





# “Living Together with Dementia”—A psychoeducational group programme for family caregivers

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## Abstract

**Purpose:** To evaluate the effectiveness of the psychoeducational programme “Living together with dementia” applied to a group of family caregivers of people with dementia.

**Design and Methods:** A quasi-experimental study with pretest and posttest and a 4-month follow-up. Fifteen family caregivers of people with dementia were recruited in a community care unit in northern Portugal.

**Results:** A positive and statistically significant impact on these caregivers' burden was found.

**Practice Implications:** The programme could be an important mechanism to train family caregivers of home-dwelling people with dementia.

## KEYWORDS

dementia, family caregivers, nursing, training programmes

## 1 | INTRODUCTION

Around 50 million people worldwide live with dementia, and nearly 10 million new cases are diagnosed every year. The World Health Organization (World Health Organization, 2020) has estimated an increase of cases to 82 million by 2030 and 152 million by 2050. This demographic context turns dementia into a public health priority.

Dementia is a progressive degenerative syndrome that evolves in three stages—early, middle, and late. Each stage comprises a complex set of symptoms that translates into different needs. The complexity of this syndrome implies that most people with dementia need the support of a caregiver, which often is a family member.

Being the family caregiver of a person with dementia is a demanding role that carries a set of physical, emotional, financial, and

social difficulties (WHO, 2020). These difficulties are reflected in needs and problems that family caregivers encounter and that are associated with psychological and behavioural symptoms of dementia expressed in the early and middle stages of the disease (Sousa et al., 2017).

Thus, it is crucial to work with the family caregivers of people with dementia. Training these carers for their role and providing emotional support is paramount. Psychoeducation is an example of an intervention strategy used with these caregivers. Psychoeducational interventions seem to aid in reducing burden and depression, improving subjective well-being, and increasing knowledge and abilities of the family caregiver (Pinquart & Sorensen, 2003; Silva et al., 2018).

Psychoeducational programmes can be developed and applied individually or in groups since both modalities benefit family caregivers substantially. Group interventions require the commitment and participation of the family caregivers during the sessions to foster social interaction and establish a vital support mechanism for sharing their experiences (Samia et al., 2012).

According to the Organization for Economic Co-operation and Development (OECD), Portugal is reported to have more cases of dementia (20 per thousand), but still scarce systematic training programmes for family caregivers of people with dementia (Organisation for Economic Co-operation and Development, 2017).

The programme “Living Together With Dementia” is a psychoeducational approach to empower caregivers of home-dwelling people with early or moderate stage dementia. The entire programme was built and validated within a conceptual framework using a focus group, integrative literature review, and a Delphi study (Sousa et al., 2018, 2016a, 2016b). A randomised controlled trial protocol was developed to address its experimental validation, after which a short-term efficacy study took place (Sousa et al., 2020).

Initially, this programme was built and validated to be applied individually, showing positive results, mainly reducing the burden on caregivers (Sousa et al., 2020). However, its individualised application leads to some constraints in clinical practice, such as longer intervention time, fewer caregivers included and a greater expenditure of human resources and time. Therefore, we aim to validate this programme for group application.

## 2 | AIM

To evaluate the effectiveness of the programme “Living together with dementia” applied to a group of family caregivers of home-dwelling people with early to moderate stage dementia.

## 3 | MATERIALS AND METHODS

A quasi-experimental study with pretest and posttest and a 4-month follow-up was conducted. The study was carried out in a community care unit in northern Portugal.

### 3.1 | Participants

Any participant in the study had to meet two inclusion criteria: (1) be the primary caregiver of a person with early to moderate stage dementia and (2) be sufficiently literate. Any participant caring for a person with late-stage dementia or other mental disorders was excluded.

### 3.2 | Recruitment

Overall, 15 participants were recruited by intentional sampling during September, October, and November 2019. The attending physician referred participants who met the inclusion criteria to the mental health nursing team of the community care unit.

### 3.3 | Ethical considerations

The study was approved in June 2019 by the care unit's Administration Board (No. 102/19/SGC) and by the institution's Health Ethics Committee (No. 56/CE/JAS). All those participating in the study signed an informed consent form required by the health institution. The Helsinki Declaration ethical principles were followed throughout the process.

