Research Article

Ambiguities of care in Alzheimer's disease: To care/become a caregiver by obligation or by the charity

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Abstract

Objective: To understand the meaning of the ambiguities of being a caregiver experienced by family caregivers of people with Alzheimer's disease and health workers inserted in community Mutual Help Groups.

Method: a study based on the ontology of Maurice Merleau-Ponty's experience based on the notion of the body itself. It is revealed by the participation of 12 women, family caregivers, and health workers, members of community mutual aid groups, in the city of Jequié, Bahia, Brazil. The production of the experiential descriptions took place in three Focus Group meetings, during April and December 2019, whose resulting material was submitted to the Ambiguity Analysis.

Results: The results reveal the ambiguities of taking care mobilized by the tradition of fulfilling social, cultural, and religious duties. Inserted in the groups, they experience openness to the other, reconfiguring "doing for doing" in "doing for pleasure" in care practices, becoming another.

Conclusion: the experience of caring as an obligation, which was previously expressed by anguish, sadness, and illness, after insertion in the group, opens up to the experience of the other and makes care a manifestation of otherness, which privileges the care of the self to care from the other. The study points out the group strategy in health services as a possibility of transforming social actors in the community in the context of Alzheimer's disease.

Introduction

Living with a chronic illness leads the people involved to center their lives around illness and treatment. In Brazil, a country in an accelerated aging process, dementias start to occupy the stage of neurodegenerative and incurable diseases making the family, and not just the person affected, the protagonist of an ambiguous scenario of insecurities, learning, conflicts, reconstruction, illness, and cure.

Alzheimer's disease (AD) has been considered the most frequent dementia, being estimated, the amount of 46.8 million people affected, of these, 8.5% are in Latin America and 1 million only in Brazil [1]. Projections indicate that, by the year 2030, it will reach around 65.7 million individuals in the world population, increasing to 115.4 million in 2050 [2].

In the daily dimension, the responsibility for caring for the elderly with AD flows into the family context and is guided by the bonds of affection, solidarity, and fraternity linked to

079

the social burden and the moral duty to care for those who are unable to provide their care [3]. Based on this premise, the ethical, legal, and cultural issues of our Western society are framed to provide support to elderly people with AD who are once again welcomed into the family.

The experience in the Support Group that integrated family caregivers of people with Alzheimer's disease, the place where the narratives of this article were constituted, led us to the perception of other nuances that involve the process of "retribution" of care with a view the inverse non-abandonment of affection, recognized as the breach of the descendants' care and affection duties towards their ancestors, as required by the Federal Constitution in its art. 229 [4].

The caregivers who integrate the groups have differences in the way of thinking, being, and caring for the family member with AD, and this is because each family unit experiences the illness in a unique way. We believe that it is in the space of time that its members are inserted as being in the world and start to experience the perception of the other and the things around them in practical involvement with the experienced reality that only happens through the body [5,6].

In this perspective, the family caregivers of people with AD exercise informal care imbued with the duty of being a caregiver, which involves the free provision of affection, protection, affection and the supply of basic needs of daily life. During this journey, many of them, elected by the other family members, feel lonely, judged, and helpless by family members, the state, and society [7,8].

Therefore, the aim of the study was to understand the meaning of the ambiguities of being a caregiver experienced by family caregivers of people with AD and health workers during the implementation of Community Support Groups.

Methodology

It is, therefore, an intervention study with a qualitative approach, supported by the theoretical-philosophical framework of Maurice Merleau-Ponty and whose methodological operationalization was thought from the framework of Paulo Freire [5].

The research was developed in two stages: the first, of an interventional nature, was consolidated with the implantation of two Support Groups in the community and whose phases were guided by the dialogical systematization of the philosopher and educator Paulo Freire [9]; the second, considered a stage of production of the lived descriptions (data collections), was consolidated with the realization of three meetings of the Focus Group (FG) – a strategy used due to its approximation with the adopted theoretical-philosophical framework which values the dialogic experience and collective [10,11].

This article consists of an excerpt from the doctoral thesis entitled "The meaning of the collective construction of Support Groups integrating family caregivers of people with Alzheimer's disease in the community", whose development was mobilized by the experience in the Continued Extension Project "Support Group for family caregivers of people with Alzheimer's disease" at the State University of Southwest Bahia, in the city of Jequié, Bahia, Brazil.

