

# SOCIAL-HEALTHCARE COORDINATION AND INTEGRAL EVALUATION IN DEMENTIA: THE ROLE OF ALZHEIMER FAMILY ASSOCIATIONS

### María Eugenia Domínguez Orozco

Psychogerontologist

Coordination of social and healthcare services in Spain is a task that has just recently begun to develop. Fitting dementias in dependency evaluation is one of the questions that is analyzed in this article, where the contribution of family associations in the diagnostic process, caregiving and provision of services and/or resources are discussed. A general evaluation protocol for diagnosis of dementia is presented and the relevance of early detection of the initial stages as mild cognitive impairment is analyzed. Professional psychologists could be considered "case management" facilitating agents in evaluating and allocating services.

Key words: Dementia, Early diagnosis, Dependence evaluation, Social-healthcare coordination.

La coordinación de servicios sociales y sanitarios en España es una labor que recientemente ha comenzado a desarrollarse. La adecuación de las demencias en la valoración de la dependencia es una de las cuestiones que se analiza en este artículo, donde se reflexiona sobre la aportación de las asociaciones de familiares en el proceso diagnóstico, la atención asistencial y la provisión de servicios y/o recursos. Se presenta un protocolo de evaluación general para el diagnóstico de demencia y analizaremos la relevancia de la detección temprana de estadios iniciales como el deterioro cognitivo leve. Los profesionales psicólogos podrían ser considerados como agentes facilitadores para los "gestores de casos" en el proceso de las valoraciones y la adjudicación de los servicios.

Palabras clave: Demencia, Diagnostico precoz, Valoración dependencia, Coordinación sociosanitaria.

n the active aging paradigm, one of the relevant goals is early diagnosis to prevent dependency and disability.

Dependency comes with age or because of a disability or a combination of both. Regardless of the cause, the social population affected has difficulties in performing basic activities instrumental to their daily lives, and find themselves all the more dependent and more vulnerable the fewer social services there are and less developed social-healthcare spaces are (Gómez-Jarabo and Peñalver, 2007).

The purpose of this article is to analyze the adequacy of dementia dependency evaluation, and the contribution of associations and the role of the psychologist in the dementia patients' social-healthcare assistance system access itinerary.

## DEMENTIA EVALUATION AND HOW IT ADAPTS AS A DEPENDENCY

Law 39/2006 on Promotion of personal autonomy and care of dependent persons (LAPAD) was created as a

Correspondence: María Eugenia Domínguez Orozco. Granja San Juan, 26. 11650 Villamartín. España.

E-mail:medorozco@cop.es

regulating framework for providing social and healthcare attention to the groups involved evaluated by degree (moderate, severe or great dependency) and severity. The Dependency Evaluation Scale (BVD) (RD 504/2007 of April 20<sup>th</sup>) was designed as an evaluation instrument for determining their need for benefits and services.

In the specific case of dementia, certain difficulties in classifying their dependency have become explicit, since no correlates of equivalence have been identified among the degrees of dependency and levels of severity set by the LAPAD and the cognitive and functional staging established in the different types, especially in the early

This is how Méndez (2007) analyzed it in his discussion of a person's psychological features in classifying his dependency. He questioned the lack of evaluation of cognitive functions or behavioral difficulties, and comprehension of his social setting, etc., that could impede development of the most basic activities, giving priority to evaluation of physical difficulties. The involvement of these processes in their evaluation was reflected in the BVD in tasks such as "decision-making", and specifications such as mental capacity or initiative in



performing activities and tasks, as well as comprehension of the need for help and the influence of behavioral disorders, or, for example, the involvement of cognitive processes such as spatial orientation in any activity requiring mobility.

However, BVD evaluation is based, apart from the application of the questionnaire itself, on the direct observation of performance in tasks and health condition, for which the *Instituto de Mayores y Servicios Sociales* (Institute for the Elderly and Social Services) (IMSERSO) has prepared a "Manual for use of the BVD" as a protocol to be followed by the evaluating professionals in which all the tasks to be evaluated and their performance levels are described. For instance, for the task "health maintenance", evaluation of the indicator "applies recommended therapies" is included.

