

## MARRIAGE AND CARE OF A SPOUSE WITH DEMENTIA: A CROSS-CULTURAL STUDY BRAZIL-PORTUGAL<sup>1</sup>

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**ABSTRACT.** This study aimed to analyze the meaning of marriage and care of the spouse from the perspective of Brazilian and Portuguese caregivers of elderly people with Alzheimer Disease (AD). Twelve women participated in the study, being the sample obtained by convenience using the snowball technique. We used a questionnaire and a semi-structured interview, data were analyzed by the Bardin content analysis technique. The results pointed out that although the cultural differences between Brazil and Portugal, some meanings related to marriage and care of the spouse in the context of AD were similar for Brazilian and Portuguese wives. Despite marital changes related to dementia, most wives felt well performing their role of caregiver, perhaps because among other variables, this is a task traditionally and culturally expected to be performed by women of both countries.

**Keywords:** Marriage; caregivers; Alzheimer's disease.

## CASAMENTO E CUIDADOS COM O CÔNJUGE COM DEMÊNCIA: UM ESTUDO TRANSCULTURAL BRASIL-PORTUGAL

**RESUMO.** Este estudo teve por objetivo geral analisar o significado de casamento e do cuidado com o cônjuge na perspectiva de esposas cuidadoras brasileiras e portuguesas de idosos com doença de Alzheimer (DA). Participaram da pesquisa 12 mulheres sendo a amostra obtida por conveniência utilizando-se a técnica *snowball*. Foram utilizados um questionário e uma entrevista com roteiro semiestruturado sendo os dados analisados pela técnica de análise de conteúdo de Bardin. Os resultados destacaram que apesar das diferenças culturais entre Brasil e Portugal, alguns significados referentes ao casamento e ao cuidado com o cônjuge no contexto da DA, foram semelhantes para as esposas brasileiras e portuguesas. Apesar das mudanças conjugais relacionadas à demência, a maioria das esposas sentia-se bem executando seu papel de cuidadora, talvez, porque dentre outras variáveis, essa seja uma tarefa tradicionalmente cultural e esperada para ser desenvolvida por mulheres de ambos os países.

**Palavras-chave:** Casamento; cuidadores; doença de Alzheimer.

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## CASAMIENTO Y CUIDADO CON CÓNYUGE CON DEMENCIA: UN ESTUDIO TRANSCULTURAL BRASIL-PORTUGAL

**RESUMEN.** En este estudio se tuvo por objetivo analizar el significado de matrimonio y del cuidado con el cónyuge en la perspectiva de esposas cuidadoras brasileñas y portuguesas de ancianos con enfermedad de Alzheimer (EA). Participaron de la investigación 12 mujeres siendo la muestra obtenida por conveniencia utilizando la técnica snowball. Se utilizó un cuestionario y entrevista con guion semiestructurado y los datos analizados por la técnica de análisis de contenido de Bardin. Los resultados destacaron que, a pesar de las diferencias culturales entre Brasil y Portugal, algunos significados referentes al matrimonio y al cuidado con el cónyuge en el contexto de la EA, fueron semejantes para las esposas brasileñas y portuguesas. A pesar de los cambios conyugales relacionados con la demencia, la mayoría de las esposas se sentía bien ejecutando su papel de cuidadora, tal vez, porque entre otras variables, esa es una tarea tradicionalmente cultural y esperada para ser desarrollada por mujeres de ambos países.

**Palabras clave:** Boda; cuidadores; enfermedad de Alzheimer.

### Introduction

Alzheimer's disease (AD) is a multifactorial and complex degenerative brain disease, the most common cause of dementia. Around the world, about 50 million people suffer from dementia, with almost 60% living in low- and middle-income countries (World Health Organization [WHO], 2017). In Brazil, approximately 1.2 million people suffer from this disease (Associação Brasileira de Alzheimer, 2016), and in Portugal, this number reaches between 80,144 and 112,201 patients (Santana et al., 2015). There is still no cure for AD, and because of its high prevalence and increasing incidence, poses a major threat to personal, family, and public health. In general, patients have a progressive decline in cognitive abilities, with initial loss of episodic memory, difficulties with language and problem solving, resulting in complete dependence and death (Alzheimer's Association, 2018; Verheijen & Slegers, 2018).

