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THE PERCEPTION OF CAREGIVERS OF ELDERLY WITH ALZHEIMER'S: GESTALT EXPERIENCE IN GROUP

A PERCEPÇÃO DO CUIDADOR DE IDOSOS COM ALZHEIMER: EXPERIÊNCIA GESTÁLTICA EM GRUPO

LA PERCEPCIÓN DEL CUIDADOR DE ANCIANOS CON ALZHEIMER'S: EXPERIENCIA GESTALT EN GRUPO

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ABSTRACT

Objective: understanding how caregivers feel in relation to the elderly with Alzheimer's disease. **Method:** a qualitative study, conducted during participation activities directed to Caregivers of Elderly with Dementia (PRÓCUIDEM). Data production was based on interviews and a field diary in a group of ten participants for five meetings lasting four hours. Data were analyzed based on the phenomenological method of Clark Moustakas seeking senses and meanings in the experience. The research project was approved by the Research and Ethics Committee, CAEE 31286814.9.000.5243. **Results:** caregivers presented the categories: powerlessness, loneliness, fear of prognosis, fear of failing in care, leaving the family with overhead activities and attachment to the elderly. **Conclusion:** the caregivers had feelings and emotions that could not perceive that can interfere with quality of care, confirming the need for opportunities to listening and support. **Descriptors:** Care; Alzheimer's Disease; Gestalt Therapy; Perception.

RESUMO

Objetivo: compreender como o cuidador se sente na relação com o idoso com Doença de Alzheimer. **Método:** estudo qualitativo, realizado durante a participação de atividades direcionadas aos Cuidadores de Idosos com Demência (PRÓCUIDEM). A produção dos dados foi a partir de entrevista e um diário de campo em um grupo de dez participantes, durante cinco encontros com duração de 4 horas. Os dados foram analisados com base no método fenomenológico de Clark Moustakas que busca sentidos e significados na experiência. O projeto de pesquisa foi aprovado pelo Comitê de Ética e Pesquisa, CAEE31286814.9.000.5243. **Resultados:** os cuidadores apresentaram as categorias: sensação de impotência, solidão, medo do prognóstico, medo de falhar no cuidado, abandono da família com sobrecarga de atividades e apego ao idoso. **Conclusão:** os cuidadores apresentaram sentimentos e emoções que não conseguiam perceber, que podem interferir na qualidade do cuidado, confirmando a necessidade de espaços de escuta e apoio. **Descritores:** Cuidado; Doença de Alzheimer; Gestalt-Terapia; Percepção.

RESUMEN

Objetivo: comprender cómo el cuidador se siente en relación a las personas mayores con la enfermedad de Alzheimer. **Método:** estudio cualitativo, realizado durante las actividades de participación dirigidas a cuidadores de ancianos con demencia (PRÓCUIDEM). La producción de los datos se basó en entrevistas y un diario de campo en un grupo de diez participantes por cinco reuniones con duración de cuatro horas. Los datos se analizaron con base en el método fenomenológico de Clark Moustakas, en busca de sentidos y significados en la experiencia. El proyecto de investigación fue aprobado por el Comité de Ética e Investigación, CAEE 31286814.9.000.5243. **Resultados:** los cuidadores presentan las categorías: la impotencia, la soledad, el miedo de pronóstico, el miedo al fracaso en la atención, dejando a la familia en las actividades generales y el apego a las personas mayores. **Conclusión:** los cuidadores tenían sentimientos y emociones que no podía percibir, que pueden interferir en la calidad de la atención, lo que confirma la necesidad de espacios de escucha y apoyo. **Descritores:** Cuidado; Enfermedad de Alzheimer; La Terapia Gestalt; Percepción.