In spite of this, the difficulties have become patent, and the BVD (RD 174/2011, of February 11<sup>th</sup>) had to be modified to make improvements in the scale so the situation and classification of degrees would be more in agreement with the sequence of their implantation, and in addition evaluated by the Technical Committee for Coordination and Follow-up of Dependency Evaluation (CTVD).

This was also shown by Rivero and Salvá (2011), who suggested the presence of complex situations in categorizing, such as cases of cognitive impairment or undiagnosed dementia, illnesses with intermittent onset or those that develop rapidly.

Therefore, the team at the Centro de Referencia Estatal Alzheimer-Salamanca (The Alzheimer State Reference Center-Salamanca) has prepared guidelines for people with Alzheimer's Disease (AD) and other dementias, severe mental disorder with blindness and severe visual deficiency, and blindness and deafness. They consider specificities and particularities as technical support in evaluation, including the health report, interview and evaluation of the physical and human setting.

The health report is a document which would have to be handed in with the application for an examination of dependency, and the other two are the competence of the professional evaluators. The specific guideline for AD and other dementias (Sánchez et al., 2011) includes a series of guidelines for evaluators in the applicant interviews and home visits, information about dementias (classification, diagnoses, evolution, treatments, etc.), suggestions for interpreting the report, what test for cognitive and functional screening should be used, and other explanations.

The concrete contribution to this process by Alzheimer's and other Dementia Family Associations (AFAs), which could well be similar to the possibilities of other organizations for intervention categorized in the LAPAD, and which have their own regulations and protocols, is described below.

## The integral approach in evaluation: the case of the AFAs

From the time a possible case of dementia is suspected (perceived mainly by a family member) until that patient is specifically diagnosed and receives intervention and/or treatment, several agents are involved, specifically: a) family members, b) healthcare (Primary Attention team (AP), Specialized Attention team (SA) and social professionals, c) the AFAs, d) related government administrative departments, and e) public entities, and private and/or associated service providers.

As Espinosa, García, Gómez, López and Oliver (2010) have suggested, each of these agents usually shows an attitude in the suspicion of a dementia process, roughly manifested as little action in the early stage, little relationship between the district social service and healthcare professionals of reference, or else little relationship between healthcare attention teams and the AFAs.

In Andalusia, through the Andalusian Alzheimer's Plan (2007-2010) along with the CONFEAFA (Andalusian Confederation of AFAs), AFAs have been classified in three types, differentiating between basic services (compulsory) and optional: a) Type III, basic information and advisory services, publicizing and awareness, and as an optional service, mutual help groups, b) Type II, in addition to Type III services, would manage psychostimulation workshops a minimum of three days a week, and train family members, volunteers, etc., and optionally, individual psychological and social attention and home services, and c) Type I, offer basic services (Types III and II) as well as a daycare unit, and optionally, temporary and/or permanent residence.

This classification is valid for other regions, because concentrating on the services that it provides leads to more rigor in both intervention and evaluation of its users, by requiring as complete a protocol for action as possible with specific guidelines.

In diagnosis of dementia, the potential of developing instruments has been specified, as has integral evaluation as a common practice, which may be supplemented by



the work of the SA team (neurology/geriatrics) and the AFA professionals.

The evaluation protocol used in an association is related to the intervention strategies used, and therefore, to the services and/or programs it carries out. Specifically, the integral evaluation approach is directed at two types of users: the family member and/or main caregiver requesting the attention, and the patients themselves.

Assessment requires information to be acquired in a certain sequence in order to be able to make the geriatric orientation and clinical diagnosis, and prepare the individualized intervention plan, which must be explicitly described in the center's reception and adaptation protocol (Martínez et al., 2008).

This protocol should include:

1. The *first interview* for a first approach to the case and to inform of the possibilities of existing resources.

This usually employs a semi-structured questionnaire on the user designed for the purpose. It collects personal information, family history, illnesses and pharmacological treatment.