In the initial stage of AD, most people are able to engage in daily living activities, however, they may need assistance in specific activities to remain safe. At the moderate stage, changes in personality and behavior are common, difficulty in performing routine tasks, and confusion about spatial and temporal orientation. At the severe stage, the ability to communicate verbally is limited and the level of dependency increases to develop activities such as eating and using the toilet. Commonly, the patients are bedridden and death occurs as a result of complications such as dehydration, blood clots, pneumonia, and bloodstream infections that can result in organ failure (Alzheimer's Association, 2018).

The diagnosis of AD requires a careful and comprehensive evaluation, involving several professionals and observing the compatible clinical condition, the exclusion of other causes of dementia and disorders with impact on the central nervous system (Frota et al., 2011). Faced with the probable/possible diagnosis of AD, the patients and their families react unfavorably by experiencing feelings such as fear, indignation, crying, revolt, guilt, denial and despair (Falcão, 2006; Garcia et al., 2017). In addition, with the progression of dementia, changes in marital and family structure and dynamics can be observed, which

may favor cohesion among the members or trigger conflicts in interpersonal relationships (Falcão, Teodoro, & Bucher-Maluschke, 2016).

Care can be taken by family members, by health professionals and institutions. The main activities carried out by family caregivers of persons with AD are often instrumental (e.g. taking to the doctor, financial and domestic assistance, controlling, guiding, caring for food and medication, walking, hiking, caring for personal hygiene) and affective, such as giving emotional support, talking and caring (Falcão et al., 2018). The national and international scientific literature corroborates that the role of primary caregiver of people with AD is frequently assumed by the women of the family, especially wives, daughters or daughters-in-law (Carvalho et al., 2015; Falcão, 2006; Mendes & Santos, 2016; Vigia, 2012; Pimentel, 2013).

In this study, emphasis will be placed on wives who, in exercising the task of caring, face the challenge of retaining their identity as spouses and of reconstructing the meaning of marriage with someone who progressively assumes a different mode of being and acting, although the physical traits remain (Castellani & Falcão, 2018). They live the experience as if the marriage is 'disrupted', since the husband is no longer able to perform the same social roles and functions he played prior to the illness (Boylstein & Hayes, 2012). The meaning of caring can be based on the relationship of obligation, gratitude and responsibility for the person who is dependent (Moreira, Bucher-Maluschke, Carvalho, & Falcão, 2018).

Conjuality understood as the structure and relational dynamics of each dyad is influenced by cultural, biopsychosocial, historical, economic, family, educational, normative and non-normative events throughout life. Each couple constructs an identity and a history based on the desire and the project of life in common (Falcão, 2016). In this context, the meaning of marriage for wives caring for spouses with AD can be represented by attitudes related to respect, loyalty, companionship, affection, altruism and compassionate love (Castellani & Falcão, 2018)

Kaplan (2001) developed a typology of marriages, in which one of the spouses experienced AD describing the different degrees of separation caused by dementia that varied between feelings that are part of the 'we' and the 'I', namely: a) until death do us part; b) we, but ...; c) lifeless wives/husbands; d) becoming an 'I'; e) experiencing a marriage as if he/she had not married, indicating the contradiction of the physical presence of the spouse and his/her cognitive absence. In this sense, the term 'married widow' is used. Chesla, Martinson, and Muwaswes (1994) also divided the relationships between couples living with AD into three types: a) a continuation of the bond that the caregiver had with the spouse before dementia; b) a relationship that has been altered by the disease; c) a relationship characterized by emotional distance, however, with the caregiver committed to the person with AD.

