## JNHA: CLINICAL NEUROSCIENCES

# **CONSENSUS STATEMENT ON DEMENTIA EDUCATION AND TRAINING IN EUROPE**

# M. TSOLAKI<sup>1</sup>, V. PAPALIAGKAS<sup>2</sup>, G. ANOGIANAKIS<sup>2</sup>, R. BERNABEI<sup>3</sup>, M. EMRE<sup>4</sup>, L. FROLICH<sup>5</sup>, P.J. VISSER<sup>6</sup>, J.-P. MICHEL<sup>7</sup>, T. PIRTTILA<sup>8</sup>, M. OLDE RIKKERT<sup>9</sup>, H. SOININEN<sup>8</sup>, T. SOBOW<sup>10</sup>, B. VELLAS<sup>11</sup>, F. VERHEY<sup>6</sup>, B. WINBLAD<sup>12</sup> AND THE EUROPEAN ALZHEIMER DISEASE CONSORTIUM

1. 3rd Department of Neurology, Aristotle University of Thessaloniki, Greece; 2. Department of Experimental Physiology, Aristotle University of Thessaloniki, Greece; 3. Department of Gerontology, Catholic University Sacred Heart, Rome, Italy; 4. Department of Neurology, Istanbul Faculty of Medicine, Istanbul University, Turkey; 5. Abteilung für Gerontopsychiatrie, Zentralinstitut für Seelische Gesundheit, Medizinische Fakultät Mannheim, Universität Heidelberg; 6. Department of Psychiatry and Neuropsychology, University of Maastricht, The Netherlands; 7. University of Geneva Medical School, Switzerland; 8. Department of Neurology, University of Kuopio; 9. Department of Geriatrics, Radboud University Nijmegen Medical Centre; 10. Department of Old Age Psychiatry & Psychotic Disorders, Medical University of Lodz, Poland; 11. Department of Geriatric Medicine, University of Toulouse; 12. Department of Geriatrics, Stockholm, Sweden. Corresponding author: Vasileios T. Papaliagkas, MD/PhD, Department of Experimental Physiology, Faculty of Medicine, Aristotle University of Thessaloniki, 18 Amfoterou street, 54250 Thessaloniki, Greece. Tel. Number: +302310313178, Fax number: +302310313178, e-mail address: vpapal@auth.gr

> Abstract: Objectives: The aim of the current statement is to agree on: (1) what is the current situation with education and training on dementia in Europe; (2) what are the minimum educational requirements for professionals (neurologists, psychiatrists, primary care providers, nurses, biologists, neuroradiologists, etc.) regarding Alzheimer's disease and dementia, and (3) how to start a course of action for the future. Design: In 2005, a simple questionnaire was sent to members of the European Alzheimer's Disease Consortium (EADC) concerning the education and training on dementia in their countries. Fourteen universities of the respective countries responded to this simple questionnaire. The answers varied, and the conclusion of this effort was that little was done concerning the training of students and health professionals on dementia. In 2008, another more structured and specified questionnaire was sent to professors in different universities of the same countries. Results: The answers obtained were different from those of the previous questionnaire and demonstrated that it is very difficult to know about training and education in the field of dementia in every European country. Conclusion: From the data collected, it seems that although in the recent past little had been done concerning training on dementia, nowadays training has been developed in most European countries, and relevant educational projects exist both for medical students and doctors during their specialty training. Our main purpose is to develop training material or develop specific courses to improve the professional knowledge about dementia so that best medical and non-medical practice is implemented.

Key words: Education, Alzheimer's disease, dementia, consensus statement, Europe.

