



# Effects of a community intervention program for dementia on mental health: the importance of secondary caregivers in promoting positive aspects and reducing strain

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## Abstract

The study presents a community intervention program targeted at caregivers of individuals with dementia, and assesses its main outcomes in terms of caregiver strain, positive aspects of care, and physical and mental health. A total of 187 caregivers completed a 10-week psychoeducational program and were assessed at baseline, post intervention and at 6-month follow-up. The evaluation of the program was performed using multivariable linear mixed effect models. Results showed an improvement in mental health, an increasing of satisfaction with care, and a lessening of caregiving strain. Nevertheless, such effects were distinctively associated with important objective circumstances of care, namely the existence of a secondary caregiver, the number of hours of care, the dependency level of the care-recipient, and the age of the caregiver. To foster wellbeing of the caregivers, intervention should particularly focus on the share of caregiving with others, and on uncovering positive aspects of care.

**Keywords** Caregiving · Dementia · Psychoeducational intervention · Burden · Positive aspects of care

## Introduction

In 2016, the World Alzheimer Report estimated that there were 46.8 million people worldwide living with dementia, and that this number will reach 131.5 million in 2025 (Alzheimer's Disease International 2016). In a recent meta-analysis, Niu and colleagues (2017) concluded that the prevalence of Alzheimer's Disease (AD) in Europe is of 5.05%, with an incidence of 11.08 per 1000 person-years; considering the trends by sex, the prevalence in men was estimated as 3.31%, and in women as 7.13%. The World Health Organization (WHO 2012, 2015) acknowledges these trends and concludes that dementia must be considered as a global health priority.

In what concerns the societal costs for dementia, these are supported in great proportion by social services (e.g., home services) and by the informal care sector, i.e., non-professional caregivers (Wimo et al., 2010). It is estimated that informal caregivers—relatives, in its majority—account for around 75% of all support received by older adults with some degree of dependence, which includes older adults living with AD (Marín and Casanovas 2001). In being associated with long care hours and physically demanding tasks, providing care to an older adult diagnosed with dementia is

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frequently required over a 24 h period and may be needed for a long period of time, since the illness process usually extends over seven years on average (Zwaanswijk et al. 2013).

Informal caregivers of people with dementia are more likely to develop major depression, anxiety disorders, and physical health disorders, such as hypertension, digestive and breathing problems; moreover, they have a higher mortality rate when compared to the general population (WHO 2015). Social consequences often include being forced to quit or enrol in less demanding jobs, and lose or face a decrease on leisure and social interaction opportunities (WHO 2015). The intensity of care needs in advanced stages, and the absence of gratitude or even recognition of close relatives is also highly disruptive of personal relationships. Therefore, informal caregivers of individuals affected by dementia can also pay a high price in terms of their quality of life (Duthey 2013).

In Portugal, older people (65+) represent about 20% of the total population (N = 2,122,996). This leads to the existence of a large amount of people in need of different levels of support and care in a daily basis, mobilizing informal caregiving, mainly within family. Particularly for dementia, although there's a lack of exact figures at a national level, Nunes et al. (2010) estimated that the prevalence of cognitive impairment and dementia were 16.8% and 2.1% in rural areas, and 12% and 2.7% in urban areas, respectively. The national coverage rate of formal services for older people (e.g. nursing homes, home care or day centres) is 12.7% (GEP/MTSS 2015), and in relation to informal caregiving, OECD (2013) presented 15.6% of Portuguese people aged 50 and more years as carers, equalizing OECD mean, with 62.3% being women and 87% providing care on a daily basis.

In a large study based on SHARE wave 4 (2010–2011), Barbosa and Matos (2014) showed that in Portugal people 50 years and over have important roles in co-residential care. When compared with other 15 European countries, authors concluded that Portugal had the highest rate of co-residential care (12.4%), and the lowest rate of provision of extra-residential help/care (10.8%). The quality of life (QoL) of Portuguese co-residential caregivers appeared as lower than the QoL of non-caregivers, but that extra-residential help/care provided once a month or less had a positive impact on the QoL of the providers.