With the evolution of dementia, it is common for caregiver wives to experience ambivalent feelings; constraints; loss of reciprocity in the relationship; decline in intimacy and sexual activity; low levels of marital satisfaction; financial burden; social constraints; lack of family support and health services, and sometimes feel alone and isolated, presenting high risks of overload and depression (Manoel, Teston, Waidman, Decesaro, & Marcon, 2013; Lima, Trotte, Souza, Ferreira, & Caldas, 2015). The meta-analysis performed by Erol, Brooker e Peel (2016) found that there appears to be a consensus that the experiences of female caregivers of spouses with AD include higher levels of overload and stress as well as symptoms of depression compared to male caregivers with similar effects reported in different configurations and countries. Women tended to report that they had no choice but to assume the role of caring.

The gerontological literature presents some classic theoretical models about the care process and the wear and tear of caregivers, mainly related to stress. The most used model is stress and coping (Lazarus & Folkman, 1984) adapted to care (Pearlin, Mullan, Semple, & Skaff, 1990). For Lazarus and Folkman (1984), the way people deal with stressful situations occur from their evaluation of the meaning they attribute to these experiences, considering personal and social resources, and that a stressor can be stressful for one individual, but not for the other.

The model of Pearlin et al., (1990) considers that caring experience can generate tensions and feelings of malaise in various areas of the caregiver's life, which are influenced by primary stressors (related to the characteristics of the dependent elderly - both in objective and subjective terms) and secondary stressors (refer to the pressures related to the caregiver role). However, the outcome in the role of caregiver will also depend on mediators as resources (personal, social and material) that help to modify or regulate the causal relationship between stressors and outcomes. This model postulates that family dynamics influence the caregiver's stress in the context of interpersonal relationships, assuming that several intervening factors influence the way individuals react to stress and suggests that care may be adverse to dyadic relationships, such as between spouses. When a member of a dyad develops dementia, the reciprocity relationship changes and becomes unbalanced, since it requires more efforts and dedication from the caregiver than from the care recipient (Fauth et al., 2012).

Campbell et al. (2008) revised the model of the stress process and concluded that the strongest predictors of caregiver burden were: the relationship they had with the patients before the illness; the sense of self-efficacy in the role of caring; the caregiver's experience of adverse life events beyond the role of caring; the time they dedicate to themselves and self-care; and the quality of the current relationship with the patient. Low levels of proximity and quality in the current relationship, as well as modification in the intimacy of the relationship since the onset of dementia (e.g. feelings of loss) may contribute to the caregiver's stress and adverse effects of the caregiver.

In turn, the model of Knight and Sayegh (2010), based on the stress and coping model, originally developed by Lazarus and Folkman (1984), postulates that the negative effects of stress on individuals are mediated by several variables, including overload, coping styles, and social support. This model emphasizes the role of cultural and ethnic dimensions in the process of stress and coping, presuming differences in cultural values that may affect the caring experience. The present study is based on the theoretical models of Pearlin et al. (1990) and Knight and Sayegh (2010).

Based on this information, it is important to understand the challenges of caring for a spouse with dementia in different contexts, such as Brazilian and Portuguese. AD has been a worldwide public health problem and it is important to understand the cultural differences of both countries in order to contribute to interventions and coping strategies that enhance the abilities of caregivers. This work may also favor the elaboration of future research and public policies aimed at reducing the negative impacts of AD on the quality of life of caregivers.

This study aimed to analyze the meaning of marriage and care of the spouse from the perspective of Brazilian and Portuguese caregivers in the context of Alzheimer's disease. Specifically, we sought to investigate from the perspective of these women: a) the initial reaction to the discovery of probable/possible diagnosis of AD; b) the meaning of marriage; c) the meaning of care of the spouse; d) care activities performed in relation to the spouse and; e) the feelings experienced before the task of caring.

## Method

**Design:** this is an exploratory, descriptive and cross-sectional cohort study.

**Participants:** the sample consisted of 12 participants, 6 Brazilian wives and 6 Portuguese wives caring for their elderly spouses with AD. Data collection was carried out from September 2016 to March 2017 and was obtained for convenience, being the choice of the number of participants made by saturation, which was reached when the interviewees began to repeat the contents already obtained in previous interviews, without adding new relevant information to the research (Vinuto, 2014). The study included the participation of women with the following inclusion criteria: a) Brazilian nationality (research in Brazil) or Portuguese (research in Portugal); b) to exercise care activities with the spouse with the probable/possible diagnosis of Alzheimer's disease; c) be married to the patient for at least 10 years; d) to accept to participate in the research; e) to have psychic conditions to understand the objectives of the study and; f) to sign the free and informed consent form.

