

# About caring and being cared for in home care

## *Sobre o cuidar e o ser cuidado na atenção domiciliar*

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**ABSTRACT** The purpose of this article is to highlight experiences of caring and being cared of and present the perspective of family caregivers about a Home Care Service. It is a case study that applies the cartography as *ethos* in the research field to capture experiences during home visits and the interviews with five caregivers. The empirical research analysis used Cutting Plans, of which Visibility Plans were applied as for reflexivity exercise. Otherness lived by caregivers and their responsibility overload are some expressions captured in the field of research that reveals the need to associate health services with social support services.

**KEYWORDS** Home care services. Home nursing. Caregivers. Homemaker services.

**RESUMO** *O objetivo deste artigo é evidenciar experiências do cuidar e ser cuidado e apresentar a visão de cuidadores familiares sobre um Serviço de Atenção Domiciliar. É um estudo de caso que aplica a cartografia como ethos no campo de pesquisa para captar as experiências durante as visitas domiciliares e entrevistas com cinco cuidadoras. Para análise da dimensão empírica, foram eleitos Planos de Corte e, dentro destes, Planos de Visibilidade para exercício da reflexividade. A alteridade vivida pelos cuidadores e a sobrecarga de responsabilidades são algumas expressões captadas no campo de pesquisa que indicam a necessidade de associar serviços de saúde a serviços de apoio sociais.*

**PALAVRAS-CHAVE** *Serviços de assistência domiciliar. Assistência domiciliar. Cuidadores. Serviços domésticos.*

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## Introduction

The dependence of long-term care in the home environment and the dedication of caregivers to these dependents people have been studied by several researchers, that reveal the various difficulties associated with caring, an activity that is almost always exercised in a solitary way.

Research reveals that from 83.1% (GAIOLI; FUREGATO; SANTOS, 2012) to 93,4% of the caregivers are women (FELGAR, 2004). From the research of Karsch (2004), conducted in the early 1990s, there is the realization that caregivers are at home, caring for their dependents, with little or no guidance and, in their majority, they are alone in caring tasks.

According to Cruz *et al.* (2010), Muniz *et al.* (2016) and Gutierrez, Fernandes and Mascarenhas (2017), among the difficulties listed by caregivers are family conflicts, societal demand, ignorance about pathologies that affect the patient and techniques inherent to care, lack of patient collaboration, lack of economic resources, among other setbacks raised in relation to the world of care.

Felgar (2004) revealed that 39.6% of the caregivers questioned in their research reported feelings of helplessness and related this feeling to the illness of the patient.

In much of the world, people are getting older and, even with the whole framework of information about the best way to maintain health for longer or the quality of life, the time comes when we need to be cared for by other people, who, in most cultures, are family or friends.

The caregiver assumes, therefore, responsibility for home care that would be performed by the health team if the sick person dependent on long-term care was hospitalized. Thus, home care as a care model enables the care to be performed in a known space, with affective meaning for the sick person and which minimally preserves some autonomy of the sick patient (LACERDA, 2010).

For Agich (2008, P. 32-33, FREE TRANSLATION), autonomy is “irremediably dependent of the context”. The author considers that to try to develop a definition of autonomy one must take as a starting point an ethical and practical analysis of long-term care, considering that autonomy is a significant cultural ideal. Autonomy is related to independence, which contrasts with long-term care, because the person who depends on this type of care feels vulnerable to this condition of dependence, “he is seen as a burden, as a less complete person” (AGICH, 2008, P. 40, FREE TRANSLATION).

If we reflect about our human condition, we will realize how vulnerable we are, since we are often exposed to various types of danger: danger of becoming ill, being beaten, failing, dying. Living humanly means, therefore, living in vulnerability (ROSELLÓ, 2009). As one character from Guimarães Rosa (2001, P. 33, FREE TRANSLATION) would say, in an anthological phrase of the book ‘Grande Sertão Veredas’: “living is very dangerous”.

For Butler (2006), vulnerability is a condition of our being in the world, it is an original vulnerability to the other. For Roselló (2009), vulnerability means fragility, precariousness and we experience it personally and collectively.

