

## Dementia in Mexico: The need for a National Alzheimer's Plan

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### Abstract

*Dementia is one of the facts than most contributes to the disability and dependence in elderly people. Alzheimer's disease is the cause more common of dementia in the world. In Mexico, the prevalence of Alzheimer's disease is 7.3% and incidence of 27.3 per 1,000 people/year. Mexican population studies have determined that Alzheimer's disease is highly associated to women and their risk to develop it is increased with metabolic syndrome, cardiovascular disease, or depression. The projections are that there will be 3.5 million elderly people affected by Alzheimer's disease by 2050 in Mexico; this will have a major impact on the healthcare system. The National Institute of Geriatrics from Mexico's Ministry of Health has released a first proposal for a National Alzheimer and Other Dementias' Plan. The central aim of this plan is to promote the well being of people affected by Alzheimer's disease and their families through of the strengthening of the Mexican healthcare system and the support of other responsible institutions. (Gac Med Mex. 2015;151:620-5)*

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### Dementia: a world-wide public health problem

Worldwide prevalence of dependence among older people is 13%. This figure reflects the transformation of worldwide requirements for their care due to the accelerated aging of population. Estimates are that between 2010 and 2050, the total number of dependent persons world-wide will almost double, with an increase from 349 to 613 millions, and more than one third of these people (with an increase from 101 to 277 millions) will be senior citizens. The increase in the number of old dependent people is disproportionately higher in emergent and developing countries.

In Mexico, unpaid care work (TNS – *trabajo no remunerado en salud*) is an area that represents 19% of

health gross domestic product GDP according to the report of the national health budget of 2011. This TNS reflects the economic burden of care in our country.

And, why open this discussion referring to dependence? Well, because its main determinant in old age is dementia. If long-term care of older people is already an enormous challenge for any health system, it is even greater if the particular needs of those with major cognitive deterioration, as dementia is now referred to, are considered. People affected by this condition require specialized care and trained personnel for their attention. This, beyond the nature of their condition, due to the comorbidity they have and that often contributes to disability and dependence and to an increase in the cost of their attention and care.

According to the report on disease global burden, dementia is estimated to have contributed with 12% of the years lived with disability in people older than 60 years.

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This is higher than the contribution of cardiovascular (9%) or musculoskeletal diseases (8%) and cancer (4%)<sup>1</sup>. Hence, world-wide economic impact by the care of dementia reaches US\$604 billion, which equates to almost half of Mexico's total GDP<sup>2</sup>.

Alzheimer's disease (AD) is a chronic, neurodegenerative and progressive condition characterized by alterations in cognitive processes, behavior and mood; it generates disability and dependence in those who suffer from it. AD is the most common type of dementia affecting old people. According to the worldwide report on AD, in 2010, nearly 35 million old people in the world suffer from it. This figure is estimated to increase to 66 million by 2030, and to reach a figure of 115 million people affected by 2050. This means that every 4 seconds there is a new case of dementia<sup>3</sup>. By 2020, an estimate of 60% of people affected with AD will live in developing countries, reaching up to 71% of all cases by the year 2040<sup>4</sup>. World-wide estimated prevalence for dementia in old age people ranges from 5 to 7%, distributed in 4 world regions. In the case of the Latin American region, prevalence reaches 8%, surpassing more economically developed countries, such as those in Northern America or Western Europe<sup>2</sup>.

The elevated prevalence and economic impact of the disease on families and caregivers, as well as the stigma and social exclusion thereof derived, represent an important challenge for public health. For this reason, the World Health Organization (WHO) and Alzheimer's Disease International (ADI) jointly developed in 2012 the report entitled: "Dementia: a public health priority"<sup>5</sup>. The central concepts of the report are:

- With appropriate support, people affected by dementia can and should be enabled to continue to engage and contribute within society and have a good quality of life.
- Primary caregivers require adequate support by the financial, legal, social and health systems.
- Countries must include dementia on their public health agendas, through coordination between different sectors.
- People with dementia and their caregivers should be involved in formulating the policies, plans, laws and services that relate them.
- Public and professional attitudes to, and understanding of, dementia should be improved.
- Investment should be made in social and health systems to improve care for people with dementia and their caregivers.
- Basic, clinical and social research favoring early and opportune detection should be increased.

