



ORIGINAL ARTICLE

Understanding of legal aspects of Alzheimer disease among caregivers, medical students, and healthcare professionals[☆]

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Received 12 November 2018; accepted 7 March 2019

Available online 27 December 2020

KEYWORDS

Alzheimer disease;
Legal capacity;
Law;
Dementia;
Health education

Abstract

Introduction: Modification of legal capacity is a protective measure involving a judicial procedure; a deeper understanding of this concept is necessary for its execution in such vulnerable populations as patients with Alzheimer disease (AD). Unawareness of a patient's legal capacity and failure to adequately protect them may give rise to situations of avoidable risk.

Patients and methods: We designed a closed survey for informal caregivers of patients with AD, the general population, medical students, and healthcare professionals to determine the degree of understanding of the concept of modified legal capacity.

Results: The survey was administered to a total of 401 individuals: 100 caregivers, 117 members of the general population, 128 medical students, and 58 healthcare professionals. Women accounted for 66.1% of the sample (n = 265); mean age (SD) was 43.2 (0.9) years. The overall mean survey score was 7.7 (0.9). By group, caregivers scored 7.5 (0.18), the general population scored 6.9 (0.16), students scored 8.4 (0.17), and healthcare professionals scored 8.7 (0.20) (P = .000). Of all respondents, 78.8% had not received information on legal issues related to dementia. Among students, no significant differences in survey score were observed between members of different years (P > .05).

Conclusions: There is a low level of understanding of modified legal capacity and of the legislation governing issues related to cognitive impairment among caregivers, the general population, and even medical students. It is important to design strategies to improve understanding of the concept, particularly among future healthcare professionals.

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[☆] Please cite this article as: Lacampre R, Perez Pérez RM, Piñol-Ripoll G. Nivel de conocimiento de aspectos legales de la enfermedad de Alzheimer en cuidadores, estudiantes y profesionales sanitarios. Neurología. 2021;36:34–38.

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PALABRAS CLAVE

Enfermedad
Alzheimer;
Capacitación civil;
Legal;
Demencia;
Educación sanitaria

Nivel de conocimiento de aspectos legales de la enfermedad de Alzheimer en cuidadores, estudiantes y profesionales sanitarios

Resumen

Introducción: La modificación de la capacidad civil es una medida de protección que implica un procedimiento judicial del cual es necesario conocer algunos indicadores para facilitar su aplicación en una población tan vulnerable como en los pacientes con Enfermedad de Alzheimer (EA). Cuando no se conoce y no se protege adecuadamente a esta población pueden darse situaciones de riesgo que los profesionales de la salud deben evitar.

Sujetos y métodos: Se diseñó una encuesta cerrada a cuidadores informales de EA, población general, estudiantes y profesionales sanitarios para determinar el grado de conocimiento del concepto de modificación de la capacidad civil.

Resultados: Total de 401 personas; 100 cuidadores, 117 personas de la población general, 128 estudiantes y 58 profesionales sanitarios. El 66.1% (265) fueron mujeres. La edad media fue de 43.2 ± 0.9 años. La puntuación media de la encuesta fue de 7.7 ± 0.9 . En los cuidadores fue de 7.5 ± 0.18 , 6.9 ± 0.16 en población general, 8.4 ± 0.17 en estudiantes y 8.7 ± 0.20 en profesionales sanitarios ($p = 0.000$). El 78.8% de los sujetos encuestados no habían recibido información sobre las cuestiones legales de la demencia. En relación a los estudiantes no presentaron diferencias significativas en relación a los diferentes cursos ($p > 0.05$).

Conclusiones: El grado de conocimiento de la modificación de la capacidad civil y la legislación en relación a los aspectos legales relacionados con el deterioro cognitivo es bajo entre cuidadores, población general e incluso entre estudiantes del grado de Medicina. Sería importante diseñar estrategias para mejorar el conocimiento, sobre todo en los futuros profesionales sanitarios.

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Introduction

Legal capacity is defined as the capacity to have and to exercise rights and duties. This capacity can be modified through judicial proceedings as a protective measure and to assist in decision-making. This typically occurs when an individual, for any of a range of reasons, needs support in assessing and making decisions with respect to certain aspects of their personal lives and assets and to protect their interests, defend their rights, and to meet their duties.

