

## Brief communication

# Efficacy of a psychoeducational group with caregivers of patients with dementia

Eficácia de um grupo psicoeducacional com cuidadores de pessoas com demência

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## Abstract

**Background:** The use of intervention strategies aimed at dementia caregivers objectives the information and the creation of coping strategies to deal with the difficulties caused by dementia. **Objectives:** To assess the correlation between the participation in a psychoeducational group and the decrease of burden, and depressive and anxious symptoms of caregivers of people with dementia. **Methods:** Caregivers (n = 18) assessed in a longitudinal study at baseline and after six months of participation in a psychoeducational group. There were used the Clinical Dementia Rating (CDR), Pfeffer Functional Activities Questionnaire (PFAQ), Cornell Scale for Depression in Dementia (CSDD), Quality of Life Scale in Alzheimer' Disease (QoL-AD), Neuropsychiatric Inventory (NPI), Zarit Burden Interview (ZBI), Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI). **Results:** In the baseline, there was correlation between the burden and the caregivers' depressive symptoms (p = 0.048). The analysis of the differences between the baseline and the second moment has shown a decrease in caregivers' depressive symptoms in moment 2 (p = 0.011). There were no significant differences in the other variables. **Discussion:** Psychoeducational groups can be considered efficient interventions on the decrease of the depression of caregivers of people with dementia.

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**Keywords:** Caregiver, dementia, burden, psychoeducational group.

## Resumo

**Contexto:** O uso de intervenções direcionadas ao cuidador objetiva a informação e a criação de estratégias de enfrentamento para o manejo das dificuldades causadas pela demência. **Objetivos:** Avaliar a relação entre a participação em um grupo psicoeducacional e a diminuição da sobrecarga e dos sintomas depressivos e ansiosos de cuidadores de pessoas com demência. **Métodos:** Cuidadores (n = 18) avaliados longitudinalmente no momento linha de base e após seis meses de participação em grupo psicoeducacional. Utilizaram-se: Estadiamento Clínico das Demências (CDR), Questionário de Atividades Funcionais de Pfeffer (PFEFFER), Escala Cornell de Depressão na Demência (CORNELL), Escala de Avaliação da Qualidade de Vida na Doença de Alzheimer (QdV-DA), Inventário Neuropsiquiátrico (NPI), Inventário de Sobrecarga de Zarit (ZARIT), Inventário de Depressão de Beck (BDI) e Inventário de Ansiedade de Beck (BAI). **Resultados:** No momento linha de base foi encontrada correlação entre a sobrecarga e sintomas depressivos dos cuidadores (p = 0,048). A análise das diferenças entre os dois momentos encontrou diminuição dos sintomas depressivos dos cuidadores no segundo momento (p = 0,011). Não foram encontradas diferenças significativas nas demais variáveis. **Conclusão:** Os grupos psicoeducacionais podem ser considerados intervenções eficazes na diminuição dos sintomas depressivos de cuidadores de pessoas com demência.

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**Palavras-chave:** Cuidador, demência, sobrecarga, grupo psicoeducacional.

## Introduction

Caregiver burden comprises the physical, psychological, emotional, social and financial problems experienced by the ones who care for people with any impairment<sup>1</sup>.

Psychoeducational interventions present a structured model aimed at offering information about the disease and training caregivers to deal with cognitive and behavioral symptoms of dementia. Studies indicate that these interventions show significant results in the relief of caregivers' burden and depressive symptoms, increasing caregiving skills and quality of life (QoL)<sup>1,2</sup>.

This study aims to evaluate the relation between the participation in a psychoeducational group and the decrease of dementia caregivers' burden, depressive and anxious symptoms.

## Method

### Sample

- Caregivers (n = 18) who take part in a weekly psychoeducational group developed at the Center for Alzheimer's Disease and Related Disorders (CDA/IPUB/UFRJ), assessed in two moments: at the beginning of the group (baseline) and after six months (2<sup>nd</sup> moment).
- The primary caregiver was defined as the most important person taking care of the patient. All caregivers were informed about the diagnosis.
- All the individuals signed the informed consent form. The study was approved by the Research Ethics Committee of IPUB/UFRJ.

