



## Articles

# Family Cohesion: A Study on Caregiving Daughters of Parents With Alzheimer's Disease

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## Abstract

In this regard, investigating these aspects might facilitate the evaluation of family relations and the development of interventions that create, keep, restore, or enhance the skills families need to better deal with the disease. Based on this information, the objective of this chapter is to present and discuss investigative research on family cohesion and hierarchy from the perspective of caregiver daughters of elderly with Alzheimer's in four situations: before the disease, currently, in conflict, and ideally. 32 women caretakers and their respective parents (6 fathers and 26 mothers) diagnosed with possible or probable AD participated in the survey. The instruments used were the Mini-Mental State Examination (MMSE) in an Open Interview with a Semi-Structured Script, and the Family System Test (FAST). We observed that before onset of the disease, the caregivers generally perceived themselves to have more hierarchy than their siblings,  $\chi^2(2) = 4.92$ ,  $p < .10$ . The current situation showed a greater number of caregivers in higher hierarchical positions than their siblings (72%), and a lesser number of siblings than expected in higher hierarchical positions than the caregivers,  $\chi^2(2) = 18.32$ ,  $p < .001$ . The ideal representation showed that most caregivers did not want themselves or any of their siblings to have more power than the other (66.7%),  $\chi^2(2) = 14.89$ ,  $p < .001$ . Comparing conflict representations to ideal representations showed that family members demonstrated lower cohesion in conflict situations than in ideal situations,  $z = -2.86$ ,  $p < .01$ .

**Keywords:** family, cohesion, Alzheimer

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With the increase in the number of older people comes a rise in the cases of dementia, the most apparent one being Alzheimer's Disease (AD) which poses significant epidemiological, economic and social impacts (Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014). According to data from the Alzheimer's Association (2014), around 5.2 million Americans are affected by this disease representing the sixth leading cause of death in the United States. In Brazil, there are an estimated 55,000 new cases per year which represents around 7.9% of the population over 65 years of age; a higher prevalence than the global average (Burlá, Camarano, Kanso, Fernandes, & Nunes, 2013). AD is a progressive and degenerative disease of the brain affecting numerous cognitive areas resulting in declines in functional ability and behaviour changes (Kang et al., 2014). It begins with short-term memory loss which gets progressively worse. As it advances it affects other cognitive functions such as language and executive functions. Examples are difficulties reasoning and assessing situations as well as disorientation which compromises

social and functional activities (Ortiz & Bertolucci, 2005; Nunes, Aprahamian, & Forlenza, 2012). Therefore, Alzheimer's is a disease which demands more and more complex care as it advances.

Every family has their own resources and, consequently, different ways of dealing with the challenges presented by AD. However, the caretaking responsibility usually falls on one person, most commonly the wife, daughter, or daughter-in-law of the elderly affected by the disease (Falcão & Bucher-Maluschke, 2010; Neumann, 2014). This is a difficult, overwhelming task which can potentially lead to stress, anxiety, fear, and suffering. When necessary, these women tend to reach out to other family members for help, especially brothers and sisters, so that they too become more involved in the caretaking. This generally means having to distribute tasks among family members which can bring about conflicts and dissension, and sometimes leads to an imbalance within the family (Fernandes, 2009). Therefore, family support is an essential resource towards reducing the effects of the numerous stressful events this disease presents. It has a positive influence on the results of psychotherapeutic treatment and helps to reduce recurrent behavioural disorders as well as various others. Furthermore, it is a factor for protecting physical and psychological well-being, and strengthens the caregiver's resilience (Juliano & Yunes, 2014).

In Salvador Minuchin's structural family therapy, cohesion, hierarchy and flexibility are key dimensions for describing the structure of family relations. Cohesion represents the affection family members feel for one another, in other words, it is an emotional bond or connection between family members (Fleck & Bowen, 1961). As for hierarchy, Haley (1976) described it as "levels of status and power", while Minuchin (1982) described it as "different levels of authority", in other words, each member has a level of authority within the family. Both Haley and Minuchin used the expression "hierarchy of power", which shows just how similar these terms are. Hierarchy has also been used for investigating structural changes of roles and rules within the family. According to Beavers and Hampson (1995), it is essential to understand and value the structural hierarchy of interaction in internal and external family systems. This also includes systems of higher order such as the extensive family and broad social networks. For Miermont (1994), hierarchies allow for diversified decision-making and functional task distribution by a more or less balanced and accepted ritual of dominators and dominated. The dominator and dominated relation is not only based on dyads, but also on triangulations and coalitions. The position of the dominator is not necessarily a negative one as it can be favourable when organizing territories.

