

## Dementia, family caregivers and health service: the care of yourself and the other

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**Abstract** *This study sought to identify the perception of the family caregivers regarding care provided by them and the ESF to the elderly with dementia. This qualitative, analytical and descriptive research was carried out through semi-structured interviews, with five family caregivers users of a primary care facility organized by the ESF, located in the city of Rio de Janeiro. The collected material was submitted to the French School of discourse analysis. Analysis of the symptoms that affect the routine and the feelings of the caregiver generate considerable changes. Family history, family coping with difficult situations, and support for backwardness represented by lack of support from other family members and the State intensify care-related problems. Self-abdication, isolation, and negative subjective interpretations are the producers and aggravators of the psychic distress of family caregivers. Despite its limitations, the ESF receives seniors with dementia and caregivers, but it is not considered a reference of care by family caregivers. Family caregivers affirm that what intensifies the challenges of care is the situation of abandonment experienced by them, impacting as subjective dynamics of oppression and self-abdication, leading to conflicts that reflect in the care situation.*

**Key words** *Dementia, Elderly, Family caregivers, Public health service, Family clinic*

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## Introduction

Population aging and dementia as a public health priority by the World Health Organization<sup>1</sup> predicts the impact on the dynamics of care and the health system. Dementia is a disease directly associated with the aging process, characterized by cognitive impairments that initially affect memory, spatial and temporal concept, reasoning and judgment. In more advanced stages, it evidences the severe impairment of the cognitive capacities, nearing total dependence. Dementia significantly affects the family of the elderly, especially the family caregiver, who becomes responsible for every care routine. The dependency situation is exacerbated by the social vulnerability of many households of Brazilian older adults. Subsistence hardships end up turning the sickness of seniors into an experience even harder to bear. Sometimes the burden of care for older adults with dementia transcends the bearable limits of caregivers and end up generating conflicts and breakup in the family structure, which in many cases is responsible for the risk of elderly institutionalization.

Power relations may directly impact the caring relationship of family caregivers with the elderly with dementia and the relationship with health professionals. In the face of this reflection, Foucault's concept<sup>2</sup> of self-care is shown to be a relevant factor for the upkeep and balance of relationships, because when one becomes aware of oneself, one's desires are controlled, subjects do not abuse their power over others and take care of others.

Self-care is shown as a free reflection that favors not only the individual life, but also provides an awareness of the group, of life in society as one gets to know oneself more. The act of caring is immersed in human relationships, people like family caregivers, whose own central social role is one of the actions that human nature cherishes for its existence – caring for the other. Bauman<sup>3</sup> values emotions when discussing morals and caring for others. The author argues that the emotional attitude is a resistance to the objectification of the being, because it promotes relations of partnerships between humans and not relations that make them objects.

Given this perspective of care, this study aims to identify the perceptions and strategies of care that family caregivers use to deal with older adults with dementia from the viewpoint of subjective, social and household management implications and to elucidate their perception about care provided by PHC, represented by the ESF.

The relevance of this study is in the low academic production focused on health care for the elderly with dementia serviced in primary care from the perspective of family caregivers. A national and international bibliographic review by authors between 2010 and 2016 using descriptors *idoso* OR *pessoa idosa* AND *dementia* OR *Alzheimer* AND *atenção básica* OR *cuidados primários* OR *estratégia de saúde da família*, and their correspondents in English, returned 30 papers on the subject, but none addressing the perspective of family caregivers were found.

## Study design

A descriptive, analytical qualitative study allows an understanding of the subjects' perceptions and beliefs in the face of a situation, revealing the history, senses, meanings and ideologies involved in this way of seeing the world. Minayo<sup>4</sup> states that this type of research causes the saying to reveal structural conditions, value systems, standards and symbols.

