



'Living Together With Dementia': preliminary results of a training programme for family caregivers

Lia Sousa PhD, MSc, RN (Professor, CINTESIS-FMUP Researcher, Editorial Coordinator of Portuguese Journal of Mental Health Nursing)^{1,2} , **Carlos Sequeira** RMHN, MSc, PhD (Coordinator Professor, Coordinator Group of Nursing Research, Director of Portuguese Journal of Mental Health Nursing, President of The Portuguese Society of Mental Health Nursing)^{3,4} , **Carne Ferré-Grau** MSc, PhD, RN (Assistant Professor, Member of Accredited Research Group of Advanced Nursing of URV, Coordinator of the PhD of Research in Nursing Science from the URV)⁵ and **Luís Graça** MSc, PhD, RN (Coordinator Professor)⁶

¹Superior School of Health, Vale do Ave. North Polytechnic Institute of Health, Nova de Famalicão, Portugal, ²Portuguese Society of Mental Health Nursing Board Member, Porto, Portugal, ³Porto Nursing School, Coordinator Scientific Pedagogical Unit, "Management of Signs & Symptoms", Porto, Portugal, ⁴Research Unit, CINTESIS, Faculty of Medicine, University of Porto, Porto, Portugal, ⁵Department of Nursing, University Rovira i Virgili, Tarragona, Spain and ⁶Viana do Castelo Health School, Viana do Castelo, Portugal

Scand J Caring Sci; 2020

'Living Together With Dementia': preliminary results of a training programme for family caregivers

The aim of this article was to present the preliminary results of a training programme for family caregivers of people with dementia at an early to moderate stage living at home – 'Living Together With Dementia'. In this randomised controlled trial, 27 family caregivers who met the inclusion criteria were recruited from the neurology outpatient consultation clinic of a hospital in the north of Portugal and randomised into two groups (control and experimental) between October 2015 and March 2016. The programme 'Living Together With Dementia' was applied to the participants of the experimental group. The strategies used, overload, difficulties and satisfaction of the caregivers were assessed at three different stages (at the beginning and end of the intervention, as well as at follow-up). For the data analysis, quantitative parametric measures were applied. The Health Ethical Commission of the Hospital Centre approved the study, and its protocol

and Helsinki Declaration ethical principles were considered throughout the process. In the final assessment, an improvement in the overload and difficulties was confirmed, as was an increase in the caregivers' satisfaction level and an improvement in coping/problem-solving strategies. In the follow-up stage, the results tended to revert towards those of the initial assessment. The programme 'Living Together With Dementia' appeared to be a major contribution enabling family caregivers of people with dementia, although there is a need to develop an efficacy study using a more substantial sample. The programme contributed to a reduction in the overload and difficulties borne by the family caregivers of people with dementia at an early to moderate stage living at home and to increased caregiver satisfaction.

Keywords: dementia, family caregivers, training programmes, randomised controlled trial, quantitative research, nursing.

Submitted 26 April 2019, Accepted 9 January 2020

Introduction

It is clear that global ageing is occurring, and it is estimated that in the next 10 years, the number of people aged over 60 years will surpass one billion (1). Accompanying the ageing of the population, there is an increase in the

number of people with dementia, which is expected to rise from 36 million to 115 million in 2050 (1). Presently, most people with dementia live at home under the care of family members. In 2012, approximately 15 million family caregivers spent 17.5 billion hours in the provision of care to their family members with dementia (2).

In Organization for Economic Co-operation and Development (OECD) countries, more than 19 million people live with dementia. Of this group, Portugal has the fourth-highest number of cases of dementia (20/1000 inhabitants) and is one of the countries where institutional responses are lacking and are difficult to access, and the number of specialists available to monitor these cases is lower (3). In

Correspondence to:

Carlos Sequeira, Porto Nursing School, Coordinator Scientific Pedagogical Unit, "Management of Signs & Symptoms", Edifício Sede, Rua Dr. António Bernardino de Almeida, 830, 844, 856 4200-072 Porto, Portugal.
Email: carlossequeira@esenf.pt

this setting, caring for people with dementia usually passes to family caregivers. In Portugal, family caregivers report spending approximately 8 hours a day caring for their relatives with dementia (3). It is also verified that most of these caregivers do not have access to institutional support to care for their family members with dementia and do not have the training to do so.

Continued care imposes a physical, emotional, social and economic burden on both the caregivers and the family. As a result of the behavioural and psychological changes associated with the early and moderate stages of dementia, family caregivers who undertake this responsibility are more prone to stress than other caregivers (4).

In this context, the family caregivers of people with dementia are a priority setting for health professionals such as mental health and psychiatric nurses. To respond to these needs and to support family caregivers in this situational transition, it is important to develop training programmes/strategies that allow the acquisition of knowledge and the development of competencies.

The development and implementation of nonpharmacological measures that enable family caregivers to provide care to people with dementia living at home are paramount so as to reduce the negative effects of the caregiver role and promote a better quality of life. Diverse nonpharmacological interventions with family caregivers of people with dementia, such as support groups, psychotherapy, technology-based interventions and psychoeducation, among others, can be found in the literature (5). However, psychoeducational interventions seem to provide a better response for the reduction of burden and depression, the improvement of subjective well-being and increase in knowledge and abilities of the family caregiver (6). In Portugal, there is a lack of systematised and implemented psychoeducational programmes for these caregivers, and given the ageing of Portuguese society and the incidence and prevalence of dementia, this lack of programmes needs to be addressed, with a consideration of the well-being of people with dementia and their caregivers and more adequate care at home.