The project that had existed for more than a decade led us to realize that we had built a strategy "for" caregivers and not "with" them. Several showed dependence and little collective involvement with the group. Despite recognizing the benefits of Support Groups / Extensions, they did not engage in new actions, always waiting for the other. The access of new caregivers to the meetings was also compromised, being justified by the distance between the University and their places of residence.

In this perspective, we are engaged in a new project for the implementation of the Support Group in the community, in the territories where Support Group/Extension caregivers are linked to the Family Health Strategies (FHS). Thus, we seek to approach new caregivers, in a territorial sense, strengthening the bond with health teams, in addition to activities involving the participation of these social actors, Support Group/Extension caregivers, and health workers, by recognizing their potential in the collaboration process.

After delimiting the neighborhoods and Basic Health Units (BHU) which would be implanted from Support Group, Amaralina – BHU João Carichio, Joaquim Romão – BHU Doralize Vidal and Jequiezinho – BHU José Maximiliano, we started the actions following the phases of exploration of territories and implantation of groups. Occurring some mismatches and difficulties in joining and engaging one of the health teams in the project, he had active participation until the end of the research of two of the three selected units, Support Group/Amaralina and Support Group/Joaquim Romão.

In the first phase of the intervention – an exploration of the territories – we presented the project to BHU, training workers to actively search for new caregivers in the community, such as through home visits for presentation and inviting new caregivers to participate in the project. In the second phase, we held meetings for problematization/reflection/action with culture circles, discussion of case studies reported by the caregivers themselves, and re-looking at their problems without a naïve view but a critical one, in an attempt to recognize them as transforming beings of the world that are inserted [9]. It is worth mentioning that, in all phases, our priority was the active participation of caregivers (Support Group/Extension) and health professionals. The idea of doing it with them was the main motivator for the actions.

Having accomplished the implementation process, which took place between October 2018 and April 2019, a meeting was held with the Support Group participants implanted for the democratic and intentional election of the representatives who would make up the FG meetings, whose number of participants, between six to 12, it was delimited by the very character of the strategy. Thus, 12 women participated in the study, parity division was made up of six representatives of Support Group / Amaralina (four caregivers and two health workers, two of whom held both roles) and six representatives

of Support Group/Joaquim Romão (three caregivers and three health workers).

For the selection of caregivers, we established that they should be family caregivers, principal and non-formal; taking care of a person whose diagnosis of AD was issued by a doctor (geriatrician/neurologist) and be over 18 years old. Concerning health workers, the invitation was made to all members of the ESF team (nurse, doctor, dentist, nursing technician, and health agents), with at least one year of experience in the territory. The difference between caregivers and health professionals was in the form of participation in the group, the questions that were created were the same for all of them, and each revealed the experience inserted in their place of speech.

Thus, 12 participants composed the final stage of this work, the research stage, namely: eight caregivers, two from GAM/Extension mediating the implementation of GAM/Amaralina and Joaquim Romão, four identified in the community, and two community health agents and caregivers; two nurses and two other non-caregiver community health agents, FHS health workers.

Initially, two FG meetings were scheduled, with an average duration of two hours, and took place at BHU, where they were implemented in the groups (1st meeting–BHU/Amaralina; 2nd meeting–BHU/Joaquim Romão). The FGs were conducted by a moderator (researcher) and a facilitator (research collaborator); were recorded, transcribed, and validated by the participants at each new meeting. After this stage, the learning groups continue the Support Group in the community independently and, in December 2019, the third FG meeting was held, evaluating the entire process.

The produced descriptions were submitted to the *Ambiguity Analytic*, a technique developed by Sena [12] for an analysis of empirical descriptions in studies with a phenomenological approach. Its theoretical matrix is the phenomenology of Edmund Husserl and the ontology of the experience of Maurice Merleau-Ponty. The focus of the analysis is not on the interpretation of experiences, but on the identification of ambiguities that are shown in the intersubjective experience between the researcher and study participants.

The research was approved after approval by the Ethics and Research Committee of the University of the State of Bahia, according to the resolution of 2.782.564 and CAAE: 91272918.9.0000.0057, as provided for in the Resolution of the National Health Council of Brazil, N° 466/2012. The participants signed the Free and Informed Consent Term (ICF) and, to preserve their anonymity, they chose, as substitutes for their names, feelings that mobilized them to care.