This study was a part of the results of a research conducted for master's dissertation. Only one primary care facility was selected as the field of study due to the reduced time for field research after the paperwork and opinion of two ethics committees. The establishment consists of the Family Health Strategy (ESF), located in the northern part of the city of Rio de Janeiro. The service attends around 14,000 users and the coverage area is 2,450,000 m<sup>2</sup>. Some family caregivers who were health service users were appointed by the health professionals of the ESF and five agreed to participate in the interview. We conducted in-depth semi-structured interviews to cover the objective of the study, and this method allows the establishment of a more symmetrical relationship between interviewer and respondent, favors the expression of feelings, perceptions and expectations, reveals the subjectivity of this individual, allowing the analysis as per the respondent's perspective. The number of participants in the qualitative study is not relevant given the say power of the interviewed subjects. Each life history pervaded by the care experiences described in this study is relevant to unveiling the senses, meanings and ideologies involved in established care relationships.

The criteria for the inclusion of subjects in the research were: being a relative and caregiver of a person 60 years of age or older diagnosed with dementia. Professional caregivers were excluded. The respondents signed an Informed

Consent Form. The names used in this text are fictitious to preserve confidentiality. This study was approved by the Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro, by the Ethics Committee of the Sérgio Arouca National School of Public Health (Fiocruz) and complied with the norms of Resolution 466/12 of the National Health Council.

The interviews were recorded and transcribed in full for the French School of discourse analysis. The analysis of the discourse addresses the content collected in the interviews as a process of signification, transcending the idea that the respondent's statement would have the purpose of transmitting information. The discourse in the content of the interviews is understood as an object that fuses language, subject and history. The discourse is understood as an event and whose fundamental place is subjectivity<sup>5</sup>.

The Discourse Analysis began with the exercise of “*denaturalizing the word-thing relationship*”<sup>5</sup>, understanding that the meaning of the word is not born with it and there is not just one way of saying about something, thus transforming the linguistic surface into a discursive object. Then, the conceptual axes that appear throughout the respondents' discourse became visible. In the face of these conceptual axes, the significant core as per the singularity of each statement, gesture and the unsaid. In the analysis of the process of signification, we articulated the core of signifiers explored with the discussions on care by Zygmunt Bauman and Michel Foucault. During the analysis of the data in the shape of discourse analysis, a significant mosaic was constructed consisting of the conceptual axes identified in the discourse of family caregivers and the significant core in each axis.

## Results and discussion

### The respondents

*Maria*, 64 years. Takes care of sister with dementia. She never worked, lives with her sister and a brother. There are five more brothers living nearby, but they do not help in the care.

*Celina*, 57 years. Single daughter, she lives with her mother whom she has been caring for nine years. She was bank clerk, became unemployed and is retired today. The only close relative is a cousin who helps her twice a week.

*Joana*, 68 years. She's been taking care of her husband for six years. They have been married

for 49 years with a history of alcoholism and domestic violence. She has three children who live nearby and help in some trips to medical visits.

*Filomena*, 65 years. Abandoned by her husband when the two children were small. Nowadays, she takes care of her mother, but has already taken care of her father, aunt and sister with dementia. She suffers threats from her brother who supervises her care.

*Teresa*, 47 years. She takes care of her mother. She is a nursing technician and worked for some years as a professional caregiver. She has taken care of her mother for seven months.

### The discourse of family caregivers

Figure 1 shows the significant mosaic, with the conceptual axis of analysis and the significant cores.

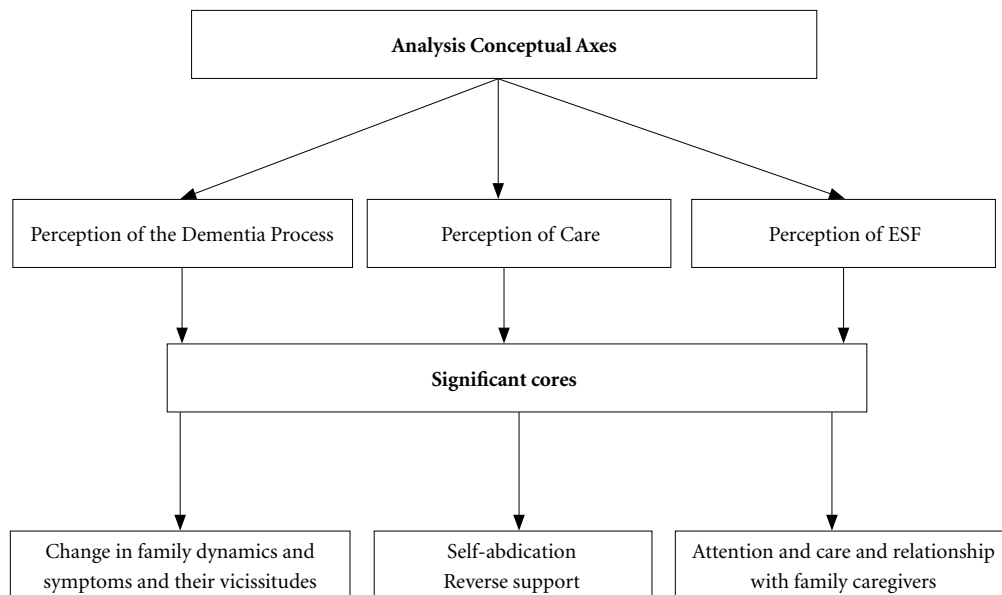
#### Conceptual axis – Perception of the dementia process