#### Introduction

Alzheimer's disease (AD) is a neurodegenerative disease that slowly and progressively destroys the brain. In 1907, Alois Alzheimer first described the symptoms as well as the neuropathological features of Alzheimer's disease such as plaques and tangles in the brain (1). The disease affects memory and other cognitive abilities (e.g., thinking and speaking, etc.), but it can also lead to other problems such as confusion, changes of mood, and disorientation in time and space. AD is the most common cause of cognitive impairment in elderly, with an incidence that doubles every five years after the age of 60 years (2). This disease affected approximately 24 million individuals worldwide in the year 2002 (3), 25 million in the year 2005, and is expected to be over 80 million cases by 2040 (4). It is estimated to cost the world economy over \$315 billion (5) and the U.S. economy \$100 billion annually (6, 7).

The last decade has witnessed serious advances in the clinical diagnosis and treatment of Alzheimer's disease, and several professional organizations and workgroups have developed consensus statements and guidelines for its'

diagnosis and treatment. Namely, the European Federation of Neurological Societies (EFNS) has produced guidelines (8), and Guidelines from the National Institute for Clinical Excellence (NICE) (9), Guidelines of the German Society of Neurology (10), Italian Guidelines (11), Canadian Guidelines (12, 13), and British Guidelines (14) have been developed.

Despite the rapid increase in the knowledge of epidemiology, genetics, risk factors and underlying neuropathological mechanisms, there is no cure for AD yet. At the same time, in comparison, little has been done concerning the education of professionals on dementia and AD.

In one recent study (15), data on the education of European neurologists on dementia were collected from 25 European countries that were members of the European Federation of Neurological Societies Scientific Panel on Dementia. According to the results of this study, there was a gradual decrease in teaching activity from medical school to specialty. In most countries, the teaching of medical students about dementia is obligatory, whereas there is no formal obligatory education on dementia after graduation from medical schools. Moreover, in half of the countries that participated in the study,

# CONSENSUS STATEMENT ON DEMENTIA EDUCATION AND TRAINING IN EUROPE

obligatory dementia courses were part of training during the specialty of neurology. Furthermore, based on published European guidelines, national guidelines for dementia management should be published in all countries. There is a great need for education and training of all health professionals worldwide in order to be able to diagnose and treat dementia.

The objectives of the present consensus statement are:

1. To describe, in detail, the situation of educational programs about dementia in Europe in the years 2005 and 2008.

2. To propose rules and guidelines on the education of professionals (neurologists, psychiatrists, primary care providers, nurses, biologists, neuroradiologists, psychologists, ergotherapists, physiotherapists, dentists) on the subject of Alzheimer's disease.

## Previous efforts in reaching consensus

In 1997, a report on knowledge and attitudes about dementia was organized by the European Medical Association in collaboration with Pfizer Pharmaceuticals (16). With regard to the key objectives of the research, doctors from ten European countries responded as to: (a) the level of their knowledge about dementia, (b) their attitudes towards the diagnosis of the disease and its management/follow-up care, and (c) their approach to the treatment of the disease. The conclusions of this survey were:

1. The level of knowledge about dementia was variable with general practitioners (GPs), and they asked for more theoretical data on dementia along with information to help them in diagnosing dementia.

2. GPs accepted that the care of patients with mental illness should involve a close collaboration between themselves and the patients, especially considering how long it takes.

3. hey realized that they have a pivotal role in the longterm care/management of patients with dementia and that they clearly need to be more knowledgeable about all the aspects of dementia.

4. They perceived that they have a role in caring for the family as well as the patient, and they welcomed any additional information/resources that can be made available to them.

Another European Educational project for Professionals was prepared by Janssen-Cilag (17). The purpose of this project was to disseminate information about the different forms of dementia including research, diagnosis, investigation, meaningful activity and treatment options. The objectives of this project were:

1. To improve the overall level of care of dementia patients.

2. To gain a better understanding of dementia nursing care principles and of relations with confused people.

3. To understand what the care of people with dementia means for staff.

4. To develop nursing care and employee training.

5. To redress deficiencies in further training in the field of dementia.

6. To improve cooperation between professionals, relatives, and institutions.

7. To pass on, exchange, and develop well-established tips and tricks.

### Methods

Our consensus building process began in 2005 (18, 19) and was started by a simple questionnaire consisting of five questions that were circulated to all EADC members asking:

1. Are there any relevant educational programs running in their country, and if so, how could these be connected with the consortium aim?