As a consequence of a *familialistic* approach to welfare in Portugal (e.g., Lopes 2013; González et al. 2000), the idea that families are responsible for their older adults is commonly accepted and assumed as a natural process, culturally and socially justified and accepted. Specifically for dementia cases, there is a need for specialized interventions with the caregiver that promote the development of personal resources to deal with the care provision and mitigate the perceived overload, and to prolong the caregiving

dyads' permanence in the community (Brandão et al. 2016; CASTIIS and UNIFAI 2013). Supporting the caregiver is, therefore, recognized as a pivotal part in the treatment strategy for AD (DGS 2016), and fully recognized as a fundamental dimension in both gerontological intervention and psychogeriatric services (Gonçalves-Pereira et al. 2011).

Psychoeducational programs targeted at informal caregivers of people with dementia are one of the available interventions increasingly valued by health and social professionals, and their effectiveness has been assessed by a broad number of studies that stress its positive effects in dimensions such as perceived overload, depression, global well-being, skills in the provision of care, and perceived self-efficacy (Losada-Baltar et al. 2006; Pinquart and Sorensen 2006; Sörensen et al. 2002; Tompkins and Bell 2009). Investments of this nature are however scarce in the Portuguese context though there's an increasing recognition of their importance (Alves et al. 2016). According to several authors, intervention programs for dementia caregivers should address their difficulties and burden as a way to promote satisfaction with providing care (Sequeira 2013).

Rooted in a community-based initiative entitled “Caring for the Caregiver” (Ribeiro and Martín 2011) that took place in a Northern region of Portugal involving five distinct municipalities and a wide-ranging list of partners (City Councils, a Hospital, Health Centres, Volunteer's Institutions, Social Solidarity Private Institutions, among several others), a psychoeducational intervention program was designed targeted to informal caregivers of people with dementia. This paper aims to present such program, and the evaluation of its main outcomes in each of the following domains: physical and mental health, positive aspects of care, and caregiver strain.

## Methods

### The Psychoeducational Intervention Program

The psychoeducational program is incorporated in a major community intervention project entitled “Caring for the Caregiver” which resulted from a needs assessment study that motivated a non-for-profit organization and a R&D centre to design an intervention project targeted at caregivers of people living with AD in a specific geographical region in Northern Portugal - the region of Entre Douro e Vouga (Ribeiro and Martin 2011). The limited number of responses specifically targeted at caregivers in that region lead to the development of a psychoeducational program which assumed the inputs of professionals from both health and social sectors who worked directly with caregivers, and the guidelines from the European project “Health Promoting Intervention for Alzheimer's Family Caregivers” (Apel

et al. 1998), as well as available national and international literature on the topic.

The general objectives of the psychoeducational specific program were to increase knowledge on AD, develop strategies for the provision of care and problem-solving skills, promote a positive and rewarding involvement with the AD patient throughout daily activities of care provision (positive aspects of care), incentivize caregivers' self-care, offer information on the available community resources, and provide information and support on legal aspects of care provision. The program also aimed to target geographically isolated caregivers and reduce their perceived solitude, fomenting the establishment of supportive informal networks that could allow the sharing of experiences and feelings throughout the intervention and afterwards.

The psychoeducational program was organized in 10-weekly sessions, each one with the duration of 2 h (20 h total). The 10 sessions were designed to approach a flow of topics ranging from care-receiver's needs to the caregivers' own needs (see Table 1). Two professionals (a psychologist and a nurse) were the leaders of all sessions and received the complimentary contributions of a gerontologist (sessions 2, 3 and 4), social workers (sessions 6 and 10), and lawyers (session 6). All professionals involved received extensive training. In overall, 30 intervention groups were implemented and these took part in all municipalities involved in the project (CASTIIS and UNIFAI 2013). The program was assessed in three distinct moments: baseline, post intervention and at 6-month follow-up focusing on mental and physical health (SF12), positive aspects of care (PAC) and strain of caregiver M-CSI.

The project was first submitted to the ethic commission of UNIFAI/ICBAS, University of Porto obtaining its agreement by assuring that all ethical procedures of the Declaration of Helsinki (1964) and the Nuremberg Code (1949) were respected.