In this regard, investigating these aspects might facilitate the evaluation of family relations and the development of interventions that create, keep, restore, or enhance the skills families need to better deal with the disease. Based on this information, the objective of this chapter is to present and discuss investigative research on family cohesion and hierarchy from the perspective of caregiver daughters of elderly with Alzheimer's in four situations: before the disease, currently, in conflict, and ideally. The method, results, and discussion are presented below.

## Method

The research was done at the Reference Health Care Centre for seniors with AD, operating out of the Medicine Centre for seniors at the University of Brasilia (HUB) in the Federal District. This centre provides clinical and multidisciplinary treatment for people with AD and other dementias.

## Participants

32 women caretakers and their respective parents (6 fathers and 26 mothers) diagnosed with possible or probable AD. The seniors (6 men, 26 women) were between the ages of 70 and 92 ( $M = 79$ ), 10 of whom were married, 4 separated/divorced, and 18 widowed. The average length of marriage for married couples was 50 years. Before AD, most were in the intermediary phase of the disease, were high school graduates, practicing Catholics, and worked from home. The seniors' income varied between 1 and 33 minimum salaries ( $M = 3$  salaries). The average length of time living with their caregiver daughters was 14 years.

The caregiver daughters in this study were between the ages of 35 and 64 ( $M = 51.38$ ,  $SD = 7.17$ ), most of whom were middle-aged. 15 were married, 10 single, 4 separated/divorced, and 3 were widows. The average length of marriage was 26 years. Most of them were the eldest daughter ( $N = 13$ ), had between 1 and 10 siblings, two children ( $M = 25$  years old), and no grandchildren. They practiced Catholicism, had university degrees, were retired or worked from home. Their incomes varied between 1 and 51 minimum salaries ( $M = 5$  salaries). Of the 13 caretakers who worked away from home, 10 were employed part-time.

The *inclusion criteria* required all caregivers: (a) to be daughters of the elderly person diagnosed with possible or probable AD; (b) to be responsible for their care and; (c) to live with the elderly person with AD. For the parents, they had to (a) be attended by the previously mentioned Reference Centre; (b) be diagnosed with probable/possible AD and; (c) be in the initial to moderate stages of the disease. This data was obtained from the evaluations and results included in reports issued by professionals at CMI. It is important to note that many subjects did not match the inclusion criteria and therefore could not participate in the study, yet many others were also excluded from the study due to the following factors: (a) the seniors only participated in the first consultation, opted out of treatment, or passed away or (b) family members came to the Reference Centre believing their parents were suffering from AD yet, after evaluation, they were discovered to be suffering from different type of dementia.

## Instrument

The instruments used were the Mini-Mental State Examination (MMSE) in an Open Interview with a Semi-Structured Script, and the Family System Test (FAST). The Family System Test, developed by Thomas M. Gehring in 1993, was based on Minuchin's structural-systemic theory. It is a quantitative and qualitative research process designed for structurally and systematically analyzing its subjects' perceptions of relational structure in a variety of research and clinic-based situations. This chapter will present the quantitative results. The main dimensions analyzed are cohesion and hierarchy. The respondents used a monochromatic board (45 cm x 45 cm) with 81 squares (5 cm x 5 cm) placed vertically and horizontally, with each square given a number between 1 and 9. They also used twelve wooden figures (six representing females and six representing males) and six coloured wooden figures (orange, green, and pink), three for each sex. After introducing the material, it was explained that a figure could be placed on each square. The closer together the family members are (represented by the figures), the more cohesion they had; the further apart they are, the less cohesion they have.