#### Significant cores: Change in Family dynamics and symptoms and their vicissitudes

##### *Much, much change*

Family caregivers follow the stages of illness, represented by cognitive, behavioral and physical alterations that promote considerable changes in the routine of care. Memory loss leads to the loss of self and the consciousness of self, and of the world as a whole, from the moment the identifying layers are progressively undone. Dementia, therefore, reaches subjects with dementia in their most singular feature: the consciousness of self as themselves<sup>6</sup>. As in the elderly, these identifying traits become weak in the relatives. This is what Discourse Analysis calls the decentralized subject<sup>7</sup>.

*Celina* reports the increased dependence on her mother and, consequently, the overload in her routine. She and her mother live alone; she worked before, but is currently exclusively dedicated to her mother. She is an only daughter and without a father, and takes responsibility for every routine of care. The mother went through the psychomotor agitation stage, when the older adult explores the environment and wanders around the house. She now says she is in a more passive stage, when cognitive loss affects the motor act by promoting a slowing-down process. In the discourse one perceives an idea of opposition, because new problems arise impacting the



**Figure 1.** The significant mosaic.

Source: Own elaboration.

illness condition, even overcoming the previous stage and the mother getting calmer. The feeling on her face throughout her statement was one of frustration. Her gaze expresses fatigue and desolation in the face of disease progression and new challenges. *Celina* cries during the interview. Freud<sup>8</sup> affirms that frustration is translated as dissatisfaction, displeasure, annoyance. It usually implies a refusal to be satisfied by reality and is linked, in this case, to the presence of an external element that is refused in the face of a higher level of demand, such as inhibition, constraints and ego defenses.

*Joana* says about the changes: *He remembers me indeed, but he does not know that I'm his wife. I knew how to address it before, and now I don't.* It is noteworthy that she knew how to deal with it, referring to a past remembered and experienced with domestic violence (her husband was an alcoholic), minimizing the intensity of the suffering in that period. *Joana* feels lost. Forgetfulness, aggressiveness and dependence are perceived as disorienting factors. Suffering is clear in her account, although not expressed facially, but denoted in her agitation, manifested by walking from one side to another and the accelerated speech,

showing a high anxiety burden. *Joana* is an elderly living with her husband, with three children living nearby, but the daily care, such as hygiene, feeding and changing diapers are performed by her. Her house is under construction and her husband is bedridden in the living room.

The accounts by *Joana* and *Celina* show that the negative evolution of the symptoms is an aspect that not only affects the routine, but also the affective field, promoting changes in the attitudes, behaviors and way of existing of seniors with dementia, as well as that of the family caregiver, who needs to be reorganized at every turn, at every stage of dementia. The frustration with this imposition of the disease is evident in their statements.