## Recruitment of Participants

The project holds a community scale intervention dimension, and the referral of informal caregivers to enrol in the psychoeducational program was non probabilistic, made by community partners (e.g., primary health care centres). Participants eligible to integrate a psychoeducational program were those who (i) assumed the primary role of an informal caregiver of someone with AD living in the community; (ii) were autonomous; and (iii) had no physical or cognitive impediments to integrate a group intervention (e.g., severe sensory problems). Caregivers were initially approached by the Primary Health Care Centre or by NGOs' professionals who asked for permission to give the contact to the project team that subsequently confirmed their interest in participating. All the participants signed an informed consent form after being cognizant of the study goals, procedures, discomfort (time spent collecting data), the possibility of abandoning the study at any time, and about the potential benefits of participation.

## Measures

Caregiver's data were collected by a structured interview, which included sociodemographic characteristics, mental and physical health, positive aspects of care and strain of the caregiver.

## Socio-demographic Characteristics

Information collected were caregiver's age, gender, marital status, work situation, educational level, co-residence with the care-receiver (yes/no), relationship with the care-receiver, frequency of care provision, and presence of a secondary caregiver. Information on the care-receiver's age, gender, and dependency level was also collected.

**Table 1** The Psychoeducational Program “Caring for the Caregiver”

Sessions	Theme	Purpose
Session 1	Understanding Alzheimer Disease	Educative purpose
Sessions 2, 3 and 4	Providing care to a person with AD: tasks and emotions	Blended educative-emotional focus
Session 5	Behaviour changes due to the disease	Blended educative-emotional focus
Session 6	Available services for legal and assistance support in the community	Educative purpose
Session 7	Disease acceptance	Blended educative-emotional focus
Session 8	Stress management within caregiving	Emotional focus
Session 9	Self-care	Blended educative-emotional focus
Session 10	Recreational and leisure time	Blended educative-emotional focus

## Mental and Physical Health

The Portuguese version of the 12-item Short-Form Health Survey was used (SF12, Ware, Kosinski & Keller, 2000; Ferreira 2000). This is a 12-item self-report questionnaire distributed by two dimensions: physical and mental health. All items present five response options, ranging from 1 (great, always, absolutely nothing) to 5 (weak, ever, huge). Higher values mean best health.

## Positive Aspects of Care

The Portuguese version of the Positive Aspects of Caregiving (PAC, Gonçalves-Pereira et al. 2010) originally developed by Tarlow et al. (2004) was used. This instrument measures the positive aspects of care and has eleven items, in a Likert scale of five points, ranging between 1 (strongly disagree) and 5 (strongly agree).

## Strain of Caregiver

The Modified Caregiver Strain Index (M-CSI, Thornton and Travis 2003) is a modified version of the Caregiver Strain Index originally developed by Robinson (1983). The modified version has three options, while the original version has only two options, increasing the sensibility of the instrument. This index has thirteen items with three answer options, 0 (no), 1 (yes) and 2 (yes, regularly). Higher values correspond to greater strain.

## Data Analysis

Exploratory analysis was performed to obtain characterization of the sample according to the caregivers, care-receiver and care provision situation, using absolute and relative frequencies for qualitative variables and mean and standard deviation (sd) for quantitative ones. The evaluation of the impact of the program in each specific dimension (physical and mental health, positive aspect of care and caregiver strain) was performed using multivariable linear mixed effect models considering time as a fixed effect and individual as a random effect. Potential confounding factors such as age and gender of the caregiver, existence of a secondary caregiver, dependency level of the care-receiver (1. highly dependent; 2. moderately dependent; 3. partially dependent/independent) and number of hours of care/day (1. < 24 h/day; 2. 24 h/day) were considered. Estimates of fixed effect and respective standard error (se) and 95 % confidence interval (95% CI) were obtained. A preliminary analysis of the distribution of each outcome was considered and, in this study, results revealed a skewed distribution for PAC. For this reason, a modified score was considered in order to obtain an improvement in the distribution of this outcome

considering the following transformation: PAC (modified score) =  $\sqrt{60 - \text{PAC}}$ . Considering this transformation, the interpretation of the score of PAC was modified, in the sense that lower values of modified scores were associated with higher positive aspect of care. All the analyses were performed using SPSS software version 21 and a significance level of 0.05 was considered.

## Results

The final sample comprises 187 caregivers whose basic characteristics are presented in Table 2. Care-receivers' mean age was 78.4 years (sd = 7.9 years), with a range between 60 and 97 years. Fifty-six (29.9%) were females; 67 (36.4%) were highly dependent, 63 (34.2%) moderately dependent and 54 (29.3%) partially dependent.