The programme 'Living Together With Dementia' is a psychoeducational approach to empower caregivers of people with dementia at an early or moderate stage living at home. This programme and all its characteristics were built and validated in a conceptual fashion by means of a focus group integrative literature review and a Delphi study (7–9). A randomised controlled trial protocol was developed (10) to address its experimental validation, after which a short-term efficacy study took place. The aims of the pilot study were to evaluate the effectiveness of the programme 'Living Together With Dementia' when compared to the usual nursing care provided to these caregivers and to evaluate coping/problem-solving strategies, the burden, satisfaction and complications of family caregivers after participation in the programme.

The study

Aim

The aim of the study was to access the preliminary results of 'Living Together With Dementia', a training programme for family caregivers of people with dementia at an early to moderate stage living at home.

Methods

A randomised controlled trial with a 4-month follow-up was the basis of this pilot study. The study was developed at the neurology outpatient consultation clinic in a hospital located in Porto, Portugal. All procedures were performed in accordance with Consolidated Standards of Reporting Trials (CONSORT) (11).

Participants

Inclusion and exclusion criteria. These were the inclusion criteria that caregivers had to meet to be eligible to participate in the programme 'Living Together With Dementia': (i) be the main caregiver of the person with dementia at the early or moderate stage; (ii) be literate; (iii) be motivated to participate in the programme; and (iv) reside in Porto. The following were the exclusion criteria: (i) the person under care did not have dementia at the early or moderate stage and (ii) the person with dementia was experiencing other severe mental pathology.

Recruitment/randomisation. For a period of 6 months (between October 2015 and March 2016), after the neurology outpatient consultation by the dementia group, family caregivers were approached and recruited. Caregivers who met the inclusion criteria were identified by the neurologists attending the dementia consultation, and permission was requested to contact them afterwards by telephone so that information about the study could be provided, thus giving the caregivers the opportunity to consider participation in the study. Contacting the caregivers by telephone was the responsibility of one of the auxiliary researchers. The family caregivers who agreed to participate in the study were classified in a random numerical listing and were assigned a participation code (from FC1 to FC27). The allocation was decided by the drawing of lots of numbered slips of paper under the responsibility of the research supervisors. The caregivers who integrated the experimental group were the first 12 whose numbers were drawn.

Ethical considerations

The Health Ethical Commission of the Hospital Centre approved the study protocol in September 2015 (CES

177-15). The study is registered on clinicaltrials.org with ID number NCT 03015428. All those participating in the study signed an informed consent form required by the health institution. Helsinki Declaration ethical principles were considered throughout the process.

'Living Together With Dementia' programme vs. conventional care

The family caregivers who were part of the experimental group were enrolled in the 'Living Together With Dementia' programme. This was an individual psychoeducational programme developed and applied by mental health and psychiatry specialist nurses with the goal of training the family caregiver who undertakes the care of people with dementia at the initial or moderate stage living at home. This was a 7-week programme comprising 7 weekly individual sessions with an average duration of 60 minutes each as well as two 90-minute group sessions with all the caregivers who were participating. The individual 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 group sessions were aimed at sharing challenges, emotions, expectations and strategies of being a caregiver of a person with dementia. Methodologies that were utilised during the programme were as follows: topic presentation, discussion, practical examples/demonstrations, skill training, practical exercises and movie displays. The researcher (nurse) who applied the programme was the same throughout the entire process to curtail distortion. The participants of the experimental group were assessed at the beginning of the study (T1), at the end of the programme – 7 weeks afterwards (T2) and at a 4-month follow-up (T3). For the participants of the experimental group to remain in contact after the programme ended, a Facebook® page was created.

Family caregivers who were part of the control group had access to standard health care in the health institution where the study took place, such as a neurology appointment every 6 months and the possibility of clarifying doubts about the pathology, care provision and therapeutic regime with the healthcare professionals' team (doctor, nurse, social worker and psychologist). The members of the control group were assessed at the beginning of the study (T1), 7 weeks after the end of the study (T2) and at a 4-month follow-up (T3).

Outcomes and measures

Assessment of all the family caregivers who were part of the study was performed at all three moments: at the beginning of the study (T1), 7 weeks after the study ended (T2) and at 4-month follow-up (T3) by means of the following:

- Features of the family caregiver (age, sex, 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 by means of 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 for the care for the person with dementia? On whose help do you rely? What was your previous relationship with the person with dementia? Do you have any training as a caregiver?
- Three open questions were asked regarding the number and type of strategies used as a daily resource: In your daily routine as a caregiver, how do you handle unexpected happenings/problems? In your daily routine as a caregiver, how do you deal with stress symptoms? In your daily routine as a caregiver, how do you regard less positive happenings?
- Twenty-two items evaluating the objective and subjective overload of the family caregiver composed the Scale of Caregiver Burden (SCB) (validated for the Portuguese population) (12). 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) (12,13) is composed of 30 potential queries related to the caregiver. The caregiver scored each item between 1 (does not take place in my case) and 4 (it happens and disturbs me very much). The higher the score, the greater the number of queries (90 is the higher score).
- The Caregiver Assessment of Satisfaction Index (CASI) (validated for the Portuguese population) (12,13) is composed of 30 positive items associated with the provision of care. The caregiver scored each item between 1 (provides no satisfaction) and 4 (provides much satisfaction). The higher the score, the higher the satisfaction level (120 is the higher score).

