While normal aging has been associated with the impairment of executive functions, it has been found that the prevalence of impaired decision-making increases significantly in a wide range of neurological disorders commonly seen in the elderly, and that this is seen particularly in the dementias. Impaired functional capacity — above all in decision-making — gives rise to ethical and legal questions that may have legal consequences. One of these situations is the possibility of a guardianship proceeding for dementia patients, depriving them of legal capacity in taking decisions and managing their own assets. In Brazil, the judicial determination of incapacity is a legal institution laid down in the legislation.

The guardianship proceeding

Four thematic categories appear consistently in descriptions: 1) professional, including palliative, care; 2) end-of-life issues including euthanasia; 3) issues concerning decision-making and the judgment of a substitute when the patient is incapable; and (4) decisions concerning clinical treatments.

For decision-making capacity, it is important to clarify what form the legal procedure of declaring a patient incapable will take. According to the legislation, guardianship proceedings — the declaration of incapacity — are a judicial measure by means of which an authority deprives an individual who is of age — in other words over eighteen — of the right to manage his or her own affairs and engage in the activities of civil life. This measure presupposes that the individual is incapable. The declaration of incapacity involves the appointment of a guardian who administers the individual’s life and the affairs(s) he is unable to manage by himself or herself. The guardian is responsible for carrying out all those civil acts that embody the conservatee’s rights.

However, capacity is a state that is as difficult to define as it is to assess. A working definition of capacity might be what is minimally necessary for an individual to be able to maintain personal decision-making ability. Capacity, legally defined,
is the ability to acquire rights and take on duties. Article 1 of the Brazilian Civil Code lays down that every person is capable of rights and duties within the civil order. Legal incapacity is, therefore, a restriction or constraint upon civil acts. The concept of legal capacity differs from the medical concept of capacity, which defines a set of skills required such as memory, judgment and decision-making, in order to manage affairs and carry out daily tasks. Mental capacity is not universal. Absence of the capacity in a given situation may not imply its existence in other situations; it may therefore change.

The legal entity of incapacity aims principally to protect individuals who are significantly impaired, from a legal standpoint, and the forms of protection are graded. Guardianship proceedings ("interdiction" in Brazilian legal parlance) are regulated by the Code of Civil Procedure.

The aims of the present study were to: (i) evaluate the prevalence of guardianship actions in patients diagnosed with dementia in a neurological outpatient clinic; (ii) evaluate in which period of Alzheimer’s disease (AD) the interdiction of the patient was determined and any difficulties in obtaining guardianship; (iii) in the case of absence of the guardianship, to evaluate how families resolve the legal problems in practice.

METHODS

Participants

In a six-month period, 97 patients were recruited from an outpatient clinic at the Behavioral Neurology Section. All patients met Diagnostic and Statistical Manual of Mental Disorders—DSM-IV diagnostic criteria for dementia. The clinical diagnosis was arrived at in accordance with published criteria: The National Institute of Neurological Communicative Disorders and Stroke—Alzheimer’s Disease and Related Disorders criteria for Alzheimer’s disease; the National Institute of Neurological Communicative Disorders and Stroke—Association Internationale pour la Recherche et l’Enseignement en Neurosciences criteria for vascular dementia; and the revised diagnostic criteria for the behavioral variant of frontotemporal dementia (bvFTD). On all occasions, a written explanation of the research design was read by the principal researcher or the primary family caregivers for the patient, and additional explanations were given when necessary, after which an informed consent form was signed. All proceedings were approved by the Institutional Review Board.

After patients and their caregivers consented to participate in this study, by signing an informed consent form approved by the local ethics committee, the objectives of the study were presented to them.

The inclusion criteria for assessing the patients were: prior determination of a diagnosis of dementia; pre-established Clinical Dementia Rating Scale (CDR); Mini-mental State Examination (MMSE) and/or severe Mini-mental State Examination (SMMSE) and the presence of the caretaker on the date of application for the attached protocol.

Data analysis

A descriptive analysis was employed for all subjects in regard to gender, age at examination, schooling, CDR, MMSE and SMMSE scores. The threshold of significance was set at p < 0.05.