The International Convention on the Rights of Persons with Disabilities and its Optional Protocol, adopted by the General Assembly of the United Nations on 13 December 2006, offers a new perspective of the rights of individuals with disabilities.¹ The document established that these individuals must no longer be objects of treatment or rehabilitation; rather, they must be considered full legal subjects.

This new approach is known as the “social model,” as opposed to the previous “rehabilitation model.” Therefore, “disability is an evolving concept and [...] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”

Alzheimer disease (AD) is the leading cause of dementia, accounting for 60%–80% of cases in individuals aged over 65 years.² The total number of patients worldwide is estimated at 47 million, a figure expected to increase to 130 million by 2050.³ During the progression of the disease, patients will encounter difficulties exercising their rights and duties. These difficulties lead to situations of risk, in which protection of these individuals is crucial.

Despite the paradigm shift in incapacitation, which has been recognised by legal and administrative agencies in Spain, there remain differences in the views of people in patients’ social setting

and healthcare professionals on this legal proceeding. This issue is hugely important, as societal views of legal incapacitation as a potentially beneficial intervention will determine the acceptance of this resource, the ways in which it can be employed, and its purpose.

In the light of these considerations, we performed a study aiming to establish the understanding of legal incapacitation in the social setting of patients with dementia. To this end, we created a questionnaire on legal aspects potentially relevant to the management of patients with dementia and evaluated the understanding of these issues among these patients’ informal caregivers, the general population, and practising and trainee healthcare professionals.

Subjects and methods

We performed a descriptive cross-sectional study in which subjects anonymously responded to a survey designed to assess their understanding of the legal capacity of patients with cognitive impairment. To create the survey, we initially posed 30 open-ended questions to caregivers until no new responses were given (30 caregivers). Based on their answers, we developed a multiple-choice questionnaire. The final questionnaire comprised 20 questions, 15 of which included options related to the degree of the respondent’s understanding of the process of legal incapacitation. Each correct answer was scored with one point, with a maximum total score of 15 points. The remaining items lacked a correct response, and instead were intended to gather subjective information on respondents’ level of understanding of legal questions related to the disease.

The questionnaire was completed in the waiting room of our hospital’s cognitive disorders unit, before consultations. The sample of caregivers included all informal caregivers of patients diagnosed

Table 1 Characteristics of the respondents.

	Caregivers n = 100	General population n = 117	Medical students n = 128	Healthcare professionals n = 56
Mean age (SD)	55.6 (1.4)	51.6 (1.4)	23.2 (0.3)	49.2 (1.2)
Women	65 (65%)	73 (62.4%)	85 (66.4%)	42 (75%)
Level of schooling				
Illiterate	4 (4%)	17 (14.5%)		
Primary education	32 (32%)	29 (24.8%)		
Secondary education	21 (21%)	39 (33.3%)		
Further education	43 (43%)	32 (27.4%)		
Mean total score (SD)	7.5 (0.2)	6.9 (0.16)	8.38 (0.17)	8.6 (0.2)
> 50% correct responses	48 (48%)	72 (60.7%)	83 (64.8%)	46 (82.1%)

with probable or possible AD according to the NIA-AA criteria.⁴ We excluded professional caregivers, companions of institutionalised patients who were not their primary caregivers, and caregivers of patients with other types of dementia. Members of the general population were recruited at 2 primary care centres in the city of Lleida.

Subsequently, we conducted telephone interviews to administer the questionnaire to practising healthcare professionals (social workers and physicians) and third-, fifth-, and sixth-year medical students: different years were included to establish whether understanding of the subject increased as students progressed through their degree, since the legal medicine module is taught in the third year.

The following variables were collected for the general population and for caregivers: age, sex, level of schooling, family history of cognitive impairment, and previous experience with the disease. For caregivers, we also established whether the patient they cared for was newly diagnosed or whether diagnosis was long-standing.