The material is also made up of 18 cylindrical blocks of three different heights (1.5 cm, 3 cm and 4.5 cm), six for each height. They were explained that these blocks represented hierarchy among family members, and that the figures could be placed on one, many, or none of the blocks. Each block represented the power of hierarchy, for example, a figure that was placed on a 1.5cm block would have less power than a figure placed on a 4.5cm one, or that was placed on various blocks. Any figure not placed on a block had no power whatsoever over the others.

It is worth noting that the figures representing the family members did not necessarily have to be the same ones in all four FAST situations (before the disease, currently, in conflict, and ideally) as it was the participants who identified who their family members would be in each test phase. The only requirement was that they include the person with Alzheimer's in all steps. This was necessary in order to investigate their relationship with the presented family members.

It is also worth noting that all the figures and blocks were removed from the board and returned to their original positions at the beginning of each representation. This was in order for participants to reflect on the cohesions and hierarchies of family members in each representation as it was presented. Outside of using the board, the coloured and non-coloured wooden figures, and the blocks, the caregiver daughters also filled out a report on how they viewed the family representations. We would like to point out that [Gehring's \(1993\)](#) model represents three family situations: typical (current), ideal, and conflict. The caregiver daughters were told they could present a situation which occurred either before or after the disease. This criteria was adopted in order to assess whether family conflicts were more prevalent in the periods before or after the dementia. This chapter will focus on parental, filial, and fraternal subsystems.

Another phase was added to the test for study purposes: the representation of the caregiver daughter's family before her mother/father had been diagnosed with probable/possible Alzheimer's. In other words, the participants were asked to represent their families before the disease had affected them. The decision was made to include this other phase due to the impossibility of carrying out a longitudinal study on the family's experiences before and after AD.

## Data Processing

The quantitative results of the FAST test were analyzed through the SPSS WIN/PC 13 program (Statistical Package for the Social Sciences – Windows Personal Computer – version 13). The data was analyzed using a set of nonparametric tests to determine the differences between independent and dependent samples. As the data was not random and did not present a normal distribution in accordance to the Kolmogorov-Smirnov test, it was deemed necessary to use nonparametric statistics in order to obey the natural logic of the collected data. The Chi-square test was used to analyze the frequency of responses in each category (nominal data). The McNemar Test was applied to those analyses showing a change in frequency *before* and *after* the emergence of Alzheimer's, for example, the number for hierarchy reversal and cohesion (FAST). In this case, only two categories were observed (the presence or absence of hierarchy reversal). Nonparametric tests (Friedman Test and Wilcoxon Test) were used to determine cohesion and hierarchy in the various family subsystems, as well as to compare different family representations related to these variables (before and after the disease, conflict, and ideal).

The [Bardin technique \(1977/2000\)](#) was used to analyze the interviews in three stages: pre-analysis, exploring the material, and treating the results. These analyses together with the transcribed interviews made up the *corpus* of the study. A *brief reading* is made in the pre-analysis stage. The following rules were applied to exploring the material: (a) thoroughness – exhausting all communication, not leaving out any information; (b) representation – represented the universe of the sample; (c) homogeneity – the data referred to the same subject and was obtained through equal techniques, applied by similar individuals; (d) relevance – the interviews were adapted to the research objectives; and (e) exclusiveness – an unclassified element in more than one category.

## Procedures

The research project was initially handed in to the Faculty of Medicine's Research Ethics Committee at the University of Brasilia (UnB). After the research application had been accepted, a sample survey was made based on all the medical records of patients who had been served by the Centre's multidisciplinary team. Each potential survey participant was contacted and informed about the study, and then invited to the Centre at specific times and dates. The general objectives of the study and how it was to be applied were explained in-person to the participants. After the participants had agreed to participate, they were given instructions on how to complete the individual part of the FAST test. The interviews were recorded, transcribed, and analyzed.

## Results

We observed that before onset of the disease, the caregivers generally perceived themselves to have more hierarchy than their siblings,  $\chi^2(2) = 4.92, p < .10$ .

The current situation showed a greater number of caregivers in higher hierarchical positions than their siblings (72%), and a lesser number of siblings than expected in higher hierarchical positions than the caregivers,  $\chi^2(2) = 18.32, p < .001$ .

The ideal representation showed that most caregivers did not want themselves or any of their siblings to have more power than the other (66.7%),  $\chi^2(2) = 14.89, p < .001$ .

