Being A Caregiver In Home Care: Choosing Between The Duty And The Moral Desire Of Taking Care

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Abstract

Background: to analyze the process of development of the caregiver in a home care program, focusing on the attributes, feeling and needs of those individuals.

Methods: regarding our method, we made use of a qualitative research, which has been carried out at the Home Care Service of Belo Horizonte. The data has been collected through interviews performed with all the 7 caregivers and 6 healthcare practitioners. All the info has been analyzed under the scope of the the discourse analysis research method.

Results: the caregiver acts with his/her heart, he/she listens and looks very carefully and attentively. Care is characterized by an intense and permanent process of conflict between the duty due to the assigned functions and the moral desire of taking care of other human beings. Those two dimensions can be expressed sometimes by affection, gratitude and solidarity, but, in other times, it is guided by duty, resulting in work overload and concerns that make the caregiver unique in his/her moral condition.

Conclusion: the person in charge of being a caregiver finds himself/herself surrounded by feelings and responsibilities, in a heavy load of relationships that are shaped by the subjective and subjectifying experiences, which makes critical the implementation of supportive social networks to aid the caregivers.

keywords: Caregiver; Home Care Services; Home Care.

Background

Brazil is experiencing the epidemiological transition via the changes in the standard of morbimortality, which can be characterized by several factors. This country is undergoing the decrease of acute and infectious diseases and an increase in the number of chronic disorders and external causes, not to mention an increase in life expectancy. In this connection, Home Care arises as one of the caring options.

The incentive of Home Care happened by means of a need of new public health strategies that sought effective actions in the face of the scenario that took place in the 20th century. The home care service aims to restructure the work process, focusing on providing care for people in their own homes. Home Care contributes a lot with the health system, but it still needs to be refined in order to overcome all the field challenges, especially regarding the participation of the caregiver and also referred to the profile of the population, predominantly of elderly people. Caring in home care is supported by an informal caring system model⁽¹⁾. And this informal system has, as one of its characteristics, the fulfillment of non-professionalized caring, done by relatives and friends, pro bono, for the execution of the activities⁽²⁾. Following this line of thought, caregivers interpret caring as a mission, which is strengthened by the feelings of the relatives^(1;3).

Generally, the dedication to the role of being a caregiver is related to a parental bond that is sometimes carried out by women due to the fact of the institution of the predetermined social structure, in which she

is responsible for taking care of her relatives and also for all the housework, besides the role that they play in being affective with her beloved ones⁽⁴⁾.

Linked to this relationship, there are feelings and needs that interfere in the formation of the caregiver. Taking care of someone can be referred to a complex process, constituted of several reactions, feelings that are sometimes, contradictory. So, what are the mandatory feelings and strategies in order to keep the integrity of the caregiver?

In the face of such aspects, the goals of this paper are to understand the constitution of the caregiver in providing care in home care, also identifying the attributes, feelings and needs involved in this process.

Methods

This article was supported by a qualitative research method that allowed us to comprehend the social phenomena, extracting from the day-to-day context the relationships with the individuals in their work/living environment/process⁽⁵⁾.

We have performed this research at the Home Care Service, linked to the “Melhor em Casa”, Better at Home Program, in a city located in the metropolitan region of Belo Horizonte, in the state of Minas Gerais, Brazil. A team has been chosen out of 12 staff that were able to provide home care, and they had a profile of caring patients that presented diagnoses that required long-term care, like Chronic Obstructive Pulmonary Disease, Degenerative Nerve Disease, under ventilatory support, like mechanical ventilation, oxygen therapy or aiming bronchial hygiene therapy. The data collection took place between the 8th of February, 2018 and June, 4th, 2018, having as responsible for all the collection, interviews, the authors of this study, for having extensive research experience acquired throughout the training.

To understand the context and setting, a meeting was held with the coordination of the program. Afterwards, the field insertion was performed and, consequently, the identification of the study participants. In the initial visit to each family, the professionals presented the researcher and the purpose of the study.