One possibility of health service organization that collaborates to preserve the autonomy of the person dependent on long-term care and experiences close to human vulnerability is home care.

In Brazil, home care has been part, since August 2011, of the Urgency and Emergency Network (RUE) under the heading ‘Better at Home Program’ and is currently regulated by Administrative Rule GM/MS nº 825 of April 25, 2016. In the referred program, home care is considered a

modality of health care integrated to the Health Care Networks (RAS), with actions

of prevention, treatment of diseases, rehabilitation, palliation and health promotion, provided at home. (BRASIL, 2016, P. 33).

It is developed through the Home Care Service (SAD) and consists of Multidisciplinary Home Care Teams (Emad) and Multidisciplinary Support Teams (Emap). The program understands as

caregiver person(s), with or without family bond with the user, able to assist him/her in his/her daily life needs and activities and depending on the functional and clinical condition of the user, in home care. (BRASIL, 2016, P. 33).

As criteria for admission to SAD, the sick person should be bedridden, need assistance at least once a week and have a responsible caregiver daily.

The Better at Home Program organizes home care at three levels: Home Care Type 1 (AD1) for low complexity chronic patients, who should be followed once a month by professionals from the basic units of the Basic Attention Network (RAB); AD2 for patients of medium complexity, requiring weekly follow-up of SAD; and AD3 for patients with greater complexity and needs, receiving SAD assistance more frequently (BRASIL, 2016).

The home visits carried out by the SAD intend to evaluate the degree of dependence of the patient and the capacity of the caregiver for the necessary care, preliminary conditions for admission to the program, as well as having as attribution to accompany the person dependent on long-term care until reaching discharge of the program for cure, hospitalization or death.

Professionals of the home care services find, often, people in vulnerable situations, who, many times, are unaware that they are being neglected or violated by others. They are people, most of them

elderly, who live realities that demand actions of social service intervention and, sometimes, justice action to protect their fundamental human rights.

To meet the needs coming mainly from the elderly population, in developed countries, it can be seen, in addition to home health services (Home Care), the existence of social support services at home, which offer a range of services such as meals, cleaning, shopping delivery service, bath assistance; respite care, i.e., caregiver to cover the respite period of the main caregiver; nursing service; remote monitoring; among others (GENET, 2011).

Another innovation in home and health services and social services was made in Japan and is based on a bank of hours system in which volunteers earn 'time credits' to care for older people in their community. Volunteers can use credits to buy similar services for themselves, later in life or present, for their frail elderly relatives living in another remote city, or for other people in need (HAYASHI, 2011).

In this research, the aim was to understand the care process developed by an SAD of a medium-sized municipality in the state of São Paulo, in which the relations of SAD with the other RAS services were verified. More specifically, the relationships between the services that make up the RUE with hospitals, Emergency Care Units (UPA), Emergency Rooms and RAB were analyzed.

And, in addition to the issues of organization and planning of home care under the Unified Health System (SUS), it was highlighted, in the research, the encounter with the sick patients, users of SAD, as well as the experience of care taken by family-caregivers.

Therefore, the purpose of this article is to evidence experiences of caring and being cared for and presenting the vision of family caregivers about an SAD.

## Methodological pathway

This research is a case study of a SAD of a medium-sized municipality in the state of São Paulo, with a population estimated for 2015 of 233.249 inhabitants and a territorial area of 1.136.907 km<sup>2</sup> (SEADE, 2017). The name of the municipality was omitted to preserve the identity of the professionals involved in the research and the letter 'N' was adopted as a reference to the municipality.

The home care service in the municipality N began its activities in 1997 as a Home Hospitalization Program (PID). In mid-2002, it was renamed the Home Care Program (PAD) and, at the end of 2012, it was qualified as SAD of the 'Better at Home Program', with two Emad and one Emap enabled, dividing the municipal territory into two large regions.