Comparing conflict representations to ideal representations showed that family members demonstrated lower cohesion in conflict situations than in ideal situations,  $z = -2.86, p < .01$ .

A hierarchy reversal was revealed when comparing the hierarchy of the mothers with Alzheimer's to that of their caregiver daughters, both before and after the disease. The caregivers had more power than their mothers in the current representations,  $z = -3.6, p < .001$ , in the ideal representations,  $z = -2.28; p < .05$ , and in the conflictual representations,  $z = -2.48, p < .05$ . In other words, there was no hierarchy of power over the mothers before the disease, but there was after disease had set in.

Comparisons showed the caregiver daughters would have liked to have less power (hierarchy) over their mothers in current family representations,  $z = -3.6, p < .001$ , and in ideal family representations,  $z = -2.28, p < .05$ .

Further comparisons of hierarchy both before and after the disease showed the caregiver's siblings to have higher hierarchy than their mothers with Alzheimer's in current situations,  $z = -3.37, p < .001$ , in ideal situations,  $z = -3.14, p < .01$ , and in conflict situations,  $z = -2.8, p < .01$ .

In 65% of the cases in this study, the caregiver daughters said they were the ones who had been most committed to the family before their mother or father developed Alzheimer's, and 85% of them took on or maintained this commitment to family (to their parents in particular) after the disease had set in.

When the interviewees were asked about loyalty between family members, 17 caregiver daughters said not all family members were loyal before the disease, 10 said all the members were disloyal, and the other 5 said all were loyal. After the disease, 21 said that not all family members were loyal, 9 said they were all disloyal, and only 2 said that all family members were loyal to each other.

## Discussion

Most of the caregiver daughters presented the fraternal subsystem during the FAST representations, especially before Alzheimer's had affected their parents. All the data showed that cohesion in fraternal subsystems did not change significantly from one family representation to another (before the disease, current, ideal, and conflict). However, some cases presented a greater distancing or approximation between certain family members.

In current situations, the caregivers' siblings had more hierarchical power over their mothers with Alzheimer's. There were also a higher number of caregivers with more hierarchical power than their siblings, and an unexpectedly lower number of siblings with more hierarchical power than the caregivers.

Before the disease, many caregiver daughters believed they had more hierarchy than their siblings. This was due to how they perceived the power they already had within the family, especially in relation to their parents with Alzheimer's. Over time, as their parents began to lose their autonomy, the caregivers gained more control, and consequently more power, over their parents' lives. This was particularly a result of being in a caretaking position. They did not, however, want either their siblings or themselves to have more power than the other.

The fact is that elderly people with Alzheimer's are in a progressive state of alteration, even though physically they remain the same. [Boss \(1998\)](#) called it *ambiguous loss*; a situation where a family member is physically present yet psychologically absent, as in the case of dementia. She explained that this situation generates conflict because the family members do not know who is in or out of the family system, resulting in stress and changes within the family hierarchy. According to [Boss and Yeats \(2014\)](#), the chronicity and complexity of ambiguous loss may lead to health problems such as depression or persistent grief disorder complex. In order to research *ambiguous loss*, [Dupuis \(2002\)](#) interviewed 38 daughters and 23 sons who were looking after their elderly parents with Alzheimer's. Their stories revealed that this loss occurred over an extended period, in other words, there were various phases involved in the process including the feeling of anticipation of loss, the progressive loss itself, and understanding it. Acceptance and avoidance of this reality are how most of these family members dealt with it.

A systemic perspective of these discussions shows us a circularity and independence between these family members. The internal commitments of each family member are intertwining; they form a complex balance of group forces and unconscious obligations. Commitments, devotion, and loyalty are the most important determinants in family relations. This web of obligations derives from the multigenerational structure of justice within the human universe, based on the history of family members' actions and attitudes ([Boszormenyi-Nagy & Spark, 1973/2003](#)).

