

## O IMPACTO DO COMPORTAMENTO DO IDOSO COM DOENÇA DE ALZHEIMER NA VIDA DO CUIDADOR

### THE IMPACT OF THE BEHAVIOR OF THE ELDER WITH ALZHEIMER'S DISEASE IN THE CAREGIVER'S LIFE

### EL IMPACTO DEL COMPORTAMIENTO DEL ANCIANO CON ENFERMEDAD DE ALZHEIMER EN LA VIDA DEL CUIDADOR

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#### RESUMO

**Objetivo:** propor uma reflexão, à luz do Interacionismo Simbólico, sobre o comportamento do idoso com doença de Alzheimer e seus desdobramentos na vida do cuidador. **Método:** reflexão teórica fundamentada nos preceitos do Interacionismo Simbólico. Optou-se por essa abordagem, pois utiliza como ferramenta a concepção dos próprios atores a respeito do mundo social no qual estão inseridos, atribuindo-lhe significados que refletem nas próprias ações. **Resultados:** o mundo social do cuidado, vivenciado pelo idoso e seu cuidador não pode ser interpretado em termos de relações determinísticas, pois a natureza dos símbolos é manipulada pelo processo interpretativo e subjetivo de cada cuidador. À medida que ele vivencia sua realidade de cuidado, são estabelecidas transações e interações que se desdobram em demandas de cuidado. **Conclusão:** Essas demandas apresentam possibilidades reais de intervenção de enfermagem e precisam ser conduzidas a partir da interpretação atribuída e individualizada por cada cuidador.

**Descritores:** Idoso; Doença de Alzheimer; Enfermagem; Cuidadores.

#### ABSTRACT

**Objective:** to propose a reflection, in the light of Symbolic Interactionism, about the behavior of the elder with Alzheimer's disease and its unfolding in the caregiver's life. **Method:** theoretical reflection based on the precepts of Symbolic Interactionism. This approach was chosen because it uses as a tool the actors' own conception of the social world in which they are inserted, attributing to it the meanings they reflect in their own actions. **Results:** the social world of care experienced by the elder and his/her caregiver cannot be interpreted in terms of deterministic relations, since the interpretative and subjective process of each caregiver manipulates the nature of the symbols. As he/she experiences his/her care reality, transactions and interactions are established, unfolding into care demands. **Conclusion:** These demands present real possibilities of nursing intervention and need to be driven from the attributed and individualized interpretation by each caregiver.

**Descriptors:** Aged; Alzheimer's disease; Nursing; Caregivers.

#### RESUMEN

**Objetivo:** proponer una reflexión, a la luz del Interaccionismo Simbólico, sobre el comportamiento del anciano con enfermedad de Alzheimer y sus desdoblamiento en la vida del cuidador. **Método:** reflexión teórica fundamentada en los preceptos del Interaccionismo Simbólico. Se optó por ese enfoque, pues utiliza como herramienta la concepción de los propios actores a cerca del mundo social en el que están insertados, atribuyéndole significados que reflejan en las propias acciones. **Resultados:** el mundo social del cuidado vivido por el anciano y su cuidador no puede ser interpretado en términos de relaciones deterministas, pues la naturaleza de los símbolos es manipulada por el proceso interpretativo y subjetivo de cada cuidador. A medida que vive su realidad de cuidado, se establecen transacciones e interacciones que se desdoblan en demandas de cuidado. **Conclusión:** Estas demandas presentan posibilidades reales de intervención de enfermería y necesitan ser conducidas a partir de la interpretación atribuida e individualizada por cada cuidador.

**Descritores:** Anciano; Enfermedad de Alzheimer; Enfermería; Cuidadores.

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## INTRODUCTION

Most countries in the world have experienced an increase in the number and proportion of elders in their population. Dementia frames are very common in this clientele. Its prevalence increases with age, with Alzheimer's disease (AD) as its leading cause<sup>(1)</sup>.

Dementia is a neuro psychiatric syndrome due to multifactorial causes, with cognitive and non-cognitive (behavioral/psychological) impairment. AD corresponds to the most common form of dementia in contemporary times<sup>(2)</sup>.

Alzheimer's Disease (AD) is a progressive, fatal neurodegenerative disorder manifested by cognitive and memory deterioration, progressive impairment of daily activities and a variety of neuropsychiatric symptoms and behavioral changes<sup>(3)</sup>.