In this qualitative study, a 'cartographic *ethos*' was adopted throughout the research route. In cartography, the data are produced from the observation of daily actions, the monitoring of work processes and the interpersonal relationships that are involved in the production of care. This relationship between the researcher or the cartographer and the subjects of the study produces, according to Melucci (2005, p. 329, FREE TRANSLATION), "modifications in the field", which are interventions that "provoke cognitive transformations due to the circulation of ideas that it introduces".

This article reports scenes registered during home visits by the professionals of the SAD and transcriptions of recordings of the interviews with five caregivers of patients assisted by the service.

Field work occurred in the period from 1/15/2015 to 8/6/2015, once a week, eight hours a day, and the scenes experienced in the field were recorded in field diaries in the form of narratives, resulting in the empirical material of the study.

For the selection of the caregivers to be

interviewed, spreadsheets were adopted to consolidate the information of all the patients served by the SAD, which includes the names of patients and caregivers, addresses and contact telephones. Caregivers were selected from ten patients with different pathologies and degrees of dependence and admitted to SAD for periods ranging from one month to five years. After telephone contact with caregivers of these patients, five caregivers agreed to grant an interview, which were scheduled at different days and times.

The interviews with the caregivers were carried out with the intention of knowing the vision about SAD and its experiences. In these interviews, the life experiences narrated by caregivers in the care process were valued, taking as reference three guidelines:

The interview aims not at the speech 'about' the experience but rather experience 'in' speech; the interview intervenes in openness to the experience of the process of saying; the interview seeks the plurality of voices. (TEDESCO; SADE; CALIMAN, 2013, P. 304, FREE TRANSLATION).

Each caregiver was asked to talk about how she had known about SAD; the waiting time to receive the first visit at home; the frequency of visits; the evaluation about the SAD; as well as suggestions for improving care. Also, it was considered important to know if the caregivers have some free time for rest and leisure and what the impacts of the activity on their lives.

At the end of the interviews, the experience of each caregiver illuminated aspects about home care considered very important to complement and enrich the observations in the accompaniment of the teams.

As a data analysis strategy, the first approximation was the definition of Cutting Plans, for a first systematization of the empirical material. In this sense, an

extensive reading of the recorded scenes and the transcriptions of the interviews recordings was carried out.

As the field journals were read and the interview transcribed, certain Cutting Plans were defined, which corresponded to a large extent to the aspects present in the recommendations and guidelines of the Home Care Policy, having as guidelines the objectives proposed in the research.

From these options, four Cutting Plans resulted: (i) The frame of the municipal management and the limits of the management; (ii) Production of the team; (iii) The binomial patient-caregiver; and (iv) SAD in attention networks.

This reading movement, effectuated countless times, which cut scenes and speeches of the interviewees and placed them in 'boxes' of the type file-folders, organized in the word processing program Word®, corresponded to the Cutting Plans, resulting in the first analytical approximation of the empirical. Of the Cutting Plans presented in this article, it's interesting to deepen the 'binomial patient-caregiver'.

In the second analytical approach, more expressive Visibility Plans were evident within the Cutting Plans.

The Visibility Plans result from the analysis of registered scenes that have some relation to each other, and that, when connected, reveal important elements of the daily work of the team that are not always visible when 'looked at from the outside'. The 'Plans' gain visibility from 'scene connections' that show inter-human relationships and their intensities, which, at the end, result in health care or internal relationships with the staff or the family.

For the Cutting Plan 'The binomial patient-caregiver', the Visibility Plans were identified: (i) 'The universe of the loss of autonomy: the bedridden', presenting the encounter with human vulnerability and the reality of the loss of autonomy of people in bed; (ii) 'The universe of the

caregiver', in which the experience of the people who care for others is seen; and (iii) 'The point of view of the caregiver', which presents the voice of caregivers of SAD users, making it possible to know what they think about this service and the health services network, as well as the impact of caregiving on their lives.

This research was approved by the Research Ethics Committee of the Federal University of São Paulo (Unifesp) under the number CAAE 39179014.0.0000.5505 and opinion nº 907.048 of 12/16/2014, in compliance with the requirements of Resolution nº 466/12 of the National Health Council. The participants of the research, when invited, were given a first explanation of the research procedures and, then, proceeded to the reading of the Informed Consent Form (ICF). After agreeing to participate, they signed two copies of the Form, remaining the first copy with the researcher and the second copy with the participant.