## Instruments

### Patients' evaluation

1. **Assessment of Alzheimer's disease (AD) severity:** complete protocol of the Clinical Dementia Rating (CDR)<sup>3</sup>, in order to assess the dementia stage.
2. **Assessment of functional activities:** Pfeffer Functional Activities Questionnaire (FAQ), which assesses the independence rate in the development of instrumental activities of daily living<sup>4</sup>.
3. **Assessment of depression in dementia:** Cornell Scale for Depression in Dementia (CSDD), in which scores above 7 indicate the presence of mild, moderate or severe depression<sup>5</sup>.
4. **Assessment of behavioral and psychological symptoms of dementia (BPSD):** Neuropsychiatric Inventory (NPI)<sup>6</sup>, which evaluated the presence of delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, night-time behavior disturbances, and appetite and eating abnormalities.

### Caregivers' evaluation

5. **Assessment of QoL in AD:** caregivers' version of Quality of Life in Alzheimer's Disease scale (QoL-AD)<sup>7</sup>, which ranges from 13 (poor) to 52 (excellent).
6. **Assessment of caregiver burden:** Zarit Burden Interview (ZBI)<sup>8</sup>. In its Brazilian version<sup>9</sup>, it comprises 22 questions focused at caregivers, with the objective of evaluating their physical and mental health, as well as their emotional well-being, financial conditions and social life. The score ranges from 0 to 88 and higher scores mean higher caregiver burden.
7. **Assessment of caregivers' depressive symptoms:** Beck Depression Inventory (BDI)<sup>10</sup>.
8. **Assessment of caregivers' anxious symptoms:** Beck Anxiety Inventory (BAI)<sup>10</sup>.

## Intervention

The intervention was developed as a 90-minute weekly session, during six months, starting with 18 familiar caregivers of dementia patients. We performed individual assessments in order to collect sociodemographic data about the premorbid history, disease history, family relationship context and main problems related to activities of daily living of patients and caregivers.

The intervention followed the STAR-Caregivers model<sup>11,12</sup>, which aims at helping caregivers to identify, reduce and manage behavioral symptoms of people with dementia. The model has five basic steps<sup>11,12</sup>:

- (1) identify, describe and recognize the frequency of behavioral symptoms which are difficult to cope with;
- (2) identify the precedents of each problem and its consequences;
- (3) establish modifying strategies;
- (4) improve the communication between the caregiver and the dementia patient;
- (5) and create pleasurable events for caregiver and patient.

The sessions started with a warm-up, in which the participants were encouraged to make comments or raise questions about events that happened during the week, regarding their general state or caregiving tasks. In this first step, based on caregivers' speech, we elected a main theme to be discussed by the group, with room for exchanging experiences and expressing emotions and feelings about the subject.

We also had presentations of several sources (newspaper or magazine articles, pictures) and lectures about AD, vascular dementia, BPSD and hygiene care. The presentations conveyed educational content, but the group was always motivated to talk about emotional aspects related to caregiving.

## Statistical analysis

All statistical analysis were performed with SPSS software for Windows release 17.0. We used descriptive statistics to the sociodemographic characterization (gender, age, marital status, years of education, duration of the disease) of patients and caregivers. The parametric variables were described by their mean and standard deviations (SD), and the non-parametric variables were described by their median and interquartile ranges. The paired Wilcoxon's t-test was used to compare the baseline and the second moment of evaluation. We used Spearman's correlation to investigate the relationships between caregiver burden and depressive symptoms, anxiety, patients' QoL (caregiver version), neuropsychiatric symptoms, functional activities, presence of patients' depressive symptoms. All of the significance tests were performed at a two-tailed  $\alpha$ -level of 0.05.