In order to evaluate the impact of the program in physical and mental health, positive aspect of care and caregiver strain, an adjusted linear mixed effect model was considered for each outcome. Results obtained are presented in Table 3 and in Figs. 1, 2 and 3.

Analysing health outcomes, time was a significant factor only for the mental health dimension. As that can be observed in Fig. 1(b), differences between pre and post-test and between pre-test and follow-up were found. Improving in the mental health dimension was observed after the implementation of the program, with higher scores of SF12 mental health dimension in post-test comparing to the pre-test, and the benefits were maintained until follow-up (no differences between post-test and follow-up were found). Presence of a secondary caregiver ( $p = 0.026$ ) and number of hours of care/day ( $p = 0.008$ ) were also associated with mental health improvement.

Considering positive aspect of care, similar results were found, with differences between pre and post-test, and between pre-test and follow-up (Fig. 2). A decrease in the PAC modified score was observed between pre and post-test, translated in an increase in the levels of positive aspects of care. These levels were maintained after post-test until follow-up. Factors associated with positive aspects of care were age of the caregiver—being younger ( $p = 0.005$ ) and the presence of a secondary caregiver ( $p = 0.005$ ).

Finally, analysing the caregiver strain, a similar pattern was observed: significant differences were found between pre-test and post-test and between pre-test and follow-up. The score of M-CSI decreased along time, which can be interpreted as a decrease in caregiver strain levels (Fig. 3). Dependency level of the care-receiver ( $p < 0.001$ ), the presence of a secondary caregiver ( $p = 0.042$ ) and the number of hours of care/day ( $p = 0.001$ ) were also identified as predictive factors of more caregiver strain.

**Table 2** Characterization of the caregivers and care provision aspects

	N	n	%
Age, mean (sd)	187	58.1 (13.4)	
Gender	187		
Male		37	19.8
Female		150	80.2
Marital status	185		
Married		149	80.5
Divorced		10	5.4
Widowed		5	2.7
Single		21	11.4
Work situation	187		
Full-time		18	9.6
Part-time		8	4.3
Retired		76	40.6
Unemployed		39	20.9
Housewife		39	20.9
Other		7	3.7
Education level	187		
Illiterate		7	3.7
1–4 years		93	49.7
5–6 years		22	11.8
7–9 years		26	13.9
10–12 years		28	15.0
>12 years		11	5.9
Relation with the care receiver	187		
Partner		61	32.6
Son/daughter		85	45.5
Brother/sister		6	3.2
Son/daughter in law		16	8.6
Friend/neighbour		7	3.7
Other relative		12	6.4
Living with the care receiver	186		
Yes		126	67.7
No		60	32.3
Number of hour of care/day	167		
< 24 h		80	47.9
24 h		87	52.1
Presence of secondary caregiver	186		
Yes		132	71.0
No		54	29.0

## Discussion

Results corroborate the family based welfare in the management of care for older people in Portugal (Lopes 2013). This author locates the social policy in Portugal in the scope of Mediterranean (South European) countries characterized by relying on families as care providers and on gender division of household labor to count on women for caring tasks. Cultural values based care provision for dependent old people

**Table 3** Multivariable linear mixed effect model for physical and mental health, positive aspects of care, and caregiver strain

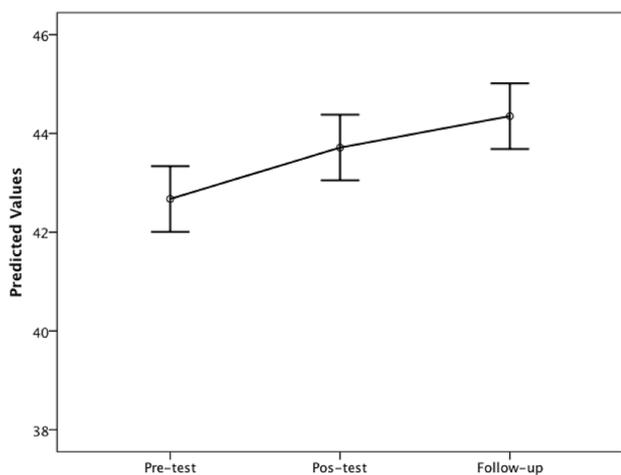
Outcome	Time	Adjusted estimates		
		B (se)	95% CI	p
SF12—physical health	Pre-test	−1.68 (1.20)	−4.05 to 0.69	0.165
	Post-test	−0.64 (1.34)	−3.26 to 2.00	0.636
	Follow-up	–	–	–
SF12—mental health	Pre-test	−5.25 (1.66)	−8.51 to −1.99	0.002
	Post-test	−0.76 (1.85)	−4.39 to 2.87	0.680
	Follow-up	–	–	–
PAC modified score	Pre-test	0.42 (0.14)	0.15–0.70	0.003
	Post-test	−0.02 (0.17)	−0.35 to 0.31	0.912
	Follow-up	–	–	–
M-CSI	Pre-test	2.10 (0.73)	0.66–3.54	0.004
	Post-test	0.90 (0.81)	−0.70–2.50	0.271
	Follow-up	0	–	–