Results and discussions

The results will be presented based on the understanding of the empirical descriptions based on the notion of the *own body* of the philosopher Maurice Merleau-Ponty [5]. In his work Phenomenology of perception, the author states that we can only "understand the function of the living body by performing it myself since I am a body that rises towards the world [5]". This *body* refers to the dynamics of perceptual experience, which happens through the operation of the totality of the senses of human beings intertwined in the world, which the philosopher called porous flesh. In this way, the human perception or experience of one's *own body* implies openness and intercorporality with the similar, with things and with the world, a process that occurs in five dimensions: *habitual body, perceptive body, speaking body, sexed body, and the body of the other* [5,12].

In this article, we are concerned with establishing a dialogue involving the descriptions of caregivers and health professionals that emerged from the FGs; the notion of the *perceptive body, sexed body, and the body of the other*; and studies that deal with the theme of care relationships between family caregivers and people with AD.

It is worth mentioning that, in the *sexed body*, the sexual is not genital, but the joyful experience of dialogue, intersubjectivity and intertwining that occurs in the collective experience of the group and of sensitive care that makes the subject *other*. Thus, in a temporal perspective, which involves a spiral movement of opening to the other, reflection, transcendence to the other myself, and a new opening, new reflections and a new *other*, we mean the making of the Support Group, as *embodied beings*, as a living experience.

Therefore, we have eternalized this movement with the elaboration of two categories: *Caregiving by tradition: the experience of the perceptive body and the body of the other; Caring by decision: openness to the other, and the pleasure of the sexed body.*

Caring out of obligation: the experience of the perceptive body and the body of the other

Caring truly involves an interactive action [13]. This action and behavior are based on values and on the knowledge of the being who cares "for" and "with" the being who is cared for. The objectivist theses addressed in studies on the relationship between family caregivers and people with AD always bring the profile of the mobilizing factors to become a caregiver. Most of these are related to the fulfillment of the moral duty of care [14,15]. The obligatory relationship between children and parents is increasingly present in our society in the face of the expressive increase in the number of elderly people and what we see are family members, mostly women (daughters, granddaughters, wives, daughters-in-law) in the illness and helplessness process [16].

On the other hand, studies in the Merleau-ponty perspective present the ambiguous dimensions of the caregivers' experiences and reveal a secondary gain for the act of caring, corroborating with the suspension of the thesis that doing the caregiver corresponds only to a negative connotation (tiredness, wear, and tea, fear), given the dimension of transcendence of experience through openness to the *other* [17,18].

It turns out that, even understanding the ambiguous dimensions of the care experience, we realize that there are

issues to be debated around the duty to do, as a cultural, moral, and even legal tradition, and the desire to be a caregiver, as a sensitive expression of autonomy and responsibility that lead, sometimes to illness, now to the well-being of family members.

In the face of a relative with AD, the caregivers are driven to action, mobilized to the act of caring for the *perceptive body*, which, in turn, is driven by the *habitual body*. However, if the "driving force" of caregivers is expressed by the *habitual body*, which represents the creative and current resumption of an experience, we identify a habit expressed by the sociocultural and moral values for the duty to care.

The *perceptual body* moved by these values, taken up and updated, takes the current *body* forward towards something; when they find this something, which also presents us with an anonymous history, they merge and open themselves towards a future [5,12]. In this way, we elaborate our history, according to the resonant understanding in the descriptions of the members of the Support Group:

I have always heard that it overloads just one, and it is that thing of tradition, of obligation, and [...] nobody complains. Of course, the work is hard, but for years it was always alone and she never even questioned other people not helping. But [...] this is already a characteristic of her too, that she thought she was fulfilling her duty as a daughter-in-law (Kindness-Nurse). What wears me out is because everything I do for her I try to do my best, even though I often have to give up my life; a walk with my family, a lot, but I do it, because I'm a daughter too (Retribution - Caregiver). [...] I think the son has to stop everything and take care of his mother. [...] (The group disagrees shaking his head) [...] this Alzheimer's disease I am scared to death and I always talk to my children, don't abandon me [...] I already set an example with my father and my mom and you have to follow my example. So when I took care of my father, my life was blessed, God blessed my life and I think that God does not bless if you think about leaving your mother at a time like this (Courage - Caregiver).