2. Who sponsors these programs?

3. Who teaches in these programs?

4. The contact details (name and e-mail) of one person from each scientific team that would be responsible for collaborating with the consortium regarding the preparation of our consensus statement.

5. To check the information provided in the consensus statement and correct any elements that in their opinion were not correct.

Fourteen representatives of their countries answered to this questionnaire. According to their responses, little had been done at that time concerning professional training on dementia. In most countries, there were no educational programs, or there was little or no financial support, therefore a lot of action should be taken in order for it to reach a satisfactory standard. In particular, we would like to point out that France and the UK were the only countries in 2005 where such training programs existed, supported by the French and British Ministries of Health, respectively. Unfortunately, in Italy and Switzerland, which are countries with a tradition of medical and university education, there was nothing reported to promote dementia training, at least according to the contact persons that gave the information.

At the beginning of 2008, another questionnaire, approved by the members of the European Alzheimer Disease Consortium (EADC), was distributed to different EADC centers of the same European countries as in 2005, in order to compare the current situation between the European countries. The questionnaire consisted of more specific questions such as:

1. How many hours of dementia training in your University are spent for medical students and during which year of their education?

2. Which health professionals participate in this training?

3. How many hours did pharmaceutical companies spend educating physicians during the last year?

4. How many hours do the scientific and family Alzheimer associations spend educating physicians per year?

5. Is there any dementia teaching for doctors during their specialty training? If so, how many hours?

Ten university professors participating in the EADC responded to this questionnaire. Moreover, national neurological, psychiatric, and Alzheimer societies and associations were contacted. We also sent the same questionnaire to pharmaceutical companies. Finally, following

# JNHA: CLINICAL NEUROSCIENCES

an extensive discussion among its members, the European Alzheimer Disease Consortium prepared a consensus statement about the current situation in Europe.

# Results

The data collected from the European countries that answered the 2008 questionnaire are presented below and in Table 1.

# **Medical Students**

Dementia training in medical students was present in all countries that answered the questionnaire. Not all countries that were contacted responded to our questionnaire. Medical school consisted of six years in all countries that participated in the study. The mean  $\pm$  SD time spent for dementia training was 12.30 $\pm$ 8.67 hours, and it ranged from 3 hours (in Switzerland and Turkey) to 30 hours (in Sweden) (Figure 1).

# Specialty Training

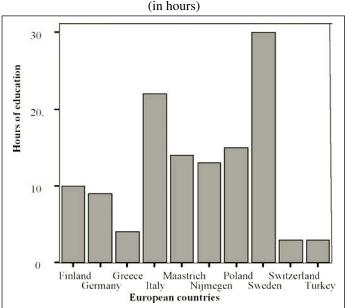
There is a great variation in the time spent for dementia training and education during medical specialty training. Since dementia is a multifactorial disease, its treatment is multidisciplinary, and the medical specialties that are involved are neurology, psychiatry, and geriatrics. In Holland, according to the Nijmegen center, dementia training takes place only in the specialty of geriatrics. It is interesting to note that the most time for dementia training and education during specialty (neurology, psychiatry, and geriatrics as mentioned above) is spent in Switzerland (12 months), where the least amount of time is spent for education of medical students. In two countries, education on dementia during the above specialty training is optional. In particular, in Finland, there is a sixmonth optional training on dementia, and in Poland, there is no specific dementia training but facultative meetings of about six to eight hours.