The evaluation is usually completed with the informant test (TIN) (IQCODE, Informant Questionnaire on Cognitive Decline in the Elderly; original by Jorm and Korten, 1988) as a scale of indirect observation by a close informant of the skills that have become impaired and the patient's changes in cognitive functioning in the last 10 years. A short version may be found in Forcano and Perlado (2002). Table 1 shows the list of questionnaires and instruments for integral assessment used in an AFA.

For a multidimensional approach of the assessment over the course of the illness and multi-composition during intervention, assessment of the burden of care on family members and/or main caregiver is also included.

2. Integral assessment of patients

The areas to be considered for assessment are functional, behavioral and cognitive, the last being the most relevant. In this sense, a combined neuropsychological assessment made up of a basic battery and another flexible one with specific instruments is recommended (Pinto, 2007; Pérez, 2012).

A basic battery would include a first cognitive exploration as screening, although the short tests are designed for detection and screening dementia and not for its diagnosis, which is a clinical task based on DSM-IV-TR or CIE-10 criteria (Villarejo and Puertas-Martin, 2011; Working Group on the Guía de Práctica Clínica sobre la Atención Integral a las Personas con EA y Otras Demencias<sup>1</sup>, 2010).

Boada and Tárraga (2000) considered the wide diversity of symptoms one of the strongest diagnostic difficulties in dementia, and therefore, it would be necessary to include a short-intermediate-type battery such as the CAMDEX-R (The Revised Cambridge Examination for Mental Disorders of the Elderly) "CAMCOG" cognitive subscale, validated in Spanish by López-Pousa (2003) in the protocol. This test includes the most important neuropsychological areas (orientation. language, memory, concentration, reading comprehension, praxis, touch and visual perception, calculation, abstract thought and passage of time), containing criteria for the differential diagnosis and even enabling classification of the severity of impairment. Therefore, we must find out what cognitive skills have changed and which have not with respect to their normal condition, in order to be able to design the intervention plan (Fernández-Ballesteros and Iñiguez, 2003). To make the ideographic exploration of a concrete case, the psychologist may supplement it with other neuropsychological tests as he deems fit. The professional must consider that the use of multidimensional, multilevel and multiple-method instruments is a necessary strategy in evaluation (Fernández-Ballesteros and Pinquart, 2011), for example, for the early detection of mild cognitive impairment as discussed in the following section.

Interest in functional evaluation derives from the interference of the cognitive deficit symptomatology in activities of daily life, and is one of the defining criteria of dementia. Behavioral evaluation is also relevant in as much as behavioral disorders can be one of the main reasons for the visit and even the differential criterion between types of dementia, for example, the differentiation between frontotemporal dementia and EA (Liscic, Storandt, Cairns and Morris, 2007).

<sup>&</sup>lt;sup>1</sup> Clinical Practice Guide to Integral Care of Persons with Alzheimer's Disease and Other Dementias



#### The relevance of early detection in dementia

The benefits of early diagnosis of dementia are shown in both the patient and the caregivers, since the wellbeing and quality of life of both would improve. Cognitive decline in the patients would slow down, their functional status would be maintained for a longer time, behavioral changes would improve, and institutionalization would be delayed, etc. (Prince, Bryce and Ferri, 2011).

One of the advances in early detection of dementia in recent years has been clinical identification of mild cognitive impairment (MCI) which attempts to clarify the "cognitive continuum" of normality through the gradual progression to dementia, identified by Petersen et al. (2001) as a transitional stage (Cited in lñiquez, 2004).