As a reflection of AD global impact, during the past G8 World Leaders Summit held in the United Kingdom in 2013, a summons was issued to build an international effort addressing the problem of dementia<sup>6</sup>. The outstanding points of this declaration are:

- To promote quality of life improvement of people with dementia and their caregivers while reducing emotional and financial burden.
- To identify a cure for dementia before the year 2025.
- To share information on research funded for this purpose and to identify strategic priority areas for collaboration and cooperation between nations.
- To develop a coordinated international research plan of action to identify the current status of science on this field in order to identify gaps and opportunities that allow for a joint working plan to be generated.
- Access to information about research on dementia, respecting and protecting the individuals' privacy, as well as the legal and political guidelines of the countries where such investigation is carried out.
- To jointly work with the Organization for Economic Co-operation and Development (OECD) in order to consider the changes required to promote and accelerate the discovery of a cure.
- To recognize dementias as a growing threat to global health and support the countries to strengthen welfare and health systems in order to improve services and care for people with dementia.
- To jointly work with the United Nations on human rights for older people affected with dementia.
- To improve dementia prevention, care and treatment interventions.
- To involve civil society to continue with global efforts to reduce the stigma, exclusion and fear associated with this condition.

## **AD and other dementias in Mexico**

Currently, there are more than 13 million adults older than 60 years in Mexico; in this context, dementia-generated disability is a significant threat to the quality of life and autonomy of our elderly. Some of the sociodemographic risk factors for the onset of dementia are: social disadvantage and illiteracy, which promote early exposure to risk factors that alter the biological process of aging, and multimorbidity, in particular cardiovascular and metabolic (diabetes). On the other hand, limited access to health systems and heterogeneous quality of healthcare in this regard contribute to late diagnosis; and the lack of a long-term care system makes for the burden of care to entirely fall on the families.

The first national study on cognitive deterioration prevalence and associated factors in older people was conducted with data from the National Study on Health and Aging in Mexico (ENASEM – *Estudio Nacional sobre Salud y Envejecimiento en México*) in 2001. At that moment, 7% of the Mexican population had minor cognitive deterioration and 3.3% major cognitive deterioration, with functional dependence. Prevalence was higher among females and at older age. Most clearly associated factors were: illiteracy, diabetes, cerebrovascular disease, heart disease and depression<sup>7</sup>. The results obtained 6 years later by ADI's 10/66 Dementia Research Group show a markedly higher prevalence. This research group conducted population-based surveys of dementia prevalence from 2003 to 2007 in 14 areas from ten low- and middle-income countries (Brazil, China, Cuba, Dominican Republic, India, Mexico, Nigeria, Peru, Puerto Rico and Venezuela). The assessment methodology was rigorously standardized in order to ensure its comparability. At each center, between 1000 and 3000 people were assessed. The studies have the same core information, established by means of cross-culturally validated assessments (dementia diagnosis and subtypes, mental disorders, physical health, demographics, anthropometry, general questionnaires on risk factors for non-transmittable diseases, disability/functioning, health services utilization, care planning and care provision and caregiver strain). The final result is a unique resource of directly comparable data, comprising 21,000 older adults from three continents. The information obtained in these studies has allowed for the prevalence of dementia in Mexico for urban areas to be established at 7.4% and for rural regions at 7.3%<sup>8</sup>. An incidence phase was completed in 2010, following up participants 3-5 years after baseline in China, Cuba, Dominican Republic, Mexico, Peru and Venezuela. This phase of the project included over 12,000 older people and provided in excess of 35,000 person-years of follow-up, making it the largest study of the incidence of dementia and associated factors ever conducted. The data obtained from this study for the incidence of dementia in Mexico were 16.9 per 1,000 person-years for urban regions and 34.2 per 1,000 person-years for rural regions, with a mean of 25.55 per 1,000 person-years<sup>9</sup>. These results have been confirmed by incidence data obtained through the ENASEM, where a dementia incidence of 27.3 cases per 1,000 person-years is estimated nation-wide in adults older than 60 years. The risk factors for incident dementia identified in this cohort are in decreasing order of importance: pre-existing functional instrumental deterioration, presence of diabetes, sensory

deterioration (auditive and/or visual), depression, age and female sex<sup>10</sup>. On the other hand, currently we also have, for the first time, data on prevalence originating in the 2012 National Survey on Health and Nutrition (ENSA-NUT 2012 – *Encuesta Nacional de Salud y Nutrición 2012*). This survey confirms, now nation-wide, the figures for prevalence found in Mexico City and the State of Morelos in the 10/66 study, as well as the associated factors<sup>11</sup>.