It is emphasized that the names used in describing the scenes for caregivers and patients are fictitious in order to preserve their identity.

## Results and discussion

In the Visibility Plan (i) 'The universe of the loss of autonomy: the bedridden', different social and human realities are present facing the same problem – the disease, which requires long-term care. The registered scenes reveal the meeting of the SAD team with human vulnerability in some extreme situations experienced by people, mostly elderly people, dependent on long-term care caused by chronic and degenerative diseases.

The scenes chosen to compose this Visibility Plan are examples of several types of vulnerabilities perceived in the different contexts of illness.

In the case reported below, the patient has remained alone in her home, even needing help to make a dressing, among other demands. The SAD admitted her because a niece said she was her caregiver and the intention was to find this ‘caregiver’ to make her aware that the patient cannot remain alone, besides raising possibilities to solve this situation.

*We went to Mrs. Rita's the house, 84 years old; she lives alone and has a varicose ulcer in her right lower limb, which limits her movements by remaining with her bandaged leg. The wound is extensive and purulent. The nursing assistant (D) and Enfa. (H) make the dressing. Mrs. Rita is repetitive in the conversation and forgetful of the present moments. In the house there is a gentleman who is cutting the bush in the yard; he is a neighbor. The niece did not attend the meeting previously scheduled by the social worker (R). Arrives, passing in front of the house, a lady known by Mrs. Rita, who enters the house and, after understanding who we are, provides a phone number for (R), which belongs to another niece of Mrs. Rita. (R) tried cell phone contact with this niece, who hung up the phone in the middle of the subject. (R) talks to Mrs. Rita, calmly, trying to explain that she cannot be alone at home and needs someone to do dressing and care for her. During the conversation, she learns that Mrs. Rita ‘helps’ with money the niece enrolled as a caregiver. The team will know the conditions of life of the patient and notes that, in the kitchen, there are only rice, beans and corn meal to eat; there are many rotten potatoes in a fruit bowl and the refrigerator is empty. In the tank, there were several crepe bands to wash and dirty clothes. The person known who had come in to speak with us promised to prepare lunch that morning for Mrs. Rita and see if, in the Health Apostolate, someone could come daily to change the dressing. We said goodbye. [The scene was recorded on 01/15/2015].*

In the situation experienced, there is a clear neglect of care, solitude and financial exploitation, that is, ethical, social and cultural vulnerabilities.

Ethical vulnerability, from the philosophical point of view, refers to the moral duty to protect the most fragile and depreciable individual. In Lévinas's view quoted by Roselló (2009, p. 63, FREE TRANSLATION), “to suffer for another is to care for him, to support him, to be in his place, to consume yourself for him”. Social vulnerability is characterized by isolation, lack of protection; in this case, the elderly was also economically exploited. Cultural vulnerability refers to ignorance and unawareness about a particular knowledge, in this case, the disease, its implications and care.

A possibility of response to better follow-up of the vulnerable population is the Family Health Strategy (FHS) model, which increases coverage in the Brazilian municipalities, because these health units are closer to the population due to their care model (BRASIL, 2017). Another possibility that collaborates to the reduction of vulnerabilities is the social awareness of the Statute of the Elderly, published in the form of Law nº 10.741 of 10/01/2003, which regulates the rights of persons aged 60 and over (BRASIL, 2003). It is a protective legislation, which has been in application since its publication, although it is still far from being effective, because it needs greater dissemination in society and greater social mobilization to force necessary changes and investments in social transformation projects.

In the next scene, there is a ‘cry for help’ with a request for day-to-day nursing care at home.