*Joana* and *Celina* continue to report their emotional and objective difficulties and, thus, are accompanied by *Maria*, *Filomena* and *Teresa* who report memory loss, sleep disorders, excessive wandering, falls, incontinence, psychotic manifestations (hallucination) and aggressiveness. Memory loss characterized by forgetfulness are recurrent episodes in the dementia process. Initially, this symptom causes considerable discomfort to relatives who interpret negatively the

complaints of the elderly in this respect. But *Filomena* laughs at her relative making a fuss at dawn due to memory loss: *So I hear her screaming: I'm hungry! I'll tell the police you do not feed me.* Laughter emerges as an emotional defense strategy. At other times in her statement, she refers to the brother who is observing how she treats the mother and often in an aggressive tone asks if she is taking good care of her. She gets nervous, worries about what others think about her care. Her mother's screaming generates tense moments for her. She reports that, in her family, the father who died during her childhood was very violent, he battered the mother, and children feared him. *Filomena* takes care of her mother after taking care of her father, her aunt and a sister with dementia.

*It's beyond the bearable limit, night and day are confused, sometimes she wakes up screaming at night: you never have a normal night, Celina's* emphasis shows a negative expectation about the coming of the night that should be the moment of rest and becomes another moment of work and fatigue. The continuation of day symptoms into the night prevents the family caregiver from having time to recover the energies for the next day. The respondents described the need to rearrange furniture at home, to change the house's structure and habits to foster resolution of nocturnal events resulting from the dementia process. House with rooms on the second floor had to move the bed to the first floor, the living room became the room of the elderly in three of the five residences; sleeping time was fragmented for monitoring purposes.

The subjective interpretive content regarding the symptoms is associated with the family history and the family profile addressing difficult situations. Some situations may be interpreted by the family caregiver as an implication or pressure generating annoyances due to the overloaded care process or by reflecting previous affective relationships. The experience of these symptoms involves various subjective interpretations, feelings such as sadness and irritation, the loss of their history from the perspective of the other, and the successive loss of consciousness of the other is an ordeal for family caregivers.

The dementia process in the elderly radically changes the daily lives of their families. The unique evolution and the production of an insidious, progressive and chronic framework emotionally and socioeconomically affect families, generating physical, emotional and social demands. This situation ends up making caregivers exhausted, depressed, stressed, especially the pri-

mary caregiver. It is common for the caregiver to have difficulty accepting the changes to which the dementia sufferer is gradually submitted, since another way of being is established, although the same physical appearance is preserved<sup>9</sup>.

*Filomena's* discourse refers to the fear of the other people's staring at the family caretaker. Laughter during the interview functions as an emotional defense strategy, but the feeling of fear prevails and destabilizes the perception of the evaluation of the other. *She would fall, hit her head on the floor, I would call emergency, arrive at Carlos Chagas (Hospital) and people stared at me, and I felt they thought I had pushed her.*

*Maria, Celina, Joana, Filomena* and *Teresa* refer to the urinary and fecal incontinence that affects the elderly with dementia. The use of the geriatric diaper in the face of behavioral difficulties can cause mental confusion, and the elderly person tries to remove the diaper and handle the stool: *Sometimes he rubs his hand over, I see it... He does it right, but there are times that he doesn't (Joana) Let's go there and pee? Because she does not want to wear a diaper, she rips off her diaper (Filomena).* The family caregiver may understand this action as a "pang" and "tantrum", and "forget" that these episodes are part of the clinical picture of dementia. Conflicts related to incontinence and other difficult-to-manage symptoms eventually lead to a variety of interpretations, and past history of the emotional relationship between the elderly and the family caregiver can cause older emotional issues to surface again in these episodes.

With psycho-functional limitations, new demands arise that can be distressing for those who care because of affective involvement. Subjective constructions are fundamental elements in up-keeping the relationship of care<sup>10</sup>.

Besides the psychological aspect involved in the loss of identity and the specific cognitive aspects of dementia, some behavioral and psychiatric changes are important even in the consultation with the ESF professionals: psychotic symptoms, agitation and aggression, mood swings, disinhibited behavior and euphoria, apathy and insomnia. Some studies<sup>11-13</sup> pointed out the significant association between the presence of apathy and a faster cognitive and functional decline in these patients. Another very relevant situation regarding the appearance of neuropsychiatric symptoms is the association of these symptoms with the institutionalization and shorter patient survival. They also showed that the highest Neuropsychiatric Inventory (NPI) score was signifi-

cantly associated with more severe cognitive impairment, greater caregiver distress, and higher cost, but was not associated with a formal diagnosis of dementia performed by the primary care physician.