The assessment tool was composed of self-completed scales made available to the caregivers as well as a period to fill in the form individually and privately in the three assessment moments, to reduce assessment bias.

In the first assessment moment (T1), people with dementia were also under assessment to allow the

identification of the exact stage of the condition and the main disabilities, and thereafter, the adjustment of the individual intervention to the real needs was possible. The following items were applied to allow the assessment to be performed:

- Features of the person with dementia (age, sex, schooling, professional occupation, marital status, time since dementia diagnosis and type of dementia).
- Mini-Mental State Examination (MMSE) (validated for the Portuguese population), (14) which is a short test for a general cognition assessment, composed of 30 questions that assess orientation, attention and calculation, retention, evocation, language and constructive skill. A total score of 30 points may be obtained. Schooling is also considered for the evaluation, with the following cut-off points acknowledged as a cognitive handicap: schooling 0–2 years – 22 points; schooling from 3 to 6 years – 24 points and schooling 7 + years – 27 points.
- The Dementia Clinical Scale (DCS) (validated for the Portuguese population) (15) consists of a global evaluation that calculates the influence of cognitive disabilities in daily life activities without presenting cut-off values, as a person's performance is compared with their own initial performance. This instrument assesses memory, time and space orientation, judgement, problem resolution, social interaction, hobbies and personal care. A score is assigned according to the degree of involvement as follows: 0 = Healthy; 0.5 = Open to question; 1 = Light; 2 = Mild; and 3 = Serious. Only the category 'personal care' does allow a score for 'Open to question'.

Table 1 contains the outcome measures and data collection of family caregivers of people with dementia and people with dementia.

Statistical analysis

For the data analysis, SPSS software 21 (SPSS® Inc., Chicago, IL, USA) was used. To compare the mean of the quantitative variables, when there was homogeneity between the independent groups, Student's *t*-test was used. When there was no homogeneity, the Mann–Whitney *U* test was used. To compare the qualitative variables between the groups, the chi-square test was used. To compare the scores obtained by the participants of the two groups, at the three assessment moments, the ANOVA test was used for repeated measures. To present the intervention effect size, the choice was partial beta-square. Data analysis assumptions were verified. The level of confidence was set at 95%, with a significance level of 5%.

Hypothesis

The hypothesis that we endeavoured to prove (H_0) was that the family caregivers who integrated the experimental group and participated in the 'Living Together With Dementia' programme would present with more coping/problem-solving strategies, lower overload levels, greater satisfaction levels and less difficulties associated with the caregiver role than the control group participants.

Results

During the recruitment process, 48 family caregivers who achieved compliance with the inclusion criteria were identified, and of these, 27 agreed to take part in the study (control group = 15 and experimental group = 12). The intervention protocol was fully applied during the study, as planned. Adherence for the participants who completed the study, assessed by the proportion of

Table 1 Outcome measures and data collection for family caregivers of people with dementia and the people with dementia themselves

Outcome and instrument	Evaluation target	Data collection time		
		T1 (initial evaluation)	T2 (final evaluation)	T3 (follow-up at 4 months)
Family caregiver characterisation	Family caregiver	X	X	X
Open questions about the strategies they use every day	Family caregiver	X	X	X
SCB	Family caregiver	X	X	X
CADI	Family caregiver	X	X	X
CASI	Family caregiver	X	X	X
Choose the top 5 daily needs	Family caregiver	X	X	X
People with dementia characterisation	Person with dementia	X		
MMSE	Person with dementia	X		
DCS	Person with dementia	X		

CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index; DCS, Dementia Clinical Scale; MMSE, Mini-Mental State Examination; SCB, Scale of Caregiver Burden.