*We arrived of Carlos' home, carrier of Amyotrophic Lateral Sclerosis (ALS), for a socio-economic evaluation. It is a process that was conducted in the Public Prosecution and resulted*

*in a family-friendly injunction, determining to the Municipal Secretariat of Health the provision of nursing care at home daily. The Social Assistant of the SAD went there to make a social evaluation determined by the legal counsel of the Health Secretariat.*

*The action was requested by the wife and caregiver who claims to have no more physical and psychological conditions to take care of Carlos, because it's been already eight years of dedication.*

*Carlos is a young man, around 45 years old, is lying in a hospital bed in a dark room, because he did not want light. He is thin and with signs of paralysis of the lower limbs. The house, inherited from his parents, is simple and next to it runs a hairdressing salon, where his sister works. Until a week before the visit, the patient was living in his apartment, but due to the difficulty of transporting him to the bathroom, the family decided to build a room in the parents' house, because there is more space and the bathroom door is wider, allowing a bath chair to pass through it.*

*It is perceived so much suffering, many deprivations caused by the patient's illness; the wife is visibly worn and depressed. As she answered the social questionnaire, we realized that it was the only way this woman could see, mainly because she lived under strict economic control, counting only on a pension and the help of her teenage daughter, who works during the day and studies at night. Still, they pay a Unimed plan to insure Carlos's physiotherapy twice a week. The rest, she appeals to the SUS at the BHU, where she gets diapers and medication.*

*The social assistant (R), after listening to the demands and motives of the caregiver, explained that the determination of the injunction may be delayed due to lack of staff in the city hall, but did discount the possibility of the state sending an employee to enforce the judicial determination. We said goodbye and we were devastated by the situation. [The scene was recorded on 01/15/2015].*

As in so many other cases, the lack of support from the health sector overwhelms the family in relation to care. Many judicial proceedings occur due to family despair with the lack of effective support to caregivers, as there are no home social support services, such as those identified by Genet (2011).

The possibility of other forms of home care, with tax-supported or voluntary caregivers, is an experience that has been used in a number of developed countries, such as Japan and England (HAYASHI, 2011).

Here also arises the question of the arrangements organized by the population to achieve health care needs, such as the use of the complementary health system for physiotherapy and the physician of the Basic Health Unit (BHU) for other demands, configuring the 'care maps' of Cecílio, Carapinheiro and Andrezza (2014).

During that visit, the caregiver described the patient's irritation and suffering behavior with the disease situation, causing a feeling of impotence. One wonders what goes on in the head of a person who has been facing the evolution of a chronic disease for eight years.

The awareness of 'being sick', according to Caretta and Petrini (1998), is happening according to the limitations that arise during the disease process, and this awareness is painful, not only physically, by the loss of functional capacities, since is accompanied by a complex and deep pain that arises from the growing awareness of his/her condition, as masterfully described by León Tosltói in one of his best known novels, 'The Death of Ivan Ilyitch', written in 1886, which was analyzed by Cecílio (2009).

It is the pain of a person who, at some point in life, must suspend their expectations in the future and face the reality of suffering, which is burdened by fear of disease and its evolution, fear for the future of the family, concern for the

economic the family, in short, are many sufferings that need to be worked out internally by the patient. Each person, then, gives a meaning to their illness (CARETTA; PETRINI, 1998).

Faced with the meanings that the sick person adopts for the disease, he/she uses certain behaviors as defense mechanisms to deal with it. According to Caretta and Petrini (1998), they can be behaviors of denial of the disease; concealment; division, when you now agree with the fact, now disagree; projection, which attributes the disease to other things, such as remedies etc.; regression, infantilizing; complacency, which makes one become a victim; submission, which makes one become extremely obedient to medical conduct; rationalization, which allows us to adapt to reality; and depression. These behaviors may be attenuated by the improvement of the disease's condition until it disappears, when there is a cure.

In addition, for people who are close to death, the emotional state can vary progressively, alternating between fear and hope, states of denial of illness, anger, negotiation with doctors or family members, depression and acceptance (CARETTA; PETRINI, 1998).