Changed behaviors and even risky behaviors, such as turning on the gas switch and not turning off, stirring in pots on a hot stove, or ingestion of liquids or toxic materials are situations in the face of neuropsychiatric manifestations in dementia. *Filomena* reports several neuropsychiatric symptoms of her husband. She compares his behavior to that of children who explore the environment to discover the cause and effect of things and the sensations obtained by the senses. Her role in this context resembles that of a mother trying to prevent the child from getting hurt: *He lights up the gas switch, he's just like a child, sometimes he starts to eat the slipper, I have to get it out of his mouth.*

Hallucination is another neuropsychiatric symptom described by family caregivers. *Joana* reports that when the husband talks to people who have died, the family members feel fear and distance themselves. *Filomena* has fun when her mother speaks with those who have died: *"She talks to those who have passed away, she sends the dog out, which does not exist"*. Each family caregiver experiences the symptoms presented by the dementia in a unique way, and ways to address and interpret this phenomenon and give meaning to their experience.

The negative development of dementia perceived by *Celina*, *Filomena*, *Maria*, *Teresa* and *Joana* show that the disease follows a course that transcends the biological event itself. The dementia process evidences psychological and sociocultural constructions permeated by meanings and interpretations according to those who live and those who maintain interpersonal relationships with the elderly person with dementia.

In the discourse of family caregivers, seniors with dementia have aggressive behaviors such as *agitation, spitting, cursing, clawing, throwing objects*, revealing a level of aggression that can impact the feelings and interpretations produced during the care routine. Freud<sup>14</sup> affirms that human instincts are of two types: *Those who tend to preserve and unite, which we call 'erotic' [...] with a deliberate expansion of the popular conception of 'sexuality'; and those who tend to destroy and kill, which we group as an aggressive or destructive instinct.* All actions in human life involve the confluence of these two instincts of preservation and destruction. The ideal situation for life in society would be the dominance of reason over the

instinctual life controlling destructive impulses, which is utopian. In this perspective, aggressiveness is inherent in the human condition.

In seniors with dementia with a declining psychological realm of the Self, the progressive loss of identity and the repercussion of cognitive decline, an actual decline in the rational realm of psychic life emerges. This decline refers to the cerebral aspect of inhibitory control and social cognition, showing that the emergence of aggressive behaviors is related to the biological component. The declining reason turns its demands and needs into instinctual acts and more basic reflexes, and can produce a continuous imbalance in the expression between the instincts of preservation and aggression.

Aggressiveness can be triggered by situations of frustration, when they do not get what they want, when they are afraid or consider some humiliating situation, when they are exposed to environmental overstimulation or feel any physical pain or side effects from medication. It may initially appear as agitation, as verbal violence, throwing of objects or physical violence itself.

*Filomena* reports situations of physical and verbal aggression directed at her by the mother in some moments of mental confusion and irritability, especially when contradicted or in bathing, feeding or bedtime: *She would claw me. She sometimes doesn't want to take a shower; she swears at me, curses me.* *Filomena* denotes in her speech tranquility vis-à-vis her mother's behavior, but fears the brother who uses the mother's care as a way to threaten and intimidate the family caregiver. Thus, fear and tension accompany the daily caregiver.

The aggressiveness brought on by the discourses of *Filomena*, *Celina*, *Joana* and *Maria* in dementia promotes limitations and produces feelings that are difficult to overcome, and situations experienced by the family caregiver may emerge and trigger a violent relationship between caregiver and care.

The changes in family dynamics and the symptoms and their vicissitudes produce feelings of frustration, loneliness, much sadness, disorientation, anxiety, humor as a defense strategy in the face of difficult situations and the fear of unrelated eyewitnesses regarding care. The subjective interpretive content of the symptoms strengthens the feelings experienced. These contents are associated with the life history of the caregivers, the families' profile addressing difficult situations and the abandonment and isolation of the care routine.