**Instruments:** a questionnaire composed of closed questions and an interview with semi-structured script, elaborated from a literature review containing the following variables:

**Block A - Sociodemographic and health variables:** 1) 'of the caregiver's wife': name, age, nationality, years of education, approximate family income, perception about the economic situation, time of marriage, dating time before marriage; 2) 'of the spouse with AD': name, age, years of education, how long did he receive the probable/possible diagnosis of AD; in which phase of AD the elderly is (according to the description of common symptoms of the early, moderate, advanced phases).

**Block B – Initial reaction to the discovery of AD, meaning of care of the spouse and the care task; feelings experienced during the execution of this function:** initial reactions of the wife upon receiving the possible/probable diagnosis; activities (instrumental/affective) that they exercise in relation to the care of the spouse; meaning of 'care' and feelings about this task, evaluated by the items: 'For you, what does it mean care?' and 'How do you feel about taking care of your husband?' with five scalar items ranging from very bad to very good, followed by the question, why?

**Block C – Experiences of conjugality:** the meaning of 'marriage' for caregiver wives, evaluated by the question: [...] for you, what does 'marriage' mean?

## Procedures

**Data collection and ethical issues:** Initially, contact was made with support groups for family caregivers, the Brazilian Alzheimer Association, the Alzheimer Portugal Association, and the Hospital do Mar in Lisbon. After permission to perform the work and evaluation from their respective ethics committees, the research was disseminated in the groups, inviting the wives who met the inclusion criteria to participate in the study. The selection of the participants was made through the technique of snowball, also called snowball sampling. This technique is a non-probabilistic sampling form, in which the initial participants of a study indicate other participants and so on, until the proposed goal ('saturation point') is reached (Glaser & Strauss, 1967).

Data was collected in places that had favorable environmental conditions for the development of the research, using individual rooms of the institutions that promote support groups and at the home of caregiver wives in São Paulo - Brazil and in Lisbon - Portugal. It is emphasized that, in the households, the interviews were conducted in places where there was no interference from other people. The interviews were recorded and later transcribed. This paper was submitted to the Research Ethics Committee in Human Beings of the School of Arts, Sciences and Humanities (EACH) of the Universidade de São Paulo (USP), receiving a favorable opinion CAAE: 58525516.8.0000.5390. The participants were given the Free and Informed Consent Form, preserving their identity, using fictitious names for this article.

**Data analysis:** the interviews were analyzed using the technique of Bardin (1977/2000), in which one can analyze the meanings and the signifiers, being characterized by three periods: the pre-analysis, the exploitation of the material and the treatment of the results. By gathering the interviews transcribed, the corpus of the research was constituted. In the pre-analysis phase, a floating reading was performed. In the exploration of the material, the following rules were followed: (a) completeness - exhausting the entire communication of the participants, not omitting any information; (b) representativeness - the contents represent the sample of this study; (c) homogeneity - the data refer to the same theme, obtained by the same techniques and applied by similar individuals; (d) relevance - the interviews were adapted to the research objectives; and (e) exclusivity - the elements were not classified in more than one category. Thus, analytical categories were created that allowed to cover all the interviews in major thematic axes, being possible to identify subcategories. In this way, the treatment of the results had interpretations comprised in simple frequency of the units of analysis. The direction of the analyzed content was classified as 'favorable' (positive aspects of affirmations), 'unfavorable' (negative aspects of information) or 'neutral' (indefinite, vague, indeterminate, indifferent or impartial, not expressing a party neither against nor in favor). Nvivo Pro software was used for image elaboration containing the most frequent words used by the interviewees.