In the next scene, there is another way of facing the suffering of total dependence:

*We arrived in another house, a very worn and dirty place. Who answers the door is Ivo, who, later, I understood that he is the husband and caregiver of the patient Luiza. We entered a dark and very disorganized house. We climbed a narrow staircase and came to an isolated room. There we find Luiza, 42 years old, lying in a hospital bed, very thin, with nasoenteral tube for feeding, her eyes half open and dyspneic, with a little pulmonary secretion. Ivo says he went to Santa Casa and the doctor said Luiza might need a tracheostomy, but the caregiver demonstrates his knowledge of the technique and knows that Luiza's case is irreversible and he wants to avoid it. He also tells*

*Dr. (K) about the gastrostomy that should be done at the Santa Casa and that he's waiting for the appointment by the team. He is excited because he knows that this facility can improve Luiza's nutrition condition. Ivo says he's wiping Luiza's eyes, that she cannot see anymore, but thinks she still sees shapes. As he goes telling us he talks to her too: - Isn't that right Luiza?! He says that gastric reflux has improved with the use of Domperidone, which he used increasing the dose, also, to resolve abdominal distension and intestinal constipation. He says: - She shat a lot, I was quite happy! [Laughs]. [...]. I ask how long Luiza had fallen ill and he answered: - It's been nine years since she started with a knee pain, she went to the orthopedist, did tests, everything was fine. Then it got worse, she went to the neurologist, did tomography and from then on, she began to have the mobility compromised and she's been bedridden for three years. He also tells us that the disease is present in her family. [...] As we left the room and went down the stairs, we found one of the daughters, the oldest; she was in the kitchen washing dishes. A beautiful young woman who was very like her mother. I thought Luiza must have been a very beautiful young woman before she fell ill. [The scene was recorded on 04/06/2015].*

When this family was known, it was amazing the way the caregiver husband related to his wife. The caregiver communicated all the time with the patient, aphasic, making the connection with the doctor and the nursing staff with a joy that was contagious.

In the narrated situation, the relationship between the caregiver husband and the sick and completely dependent wife revealed the existence of an autonomy preserved in their human dignity and integrity, principles that are also part of autonomy, according to Agich (2008, p. 32, OUR EMPHASIS):

Autonomy is considered equivalent to freedom, whether positive or negative, in



the sense of Isaiah Berlin (1969, p. 118-172, FREE TRANSLATION), to self-rule, to self-determination, to freedom of will, 'to dignity, to integrity', to individuality, to independence, to responsibility and to self-knowledge [...].

In fact, disease, considering common sense, removes the freedom of the person, withdraws its autonomy, limits its achievements and, especially, when there is pain, leads to the perception of the fragility implicit in the human being. This experience naturally frightens us with the evolution of aging, but it is present throughout the course of life.

In this sense, looking at the experience of Ivo and Luíza, it is observed that the disease process is faced more lightly when the sick person feels accompanied and considered by a caregiver who expresses affection, respect and closeness, attitudes of both caregiver and of the patient when they accept suffering and face pain with a sense. And this posture can give them greater inner freedom.

According to Viktor Frankl (1999, p. 76, FREE TRANSLATION):

In the last resort, living means nothing more than bearing responsibility for responding adequately to the questions of life, for fulfilling the tasks of life for each individual, for fulfilling the exigency of the moment.

The view of Frankl (1999) is shared, because it is quite concrete; the exigency of the moment to which it refers comes accompanied by a sense of existence that is singular for each person. Therefore, no destiny can be compared with another, it is not repeated, because each experience must give an answer.

Continuing with the thinking of Frankl (1999, p. 77, FREE TRANSLATION) to enter into the dynamic of the sense of suffering, which, sometimes, makes no sense to outsiders.

When a man discovers that his destiny has reserved him suffering, he must also see in this suffering a task of his own, unique and original. Even in the face of suffering, one must conquer the awareness that it is unique and exclusive in the whole cosmos within this destiny suffered. No one can take fate from it, and no one can replace the person in suffering. But the way in which he himself suffers this suffering is also the possibility of a unique and singular fulfillment.

Even with this proposition in front of life, it is very important that there is social support that gives the necessary support in facing the most difficult moments.

In the Visibility Plan (ii) 'The universe of the caregiver', it was found that, in most families, care is taken by a woman – daughter, wife, mother, sister, niece –, often, alone in this activity, generating changes in various aspects of life. In this survey, 83% of caregivers are women.