Being a caregiver child quite frequently increases tensions among family members, especially siblings. Those siblings who provide care are more likely to experience higher levels of conflict, criticism, and demands than those siblings who do not ([Kwak, Ingersoll-Dayton, & Kim, 2012](#)). Once the parents start experiencing a serious decline in health, the siblings then have to start planning out caregiving duties. At this point, they are embarking on a journey through a process which they have little knowledge about. These situations are difficult in any circumstance; however, they tend to be more problematic when parents show favouritism towards who their future caregivers in the family will be ([Suitor, Gilligan, Johnson, & Pillemer, 2014](#)). This perception of favouritism has a strong impact on sibling relations and is a precursor of tensions among them. Some signs of favouritism between mothers and their children are: the sex of the child (mothers usually prefer daughters as caregivers), and a tendency to favour younger children ([Suitor, Gilligan, & Pillemer, 2013](#)).



Most of the daughter caregivers in this study stated that they were the ones who were most committed to their mothers/fathers before and after Alzheimer's. In addition to socio-cultural, socio-historical, and economic factors, the principles parents pass on to their children and any unsettled family issues from previous generations may result in a symbiosis, or conversely, a lack of commitment among family members which may ultimately create a family anomie. The lack of commitment siblings exhibit towards their parents with AD touches upon a few questions of morality and sense of justice within the family and society. In some other cases, married siblings felt exempt from the responsibility of taking care of their parents, citing the fact that they had their own families to take care of, or because there were relational conflicts between members of their family of origin and current relatives. The siblings' opinion that their single sisters should be more responsible for their sick parents may be explained through sociocultural, economic, structural, and dynamic factors of every family system.

Additionally, geographical or emotional distance and a general lack of interest in the treatment were also mentioned as factors towards a lack of commitment. In an attempt to gain more support, some caregivers held family meetings or contacted their siblings to explain the importance of sharing the caretaking responsibilities, especially when they feel stressed and overwhelmed.

[Aumann and Dreze \(1974\)](#), a Nobel-prize winner in Economics in 2005 (Robert Aumann), used the game-theory analysis as a tool towards understanding the decision-making process in the real world. His theory was that cooperation is often a "balanced solution" and occurs less frequently when: (a) there are many participants in a game; (b) interactions are not frequent; (c) there is little time to solve the problem and; (d) other participants' actions cannot be clearly observed. Aumann's view might lean slightly more towards understanding family conflicts experienced on the caregiver's part.

This difficulty in obtaining support for sharing out caretaking responsibilities might affect the caregiver's abilities, particularly when those responsibilities start to become stressful and burdensome. Once this happens, the daily concerns and affections shared between people who are close to each other are substituted by different concerns and affections, governed by the need to do everything for and guarantee the survival of the other ([Falcão & Bucher-Maluschke, 2009](#)). This responsibility can impose limits on the caregiver's daily life, for example: less recreational time or no time for vacations; no time for self-care, for friends, or for looking after other people the way one would like to; tiredness; depression; health and money problems ([Santos, Pelzer, & Rodrigues, 2007](#)).

Conversely, some families were more committed and successful than others at managing their own resources when it came to coping with the disease. Those families who communicated and kept in contact more often with each other and the elderly dementia sufferers had a better understanding of the illness itself and the day-to-day life of the caregivers. Consequently, there was more cooperation and sharing of responsibilities in those families than there was in other families whose members were distant, both geographically and emotionally. Additionally, smaller families with less cohesion were less likely to support each other when it came to caring for the Alzheimer's sufferers.

It was clear that even though the caregivers said they had more power than their siblings, most of them could not get their siblings' help when they needed it. According to a study by [Panyavin et al. \(2015\)](#), which examines the pattern of family dynamics for dementia sufferers who have the biggest impact on the quality of family care, the most important qualities (provide and respect) of informal care were related to higher levels of empathy and a reduction in the levels of family dysfunction. The more empathy and better overall functioning a family had, the

better the quality of care was. This is what “provide” refers to. “Respect” was positively correlated with empathy, cohesion, flexibility, communication, and satisfaction within the family.

This study showed that when family members worked together and overcame stress and conflicts, they also strengthened their bonds and feelings of identity and belonging to the family. Another important result was that the emotional bonds and task sharing were more pronounced between sisters or between the women of the family. These results confirm the gender roles inherent to a society’s culture where women are the ones responsible for strengthening relationships within the family. In a family relations system, the interactions between the subsystems and each member’s future roles are governed by the intergenerational and transgenerational aspects of expectations, aspirations, restrictions, and obligations.