## Results

The participants of the present study were from 60 to 85 years (Brazilian:  $M = 73.16$  and Portuguese:  $M = 68.16$ ). As to the education level, it was verified that the average years of study of the Brazilian women were 10.25 and of the Portuguese of 10.16. During the interviews, there were no significant differences in the responses given by the more educated wives or the less educated wives. The average family income of Brazilians was R\$ 10,050.00 and the Portuguese R\$ 5,947.07 (considered the value of 1 Euro = 3.65 Reais - quotation referring to September 2016). As for the perception about the socioeconomic situation they had, two Brazilians believed to be 'neither good nor bad', three classified as being *good* and one as 'very good'. The Portuguese wives classified as 'bad' ( $n = 2$ ), 'neither good, nor bad' ( $n = 1$ ) and 'good' (3). The average marriage time of the caregivers was 50.05 years for the Brazilian women and 44.83 years for the Portuguese women, all of whom had more than 35 years of marriage, that is, they were in a long-term relationship. All the couples had at least one child (Brazilian:  $M = 3$  and Portuguese:  $M = 2$ ). Before marrying, Brazilians dated on average 3.4 years and Portuguese women, 2.7 years.

As for the husbands with AD, the mean age of the Brazilians was 79.83 years and the Portuguese of 73.83. The schooling of Brazilians was 12.41 years and 10.5 years for the

Portuguese spouses. According to the information expressed by the caregivers about which stage their respective spouses were in relation to AD, it was detected that in Brazil the majority were at the initial and moderate stages and in Portugal at the moderate and advanced stages.

Regarding the 'initial reaction of the caregiver wives to the probable/possible diagnosis of Alzheimer's disease', the Brazilian wives presented a more unfavorable reaction to the discovery of the disease, representing 73.91% (n = 17) of the speeches, than the Portuguese caregivers with 40% (n = 16). Portuguese wives presented a higher content of speeches with 'favorable reactions' to the discovery, 52.50% (n = 21), than the Brazilian ones, 17.39% (n = 4). There were neutral contents, being represented by 8.70% (n = 2) and 7.50% (n = 3), of the Brazilian and Portuguese, respectively. Table 1 lists examples of favorable, unfavorable and neutral content.

The activities performed by the caregivers wives of elderly with AD were divided into two categories, that is, 'instrumental activities' and 'affective activities'. Table 1 shows that affective activities in general were the most performed, both in the Brazilian wives group and in the Portuguese wives. In the group of Brazilians, the most signaled subcategory was to 'talk' (37.50%); and for Portuguese women to 'give affection' and 'emotional support' (35.29%). The most instrumental activities performed by the Brazilian women were: 'control/guide' the patient, 'take care of food and medication', and 'take the elderly to the doctor' (19.35% each). For the Portuguese, the most cited activities were distributed in the following subcategories: 'control/guide, take care of food and medication, take to the doctor, financially assisting, taking care of personal hygiene, walking', representing 14.81% each.

**Table 1.** Activities performed by caregiver wives with the elderly with Alzheimer's disease

Instrumental activities	Brazilian wives		Portuguese wives	
	Absolute	Percentage	Absolute	Percentage
Control/guide	6	19.35	4	14.81
Take care of food and medication	6	19.35	4	14.81
Take to the doctor	6	19.35	4	14.81
Financial assistance	4	12.90	4	14.81
Care of personal hygiene	3	9.68	4	14.81
Walking	4	12.90	4	14.81
Assistance in domestic chores	2	6.45	2	7.41
Other activities	-	-	1	3.70
<b>Total</b>	<b>31</b>	<b>100</b>	<b>27</b>	<b>100</b>
<b>Affective activities</b>				
Talking	6	37.50	5	29.41
Give affection	5	31.25	6	35.29
Give emotional support	5	31.25	6	35.29
<b>Total</b>	<b>16</b>	<b>100</b>	<b>17</b>	<b>100</b>

Source: The authors.

In Table 2, which concerns the meaning of marriage, the following attributions were found: 'union between two lives; is caring for each other/caring for the family; it is love; to like/passion/affection; over time the meaning of the relationship changes; is to be together in good and bad moments/companionship/tolerance; have children; have projects and dreams in common'. The Brazilian women defined marriage mainly as the 'union of lives' (22.22%); (22.22%), 'to like/have affection' (22,22%) and 'being together in the good and bad times of life' (18.52%), 'children' were not mentioned, or having 'projects in common'. For the Portuguese, marriage was more associated with 'being together in the good and bad moments of life' (35.71%), and the 'union between two lives' (21.43%), not appearing in the content 'to care for each other and the family'.