The patient's behavioral disorders affect the caregiver's life<sup>(4)</sup>. A study with 49 patients with dementia syndrome of various etiologies, and their respective caregivers, pointed out several features associated with the impact on caregivers, and, among them, the elder's behavioral disorders had the highest average of impact<sup>(5)</sup>.

Investigating the behavior of the elder with AD is relevant, because the nurse can develop educational, informational guidelines or management strategies from a dialogic interaction, which contributes to the care provided by caregivers to that elder.

The interaction is an important concept in an investigation that aims to contribute to nursing care. In this sense, the precepts of Symbolic Interactionism<sup>(6-7)</sup> can be used to support the discussion of a study on the elders and their caregivers, since the nurse can interact with the binomial caregiver-elder. Health professionals should view the family as a complex unit, with interactions between its members, so that the professional conduct become natural and multidimensional<sup>(8-9)</sup>.

When doing an exercise of reflection, the following questions emerged: what is the studied phenomenon? Where does it manifest? What are the elements involved in this phenomenon?

Therefore, this study proposes a reflection, the Symbolic Interactionism, on the behavior of the elder with Alzheimer's disease and its consequences in the caregiver's life.

## METHOD

This is a study of reflection based on theoretical concepts of Symbolic Interactionism (SI), from an analysis presented in the doctorate's thesis entitled: Behavioral changes in the elder with Alzheimer's disease and the informal caregiver: contributions to the gerontological nursing<sup>(10)</sup>.

The SI is a perspective of social theory and its main origin is the thought of George Herbert Mead, a professor of philosophy at the University of Chicago, which had a vision filled by pragmatic school<sup>(11)</sup>. The historical trajectory of this interaction approach had decisive influence of pragmatism on sociology, with emphasis of John Dewey and George Herbert Mead. These two scholars realized the critical need to re-found the social and biological sciences' pragmatism.

Nevertheless, George Herbert Mead became the strategical central figure of the Chicago School when analyzing the origin of human sign and linguistic communication. This scholar developed the conditions of possibility of self-reflection from a theory of the origins of specifically human communications and sociality. In a series of articles written around 1910, he gradually achieves the symbolically-mediated theory<sup>(6)</sup>.

With the decline of the Chicago School, in the 1930's, Herbert Blumer continued this tradition, devoting himself mainly to the programmatic writings about social psychology. In 1938, Herbert Blumer submitted the name of a line of sociological and sociopsychological research, focused on the interaction processes<sup>(6)</sup>. The SI stressed the symbolic nature of social life, with the actors' design about the social world as the essential object of sociological research<sup>(12)</sup>.

This theoretical framework focuses on social nature, which means that people's activities are dynamic and occur between and within them<sup>(13)</sup>.

The SI has three basic premises: (1) the human being acts in relation to the object based on the meanings of such objects for them; (2) the meaning attributed to the objects/things derives from the social interaction among human beings; (3) the meanings are manipulated and modified through an interpretive process, developed by the human being when facing objects and him/herself<sup>(7)</sup>.

Although called "basic" premises, they cover elements and complex issues since the

meaning of an element is born the way other people act towards one another in relation to the element. All their actions focus on setting it to the individual. In this way, the symbolic interactionism considers the meanings of social products, elaborated creations in and through human activities determining their interactive process<sup>(14)</sup>.

There are implicit questions<sup>(15)</sup> and/or basic concepts<sup>(13)</sup> related to Symbolic Interactionism that deserve to be highlighted, such as: Interaction (reciprocity, understanding of elements of nonverbal communication, facial expressions, an exchange of glances, body movement, space and extra-linguistic behavior, among others), Interactionism (directly connected to the causes and consequences of the interactive behaviors, actions and reactions of the society's routine), Mind (which would be the vehicle that interprets the others' attitudes and plans them through the reflective process based on the actions and behaviors (of others) internalized in social relations), Self (social object through which the individual acts, interacts with the others, thus, it is defined, redefined and constantly changing), Symbols (which allow constructing meanings from mental relations established from reflections carried out regarding the behavior of the different individuals that coexist in certain space), Symbolic (metaphoric, hypothetical representations made from social relations by the individual).