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INTRODUCTION

Alzheimer's disease (AD) and its manifestations have been a challenge not only for researchers but also for the family in the search for strategies that can minimize the suffering both for the elderly and for the caregiver. With the progressive and inexorable aging of the population, the AD will gain prominence as an epidemic of the new millennium.¹

Due to the complexity of the disease and difficult identification in its prodrome, some people confuse AD with depression or do not understand the behavior changes of the elderly, and believe to be due to aging, a manifestation of "rebellion" and presented do not consider the diagnosis Alzheimer's for lack of information.

The AD, defined as a chronic degenerative disease caused by genetic, social and environmental factors have a direct relationship with age and it is estimated that formal education interferes with neuronal plasticity.² Thus, there is a need to think about the political, economic, social aspects, therefore its progress over time directly impacts the lives of families in the health system. Brazil needs to be structured, regarding its health policies to face this reality, since experience of both the old and the family of a dementia process requires network and psychological support.³

It is important that the family receive counseling regarding the disease since that time, have changed the dynamics of life as there is the advancement of same being can notice the increased dependency of the elderly, the need for continuous supervision by family members and caregivers. In addition, the care that they need to carry for those that are directly linked to an elderly suffering from Alzheimer's disease, a level of both physical and emotional overload interfering in their relationships.⁴ Note that you need to think of strategies to support the emotional discharges as these will reflect on the physical and mental health of the caregiver. For this, it considers the Gestalt therapy an approach that may favor this time of truly troubled experience, in which the caregiver is, involving a complex care that is what characterizes an elderly with dementia.

Gestalt therapy is an approach to clinical psychological treatment that relies on humanistic existential-phenomenological philosophy, seeking to approach the emotional experience of the person in order to help its becoming aware of the processes that are experienced in providing care to the elderly

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with dementia and leaving aside their own needs. The theoretical foundation of this approach involves the Gestalt psychology (Koffka), Field Theory (Lewin) and Holism (Smuts).

In this approach is as assumptions that man exists from the relationship established in the world and it is through the boundaries of contact that allow differentiation and therefore expression of subjectivity.⁵ From the awareness that the man perceives and print his way to exist in the world. Thus, the contacts you make with each other or with the world, a relationship man - another - world performs creative adjustments that are ways to adapt and integrate into the environment. The contact is the result of these reactions over time in the various fields in which we live.⁶

When the therapist approaches the story told by the caretaker there is a quest to understand how that experience is being signified in an attempt to enlarge transforming the intrapersonal, interpersonal and transpersonal perception that there may be a crystallization of feelings and sensations that interfere directly towards the life for that person.⁷

Reflecting on the behavioral changes that occur with the elderly throughout the development of Alzheimer's disease is questioned in this article: "How the caregiver feels to deal with that old?" It is noteworthy that there are two types of caregivers: the primary caregiver, classified as the one who directly takes care, has full or most of the responsibilities for the care of the elderly at home, and the secondary that assumes complementary activities.⁴

OBJECTIVE

- Understanding the gestalt perspective, of how the caregiver feels in its relationship with the elderly with Alzheimer's disease.

METHOD

Study of qualitative, descriptive approach conducted with caregivers of patients with Alzheimer's disease during participation activities directed to Caregivers of Elderly with Dementia (PRÓCUIDEM).⁸ PROCUIDEM is a project inserted into a multidisciplinary Extension Program of the Faculty of Nursing of the Fluminense Federal University, with interdisciplinary activities known as EASIC/UFF. The program is located in the Campus Mequinho in the city of Niterói/RJ for the purpose of service to seniors and their caregivers.

The PROCUIDEM started in 2007; it holds weekly meetings with caregivers for a period of 4 hours with about 10 participants, with different professionals. It was requested for the Psychology Service to implement an activity to meet the emotional demands arising from the group of caregivers. Thus, from March to August 2013 during activities of PROCUIDEM were performed in the group phenomenological interviews and field journal that aimed to record the emotional manifestations during activities. It is noteworthy that the interview was based on the Gestalt Theory.