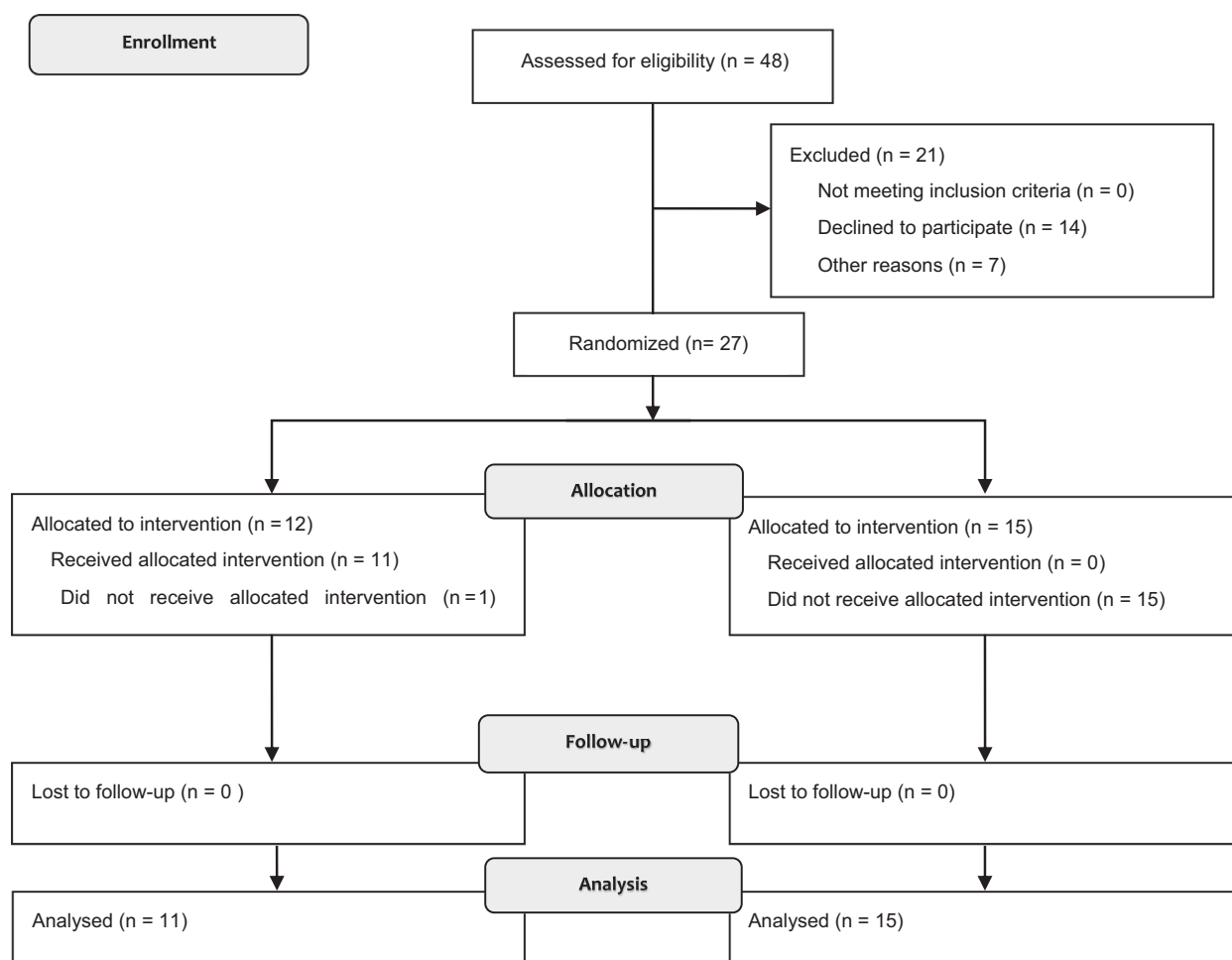


Figure 1 Participant flow through the phases of the randomised controlled trial.

sessions attended, was 100%. Through the randomisation process, two groups with similar characteristics were formed. The enrolment process can be observed in Figure 1. The participants' features at baseline are summarised in Table 2.

According to Table 2, there were no statistically significant differences in the characteristics and the MMSE or ECD global scores between the group of people with dementia under the care of family caregivers who were part of the control group and those who were part of the experimental group. In both groups, the global scores obtained in people with dementia positioned them within the interval that corresponded to dementia at an early or moderate stage, as intended. In turn, the family caregivers who were part of the experimental control group showed homogeneous characteristics, as evidenced in Table 2.

Descriptive statistics for mean scores at the initial evaluation, final evaluation and follow-up are presented in Table 3. In the experimental group, between T1 and T2, there was an increase of 1 point in the average coping strategies (2.6–3.6), a decrease of 6.8 points in the

overload (56.5–49.7), a decrease of 5.9 points in difficulties (58.7–52.8) and an increase of 9.6 points in the satisfaction of the caregivers (84.8–94.0). In the control group, between T1 and T2, there was a maintenance of the mean values for the coping and satisfaction strategies and a slight decrease in the overload and difficulty values, although more discrete than in the experimental group.

At follow-up (T3), in general, there were changes in the variables under study, both in the experimental group and in the control group. The experimental group almost regressed to the maximum values of the initial evaluation, which demonstrated the importance of maintaining the intervention over time.

A mixed between-within subjects analysis of variance was conducted to assess the impact of the intervention/control on participants' scores across the three time periods (T1, T2 and T3). To apply this test, there was a previous assessment of the prerequisite criteria, such as being a random sample, with both normal distribution and homogeneity of the variance of independent observations of each group among themselves