According to the daughters’ accounts of their family experiences, some cases experienced caregiver role reversals, mainly among the women; a kind of “caregiver rotation”. This frequent rotation left the patients feeling more confused and agitated. Therefore, the possible advantages and disadvantages of this situation were explained and discussed in the interviews. An important point here is that the 10 married dementia sufferers also had their caretaking duties shared between caregiving daughters and spouses, however, most often the daughters were the ones who were overburdened by having to take care of both parents.

According to a study by [Pinquart and Sörensen \(2011\)](#), caregiving spouses differ from caregiving children with regard to older adults with Alzheimer’s. Spouses provide more support, report more depression symptoms, greater financial and physical burden, and lower levels of psychological well-being. This study noted that despite active support from the nuclear or extensive family, domestic servants, or even neighbours, some daughters were still very much “alone” in the caretaking process. They did not count on the other family members for support. This poses a possible risk to the care receiver’s health because if they cannot be left with anyone else or a professional cannot be paid to look after them the only alternative left is to lock them in the house or in the room.

In general, these women experienced situations which left them emotionally fragile, especially when relatives did not offer any support. In addition to the isolation, there were some cases in which they felt they were being exploited financially and emotionally by other family members. According to [Boszormenyi-Nagy and Spark \(1973/2003\)](#), the hierarchies of obligation which occur in day-to-day life cannot be defined by individual psychological terms; they are unconscious needs and commitments which all members have.

The respondents were questioned about feelings of loyalty among family. 17 caregiver daughters said that not all family members were loyal before the disease, 10 of them said all members were disloyal, and the other 5 said all members were loyal. After the disease, 21 of them reported that not all family members were loyal, 9 reported that they were all disloyal, and only 2 reported that all members were loyal to one another.

[Boszormenyi-Nagy and Spark \(1973/2003\)](#), define loyalty in moral, ethical, political, and psychological terms. The word “loyalty” originates from the French word “loi”, meaning law. Its real nature lies in the invisible fabric of group expectations, and not individual ones. The origins of loyalty are of a dialectic nature. To be a loyal member of a group implies internalizing the spirit of its expectations and complying with its internalized mandate. These authors describe the structure of loyalty as being determined by the history of the family group, human justice, and its myths. The extent of each individual’s obligations and how to fulfill them are determined by both the emotional disposition of each member and the position they occupy within the family system.



Taking these ideas into account, the families in this study had to balance out the obligations of loyalty while dealing with the dementia. The multigenerational balancing of justice and injustice made up a dynamic and motivational dimension which was a form of self-regulation. [Boszormenyi-Nagy and Spark \(1973/2003\)](#) state that loyalty is not synonymous with love or positive emotions and may lead to the emergence of pathological behaviour in one of the family members. For example, a criminal action committed by a child might actually prevent a dangerous change for the parents, such as the development of Alzheimer's. This type of behaviour might bring the member closer to more distant relatives, including missing ascendants.

These invisible loyalties reveal the weight of unconscious transmissions over several generations and refer to movements that affect individuals, families, and societies. According to [Imber-Black \(1994\)](#), loyalties between generations are often shaped by secrets. They can arise over generations out of unexplainable behaviours such as seclusion and delinquency. [Zuim \(2005\)](#) states that positive transgression can change something which has no other way to change itself in an attempt to transform or abolish a family rule. Secrets within families are intrinsically linked to the transgression of a law which requires one to say nothing.

Four caregivers from this study reported that, shortly after the onset of AD, one of their siblings had spent some of their mother's money without her permission. Transgression is visible in both the family and the legal prism. It is vital to see how laws are instituted within the family system and, comparatively, how they are represented in the world of justice. When we talk about laws within the family, we are talking about concepts such as myths, secrets, and rules. These often overlap with social laws. Looking at how subjects deal with the laws within their family system, how these laws are established and followed, and what the family's mythical model is underlying such rules helps towards understanding the value of transgression in family or social contexts. Such assessments show the uniqueness of each individual or system, in addition to broader social law.