Being a daughter, daughter-in-law and mother, are social roles that unconsciously and historically refer to the obligation to care, a function that mobilizes the action of doing caregivers, but that reveals in profile the need for recognition and fear for the punishment of not having fulfilled their duty. In the descriptions, we realize that the social imperative is not only in the caregivers but also in the health workers who react to hearing from the oldest caregivers of the Support Group about the need to take care of themselves more and to find a balance between duty/doing and desire/being a caregiver.

So, whenever we are driven to do something, we are talking about the *perceptual body*, because, immediately, we are mobilized to do it. Then, we are swept away by some feeling and we react with an action. At that moment, our body is thrown forward to do something, to make decisions, to question, in short, to react. This is mobilized by a feeling and the immediate reaction that occurs to us corresponds to the *perceptive body* [5].

Studies indicate that caring for someone in old age is influenced, above all, by values, beliefs, and priorities, and is strictly dependent on the previous and current relationships

between those who care and those who are cared for [7,19]. It is not the only illness that is the great sensitizer/motivator of the family to carry out the care, but also the effects, the companionship, that is, the importance of maintaining the bonds and continuity of life [19]. Moral support based on affection, care, respect, and cooperation is based on the principles of human dignity, solidarity, and, mainly, on the principle of affectivity [4].

However, even though this support is supported by positive feelings and there is a relationship built based on affection, respect, companionship, and cooperation, the lack of reflection on the need to take care of yourself and find balance in this relationship makes us see the way how caregivers take responsibility for caring for their family members. The steps taken until this affective commitment and action were internalized by the caregivers, brought to our attention the negative reflexes that emerged in the meetings:

Because my mother was nervous, if she was stressed, there were many remedies. I went on a path of medication, of medication, both for my mother and for me. Because I was going to have medicine for sleep, medicine for this, for that. So, I was getting stuffed with pain medication and I found myself already wanting medication to feel good so I could take care of it. It was a difficult way to live (Gui). I came here, I left my job, I left the city I lived in and I'm out of a job, without a person to date and that's what is pushing me to the limit, the lack of occupation in my mind. Because occupying my mind only with my mother's health problem is leading me to despair [...] not having someone to vent, with whom to cry, with whom to laugh, with whom to vent, is taking me to the extreme of behavior [...] Stop life, "Courage"? I don't know if that is what you agree with, but for me, it is much more harmful and harmful for care (Hope - Caregiver). It is not because I am a daughter that I have to suffer so much, no! God knows about my fight and when I'm at Support Group and I'm not with her, I accidentally take care of her too, taking care of myself (Humor - Caregiver).

In the experiential descriptions of the caregivers who start attending the Support Group in the community, we can see how much the speech of the community agent Courage resonated with the fulfillment of the obligation and the moral duty for care. When establishing what to do under any circumstances so as not to be punished in any way by society or even by God, the coexistence present in the group between caregivers (new and old from Support Group/Extension) made the body react and update the concept of responsibility for care. Even though they understand it as a duty/doing caregiver, they reflect the exclusive and solitary dedication to the process of becoming ill and abandoning themselves and others. At that moment, there is a divergence based on the experiences of each one, which is taken up again by the possibility of dialogue and the intersubjective relationship present in the meetings.

It can be inferred that health is culturally defined, valued, and practiced, reflecting the ability of individuals (or groups) to perform their usual daily activities, beneficial or not, but standardized, as a tradition [20]. However, these standards start to be updated when, being in a group, we have different and possible experiences. The change in health care modes is

closely linked to the individual's ability to achieve a balance of living standards in search of his or her good life, based on the reconstruction of values inserted in the cultural and social context of the human being. Since the way that each family member performs daily care depends on the knowledge they acquire and put into practice, it can be said that the care actions reflect the culture of the caregiver and his family [21]. Therefore, culture determines patterns and lifestyles, influences people's decisions, and should be reframed through reflection on the suffering that the obligation of conduct can take you.

The Support Group, as a technology of care, provides opportunities for welcoming, listening, and dialogue, meaning, consensually for the authors presented here, a privileged field for the exercise of self-government and the rapprochement of doing in health with people's life projects. The reference to the subjectivity of health work is related to the subjective production of care, which is marked by a constant deconstruction and construction of existential territories, according to certain criteria that are given by knowledge, but also and fundamentally, following the sensitive dimension of perception of life and oneself, inflows of continuous teaching between subjects who work in the construction of social reality [22].