Table 1				
Dementia education for medical students and doctors during specialty training				

	COUNTRY (EADC center)	PROGRAMS FOR MEDICAL STUDENTS AND DOCTORS DURING SPECIALTY TRAINING	TEACHERS	HOURS PER YEAR SPENT ON EDUCATION OF PHYSICIANS
1	Switzerland (Geneva)	3 hours for medical students and 12 mandatory months during specialty	Doctors (specialty is not specified)	One session of two hours each year from scientific associations
2	Holland (Maastricht)	<ul><li>8 hours theoretically, 4-8 hours during practical training for medical students.</li><li>4 hours during specialty</li></ul>	Old age psychiatrists, neurologists, geriatricians	No data
3	Sweden (Stockholm)	30 hours during the second year for medical students, for doctors during specialty varies throughout the country	Physicians and other staff from the dementia ward	30 hours from family associations. Not allowed from pharmaceutical companies
4	Finland (Kuopio)	10 hours for medical students, 6 month training in dementia is suggested but not obligatory in specialty	Neurologists and geriatricians	2 days/month from pharmaceutical companies, 1 day/month from scientific associations, 1 week/month from family associations
5	Poland (Lodz)	15 hours during the sixth year of studies for medical students, 6-8 hours for doctors during their specialty	Psychiatrists and geriatricians	10 hours from pharmaceutical companies, 20 hours from scientific associations, none from family associations
6	Holland (Nijmegen)	<ul><li>13 hours for medical students,</li><li>40 hours during geriatrics</li></ul>	Neurologists, Geriatricians, Psychiatrists, Nursing home medicine doctors	6 hours from pharmaceutical companies, 8 hours from family and scientific associations
7	Germany	9 hours for medical students	Professors (medical doctors)	30-100 hours from pharmaceutical companies
8	Italy (Rome)	22 hours for medical students	No data	<ul><li>6-8 hours from pharmaceutical companies,</li><li>10-14 hours from scientific associations,</li><li>1 hour from family association</li></ul>
9	Turkey (Istanbul)	3 hours of lectures	No data	No formal education program from Alzheimer Society, meetings from pharmaceutical companies
10	Greece (Thessaloniki)	4 hours of lectures for medical students	Neurologists and Psychiatrists	Seminars and conferences organized by Greek Association of Alzheimer's Disease, Neurological Society, Psychiatric Society, General Practitioner's Society in cooperation with pharmaceutical companies

## CONSENSUS STATEMENT ON DEMENTIA EDUCATION AND TRAINING IN EUROPE

Figure 1 Education and training on dementia in medical school



#### **Dementia Educators**

Since the medical specialties involved in dementia management are neurology, psychiatry, and geriatrics, health professionals that are responsible for dementia training are doctors, in particular psychiatrists, neurologists, and geriatricians. Neurologists do not participate in dementia training in one country (Poland), whereas in Holland, according to the answers of the Nijmegen center, nursing home doctors are among the doctors responsible for training.

In Greece, a National Conference on Alzheimer's disease and Related Disorders has taken place every two years since 2000. During this conference, where more than 1000 health professionals participate, several educational programs for psychologists, social workers, physiotherapists, ergotherapists, logotherapists, dentists, etc. are organized. Similar conferences are organized in other countries as well.

# Associations and pharmaceutical companies involved in the education of physicians

In Finland, pharmaceutical companies and scientific and family associations offer more time for the education of physicians. On the other hand, in three of the countries that responded, family Alzheimer associations are not actively involved in the education of physicians, although in two of them (Sweden and Germany) they are involved in the education of the patients and their relatives (no data was included from one center). Although pharmaceutical companies are involved in dementia training in the majority of the countries that participated in this consensus statement, but not any more in Sweden, they did not provide us with information about their educational programs. From the data collected from European countries, it was observed that in most of them, pharmaceutical companies and scientific associations are responsible for the education of health professionals on dementia in most of them. Only in Sweden are pharmaceutical companies not allowed to perform training on the area of dementia. Scientific associations are involved in dementia education in 60% of the countries that participated in this consensus statement. On the other hand, the role of family associations in dementia training is reduced. They participate in dementia training in less than half (40%) of the countries studied. Therefore, the role of these associations in organizing courses for dementia teaching and training should be enhanced.