**Table 2.** Perspective of Caregiver Wives on the Meaning of Marriage

Perspective of Caregiver Wives on the Meaning of Marriage Subcategories	Brazilianwives		Portuguesewives	
	Frequencyofanalysisunits			
	Absolute	Percentag e	Absolute	Percentag e
Union between two lives	6	22.22	6	21.43
Caring for each other / caring for the family	2	7.41	-	-
Love	4	14.81	4	14.29
Like / Passion / Affection	6	22.22	2	7.14
Over time the meaning of the relationship changes	4	14.81	3	10.71
It is to be together in the good and bad moments / companionship / tolerance	5	18.52	10	35.71
Have children	-	-	1	3.57
Have projects and dreams in common	-	-	2	7.14
Total	27	100	28	100

Source: The authors.

Figure 1 depicts the words most often spoken by Brazilian and Portuguese caregiver wives when asked about the meaning of marriage and caring. It turns out that in the group of Brazilians the words 'love, liking', and 'union' stood out on the meaning of marriage. In the Portuguese group, the words 'life, everything, together, family, marriage' were evidenced. Regarding the meaning of care, the group of Brazilians highlighted the words 'everything, understand, care' and 'love'. In the Portuguese group, the words 'everything, to do' and 'task' were highlighted.



**Figure 1.** Perspective of wives on the meaning of marriage.



Source: NVivo Pro-Word Cloud Program.

Regarding the meaning of caring of the spouse, the caregiver wives defined it mainly as 'helping in instrumental and basic tasks/directing and supervising the patient' (Brazilian: 48.48% and Portuguese: 60.53%). Also presented content such as 'put yourself in the other's shoes/be with the person to the end' (Brazilian: 15.15% and Portuguese: 10.53%); 'give affection and (love/care)/provide well-being' (Brazilian: 12.12% and Portuguese: 13.16%) (Table 3).

When analyzing the 'feelings of caregiver wives when caring for the elderly with AD', it was believed that these could be more negative, due to the changes in the social roles and the great challenges that are imposed by the disease. But in this sample the results showed the opposite, because, no participant reported feeling bad or very bad when taking care of their spouse. Of Brazilian wives, 16.67%, reported feeling 'more or less' in the caring task, and 33.33% of Portuguese women had the same feeling. In addition, 83.33% of Brazilian wives reported that they felt 'well' caring for their spouses with AD, and 50% of Portuguese women also felt the same way. No Brazilian woman reported feeling 'very well' about caring, but 16.67% of Portuguese women reported feeling 'very well'.

**Table 3.** Perspective of caregiver wives on the meaning of taking care of the spouse

Perspective of caregiver wives on the meaning of taking care of the spouse	Brazilian wives		Portuguese wives	
	Frequency of analysis units			
	Absolute	Percentage	Absolute	Percentage
Subcategories				
It is to help in the instrumental and basic tasks / directing and supervising the patient	16	48.48	23	60.53
It is marital obligation	3	9.09	1	2.63
It is giving affection (love, affection)/providing well-being	4	12.12	5	13.16
It is patience / good communication with the patient	4	12.12	2	5.26
It is putting yourself in the other's shoes/ being with the person to the end	5	15.15	4	10.53
It is a hard/tiring task.	1	3.03	3	7.89
Total	33	100	38	100

Source: The authors.

Below the box with a summary of the categories, subcategories, codes, definitions and examples of excerpts extracted from the interviews.

