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SHORT COMMUNICATION

Humanized Care and Challenges in the Care of Alzheimer's Patients

Cuidado Humanizado y Desafíos en la Atención a Pacientes con Alzheimer

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ABSTRACT

Alzheimer's disease, described by Alois Alzheimer, affected millions, being the most common dementia (60-70%). The importance of multidisciplinary teams and the crucial role of nursing in specialized care were highlighted. Patients faced progressive deterioration in memory, mobility and autonomy. Quality of life required attention to depression, pain and falls. Research reflected physical, psychological and social needs to improve humanized care.

Keywords: Alzheimer's disease; dementia; nursing; care; quality.

RESUMEN

El Alzheimer, descrito por Alois Alzheimer, afectó a millones, siendo la demencia más común (60-70%). Se destacó la importancia de equipos multidisciplinarios y el papel crucial de enfermería en el cuidado especializado. Los pacientes enfrentaron un deterioro progresivo en memoria, movilidad y autonomía. La calidad de vida requirió atención en depresión, dolor y caídas. Las investigaciones reflejaron necesidades físicas, psicológicas y sociales para mejorar el cuidado humanizado.

Palabras clave: Alzheimer; demencia; enfermería; cuidados; calidad.

Alzheimer's disease (AD) – first described by the German neurologist Alois Alzheimer – is a form of dementia that affects an increasing number of people. Dementia or dementia syndrome is understood to be the generally degenerative morbid processes that affect the brain. Dementia affects more than 50 million people worldwide, according to the World Health Organization (WHO, 2019), with AD being the

most common form of dementia, accounting for 60-70% of cases. The total number of people with dementia is expected to triple by 2050.

Aging leads to an increase in degenerative diseases. This raises a series of needs that society must face in offering specialized professional services that help maintain the quality of life of the elderly and their environment. In Argentina, it is estimated that 1 in 8 adults over the age of 65 suffer from AD, totaling more than 500,000 people (Chávez, 2019).

According to the WHO:

People with dementia are often denied the fundamental freedoms and rights that other people enjoy without problems. In many countries, the use of physical and chemical means of immobilization is commonplace in homes or intensive care services, even though there are regulations in place that defend people's right to have their freedom preserved and make their own decisions. An appropriate and favorable legislative framework in internationally accepted human rights standards is needed to guarantee the highest quality of service provision to people with dementia and their caregivers (WHO, 2020).

The plan of action on the health of the elderly, including active and healthy aging, adapted by the Pan American Health Organization (PAHO) at the 144th meeting of its executive committee, states that:

Health systems must face the challenge of caring for users with characteristics and needs that are different from the usual. To this end, workers in the sector need new skills that will enable them to respond to the needs of this population group, so it is essential to define the minimum competencies and content in geriatrics and gerontology for health professionals and workers according to the needs of each country, to include content on aging in the undergraduate and postgraduate training of all health and related science professionals, and to promote specialized training in geriatrics and gerontology (PAHO, 2012).

The nurse is one of the fundamental pillars of the team that provides care for Alzheimer's patients and their families. They must be trained and educated at all levels of care because they will be by their side, caring for them throughout the different stages of the disease. The course of the Alzheimer's patient is divided into phases that change in number according to the theoretical approach - as will be seen in the corresponding section - but which express, in common, the presentation and progressive advance of the physical, cognitive, and social, deterioration of the person who has this dementia.

The disease will have an onset - a pre-dementia phase - up to 10 to 20 years beforehand, with episodes of forgetfulness that will go unnoticed or will be attributed to isolated events. Gradually, a progressive and irreversible process of dementia will set in. The Alzheimer's Foundation of Spain (2022) reports that mild dementia produces memory disturbances and sudden mood changes. People continue to be independent in their daily activities and continue to work, but they begin to have problems following a conversation. In moderate dementia, the deficit in recent memory and sensory memory interpretation is accentuated. There are aggressive reactions and unjustified fears. Increasing muscle weakness alters posture and gait, so they have lost autonomy and must be permanently controlled. Severe dementia brings with it serious deterioration in all areas, and patients no longer recognize their partner or children; they have no control over their gestures, they cannot get up or sit down unaided, they have difficulty swallowing, and they are incontinent. In addition, muscle rigidity is accentuated, and patients are dependent on any activity. They are frequently confined to bed and, as a consequence, suffer from pressure ulcers (PU) and respiratory infections, which are often the cause of death in Alzheimer's patients.

In the context of the progressive increase in the aging of the world's population and the consequent prevalence of chronic diseases, Sánchez (2014) raises the need to build multidisciplinary teams to address the problem. These teams cannot do without the inclusion of the role of Nursing as a key player in the care of the elderly, and "it is also an opportunity for Nursing to be there where advanced care is required, provided by professionals with advanced and recognized clinical skills, to carry out case management and the monitoring and control of complex chronic patients." In this sense, he says, the figure of the

Advanced Practice Nurse could be incorporated as a manager of the - much-needed - humanized care of patients with this type of dementia. Along the same lines, Darpon (2013) affirms the need to "strengthen the role of nurses, important professionals in healthcare, who will gradually assume greater responsibilities in patient care."

Nursing professionals have an important and recognized role in the care and monitoring of Alzheimer's patients to improve the quality of care and life. Goodman, Morales, and Aboki (2013) present two predominant and overlapping scenarios in creating the functions of the nursing professional, one with a more or less extensive orientation from the nursing approach and the other with a more medicalized orientation. An emerging role, such as that of the Advanced Practice Nurse (APN), presents the challenge of establishing the level of experience and training necessary to fulfill the role, "such as establishing where the practice of the general nurse ends and where the practice of the APN begins."

Miguel Gonzalez (2017) lists the specific quality of life indicators for the patient with AD that allows the care plan strategy to be oriented concerning the actual and potential problems that the patient faces in the evolution of their disease:

1. The presence of depressive symptoms.
2. The use of psychotropic drugs.
3. The mortality rate.
4. Nutritional status.
5. The use of physical restraints.
6. The presence of pain.
7. The presence of pressure ulcers.
8. Falls.

Therefore, it is the possibility and the opportunity to study and learn more about the care of the elderly that improves their quality of life in response to growing demand and a need to emphasize the humanized care approach. This type of research is helpful for nurses, especially those who work in geriatric institutions. These institutions are an ideal context for applying these new quality approaches with implications for people with Alzheimer's disease and their families.

Alvarado García et al. (2019) systematically reviewed articles published from 2012 to 2019 in the databases Embase, Ovid, PubMed, Proquest, SciELO, ISI Web of Science & Scopus, and Redalycs. They included 20 articles from primary source research where categories such as physical, psychological, and social care needs are presented and discussed. They concluded that there is a knowledge gap in the Latin American context that turns its back on the complex reality of the patient with dementia and their caregiver. "Knowing the care needs of patients with dementia becomes a priority for healthcare professionals since providing adequate intervention promotes the quality of life of both the patient and the caregiver." Therefore, this research is justified in describing how nurses assess the role of nursing and the care necessary to improve the quality of life of institutionalized Alzheimer's patients. For this reason, it has been of interest in this research to know the opinions and views of a nursing team with experience in the care of Alzheimer's patients to begin to design care activities that favor the patient's quality of life. This work has come this far, and it would be interesting to initiate a line of research to go further and lay the foundation for subsequent studies.

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CONFLICT OF INTEREST

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