Social Representation of Dementia: An Analysis of 5,792 Consecutive Cases Evaluated in a Memory Clinic

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Abstract.
Background: Different interpretations of cognitive impairment and dementia due to differences in health structures, such as cultural differences could affect the diagnosis and treatment of the condition. it is reasonable to expect that the social and family impact of the disease and coping strategies will differ among societies.
Objective: The general aim of this study is to understand the social representations of dementia, its associated practices, and the effects they imply.
Methods: People diagnosed with clinical dementia and their families were assessed from 2005 to 2015 in the memory clinic of the Fundació ACE, Institut Català de Neurociències Aplicades in Barcelona, Spain.
Results: 9,898 people were examined and 5,792 were diagnosed with dementia. For those with a caregiver (71%), the decision-making fell on the person with dementia in 16.2% of the cases; and for those without a caregiver, in 26.4% of the cases the family did not perceive the deficits as a disease, which led to multiple risk situations (74.6%).
Conclusions: The recognition of dementia as part of aging is common among families. Consequently, risk situations may arise and diagnosis and access to treatment may be delayed. The incorporation of a social appraisal to the diagnostic process is a necessity to evaluate these situations.

Keywords: Alzheimer's disease, beliefs, caregiver, dementia, social perception, social representation, social-cultural

INTRODUCTION

The aging population is a worldwide reality. In 2015, approximately 12.2% of the world population was older than 60 years, and it is expected to grow up to 21.2% by 2050 [1]. In Spain, it is estimated that the age group over 60 years will constitute 43%

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of the population by 2050 [2]. The aging population has prompted an increase in the incidence of multiple chronic diseases, including dementia syndrome, affecting public pension programs, healthcare and social assistance, and implying an obvious economic impact on Western countries [3].

Currently, around 46.8 million people worldwide have dementia. This number is expected to reach 131.5 million by 2050 [1]. In Spain, the current prevalence of dementia ranges from 5 to 14.9% for people over 65 years of age and from 6.6 to 17.2% for those over 70 [4]. Nowadays, everything indicates that the cost of the disease will rise even faster than its prevalence itself [1]. Dementia syndrome has many different causes, with Alzheimer's disease (AD) the most important. In Catalonia, Spain, AD affects almost 70% of the people diagnosed with dementia, and the prevalence is 6.6% for those of 70 years of age or older, reaching almost 32% for the age group 90 to 95 [5].

Dementia, regardless of its cause, can be used as a model to understand families' behaviors within every culture, and how different health service frameworks pinpoint what is health and what is illness, as well as the practices related to these categories. Papers about dementia's social aspects become more frequent; the majority of them are, however focused on American, Anglo-Saxon, and North European realities. Human and social sciences have shown that there is a lack of research on caregivers and their experience with dementia and its impact on other societies with different social and health structures, as well as other ways of understanding cognitive impairment [6–11]. Therefore, due to differences in health structures, such as cultural differences (conception of and meaning given to the manifestations of dementia, differences between family and social values, differences in approaches for caregiving), it is reasonable to expect that the social and family impact of the disease and coping strategies will differ among societies.

Based on the aforementioned information, this research attempts to disclose the particular reality in Catalonia, specifically in Barcelona. The general aim of this study is to understand the social representations of dementia, its associated practices, and the effects they imply. Thus, we studied clinical and social situations in which the person with dementia presents at a memory clinic for a first evaluation. We have looked at the individual's clinical conditions (cognitive status, dependence, and behavior); sociodemographic characteristics of their social and family environment; representations they have about

cognitive impairment and care structure characteristics, and effects—both on the caregiver and the caretaker—at the very moment the person is diagnosed with cognitive impairment.

METHODS

Geographic reference area

The study geographic area is Barcelona city, with an average population of around 1,600,000, of whom 18.5% are over 65 years old [12].