The most significant risk factors associated with the development of AD in older people in Mexico are the presence of diabetes and metabolic syndrome. A case-control study conducted in 270 Mexican elderly patients showed that, among patients with AD, the probability of having metabolic syndrome was nearly seven-fold higher than in patients without dementia<sup>12</sup>. The genomic risk factor most strongly associated with AD is the presence of the apolipoprotein e4 (*APOE-e4*) allele. Available studies demonstrate that Mexican-origin hispanics and Mexicans themselves are less prone to carry an *APOE-e4* allele and have lower risk for *APOE-e4* allele-associated AD than non-hispanic whites. These findings are consistent with previous publications that report on similar *APOE-e4* allele frequencies between hispanics and caucasians, and also find a significant association between the *APOE* genotype and AD for caucasians, but not for hispanics<sup>13,14</sup>. This apparent paradox might be explained by the greater relative weight of other highly prevalent risk factors in this population, as it is the case of social disadvantage<sup>14</sup>.

## The need for an APA in Mexico

The economic impact that represents the expenditure for TNS resulting from the care of people affected with dementia in the American continent is approximately US\$236 billion. In the case of Mexico, estimated total cost per capita is US\$6,157 for the care of a person with dementia. The proportion of patients with dementia that require specialized care is 40% of total affected subjects. Catastrophic out-of-pocket expenditure reaches up to 60% of the families that assume the care of a person affected with dementia<sup>15</sup>.

According to data presented on dementia prevalence in Mexico, 86,000 affected persons are estimated to exist in the country in 2014. The projection of the number of dementia-affected Mexicans for the year 2050 will reach the alarming figure of 3.5 million and, therefore, the impact of the disease on economic, social and health systems will be even more serious. The economic impact associated with the care of a person affected with AD, the lack of a cure that prevents progressive

deterioration, disability and dependency; the heavy physical and emotional load for the family and caregivers, as well as limitations prevailing in the healthcare system with this regard often have us confronted with ethical dilemmas. The first challenge that arises in this regard is: how to live well with dementia?, i.e., how to live with dignity and quality of life for those who suffer from the disease and those surrounding them? And then: how to answer to the needs determined by this disease only with the available medical, familiar and social resources?

On the other hand, over the past few years we have been accumulating evidence with regard to the possibility to prevent, or at least postpone, the incidence of these conditions. Notably, the prevalence of dementia and cognitive deterioration in some western countries is now lower than expected, probably as a result of lifestyle changes and reduction of cardiovascular risk factors, although this might not necessarily mean that world tendencies in the burden of dementia are going to be substantially reduced. Additionally, approximately half of the AD cases in the entire world have been estimated to likely be attributable to known risk factors. Taking immediate action against known risk factors perhaps would prevent up to a fifth part of the new cases predicted for 2025. The prevention of dementia would not only avoid suffering, but would also spare large amounts of money. Scientific advance has yielded enough proofs to justify immediate action. Currently, studies are ongoing, and should be replicated, aimed at people at risk for the development of dementia with a range of interventions: exercise, glycemic control, including the treatment of diabetes, treatment of arterial hypertension, vitamins of the B-group, omega-3 fatty acids, cognitive training and social activities.

Public health policies should encourage older people to stop smoking, practice exercise, consume diets rich in fruits and vegetables and fish (Mediterranean diet), avoid becoming obese, avoid excessive consumption of alcohol and treat high blood pressure. In other words: adopting a healthy lifestyle can help to draw dementia away as it is done with other diseases.

In view of all the above, the National Institute of Geriatrics of Mexico's Ministry of Health, together with organized civil society interested in improving comprehensive care for Mexicans who suffer from some kind of dementia, have promoted the creation of a first proposal for an Alzheimer's Plan of Action (APA)<sup>16</sup>.