We have chosen the interviewing method to collect data. It has been carried out interviews with 6 healthcare practitioners and 7 caregivers in order to understand the feelings, experiences and perceptions that lie behind the condition of caring. The interviews were guided by an open and non-structured guideline. The guideline of the interview with the healthcare practitioners and the caregivers had questions related to the life of the caregiver, his/her feelings, perceptions and the context of home care. The criteria that was chosen to include those practitioners took into account the participation of at least one interviewed person, from each active labor category at Home Care Service, with the inclusion of: 1 doctor, 2 nurses, 1 physiotherapist, 1 phonoaudiologist and 1 occupational therapist. Eight caregivers were invited for the interviews. The selection of the caregivers took into consideration the participation in a previous step of this research, in which there had been the analysis of the home care scenarios. There has been a non-compliance, having being documented, therefore, the participation of 7 caregivers (6 who

worked casually and 1, in formal work) in the interviews. The empirical data has been classified according to a code: Interview and Type of professional, patient or caregiver that has been interviewed. It determined as a saturation criterion the inclusion of users with different assistance profiles and dependence for daily life and instrumental activity.

The interviews had an average length of 11 minutes and a total amount of 64 hours and 23 minutes of recording. They have been entirely recorded and transcribed in order to allow the formal documentation of the narrated speech about the topic. In the transcription process, it has been developed the codification of meanings that were in the text due to improve the understanding of the oral language. In order to indicate the partial transcriptions of the removal of an excerpt, we have made use of the character “[...]”; in the moments of lengthening, we made use of the following symbols – “:::”; and finally, when there were pauses and moments of silence, we made use of “(+)” for every 0.5 second. No, if applied, data analysis management programs. The study will be returned to the service and participants.

To assure the anonymity of the participants, they were classified according to codes. The health practitioners were classified with the letter E and also a number (for example, E1 up to E6); and the caregivers were identified with the letter C and a number, being classified, thus, from C1 to C29. From these, eight caregivers were invited for the interviews (C7, C9), (C16, C29), (C18) and (C22, C27). However, the caregiver 1 refused to be interviewed, thus totaling 7 interviews with the caregivers.

The analysis of the data has been supported by the discourse analysis framework, mainly based on the works by Michel Foucault. We sought to capture the perspective of what has been said, what meant to be said, what was behind those discourses, its constitution, its differences⁽⁶⁾. Besides that, the analysis aimed to clarify the principles of inversion that sought to understand the negative configuration of the excerpt and the rarefaction of the discourse, the discontinuity to capture what can be ignored, intertwined or even excluded, which is specificity, because it is on the everyday measures that the events and its exteriority, manifestation and regularity can be captured⁽⁷⁾.

The ethical precepts applied in this research were complied according to Resolution No. 466, from December, 12th, 2012, having the participants signed the Informed Consent Form. The project has been approved by the ethics committee of the Federal University of Minas Gerais: Certificate of Compliance of Ethics No. 67123317.0.0000.5149 and Approval Number: 2.422.020.

Results

Caregiver: assignments, feelings and needs of becoming a home care professional

The individual who is a caregiver is considered a person who is capable of overcoming obstacles, of breaking the untimeliness of everyday life when it comes to being a caregiver, besides absorbing the demands and changes.

As a caregiver, this person makes use of his/her mental capacity and habilities on behalf of other people, kindly, sympathetically and tolerantly. In moments like that, the caregiver acts with empathy, with his/her "heart opened", expressing concern, accountability and compassion regarding other people.

O:: first of all, everything we do is with love, and love teaches us, it encourages us, it improves us. Every thing that has love on it perseveres, we learn things, we keep learning throughout days, hours, minutes and seconds. (Interview C8).

É:: I feel very useful here, so I don't know if she is satisfied with me, right? But those things that I know how to do, I'll do with all the love from my heart. (Interview C16).

As a home care professional, it is mandatory to listen actively and tenderly in order to capture the needs, fears, wills and feelings of the patients. Connected to this process of listening to others, it is necessary to speak in order to report the professionals the expressions, looks and discourses of the patients. Active listening also allows the understanding of the patients' griefs, in a process of empathy, of feeling his/her needs and seeking to relieve them.