Symbolic interaction is taken to develop an analytical scheme of human society and of human conduct that involves certain basic ideas related to the nature of the following themes: human groups or societies, social interaction, objects, the human being as an actor, human action and the interconnections between the lines of action. In general, these ideas represent the way the symbolic interactionism see human society and conduct<sup>(16)</sup>.

In this way, the SI is a theoretical tool that allows understanding the phenomenon in a broader way, in addition to revealing and pointing the meaning that things have for the social actors. It allows understanding whether this meaning arises from the interaction of the elements involved in the process. It seeks to know whether these elements are significant, every time they interact, and the way they use the interpretive process to act mutually with the most significant objects of their reality<sup>(12)</sup>.

Using the Symbolic Interactionism as guiding axle, this study presents reflections and contexts regarding the behavior of the elder with Alzheimer's disease and its consequences in the caregiver's life.

## RESULTS AND DISCUSSION

In the light of the SI concepts, this study sought to identify the social actors, symbols, significant and meanings.

From the interaction between caregiver and elder with AD, this study sought to grasp the concepts or relations established and mediated in the everyday experience of the person that takes care of an elder with dementia, specifically with AD process, and his/her behavioral changes. Therefore, this study identified that the studied phenomenon "saved" a complexity of reflections and interpretations, since it dealt with two social actors that complemented each other, caregiver and elder with AD.

The studied phenomenon is the implication or the unfolding of the behavior of the elder with AD in the caregiver's life. This behavior comes to life and expression in a given scenario of the caregiver's everyday life. The actors or subjects of this phenomenon, caregiver and elder with AD, relate by forming a "web of interactions" established and sustained in the social world. Thus, the elements involved in this phenomenon are: elder and caregiver, social environment, actions and interactions of social actors in the social world.

These elements "talk" to each other in the social world. The social world is a type of symbolic and meaningful relations sustained through a process of human action and interaction<sup>(17)</sup>.

Since the society consists of humans' interaction, human beings interpret or "define" each other's actions instead of merely reacting to each other's actions. Their answers do not merely react to the others' actions, but base on the meanings they attach to such actions. Therefore, human interaction is mediated by the use of symbols, interpretation or determination of meanings to the others' actions. The symbols can be physical objects, human actions or words, socially developed through interaction<sup>(11)</sup>.

Knowing that human interaction is mediated by the use of symbols and meanings, allocated from the interpretation of the individual in the social world, the behaviors of elder with AD affect and gain differentiated intensities in the

caregiver's life. These behaviors can be recognized as characteristic manifestations of the AD and/or can cause suffering in the caregiver's life. The caregivers interpret and modify them according to their interpretation or the way they face with things and objects in the everyday world.

Behavior issues involving Alzheimer's disease refer to safety and most affect the caregiver's life. They were brought into perspective as a multidimensional overload and fatigue in the caregiver's life, in particular, emotionally and affectively<sup>(18)</sup>. Family members perceive care and disease as sources of physical and emotional overload, imminent or consumed<sup>(19)</sup>.

The management of behavioral disorders is one of the most stressful tasks for the caregiver. Behavioral changes of the elder with Alzheimer's disease can generate constraints for the families and stressful situations on a daily basis, causing difficulties for these caregivers<sup>(20)</sup>.

The caregiver's relationship with the object of interaction, which, in this case, is the behavior of the elder with AD, results in changes, which may reflect: in the relational standard, habits and routine. These changes indicate that the meanings assigned by the caregiver to the elder's behavior with AD are designed and perceived from the dimension that this behavior (object) has for the caregiver (subject and social actor). In this sense, this dimension is expressed and processed internally, in an interaction of the individual himself, "as a self-dialogue".

Self represents a social process within the individual involving two analytical phases: the "I" and "me". The "I" is the reaction of the organism to others' attitudes, it is the individual as subject, impulsive and spontaneous, that impulsionates the act and that causes the "me". The "me" is the series of organized attitudes that a person adopts, which determines our conduct as it is self-conscious character. It is the social self, the object that arises in the interaction<sup>(11)</sup>.

Considering the interaction "I", "me" and "social actors in the social world", caregivers, especially family members, expose or depict links and stories previously built and shared during the elder's course of life, prior to the AD. These links and stories are full of symbols and signifiers that, with the appearance of the Alzheimer's disease, (re)design in an individualized manner. The relational pattern is shaken, as the experiences of (before) AD and (after) AD are compared.