The core objective of the APA is to promote the wellbeing of people with AD and related conditions and of their families, by strengthening the response of the Mexican Healthcare System, in synergy with all responsible

institutions. In order to fulfill this objective, four guiding lines have been determined: 1) to increase awareness-raising on the problem; 2) to de-stigmatize; 3) to promote wellbeing for both affected people and their families, and 4) to prioritize the care of this condition.

To successfully accomplish all this, thorough and coordinated inter-institutional work is required, in order for public health bodies, social development sector and organized civil society's concerted approach strengthen and enrich it to efficaciously deal with the noxious effects of this disease, while favoring better quality of life at the individual level and higher social visibility of this condition.

To ensure the success of the proposed APA's objectives, a feasible proposal has been formulated, without duplicity of resources and oriented to the specific needs of the Mexican population. In order to achieve this, the APA has been aligned with two of the national goals: An Including Mexico and Mexico with Quality Education, which are part of the National Plan of Development (2013-2018) of the Federal Government. In addition, the APA has been aligned with the objectives of the Sectorial Health Program (2013-2018), through: a) consolidation of health protection and promotion and disease prevention actions; b) granting effective access to quality health services, and c) ensuring the generation and effective use of health resources.

Strategies and specific actions proposed in the APA are presented in table 1.

In summary: AD and other related diseases inexorably progress with age. As of 85 years of age, one woman out of each 4 and one man of each 5 are affected; overall, more than 800,000 Mexicans are estimated to suffer from some of these conditions. The WHO recognizes it as a public health priority in middle-income countries such as ours.

In the face of the triple scientific, medical and social challenge this represents, the National Institutes of Health, led in this case by the National Institute of Geriatrics, the National Institute for the Elderly and the Mexican Federation of Alzheimer, have prepared a proposal for a Plan of Action to face these diseases with specific actions.

Focused on the patient and his/her family, the Plan attempts to promote an unprecedented effort in the prevention, the promotion of early diagnosis and the support of patients and their caregivers.

During our work in the preparation of the Plan, we never forgot those for whose welfare we have been developing it: people with AD and other related dementias and their families. All members of the work group dedicate a significant part of our daily efforts to these patients and, therefore, there is no exaggeration

**Table 1. Strategies and specific actions proposed in the APA**

Strategies	Actions
1. Prevention and promotion of mental health	<ul style="list-style-type: none"> <li>- To consider dementia as a relevant public health problem.</li> <li>- To raise awareness in the population in order to favor mobilization around dementia.</li> <li>- To strengthen prevention campaigns against diabetes, obesity, hypertension and physical inactivity, in order to reduce risk factors associated with dementia.</li> <li>- To integrate civil society, private institutions and industry in the fight against dementia.</li> <li>- To promote the care of mental health through all stages of human development.</li> </ul>
2. To ensure access to quality services	<ul style="list-style-type: none"> <li>- To have human, material and financial resources available according to the number of patients with dementia at all three levels of health care.</li> <li>- To improve the quality of geriatric, neurological and psychiatric care in order to achieve comprehensive medical management at advanced stages of the disease.</li> <li>- To strengthen community- and family-based care with a comprehensive outpatient care, not hospital-based, vision for the long-term care of patients with dementia through specific rehabilitation programs.</li> <li>- Establishment, growth, maintenance and regulation of daycare centers as an alternative for the comprehensive management of the patient with dementia at early stages of the disease.</li> <li>- To assign the tertiary care level for the study and management of difficult cases for adequate differential and final diagnosis.</li> </ul>
3. Opportune diagnosis and treatment of people affected by the disease	<ul style="list-style-type: none"> <li>- To create a comprehensive care model that responds to activities of each level within the national health system in our country.</li> <li>- To strengthen education and training of healthcare professionals, especially at the primary care level, in order to detect affected persons at early stages of the disease.</li> <li>- To reduce the impact of disability and dependence at the individual, familiar and economic level.</li> <li>- To create a training, assessment and care model for primary caregivers and family members.</li> <li>- Generation of an online inter-institutional communication network between healthcare professionals for update and feedback of personnel involved with the care of this condition.</li> <li>- To identify, through an updated catalogue, all human, material and financial resources available in each public institution attending patients with dementia to make a more efficient use of available resources.</li> </ul>
4. Training of specific and sufficient human resources	<ul style="list-style-type: none"> <li>- To continuously increase the number of specialists to provide care for patients with dementia, in agreement with the needs of the country.</li> <li>- To implement permanent training programs in order to keep healthcare professionals and non-professional personnel updated.</li> <li>- To promote the inclusion of contents on aging during the pre-grade and post-grade training of all healthcare professionals, with an emphasis on subjects associated with dementia.</li> <li>- To promote advanced strategies in the training of human resources, taking advantage of new information technologies and inter-institutional collaboration.</li> <li>- Creation of grants for the training of non-physician healthcare professionals specialized on the care of older people with dementia.</li> <li>- To promote counseling to the families for better care and management of their relatives affected by dementia.</li> </ul>
5. Promotion of respect to the human rights of people affected with dementia and their caregivers	<ul style="list-style-type: none"> <li>- To promote the combat against discrimination at all levels.</li> <li>- To inform older people in situation of disadvantage on their human rights and let them know the forms to access to adequate services and places in case of need, particularly in case of being victims of abuse or discrimination.</li> <li>- To treat informal caregivers as partners who require support.</li> <li>- To continuously incorporate civil organizations in the activities of public and private institutions in order to broaden the diffusion.</li> </ul>
6. Increase research on dementia	<ul style="list-style-type: none"> <li>- To include the research on aging with an emphasis on applied research studies to improve treatments and the cure of the disease as a priority in the demands for sectorial research funds.</li> <li>- To favor inter-institutional bonds with national and international scientific groups around the disease.</li> <li>- To increase and strengthen investigation on the subject, through collaboration between the different scientific groups that comprise the <i>Red Temática Conacyt: Aging, Health and Social Development</i>, throughout the country.</li> <li>- To promote research on public health around the subject of aging, with particular emphasis on the subject of dementia, on behalf of academic and scientific institutions.</li> <li>- To develop new sources of information for the construction of a permanent epidemiological surveillance system for the monitoring of cases of dementia in Mexico.</li> <li>- Establishment of an inter-institutional collaboration network for molecular, clinical and imaging diagnosis of the disease, with the scope being national.</li> </ul>