That person, the caregiver, also suffers because of the patient's griefs, either physically, through pain, fears, sadness and the absence of relatives and beloved ones that are so crucial for the patients. Even because the patients are mainly elderly people and handicapped ones. This lack or absence of family support leads to work overload for the caregiver. However, it also causes sadness because that professional is able to perceive the discouragement of the patient in terms of the lack of affection, communication and interaction with family members.

Being a caregiver is being a companion for the person, it means exchanging life experiences with him or her, right? :: it means to exchange feelings, to place yourself on the other person's shoes and :: their needs, right? [...] Then, you are able to tell the health professionals what you have heard or lived. (Interview C22)

That's because you see, you hear with your heart all that atmosphere of grief and pain and you do not see, for example, a solution, you see? And then you get worried and sad. (Interview C28)

So, the person gets upset on his/her birthday, on Christmas [...] I also get upset, [...] and the pain and grief of the patient, the fear of him/her getting hurt, of doing the wrong things, we end up feeling that pain too. You establish a bond, love, when you see the person crying, you cry too, when the person is in pain, you can feel it too. (Interview C16)

The caregiver must analyze the situation very carefully, like through the eyes of an eagle, to assist the patient precisely, accurately, all the time. There is a constant monitoring of the patient. The caregiver who possesses the eyes of an eagle is very cautious and strategic, besides having as focus the normalization of the patient's acts, so that he/she follows the preestablished rules and orders. That sharp and controlling look also intends to know the patient, to capture his/her needs and desires. It has to be emphasized that there is some reluctance by the patients concerning that monitoring and, consequently, regarding the impositions, driving to tension in care.

So, in order to handle the patient correctly, something always happens, he/she complains about pains and we were also hurting them, right? There is also that bedsore, so we know that he/she also feels a lot of pain. (Interview C27)

Taking care of him/her, taking him/her to the doctor, paying attention to how to give him/her the medications, being always aware of what he/she needs, right? (Interview C17)

All of the caring processes are associated to making decisions and applying measures. The caregiver is an active individual who seeks to solve the demands, someone who gives his/her best so that the care process can be accomplished entirely. It means to act responsibly.

It is :: enthusiasm, you know? The forces that he/she gathers, you see? Doing like that I have wills, I can do it, I seek it, I look for what is necessary for all the cares. (Interview C27)

The duties of the caregiver seem simple at first glance. However, when you look carefully, it is possible to realize that there are several feelings that inter-connect that care process and that lead to insecurity in the care process. This feeling of insecurity is sometimes associated to the lack of knowledge, which compromises the fulfillment of that task.

C28: Well! Actually, it is :: all you can see, it is :: even a matter of the need, itself, right? So, sometimes, something that you are not too skilfull to do, but even though you do it because of the need of doing it, in the beginning with some difficulties, and then you assimilate and you keep doing, somehow, even well, you see?

P: Yeah, I do.

C28: And the more time passes, the more you get familiarized with things, with situations, with the difficulties, and you keep trying to do it better, you see?

C28: There was nothing I did not know. So, even due to the experiences iself and :: living with other people too :: the struggle of being aware of :: the symptomatology of the diseases. (Interview C28)

C27: So, thus, the emotional side of those things are very important, right? I have many difficulties regarding this, the emotional side. [...] it was very sudden, fast. (Interview C27)

Being a caregiver and its moral dimensions

Home care is strongly characterized by the moral dimension. The discourses express the feeling of social and moral obligation of the caregivers due to their roles that are represented in home care.

To me, it was, like that, magnificent, first of all because he was my father, right? So, it is satisfying, and :: it was really good, it is an experience, it is such an enormous lesson. (Interview C9)

That's because, like, for example, we have always lived together, everybody has always been so connected at home, everybody has already experienced very bad moments and they were always gathered as a family. I think that nothing else now is the same thing, right? Now it is a problem that he is having, I think that the whole family is supporting. (Interview C22)

Most of times, unfortunately, it is still the daughter, or the wife, it is just another imposition. Generally, is... generally it is who was available to provide all the care, when it comes to children, it is almost always the mother, in the case of the domicile, the husband, the man that gets sick generally will demand care from the wife or daughter, when it comes to the mother, it is generally the daughter. (Interview E4)

It can be observed, in those narratives, the feeling of obligation attached to the role played by wives, daughters, granddaughters, of taking care of their relatives. In parallel, the wife plays this role through the contractual relationship, for the promise made of always being together, of taking care of each other.