Data collection center

The study data were collected in the Memory Clinic of the *Fundació ACE*, *Institut Català de Neurociències Aplicades*, a non-profit organization, and their service area is the city of Barcelona. The Memory Clinic has a contract by a public bidding process since June 22nd, 2012 with the *Servei Català de la Salut del Departament de Salut de la Generalitat de Catalunya*. People were referred to the center by Primary care physician or specialists due to persistent memory complaints (or other cognitive impairment), perceived by themselves, their families or medical doctor.

Diagnosis was done systematically and following a protocol to collect as much information as possible. In this process, a professional expert in social evaluations made the first visit with the family, presented the service, explored the reason for consultation, and carried out a detailed social and family study to place the evaluated person within their social context (Supplementary Figure 1). A neurologist had a second visit with the family and the evaluated person for anamnesis and neurological examination. Thirdly and finally, a neuropsychologist completed the study with an extensive evaluation of the person's cognitive functions and with additional tests (lab test and neuroimaging) required by the neurologist. When all data were available, the diagnosis and plan of action, including the management of the person and their family or caregiver, were carried out by consensus of the entire team of the diagnostic unit [13, 14] (Supplementary Figure 2).

Clinical and social data obtained after diagnosis have been collected and systematized since 1996 and were recorded in the computerized database created ad hoc to configure the medical history of the subject.

Written informed consent was obtained for all participants. In order to maintain confidentiality, all

participants' details were anonymized in the transcripts of the interviews.

General aspects of the methodology

The analysis was done studying the medical records of people evaluated in the memory clinic. We presented data of people diagnosed with dementia in particular, according to the diagnostic criteria DSM-IV-TR [15] and DSM V [16] in the *Fundació ACE* from 2006 to 2015.

The diagnostic criteria used to classify the etiology of dementia were: for AD, the National Institute of Neurologic, Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association criteria (NINCDS-ADRA) [17]; and the National Institute on Aging - Alzheimer Association criteria (NIA-AA) [18]; for the diagnosis of vascular dementia, the National Institute of Neurological Disorder and Stroke and *Association Internationale pour la recherche et l'Enseignement in Neurosciences* criteria (NINDS-AIREN) [19]; the Neary et al. [20] for the diagnosis of frontotemporal dementia; McKeith criteria et al. [21] for Lewy body dementia.

We conducted a descriptive and observational study to achieve the abovementioned objectives, a strategy that combined the qualitative and quantitative perspectives.

Quantitative perspectives included the exploitation and analysis of the information in the medical record. The qualitative analysis was performed based on the analysis of data recorded in the notes, systematically collected by the professional expert in social evaluations in interviews. These data are mainly an extension of information that helps understand the quantitative data.

Terminological definitions

In this study, we presented terms that were used by specialists and the general population with different meanings and nuances.

We used "care" as a purpose rather than a task. Therefore, we consider a caregiver to be the person that takes decisions about the needs of the patient and about how these needs could be met, regardless of whether this person actually carries out the tasks or not. In this study, we have started from the premise that there is no direct relationship between being a caregiver and living with the person with dementia. Hence, in situations where the dementia patient lived with a relative, if this relative did not carry out

care-related tasks (consciously or not), we did not consider the relative as a caregiver. On the other hand, if an assistant was contracted by a relative to take direct care of the patient, we did consider the relative—who took responsibility for managing and deciding on the patient's care—as a caregiver.

Representations consisted of information, images, beliefs, values, opinions, cultural, and ideological elements that will guide the action, or non-action, of the subjects [22]. Disease representations are based on cognitive rules and regulations that are used to interpret our experience of the disease. These rules are deeply rooted and become tacit [23]. Changes in representations can be a long-term process; hence, we could find discrepancies and conflicting uses of certain terms and concepts.

"Impact" is a concept that we used to value the emotional and social consequences of caregiving, such as disturbance in family relationships, and in occupational, leisure, and economic activities [24].

We used the concept of "role restructuring/reorganization" for the delegating of responsibilities and functions to another person as a consequence of cognitive impairment of dementia, which provokes a decreasing ability of the subject to perform functions and take on responsibilities.

