

# Quality of life and Alzheimer's dementia – a new challenge

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*Progressive aging of world population is directly associated with an increase in neurodegenerative pathologies. Among these, Alzheimer's disease is the most prevalent type of dementia worldwide, which is associated with deterioration of life quality, not only in patients, but also in their caregivers and their family environment. In this context, during the last few years it has become important to evaluate life quality of patients who suffer Alzheimer's dementia. This is an area of growing interest in clinical and public health, as it is considered an indicator to measure effectiveness of the different types of pharmacological/non-pharmacological interventions, regarding the disease and its evolution. Health teams know quality of life concept and its clinical evaluation in patients with Alzheimer's dementia, as it has become a fundamental support, both for management and use of information for decision-making on public policies, regarding patients suffering dementia. This work will address this issue from three perspectives -importance of Alzheimer's disease, -quality of life in time, -how the latter can be used to handle neurodegenerative diseases, such as dementia.*

**Keywords:** quality of life, Alzheimer's disease, neurodegenerative diseases (MeSH, NHL)

## PROLOGUE

This paper is aimed to reflect about the importance to include quality of life for treating patients with Alzheimer-type dementia in our country. In order to do so, we will discuss three main topics.

First, we will discuss about the current situation of Alzheimer's disease around the world

and in Chile. Second, dealing about quality of life related with this type of dementia. Third, it shows the contributions that measuring quality of life may help on therapeutical decision making for management and follow-up of these patients. Finally, we will discuss some considerations about quality of life in holistic management of patients suffering this disease.

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## Alzheimer's disease around the world and in Chile

It is generally known that population around the world is aging. According to UN statistics, for 2050, population older than 60 years old will become 22% of the world's population. Therefore, age-related pathologies will also increase significantly. Among them, cardiovascular diseases, osteoporosis, cancer, diabetes and neurodegenerative diseases<sup>(1)</sup>.

Within neurodegenerative diseases, most prevalent dementia is Alzheimer's disease (AD). This disease has a clinical picture of progressive compromise of people's cognitive/behavioral and functional skills<sup>(2,3)</sup>. It is deemed as an irreversible/incurable disease affecting both the patient and their environment. Its treatment is only symptomatic, by using some drugs, aimed to slow down the course of the disease and optimize quality of life of patients and their care takers.

Currently, 44 million people suffer dementia around the world. In USA it is the sixth cause of death<sup>(4)</sup>. In Chile, this disease is estimated to affect around 1.06% of the population who suffers some type of dementia<sup>(5)</sup>. This disease is ranked 18 among causes of years of healthy life lost (YLL)<sup>(6)</sup> in general population. It is the third cause of death in elderly people, older than 65 years old<sup>(7)</sup>. In 199, in Concepción, the study "Demencias Asociadas a edad, OMS-Chile" (age-related dementias WHO-Chile) stated that yearly incidence of dementia in urban/rural population was 1,7%<sup>(6)</sup>. It is important to highlight that these figures were probably underestimated, whether because of a low clinical awareness or because of a difficult access to health in a portion of the population.

## Quality of life in patients with Alzheimer's disease

The term "quality of life" has long been used. In time, many definitions have been found for it. It started, after the WW-II. The objective was to find out about people's perception if they had or not a good quality of life<sup>(9)</sup>. The term was widened after the 70's. It became a significant point of view when valuing effectiveness of various social interventions, not only in health areas, but also in all aspects impacting society<sup>(6)</sup>.

Just like other abstract concepts, quality of

life is a highly subjective construct, hard to define in an accurate manner<sup>(10)</sup>. It is a very wide and multidimensional concept, highly influenced by people's physical health, psychological status, independence, social relationships, as well as their relationship with their surrounding environment<sup>(11)</sup>.

Even though, currently there is no consensus about quality of life definition, there is a significant consensus about its importance, as it is an indicator for evaluating implemented interventions effectiveness, for handling diseases or the impact such diseases cause on patients<sup>(9)</sup>. Notwithstanding the foregoing, its measurement in our daily life has not been valued, as it is subjective.

In general terms, quality of life involves various areas, including mental/physical/social health of the subject. As previously mentioned, these aspects are severely affected in patients suffering dementia. Therefore –in time– its measurement has become a therapeutical objective, when evaluating patients with neurodegenerative diseases<sup>(12)</sup>.

Regarding how to measure this construct, there are many ways to face that; among them, we have self-reports, third parties evaluation and direct observation by an examiner. Regarding this, specific scales have been designed for measuring quality of life in patients suffering dementia<sup>(12,13)</sup>. However, currently there is not any validated scale in our country to be applied in patients suffering Alzheimer's dementia.