Caregivers, in the face of the moral codes, explain that becoming people who provide home care comes from a natural and subjective feeling, bonded to the commitment, built throughout years of family coexistence. But they also carry the moral obligation, or the burden of the cohabitation agreements established during the relationship with the patient.

The partners generally take care due to obligation, a result of the marriage agreement and also because of the kids, who take place in the family. The reasons for doing so are feelings of affection, gratitude, solidarity or a moral duty, an obligation, a desire of repaying, the desire of getting back the same care.

A:: being a caregiver, above all, means to have all responsibility, all affection, all goodwill with people you take care of, right? Because the person that suffers from the difficulties of the disease, and then you have to be there just in time for everything, at every moment, to do things the best and possible way we can and also to help the person. In my case, there is something even more special due to the fact that he is my son. (Interview C28)

That kind of medical care drives to an increase in costs with health services, which, in general, are associated to feelings and sensations that coexist in a duality between the duty of taking care of the patient or the obligation of providing financial resources for his/her care. There is also the obligation of the caregiver of always being physically and emotionally well in order to do all the activities for and with the patient.

Look, he retired due to disability because :: he just couldn't walk anymore, he was already on a wheelchair. So, he used to receive a minimum wage, but I used to work, I used to make snacks/savories, dear girl, we used to make all of that at home, right? and :: and that's how we have been surviving. And there were some people that sometimes donated something, right? Sometimes a friend, a priest who was an acquaintance of ours, but it wasn't like, you know, something regular, in which every day there was something to eat :: sometimes, but God blessed us, so we endured everything, throughout all these years. It has been :: well :: saving, here at home we used to use like that, spending money with cleaning supplies and food and :: an EXTREME saving in order to not let something lack for him, and he died in a scenario

in which nothing really lacked in terms of food here at home. And I could donate many things that I still had, because we used to buy a lot, with great abundance. Every month I used to do, I received his paycheck and called there to :: bo (Name of the company) and I ordered things. (Interview, C9)

It can be observed, from that excerpt, that the caregiver has, indeed, some time to take care of herself/himself. When the caregiver works under the labor laws, there is a predetermined amount of time to perform all the caring tasks, thus having an established schedule to dedicate to all activities. This could turn caring into something less exhausting, with the possibility of having some time to rest and take turns of the responsibilities of the job. On the other hand, the caregivers who work casually, without all the labor rights, lack in psychological structure and time to dedicate to themselves regarding private issues and activities.

Oh, I do help :: (+), I always check her blood sugar, I dyed her hair, I help her, sometimes, to get dressed in some occasions when she can't do it by herself (+) What else? ::, I make her food, I prepare, I :: take care of her dirty laundry, right? Hygiene. Even today I helped her to take a shower, to wash her hair, to comb it, so :: I cut off her nails, that kind of stuff. I arrive early in the morning and I leave at 6 PM during the week. (Interview C16).

Their background cause impacts and turnarounds in the lives of caregivers in terms of social, psychological, emotional and physical/functional aspects. The main indications of the degree of work overload are related to the conditions of the cared patient in the presence of dependence, comorbidities, various diagnoses that are physically handicapping, besides the existence of another sick individuals or those people that demand care and attention, at their homes, and the troubled behavior of the patient. The caregivers also mentioned the fact that they lived with the patient and needed to sleepover at his/her house, not to mention when they carried out something outside their own homes. Care cannot be detached from the background knowledge and life of the caregiver.