### 3.4 | The programme “Living Together with Dementia”

The first validated version of the programme includes an individual intervention (Sousa et al., 2020). This study sought to validate its effectiveness through a group approach. The present version was a psychoeducational programme developed and applied by nurses specialising in mental health and psychiatry to train the family caregiver caring for home-dwelling people with initial or moderate dementia. “Living Together with Dementia” was a 7-week programme comprising seven weekly individual sessions of about 60/90 min each. The sessions encompassed topics such as dementia, its stages and symptoms; communication and behaviour management; pharmacologic intervention; emotions, expectations and demands of performing the role of a caregiver; assistance strategies for the basic and instrumental daily life activities; cognitive stimulation and environment management; coping strategies and problem-solving techniques; management of the caregiver's physical and mental health condition; and resources available in the community.

The researchers (three mental health and psychiatry nurses) who applied the programme were the same throughout the entire process to curtail distortion. The participants were assessed at the beginning of the study (T1), at the end of the programme—after 7 weeks (T2), and at a 4-month follow-up (T3). The programme was implemented from December 2019 to January 2020. After the programme was completed, the family caregivers maintained telephone contact with

the mental health and psychiatric nursing team. The nursing team also made weekly home visits; however, due to the COVID-19 outbreak and the physical restrictions imposed, visits were suspended from March 2020, and only telephone contacts were maintained.

### 3.5 | Outcomes and measures

In the three evaluation moments, a questionnaire was applied to the family caregivers composed of:

- Characteristics of the family caregiver (age, gender, schooling, professional occupation, marital status and kinship with the person with dementia). The care for the person with dementia was also considered in this evaluation through questions such as “For how long have you been a family caregiver?”; “How many hours a day do you dedicate to the care of the person with dementia?”; “Do you rely on any help when caring for the person with dementia?”; “On whose help do you count on?”; “What was your previous relationship with the person with dementia?”; “Do you have any training as a caregiver?”
- The Scale of Caregiver Burden (SCB) (validated for the Portuguese population by Sequeira, 2007) is composed of 22 items evaluating the objective and subjective overload of the family caregiver. The caregiver scored each item from 1 (never) to 5 (always), and a global score with a variation from 22 to 110 was given. A score below 46 indicated an absence of overload, a score from 46 to 56 indicated mild overload, and a score over 56 indicated intense overload.
- The Caregiver Assessment of Difficulties Index (CADI) (validated for the Portuguese population by Brito, 2000; Sequeira, 2007) comprises 30 potential queries related to the caregiver. The caregiver scored each item from 1 (does not apply to my case) to 4 (it happens, and I find it extremely disturbing). The higher the score, the greater the difficulties (90 is the highest score).
- The Caregiver Assessment of Satisfaction Index (CASI) (validated for the Portuguese population by Brito, 2000; Sequeira, 2007) comprises 30 positive items associated with care provision. The caregiver scored each item from 1 (provides no satisfaction) to 4 (provides much satisfaction). The higher the score, the higher the satisfaction level (120 is the highest score).

The assessment tool was composed of self-completed scales made available to the caregivers. Time was set to fill in the form individually and privately in the three assessment moments to reduce assessment bias.

### 3.6 | Statistical analysis

The data were analysed using SPSS software 27 (SPSS® Inc.). For the analysis of the features of the family caregivers, descriptive statistics were reported, including means, standard deviation, absolute and

relative frequencies, median and amplitude. The Student *t* test for paired samples was used to compare the scores obtained in the different evaluation moments (the evaluation moments were compared 2 to 2). A normal distribution (Shapiro–Wilk test) and positive correlation were verified between different scores at different times. The level of confidence was set at 95% with a significance level of 5%. Given the small sample size, the effect size of the intervention was calculated in the different stages of evaluation for each of the variables under study. Cohen's *d* was used to calculate the effect size based on the means and standard deviations.