The group was open-ended, lasting two hours of the meeting, in which there is no need to always keeping the same people, they are free to participate or not of the meeting.⁹ The number of participants were ten when they directed themselves to the group from which they will discuss their difficulties, it was not a mandatory presence. It was established the exclusion criteria. There was a psychologist as a coordinator and a psychologist intern performing notes (field journal) concerning what happened when each participant had its account because the group lives all the time, with a dual process, a visible and visible apparently an affecting the other and allowing the reality view, and modify it if transforms.⁹

The working group had the following script: in the first encounter was performed a dynamic presentation/sensitization with use of figures representing the care that they chose for identification and other dynamic integration, which should form through the double figures. At the second meeting a question was directed to all participants to trigger the dialogue was used: How is care for you? At the third meeting the question was: What are the difficulties you have experienced when providing care? At the fourth meeting the question was: How is your relationship with your family? In the fifth meeting was held an activity group of closure and thanksgiving.

The meetings were recorded, and transcripts were made comparing the data with the daily field to integrate information. The statements were coded in an order of presentation of the responses by participants (C1, C2, C3 ...). Each meeting was held a codification, being extracted from each meeting the categories that emerged.

To make it possible identifying the categories there were analyzed the data seeking to identify four types of internal movements: perceptions, feelings, emotions and fantasies⁹ of them about the disease and

about the elderly. After this phase it was possible to passing to the analysis of the data, after a period of estrangement for suspending data values and judgments and stay with the experience of the person, epoché.¹⁰ The analysis was based on the phenomenological method of Clark Moustakas, which aims at seeking ways and meanings statements by Eidetic variation, this is the description/expansion of the phenomenon that aims to find its essence.¹¹

It is noteworthy that the proper ethical precautions were taken keeping the confidentiality of personal information of each participant. The study followed the Resolution 466/2012 of the Ministry of Health; the research project was approved by the Research Ethics Committee at the Fluminense Federal University, under CAEE: 31286814.9.000.5243.

RESULTS

For this research participated ten subjects, most were female (9) and one male. These caregivers occupied the position of daughter (2) wife (1) son (1) cousin (1). Of the ten subjects, five were secondary caregivers. It is noteworthy that a participant ran both the mother and the mother-in-law.

The time of care provided to elderly ranged 3-10 years, and the period of dedication to the care was 24h for three of them residing with elderly and had no occupation; Two caregivers providing care to their elderly twice a week and a secondary caregiver who was not working at the time of the search but collaborated in the care of an elderly man with Alzheimer's Disease. This information, the relationship between duration of care and time with staying with the elderly, helped in observing the emotion expressed during their speech.

It was noted that family caregivers with more time together had more difficulty expressing their emotions, had watery eyes, avoided some subjects, a person asked to leave because it did not want to know how its family could be, being offered individual support in this case. It can be noticed that caregivers who were recognizing the disease had anxiety about the needs they would have with elderly during the disease, others were technical questions, such as medication use, nutrition and others. It was observed that secondary caregivers revealed their emotions according to the account of the main caregivers.

The categories that emerged based on the framework of identifying perceptions,

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feelings, emotions and fantasies, the main caregivers were: powerlessness, loneliness, and fear of prognosis. Regarding the secondary caregivers there were: fear of failing in care, leaving the family with overhead activities, attachment to the elderly.

There is a need to update and adapt both people and the environment/world they are located, this occurs by internal processes of creative adjustments and processes of organismic self-regulation.⁵Caregivers had a favorable domestic availability to learning and demonstrated need to be heard revealing that the demands of caring generate an automatic life, in everyday life. There is concern in meeting the demands that emerged in the elderly-caregiver relationship. In addition, the caregiver does not perceive in their existence, ie can disregard their biopsychosocial and spiritual needs, affecting their quality of life since the body absorbs the emotional load that produces effects in the body.