## Results

The psychoeducational group was initially constituted by 18 caregivers. However, in the second moment of evaluation, seven participants were excluded from the study due to the lack of attendance to the sessions. Four participants did not continue attending the sessions because they did not have a secondary caregiver to look after the patient during the group. Three participants could not take the day off at work. The caregivers presented mean age of 61.27 years old and 11.63 years of education. The majority was female (81.8%), daughters (45.4%) and spouses (36.4%). The patients presented mean age of 78.09 years old, 7.63 years of education and 5.18 years since the first diagnosis. Sixty-three point six percent of the patients were female and 36.4% participated of interventions such as: music therapy, physiotherapy, gymnastics and ballroom dancing.

The analysis of correlation between caregiver burden and the other variables evaluated showed statistically significant difference between caregiver burden and depressive symptoms in the first moment ( $p = 0.048$ ), pointing that higher caregivers' depressive symptoms may indicate higher caregiver burden.

In the comparison between the baseline and the second moment, we found a decrease of caregivers' depressive symptoms ( $p = 0.011$ ). We did not observe statistically significant differences between the baseline and the second moment in the evaluation of dementia stage, functional activities, depression in dementia, neuropsychiatric symptoms, QoL (caregivers' version), caregiver burden and caregivers' anxiety, as it is shown on table 1.

**Table 1.** Comparison between baseline and second moment

	1 <sup>st</sup> Assessment 50 (25-75)	2 <sup>nd</sup> Assessment 50 (25-75)	p value
ZBI	17 (38-33)	17 (40-20)	0.332*
QoL-DA	24 (34-30)	24 (32-29)	0.332*
NPI	9 (45-22)	10 (29-13)	0.722*
BAI	0 (13-5)	2 (8-6)	0.474*
BDI	4 (19-15)	2 (9-4)	0.011*
FAQ	13 (28-25)	18 (28-23)	0.553*
CDR	1 (3-2)	1 (3-2)	0.100*
CSDD	5 (11-8)	6 (14-12)	0.138*

p: significance; ZBI: Zarit Burden Interview; QoL-DA: Escala de Qualidade de Vida na Doença de Alzheimer; NPI: Neuropsychiatric Inventory; BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; FAQ: Pfeffer Functional Activities Questionnaire; CDR: Clinical Dementia Rating; CSDD: Cornell Scale for Depression in Dementia.

\* Values expressed by median and interquartile range.

## Discussion

This study demonstrated that psychoeducational groups may be considered efficacious interventions in the decrease of dementia caregivers' depressive symptoms. We found correlation between burden and caregivers' depressive symptoms in the first moment and decrease of depressive symptoms in the second moment of evaluation.

tion. We did not find significant differences in other variables such as burden and quality of life, and this may be related to the greater severity of depressive symptoms in the first moment of evaluation. Although there was a decrease in the burden interquartile deviation in the second moment of evaluation, it was not sufficient to show a significant difference. Our results are corroborated by studies which verify improvement of dementia caregivers' depressive symptoms after the participation in psychoeducational interventions with a structured approach<sup>13,14</sup>.

In our study, we adopted a highly structured psychoeducational model, STAR-Caregivers<sup>11,12</sup>, with predetermined objectives and steps. A problem in the area of psychoeducational interventions for caregivers of people with dementia is that great part of the studies develop their own intervention model based on miscellaneous techniques, which hinders the replication of the studies' results<sup>1,15</sup>.

This study has some limitations. First, the small sample, since intervention studies with more significant samples may better evaluate the relation between the participation in psychoeducational groups and the decrease of burden, anxiety and depression levels. Another limitation is related to the lack of a control group of family members who did not participate in psychoeducational groups. Finally, we can point to the heterogeneity of the studied population, since we included in our study caregivers of people with AD, vascular dementia and mixed dementia in several stages of severity. However, this limit may also be an advantage to the proposed intervention, since the caregivers benefited from the exchange of different experiences. It is necessary, in posterior studies, to randomize researched groups in order to constitute a more homogeneous sample, which would allow better assessment of the advantages of the psychoeducational intervention in caregivers of different genders and age groups.

