in relation to attitudes.³⁰

From the above, the moral dimension of the constitution of the caregiver reflects the contract established with the user in parental relationships and in the bond established throughout life and facing the process of illness and dependence on care.

In the study, it was also possible to analyze resignation and conformity, intertwined with love and the obligation to care for others as expressions of the caregivers' constitutive plans. The condition

of caregiver also seems to obey the socially established norms of solidarity²⁷ and the feeling of contract between the parties, being necessary to comply with the determined clauses.

The way in which the individual is constituted as a moral subject is related to the modes of subjectification, that is, the forms of relationship with his/her own self.³¹ The practices that allow the subject to transform his/her own being were explained in this analysis. The expression of the subjectified subject occurs through criticism and reflection in the face of established norms or escapes from moral codes, rising to self-care, which was not possible to present in this text.

In view of this analysis, it is clear that the caregiver is characterized by the process of subjectification and is constituted by truths that shape and dictate conduct and morals. Subjectification is the result of the subjects' positionings, facing the rules that determine what is true and what is false, what is right and what is wrong.

It is essential to recognize the centrality of the caregiver in home care. In addition to taking responsibility for care actions, these individuals are affected by an intense and complex load of feelings and direct the way care will be carried out in daily life, disputing this production amid subjective and subjectivizing experiences.^{5,8}

It is necessary to affirm that it is pertinent to carry out future works covering other types of team, caregivers and users, as well as expanding the number of participants. It is recognized that the results obtained may have been influenced by the organizational circumstances of the studied team and the profile of the caregivers and users included in the study. The small number of caregivers participating in the in-depth analysis can also be considered a limiting aspect.

FINAL CONSIDERATIONS

It is concluded that the constitution of the caregiver subject in home care is crossed by subjectivation processes revealed by three dimensions: psycho-affective, cognitive and moral. The psycho-affective dimension is built by coexistence, bonds, proximity, identity and aptitude. Through it, it was possible to understand that the greater the involvement, the more productive the constitution relation of the caregiver.

The second dimension is centered on the cognitive, on continuous and progressive learning to deal with the demands and needs of the user. The user goes through phases and the caregiver is transformed in this path, in a constant learning and relearning.

Finally, the subjectivation of the caregiver is marked by a moral conduct in which the role is assumed by the imposition and subjection to what is expected of this subject in the established social relations, especially in the family hierarchy and social composition. In this case, morality is based on the ways of conducting life, in the relationship with oneself and in the constitution of being oneself as a subject who has as principle certain ways of living, which includes assuming the role of caring for the other and performing this role with resignation, surrender and gratitude.

It is concluded that the caregiver's subjectivation derives from the relationship of their own self, constructed in the way they were related to the speeches, with the power relations, with the experiences that affected them and led to the affective acceptance process, through the moral and emotional commitment due to the transformations that enabled the formation, understanding and performance of the caregiver role.

Among the implications of the study, the appropriation of the findings by the team, especially by the nurses who are central to the internationally recognized HC, stands out. It is also up to these professionals to educate caregivers and support them in the identification and/or creation of partnership networks. Together with the team, the nurse must provide moments of reflection with the caregivers, establishing times and movements so that experiences can emerge through which they learn about who they are, their position and their value in care in HC.

AUTHOR'S CONTRIBUTION

Study design. Acquisition, data analysis and interpretation of results. Writing of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and the integrity of the published article. Yara Cardoso Silva. Study design. Data analysis and interpretation of results. Critical review of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and the integrity of the published article. Kênia Lara Silva

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REFERENCES

1. Saito DYT, Zoboli ELCP. Palliative care and primary health care: scoping review. *Rev Bioet.* 2015;23(3):593-607. <http://dx.doi.org/10.1590/1983-80422015233096>.
2. Burns E, Nair S. New horizons in care home medicine. *Age Ageing.* 2014;43(1):2-7. <http://dx.doi.org/10.1093/ageing/agt186>. PMID:24334750.
3. Portaria n. 825, de 25 de abril de 2016 (BR). Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde e atualiza as equipes habilitadas. *Diário Oficial da União, Brasília (DF)*, 25 abr. 2016.
4. Procópio LCR, Seixas CT, Avellar RS, Silva KL, Santos MLM. Atenção Domiciliar no âmbito do Sistema Único de Saúde: desafios e potencialidades. *Saúde Debate.* 2019;43(121):592-604. <http://dx.doi.org/10.1590/0103-1104201912123>.
5. Silva YC, Silva KL, Brito MJM. Relações de poder na atenção domiciliar: tensões e contradições entre profissionais, usuários e cuidadores. *Rev Enferm UFPE.* 2018;12(4):897-907. <http://dx.doi.org/10.5205/1981-8963-v12i4a110272p897-907-2018>.
6. Pilapil M, Coletti DJ, Rabey C, Delaet D. Caring for the caregiver: supporting families of youth with special health care needs. *Curr Probl Pediatr Adolesc Health Care.* 2017;47(8):190-9. <http://dx.doi.org/10.1016/j.cppeds.2017.07.003>. PMID:28803827.
7. Benson JJ, Parker Oliver D, Demiris G, Washington K. Accounts of family conflict in home hospice care: the central role of autonomy for informal caregiver. *J Fam Nurs.* 2019;25(2):190-218. <http://dx.doi.org/10.1177/1074840719828091>. PMID:30773970.
8. Silva, YC, Silva K. Relações de poder estabelecidas na atenção domiciliar entre cuidadores e profissionais. *Rev Bras Aten Dom.* 2017;3(3):1-141.