#### Discussion

Everybody who provides care for patients with Alzheimer's disease or their families should be able to receive formal education and professional training. All care providers including (a) physicians, (b) nurses, (c) social workers, (d) support group leaders, and (e) biologists who are involved in the diagnosis and treatment of Alzheimer's disease should be adequately trained, especially neurologists, who should be the most involved in the diagnosis and management of dementia. Also, training on dementia must be included in the curriculum of medical schools, taking into consideration that it is a disease affecting millions of elderly people worldwide, and its prevalence is continuously growing over the years. Moreover, dementia training should be included as compulsory in neurology and geriatric specialty training. Experts in the field of dementia should be responsible for this training.

It seems that professional training on dementia has been greatly developed recently, in contrast to what was recorded in our previous study (18) three years ago, in which some countries were reported not to have any type of dementia training. However, along with the observation that there were different answers from centers in the same country, this difference might be due to the fact that the training programs vary, and there is no standard dementia training in each country. Therefore, the results we had in each study varied according to the university that responded to the questionnaire. In the countries that participated in our consensus statement, such training programs are provided for medical students during their studies and doctors during their specialty training.

Compared to the study of Hasselbalch et al., (15) no progressive decrease in teaching activities from undergraduate to postgraduate studies was observed in our study. Moreover, our consensus includes the role of the pharmaceutical companies in the education of physicians on dementia and the hours spent on dementia training for medical students and doctors during specialty training (in the university, from pharmaceutical companies, and scientific associations).

Pharmaceutical companies and scientific associations play a major role in preparing such programs. In Poland,

# JNHA: CLINICAL NEUROSCIENCES

pharmaceutical companies have prepared such educational projects. In Finland, the organizations that are coordinating training in dementia are Finnish Alzheimer Research and the Finnish Alzheimer Association. In Greece, universities and scientific associations (neurological, psychiatric, Association of Alzheimer Disease and Related Disorders) have the main role in the education sponsored mainly by pharmaceutical companies (Novartis, Pfizer, Janssen, Lundbeck).

Education and training of doctors on dementia should take place at all stages (medical school, during specialty, after specialty). Moreover, dementia training for care providers must include instruction in several relevant dimensions. Emphasis should be given in the areas of early detection and diagnosis of dementia, e.g., through the most recent neuroimaging techniques (MRI, PET, SPECT, fMRI), CSF biomarkers, and electrophysiological methods (EEG, ERPs). Moreover, there should be a continuous update of information and knowledge on new methods and research being performed for the pharmacological and non-pharmacological treatment of Alzheimer's disease. What is also very important is the development of a very good, friendly, and trusting relationship between the patient and the health care provider, therefore specific attention should be given in the development of communication with the patient and elements such as respect, support, compassion, and humor. The trainers should be at a Master's level or above, professionals with well-known scientific status and expertise in the field of aging and dementia care. After the end of the professional training, each participant should receive a certificate of completion. Useful information like telephone numbers of local support services, contact information for dementia care specialists, and web page addresses containing information on dementing diseases, should be provided for free for anybody, either patient, caregiver, or health professional. After the French initiative for dementia to be a European Priority, we suggest development of a European Educational Program, which could run in all European countries.

National Alzheimer's associations and other scientific associations all over the world need to encourage their respective governments to train more health professionals in all areas of dementia care. Each government, and also pharmaceutical companies and local scientific associations should support and fund the development of dementia care training and research centers. Furthermore, conferences and seminars should be held and supported by all associations mentioned above, regarding all aspects of AD. These conferences and seminars should be open both to health professionals and caregivers. These actions could give a great stimulus to the diagnosis and treatment of AD.