**Box 1.** Categories, subcategories, codes, definitions and sample excerpts from interviews.

Categories, codes, definitions	Nationality of wives	Subcategories, codes, examples of excerpts from interviews
<p>Category 1: Initial reaction of caregiver wives to the discovery of probable/possible diagnosis of Alzheimer's disease (Code: RIEDA).</p> <p>Definition: in this category the contents of the speeches related to the initial reactions of caregiver wives are present in the face of the probable/possible diagnosis of AD.</p>	Brazilian	<p>a) Favorable initial reaction (Code: RIFB). E.g.: "well; from the beginning I have helped him in everything he needs" (Margarida);</p> <p>b) Initial unfavorable reaction (CRIDB). E.g.: "I was really discontented, I cried all week" (Acácia)</p> <p>c) Neutral initial reaction (RINB). E.g.: "I thought it was distraction, it did not affect me much" (Gérbera)</p>
	Portuguese	<p>a) Favorable initial reaction (Code: RIFP). E.g.: "with his diagnosis I have to have a lot of strength [...] I have to always be with a smile and do everything that is within my reach" (Tulipa);</p> <p>b) Initial unfavorable reaction (CRIDP). E.g.: "With a deep sadness that remains" (Iris)</p> <p>c) Neutral initial reaction (RINP). Ex.: "I had no reaction [...] I stayed the same" (Frésia)</p>

Source: The authors.

## Discussion

The gerontological literature indicates that in Brazil and in other countries of the world, such as in Portugal, there is an increase in the number of elderly people caring for other elderly people. Women (wives, daughters, granddaughters and daughters-in-law) are usually the main caretakers for this population. In general, they reside with the sick and do not receive help for care tasks (Santos-Orlandi et al., 2017). In the present study, it was also found that all wives interviewed were elderly who cared for their elderly spouses, with the average number of schooling years by the Brazilian women was 10.25 and the Portuguese women was 10.16. In this context, it is emphasized that the level of education of caregivers is a variable that influences the quality of care for the elderly with AD, because when there is a greater education and capacity to understand the disease, the caregiver can better provide care to the patient, contributing to the elaboration of strategies to solve possible adversities, thus developing their practical capacities and social resources (Villars, Dupuy, Perrin, Vellas, & Nourhashemi, 2015).

The schooling of sick Brazilian spouses was 12.41 years and 10.5 years of Portuguese. Formal schooling is one of the variables with the greatest impact on cognition, and along with old age they act as risk factors for cognitive decline and the development of dementia. Researchers found an increased risk for Alzheimer's disease in individuals with a schooling level of less than 8 years, while others could not find any evidence regarding schooling (Azevedo, Landim, Favero, & Chiappetta, 2010).

With respect to the 'initial reaction of the caregiver wives to the probable/possible diagnosis of Alzheimer's disease', the Brazilian wives presented a more unfavorable

reaction to the discovery of the disease and the Portuguese highlighted a greater content of speeches with 'favorable reactions'. This result may have favored a greater acceptance and understanding of the disease by them. Researchers (Bessa & Waidman, 2013; Falcão et al., 2016) pointed out that the news of the diagnosis and the dementia process alter the family dynamics and structure, since after the discovery, the family goes through a period of adaptation, which requires changes in the routine and in the relationship between its members. Therefore, faced with the challenges after diagnosis, each family creates its own demands and different ways of dealing with suffering.

Coexistence with the patient brings to the caregiver several sensations that may result in conflicting situations, since it is necessary, first of all, to accept the disease and then to reconstruct the meaning and function of the member with AD in the family dynamics and in the marital relationship (Neumann, 2014). These feelings are going through changes due to the situations experienced in the day to day, going from denial to inquiry and, finally, acceptance. However, these stages are not linear, and there may be comings and goings in their dynamics with the onset of dementia (Oliveira & Caldana, 2012).

The meaning of caring and the perceptions of caregivers in the face of this task can affect the evaluations of caring experiences (Daley, O'Connor, Shirk, & Beard, 2017). The caregiver of an elderly person with AD perceives the care according to its daily routine, their formation, their customs, beliefs and values shared with other families and with other systems of the social structure. Culture influences the meaning and value of health as well as caregiving actions. In this sense, care rituals are shown to be intertwined with caring behaviors, based on a complex network of interactions (Mendes, Fernandez, & Sacardo, 2016). Care is influenced by culture and to promote more resolute actions with caregivers, it is necessary to have prior contact and an understanding of the aspects that permeate the daily life of the couple, the family and the illness (Ramos, 2011).