Characterization of the relevant variables in the study

Variables analyzed in this study were divided into three blocks and are as follows:

a) Sociodemographic variables of the patient: age, sex, education, marital status, the person or people they live with, occupation, etc.
b) Diagnosis: etiological diagnosis, degree of cognitive and physical autonomy (according to the scores in the Mini-Mental State Examination (MMSE) [25], Blessed Dementia Rating Scale [26], Rapid Disability Rating Scale-2 [27] and Global Deterioration Scale (GDS) [28]).
c) Interpretations on the cognitive impairment: Knowledge about dementia, how the impairer's situation is understood, on-setting of therapeutic pathway.
d) Features/particularities/details of the care structure: existence of a caregiver, caregiver's gender, family relationship with the subject, way in which the role of caregiver was assumed, caregiver activity and impact on caregiver's

life expectations care strategies, people without caregiver and their reality, existence of risk.

Data analysis

A descriptive analysis of the variables was performed using frequency analysis and measures of central tendency and dispersion for quantitative variables. Results were expressed as absolute numbers, percentages, mean and standard deviation.

Data processing and analysis were conducted using SPSS statistical software v. 19.0, Chi-square test was used to compare the variables. Alpha level was set at 0.05.

Qualitative data from clinical records were checked. These data were codified into category labels, and were then ordered into groups. Data were analyzed and compared; first within each category, and then between categories. The goal was to find links between them. To do such analysis, latent contents and context were taken into account.

The statement of the informants has been transcribed verbatim. These transcriptions have been filed separately from the text and in quotation marks.

RESULTS

We evaluated 9,898 people from January 2006 to July 2015; all of them received social and family assessment as part of a comprehensive process of diagnosis. 67.5% were women, mean age was 77.3 (SD = 8.9). Of all people evaluated, 5,840 (59%) had dementia syndrome, 3,335 (33.7%) mild cognitive impairment, and 723 (7.3%) no cognitive impairment.

Current data presented in this article correspond to 5,792 people who were diagnosed with dementia syndrome, 48 cases were excluded because data were not available.

Diagnostic and sociodemographic characteristics are presented in Table 1.

Representations of dementia

Regarding social representations of dementia, our study found inconsistencies in terminological and conceptual aspects of the term "dementia". Many people considered cognitive impairment produced by dementia as a natural fact in the elderly, and a part of the aging process, but it is not considered as a disease. The recognition of dementia as a part of the aging process promoted an acceptance of the symptoms and a

Table 1
Diagnostic and sociodemographic characteristics

Dementia patients *n* (%)	5,792 (58.5)
Age (mean/SD)	79.9 (± 7.7)
Gender *n* (%)	
Male	1,739 (30)
Female	4,053 (70)
Education *n* (%)	
<6 years	3,018 (52.1)
Primary	1,743 (30.1)
Secondary	631 (10.9)
University	400 (6.9)
Marital Status	
female (%)/male%	
Married/couple	36.5 / 77.9
Divorced	2.9 / 2.8
Single	6.7 / 4.4
Widow(er)	53.9 / 14.8
n (%) of patients living	
In a Couple	2,473 (42.7)
Alone	1,355 (23.4)
With Son or daughter	655 (11.3)
In a nursing home or with professional caregiver	319 (5.5)
Other	990 (17.1)
Types of dementia *n* (%)	
Alzheimer's disease	4,102 (70.8)
Vascular dementia	770 (13.3)
Lewy body dementia	439 (7.6)
Frontotemporal dementia	280 (4.8)
Other	201 (3.5)
MMSE *n* (%)	
MMSE >20	3,011 (52)
MMSE 10–20	2,491 (43)
MMSE <10	290 (5)
Global Deterioration Scale *n* (%)	
Mild dementia (GDS 4)	3,469 (59.9)
Moderate dementia (GDS 5)	1,830 (31.6)
Mod-severe dementia (GDS 6)	452 (7.8)
Severe dementia (GDS 7)	41 (0.7)
RDRS-2 (mean SD)	
Activities of daily living	13.5 (± 4.6)
Degree of disability	12.1 (± 2.3)
Special problems	5.3 (± 1.1)
Blessed (mean SD)	
Changes in performance of everyday activities	3.66 (± 1.4)
Changes in habits	1.63 (± 1.8)
Changes in personality, interests, drive	3.15 (± 1.3)

less negative association, despite being considered as a disease in the medical discourse.