9. Ribeiro BF, Oliveira SG, Tristão FSA, Santos-Júnior JRG, Farias TA. Práticas de si de cuidadores familiares na atenção domiciliar. *Rev Cuid*. 2017;8(3):1809-25. <http://dx.doi.org/10.15649/cuidarte.v8i3.429>.
10. Foucault M. *Ética, sexualidade, política*. Rio de Janeiro: Forense Universitária; 2006.
11. Foucault M. *A arqueologia do saber*. Rio de Janeiro: Forense Universitária; 2007.
12. Candiotti C. *Foucault e a crítica da verdade*. Curitiba: Champagnat: Autêntica; 2013.
13. Freitas IBA, Meneghel SN, Selli L. A construção do cuidado pela equipe de saúde e o cuidador em um programa de atenção domiciliar ao acamado em Porto Alegre (RS, Brasil). *Cien Saude Colet*. 2011;16(1):301-10. <http://dx.doi.org/10.1590/S1413-81232011000100032>. PMID:21180837.
14. Minayo MCS. *Pesquisa social: teoria, método e criatividade*. Petrópolis: Vozes; 2016.
15. The Hartford Institute for Geriatric Nursing. *Katz Index of Independence in Activities of Daily Living (ADL)*. New York; 2005.
16. Hajek A, König HH. Informal caregiving and subjective well-being: evidence of a population-based longitudinal study of older adults in Germany. *J Am Med Dir Assoc*. 2016;17(4):300-5. <http://dx.doi.org/10.1016/j.jamda.2015.10.015>. PMID:26705001.
17. Foucault M. A ordem do discurso: aula inaugural no Collège de France, pronunciada em 2 de dezembro de 1970. São Paulo: Edições Loyola; 2013.
18. Fischer RMB. Foucault e a análise do discurso em educação. *Cad Pesqui*. 2001;(114):197-223. <http://dx.doi.org/10.1590/S0100-15742001000300009>.
19. Dixe MACR, Teixeira LFC, Areosa TJTCC, Frontini RC, Peralta TJA, Querido AIF. Needs and skills of informal caregivers to care for a dependent person: a cross-sectional study. *BMC Geriatr*. 2019;19(1):255. <http://dx.doi.org/10.1186/s12877-019-1274-0>. PMID:31533637.
20. Bove DG, Zakrisson AB, Midtgaard J, Lomborg K, Overgaard D. Undefined and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *J Clin Nurs*. 2016 fev;25(3-4):483-93. <http://dx.doi.org/10.1111/jocn.13076>. PMID:26818373.
21. Gomes MLP, Silva JCB, Batista EC. Escutando quem cuida: quando o cuidado afeta a saúde do cuidador em saúde mental. *Rev Psicol Saúde*. 2018;10(1):3-17. <http://dx.doi.org/10.20435/pssa.v10i1.530>.
22. Isaac L, Ferreira CR, Ximenes VS. Cuidar de idosos: um assunto de mulher? *Est Inter Psicol*. 2018;9(1):108-25. <http://dx.doi.org/10.5433/2236-6407.2018v9n1p108>.
23. Stall NM, Kim SJ, Hardacre KA, Shah PS, Straus SE, Bronskill SE et al. Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: a systematic review. *J Am Geriatr Soc*. 2019 mar;67(3):609-17. <http://dx.doi.org/10.1111/jgs.15690>. PMID:30536383.
24. Foucault M. *A hermenêutica do sujeito*. São Paulo: Martins Fontes; 2011.
25. Guerra HS, Almeida NAM, Souza MR, Minamisava R. A sobrecarga do cuidador domiciliar. *Rev Bras Promoç Saúd*. 2017;30(2):179-86. <http://dx.doi.org/10.5020/18061230.2017.p179>.
26. Andrade AM, Castro EAB, Brito MJM, Braga PP, Silva KL. Prática da enfermeira na atenção domiciliar: o cuidado mediado pela reflexividade. *Rev Bras Enferm*. 2019;72(4):956-63. <http://dx.doi.org/10.1590/0034-7167-2018-0431>. PMID:31432952.
27. Almeida LPB, Menezes TMO, Freitas AVS, Pedreira LC. Características sociais e demográficas de idosos cuidadores e motivos para cuidar da pessoa idosa em domicílio. *Rev Min de Enferm*. 2018;22:1-7. <http://www.dx.doi.org/10.5935/1415-2762.20180004>.
28. Dreyfus H, Rabinow P. *Michel Foucault: uma trajetória filosófica*. Rio de Janeiro: Forense Universitária; 1984.
29. Revel J. *Michel Foucault: conceitos essenciais*. São Carlos: Claraluz; 2005.
30. Foucault M. *Ditos e escritos IV: ética, estratégia, poder-saber*. Paris: Gallimard; 1994. 618 p.
31. Deleuze G. *Foucault*. São Paulo: Brasiliense; 1988.