There are reports showing quality of life is impaired, both for patients suffering Alzheimer's disease and their caretakers. This condition could possibly improve with a symptomatic treatment<sup>(14,15)</sup>. Two main conditions have been deemed as significantly impacting patients' quality of life and their environment, namely - polypharmacy and depression<sup>(16)</sup>. That is why it is necessary to do research and management.

Regarding quality of life of patients suffering dementia, such condition would encompass four subjective/objective areas: level of competence, objective environment, psychological welfare and perceived quality of life<sup>(10)</sup>. As Alzheimer's disease is not curable, quality of life evaluation allows us to check whether if interventions and actions aimed to improve patients/care takers condition are effective (cli-

nically significant benefits)<sup>(17)</sup>.

### **Therapeutical Implications, based on quality of life**

As previously mentioned, currently there are no healing treatments for Alzheimer's disease, therefore, its management is made according to its symptoms, based mostly on what patients and their caretakers report, especially during advanced stages of this disease, where cognitive patients' capacities are severely impaired. Quality of life is one of the most significant parameters to be evaluated, both for the patient and their caretakers.

Unlike other countries, in Chile there are no validated scales for assessing quality of life in Alzheimer's disease. Therefore, its interpretation is subject to the examiner's criterion, based on the information provided by the patients and their caretakers. According to the aforementioned, there is a need to standardize measurement of this variable, in order to provide a more effective care and make it more objective for other professionals who take care of these patients.

It is important to highlight that recently -in our country- the Dementia National Plan (Plan Nacional de Demencias) has been implemented. Alzheimer's disease has been included within Health Care Warranties (Garantías Explícitas en Health, (GES)). These milestones have provided various recommendations for clinical/environmental management of these patients. Specifically, the Dementia National Plan (Plan Nacional de Demencias), which is aimed to empower multidisciplinary work, thus encompassing medical/social/psychological/phonoaudiologic/functional aspects. This model has internationally proven to significantly improve quality of life for patients who suffer Alzheimer's dementia and their care takers. It is cost-effective as well. Existing evidence in outpatient services (such as APS, in Chile) for managing patients who suffer dementia has proven to be successful in handling conduct symptomatology, mainly because the teams are closer, and deploy a better capacity to control and stimulate patients<sup>(18)</sup>.

These current programs are expected to raise awareness on the population, and especially on Health Agencies, about the urgent need to consider the relevance of this pathology. Because

of the neurodegenerative pattern of this disease, instead of decreasing its incidence, it will increase in the near future. It is quite relevant that every health professional is capable to recognize, intervene and properly refer, patients, whenever necessary.

### **FINAL CONSIDERATIONS**

As, in our population, Alzheimer's disease is a frequent type of dementia, internationally and locally it has become quite important, as well. During the last few years, new public policies, aimed to boost better search, handling and follow-up have arisen. Among them we can find its inclusion in the GES program, plus implementation of the Programa Nacional de Demencias (Dementia National Program). These programs are aimed to care for patients who suffer dementia, who may be cared for in their Community Health Centers. That is why, to provide an easy access tool for patients control has become quite necessary.

If we think quality of life is a significant element to be measured, we must foster deeper knowledge about it and see how this quality of life is affected, as the disease progresses. Additionally, it is important to consider other direct/indirect factors, such as elderly people's polypharmacy or adding another untreated mood disorder. This is a quite usual situation in elderly patients and in those people who have neurodegenerative diseases.

Patients' care takers quality of life of must be taken into account as well, as it directly impacts on patients who suffer dementia. If possible, we must try to improve caretaker's quality of life, which may become a significant support tool.

Current epidemiologic context compels us to optimize handling of neurodegenerative diseases, and additionally follow-up of patients and their environment. Therefore, quality of life seems to be a quite useful parameter for controlling health of our patients, considering that many of these diseases currently do not have a healing therapy.

That is why it is important that health professionals learn how relevant quality of life is in neurodegenerative pathologies, such as dementia. They must learn how its variability impacts on therapeutical decisions, and how --many

times-- clinical control of these patients is indirectly based on their quality of life. Having standardized tools to measure quality of life is becoming a growing need in the sanitary environment, both to be applied in patient and their caretakers, in order to have an objective measuring tool in time, thus indirectly monitoring clinical progress of the disease and the response to symptomatic treatment.

In short, quality of life in dementia is a concept we will use for the next few years. It has become a must for all health professionals who should learn about its nuances, considering care of every patient and learning how to use the information provided in our daily work, so that patients suffering from dementia have a better functionality in their daily life and may cope with their disease in a better manner.

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