The dementia sufferer in the family has the role of ensuring the balance of the system and saving the myth. Metaphorically speaking, the transgressor acts as a saviour for the mother or father in some sort of family myth. Paradoxically, the transgressor also acts as the crucified one, a sacrificial offering who pays the price for his/her non-individuation due to fulfilling a role delegated by the family. In cases involving elderly people with Alzheimer's, it is important to remember that their rights and duties are protected by law. This study showed that it was common for families to use power of attorney; a document which the patient is supposed to have the requisite mental capacity to execute, granting permission to another person to manage assets, people and delegate powers to decide on legal matters, especially financial matters. However, a court order is the only legal way to meet the personal and financial interests of the elderly with AD. This document appoints a guardian to manage the daily life of another due to physical or mental limitations. The guardian may be temporary or permanent and looks after and protects the interests of the patients and their relatives.

It is a crime under the Senior Citizen's Statute of Brazil (Law 10.741/03) to "convince an elderly person not having full control of their faculties to grant power of attorney for the purposes of managing or disposing property" (Art. 106). The offender can receive a sentence of one to four years and a fine. It is also a crime to "appropriate or divert assets, salaries, pensions, or any other income for any reason other than what it was meant for" (Art. 102). In this case, the offender can receive a fine or be imprisoned for one to four years.

Family organization is grounded in a system of laws, for example, the law against incest. When laws expressed by family systems are not obeyed, family members look to the courts to resolve the issues. The courts help to reorganize the family structure after onset of the disease. However, the lack of clarification of these laws coupled

with the dynamics of family relationships, distrust, selfishness, and jealousy all end up hindering the enforcement of these laws. The changes and decision-making the courts made on behalf of the elderly with AD not only affected the nuclear family, but also the extended one.

This data also revealed that pre-existing family conflicts became more heated after the onset of Alzheimer's, and those that had been dormant, were re-awakened. However, it is important to note that the caregivers were only asked to give their reports after each FAST step had been taken (before the disease, current, ideal, and conflict). Conflicts are inherent in any family. The important question is how families deal with these differences. They can be seen as favourable if they contribute towards the members' growth and health, or unfavourable if they cause breakups and the emotional unbalancing of the system. Furthermore, the ways in which the daughters and their families resolved their differences were in line with coping strategies, and the personal and community resources made available to them.

The caregiver daughters acted more as mediators, pacifists, and counsellors under these situations. They did so according to their personality traits and the caregiver role they adopted. As previously mentioned, most of them not only took care of the dementia sufferers, but also of all those who needed their support. Most of the daughters also reported that disagreements were not frequent, but the members considered them important. They believed these conflicts were brought on by: (a) issues intrinsic to the disease and the patient (e.g., the arrival of the elderly in the caregiver daughter's home, living with the elderly, arguments with siblings over delegation of caregiving duties, etc.), (b) money, (c) drug use (legal and illegal), (d) betrayal, and (e) rape.

According to Penna (2004), families that are able to resolve conflicts well may still experience high levels of anxiety, symptoms of depression, feelings of anger, and even disagreements, but their members are capable of resolving them due to the fact that they can communicate openly and honestly with one another. Such family systems have good aspects of cohesion and adaptation. Also, families who communicate openly right from the onset of the disease, over time, seem better at dealing with the situation. Effective communication between members reduces conflicts, which in turn promotes cohesion and mutual support. On the other hand, families who are not successfully able to resolve conflicts experience high levels of aggression, they frequently disagree with one another, compete with one another, generate feelings of jealousy and resentment, all due to the fact that they feel neglected or rejected. This study found that when family conflicts were compared to family ideals, there was a lower cohesion in the conflictual situations than the ideal ones.

This data reflects the caregivers' overall dissatisfaction with the difficulties and conflicts their families face, primarily due to Alzheimer's disease. The conflicts are a result of an extension of stress on all sides accumulated throughout the generations. After Alzheimer's, some family members developed symptoms or used body language to communicate their suffering. Family interaction patterns, secrets, rules, beliefs, and values all guided subsystem behaviours of health and, consequently, how they communicated their suffering. This reveals an emotional connection between them, and these symptoms were sometimes a form of dealing with past issues.