Table 2 Characterisation of participants at baseline

Variables	EG (n = 12)	CG (n = 15)	p
People with dementia			
Age (SD)	71 years (11.4)	76 years (8.6)	$t_{(25)} = -1.346, p = 0.190$ $F_{(25)} = 0.393, p = 0.537$
Sex	Male – 7 (58%) Female – 5 (42%)	Male – 6 (40%) Female – 9 (60%)	$X^2(1) = 0.926, p = 0.336$
Schooling	0–2 years – 0 (0%) 3–6 years – 10 (83%) +7 years – 2 (17%)	0–2 years – 2 (13%) 3–6 years – 12 (80%) +7 years – 1 (7%)	$t_{(25)} = -1.405, p = 0.172$ $F_{(25)} = 0.051, p = 0.824$
Marital status	Married – 9 (75%) Not married – 3 (25%)	Married – 8 (53%) Not married – 7 (47%)	$X^2(1) = 1.815, p = 0.178$
Disease duration (SD)	2.7 years (1.8)	3.3 years (2.5)	$t_{(25)} = -0.779, p = 0.443$ $F_{(25)} = 2.253, p = 0.146$
Type of dementia	Alzheimer's – 7 (58%) Others – 5 (42%)	Alzheimer's – 8 (53%) Others – 7 (47%)	$X^2(1) = 0.333, p = 0.564$
Global score MMSE (SD)	15.8 (10.2)	14.5 (8.8)	$t_{(25)} = 0.333, p = 0.742$ $F_{(25)} = 0.473, p = 0.498$
Global score DCS (SD)	6.4 (3.8)	8.5 (4.6)	$t_{(25)} = -1.273, p = 0.215$ $F_{(25)} = 1.849, p = 0.186$
Family caregivers			
Age (SD)	48 (12,5)	55 (10,1)	$t_{(25)} = -1.752, p = 0.092$ $F_{(25)} = 0.036, p = 0.851$
Sex	Male – 4 (33%) Female – 8 (67%)	Male – 3 (20%) Female – 12 (80%)	$X^2(1) = 6.259, p = 0.012$
Schooling	0–4 years – 1 (8%) 5–12 years – 9 (75%) >12 years – 2 (17%)	0–4 years – 5 (33%) 5–11 years – 8 (53%) =>12 years – 2 (13%)	$t_{(25)} = -1.430, p = 0.165$ $F_{(25)} = 1.374, p = 0.252$
Marital status	Married – 6 (50%) Not married – 6 (50%)	Married – 12 (80%) Not married – 3 (20%)	$X^2(1) = 3.000, p = 0.083$
Occupation	Active – 9 (75%) Not active – 3 (25%)	Active – 11 (73%) Not active – 4 (27%)	$X^2(1) = 6.259, p = 0.012$
Kinship with the person with dementia	Partner – 4 (33%) Son/daughter – 7 (59%) Others – 1 (8%)	Partner – 3 (25%) Son/daughter – 9 (60%) Others – 3 (20%)	$X^2(1) = 6.259, p = 0.012$
Previous relationship with the person with dementia	Good relationship – 11 (92%) Bad relationship – 1 (8%)	Good relationship – 15 (100%)	$X^2(1) = 23.148, p = 0.000$
Years as a caregiver (SD)	2.5 (1.6)	3.9 (2.4)	$t_{(25)} = -1.734, p = 0.095$ $F_{(25)} = 3.644, p = 0.068$
Hours of day providing care (SD)	9.2 (8.8)	6.2 (6.0)	$U = 82, p = 0.719$ $F_{(25)} = 4.487, p = 0.044$
Help in caring	Yes – 9 (75%) No – 3 (25%)	Yes – 10 (67%) No – 5 (33%)	$X^2(1) = 4.481, p = 0.034$
Previous training as a caregiver	Yes – 0 (0%) No – 12 (100%)	Yes – 1 (7%) No – 14 (93%)	$X^{\chi}(1) = 23.148, p = 0.000$

CG, control group; DCS, Dementia Clinical Scale; EG, experimental group; MMSE, Mini-Mental State Examination; SD, standard derivation.

and the variables under study measured on an interval scale (16).

Regarding the coping/problem resolution strategies, the mean in the experimental group increased in the final assessment and remained similar at follow-up. In the control group, the mean remained similar during the three assessment moments, as can be observed in Table 3. The caregivers' strategies did not vary in a statistically significant manner between the groups over time,

although the effect size of the intervention was substantial (Wilks' lambda = 0.840; $F_{(2,23)} = 2.198, p = 0.134$, partial eta squared = 0.160), as shown in Table 4.

Regarding SCB, family caregivers in both groups demonstrated intense burden values at the initial assessment. These dropped to a low level in the final assessment and increased again in the follow-up phase, although the experimental group elements presented a more substantial score variation, according to Table 3.

Table 3 Mean of global scores at the evaluation moments

Variables	EG (n = 12)			CG (n = 15)		
	T1 (Initial)	T2 (Final)	T3 (Follow-up)	T1 (Initial)	T2 (Final)	T3 (Follow-up)
Mean of coping/problem-solving strategies (SD)	2.6 (1.2)	3.6 (1.3)	3.5 (1.5)	2.3 (1.2)	2.3 (1.3)	2.2 (1.3)
Mean SCB score (SD)	56.5 (13.4)	49.7 (16.1)	56.4 (16.1)	57.7 (13.4)	52.9 (11.3)	55.6 (12.9)
Mean CADI score (SD)	58.7 (21.5)	52.8 (22.2)	60.2 (22.8)	65.1 (20.4)	63.4 (19.4)	66.0 (20.6)
Mean CASI score (SD)	84.8 (16.7)	94.0 (16.3)	89.5 (16.3)	93.1 (19.7)	92.8 (21.9)	92.6 (21.6)

CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index; CG, control Group; EG, experimental Group; SCB, Scale of Caregiver Burden; SD, standard derivation.