Dementia disorders cause significant impact or changes in the life of the individual who experiences the dementia process, and, above all, important changes in the caregiver's life, especially the family member. These changes bring suffering to the families-caregivers, imposing a structural and internal reorganization<sup>(21)</sup>. There is need for careful strategies directed to caregivers, since caring for an elderly person with AD is a task that requires a lot from the caregiver and becomes difficult for everyone, whether family members or not<sup>(22)</sup>.

In this understanding, the way changes in relational pattern are incorporated in the caregiver's life, as well as the way of using management strategies to deal with these changes, describes that the "social world of care", experienced by the caregiver and the elder with AD, cannot be "interpreted" in terms of deterministic relations, because the nature of symbols works like gears, moved and manipulated by the interpretive and subjective process of each caregiver. This interpretive process influences the way caregivers negotiate their realities of care.

Thus, as the caregiver experience his/her reality of care, "transactions and interactions" are established, which subsequently deploy on care demands or needs.

These demands present real opportunities of nursing intervention and must be conducted from the interpretation and intensity assigned by the caregiver when dealing and interacting with his/her reality of care. This negotiation and interaction are influenced by the meanings and perceptions of the caregiver, built over the course of life, in interaction with the social world and, therefore, subjective and individualized for each one of them.

The health professionals who assist the elders with dementia syndromes should be alert to recognize and implement health actions or care based on a new approach to care to individuals with chronic degenerative diseases. This approach characterizes as the management of the health needs of individuals and their families and/or social support network, which are expressed from signs and symptoms, declared or undeclared, but noticeable, observed and analyzed by health professionals prepared and imbued in health care practices, not healing, directed to the quality of life and the well-being of the people involved<sup>(23)</sup>.

Studies aimed at the approach of neuropsychiatric manifestations are necessary, given their high prevalence in all stages of severity of the disease, as well as the presence of multiple concurrent events, which generate a high degree of wear of the caregiver<sup>(24)</sup>.

## FINAL THOUGHTS

In order to promote nursing actions to the caregiver of the elder with behavioral change, the nurse needs to identify the demands brought by this caregiver. They are the expression of their experiences and are full of feelings and meanings that serve as tools to facilitate and direct such actions, which will be "authenticated" by the subject and protagonist of this careation – the Caregiver.

Therefore, considering the symbolic interaction as a guiding axis of the consequences of the elder's behavior with AD in the caregiver's life, when we recognize and interpret the demands/requirements as mediating tools, we establish the caregiver as "subject-protagonist" of the care process of the elder with AD.

Thus, for the nurse to attend specifically these needs, he/she needs to: a) Know the meaning of the behavior of the elder with AD and the caregiver's attitudes and reactions when facing such behaviors; b) Evaluate the degree of intensity of these unfoldings in the caregiver's life; c) Identify management strategies implemented by the caregiver to the elder with AD; d) Identify and classify the demands brought by the caregiver; e) Promote educational-informational nursing actions to the caregiver, and subsequently evaluate these actions along with the caregiver.

To this end, professionals that work in gerontology need to receive the family, support and care dynamics to the elder with AD. With this initiative, the respect and appreciation of the life path traveled by this elder and his/her family member are guaranteed, reiterating that Alzheimer's disease is a family/social disease.

Taking care of an individual in dementia process, specifically, with AD, leads to a critical reflection on the training and qualification in gerontological nursing and on the actions proposed by the public policies for the elder's health, especially the health of the elderly population in dementia process. We must become aware of the need for investment and stimuli in the training of nursing professionals in

the technical and higher education, in the area of gerontology.

As a contribution to gerontological nursing, this study points to the need for knowledge production based on actual demands, which effectively are conducted for the construction of resolute, critical and conscious care, through the partnership of this caregiver with the nurse to develop actions to the health of the elder with AD and his/her caregiver, empowering the trinomial elder with AD - caregiver - nurse.

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**Note:** Reflections from the thesis entitled "Alterations in the behavior of the elderly with Alzheimer's disease and the informal caregiver: contributions to gerontological nursing" and discussed in the Study Group and Research on the Elderly and its Caregiver (GEPEIC - EEAN - UFRJ) and in the Project of Valorization of Aging (PROVE - UFRJ).

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