The continuous and semi-continuous data for the variables were compared with the Gauss curve and determined as parametric by means of the Kolmogorov-Smirnov test and Shapiro-Wilk test; the data were therefore represented by mean and standard deviation of the sample. The Student’s t test for independent samples was used to compare two independent groups.

Categorical data were represented by absolute (n) and relative (%) frequency, and Pearson’s chi-squared test was used to analyze contingency matrices.

For the entire study, the risk of committing a type I error was considered to be less than or equal to 5% and the beta risk for committing a type II error was less than or equal to 20%.

**Table 1. Demographic characteristics of dementia patients.**

<table>
<thead>
<tr>
<th>Demographic data</th>
<th>Individuals n = 97</th>
<th>n (%)</th>
<th>mean [SD]</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37 (38)</td>
<td></td>
<td>77.9 [8.4]</td>
<td>57–95</td>
</tr>
<tr>
<td>Female</td>
<td>60 (62)</td>
<td></td>
<td>5.5 [4.4]</td>
<td>0–15</td>
</tr>
</tbody>
</table>

SD: standard deviation.
RESULTS

We found that of the 97 patients analyzed, 28 (29%) had undergone guardianship proceedings and 16 (16.49%) had been under some other form of legal representation. The remaining 53 (54.63%) patients did not fall into either category of judicial representation.

We observed that 59 (60.8%) of the caregivers were the children of the patients analyzed, 32 (32.9%) were their spouses, four (4.1%) were second-degree relations, one (1%) was a sibling and one (1%) was a friend.

We found that after guardianship proceedings, 12 children became caregivers, making up 43% of the individuals assessed. In most cases—15 patients (54%)—guardianship was exercised by the spouse. Only one patient’s caregiver was a second-degree relation.

Relationship between patients under guardianship and patients not under guardianship

The mean age was 79.01 ± 8.13 years of age for non-assessed patients and 75.24 ± 8.74 years of age for legally assessed patients; further demographic data follows below (Table 2).

CDR: only one of the conservees (3.57%) had CDR 1, two (7.14%) had CDR 2, and 25 (89.28%) had CDR 3. For individuals not under guardianship, 15 (21.73%) had CDR 1, six (8.69%) had CDR 2, and 48 (69.56%) had CDR 3 (Figure 1).

In terms of an etiological diagnosis of dementia, we found that for AD, out of a total of 71 patients, 56 individuals were not under guardianship (81.15%) and only 15 individuals (53.57%) were under guardianship (p = 0.006). For bvFTD, only two (2.89%) patients were not under guardianship, while six (21.43%) individuals were under guardianship (p = 0.003). For mixed dementia, only three (4.34%) patients were not under guardianship, while three (10.71%) individuals were under guardianship. For vascular dementia, only three (4.34%) patients were not under guardianship, while one (3.57%) individual was under guardianship. Furthermore, we observed that three (10.71%) individuals under guardianship had other dementias (Figure 2).

DISCUSSION

We did not find significant differences between the comparative results of individuals under guardianship and patients not under guardianship for age and schooling.

Table 2. Demographic and clinical characteristics of assessed and non-assessed patients.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Under guardianship (n = 28)</th>
<th>Not under guardianship (n = 69)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>mean [SD]</td>
</tr>
<tr>
<td>Demographic data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>75.24</td>
<td>[8.74]</td>
</tr>
<tr>
<td>Schooling</td>
<td>5.75</td>
<td>[3.56]</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (61%)</td>
<td>20 (29%)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (39%)</td>
<td>49 (71%)</td>
</tr>
<tr>
<td>Clinical data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.0</td>
<td>1 (3.57%)</td>
<td>15 (21.73%)</td>
</tr>
<tr>
<td>2.0</td>
<td>2 (7.14%)</td>
<td>6 (8.69%)</td>
</tr>
<tr>
<td>3.0</td>
<td>25 (89.28%)</td>
<td>48 (69.56%)</td>
</tr>
<tr>
<td>MMSE (CDR 1 and 2)</td>
<td>15</td>
<td>[10]</td>
</tr>
<tr>
<td>SMMSE (CDR 3)</td>
<td>7.36</td>
<td>[9.25]</td>
</tr>
</tbody>
</table>