◆Feeling of impotence

Some families when they receive the diagnosis of Alzheimer's are already some time ago, having difficulties in their relationship with the elderly and failed to identify the disease. This is due to the fact unaware of the disease and caregivers dismiss the symptoms as, for example, memory loss and behavior change, this causes the elderly receiving care when the disease is in advanced stages. So it is noteworthy that family caregivers need a social support network that includes care to the elderly with Alzheimer's and the emotional, financial and psychological needs of care.¹²In the speech below we find this statement.

[...]When I saw, my mom couldn't walk, I took the doctors said it was problem of the column, but she felt no pain, but had no strength and I was told of a geriatrician, when he began to use the Alzheimer's medication appropriate, recovered some movements there, my life has changed because I realized what was happening. I sought the best for her. Today, even though she had already died, I come here to help my father. [...] (C1).

This speech, when uttered by the caregiver, presented a mix of anger because it betrays a lack of knowledge of some health technicians to take care of AD patients and the lack of information there in society about the processes of aging.

Make investments and actions that provide assistance to families is a demand that in

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Brazil there that think because caregivers assume without support effective government programs, responsibilities not only linked to the disease, but also the psychosocial context a holistic view of care is needed. There is to promote and maintain a network of social support dividing the responsibility of the individual lowering overloads that are inherent.⁴

The health team also needs to streamline support networks once the elderly care is interdisciplinary and must target the different areas of health having delays in care and commitment in the context of the elderly. There are professionals that need updating and knowledge of gerontology and mainly about the particulars involving Alzheimer's disease. The current legislation is recent, which requires prioritizing health interventions and cooperation between the various sectors of health.¹³

The expressed feeling of revolt is realized during speech when the caregiver changes the tone of voice during his speech, gesturing and tapping his hands on the leg and ends with the breath was imprisoned, being released in the form of a sigh. That shows how not to talk and share with others the difficulties may interfere with the quality of the contact established with other people. The caretaker to speak, rescued emotions that were registered in the pathways of care that Gestalt therapy being proposed through this rescue conducting an update of feeling in this moment, when she is getting support lest continues that experience crystallized previous and others can build healthier contacts. Able to look at life from another point with another perspective can facilitate the reconstruction of history itself.⁷

◆Loneliness

It was observed that family relationships modify the course of AD, because the attention is directed exclusively to the elderly as well, causing a change in the relational dynamics due to the increasing dependence of the elderly. This fact can depart the caregiver's household. The man in the relationship established with the world need to give a direction, a meaning to what they experience. To think the world you need to connect people and things, it is in the world-person relationship that constitutes the lived reality⁵. This statement demonstrates the particular need of the caregiver:

[...] God! Nobody cares asking if I need to go to the doctor, pay a bill. If it wasn't for my friends, my neighbor doesn't know how to do it, but they have no obligation, so I'm turning. [...](C3).

The group discussed the possibility of seeking support in other people, to network, join groups not to affect both regarding their self-care needs as the needs in daily life. Also scored about always be the only reference for all care and how it can interfere with the relationship of care. Consider essential that care be distributed among the people who make up the family of the elderly. They stressed that the centralization of tasks in a single person, such as: referral to exams, to medical appointments and other for being reference for the elderly, also brings many difficulties because the main caregiver himself cannot delegate these activities overloading it and away relationships and family dynamics.

The feeling of loneliness causes a feeling of emptiness, according to the description of the caregiver, which puts her hand to speak in heart region and leaves her standing with closed fingers and look gets lost. The group tries to bring back the caregiver giving guidance and tips on how they dealt with that feeling.