Adjusted for: age and gender of the caregiver, existence of a secondary caregiver, dependency level of the care-receiver, and number of hours of care/day

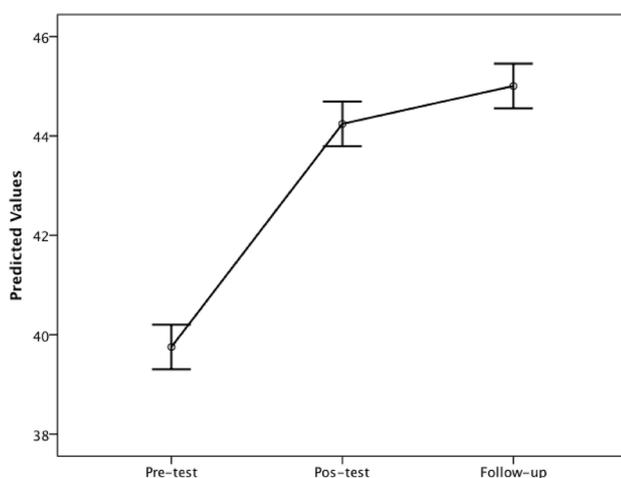
on kinship obligation, reciprocity, and as Ribeiro, Paúl and Nogueira (2007) noted, on marital vows. In fact, caregivers were mostly females, retired or not participating in the labor market, with a mean age 58 years, low education level and most of them being children or spouse of the care recipient. Care provision was mostly delivered under co-habitation (67.7%) and more than fifty percent around the clock, with 29% being the sole caregiver. This corroborates what was known about informal caregiving in the Portuguese context (e.g. Carvalho 2009; Barbosa and Matos 2014), and appears very similar to the one found in other European studies (e.g. OECD 2013).

The intervention program proved to be effective from the pre-test to the post-test or follow up in three aspects under evaluation, viz. mental health, positive aspect of care and caregiver strain. A prominent explanatory variable of each of the results, here considered as dependent variable, was the presence of a secondary caregiver that contributed for all the three indicators (better mental health, looking for the positive aspects of care and less burden). The existence of such a figure in the informal care network means that another family member, friend or neighbour, helps assisting the AD patient, either by helping or replacing the main caregiver from time to time, helping with other instrumental activities, or simply by giving emotional support. Receiving such help has been reported to correlate with higher levels of gain in other mental health conditions (Chen and Greenberg 2004), and support the feeling of imprisonment, over and over referred by primary caregivers (Ribeiro et al, 2007).

Our study also reports that a small number of hours of care/day were associated with better mental health, and