He is also a boring person, that annoys you, who perhaps, the, the patients have chronic conditions and their situations are not prolonged and there is also their family background, our background, most part of the caregivers, they are family members and they sometimes have this concern that many times the family is too big and the work overload is passed to a single person, or to two people, and it causes family argues, right? (Interview E6)

So it's that constant monitoring, so it is like this:: it's 24 hours a day right here, all the time paying attention, you see? So, it is not something that you do and then let it go, of having some privacy, it is always paying attention at it, do you understand? And every day there is a new request, it is a different grief. Then it is always a struggle with yourself for being there, every day looking to:: minimize the suffering, do you understand? (Interview – C16)

Therefore, there is a need of sharing the care with other caregivers. Even in the face of work overload, it can be observed that daily cares revolve around a minimum family circle (wife, daughter, nephew, parents, niece, granddaughter) and that other relatives occasionally help in that care when they pay visits to the

patients and when they have time or free time to take care of the relative (son-in-law, sister-in-law, brother, son).

P: It is:: and besides the multidisciplinary care team, are there other persons able to help you? C27: Yes, my nephew, my mother-in-law, my father-in-law, it is:: my sisters-in-law when they come to visit us, right? Everybody helps a little bit. (Interview C27)

So, I should be more integrated to my kids, but, in practice:: practice is not quite my case, but I don't, I don't, I don't complain, I don't complain, because I do what I am supposed to do, and I always do my best. But everyone has their duties, like in, in::/ they should have the feeling of being able to be next to the other person, right? (Interview – C28)

Discussion

The initial phase of home care is very tense, because it represents a moment of adaptation to the rules, to the diagnosis, to the new life scenario that will impact the life of the caregiver/family member. The communication and monitoring done by the multidisciplinary care team are important constituents for the maintenance of all the stimuli of feelings, like well-being, to improve the quality of care, for comfort, satisfaction, among all the individuals involved⁽⁸⁾.

Taking that role is something associated to the social pressure, to the compliance to rules, duties and the mission ⁽⁹⁾ of taking care of the elder or of the family member.

Background knowledge and experience lead to more security when performing care.⁽³⁾ Having some knowledge about the process of the disease, the patient's conditions and the treatment allow the comprehension of the implications of such process and the inclusion of its role as caregiver⁽⁸⁾. Although, a study showed that 70% of caregivers did not have previous knowledge on the care process that should be applied to the patient. Linked to this scenario, it can also be observed that 40% of the caregivers work on their own and that 16.7% of them cannot count on some health infrastructure. It is important to emphasize that the secondary caregiver helps a lot to reduce the work overload, despite he or she does not take for themselves the same level of responsibility and decision-making⁽¹⁰⁾.

Playing the role of caregiver leads to work overload and worrying. In this context, it is necessary to think of strategies that are capable of providing the caregiver some time to dedicate to himself/herself, his/her body and soul, which involved physical exercises, spiritual care, some time off duty and measures to diminish the mental and body burnout⁽¹¹⁾.

It has also been noticed that in everyday life the caregiver is affected by feelings of fear, anxiety, joy and expectation. A study revealed that one third of the caregivers presented symptoms of depression, with many associated determinants, like the severity of the illness, behavioral disorders, which include dementia, increase or boosting of dependence of the patient on instrumental and basic Activities of Daily Living⁽¹²⁾. Those factors are a very feasible combination of factors that lead to an increase on the tension

linked to the execution of care for patients, which causes a feeling of desperation, rage, guilt and isolation of social activities. An investigation points out that 68% of informal caregivers present the Burnout Syndrome – professional fatigue due to the stress that is experienced. This condition causes severe consequences for the individual's health, emanating from the loss of quality of life and the physical, psychological and social well-being⁽¹³⁾. Besides the work overload of activities performed by the caregiver, there is also the emotional grieve, because the caregivers tend to neglect their own needs on behalf of the patient⁽¹⁴⁾. Even when the caregivers reported that they felt a satisfaction due to their roles, it has been observed that this is a very difficult and tough experience⁽¹⁰⁾.

When they become exclusively busy because of the person they are taking care of, there is an abdication of himself/herself, as well as the incompleteness of subjecting himself/herself because of the lack of physical exercises for his/her own sake⁽¹⁵⁾, making room for the increase in work overload and number of negative thoughts in the care process.

Thus, it is constantly and endlessly necessary to take care of himself/herself, of having some time for himself/herself, of knowing thyself, for the existence of a balance in the relationship between the surrounding world and the individual, with his/her relationships with the other person, being such practices crucial for the process of subjectification⁽¹⁵⁾.