This data shows the interdependence between the subsystems. Based on the structural theory view (Minuchin, 1982), the most pronounced symptoms and the lack of differentiation among family members are evident of enmeshed families. The myth of unity, discussed below, and the difficulties in defining and separating boundaries between subsystems were prevalent. For these specific families, the feeling of belonging seemed to correspond with a renouncing of their independence. Some cases presented a fusion of egos between them (Bowen, 1978).

Researchers and clinics (Gehring, 1985; Minuchin, 1982) both stated that well-functioning families have clear boundaries between generations. Stress was determined to make transactional patterns in enmeshed families more inflexible. However, of note is the fact that these families' transactional processes, while adapting to Alzheimer's, went hand in hand with the lack of differentiation and the anxiety the members were feeling. For most of the caregiver daughters, it is support, unity, understanding, maintaining family bonds and cooperation that are essential to a family's well-being. The ideal situation in their eyes would be a united family, one in which its members all participate in taking care of the elderly with AD, resulting in a strong commitment between each other. They believed that in order for this to happen their families would have to work together and try to understand Alzheimer's disease and the patient, only then could there be a cure for the disease.

The FAST figures were also excellent resources for the caregivers to "see" their families and be able to express very diverse situations and feelings, as well as their dreams and ideals. Some of them placed these figures around the board in accordance to the stories they related. Others even added extra members to the board representing: (a) deceased family members (especially in the before the disease and ideal representations); (b) family members who did not exist, for example a partner/spouse who they would like to have in their life (especially in the ideal representation); and (c) people who were considered members of the family system. All these representation are evidence of the plurality of the concept of family. Literature on the domestic worker's role in caregiving has not yet been published; however, they do make the caregivers' jobs easier and allow for them to take time for themselves. In fact, they act as important mediators in the caregiving process easing tensions the main caregiver may develop (Santos & Rifiotis, 2003). In this study there were twelve caregivers who had support from domestic workers and, as a result, had more time to run errands, keep up their hobbies, etc.

Most of the caregivers thought that what their families most valued, before and after the disease, was family unity. This brings us to reflect on the presence of myths or beliefs in family systems. Family myths ensure stability of family cohesion. For example, Helm Stierlin (1979) stated that "*family myth plays the same role in relations as defense mechanisms do in individuals*" (p. 160), simultaneously protecting the family. This study looks at the myth of unity as the backbone (Krom, 1994) to determining family rules. Conflicts were more likely to occur if these myths did not exist because it made both the ideal and the real hard to reach. We noted that the caregivers really wished this situation could be altered; they wanted the ideal to become real. Due to this inability to live an ideal life, they changed their perceptions, in turn giving a sense of myth to the facts. Families create myths, replacing one reality for another one which is more suitable to their ideals.

Another important fact about myths is the position the siblings play. Some caregivers reported that their families had a kind of mission, and that the older or younger members were the guardians of the myths; they ensured that the family heritage would continue to be passed down through the generations. Some of these particular caregivers stated that it was as if they had been appointed to meet the requirements of their family's myths and strengthen the family members' meaning for life. In this sense, the family myths could be a protective force in a state of confusion by being able to disguise a rule which originated from a secret.

## Final Considerations

The study showed the complexity of interpersonal relations within the family and the state of not only the patient's vulnerability, but also that of all those involved in the caregiving process. One family member who is affected by Alzheimer's disease causes a family rearrangement, changing the shape of the family and the patterns of hierarchy and cohesion within it. The lack of sharing caretaking duties coupled with the difficulties in adapting to the demands

arising from Alzheimer's disease, including social and financial aspects, are adverse conditions which affect the caregiver's quality of life. Emotional bonds and family relations are not neutral, and this study has showed that a high level of support together with good cohesion and sharing the parental caretaking duties are all favourable towards well-being, quality of life, and satisfaction within the family. In this context, the study showed how family members may be able to develop coping strategies, highlighting the importance of quality in family relations, and not quantity or configuration.

Understanding the vulnerability that elderly Alzheimer sufferers and their caregivers face helps towards educating professionals and the community on the changes needed in intersectoral relations and social communication. This in turn helps to develop different forms of coping, not only through education and clinical treatment, but also by putting public policies in place, taking preventative actions, and having purposeful and thorough strategies for promoting health.

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