While the medical narrative uses the word "dementia" to point out a symptom associated to a pathology, for most ordinary people the word "senile dementia" refers to quite a normal, common and frequent age-related situation and not at all pathological. It is, in a way, as if abnormality has somehow been normalized.

"*Dementia yes, but she is not sick.*"

"*He has dementia, but he is in good health.*"

"He is in good health, he is just senile."

"He has age-related dementia."

"He should have something at his age, right? I do not know what the doctor expected! He is 80 years old!"

Unlike what happens with senile dementia, lay people consider the word 'Alzheimer's' as a paradigm of dementia, and is always linked to the pathological realm. Mentioning the word itself is a cause of distress:

"It's the worst you can go through because it is against every logic. It is a monstrosity, something incomprehensible [. . .]. Alzheimer is destructive, as it completely impairs the sufferer."

"I have a really bad image of Alzheimer's. That's the reason I got scared . . . To me, Alzheimer's is being dead and alive simultaneously."

While within the clinical practice there is an evolutionary criterion from lower to higher degree of impairment, ordinary people identify Alzheimer's when there is a moderate or advanced stage, but not when it is mild. A mild or low intensity of impairment is seen by lay people as something normal, and it is labelled as "senile dementia". However, when the intensity of dementia peaks, the term shifts to "Alzheimer's":

"He has a bit of Alzheimer's but not completely"

"He has suffered senile dementia for 10 years, but now he has developed Alzheimer's, because when he wakes up he is unable to put his slippers on. He doesn't remember that dad died . . . within a minute he has forgotten everything. He is never hungry, and I have to nudge him to wake him up. That's why I say that he has stridden from dementia to Alzheimer's."

"She hasn't got Alzheimer's, she's got a senile dementia according to her age. She still recognizes me."

"My grandma's got a normal senile dementia. It has nothing to do with my mother's Alzheimer's."

"Someone with Alzheimer's is a kind of living dead. They don't know where they are. "She's not like that; she's got a senile dementia."

Access to the diagnostic process

For 79.6% of all people diagnosed with dementia, access to the diagnostic process was promoted by the family; for 1.8% by the affected itself; and for 18.6% by a medical professional. These proportions vary according to the disease status measured by MMSE and GDS. We found a statistically significant difference in the patient's stage of dementia, depending on who started the diagnostic process. When the process was triggered by a relative or healthcare practitioner, 32.3% or 30.9% of the individuals with dementia were in a moderate stage and 7.7% or 8.1% were in a moderately severe stage, respectively, whereas when it was the patient itself, dementia was in a mild stage in 86.4% of the cases and in a moderate or moderately severe stage in 13.6% of the cases ($p = 0.03$) (Table 2).

When it was the clinician who had initiated the diagnostic process, the relatives of the patient either did not observe any alteration in the patient's normal state or did not place importance to any deficiencies; they attributed them to the person's age or mood, rather than to a disease:

"He has better memory than myself, he even remembers when he was a child... I do not know why the doctor says that he is losing his memory".

"If she is not well, she would have told us . . . she has not said anything".

Table 2
Cognition, disease status, and access to diagnostic process

Scale	MMSE				GDS				
Range	26–30	20–25	15–19	10–14	0–9	4	5	6	7
Access to diagnostic process									
Family									
79.6 %	8.7%	43.2%	31.4%	11.7%	5%	59.5%	32.3%	7.7%	0.5%
Evaluated person									
1.8 %	14.6%	63.1%	15.5%	6.8%	0%	86.4%	11.7%	1.9%	0%
Medical doctor									
18.6 %	7.9%	42.5%	32.5%	12.2%	4.9%	60%	30.9%	8.1%	0.9%

MMSE, Mini-Mental State Examination; GDS, Global Deterioration Scale.