Several subtypes of MCI have recently been described under the hypothesis of progressive degeneration of

Users	What is evaluated?	Name of test	Brief description
Patients with EA/other dementias	Stages of the disease	GDS (Global Deterioration Scale by Reisberg, Ferris, de León and Crook, 1982)	7 stages: From absence of deficit to severe deficit. Kappa = .88 Correlation with FAST = .87
		FAST (Functional Assessment Stages by Sclan and Reisberg, 1992)	7 stages: Differentiation Grade 6 (Moderate- severe dementia, 5 levels) and 7 (Severe dementia, 6 levels).
	Functional autonomy  Basic activities of daily living (ABVD)  Instrumental activities of daily living (AIVD)	BARTHEL Index (Mahoney and Barthel, 1965)	10 ABVD: Eating, washing, dressing, etc. 4 dependency categories. > score + independence/100. K = .88
		KATZ Index (Katz, Ford, Moskowitz, Jackson and Jaffe, 1963; validated by Álvarez et al., 1992)	6 ABVD. From A (Independent in all 6) to G (Dependent in all 6)
		FAQ (Functional Activities Questionnaire by Pfeffer, Kurosaki, Harrah, Chance and Filos, 1982)	11 items. S > 6 dysfunction
		PGC-IADL Scale (Philadelphia Geriatric Center Scale-Instrumental Activities of Daily Living by Lawton and Brody, 1969)	8 AIVD. Score from 0 (maximum dependence) to 8 (complete independence)
	Alterations in behavior	BEHAVE-AD (Behavioral Pathology in Alzheimer's Disease Rating Scale by Reisberg et al., 1987; validated by Boada, Tárraga, Modinos, Diego and Reisberg, 2006)	7 aspects of behavioral symptomatology and overall evaluation. Correlation with NPI = .69
		NPI (Neuropsychiatric Inventory by Cummings et al., 1994; in Boada, Cejudo, Tárraga, López and Kaufer, 2002)	10 aspects. Scores frequency and severity of symptom Cronbach = .88
	Cognitive deficit	MMSE (MiniMental State Examination, original by Folstein, Folstein and Mchugh, 1975; López and Martí, 2011)	30 items: orientation, memory, etc. S<24 impairment; education-matched. 87% sensitivity
		CAMCOG cognitive subscale (CAMDEX-R, Cambridge Mental Disorder of the Elderly Examination; López-Pousa, 2003).	67 items. Contains MMSE. Test-retest reliability = .86
Family members and/or informal caregivers	Social information on patient	Ad hoc interview	
	Information on symptomatology observed	TIN (validated by Morales, González-Montalvo, Bermejo and Del Ser, 1995)	
	Burden on caregivers	Caregiver Burden Interview (Zarit, Reever and Bach- Peterson, 1980; adapted by Martín et al., 1996)	
		Indice de esfuerzo del Cuidador (Caregiver Burden Index) (López and Moral, 2005)	13 items. S>7, high stress



the brain toward dementia. Mulet et al. (2005) described them and studied which was most related to AD, classifying them in three types: amnestic, diffuse and focal nonamnestic, each of which would have a closer relationship with a certain later evolution. Roughly, the results found that the most frequent type was diffuse, and after two years of follow up, 15.21% of the patients evolved to AD. They had more temporal disorientation and episodic memory alterations than stable patients.

Díaz and Peraita (2008) did a study on detecting MCI in a sample of 140 participants from 58 to 89 years of age in the Region of Madrid. Using a specific neuropsychological exploration battery, they also found three different types (amnestic, nonamnestic and combined), although they concluded that the definition of the syndrome needed to be improved.

Another study on the evaluation of MCI was done by Migliacci, Scharovsky and Gonorazky (2009) which characterized what type of cognitive function is most impaired in each subtype. An analysis of the results showed that the domains affected in the different types were: for MCI-a, memory; for MCI-mnoa, language, visuospatial and attention. The episodic memory, language (nomination and verbal fluency) and executive function tests were the best predictors of conversion of MCI to AD.