This context reveals that the needs of caregivers in the community are multiple and profound in all dimensions of health, ranging from technical learning to reorganization in the way of judging and fulfilling their duties. This means that caregivers arrive at the Support Group in need of good living conditions, adequate strategies for the management of suffering, and relationships of affection and bonding, but it is in a stimulating critical sense that they awaken independence and autonomy to lead a better life. The fatigue is real, however, it often appears as a bargaining chip for welcoming and listening. Caregivers need to be heard, so that they can, together, in a scenario of openness to the other, through the operation of the *sexed body* and the experience of transcendence by the *body of the other*, elaborate ways for a practice that leads to healing and not to suffering.

The presence of health workers in the groups becomes essential for this unknown and full of possibilities. They get to know the history of the neighborhood caregivers and the trajectories and life situations of each family, which opens the way for the development of empathy and solidarity for others and consequent pleasure in being at the BHU.

Doing/caregiver by donation: opening to the other myself through the sexed body

In the previous category, we describe the extent to which moral duty and social obligation define cultural standards in the process of caring for people with AD. However, when experiencing exhaustion and suffering in relationships, caregivers, mobilized by the Support Group, reveal how these patterns are harmful to their health, and the need to be open to the construction of new ways of becoming caregivers, for example, through the path of bestowal, as an act of love and responsibility with the existence, of oneself and the other.

Thus, we realize that in the Support Group, caregivers found, through communication and dialogue, the expression of the *sexed body*, which allowed the resignification of their past experiences, reverberating in the present, and providing them with nourishing elements necessary for the deconstruction of social patterns, moral and cultural that promote illness, and the reconstruction of sensitive, autonomous and affective models that promote health, healing and liberation.

This experience was only possible with the mobilization of groups guided by Freirian pedagogy [9], whose pillar is based on collective work, discussing with the bases and valuing common sense, in the perspective that the production of knowledge comes from people and their experiences. Certain that people do not educate themselves, but educate themselves, as they listen, listen and enjoy, in their uniqueness, the best for themselves [9]. It is not necessary to give advice or make judgments in at Support Group, each one filters what is theirs and, thus, the process takes place in the relationship that produces speech, action, and reflection, which is neither individual nor selfish, as it always has the presence of the other in itself and the elaboration of *another myself*.

Although in an unthinking way, by allowing paths for communication, interaction, and dialogue, we make the body of pleasure act and experience the enjoyment of the sexualized body, a living and genuine experience of the outbreak of the sexuality movement [5,23]. The mobilization of the participants and the expression itself in the group's meetings seem to have contributed to changing the "doing for doing" to "doing for pleasure" and, thus, they are developing new ways of being. In the following descriptions we can intertwine with this possibility:

We were chosen to improve our behavior towards those we care for. Not just Alzheimer's, but all those people who have the same feeling (coexistence). Love, people's character improves, so [...] when you take care of your life, the life of the other is no longer an obligation and you feel chosen to give love, to give affection, to give a different treatment to other people and that is the shaping of the caregiver (Love - Caregiver). Because the Support Group helping me told me so, you have to have your life, you have to travel! This opened my eyes so today I am living [...] I am in college, I am interning in the morning, I am working in the afternoon, and I do my things on the run, but I am alive and can help you much more (Tolerance - Caregiver). So, everything I did for her, I did for pleasure and love, what I could do I did for love, but, stopping my life because of her, I didn't stop! Support Group helped me to be aware of this, that I could not stop living my married life, my family life with my children, because of her (Struggle - Support Group Caregiver / Extension). Guys, you don't know how to detox this is for me. I detox from attitudes, situations, and thoughts. The Support Group brought an awareness that life can be reconciled with the Alzheimer's patient and that stopping life is not a way (Hope - Caregiver).

The social imperative that to be a caregiver is to be chosen, remains a tradition, a duty, but it brings into profile an adjustment that modifies your way of acting, that improves your conduct towards others, driven by *"love"* and *"different*

treatment ". Support Groups do *"open your eyes"* and *"help a lot more"*, leading them to an *"awareness"* that *"stopping life is not a way"*.

The importance of highlighting these descriptions consists in valuing the language that continues our opening to the world as it resumes, transforms, and prolongs the relations of meaning initiated in the perception. Therefore, Merleau-Ponty [5] differs, in this sense, from a *speaking speech* to a *spoken speech.* The first celebrates the instituting and creative act of language, that is, that moment when it is not yet known exactly what will be communicated, but there is already a meaning. *Spoken speech*, in turn, forms the basis of social communication, because it is knowledge itself based on language. Installed within a culture, the instituted language is a precursor of speech.