"*What happens is that she does not remember knowing. She is not unsound*".

"*It's normal, she is getting older*".

"*She dodders, but she is not sick; it is because of her age.*"

"*She has memory, she just forgets things.*"

The caregiver

A total of 4,110 (71%) of people diagnosed with dementia had a caregiver at their disposal; caregivers were relatives in 82.5% of the cases. Of these, in 52.8% of the situations the caregiver role was performed by one person alone, and was shared among different members of the family in 28.5%. Only 1% of the non-outsourced caregivers were not relatives. In 16.3% of the cases, the caregiver was outsourced (in-home or nursing home caregiver).

Caregiver characteristics

Primary caregivers were women in 67.2% of the cases. In 32.4%, it was the wife, followed by daughters in 27.6% of the cases. The husband in 22.3% of the cases, sons in 9.1%, and in 8.6% primary caregiving was provided by a very heterogeneous group of relatives (nephews, brothers, etc.) and professional caregivers.

Impact on the caregiver's life expectations and the way in which the role was assumed

Caregiving was in confrontation with the caregiver's life expectations in 14.5% of the cases ($n = 595$), and, it was in line with their expectations in 85.5% of the cases. The reasons stated were:

- **Moral obligation** in 48.8%:

  "*I married for better and for worse*"

  "*Who else but a son!*"

  "*She did it for me, so she will be at home with me.*"

- **Domestic task** in 2.3%:

  "*He does not cause me any trouble. If the ill had been me, it would have been a problem because he has never done anything at home.*"

"*It has always been me who has taken care of home matters. I took care of my parents, his parents, our children; this is not new to me.*"

- **Domestic task and moral obligation** in 34.5%

The caregiver role was assumed slowly and progressively over time in 73.1% of the situations. In addition, in 26.9% of the cases the role was abruptly started at a time of crisis. In relation to gender, women took on the caregiver role abruptly in 22.4% of the cases and in 15% for men ($p < 0.001$).

The caregiver's work, couple relationship, and/or leisure was adversely affected for 10.4% of those who assumed caregiving responsibilities slowly and for 27.8% of those who did it abruptly:

"*I've had to retire early to take care of her.*"

"*I have not had vacations in three years. I'm tired.*"

"*I have received a warning at my job; I cannot take so many days off to accompany him to the doctor.*"

"*I cannot see my grandchildren because she has it in for them, gets angry and yells at them.*"

The caregiver was overwhelmed ("I can't take it anymore") in 26.3% of the situations:

"*I cannot do this for much longer.*"

"*On Sundays, I want it to be Monday to go to work and leave the house.*"

"*Either something's done or we will both be hospitalized.*"

We found significant differences regarding the caregiver gender and his/her self-perceived overwhelm: 30.9% of the female caregivers were overwhelmed compared to 23.6 % of the male caregivers ($p < 0.001$).

When the care structure and caregiver were decided upon previously, the caregivers were relatives in 63.1% of the cases: 42.6% were women, 20.5% were men.

In 36.9% of the cases, other forms of care (in-home care service, daycare center or nursing home) were planned.

When neither the care structure nor caregiver were decided upon previously, 34.9% of caregivers were relatives: 23% were women, 11.9% men, and in

Table 3
No caregiver: frequency, status of dementia, and gender

GDS	Frequency	No Caregiver	Gender
GDS 4	59.9%	81.7%	Female 71.8%
		n = 1,374	Male 28.2%
GDS5	31.6%	16.8%	Female 78.1%
		n = 283	Male 21.9%
GDS 6	7.8%	1.5%	Female 80%
		n = 25	Male 20%

*All GDS-7 had a caregiver.

65.1% of the cases they were other forms of care (in-home care service, daycare center or nursing home).