## Conceptual axis – Perceptions of care

### Significant cores: Self-abdication and Reverse support

*I stopped working to take care of her (Celina)*

*I need to dye my hair, paint my nails, and now I feel a pain that must be submitted to surgery (Maria),*

*I had ischemia because of him (Joana)*

This significant core refers to the realm of care when the caregiver must completely surrender to provide care to the other, especially when he/she does not have support or a network of social and family support. Bauman<sup>3</sup> describes that the unfolding of the moral person occurs by the attitude of taking responsibility for the other, thus involving a freedom of choice without a prescription of conduct to be exercised. It is, therefore, in the care of the other that we arise as moral beings. In the situation of the elderly caregiver with dementia, the freedom of choice can be minimal and the behavior can be interpreted as imposition or obligation, that is, an external prescription, generating existential conflicts that endanger the quality of care provided. Foucault<sup>2</sup> asserts that self-care is fundamental to the balance of relationships by showing that it is associated with an ethos of freedom. This ethos of freedom means not to be a slave of self, of own desires and passions, it has to do with the ability to govern oneself involving renunciation and not just liberations. By caring for oneself one becomes aware of oneself, one controls one's desires and takes care of the other. On the other hand, self-abdication triggers an extreme renunciation insofar as it requires exclusive dedication to the other, preventing the subject from arising, thus producing a situation of subjective oppression. Self-abdication, however, represents the reverse of self-care, there is no freedom. Thus, care in the face of a self-abdication does not represent care for oneself or care for the other as described by Bauman<sup>3</sup> and Foucault<sup>2</sup>.

It can be pointed out that the place of care is still imposed in our society on women, characterizing what literature points to as gender destination<sup>15</sup>. The five family caregivers who volunteered for the interviews are women. This place of care historically and culturally determined as a place of females reduces women's possibilities of action, impacting on the social division of labor and the lives of women in general. As in the case of *Filomena*, who dedicated her life to the care of her children, and then became caretaker of the father, mother, aunt, and older sister with dementia, while the male brothers abdicated care.

Self-abdication is represented by a fixed and crystallized relationship established not between caregiver and care, but due to other strict relationships between the other relatives and the family caregiver and between the State and the family caregiver, reflecting a situation of domination<sup>2</sup>, whose imposition of care and abandonment have an important impact on the care relationship. It is revealed in cases where the family caregiver has no way out, no family, community and state support, with no other possibility of action with an imperative of exclusive dedication to the other, subjected to overload in the care, which reflects on physical health and psychological care of both caregiver and cared for.

Although *Maria* speaks of the sister whom she takes care with much admiration and devotion, a reflection of the family's previous history in which the sister cared for her, the excerpt below shows the difficulties faced when the realm of self-abdication in the relationship of care emerges: *People say, 'Ah, but you do not have time to go to a mall, to go for a walk, you have negated yourself' and I said: 'If that's what God has established for me'.* *Maria* understands the situation of care as something determined by God, justifying for herself and for others the situation she is in. Since it is determined by a superior entity, one does not question and complain, but accepts the condition established by an external order. *Maria's* discourse reveals a morality ethically legislated by God, as described by Bauman<sup>3</sup>, where God determines her actions, unlike morality by emotional engagement, in which each is his/her own director. Morality through emotional engagement comes from a freedom of choice between good and evil and the responsibility of the self for the well-being and integrity of the other. The interpretation of the act of caring as something divine was established by the family caregiver, and this understanding precluded other possibilities of acting while organizing it psychologically and providing a meaning to the need to care for the sister.

In other discourses, it was also possible to perceive the extent of self-abdication in the care and the situations arising from it: *I even had ischemia because of him. I've even lost my speech for a while, says Joana.* The overload, lack of support and isolation, besides a previous family history involving domestic violence perpetrated by the husband, have harmed the physical and psychological health of *Joana*. While reporting ischemia, her tone is accusatory, revealing a negative affective burden that is emphasized by the lack of sup-

port, situations of violence experienced before the illness, and the stress and anxiety evident in her movements and accelerated speech.

The significant core support and its reverse translate a key aspect to the familiar caregiver to perform the care of the elderly. The reverse of support – abandonment, subjective and intra-family conflict, isolation in care – weakens the caregiver, hampering the relationship of care. The family support network and social support are indispensable in the care of elderly people with dementia<sup>10</sup>.