Table 4 Differences in mean scores between groups at the three evaluation moments

Evaluation moments	Coping/problem-solving strategies		SCB		CADI		CASI	
	Mean difference (SD)	p	Mean difference (SD)	P	Mean difference (SD)	p	Mean difference (SD)	p
T1 → T2	-0.5 (0.2)	0.135	5.3 (1.1)	0.000	3.3 (2.5)	0.584	-4.0 (1.8)	0.124
T2 → T3	0.1 (0.1)	1.000	-4.7 (1.2)	0.002	-5.0 (3.1)	0.376	2.4 (2.2)	0.866
T1 → T3	-0.4 (0.3)	0.438	0.6 (1.4)	1.000	-1.7 (2.9)	1.000	-1.6 (2.2)	1.000

CADI, Caregiver Assessment of Difficulties Index; CASI, Caregiver Assessment of Satisfaction Index; SCB, Scale of Caregiver Burden; SD, standard derivation.

Over time, the burden levels varied in a statistically significant way between the groups (Wilks' lambda = 0.455; $F_{(2,23)} = 13.783$, $p = 0.000$), but there was no statistically meaningful relation between the burden level variation and participation in the training programme (Wilks' lambda = 0.903; $F_{(2,23)} = 1.233$, $p = 0.310$). However, there was a statistically significant disparity in the burden levels of the caregivers between the initial and final assessment and between the final assessment and the follow-up phase that did not occur between the initial assessment and the follow-up, as confirmed by Table 4.

Regarding CADI, both groups' family caregivers demonstrated high difficulty levels at the three assessment moments. In the experimental group, there was a slight decrease in the score obtained in the final assessment and a substantial increase in the follow-up period. In the control group, the score remained stable throughout the three assessment moments, as shown in Table 3. However, the difficulties faced by the caregivers in both groups did not vary in a statistically significant way over time, and the intervention effect size was reduced (Wilks' lambda = 0.455; $F_{(2,23)} = 1.407$, $p = 0.265$, partial eta squared = 0.027), as illustrated in Table 4.

Regarding CASI, the family caregivers of both groups demonstrated high levels of satisfaction at the three assessment moments. In the control group, the score value remained stable over time. In the experimental group, the score increased in the final assessment and

decreased in the follow-up, although it remained above the score obtained at the initial assessment, as shown in Table 3. There were no statistically significant differences in the satisfaction levels from the start and over time between both groups, although the effect size of the intervention was substantial (Wilks' lambda = 0.815; $F_{(2,23)} = 2.617$, $p = 0.095$, partial eta squared = 0.185), as indicated in Table 4.

As the caregiver's overload was the variable in which statistically significant values were found, in Table 5 we presented pre- and postintervention comparative results in both groups. The test power between the moments was also found to be high (0.985), but for the intervention, it was low (0.059).

Table 5 Results of the caregiver's burden pre- and postintervention

	Mean (SD)	T	p
EG (n = 12)			
SCB T1 – SCB T2	5.8 (5.6)	3.4	0.007
SCB T2 – SCB T3	6.6 (5.0)	4.4	0.001
SCB T1 – SCB T3	-0.8 (5.7)	-0.4	0.700
CG (n = 15)			
SCB T1 – SCB T2	4.8 (5.7)	3.2	0.006
SCB T2 – SCB T3	-2.7 (6.8)	-1.6	0.142
SCB T1 – SCB T3	2.1 (7.3)	1.1	0.289

CG, control group; EG, experimental group; SCB, Scale of Caregiver Burden; SD, standard derivation.

Discussion

Family caregivers who participated in the study were mostly women aged over 50 years who were the daughters or wives of the persons with dementia. These features are similar to those of caregivers in other international studies (17–22).

In the postintervention assessment, there was an increase in the number of coping/problem resolution strategies used by the members of the experimental group that remained stable during the follow-up. Although the difference was not significant, the effect size that was found suggested an important consequence of the programme applied in the improvement of the experimental group's strategies. These results were validated by other studies in the area, namely the systematic revision performed by Lopes and Cachioni (5) which proved that psychoeducational approaches lead to significant results regarding the use of coping strategies, since the family caregivers of people with dementia learn how to identify and use these strategies during the programme. The results obtained by the experimental group in this variable remained steady over time, possibly due to the analysis work of the main stress triggers/problems of each caregiver that was performed, strategies that they learned how to identify, selecting the ones that were most adaptive and applying them to everyday life. This allowed the caregiver to select the strategies that suited him/her better and to verify the results and preserve their use on a long-term basis. If a strategy worked, the caregivers would tend to preserve its implementation.

The caregivers' burden varied significantly during the intervention, decreasing in the final assessment and increasing again in the follow-up period. The positive effect of psychoeducational programmes on the burden levels of caregivers has been reported in other studies (5,23). However, the increase in the caregiver's burden over the long term might be related to the evolution of the family member's dementia and the awareness of the disease and its nuances. Some programmes featuring educational interventions achieved less positive results, such as the psychological suffering of the caregivers and the perception of the overload emanating from the knowledge about the evolution of dementia acquired by the caregivers throughout the intervention.

