Revista Brasileira de Psiquiatria. 2016;38:61–64
Associação Brasileira de Psiquiatria
doi:10.1590/1516-4446-2014-1603

UPDATE ARTICLE

What are the boundaries of legal guardianship in Alzheimer's disease? An evidence-based update in the context of the Brazilian Civil Code

Felipe K. Sudo,[1,2] Ana C. Salles,[1] Clarisse R. de Santiago[1]

[1]*Grupo de Apoio Técnico Especializado (GATE), Ministério Público do Estado do Rio de Janeiro (MPRJ), Rio de Janeiro, RJ, Brazil.* [2]*Instituto de Psiquiatria, Universidade Federal do Rio de Janeiro (UFRJ), Rio de Janeiro, RJ, Brazil.*

The Brazilian Civil Code, which came into force in 2002, established a functional criterion for guardianship proceedings and introduced the concept of "limited guardianship," applied to cases in which incapacity to exercise civil rights is partial. With population aging and the growth in the number of older people with cognitive impairments, such as Alzheimer's disease (AD), the need to invoke legal remedies against elder abuse increased; however, difficulties in assessing capacity still lead to a majority of decisions in favor of plenary guardianship. The present article compiled data on capacity in AD subjects. The varying degrees of decision-making impairment at different stages of AD might be compatible with limited guardianship in milder cases of the disease.

Keywords: Mental competency; civil capacity; dementia; Alzheimer disease; legal guardian

Introduction

Population aging, a global and unprecedented phenomenon, began in Brazil during the 1960s as a result of fertility decline. In 1960, the Brazilian population over 60 years old was 6 million; in 2010, this group had grown to 14 million individuals.[1] As observed in other countries, this increase in the elderly population has been accompanied by growth of the number of subjects with cognitive disabilities, such as Alzheimer's disease (AD).

Mounting evidence and emerging awareness exists concerning the nature and extent of the abuse of vulnerable older people. As a consequence, the need to invoke guardianship - a legal act that grants one person the power to make personal or property decisions for an allegedly incapacitated person – has grown. However, with recent discussions about the rights of mentally disabled persons, many law and health practitioners have stated that guardianship might impose excessive limitations to those allegedly incapable.[2]

Within this perspective, the Brazilian Civil Code (2002) represented an advance in the field. Switching from criteria based solely on psychiatric diagnosis ("insanity of all types," from the Civil Code of 1916) to a functional criterion ("those who lack discernment due to mental or intellectual disorders") aligned the legislation with current ideology in mental health, which values empowerment and relativizes the impact of mental disorders on the decisional capacity of the subject. Guardianship is now restricted to specific decisions that the protected individual is incapable of making, and the concept of incapacity is discriminated into two levels of severity: total impairment, requiring full or plenary guardianship; and partial impairment, for which partial or limited guardianship suffices.[2,3]

Nonetheless, other topics regarding the application of the new Code have since emerged. The need for evidence to support the validity of limited guardianship and the lack of validated instruments for capacity assessment mean that the majority of court decisions are still in favor of plenary guardianship.[4] With the purpose of assisting law and health practitioners when deciding on whether guardianship should be limited in AD, the present report compiled data on the capacity of individuals with different stages of the disorder. To this end, we collected evidence-based information about the abilities of subjects with AD to carry out activities that can be restricted by guardianship proceedings according to the Brazilian Civil Code, such as financial management, voting, testifying in court, consenting to sexual intercourse, making medical treatment choices and changing marital status.[2,3]

Giving consent for health issues

Capacity to consent to health treatment or to participate in research might be influenced by the diagnosis of AD, by cognitive status, and by the clinical stage of dementia. Many of the studies reviewed herein used the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) and the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), which assess four dimensions of the capability to consent: understanding relevant information (the patient's ability to manifest understanding of disclosed information related to the disease, research, or treatment), appreciating information (two subtests that assess patient ability to acknowledge the existence of the disease with which he/she has been diagnosed and to acknowledge the potential effect of the treatment/research on the disorder),

Correspondence: Felipe Kenji Sudo, Av. Nossa Senhora de Copacabana, 895/302, Copacabana, CEP 22060-001, Rio de Janeiro, RJ, Brazil.
E-mail: fksudo@gmail.com
Submitted Jun 20 2015, accepted Aug 30 2015.

reasoning about the information (assesses patient ability to think rationally about treatment options, risks and benefits of treatment/research, and consequences of treatment), and expressing a choice (assesses whether individuals are capable of stating a choice).[5]