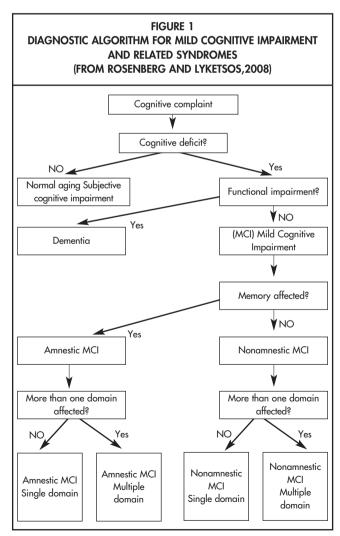
Thus, the typology of MCI syndromes has been defined as follows, although there is no consensus in the nomenclature: a) Amnestic MCI, characterized by an isolated memory deficit (usually evolves into AD), b) Multiple domain MCI, which involves a slight deficit in more than one cognitive domain (may include memory) and c) Monodomain non-amnestic MCI, which represents the affection of a single non-memory domain (prodrome of non-Alzheimer's dementia).

Coming to a consensus on the tests necessary for good detection would depend on several circumstances, so to end this section, a diagnostic algorithm has been included (Figure 1), originally by Rosenberg and Lyketsos (2008), that facilitates the process of deciding on the composition and choice of tests in a given battery for each cognitive function. It should be set up multidimensionally, including instruments on various cognitive processes, attempting to validate the definition of subtypes as medical entities and give them discriminating power for the cognitive decline associated with age.

## SOCIAL-HEALTHCARE COORDINATION FOR SERVICE DEMAND

The LAPAD has coordinated restructuring and adjusting of functions and services in thwith the focus of attention on the person, providing effective public access to them. The instructions for this were published in the *Libro Blanco de la Coordinación Sociosanitaria en España* (White Paper on Social-healthcare Coordination in Spain) (2011) by the IMSERSO and the *Agencia de Calidad del Sistema Nacional de Salud* (National Health System Quality Agency).

In keeping with the above, the role of the AFAs and other related entities could be relevant in social-healthcare coordination, insofar as they form part of the system resources for attention to dependent persons and are "agents" in the dementia process. Therefore, they could be considered one of the devices for connecting the two systems, and could serve as the link in the social-healthcare space for patients diagnosed with dementia.





## The mediating role of the AFAs and evaluating professionals

The "case managers" make this coordination effective in healthcare centers as the mediating agents in assessment and allotment of services. Their work consists of detecting the need for and types of care, setting up the service plan and mobilizing the appropriate resources, and accordingly, case referral from the healthcare system to the social system or vice versa is through these professionals. In the healthcare system this position usually is the zone nursing professional, and in the social system, the social worker would be in charge of it in coordination with the zone psychologist and/or the corresponding dependency evaluator, who together would prepare the individual dependency attention program.

An AFA contributes patient care and attempts to satisfy the needs of family members that could come up during the assistance continuum of the illness, and therefore, the role of the professional psychologist is crucial insofar as he may be the agent of first dependent/caregiver entry in any of the Sistema para la Autonomía y Atención a la Dependencia (Autonomy and Attention to Depencency System) (SAAD) access systems, and would make the clinical assessment of the case, as well as providing a possible care plan. At the same time, this professional could receive users referred from the health institution case agents, and therefore, act as the liaison in the social-healthcare coordination of their itinerary.

AFA action could be improved if there were a standardized bidirectional flow of communication between the AFAs and healthcare services in the "dementia diagnostic process", or if knowledge of the services provided by the AFAs were given by the PA, as observed by Espinosa et al., (2010). However, PA diagnosis is not practicable because of the short time allowed for the typical visit, which would hardly leave time to identify dementia using a screening test. Another of the areas that needs to be improved would be early diagnosis, whereby assessment would be a "facilitator" in the coordinated process, in addition to the AD diagnosis. The American Psychological Association Guidelines for the Evaluation of Dementia and Age-Related Cognitive Decline (2010) identifies a series of guidelines for psychologists for coordination with other healthcare professionals, and the appropriate procedures.

# The assessment protocol as a resource for measuring intervention quality

Among the measures for encouraging social-healthcare coordination is the goal of generating a shared organizational culture by equipping sectors, attempting to rebalance health and social systems to strengthen social services and resources, improving the efficiency and accuracy of attention, and so forth. Their coordination requires them to work together cooperatively.