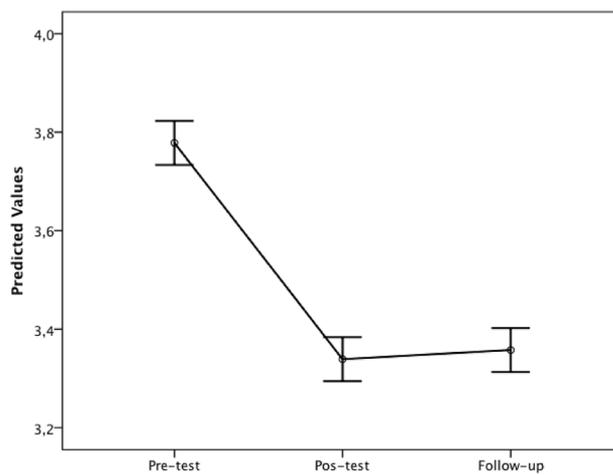
(a) SF12 – Physical Health



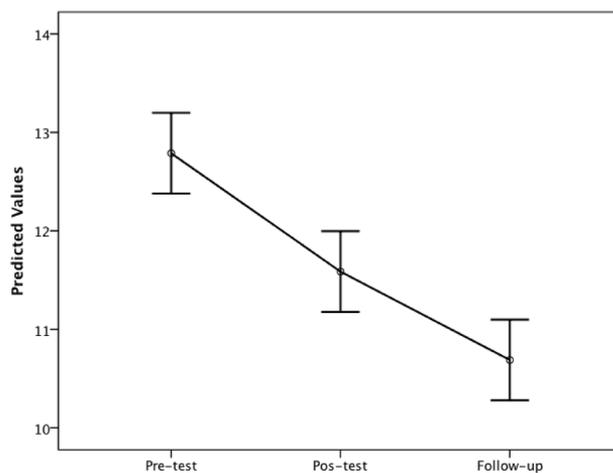
(b) SF12 – Mental Health

**Fig. 1** Predicted values of SF12 (Physical and Mental domains) considering multivariable linear mixed effects model

that the caregiver’s age (i.e., being younger) was associated with more positive aspect of care. The caregiver strain was found to be associated with higher dependency levels of the care receiver, the absence of a secondary caregiver, and with more hours of care/day. In overall, these findings are to some extent expected, but also suggest that caregiver burden is much about functional social network, family dynamics and relationships, although the physical overload of care tasks contribute to negative outcomes of caring. In this sense, emotional support and recognition from significant others, as well as trying to help them find positive aspects in caring, seems to be relevant issues to be taken into consideration by professionals organizing clinical interventions targeted at informal caregivers of people with dementia. Positive aspects tend to emerge due to enrichment in caregiver’s daily lives (Carbonneau et al. 2010) and can enable



**Fig. 2** Predicted values of PAC modified score considering multivariable linear mixed effects model (low values were associated with higher positive aspect of care)



**Fig. 3** Predicted values of M-CSI considering multivariable linear mixed effects model

the caregiver to feel useful and important. Caregiving can also be an opportunity to fulfilling one’s duty. As caregiving satisfaction has been found to be particularly present in those individuals having a consanguinity relationship with the care recipient in previous studies with similar cultural background as that reported here (Spain, cf. Labra et al. 2015), future interventions should highlight such aspects eventually within a global framework of family dynamics.

One main limitation of this work was the absence of a control group that would allow stronger scientific evidence of the benefits of the psychoeducational program. The applied nature of the community program focusing on delivering a service to respond to an urgent need detected by local agencies lead to the option of creating as many psychoeducational

groups as possible. The implementation of psychoeducational programs at community level also acted as awareness rising in the community that for the first time directed attention in an organized manner to this group of “invisible patients” that constitute the main pillar of care for people with dementia. Currently with established groups in the field we hope to be in a better condition to offer consecutive psychoeducational programs to people in the waiting list, that currently configures the control groups.

Based on the encouraging positive results of the psychoeducational program on mental health, positive aspects of care and burden of caregivers, we are in the position to suggest that interventions should focus heavily on the caregiver’s network and emotional regulation. Professional should pay attention to relationships inside the family and try to mobilize other members to the provision of care. By including a network approach and integrating the social resources and the systems of professional support, these programmes function as structured intervention measures, with increasingly recognized importance at the Portuguese context (Guerra et al. 2011; Gonçalves-Pereira and Sampaio 2011). Important clinical interventions with caregivers of people with dementia should therefore have one main objective that is to help emotional regulation of caregivers in the scope of a psychoeducational intervention that focus both on information and training of skills towards a better care provision, and on the promotion of caregivers’ self-care. Within this scope, another clinical aim will be to work at a family level, organizing the care by enrolling a secondary caregiver who is able to share tasks but also worries and joys, with the primary caregiver.

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## Compliance with Ethical Standards

**Conflict of interest** The authors declare that there are no known conflicts of interest. All authors certify that they accept responsibility for conducting the study and for the analysis and interpretation of the data, that they all helped writing the manuscript, and that they meet the definition of author as stated by the International Committee of Medical Journal Editors. All authors declare they have seen and approved the final manuscript.

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