Patients with mild and moderate AD (mean Mini-Mental State Examination [MMSE] score = 22.9±3.8, range = 16-28[5]; mean MMSE = 21.3±5.4, range = 12-29[6]) were assessed in two studies concerning health decision-making. Overall, 60% presented poorer understanding, 33% exhibited lower reasoning scores, and 68-80% performed poorer in appreciation subscales than normal older subjects (NOS). A longitudinal study reported that, at baseline, more than 90% of patients with mild AD (mean MMSE = 24.3±2.5) had preserved ability to communicate a treatment choice, 65% were capable of appreciating personal consequences, and 70% managed to reason about the treatment choice. However, all patients with mild AD were impaired in understanding the treatment situation, a finding that is in line with other studies[7] and might be partially explained by linguistic difficulties.[8] Over a 2-year period, patients with mild AD showed a marked decline in appreciation, reasoning, and understanding. The authors suggested that reasoning and understanding might decline more precipitously over time than other domains; thus, changes in those abilities might be sensitive indicators of impairment in capacity to consent as the disease progresses.[9]

Influence of caregivers on decision-making has also been assessed. In one study, most patients with mild-stage AD (Clinical Dementia Rating [CDR] = 1, MMSE $\geqslant$ 20) participated in collaboration with caregivers in decisions about their medical care, although only 9% made the final decision.[10] Interestingly, one study demonstrated that even AD patients deemed incapable to consent to participate in a clinical trial had the capacity to choose a research proxy.[11]

Studies that evaluated correlates between MMSE scores and consent capacity reported similar results. In one study, almost all patients with an MMSE score $<$ 17 were rated as incompetent to consent (sensitivity = 77.6%, specificity = 90.5%).[12] Conversely, other studies showed that MMSE detected individuals incapable of consent using a cutoff score of 19.[6,13] The cutoff of 23 in MMSE, corresponding to very mild AD, also identified incompetent subjects with high sensitivity and specificity.[13] On univariate analysis, those with MMSE $<$ 24 were at six-fold or greater risk of impairment in consent capacity (OR = 6.271, 95%CI 2.920-13.471, $p < 0.001$) than those who scored better in the test, but the significance of this association disappeared after controlling for confounders (age and diagnosis).[14] Awareness of dementia did not correlate with MMSE score, but presented significant positive relationships with the ability to understand, appreciate, and reason about health decisions.[10] Among domains of decision-making capacity, MMSE scores correlated with the understanding subscale ($r = 0.74$, $p = 0.002$[10]; $r = 0.55$, $p < 0.05$[15]) in two studies.

Voting

Studies conducted in the United States reported that 60-64% of subjects in a sample with mild-to-moderate AD voted in the 2000 presidential election. Patients who voted tended to be in earlier stages of dementia, but there was considerable variation in the severity of the disorder (MMSE scores ranged from 4 to 28).[16,17] Overall, 77.5% of the sample had questionable dementia (CDR = 0.5), 77.3% had mild dementia (CDR = 1), 37.0% were in the moderate stage (CDR = 2), and 18.2% had severe dementia (CDR = 3). When memory of the vote was assessed, patients were most impaired on free recall of information about the candidates and least impaired when asked to match identifying information to the appropriate candidate's face.[16,17]

Decision-making related to voting capacity was assessed using the Competence Assessment Tool for Voting (CAT-V) in some studies.[18,19] This structured interview also assesses four decision-making abilities (understanding, appreciation, reasoning, and communicating a choice). Most studies that used CAT-V showed correlations between capacity to vote and dementia severity. Overall, persons with very mild (MMSE $>$ 23) and mild (MMSE = 20-23) dementia scored within normal limits, whereas most individuals with severe dementia (MMSE $<$ 12) scored low on the test. Persons with moderate dementia (MMSE = 12-19) showed great variability in their scores. Understanding the nature of voting was preserved in about 53% of the patients with dementia in the studies, whereas a smaller proportion of patients understood the effect of voting (36.8-44%).[18,19] Moreover, reasoning was unimpaired in 35.3 to 42.1%.[19] Ability to state a voting choice was preserved in 25 to 89.5% of voters.[18,19]

Correlations between MMSE scores and the ability to vote showed conflicting results. MMSE scores correlated positively with measures of voting capacity in one study,[20] but failed to show a significant relationship in another.[18]

Financial management

The Semi-Structured Clinical Interview for Financial Capacity (SCIFC) is one of the few instruments available to determine the financial capacity in AD subjects. Patients with mild AD (CDR = 1) performed equivalently to NOS on basic monetary tests, such as naming coins/currency, counting coins/currency, performing cash transactions (e.g., identify item cost, purchase item from the grocery store, check change), and exhibiting conceptual financial knowledge (e.g., define the term "money", define how to obtain money, define the term "loan"). However, when analyzing complex financial skills (understanding and using a bank statement, making an investment decision), those individuals scored significantly below NOS. In relation to the domains checkbook management (tasks in which patients are asked to define a check, simulate a transaction using a check, and use a checkbook) and bank statement management (measured by tasks such as explaining the purpose of a bank statement, calculating a bank statement balance, identifying deposits, identifying balance differences), less than 30% of the sample with mild AD was considered capable. Financial judgment (e.g., explain how to determine the value of an automobile, detect and explain risk of fraud) was especially impaired in this group, with less than 15% achieving normal scores.