These results stress the importance of emotional support and the sharing of experiences that should be included in psychoeducational programmes to minimise the negative impact that an increase in the scope of knowledge might bring. With this aim in mind, the programme 'Living Together With Dementia' integrates two group sessions with the family caregivers of people with dementia. Nevertheless, psychoeducation is considered an interesting intervention to reduce the caregiver's

burden (5). Another important aspect is the fact that the programme proposes an individual approach, which seems to be particularly effective in the reduction of the caregiver's burden (24).

We also observed a decrease in the difficulties after the programme and a substantial increase at follow-up. For example, overload and difficulties were intimately related to knowledge about the disease and its progression. In our perspective, the deeper the knowledge, the higher the perception of future difficulties, which, in turn, explained the increase of the CADI score in the follow-up. The caregiver's satisfaction behaved similarly to the remaining variables evaluated. At baseline, all family caregivers demonstrated high satisfaction levels. In their study, Sánchez-Izquierdo et al (25) found similar satisfaction results. These seemed to be closely related to some aspects that promote satisfaction with the act of providing care, such as perceiving and addressing this fact as a way to give life meaning, or the existence of a previous positive relationship between the caregiver and the person to whom care is being delivered. In the present study, almost all caregivers referred to a good previous relationship with the person with dementia, which could have contributed to a positive vision of the act of providing care and a higher satisfaction level. Another aspect that seems to influence the caregiver's satisfaction was the dependence level of the person with dementia; there are studies that prove that the satisfaction levels decrease as the level of dependence of the person with dementia increases (25). The present study focused on people at an early or moderate stage of dementia who thus still demonstrated a reduced level of dependence, which positively influenced the caregiver's satisfaction. As time progressed, the satisfaction levels of the caregivers in the experimental group tended to decrease, since the burden and difficulties inherent to the provision of care increased.

The obtained results suggested the importance of continuously and strongly supporting the family caregivers of people with dementia after the programme to monitor the overload and difficulty levels, aiding in the adjustment of daily care provision to the person with dementia and fulfilling their needs. Moreover, a Facebook page was created at the end of the programme with the aim of providing a platform where caregivers could share their concerns and information and not lose contact, although this strategy was not enough to ensure support to the caregivers. In the final study, it will be paramount to ensure that the contact among them is more effective, by means of home visits or phone contact.

Strengths

The psychoeducational programme 'Living Together With Dementia' might be an asset to train family caregivers

living at home. The programme produced positive effects in the burden, satisfaction, difficulties and coping/problem resolution strategies of the caregivers. The fact that the programme featured an individual approach allowed an adjustment of the intervention to the context and experiences of each caregiver, thus increasing its potential efficacy. This study presented an answer to the lack of training programmes for family caregivers of people with dementia implemented and assessed in the Portuguese context; moreover, this was a programme built, validated and implemented by mental health and psychiatry nurses.

Another positive aspect of the study was the high acceptance of it by the caregivers, which makes clear that the participants considered the programme interesting and useful for their needs. The caregivers who did not choose to participate in the study ($n = 21$) emphasised their willingness to participate. However, they declined to participate for economic reasons, as the programme demanded weekly travel to the hospital where the study was being performed. In our perspective, such a constraint could be approached by the application of the programme in the home context, where we believe the results could be more substantial.

Limitations

The main limitation of this study was the reduced sample size, which narrowed the mainstreaming of the results. To predict the necessary sample to perform the final study, G*power 3.0 (26) was used. Therefore, making use of ANOVA: repeated measures in the within-between interaction (95%, $p = 0.05$) and estimating an average effect size (0.06) for the intervention, a sample size larger than 42 caregivers will be required to perform the final study.

Another noteworthy limitation was the fact that the programme was applied by one professional alone, which might have had an influence on the obtained results. Another possible limitation was the fact that family caregivers in experimental group had more contact sessions with the nurse may have contributed towards the significance of the intervention compared with control group findings. Last, it should be noted that the instruments used to assess family caregivers were self-completed forms, which might have led to a distortion of the questions or misunderstanding that might have influenced the assessment.

Conclusions

Notwithstanding these disadvantages, this study promoted a preliminary assessment of the programme

'Living Together With Dementia' and allowed us to provide a positive answer to the previously advanced hypothesis, which is that family caregivers who were part of the experimental group added, after the programme, more coping/problem resolution strategies, had lower burden levels and difficulties as well as greater satisfaction. However, it was not possible to obtain statistically robust results, probably due to the reduced size of the sample. It is important, therefore, to develop the final study of the programme, integrating the findings arising from the present pilot study.

Given both the global and Portuguese contexts, we believe that this programme helps fill a void in the assistance process for family caregivers of people with dementia living at home and therefore could be used as a guideline for intervention by mental health and psychiatry nurses. In the near future, it will be essential to perform a final study of this programme and test it in a home care environment, where we believe it can achieve more substantial results for these caregivers.

Acknowledgements

This article was supported by FEDER through the operation POCI-01-0145-FEDER-007746 funded by the Programa Operacional Competitividade e Internacionalização – COMPETE2020 and by National Funds through FCT – Fundação para a Ciência e a Tecnologia within CINTESIS, R&D Unit (reference UID/IC/4255/2013).

Conflicts of interest

No conflicts of interest.