### References

- Alzheimer A. Über eine eigenartige Erkrankung der Hirnrinde Allgemeine Zeitschrift fur Psychiatrie und Psychisch-gerichtliche Medizin. 1907
- Wimo A, Ljunggren G, Winblad B. Costs of dementia and dementia care: a review. Int J Geriatr Psychiatry 1997; 12: 841-56
- Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, Burke JR, Hurd MD, Potter GG, Rodgers WL, Steffens DC, McArdle JJ, Willis RJ, Wallace RB. Prevalence of dementia in the United States: the aging, demographics, and memory study. Neuroepidemiology. 2007;29:125-132.
- Ferri C, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Scazufca M. Alzheimer's Disease International: Global prevalence of dementia: a Delphi consensus study. Lancet. 2005;366:2112–2117.
- Wimo A, Winblad, B, Stoffler A, Wirth Y, Mobius HJ. Resource utilisation and cost analysis of memantine in patients with moderate to severe Alzheimer's disease. Pharmacoeconomics. 2003;21:327–340.
- Fillit H, Hill J. Economics of dementia and pharmacoeconomics of dementia therapy. Am J Geriatr Pharmacother. 2005;3:39-49.
- Meek PD, McKeithan K, Schumock GT. Economic considerations in Alzheimer's disease. Pharmacotherapy. 1998;18:68-73.
- Waldemar G, Dubois B, Emre M, Scheltens P, Tariska P, Rossor M. Diagnosis and management of Alzheimer's disease and other disorders associated with dementia. The role of neurologists in Europe. European Federation of Neurological Societies. Eur J Neurol. 2000;7:133-144.
- National Institute for Clinical Excellence. Guidance on the use of donepezil, rivastigmine and galantamine for the treatment of Alzheimer's disease. Available from URL: http://www.nice.org.uk/pdf/ALZHEIMER\_full\_guidance. pdf [Accessed 16 June 2009].
- Ruof J, Mittendorf T, Pirk O, von der Schulenburg JM. Diffusion of innovations: treatment of Alzheimer's disease in Germany. Health Policy. 2002;60:59-66.
- Caltagirone C, Bianchetti A, Di Luca M, Mecocci P, Padovani A, Pirfo E, Scapicchio P, Senin U, Trabucchi M, Musicco M; Italian Association of Psychogeriatrics. Guidelines for the Treatment of Alzheimer's Disease from the Italian Association of Psychogeriatrics. Drugs & Aging 2005; 22:1–26.
- Patterson CJ, Gauthier S, Bergman H, Cohen CA, Feightner JW, Feldman H, Hogan DB. The recognition, assessment and management of dementing disorders: conclusions from the Canadian Consensus Conference on Dementia. CMAJ. 1999;15: S1-15.
- Hogan DB, Bailey P, Black S, Carswell A, Chertkow H, Clarke B, Cohen C, Fisk JD, Forbes D, Man-Son-Hing M, Lanctôt K, Morgan D, Thorpe L. Diagnosis and treatment of dementia: 4. Approach to management of mild to moderate dementia. CMAJ. 2008;179:787-793.
- 14. Burns A, O'Brien J, BAP Dementia Consensus group, Auriacombe S, Ballard C, Broich K, Bullock R, Feldman H, Ford G, Knapp M, McCaddon A, Iliffe S, Jacova C, Jones R, Lennon S, McKeith I, Orgogozo JM, Purandare N, Richardson M, Ritchie C, Thomas A, Warner J, Wilcock G, Wilkinson D; British Association for Psychopharmacology. Clinical practice with anti-dementia drugs: a consensus statement from British Association for Psychopharmacology. J Psychopharmacol. 2006;20:732-755.
- Hasselbalch SG, Baloyannis S, Denislic M, Dubois B, Oertel W, Rossor M, Tsiskaridze A, Waldemar G. Education and training of European neurologists in dementia. Eur J Neurol. 2007;14:505-509.
- Pfizer Pharmaceuticals. Model Scenario and course on the formation of keypersons. Knowledge of and attitudes to Dementia, 1997.
- Nivalis, Circle of care for Professionals and for Relatives. The trained professional Janssen Cilag Academy.
- Tsolaki M, Papaliagkas V et al. Education of Professionals on Alzheimer's Disease. Eur J of Neurol. 2005;12:294.