For overall financial capacity, only 26% of judgments were rated capable (37% marginally capable and 37% incapable) in the mild AD group, reflecting poorer financial skills than those of NOS and of subjects with mild cognitive impairment (MCI).[21] Patients with moderate AD (CDR = 2) performed significantly below NOS and those with mild AD in all tasks (except checkbook management and bill payment, in which mild and moderate AD performed similarly).[21] One study reported that 53.5% of a sample with mild-to-moderate AD (CDR = 1, mean MMSE = 19.7±2.5) were capable of making financial decision, although performance in understanding, appreciating, reasoning, and choice-stating tasks was significantly poorer than those of NOS and MCI groups.[22] In addition, performance in Trail-Making Test (TMT) Part B correlated with ability to review a monthly bank statement in subjects with MCI, but this relationship was not significant for mild AD.[23]

Established predictors of financial management capacity in NOS, MCI, and mild AD are written arithmetic skills, simple visuomotor sequencing (measured by TMT Part A), and immediate verbal recall.[23] Dyscalculia may be present in the early stages of AD. One study that evaluated calculation skills in AD patients showed that persons with mild AD performed similarly to NOS on single-digit addition, subtraction, and division, and on multiple-digit addition and subtraction problems. Patients with moderate AD performed significantly worse than NOS in all problems, except single-digit addition. Compared with NOS, patients with mild and moderate AD exhibited a higher proportion of errors in calculation problems.[24]

Discussion

Data supported that most individuals with very mild AD (CDR = 0.5 or MMSE $>$ 23) and some with mild AD (CDR = 1 or MMSE = 20-23) retain intact capacity for some domains (voting, performing simple monetary skills) and are impaired on others (consenting to treatment/research and performing complex financial tasks). On the other hand, moderate and severe dementia (CDR = 2-3 or MMSE $<$ 20) were associated with marked disability for all of capacity domains in the reviewed studies. The role of cognitive evaluation for determining capacity remains a matter of debate, but the findings of the included studies suggest that MMSE scores and the MacCAT scales might be useful for detecting consent incapacity, and that dyscalculia, difficulties in visual tracking, and impaired verbal memory might predict poor financial management.[12,13,23] Moreover, studies that assessed MMSE cutoff scores predictive of impaired consent capacity found high sensitivity or specificity for performances consistent with moderate dementia (scores below 17-19).[6,12,13] Scores consistent with very mild AD ($>$ 23-24) distinguished those deemed capable of consenting.[14]

Little, if any, evidence-based data exist about the capacity of subjects with AD to testify in court, change marital status, and consent to sexual intercourse. Further studies should address those issues and include not strictly cognitive factors that may influence difficulties in deciding or in expressing a choice, such as language disturbances (e.g., aphasia), psychosis, and self-neglect syndrome.

In conclusion, there is evidence in the literature to support that limited guardianship suffices to manage incapacity in most cases of mild AD. Such fractional protection might be just enough to safeguard these subjects from abuse without inappropriate removal of their civil rights.

Acknowledgements

The authors thank their colleagues at GATE; its coordinator, Dr. Denise Vidal; and the coordinators of the Center for Operational Support of the State Attorney's Offices for the Protection of the Elderly and People with Disabilities (CAO-Idoso), Dr. Luiz Claudio Carvalho de Almeida and Dr. Rafael Luiz Lemos de Souza.

Disclosure

The authors report no conflicts of interest.