The description of this emptiness to Gestalt therapy represents infertile emptiness, in which there is no production of other paths, other forms of the organism to adapt and be able to find their best expression. Remember that the attitude of acceptance of the situation, "I'm turning myself" is the most adapted so that the caregiver found to deal with the problem. The repercussions of that choice itself are not perceived as the symptom is a way to reduce the area of their world, so that the centrality of its existence can be protected from the threat.¹⁴

◆Fear of prognosis

The fear was present in the speech of all, some mentioned being afraid of sleep and find the elderly on the floor, because he forgot he was in bed, others said they were terrified to see the choke elderly because they did not know what to do, others feared forget who he was, his personality, way of being, so different in this, but the fear of not knowing how long you have until the disease progresses to another stage. These lines show the mentioned:

[...]my mother was living alone and began to give everything you have in the house, brought her close to me, she does not accept, fight and threatens to fade to Bahia, where he has relatives stay on alert. (C5).

This situation denotes the stress for the caregiver, the place that now occupies deconstructs the authority of parents, leading the family to assume authoritarian attitudes

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toward the elderly, while guilt and infantilization of the elderly, which caused a strain in the relationship family.

This feeling, fear, generates an interruption in the flow of contact because the contact is the result of the relationship difference I-world, I in the world, "harmonious synthesis" of differences.⁶ In this context, blocking the contact, interferes with relationship between the caregiver and the elderly. The elderly person loses their size, passes be seen as dependent who have to comply with the determinations, also having its uniqueness is disregarded.

The C5 interviewee reported that her mother "has always been independent, never accepted orders." At this time, he makes contact with his emotion, presents intense crying, revealing the need for self-actualization. It is observed that there are two processes happening: the deconstruction of a powerful mother and at the same time, the recognition that no one knows what to do in this new configuration of the family, because you do not know to what extent it can have their opinions considered.

◆Fear of failure in the care

Appeared during the discussions in the group, the position of a caregiver to have the experience of seeing his elderly with falling level of consciousness, to be alone with him because the family lived in another city and having to take decisions as shown below:

[...]the doctor of the ambulance said I was an angel, because if you spent a bit more a little she wouldn't have survived, when her daughter found me cried a lot, she loves me and keeps giving me gifts, but if I don't care? (C7)

Another mentions that her elderly caretaker was not eating for several days, only took bread, pacing necessary thus became broths, to see if the nutritional conditions improved. The speech presents the following fact:

[...] was stimulating and I couldn't, I asked the family to take the doctor and he sent to speech therapist, and if I don't speak, was advancing disease, here understood. (C8).

It is perceived in this context that the trust is established between the elderly and the secondary caregiver, and that caregiver directs their perception of the need of the elderly. This fact favors the care, because the caregiver can develop skills to understand the more subtle needs of the present elderly. Furthermore, confirms the need for targeted programs for caregivers' information.

The quality of care also gives the sensitivity and look at the human, not only seeing the

sick person, but the human being in need of special attention. The disease or symptom should be considered in relation to the total field that the person exists as to give someone. The necessary conditions for senior care are: opening: Availability to be with each other, reciprocity. It understands as reciprocity the uncompromised giving to the reality of the other; presence the acceptance of reality and responsibility regarding how do I respond to another.

Importantly, the preparation of caregivers to care for that specific audience therefore are small details that can help in understanding the dementia process and stabilize the elderly as well as, guide the planning of the care that should be offered plan.

◆Abandonment of the family with overload activities

It was discussed that some secondary caregivers take care tasks both as the elder of the house because the activity is not regulated, there is no delimitation in some cases what should be done or not. Alzheimer's disease affects not only the individual but the whole family, generating changes in daily life and social isolation.¹⁵This generates a political discussion - economy since the family needs to work to maintain a livelihood.

Another issue that was discussed is the removal of the children of elderly care that by having the secondary caregiver, do not supervise the care provided or away from the relationship with the elderly offering only financial support. Below is this statement:

[...]Wow, the daughter only calls to confirm that the payment went into account, Mrs. F. gets angry, keeps asking to connect; the son smoke indoors leaves everything a mess, how can I look at it and do nothing? [...] (C8)

[...] I see there, the daughter only appears to bring the medicine does not affection on mother. (C6)

This demonstrates the statements above is that, entering the home environment, is to make contact with their singularities, laws and unfinished stories, so we note that there is a complexity in care that requires the caregiver sensitivity and preparation.