People with dementia without caregivers

No caregiver was at the disposal of 29% (n = 1,682) of the people with dementia. From these, 81.7% (n = 1376) were GDS-4 and 16.8% (n = 283) were GDS-5.

In those individuals with dementia with no caregivers, 73% of them were women and 27% were men. The frequency, status of dementia, and gender are shown in Table 3.

A total of 37.5% (n = 637) of people without caregiver were living alone; nonetheless, the lack of caregiver was unrelated to whether the individual was living alone or with other people. Thus, 43.9% lived with their partner, 6.6% lived with a son or daughter, 11% lived with other relatives, and 0.9% lived in a nursing home or a relative (no person responsible for decision-making was identified).

The lack of caregiver for those living alone was neither related to the type of family relationship. In 80.6% of cases, relations with relatives were good, while in 7.3% of cases, relations were conflictive, and in 6.8% were undifferentiated. Only in 5.3% of cases, the individual with dementia living alone had no family. Data showed that in 21.6% of the cases in which individuals with dementia were living alone and without caregiver, their relatives did not think they were ill.

Interpretation of cognitive impairment when there is no caregiver

In 24.6% of all situations in which there was no caregiver, the family did not perceive that the person was ill. In the remaining 75.4%—even though the family interpreted cognitive deficits of their relative as a result of a disease, relatives stated various reasons to argue their interpretation of the symptoms.

a) Waiting for clinical diagnosis to take action

"*She has always been very manipulative and now we are not sure if she is tricking us and we have to force her, or if she really cannot do things.*"

"*I'm waiting for the verdict; we'll see what I do.*"

b) They do not know how to tell the patient

"*I do not know how to tell her that she needs our help.*"

"*I do not know what I have to do or what's best for him.*"

c) Patient does not accept supervision

"*She does not accept help.*"

"*We cannot say to her that she cannot be alone; she does not accept it.*"

"*He does not want us to watch him.*"

"*If we go there, she shouts and accuses us of stealing. Now we do not go there anymore.*"

d) Potential caregiver does not want to take care of the patient

"*She has always been very selfish and has not cared about anyone. It's very hard to say, but I'm not going to take care of her... she gave us a very bad life.*"

"*These people are better in a nursing home.*"

"*I cannot take care of her in my house; she must go to a nursing home.*"

Impacts

Risk situations in care of the dementia person

In assessing risk situations in patient's care, the study found that care was guaranteed in 25.4% of the cases. However, care was not ensured for 74.6% of the patients due to existing risk.

Among the risks identified, the experts noted: 19.8% of the caregivers worked alone; 18% of the caregivers felt overwhelmed; 22.7% of the people with dementia had no caregiver; 11.6% of the families did not believe that their relative was sick.

The specialist noted further risks in care in 2.5% of the patients (lack of support, caregiver emotional distress, etc.).

Driving was also considered an unsafe situation. It was found that 5.6% (*n* = 322) of the people diagnosed with dementia were drivers. 89.1% of them had a GDS-4 and 10.9% GDS-5. In relation to gender, 80.7% were men.

Decision making

In those with a caregiver, the decision making still fell on the person with dementia in 16.2% (*n* = 666) of the cases. Furthermore, 79.5% of them were in a phase of mild dementia (GDS-4) and 18.5% of moderate dementia (GDS-5).

DISCUSSION

To the best of our knowledge, this is the first study that has evaluated the social representations of dementia and the structure of care at the moment of diagnosis.

The aim of this study was to describe the views of the Catalan population about dementia and practices associated with its representations. We started from the premise that social representations of dementia determine specific actions: the timing for evaluation in a memory clinic, the patient's needs and how these will be addressed.

Therefore, in this study, we examined and analyzed the cognitive status and autonomy of the person with dementia on the one hand, and characteristics of the care structure, representations of the situation within their social and family environment, and their consequences evaluated by a professional expert in social evaluations.