Regarding the activities performed by the caregiver wives of elderly with AD, it was observed that the affective activities in general were the most accomplished, both in the group of Brazilian and Portuguese wives. Similarly, studies by Braz (2014) and Falcão et al. (2018) also identified a prevalence of affective care activities when compared to instrumental activities. However, when asked about the meaning of caring of the spouse with AD, especially the Portuguese ones, they emphasized the assistance in the instrumental and basic tasks of daily life. On the other hand, the Brazilian women emphasized the idea of putting yourself in the other's shoes/being with the person to the end, demonstrating the importance of empathy with the patient in the process of dementia evolution.

In the theoretical model proposed by Pearlin et al. (1990), the experience of the role of caregiver is influenced by primary and secondary stressors and mediated by personal, social and material resources that help regulate the causal relationship between stressors and outcomes. The model of Knight and Sayegh (2010) highlights the influence of cultural and ethnic aspects on the stress and coping process, assuming differences in cultural values that may affect the caring experience. In the present study, most Brazilian and Portuguese wives felt good taking care of their spouses and none of them reported feeling bad or very bad when performing this activity. In the study by Couto, Castro and Caldas (2016), it was verified that the task of caring for dependent elderly people generates 'positive' and 'negative' feelings that, respectively, minimize and maximize the feeling of emotional overload and discomfort in their daily lives. Among the positive feelings, in the relationship of care, stood out the affection for the family, solidarity, gratification, appreciation of their actions, commitment and well-being.

Despite the cultural differences of the sample, the meaning of marriage for Portuguese and Brazilian women was similar, with the idea of unity and commitment to being together in the good and bad moments of life highlighted by them. For the Brazilian women the task of caring of a spouse with dementia was related to the words love, affection, liking, unity and understanding. For the Portuguese, it was linked to the words life, marriage, everything, to do together, task and family. According to Kaplan (2001), caregivers lived a model of marriage based on the belief 'until death do us part', showing attitudes of respect, loyalty, companionship and affection (Castellani & Falcão, 2018).

According to Daley et al. (2017), caregivers of elderly people with AD also benefit from the idea 'until death do us part' and the feeling of compassion they experience when exercising care tasks, favoring high levels of positive emotions. The love of companionship turns into compassionate love for a sick person in need of care (Shavit, Ben-Ze'ev, & Doron, 2017). The findings of Monin, Schulz and Feeney (2015) also indicated that caregiver spouses who felt more compassionate love for their partners with AD had less burden in caring and expressed more positive assessments of the role of caring, besides having greater psychological well-being. Hayes, Boylstein and Zimmerman (2009) found that some of the participants felt closer to their spouses after AD, probably because of 'end-of-life feelings' that lead people to feel more appreciation for what they have and to enjoy while they last.

## Final considerations

Marriage in which one spouse experiences Alzheimer's requires couples to make adjustments in their daily lives and over time may have diverse impacts on various aspects of their lives. Caring for an elderly person with AD is a complex task that requires caregiver dedication and attention. In addition to the challenges of caring, which involve affective and instrumental activities, the caregiver is faced with the constant redefinition of the social roles and meanings of care that directly affect the family and conjugal structure, as well as social interaction.

In this study, it was verified that, despite the cultural differences between the two groups (Brazilian and Portuguese), some meanings related to marriage and care with the spouse were similar, and this can be attributed to the demands of AD, which are common to any person who has this disease. Moreover, despite marital changes related to dementia, most wives felt well performing their roles as caregivers, perhaps because among other variables, this is a traditionally cultural task and expected to be developed by women of both countries.

Finally, there are limitations in this research, such as the reduced sample size and the participants being only female, and it is not possible to examine the gender differences in relation to the studied variables. However, due to the scarcity of studies on the relationship between Alzheimer's disease, care and marriage, it can be considered that this work provides innovative aspects in the studied area, providing information about the possibility of formulating intervention proposals with the caregiver wives of elderly people with dementia. For future studies, it is recommended to investigate, for example, reciprocity of the meaning of marriage and compassionate love in the context of dementia care while examining the psychological well-being of both partners.

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