Author contributions

Lia Sousa – Principal investigator – application of the intervention programme and writing of the article. Carlos Sequeira and Carme Ferré-Grau – Co-investigators, advisors and reviewers of the article. Luís Graça – Co-investigator and reviewer of statistical analysis.

Ethical approval

Approved by Health Ethical Commission of the hospital center in September 2015 – CES 177-15.

Funding

Investigation without funding.

References

- 1 HelpAge International. *Ageing in the 21st Century: A Celebration and a Challenge*. [Web page]. 2017, HelpAge International, London.
- 2 Alzheimer's Association. Alzheimer's disease facts and figures. *Alzheimers Dement* 2013; 9: 208–45.
- 3 PORDATA. *Índice de Envelhecimento*. [web page]. 2017, PORDATA, Lisboa.
- 4 Clipp E, George L. Dementia and cancer: a comparison of spouse caregivers. *Gerontologist* 1993; 33: 534–41.
- 5 Lopes L, Cachioni M. Intervenções psicoeducacionais para cuidadores de idosos com demência: uma revisão sistemática. *J Bras Psiquiatr* 2012; 61: 252–61.
- 6 Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003; 18: 250–67.
- 7 Sousa L, Sequeira C, Ferré-Grau C, Neves P, Lleixà-Fortuño M. Training programmes for family caregivers of people with dementia living at home: integrative review. *J Clin Nurs* 2016; 25: 2757–67.
- 8 Sousa L, Sequeira C, Ferré-Grau C, Neves P, Lleixà-Fortuño M. Characteristics of a training programme for family caregivers of a person with dementia living at home. *RPESM* 2016; 3: 33–38.
- 9 Sousa L, Sequeira C, Ferré-Grau C. 'Living together with Dementia' – conceptual validation of training programme for family caregivers: Innovative practice. *Dementia*. 2018; 1: 1–10.
- 10 Sousa L, Sequeira C, Ferré-Grau C, Neves P, Lleixà-Fortuño M, Monteiro A, Meireles J, Pinto M, Gomes T. Living Together With Dementia": training programme for family caregivers – a study protocol. *Porto Biomedic J* 2017; 78: 1–5.
- 11 Moher D, Schulz K, Altman D. The CONSORT statement: revised recommendations for improving the quality of reports of parallel-group randomized trials. *Lancet* 2001; 357: 1191–94.
- 12 Sequeira C. *O aparecimento de uma Perturbação demencial e suas repercussões na Família*. 2007, Tese [Doutoramento em Ciências de Enfermagem] - Instituto de Ciências Biomédicas, Universidade do Porto, Porto.
- 13 Brito L. *A saúde mental dos prestadores de cuidados a familiares idosos*. 2000, Quarteto Editora, Coimbra.
- 14 Guerreiro M, Silva A, Botelho M, Leitão O, Castro-Caldas A, Garcia C. Adaptação à população portuguesa da tradução do Mini Mental State Examination. *R Portuguesa Neurologia* 1994; 1: 9–10.
- 15 Garrett C, Santos F, Tracana I, Barreto J, Sobral M, Fonseca R. Avaliação clínica da demência – Tradução em português. In *Escalas e Testes na Demência*. (Mendonça A, Guerreiro M eds), 2008, Grupo de Estudos de Envelhecimento Cerebral e Demência, Lisboa, 15–30.
- 16 Marôco L. *Análise Estatística – com o PASW Statistics*. 2010, Pêro Pinheiro: ReportNumber.
- 17 Boise L, Congleton L, Shannon K. Empowering family caregivers: the powerful tools for caregiving program. *Educ Gerontol* 2005; 31: 573–86.
- 18 Chien W, Lee I. Randomized controlled trial as a dementia care programme for families of home-resided older people with dementia. *J Adv Nurs* 2010; 67: 774–87.
- 19 Ducharme F, Lévesque L, Lachance L, Kergoat M, Legault A, Beaudet L, Zarit S. Learning to become a family caregiver – Efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *Gerontologist* 2011; 51: 484–94.
- 20 Hepburn K, Lewis M, Tornatore J, Sherman C, Bremer K. The savvy caregiver – the demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *J Gerontol Nurs* 2011; 33: 30–36.
- 21 Judge K, Yarry S, Orsulic-Jeras S. Acceptability and feasibility results of a strength-based skills training program for dementia caregiving dyads. *Gerontologist* 2009; 50: 408–17.
- 22 Samia L, Hepburn K, Nichols L. Flying by the seat of our pants: what dementia family caregivers want in an advanced caregiver training program? *Nurs Health Sci* 2012; 35: 598–609.
- 23 Chien L, Chu H, Guo J, Liao Y, Chang L, Chen C, Chou K. Caregiver support groups in patients with dementia: a meta-analysis. *Int J Geriatr Psychiatry* 2011; 26: 1089–98.
- 24 Beinart N, Weinman J, Brady R. Caregiver burden and psychoeducational interventions in alzheimer's disease: a review. *Dement Geriatr Cogn Disord* 2012; 2: 638–48.
- 25 Sánchez-Izquierdo M, Prieto-Ursúa M, Caperos J. Positive aspects of family caregiving of dependent elderly. *Educ Gerontol* 2012; 41: 745–56.
- 26 Faul F, Erdfelder E, Lang A, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behav Res Methods*. 2007; 39: 175–91.