We combined quantitative and qualitative methodology. The quantitative approach has allowed us to evaluate manifestations of dementia, and the qualitative approach has helped us understand the logic behind the caregiver's attitudes, the meaning they give to the symptoms of dementia, and discover the aspects involved in the care structure.

Although in Spain there are no studies with a sample as large as ours, the results about demographic data both from the individual with dementia and from the caregiver obtained in the city of Madrid [29], Pamplona [30], the province of Gerona [31], the region of Baix Llobregat [32], or the results gathered in the Guide of the Clinical Practice [33] are similar to ours. That is the reason why we consider that our results also represent Spain as a whole.

The timing of information collection (at the moment of diagnosis of the disease), as well as some of the studied variables (the interpretation given by the informants about behavior, cognitive deficiencies, or how the subjects' care structure was planned) represent new data, and could not be generalizable to other cultures or countries, because previous studies were mainly focused on caregiver interviews after a period of time since the diagnosis of dementia [6–11].

Such interpretation of cognitive impairment explains 11.6% of the situations in which relatives of a person diagnosed with dementia did not identify the clinical status as a consequence of a disease; they, therefore, did not expect such clinical diagnosis. This could in some extent explain why the diagnosis of dementia in almost four out of ten individuals was done in a moderate or severe stage of the disease and not at earlier stages. The latter could also cause a delay in diagnosis, affecting the access to an appropriate treatment and intervention for the patient, and a delay in all those interventions focused on relatives to prevent and treat caregiver stress.

Even with the correct identification of the syndrome's manifestations, we found difficulties in recognizing complications and repercussions of these deficits on daily life and on the suitable care. Hence, we have been able to identify several risk situations in people who have been diagnosed with dementia in our environment: 23.4% of people diagnosed with dementia live alone, 6.6% drive, 29.3% are under nobody's supervision, and 37.7% make major decisions.

Our work establishes the "feminization of dementia"; up to 70% (*n* = 4,022) of individuals diagnosed with dementia are women. But that is not the only reason. Regardless of the gender of the individual with dementia, the role of the caregiver—even when there was no clear decision on who would take the role prior to diagnose—was eventually assumed by a woman.

For most of them, women take up this chore according to a naturalization of the role, to which affect and a moral dimension, commonly associated with family duties, add up. Other aspects also contribute to this feminization, like a maternal-role extension, the regular association between chores and genders, or the diverse dynamics arising within a family and shaped by gender.

The resulting impact and burden are directly related to how this responsibility was assumed and to a good attitude in advance to taking up this role.

Thus, both in the situations when the person assuming the role of caregiver was decided beforehand and when the prospective caregiver took up this role smoothly, the impact and the burden were less compared to when the role of the caregiver was not previously assigned and accepted, or to when it was abruptly assumed without a chance of realizing what it meant in the intermediate and long term.

Conclusion

The results presented here are an approximation to the situation at the moment of diagnosis made by a social evaluation, which gave us a more comprehensive assessment of people with dementia and the structure of care. This evaluation has been essential to understand the perception of the population regarding the syndrome, and the logic and sense behind the practices related to it.

In this study, we observed how the population found difficult to interpret the syndrome: they do not consider it as a disease and have problems understanding the needs of the patient and helping to address them. Changing this situation requires a previous modification of the representation associated to dementia. If the representation remains unchanged, we will not be able to modify risk practices.

As for now, on the one hand, our interest is to conduct a longitudinal analysis of these cases, in order to analyze whether and how the diagnosis of dementia triggers or not a change in the representations of the disease in those involved and in the care plan. On the other hand, we intend to make a multicenter and international study to learn the representations of dementia at the moment of diagnosis in different countries and cultures.

Including a social assessment in the diagnosis will allow us to study practices and social representations, allowing the development of strategies to recognize and prevent risk situations. This could favor an early diagnosis and the elimination of risk factors for the person with dementia and their caregiver. Additionally, this might change the human resources requirements in memory clinics and the promotion of activities for the early diagnosis of dementia by policy makers.

SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: http://dx.doi.org/10.3233/JAD-161119.

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