When asked about who helps with care management, *Joana* reports: *My daughter helps me when I need to take her to the hospital*. However, she is unsupported in the routine of care, in the activities of daily living such as bathing and feeding. *Joana* is a senior woman and ends up performing activities that can cause exhaustion and physical injury.

*Celina* informs that the demand for care is on a 24/7 scale: *Now I can no longer work because of her, absolutely no way*. She emphasizes the perception of isolation, people walking away in the face of the mother's illness. She realizes her need to have someone around to support and describes the feeling of hurt before loneliness: *Your friends despise you, it seems that Alzheimer's is leprosy. I miss talking, of a relative coming and talking, chatting*. The loneliness and the feeling of hurt can trigger psychic sickness, before the meanings assigned to the events. The perception of contempt and rejection of others in the face of the possibility of living with a chronic and degenerative illness produces frustration and hurt in a situation of care that imposes several limitations in her life: dreams, plans and desires are interrupted.

The abandonment of family members and society imposes on the family caregiver loss of freedom and inability to self-govern. The realm of self-care proposed by Foucault<sup>2</sup> does not occur, harming the establishment of care with the other. The reverse of support is revealed in the abandonment, isolation and family conflicts resulting from the process of sickness of the elderly. *I believe it's absurd, my niece married, called the family, called everyone, but did not invite us. My sister's daughter, mind you! So these things hurt (Maria)*.

The discourses of *Maria*, *Celina* and *Joana* on the lack of support illustrate a society that does not value caring for oneself and the other. The estrangement of a culture of solidarity, the inability to know oneself and impose own limits, and the difficulty in dealing with differences move

away those who could play a fundamental role in building a beneficial care relationship with repercussions on the health of both caregiver and cared for.

The family's previous history and the way it deals with difficult situations, as *Minayo* points out, contribute to the prediction of adverse care situations that trigger violent relationships. In this context, besides family and social abandonment, a conflict and a relationship of threat and aggression among family members is established, making the care experience harder to manage. *Minayo* emphasizes the realm of negative social imaginary about aging, where elderly is considered dead or worthless weight before a society that reproduces the idea that the person is worth how much it produces, and in this context, seniors with a dementia ongoing process are disposable<sup>16</sup>.

Subjective constructions, meanings generated about the process of care, especially in the face of abandonment, isolation and self-abdication for the sake of care, end up feeding feelings that objectively and subjectively affect the relationship of care. *I'm not much of a crier, but I was doing things at home and wanted to cry because it's so much work. I was as if I could not take it anymore*. *Celina* was in obvious psychic suffering, questioned about the support of the psychology service that was not made available by the ESF near her residence. The financial limitation and difficulty of movement prevented her from being assisted by other services.

### Conceptual axis – Perception of ESF

#### Significant cores: Attention and care and relationship with family caregivers

In this axis, the signifiers attributed by the respondents about the ESF as a health care device for dementia will be highlighted. *Teresa's* account *It took two years to send her to the clinic* is striking because it exposes the time in which older adults with dementia can expect to be attended by the network of specialists and thus carry out the specific monitoring for the symptoms of dementia. This situation involves several factors, two of which should be highlighted: the lack of preparation of health professionals in primary care to deal with the complexity of dementia, including diagnosis and scheduling problems in the referral network (SISREG). ESF health professionals still have incipient knowledge about dementia and about the problems faced by the elderly and their families.



Research from Canada and the US on dementia care training programs point out that continuing education makes practice of primary care more comprehensive, interdisciplinary, besides reinforcing early detection and improving referral to aging and dementia services in the community<sup>17,18</sup>.

The ESF accompanies the elderly at home: *They have to see that she has a hard time walking (Maria); She comes twice a year (Celina)*. Home care is essential for the elderly, especially those in advanced stages with motor impairment. However, two visits a year are not enough to accompany a person with progressive and chronic illness with comorbidities. The delivery of free medication performed by the family clinic was highlighted as a key aspect for continuity of care: *I take medicine there (Joana)*. For the family caregiver, the medication provided is a fundamental instrument for the established care relationship with the health facilities. This statement misrepresents the positive point of the ESF model that would be care to the “individual in relationship”. Gil<sup>19</sup> highlighted the weaknesses of the ESF model concerning the difficulty with integrality, in the formation of bonds, in the familiar approach, the lack of an expanded view of the health-disease process and the high reliance on secondary services, referral and counter-referral, and some difficulties remain.