References

1 Instituto Brasileiro de Geografia e Estatística (IBGE). Censo demográfico 2010 [Internet]. [cited 2013 Oct 10]. http://www.ibge.gov.br/home/estatistica/populacao/censo2010/.
2 Brasil, Ministério Público do Estado do Rio de Janeiro. Roteiro de atuação na ação de interdição: uma releitura a partir da convenção sobre os direitos da pessoa com deficiência [Internet]. [cited 2015 Sep 09]. http://www.mprj.mp.br/documents/112957/1520807/livro_v5_web.pdf.
3 Brasil, Código Civil2[a] ed.São Paulo: Saraiva; 2005.
4 Wright JL. Guardianship for your own good: improving the well-being of respondents and wards in the USA. Int J Law Psychiatry. 2010;33:350-68.
5 Kim SY, Caine ED, Currier GW, Leibovici A, Ryan JM. Assessing the competence of persons with Alzheimer's disease in providing informed consent for participation in research. Am J Psychiatry. 2001;158:712-7.
6 Karlawish JH, Casarett DJ, James BD. Alzheimer's disease patients' and caregivers' capacity, capacity, and reasons to enroll in an early-phase Alzheimer's disease clinical trial. J Am Geriatr Soc. 2002;50:2019-24.
7 Karlawish J, Kim SY, Knopman D, van Dyck CH, James BD, Marson D. Interpreting the clinical significance of capacity scores for informed consent in Alzheimer disease clinical trials. Am J Geriatr Psychiatry. 2008;16:568-74.
8 Tallberg IM, Stormoen S, Almkvist O, Eriksdotter M, Sundström E. Investigating medical decision-making capacity in patients with cognitive impairment using a protocol based on linguistic features. Scand J Psychol. 2013;54:386-92.
9 Huthwaite JS, Martin RC, Griffith HR, Anderson B, Harrell LE, Marson DC. Declining medical decision-making capacity in mild AD: a two-year longitudinal study. Behav Sci Law. 2006;24:453-63.
10 Karlawish JH, Casarett D, Proper KJ, James BD, Clark CM. Relationship between Alzheimer's disease severity and patient participation in decisions about their medical care. J Geriatr Psychiatry Neurol. 2002;15:68-72.
11 Kim SY, Karlawish JH, Kim HM, Wall IF, Bozoki AC, Appelbaum PS. Preservation of the capacity to appoint a proxy decision maker: implications for dementia research. Arch Gen Psychiatry. 2011;68:214-20.
12 Pucci E, Belardinelli N, Borsetti G, Rodriguez D, Signorino M. Information and competency for consent to pharmacologic clinical trials in Alzheimer disease: an empirical analysis in patients and family caregivers. Alzheimer Dis Assoc Disord. 2001;15:146-54.
13 Karlawish JH, Casarett DJ, James BD, Xie SX, Kim SY. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. Neurology. 2005;64:1514-9.
14 Warner J, McCarney R, Griffin M, Hill K, Fisher P. Participation in dementia research: rates and correlates of capacity to give informed consent. J Med Ethics. 2008;34:167-70.
15 Palmer BW, Dunn LB, Appelbaum PS, Mudaliar S, Thal L, Henry R, et al. Assessment of capacity to consent to research among older persons with schizophrenia, Alzheimer disease, or diabetes mellitus: comparison of a 3-item questionnaire with a comprehensive standardized capacity instrument. Arch Gen Psychiatry. 2005;62:726-33.

16 Ott BR, Heindel WC, Papandonatos GD. A survey of voter participation by cognitively impaired elderly patients. Neurology. 2003;60:1546-8.
17 Karlawish JH, Casarett DA, James BD, Propert KJ, Asch DA. Do persons with dementia vote?. Neurology. 2002;58:1100-2.
18 Irastorza LJ, Corujo P, Baãuelos P. Capacity to vote in persons with dementia and the elderly. Int J Alzheimers Dis. 2011;2011:941041.
19 Tiraboschi P, Chitò E, Sacco L, Sala M, Stefanini S, Defanti CA. Evaluating voting competence in persons with Alzheimer disease. Int J Alzheimers Dis. 2011;2011:983895.
20 Appelbaum PS, Bonnie RJ, Karlawish JH. The capacity to vote of persons with Alzheimer's disease. Am J Psychiatry. 2005;162:2094-100.
21 Marson DC, Martin RC, Wadley V, Griffith HR, Snyder S, Goode PS, et al. Clinical interview assessment of financial capacity in older adults with mild cognitive impairment and Alzheimer's disease. J Am Geriatr Soc. 2009;57:806-14.
22 Lui VW, Lam LC, Chau RC, Fung AW, Wong BM, Leung GT, et al. Structured assessment of mental capacity to make financial decisions in Chinese older persons with mild cognitive impairment and mild Alzheimer disease. J Geriatr Psychiatry Neurol. 2013;26:69-77.
23 Sherod MG, Griffith HR, Copeland J, Belue K, Krzywanski S, Zamrini EY, et al. Neurocognitive predictors of financial capacity across the dementia spectrum: normal aging, mild cognitive impairment, and Alzheimer's disease. J Int Neuropsychol Soc. 2009;15:258-67.
24 Martin RC, Annis SM, Darling LZ, Wadley V, Harrell LE, Marson DC. Loss of calculation abilities in patients with mild and moderate Alzheimer disease. Arch Neurol. 2003;60:1585-9.