At the present time, centers must be accredited by competent government authorities to provide care services for dependent persons. Thinking of the possibilities of a non-governmental organization such as an AFA, during its history, it could accredit essential services for its users in agreement with the LAPAD, for example, home help or daycare center services, and others that could be covered by intervention programs promoting the personal autonomy for Grade I dependents, and that could be time-limited. Such a program would be assessed by a service quality analysis method, or in other words, it would evaluate the capacity of the organization to effectively satisfy the needs of its users, as suggested by Domínguez (2011).

Service coverage is set up based on the user and the ratio of direct attention and the professional profiles have a linear relationship with the user profile and the extent of his dependence (Cervera and Rueda, 2012). For example, an AFA including a daycare service would provide coverage for autonomous/slightly dependent users, or Grade I dependence. Residential services would require features that are not easily covered by this type of organization.

The national Confederación Española de AFAs (Spanish Confederation of AFAs) (CEAFA) has been certified to Ad Qualitatem for quality management and social responsibility in patient organizations (GPCR-25), by Alianza General de Pacientes and the Ad Qualitatem Foundation, which is a clear initiative in joining forces in the labor of building a social-healthcare space and improving the quality of its interventions. Thus organizations with consolidated services (such as Type I daycare centers) whether run locally, by district or provincial federations, can be certified to the ISO-9001 Standard, model FQM, etc., by a quality management certifying entity which would give them more access to government association agreements/subsidies.

To complete this theoretical-practical discussion, a series of suggestions concerning the diagnostic process are



made, which as mentioned above, are intended to offer an integrating and facilitating view for unifying criteria:

- ✓ Inclusion of two tests in the basic AFA exploration protocol: a) the Short Portable Mental Status Questionnaire (SPMSQ) by Pfeiffer (1975), instrument used for PA cognitive screening and geriatric contexts (Ruipérez, 2000; Fernández-Ballesteros and Zamarrón, 1999); b) evaluation of emotional state using scales like the Geriatric Depression Scale (GDS by Brink, Yesavage, Lum, Heersema and Rose, 1982) which favors differential diagnosis from other entities such as pseudodementia.
- ✓ When making the clinical decision, it would be advisable for the clinical report to include CIE-10 diagnostic criteria in the diagnosis, although it could be supplemented with other criteria such as the DSM-IV. The debate is open since both classifications are subject to updating to the CIE-11 and DSM-V in which syndromes such as MCI are supposed to be included. It should be considered that the CIE-10 is used most in psychiatric practices, for example (70.1% in a worldwide survey analyzed by Reed et al., 2011), and it should be born in mind that there are types of dementia that debut in initial or prodromal stages with behavioral alterations, resulting in false negatives.

These suggestions, in turn, are based on the specific guidelines for dependence evaluators, which explicitly refer to one of the primary questions dealt with in this article, the framework of social-healthcare coordination in Spain, which is materializing in attention to dependency. To finish, it should be mentioned that the diagnostic evaluation report offered by an AFA could serve families and/or caregivers as supplementary justification for the application and the interview they would have in the applicant dependency home evaluation, and also supplement AD diagnosis, because of its contribution to specificities in the evaluation-treatment (non-pharmacological therapies) conjunction corresponding to the patient's individualized itinerary and care plan.

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#### **LEGISLATION**

- Law 39/2006, December 14<sup>th</sup>, on Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia (Promoting personal autonomy and care of dependent persons). (BOE № 299; pp. 44142 a 44156).
- Royal Decree 504/2007, of April 20<sup>th</sup>, approving the Baremo de Valoración de la Situación de Dependencia (Dependency Evaluation Scale). (BOE № 96; pp. 17646 a 17685).
- Royal Decree 174/2011, February 11, 2011, approving modifications in the Dependency Evaluation Scale as stipulated in Law 39/2006 Promoting personal autonomy and attention to dependent persons (BOE Nº 42; pp. 18567 a 18691).