However, the decisive factor in the expressive phenomenon is not this legacy of language, but how it is assumed to promote new meanings [24]. In the speaking speech, the cultural acquisition is mobilized for the benefit of expression when we are face to-face with the other. After all, in front of the other, no one can remain indifferent [25].

We understand, then, that when we perform a technical activity, only, without the presence of the *body* (temporality, perception), as a *porous flesh* [5], the caregiver is not taking care, but, yes, performing a procedure, doing it out of obligation. The person with AD becomes an object of manipulation. When interacting, with caregivers among themselves and caregivers and cared beings, everyone grows, updates, and realizes. The possibility of being part of a group, in a space where you can carry out different activities and, at the same time, talk, smile, and be with other people, is referred to in the descriptions as a refreshing experience. This scenario favors an increase in self-esteem, personal appreciation, and self-care and makes the caregiver freely exercise her citizenship.

It is necessary, then, to think about reconstructing a cultural standard of care for people with AD that values doing it for pleasure, as a donation, even though this action generates ambiguous feelings [21], as they are satisfied with their way of life. Being a caregiver, the difficulties will be mobilizing and not producing loneliness, guilt, pain, anguish, and bitterness.

Thus, we believe that the experiences in the Support Group constitute the possibility of collective transformation, awakening to autonomy, empowerment, and independence, as well as interaction with health workers, who are aware of the care demands arising from living with AD. Therefore, it is necessary that health services, professionals, and the community, seek to know the effects and effects that AD produces in the lives of sick people and their families so that they can translate into relevant and supportive practices, making them more effective in the ability to also positively affect the lives of these people [6].

Being in a group, with peers and feeling part of that space, through collective construction promotes openness to the other, expands collective consciousness, changes the way of being a caregiver, and expands them from the idea of the self to the self I can [24]. The power of building collective spaces involving multiple subjects, values sensitive experiences in health services, which so much lack the expansion of existential and human actions in place of the reproduction of technical and standardized knowledge, to modify health as a biological, cultural manifestation, and social.

Conclusion

Understand the meaning of the ambiguities of being a caregiver experienced by family caregivers of people with Alzheimer's disease and health workers inserted in community Mutual Help Groups.

We seek to understand, at the heart of the relationships, the meaning of the ambiguities of being a caregiver experienced by family caregivers of people with Alzheimer's disease and health workers inserted in community Mutual Support Groups. Therefore, we developed a discussion around the modeling of family care for people with AD, according to cultural, social, and religious aspects, which define patterns of becoming a caregiver, in the context of chronic illness. In this way, we seek to give visibility to the effects of the experience in the life of each person, inscribing care in the circuit of suffering and gift.

Thus, we developed the theoretical-philosophical discussion of the results based on the ontology of Maurice Merleau-Ponty, more centered on the notion of perception as the experience of the *own body.* Despite the fact that the *own body* is an inseparable whole, which operates spontaneously in intersubjectivity, we chose three of the five dimensions, described by the author, to support this article, as we consider that they are more appropriately articulated to the empirical categories emerging from the experiential descriptions, which are: *perceptive body, sexed body and the body of the other.*

In our effort to conclude the unfinished, we developed the reflection that the mobilization to care for others with AD happens as an expression of the *perceptive body*, which is driven by the resumption of experiences that take place in the tradition of caring for personal obligation and duty. However, during the collective participation in the construction of the Support Group in the community, the caregivers had the opportunity to reflect on the deconstruction and reconstruction of the sociocultural pattern in an experience of transcendence to another self, also called the *body of the other.*

In this sense, through the application of a liberating methodology, anchored in the reference of Paulo Freire, the expression of the *sexed body* was also unveiled, both as openness to the *other myself*, to transcendence, as to the similar (caregivers and others family members), which allowed viewing care as a joyful and pleasurable experience, which can give a new meaning to the caregiver's state of illness in a state of donation, family organization and good contact with the person with AD.

Therefore, we value the ability to act ethically as an "active virtue", which requires a natural will to care. When "wanting" and "duty" coincide, caring is presented as a sensitive expression in relationships. We highlight the need for the implementation of a Support Group in the community

as a social and collective initiative that encourages reflection and dialogue between caregivers and health workers, as well as conducting intervention studies that modify the status of subjects surveyed for, in fact, collaborators and study participants and the entire process.

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