*Celina's* propositional speech in view of the difficulties since the initial symptoms of the dementia: *The family clinic should have a group*, is a request for attention by health professionals to the family caregiver, and shows the need for more specific and close follow-up in these situations to guide them in regard to dementia. This statement has a sense of request for help and support in care.

On the other hand, *Maria* describes: *I receive treatment at the family clinic. She does too, when my doctor comes home*. The meaning given by *Maria* is different from *Joana*. *Maria* describes the care according to the model proposed by the ESF: a service that values the listening of the user, the bond, the family approach and the comprehension of the health and disease-health process in an extended way. In the trip by the family caregiver to the visit, the situation of the elderly woman is also evaluated at home, a home visit is scheduled, thus performing comprehensive care. Thus, the bond with the family is established and a broader understanding favors the care of the family caregivers.

The lack of knowledge about dementia by health professionals impairs the understanding of the dynamics of this disease process in

the family and community context, delays the diagnosis and treatment that are fundamental for symptom relief and disease delay, and also contribute to problems in reporting dementia in primary care. According to the discursive formations of the respondents, the ESF does not consolidate itself as a reference health service for monitoring the elderly with dementia. The ESF is not yet able to form with other devices a network of social protection and adequate health care that provides a decent life for the elderly and their family caregivers.

### Final considerations

Dementia appears as a disease that transcends biological aspects, as it affects the patient and those who are close, especially the family caregivers. The discourse of family caregivers has shown that dementia causes considerable changes in their lives: they change the conditions of the house in which they live, the daily routine, personal and work life. Some symptoms resulting from disease progression, such as aggression, hallucinations, and urinary and fecal incontinence, emphasize the overload and adversities of care management. The history, the family profile in dealing with adverse situations, the changes resulting from the dementia process and the symptoms and their vicissitudes generate objective and subjective impact in the relationship of care.

The adversities of care often lead family caregivers to relinquish care for each other. This self-abdication often reflects a subjective oppression, a situation of domination perpetrated by the other relatives and the State against the family caretaker who is isolated and abandoned and cannot take care of himself, and the possibility of taking care of the other is impaired. Some situations reveal that the family caregiver is at a dead end, without support from family, community and state or another choice, with an imperative of exclusive dedication to the other. Self-abdication leads to negative subjective interpretations about care, generating existential conflicts and leading the family caregiver to experience extreme situations. Reverse support by other family members and society imposes on the family caregiver the loss of freedom and the inability to self-govern. The discursive formations of the respondents illustrated a society that does not appreciate self-care and caring for the other. All interviews showed in their discourse self-abdication, some more intensely than others.

The presence of positive and negative feelings was associated with the way family caregivers understand their experience. Feelings of frustration, loneliness, sadness and anxiety were perceived in the statements, as well as humor as a strategy of emotional defense, gratitude and fear in the face of other people staring at the care taken.

Although presenting limitations in health care, the ESF was revealed in the respondents' discourse as a service that sometimes receives the caregiver and the elderly with dementia, as in the existence of a home visit that contributes to the care of seniors with dementia at a more advanced stage. However, in the perception of relatives, it evidences problems related to the reference of specialized services, such as delay in referral; in the multidisciplinary care, such as the lack of the

psychologist; and lack of knowledge about the process of dementia and possible care in primary care, such as guidance for caregivers of older adults with dementia, a situation that contributes to the delay in the diagnosis of dementia and in the establishment of care strategies for the elderly and their relatives.

Finally, the effective participation of family caregivers in the elaboration of processes and procedures that involve the care to people with dementia are necessary so that strategies and adaptations relevant to the demands of both the elderly and their relatives are developed. The study's limitation is that it has been performed in only one health unit composed of eight ESF teams, due to lack of time, since it is part of the results of a Master's Research.

## Collaborations

HG Nascimento and AEB Figueiredo equally participated in all stages of the paper.

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