Continue

**Table 1. Strategies and specific actions proposed in the APA (Continued)**

Strategies	Actions
7. Periodically assess the effectiveness of the proposed actions	<ul style="list-style-type: none"> <li>– Creation of a Consulting Group that assesses the relevance and viability of the proposed actions, as well as the mechanisms to execute them.</li> <li>– Generation of assessment tools to measure the impact of the implemented actions.</li> </ul>
8. Long-term care in the last stages of the disease	<ul style="list-style-type: none"> <li>– Creation of programs and training on palliative care for family members and healthcare personnel.</li> <li>– Educational programs on the rights of people at the end of life, including subjects such as wills and advance directives.</li> <li>– Adaptation of the domicile with a safe environment.</li> <li>– Facilities to the family primary caregiver, in terms of time and forms of care.</li> <li>– Legal, social and financial assistance to prevent abuse, violence or negligence in the care of the person with dementia.</li> <li>– Psychological and spiritual support programs.</li> <li>– Programs of subsidies or low cost support for funeral expenses and purchase of essential medications for domiciliary palliative care. For example, pain control.</li> <li>– To establish palliative care multidisciplinary healthcare teams, in order to avoid unnecessary hospital admissions.</li> <li>– Financial support, especially for affected people of low economic resources.</li> <li>– Creation of relief or rest units for primary caregivers.</li> </ul>

when we say that this affects us as well and, maybe because of this, we recommend a deeply humanistic and compassionate approach, focused on the person and concerned with the quality of care.

Although our interest is especially directed to people affected by this scourge, to which we owe respect and excellence in their care under any circumstance, we also worry about the members of their families, who support them in a daily basis with affection, courage and frequently at the expense of huge sacrifice. We also worry about healthcare services members, whose competence, professionalism and dedication are key elements for the successful execution of the Plan of Action, and for whom we have developed specific training programs<sup>17</sup>. Concurrent efforts by non-governmental organizations devoted to the care of these persons, under the guidance of the Mexican Federation of Alzheimer, is also key, since their members generously offer their time and energy; as also are the investigators who, motivated by the vision of future therapeutic successes, struggle to attain a better understanding of the disease in all its forms.

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