For clinical and demographic comparisons between caregivers and the general population, we used the chi-square test and the Fisher exact test. Comparisons of means were performed using the *t* test and analysis of variance with the Bonferroni correction. Correlation studies were conducted using the Pearson correlation coefficient. Statistical significance was set at $P < .05$ for all analyses. Statistical analysis was conducted with version 19.0 of the SPSS statistics software (SPSS; Chicago, IL, USA).

Results

A total of 401 subjects completed the survey: 100 informal caregivers (24.9%), 128 medical students (31.9%), 58 healthcare professionals (14.0%), and 117 members of the general population (29.2%). Women accounted for 66.1% of the sample ($n = 265$). Mean age (standard deviation [SD]) was 43.2 (0.9) years. The characteristics of the study population are shown in Table 1.

Respondents' mean score (SD) on the survey was 7.7 (0.9) points. By subgroup, caregivers scored 7.5 (0.18), the general population scored 6.9 (0.16), medical students scored 8.4 (0.17), and healthcare professionals scored 8.7 (0.20) ($P = .000$). When subjects were grouped into professionals and non-professionals, we observed no differences between informal caregivers and the general population in their understanding of the legal aspects of AD ($P = .87$). However, the comparison between healthcare professionals and medical students did identify significant differences, with practising physicians and social workers scoring higher than students ($P = .00$). No

differences were detected between third-year medical students and those in the fifth and sixth years ($P = .84$).

Overall, only 223 participants (55.5%) responded correctly to more than half of the 15 questions scored. The questions with the greatest numbers of correct responses were those related to caregivers or to the people responsible for patients' safety. For example, 79.6% of participants knew that the involvement of non-healthcare professionals is needed to ensure that both the patient and their family are protected. A total of 64.3% knew who is able to act as a patient's legal guardian, where needed, and 72.8% knew who holds legal guardians to account. Finally, while determining when a patient should stop driving is often problematic in clinical practice, 77.3% of respondents knew who has the authority to decide whether or not a patient has the capacity to drive a vehicle.

On the other hand, some issues were less well understood: only 9% of respondents knew whether a patient's legal guardian can be changed after being appointed; 66.6% did not know whether a foundation can act as a legal guardian; and only 24.7% knew how legal incapacitation can affect a patient with cognitive impairment.

In the subjective questions, 53.9% of respondents reported that they had heard of the concept of legal incapacity and 89.8% knew the difference between the figures of *tutor* and *curador* in Spanish law (different guardianship arrangements depending on the degree of incapacity), but only 13.2% knew the different types of legal protection for patients with cognitive impairment.

A total of 78.8% of respondents had not been informed about legal issues related to dementia. In terms of the information they would like to be given, 37.2% were most interested in a basic guide on legal incapacitation; 36.7% wanted to be informed about when a person should be incapacitated; 10.2% wished to know about how to proceed in the event of disagreement between family members; 6.2% were most interested in information on the responsibilities/decisions to be made by the partner of a legally incapacitated patient; and 5.2% wanted information on economic assistance, rather than legal questions.

Table 2 shows the responses to these subjective questions in each subgroup.

Among informal caregivers of patients diagnosed with dementia, age was negatively correlated with knowledge of legal issues ($r = -0.236$; $P = .018$), whereas caregivers with a higher level of schooling scored higher on the survey: illiterate participants and those with primary studies only (mean [SD] scores of 6.7 [0.2] and 6.6 [0.3], respectively) scored lower than those with secondary education (7.9 [0.2]) or further education (8.1 [0.3]) ($P = .006$). Such other variables as sex, whether the respondent was the primary caregiver, and whether diagnosis was recent showed no statisti-

Table 2 Distribution of responses to subjective questions.

	Caregivers n = 100	General population n = 117	Medical students n = 128	Healthcare professionals n = 56	P
Have you heard of the process of "legal incapacitation"? (Yes)	34 (34%)	14 (12%)	124 (96.9%)	44 (78.6%)	.00
Do you know how legal incapacitation affects patients and/or their families? (Yes)	11 (11%)	4 (3.4%)	18 (14.1%)	20 (35.7%)	.00
Do you know the meanings of the words <i>tutor</i> and <i>curador</i> ?* (Yes)	88 (88%)	107 (91.5%)	113 (88.3%)	52 (92.9%)	.66
Have you been informed about legal issues related to dementia? (Yes)	15 (15%)	3 (2.6%)	51 (39.8%)	40 (74.1%)	.00

* Different classes of legal guardianship in Spanish legislation.