## 4 | RESULTS AND DISCUSSION

The family caregivers participating in this study were mostly women, married, with an average age of 61 years, caring for a spouse or a descendant with dementia. Table 1 shows the participants' characteristics and their profiles. These data are in accordance with the previous study carried out to validate the individual programme and with most of the studies conducted in this area in Portugal (Sousa et al., 2020).

Most of the participants had assumed their role as caregivers about three years ago and had spent an average of 18.4 h/day caring for their relatives with dementia. These data are in line with the OECD report (2017), suggesting that Portuguese family caregivers are those dedicating the most time to caring for their family members from all the OECD members.

Regarding the assessment of the difficulties of family caregivers who participated in the study, in the initial assessment (T1), the study showed high levels of difficulty, with an average score of 61.1 (90 is the highest score possible). At the end of the intervention (T2), the level of difficulties was slightly higher (62.5), and at follow-up (T3), these difficulties were even more accentuated (63.9), although with no statistically significant value ( $p = 0.435$ ). From our perspective, the increase observed between T1 and T2 may be explained by two reasons. First, the programme lasted for seven weeks, and during this period, there was probably an evolution of the dementia stage likely to exacerbate the difficulties experienced by the caregivers. Second, while attending the training programme, caregivers were provided with in-depth knowledge about the pathology and its evolution which potentially influenced their ability to identify difficulties. These results were similar to those of the individual intervention since the experimental group demonstrated high difficulty levels at the initial assessment, a slight decrease in the score obtained in the final assessment (T2), and an increase at follow-up (T3) (Sousa et al., 2020).

When the individual application programme was validated, one of the main limitations observed to have influenced the less positive results obtained at follow-up was the limited accompaniment provided to family caregivers between the end of the programme and the follow-up. A more effective contact between family caregivers and nurses and home visits or phone contacts were recommended (Sousa et al., 2020). In this study, the programme ended in January 2020, and the follow-up took place from April to May 2020. Until

**TABLE 1** Features of family caregivers

Variable	n = 15
Age	Min-max = 27–84 years
	Mean = 61.8 years (SD = 15.8)
	Median: 61 years
Gender	Female: 10 (66.7%)
	Male: 5 (33.3%)
Schooling	0–4 years: 8 (53.3%)
	5–12 years: 5 (33.3%)
	>12 years: 2 (13.3%)
Occupation	Active: 1 (6.7%)
	Not Active: 14 (93.3%)
Marital status	Married: 12 (80.0%)
	Not married: 3 (20.0%)
Kinship with the person with dementia	Spouse: 7 (46.7%)
	Descending: 8 (53.3%)
Years as a caregiver	Min-max: 1–10 years
	Mean = 3.067 years (SD = 2.2)
	Median = 3 years
Hours of day providing care	Min-max: 5–24 h/day
	Average = 18.4 h/day (SD = 7.8)
	Median: 24 h
Help in care	Yes: 10 (66.7%)
	No: 5 (33.3%)
Previous training as a caregiver	Yes: 1 (6.7%)
	No: 14 (93.3%)
Experience as a caregiver	Yes: 4 (26.7%)
	No: 11 (73.3%)

March, telephone contacts and home visits from the nursing team were made to the family caregivers, as suggested in the referred study. However, upon the COVID-19 outbreak, only telephone contacts were carried out, which may have also contributed to the increase in the experienced difficulties.

Table 2 displays the average scores obtained by the caregivers in the three assessment moments regarding difficulties, overload, and satisfaction. Table 3 compares the averages obtained in these variables at the different assessment times.

Regarding the caregiver's satisfaction, the scores obtained were high and remained substantially the same throughout the three evaluation moments, as observed in Table 2. The caregivers' satisfaction was always high in the individual evaluation study, but with slight variations throughout the study (Sousa et al., 2020). The participants showed high satisfaction in caring (approximately 92 points, in a maximum of 120), which may be related to a good previous

**TABLE 2** Average score for difficulties, satisfaction and burden of caregivers in the three evaluation moments

	CADI	CASI	SCB
T1	61.1 (SD 4.6)	92.5 (SD 5.1)	59.5 (SD 3.7)
T2	62.5 (SD 4.6)	92.7 (SD 4.1)	55.2 (SD 3.8)
T3	63.9 (SD 4.8)	91.7 (SD 3.8)	52.5 (SD 3.4)