There is a need to consider that Alzheimer's disease will have a different impact on the various family types. Some are considered dysfunctional patterns of relationships are affected by stress associated with the disease, needing support, linkage to additional services for the guidance of family members¹⁵.

◆Attachment to the elderly

Some secondary caregivers expressed that in caring for the patient feel as if they were their own family and that each time you see the board suffer much worse. It was observed that when a caregiver mentions his death experience with the elderly, there was a great silence and the eyes are on the ground. This demonstrates the difficulty of talking about it "death". The speech below expresses the fact:

[...] We don't even like to imagine, I without my old lady. (C10)

One caregiver reported that its elderly was talking was going to die all day and she was so upset that she had to stop and call her pastor. From the service to the pastor, it was quieter and was chatting with the elderly and felt she calmed down and did not touch it anymore. Be seen that beyond the technical training the caregiver mentions the need sometimes spiritual care.

Repression of spirituality creates a society of highly anxious individuals. When people are isolated from the sense of relationship with others and a sense of a greater reality, experience anxiety and emptiness.¹⁴Gestalt therapy with a holistic view of being seeks to integrate the different fields of human experience, seeking not to alienate the perception finitude that arises in the relationship with the therapist. In this context, despite the attempted avoidance of contact with this sentiment, speaks during the caretaker group is touched briefly and rescued the condition of human beings.

It is possible noticing that caregivers have love, affection and create bonds with their patients due to the closeness they have with the elderly. The contact is intense. In some cases, the caregiver becomes the extension of the elderly, there is a confluence, a type of blocking contact to the subjectivities mingle and there is no differentiation, a person becomes part of another. ⁶Then she goes on to say what the elderly want in his place, criticizes the family and can reach distance the family of the elderly. Furthermore, human existence in the face of new technologies, the use of drugs, devices, creates an atmosphere of omnipotence being difficult to deal with bodily finitude, getting that means restricted to religious discussion. The anguish that brought caregiver expresses not knowing what to say, how to talk to the old woman, who presented a lucid moment and contact with her death. You can see the non-verbal language, silences, glances, prey breaths, the subject is seen as unnatural and challenging. Avoidance of contact with this theme is the attempt to control reality, that which is seen, touched and felt, but it exceeds the capability

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of controlling the senses, is the inter-relationship which gives the totality of things⁶.

CONCLUSION

The possibility of approaching the experiential dimension of caregivers in the context of Alzheimer's disease was identified that allowed some challenges for psychology as it pertains to both relational life of the family with the elderly as the service provider with the family.

There is a need for a space for listening to carers, in which shares their experiences, they will feel more empowered and may reflect the activities that develop in everyday life, taking time for themselves. This was ratified with increased demand for individual assistance with Psychology after completion of the group.

It confirms the importance of performing group for caregivers, because at the end of the same during the evaluation, the feedback was that the information is important as it helps to understand what they are dealing with and how the aged look more human. This strengthened the action of the Extension Project **PRO-CUIDEM** increasing demand of workshops for caregivers and request new training courses.

The categories that emerged in the survey favored the preparation of lectures, building topics for group discussion and individual care of the psychologist in EASIC program of the Fluminense Federal University/UFF.

The survey also showed that care for elderly with Alzheimer's dementia, generates an emotional charge to primary and secondary caregivers, and the topic of death is still hard to be discussed by the people, and the production of relevant discussions as is already done in area of palliative care.

Gestalt therapy as an approach that seeks interaction, establishing dialogic relationship, in which people can express themselves and improve the quality of contact, may also facilitate the process of becoming aware of their own needs for the caregiver as well as the possible return of self and care of their own needs. Thus, through group treatment can create a sense of belonging to the caregivers, enhance relationships and promote exchange and solidarity movements.

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