Table 3 Distribution of responses to subjective questions in medical students in different years of their degrees.

	Third year n = 43	Fifth year n = 47	Sixth year n = 38	P
Have you heard of the process of "legal incapacitation"? (Yes)	43 (100%)	45 (95.7%)	36 (94.7%)	.34
Do you know how legal incapacitation affects patients and/or their families? (Yes)	6 (33.3%)	6 (33.3%)	6 (15.8%)	.92
Do you know the meanings of the words <i>tutor</i> and <i>curador</i> ?* (Yes)	35 (81.4%)	42 (89.4%)	36 (94.7%)	.17
Have you been informed about legal issues related to dementia? (Yes)	18 (41.9%)	23 (51.1%)	29 (23.7%)	.03

* Different classes of legal guardianship in Spanish legislation.

cally significant association with knowledge of legal aspects of the disease.

Among medical students, no significant differences were observed between students in different years. Neither was any significant difference observed between students with and without family history of dementia (8.6 [0.2] vs 7.9 [0.3]; $P = .55$). In the subjective questions, only 43.9% of students with and 37.9% of students without family history of dementia had been informed about legal

issues related to dementia ($P = .52$). Table 3 shows the differences between students in different years of their degrees.

Finally, practising healthcare professionals scored highest on the survey regardless of family history of cognitive impairment (8.9 [0.4], vs 8.5 [0.2] in those without family history; $P = .68$) or years practising ($r = -0.081$; $P = .551$). Of the 2 categories of healthcare professionals surveyed, social workers scored higher than primary care physicians (9.0 [0.4] vs 8.6 [0.2]; $P = .44$).

Discussion

Understanding of the concept of legal incapacity and legal issues related to dementia, both among the general population and among healthcare professionals, is a key factor in ensuring the success of interventions to protect patients with cognitive impairment. While Spain is an international pioneer in protecting these patients,⁵ very few studies have analysed awareness of the term “legal incapacity” and the related legislation in caregivers and the general population. To our knowledge, this is the first study to analyse understanding of these issues both in the general population and among practising and trainee healthcare professionals.

Our findings indicate poor understanding of the concept of legal incapacity, now known in Spanish legal parlance as “modified legal capacity.” Only half of the respondents had sufficient knowledge of these issues. Similar results were observed among informal caregivers and in the general population. As expected, medical students showed greater awareness than these groups, although their knowledge did not increase as they progressed through their degrees; this suggests that besides the legal medicine module, teaching of these issues in other disciplines and particularly in hospital internships is insufficient. In contrast, practising healthcare professionals, and particularly social workers, had considerably greater awareness of these questions, with 82% responding correctly to more than half of the questions.

It is difficult to compare our results against those of other authors, given the lack of research on this subject in the Spanish and European populations; this highlights the need for further studies.

While our findings do allow clear conclusions to be drawn, the study presents several limitations. Firstly, the small size of our sample, and especially the healthcare professionals subgroup, prevents us from extrapolating our data. Secondly, practising and trainee healthcare professionals completed the survey online, on a voluntary basis; this may have resulted in an inclusion bias, misrepresenting the true degree of participants’ knowledge. On the other hand, the study’s strengths include the large samples of caregivers and the general population, which allow us to assess the degree of understanding of these legal issues in different population segments in contact with these patients, as well as the design of the survey, which was based on the most repeated questions arising in an open-ended questionnaire administered to caregivers.

In conclusion, we observed a low degree of understanding of legal incapacity and legal issues related to dementia, both in the general population and caregivers and among practising and trainee healthcare professionals. Change is needed in health science degree curricula: competences related to this subject should be made a mandatory part of these degrees, given the fact that many future professionals may be faced with this situation, whether they work in primary care centres, residential or palliative care centres, or dementia units. It is also essential to improve training and communication in dementia units on issues concerning the legislation on these patients’ rights and duties.

Conflicts of interest

The authors have no conflicts of interest to declare.

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