SD: standard deviation; CDR: Clinical Dementia Rating Scale; MMSE: Mini-mental State Examination; SMMSE: severe Mini-mental State Examination.
However, although the total population studied is predominantly in the moderate or severe stage of dementia (83.5%), we observed that only 44 (45.37%) of the patients were under some form of judicial representation; in other words, many patients not in the initial stage of the disease were not under any form of legal protection. There may be several reasons underlying this state of affairs. In answers given by caregivers during application of the study protocol, many claimed there was insufficient personal equity to warrant a petition for guardianship or representation, while others claimed that the high cost of the legal process militated against the procedure. We also perceived a lack of information about the need for guardianship, since most stated they were unaware of the procedure. We should consider whether there is a cultural hurdle in Brazil to the discussion and assessment of judicial guardianship procedures, since some families with strong religious beliefs find it hard to address issues of the end of life and its legal consequences.

Another important difference relates to gender. Whereas in the total population there are more female patients, only 11 were under guardianship. This may be a cultural difference. The population in the present study is predominantly women who are not committed to a bread-winning role or to the family's financial decisions. Men have mainly been responsible for financial administration and for managing the family's equity; if they are incapable of doing so, this would lead the caregivers to take steps to find a legal solution. We may expect that, in the future, the increasingly-important role of women in the workplace will alter this scenario.

A significant analysis of the diagnosis needs to be produced. While there was a predominance of AD in the total population (73%), this fell to 54% in individuals who were under guardianship. For bvFTD, this was only 8% in the total population, but among individuals under guardianship it was 21%. We need to investigate how far the prominent clinical picture in the behavioral scope of bvFTD directly impacts the decisions taken by the families involved and in the decisions of the judges, given that a more discreet clinical presentation of AD — even with apathy — may not strike those involved in guardianship proceedings so forcefully.

There is a significant difference between the main caregiver identified in a medical appointment and the legally-appointed caregiver. Whereas in the general population, 60.82% of caregivers are the children, they account for only 43% of caregivers in the case of conservatees. In most patients (54%), guardianship was exercised by the spouse. We may stress here that although it is actually the children who take care of dementia patients, the law still finds it safer to pass administrative and financial responsibility to the other spouse. In most cases the latter is the main beneficiary of the will, because before 1977, the legal regime for assets in the marriage was universal community of assets, where all the assets acquired before and after the marriage were shared equally between the couple. Given that the patients assessed are elderly, we may deduce that most of the marriages are ruled under the aegis of the law that pertained up until 1977, which may lead judges to decide for guardianship in most cases by the capable spouse.

Studies have shown that ethical and legal discussions of decisions taken in the end-of-life and dementia settings vary by local culture and religious influences. Thus, in strongly Catholic countries such as Spain and Italy, there is greater resistance to engaging in discussions on the end of life and its consequences than in countries less influenced by religion such as Belgium and Norway. In a similar Italian study with patients diagnosed with dementia, 172 individuals were assessed at the outset of the study, three of whom had been legally declared incapable before the study began. Of the remaining 169, guardianship was denied in 91 (53.8%). Of the remaining 78 (46.2%) patients, 55 were declared incapable and 23 were still awaiting the sentence. In this study, the result was that there was a small number of patients found requiring guardianship: 58 (34%) patients. This figure is slightly higher than that found in our own study (28%). The Italian study makes for an interesting comparison since Brazil is culturally very similar to Italy.

We conclude that the rate of legal guardianship proceedings in the case of patients obviously impaired by dementia is lower than expected.

The assessment of an individual's competency or capacity is a task of enormous responsibility, going beyond a merely clinical analysis. A multidisciplinary team must therefore carry out a thorough evaluation. To declare someone incapable, even if only for specific tasks, means depriving that person of fundamental rights and freedoms and causes a drastic change in the individual's life.

Few studies currently address the legal issues involved in dementias, but this discussion will grow alongside the increased incidence of the disease, which leads us to reflect on the need for greater involvement of a multidisciplinary team, the family, and society itself in these aspects.

References