Abbreviations: CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index; SCB, Scale of Caregiver Burden.

relationship with the relative and feelings of accomplishment associated with the care process (Sánchez-Izquierdo et al., 2012). Another aspect that can influence the caregivers' levels of satisfaction is the level of dependence of the person with dementia. Since this study focused on family caregivers of people with early to moderate dementia, physical dependence was mild, which may contribute to higher levels of satisfaction (Sánchez-Izquierdo et al., 2012; Sousa et al., 2020).

As for the caregiver burden, it was found that in T1, the participants had high burden levels (59.5 points). In the final assessment (T2), there was an important decrease to 55.2 points, representing a moderate overload. In the follow-up (T3), the participants maintained a moderate overload, although with an even lower average score of 52.5 points. The decrease in overload from the initial assessment to the follow-up was statistically significant ( $p = 0.042$ ).

These results reinforce the premise pointed out by several studies that psychoeducation programmes positively impact caregivers' burden (Chien et al., 2011; Lopes & Cachioni, 2012; Silva et al., 2018). In the individual version of the programme "Living together with dementia," there was also a statistically significant improvement in burden between the initial assessment and the final assessment, although with an increase in the burden at follow-up (Sousa et al., 2020). This significant improvement in overload might be explained by the increase in the caregivers' knowledge, the development and application of coping strategies and an adaptation over time to the transition to the caregiver's role.

Considering the small sample size of the study, we have calculated the effect size of the intervention to better understand and interpret the meaning of the statistical tests applied. Thus, overall there was a medium-size effect of the intervention (between 0.4 and 0.7), as seen in Table 4. This result may indicate that the group version of the programme has potential and should be validated in a larger sample of caregivers.

## 5 | CONCLUSION

This study validated the programme "Living Together with Dementia" applied in groups within a community context. The main findings are the positive and statistically significant impact of the intervention on caregivers' burden. However, we did not obtain statistically robust

**TABLE 3** Comparison of the averages obtained in the different evaluation moments

Evaluation moments	CADI		CASI		SCB	
	Mean difference (SD)	<i>p</i>	Mean difference (SD)	<i>p</i>	Mean difference (SD)	<i>p</i>
T1 → T2	-1.3 (6.03)	0.406	-0.3 (12.22)	0.934	4.3 (11.11)	0.153
T2 → T3	-1.4 (10.53)	0.615	-1.0 (2.48)	0.140	2.7 (6.99)	0.161
T1 → T3	2.7 (13.18)	0.435	0.7 (12.23)	0.820	-7.0 (12.12)	0.042

Abbreviations: CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index; SCB, Scale of Caregiver Burden.

**TABLE 4** Results of the effect size calculation

Evaluation moments	CADI Cohen's <i>d</i>	CASI Cohen's <i>d</i>	ESC Cohen's <i>d</i>
T1 → T2	-0.22	-0.22	0.39
T2 → T3	-0.13	0.40	0.38
T1 → T3	-0.21	0.06	0.58
Power analysis			
Power = 0.543	Effect size = 0.573	SD = 12.2	

Abbreviations: CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index.

results, probably due to the small sample size, which is the main limitation of this study. Nevertheless, the psychoeducational programme "Living Together with Dementia" could be an important mechanism to train family caregivers of home-dwelling people with dementia. Therefore, it is critical to continue using this programme in the community and consider conducting a randomised controlled trial to enhance the use of its results.

## 6 | IMPLICATIONS FOR NURSING PRACTICE

Nurses are an important workforce to implement nursing interventions to empower family caregivers. This programme could be an important tool to train family caregivers of home-dwelling people with dementia. Particularly in the Portuguese context, where there is a culture of caring in the family, and social responses are scarce, the training of family caregivers is essential. Thus, we believe that this programme helps fill the care gap for family caregivers of people with dementia and could be used as a guideline for intervention by nurses, particularly by mental health and psychiatric nurses.

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### CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

### DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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