The occupation of caregiver is exhausting due to the abdication of the self, the restriction of his/her private and social life and the decrease on the quality of life, besides the increase in the number of obligations⁽¹⁶⁾.

Therefore, it is mandatory the existence of intervention of health institutions in order to assure the quality of life of the caregiver, once the support provided by social media needs to be taken by the society⁽⁸⁾.

The financial aspects of home care have an implication on the constitution of the individual who is a caregiver. Thus, the financial support, as well as aids in terms of health services and social network of aid are factors that reduce the anguish of the caregiver in collaborating with the cares for the patient.

The findings of this research reveal that the caregiver always faces changes in all the several aspects of life, such as family, personal and social ones, which results from the assignment as caregiver. He or she experiences ambiguous grieves, because the family member ends up assuming the role as a caregiver. Taking that function for himself/herself is related to the moral and social obligations, to the legal duty, the proximal and sentimental relationship between the caregiver and the patient⁽¹⁷⁻¹⁹⁾.

The relationships and feelings that are built evoke, in the individual, the duty of repaying something, or of reciprocity, which results from the feeling of obligation and of human behaviors. Regarding the moral issue, the assistive provision of care ends up being connected to social judgment. In the structured moral sense, it tends to assign women the role of taking care⁽¹⁹⁾.

The presence of the moral feeling of the caregiver is guided to the social obligation on behalf of the patient because he/she is a family member, something that encompasses the responsibility, the duty and the need. The legal matter can be found on the established Constitution of our Republic, in which when kids are minors, his/her parents must assist and take care of them, and the adult kids must take care and assist their parents⁽²⁰⁾.

Reciprocity and affection are also topics that arise on choosing the caregiver to play that role⁽¹⁸⁾.

The confluence between the moral obligation of taking for himself/herself the caring of the family member and the “noble” feeling of helping, supporting, corroborating the fact that self-satisfaction and the well-being of the caregiver, when feeling useful and noble, provides strength and motivation so that they can move on and fulfill the same assignments⁽²⁰⁾. In this scenario, there is the abdication of himself/herself and self-abnegation, which leads to physical and psychological fatigue for the caregiver. This relationship takes place simultaneously with the feeling of peace of mind when taking care of someone close or not⁽¹⁷⁾, which indicates that the caregiver lives in a permanent dilemma between the obligation and the moral desire of taking care of someone.

Conclusion

We have concluded that being a caregiver in home care is an occupation surrounded by an intense and complex load of relationships, feelings and responsibilities, conformed by his/her subjective and subjecting experiences. On Home Care, the transformation of the individual takes place through the situation, by means of the circumstances, mainly because of the fact of the disease is a situation that cannot sometimes be controlled and is something unconceivable by human beings. However, for the individual to become a caregiver, it is necessary to exist interest, desire and will to apprehend, to help other persons, resilience.

It has been observed that the caregiver presents the following characteristics in his/her actions: listening, transmission of actions and self-fulfillment for doing so. When taking for himself/herself all the care process for the patient, this individual acts through his/her heart in a quest for wise actions by working with compassion, but in a precise way, by inspecting through monitoring and surveillance the patient's actions, as well as to control his/her reluctance. Another important issue is having an active listening to capture the patient's needs, fears, desires and feelings, as well as it is crucial to understand all the effective discourse of the patient in order to transmit all the necessary information to the staff. Finally, the caregivers must act by putting the actions in practice to take care of the patient.

The care process is surrounded by duties that might cause the deterioration of the quality of life, lack of time to take care of himself/herself. As a sort of aid, the caregivers attach themselves to spirituality as a source of learning, strength and transcendency. Thus, it is extremely important the implementation of social networks of mutual support for those caregivers. The ways by which the health teams capture,

decipher and include those experiences in their practices determine the intensity of the unique production of caring.

Declarations

Ethics approval and consent to participate: No. 67123317.0.0000.5149 and Approval Number: 2.422.020.

Consent for publication: All participants of this research signed the Informed Consent Form.

Availability of data and material: The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests: has no competing interests

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Kênia Lara Silva: Type of participation: conception, planning, critical intellectual review, final approval for publication.

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