## Conclusion

The results of this study show a decrease in the depressive symptomatology of dementia caregivers who participate in a psychoeducational group. The evaluation of psychoeducational interventions for caregivers allow the understanding of objective and subjective aspects which integrate caregivers' difficulties. It may allow a more adequate management of people with dementia, as well as the improvement of patients' and caregivers' QoL.

## References

1. Santos RL, Sousa MFB, Brasil D, Dourado MCN. Intervenções de grupo para sobrecarga de cuidadores de pacientes com demência: uma revisão sistemática. *Rev Psiq Clín.* 2011;38:161-7.

2. Sørensen LV, Waldorff FB, Waldemar G. Early counseling and support for patients with mild Alzheimer's disease and their caregivers: a qualitative study on outcome. *Aging Ment Health.* 2008;12(4):444-50.
3. Maia ALG, Godinho C, Ferreira ED, Almeida V, Schuh A, Kaye J, et al. Aplicação da versão brasileira da Escala de Avaliação Clínica da Demência (Clinical Dementia Rating – CDR) em amostras de pacientes com demência. *Arq Neuropsiquiatr.* 2006;64(2-B):485-9.
4. Nitrini R, Caramelli P, Bottino CMC, Damasceno BP, Brucki SMD, Anghinah R. Diagnóstico de doença de Alzheimer no Brasil: avaliação cognitiva e funcional. *Recomendações do Departamento Científico de Neurologia Cognitiva e do Envelhecimento da Academia Brasileira de Neurologia.* *Arq Neuropsiquiatr.* 2005;63(3a):720-7.
5. Carthey-Goulart MT, Areza-Fegyveres R, Schultz RR, Okamoto I, Caramelli P, Bertolucci PHF, et al. Versão brasileira da Escala Cornell de Depressão em Demência (Cornell Depression Scale in Dementia). *Arq Neuropsiquiatr.* 2007;65(3b):912-5.
6. Camozzato AL, Kochhann R, Simeoni C, Konrath CA, Pedro Franz A, Carvalho A, et al. Reliability of the Brazilian Portuguese version of the Neuropsychiatric Inventory (NPI) for patients with Alzheimer's disease and their caregivers. *Int Psychogeriatr.* 2008;20:383-93.
7. Novelli MMPC. Avaliação transcultural da escala de avaliação de qualidade de vida na doença de Alzheimer [dissertação]. São Paulo: Faculdade de Medicina da Universidade de São Paulo; 2003.
8. Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: families under stress. New York: New York University Press; 1985.
9. Sczufca M. Versão brasileira da escala Burden Interview para avaliação de sobrecarga em cuidadores de indivíduos com doenças mentais. *Rev Bras Psiquiatr.* 2002;24(1):12-7.
10. Gorenstein C, Andrade L. Validation of a Portuguese version of the Beck depression inventory and the state-trait anxiety inventory in Brazilian subjects. *Braz J Med Biol Res.* 1996;29:453-7.
11. Logsdon R, McCurry S, Teri L. Star-Caregivers: a community-based approach for teaching family caregivers to use behavioral strategies to reduce affective disturbances in persons with dementia. *Alzheimer's Care Q.* 2005;6:146-56.
12. Teri L, McCurry SM, Logsdon R, Gibbons LE. Training community consultants to help family members to improve dementia care: a randomized controlled trial. *Gerontologist.* 2005;45(6):802-11.
13. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology.* 2006;67(9):1592-9.
14. Au A, Li S, Lee K, Leung P, Pan PC, Thompson L, et al. The Coping with Caregiving Group Program for Chinese caregivers with Alzheimer's disease in Hong Kong. *Patient Educ Couns.* 2009;18:1-5.
15. Sousa MFB, Santos RL, Arcoverde C, Dourado M, Laks J. Consciência da doença na doença de Alzheimer: resultados preliminares de um estudo longitudinal. *Rev Psiq Clín.* 2011;38(2):57-60.