*We went to the home of an elderly lady, Mrs. Maria, 80 years old, she had a stroke eight years ago and has serious sequelae. She is taken care of by one of her nine children, single, around 45 years old and he does not work to take care of her mother. Worried about a rash that has come up on his mother's hip, he asks Enfa. (H) to take a look at it, (H) who decides to ask for an evaluation by the morning doctor. I ask the caregiver if someone helps him in the routine and he answers resigned that his sisters work; so, there is no help. After the visit, in the car, the assistant (D) comments: - 'Well! A mother takes care of ten children, but ten children do not care for a mother!' - she says indignantly of the situation of the caregiver doing the care alone. [The scene was recorded on 01/15/2015].*

[...]

*In the caregivers group, at the end, I*

approached an old man and started a conversation. It was Mr. Raul, about 75 years old, caregiver of his ex-wife. He said the children do not want to take care of their mother; at the most they take her by car to the doctor. He thinks the kids do it because she's always been very authoritarian. I tried to listen to him. He told of his routine, that he sleeps little at night, because his ex-wife often wakes up. She has been a smoker all her life and now depends on oxygen, she sleeps seated and coughs a lot. He gets up at 5 o'clock because she keeps calling to help her in the shower and after giving her breakfast, he can nap a little [...]. [The scene was recorded on 01/29/2015].

In the two cases narrated above, care is performed by men, which is not common. Like other caregivers, they face some isolation or loneliness in relation to the tasks of care and seem to conform to the situation, as if it were a mission to be fulfilled.

Another aspect identified in one of the scenes is the reality that many older people are under the care of other elderly people, as seen in several other scenes. As in many other developed countries, our population is aging rapidly.

In this sense, it's mentioned the example of Japan, which, because of a large elderly population, came across a long-term care problem. The coverage of health services was provided by the health insurance system, but it did not meet all the demands of caregivers. Thus, they innovated with a care socialization system, creating a mutual aid network to supplement LTCI (Long Term Care Insurance) (HAYASHI, 2011).

It is understood that reality will require the taking of new paths, with the adoption of models of innovative social support services that will serve the diverse conceptions of home care.

Here's another experience:

*Yes! Sometimes our boundary is not so much*

*physical but psychological, of being there and not be able to do anything. Of hearing the groan, the scream and not being able to help! Sometimes, the only thing we can do is send a message up there, God! [...]*

*We are walking, moving, taking things! He's not! He's still, without moving! This is my greatest suffering! [...].* [The scene was recorded on 04/02/2015].

In the narrative above, the caregiver raises two aspects. The first is the inexplicable experience of suffering, which has altered the itinerary of personal and family life, which makes it recognize the vulnerability of the sick husband and give a metaphysical meaning to suffering, that is, seek in the faith in God the strength to support herself and support her patient.

The second aspect involves alterity, the interpersonal dimension, which places the center of life not in the Self, but in the Thou. Thus, the actions, the thoughts are out of the person, living the radical opening to the other. It indicates that "caring for someone is, therefore, not only to be physically with someone, but to be-with-him, in the most existential sense of the term" (ROSELLÓ, 2009, P. 136, FREE TRANSLATION).

The experience of otherness as '*ethos*' of care is part of an ideal care for every human being and is the expected attitude of a caregiver, health professionals and community precisely because it is implicit a singular, unique care.

But, when experiencing this encounter with the caregiver, it is also noted in her speech her solitude in the caring process, as well as in the narrated scenes of the encounter with other caregivers.

Again, this feeling of isolation shows up, a sense of being alone in the daily struggle, and precisely because of this, effective and real collaboration among the people of the community, such as volunteers, health professionals and family members is fundamental in this caring process.

It ends with the Visibility Plan (iii) – ‘The point of view of the caregiver’, in which the voice of the caregivers of the user patients of the SAD emerges through the interviews, enabling them to know what they think about the service and the service network the impact of caring on their lives.

Regarding the waiting time for home care, caregivers reported:

*It did not take long, I think not even a week! It did not take long, nothing, they already came! They were a doctor and three nurses! [Transcript of interview with caregiver Gina on 06/23/2015].*

[...]

*Because she [the patient] has the doctor who attends her [private], but to come home is expensive! Then I went there on a Wednesday, and on Friday they already came! [...] they came twice with the doctor and after more than a month the physiotherapist came. [Transcript of interview with the caregiver Rosa on 10/09/2015].*

In the reports on the waiting time between the request and the first visit of the SAD, it is clear that the teams seek to make the appointments viable quickly. The division of the teams between the different professionals is emphasized, being more frequent the work of the nursing team with the doctor or the isolated action of the nursing team, as well as the physiotherapists, who frequently act in a secondary visit. Somehow, this way of operating indicates not a team work, but a work by specialty, and may result in an inadequate response to the health needs of the target population.

Another issue emerged in one of the statements relates to the composition of ‘care maps’, as proposed by Cecílio, Carapinheiro and Andrezza (2014), when there is the finding that the visit of a

private doctor is economically unfeasible and the way to solve the problem is triggering the SAD, which is a SUS service.

Regarding the quality of care, caregivers have different opinions:

*Rosa: Look! I'll tell you about the team, the doctor, the nurses; I found the service excellent. But I do not know about the physiotherapist. Ah! I found her kind of weak, I do not know why she took so long to come! Ah! She was withdrawn! [...] but if I had been waiting, if I had not had the initiative to pay [physiotherapist], maybe my mother was not walking yet! Isn't it? Because the other one I paid, she came with the ball, you know, and the one from the City Hall did not! It was just like that! Very weak! [...] The doctor and the nurses are gracious! That was 10! [...]. [Transcript of interview with the caregiver Rosa on 10/09/2015].*

In the narrative, there are strong criticisms regarding the physiotherapy service and appreciation of the performance of nursing and medical teams. It seems that quality is evaluated by observing the technical commitment, interpersonal relationship, the use of appropriate materials and the supply of consumption materials, points that influence the conditions of care, clinical evolution of the patient and establishment of bonds.

The expenses with materials, diets and medications are high, a burden on the family budget, making it imperative to search for resources offered by the health system for free, as well as the need for creativity and the information of several professionals to meet the demands generated during the disease process.

Regarding the possibility of rest or leisure for the promotion of physical and mental health, caregivers emphasized their difficulties to leave home and take time to ‘breathe’.

## Final considerations

In the investigation, the experience of human vulnerability in different perspectives and the sense that each family gives to the suffering experienced by the relative dependent on long-term care emerged with great force.

The loneliness of the caregiver in care was evident, emphasizing the need to think about other services to support the caregiver, with different social arrangements, as well as the value that the caregiver group has as a space for intervention and monitoring of physical and mental health of the caregiver.

It was possible to 'listen' to what the caregivers think of SAD, bringing their complaints and criticism, emphasizing the need for the multiprofessional team to carry out more visits during the month to the same patient; work in an integrated way, mainly in evaluation visits; build an individualized plan of care and improve the training of health professionals working in this care space, which is the domicile.

The perception that the lay caregiver has of the inability or insufficiency of the professional forces him/her to look for other professionals who can solve the identified health needs, which confirms that the people compose their maps of care with public and private services

using the creativity to solve the failures of the health system.

It was found people that, by neglecting care, could not take on the role of caregivers, especially the elderly caring for the elderly, incurring ethical, human and social problems to be managed by SAD. In these encounters with the caregivers, the dynamic and attentive performance of the SAD teams was observed, permeated by dialogue and guidance to caregivers and patients.

From the encounter with the caregivers, the worries persisted to reduce their work load and the solitude in the caring work.

It is necessary to make progress with home care through the creation of social support services aimed at serving the elderly population with some degree of dependence on chronic disease, in order to collaborate to maintain the autonomy of these dependency people, as well as the health of the caregiver.

## Collaborators

The authors also contributed to the conception, planning, analysis and interpretation of data, as well as to the elaboration and approval of the final version of this manuscript. ■

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