

Persistent and delayed effects of a psycho-educational program for family caregivers at disclosure of dementia diagnosis in a relative: a six-month follow-up study

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Abstract

Background: Disclosure of a relative's dementia diagnosis marks the family member's official entry into the caregiver role, yet caregivers seldom receive support at this early stage in order to facilitate transition. This study (2008–2011) sought to evaluate whether positive effects observed at completion of a psycho-educational program persisted and whether any delayed effects emerged six months later.

Methods: French-speaking primary caregivers of relatives diagnosed with dementia in the past nine months were recruited at memory clinics in Quebec (Canada). The 97 participants were blindly assessed using standardized measures before randomization to the experimental or the control group and were evaluated at program completion and six months later on outcomes associated with a healthy role transition.

Results: Compared with controls, caregivers in the experimental group at both time points were better able to plan for the future care needs of their relative ($p=0.05$), made greater use of the coping strategy of reframing ($p=0.05$), experienced less psychological distress ($p=0.05$), had better knowledge of available services (those with low and moderate knowledge at baseline ($p=0.001$ and $p=0.01$, respectively) and tended to be more efficacious in their caregiver role ($p=0.06$). No persistent effect regarding preparedness or confidence in dealing with caregiving was observed, and no delayed effect was observed for stress-management coping strategies or informal support family conflicts.

Conclusions: Intervention at career onset is key to fostering a healthy caregiver role transition. Greater emphasis should be placed on developing skills concerning non-significant outcomes. This trial was not registered.

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Introduction

More than 15 years ago, Aneshensel et al. [1] referred to the long trajectory of caring for an individual with dementia (IWD) as the “caregiver career”. This trajectory comprises three main stages: role acquisition, role enactment, and role disengagement. According to these authors, disclosure of the relative’s dementia diagnosis confirms the irreversibility of the illness and marks official entry into the stage of caregiver role acquisition.

The few descriptive studies that investigated this first stage of the caregiver career have revealed that novice caregivers must acquire certain skills and resources in order to adapt to the changing behaviors and cognitive abilities of a relative with dementia. These include learning new communication strategies, becoming familiar with available formal services, and planning for relative’s future care needs [2,3]. However, results from selected studies [4,5] and from systematic reviews of the literature [6,7] have indicated that caregivers receive little information about dementia, its prognosis and available services at the time of diagnosis. Research has found also that caregivers experience a loss of informal support in this early period [4,5] and express the need to learn how to discuss how care responsibilities should be shared among family members [2].

The literature emphasizes [7-9] that those entering the caregiver role have a pressing need for supportive intervention. However, relatively few interventions have been offered at the outset of the caregiving career. Indeed, new caregivers have seldom had the opportunity to benefit from a proactive approach that prepares them to meet the demands of caregiving and thus perhaps lessens any build-up of physical and emotional strain.

Against this background, we developed a psycho-educational intervention program titled “Learning to Become a Family Caregiver” (LBFG). The program [2] is based on the theoretical framework of transition developed by Meleis et al. [10]. In this model, the role of health professionals is to facilitate transitions, which are conceptualized as the passage from one state or condition to another. Empirical work revealed that a healthy role transition, such as the passage towards the role of family caregiver, is characterized by the acquisition of new skills and a sense of self-confidence and self-efficacy in dealing with situations. It is also characterized by the acquisition of

knowledge concerning relevant formal services and the establishment of satisfactory relationships with informal social support networks.

In accordance with this theoretical perspective, the central objective of the LBFC program is to foster the acquisition of the knowledge and skills that are required to ensure a healthy transition to the caregiver role following disclosure of a diagnosis of Alzheimer’s disease. The program emerged from the needs expressed by caregivers in a qualitative study and has been validated with caregivers using a participatory approach [2]. The program consists of seven weekly individual sessions lasting 90 minutes each that cover the following topics: caregiver perceptions of the care situation; coping strategies for dealing with difficulties and averting emotional turmoil; how to communicate and enjoy time spent with the ill relative; how to use one’s strengths and experiences to take care of the relative; how to get family and friends to help; knowledge of services and how to ask for them; and planning ahead for the future [2].

The efficacy of the LBFC program was evaluated in an experimental study with pre- and post-program assessments [11]. Indicators of a healthy role transition drawn from the theoretical model [10] were selected to measure outcomes. The results revealed that caregivers in the experimental group immediately after program completion felt better prepared to provide care and be more self-efficacious in their caregiver role, had significantly greater confidence in dealing with caregiving situations, were better able to plan for the future care needs of their relative, had better knowledge of available services for their relatives, made more frequent use of the coping strategies of problem solving and reframing, and experienced less psychological distress, compared with controls benefitting from regular care. However, the program had no significant effect in three areas: use of stress-management coping strategies, support received from family networks, and family conflicts.

Although these findings were encouraging, we did not know whether caregivers continued to use the knowledge and skills they acquired from the program (persistent effect) and whether other benefits might have emerged over time (delayed effect). The notion of delayed effects refers to the fact that caregivers might need some time to put into practice certain skills proposed in interventions, which could explain

why improvements in some outcomes become apparent only later [12].

To date, there has been little follow-up regarding the few empirical investigations of early intervention with caregivers, and little is known about their persistent and delayed effects. Previous studies with caregivers of IWD in the later stages of dementia have reported delayed effects on well-being outcomes at five or eight months post-program, and particularly on psychological distress [13,14]. Therefore, we conducted a follow-up evaluation six months after completion of the LBFC program. A six-month period seemed appropriate for caregivers to learn and practice abilities that require more time to emerge. More particularly, we sought to answer two questions: (1) did the positive effects of the early-stage LBFC program persist six months later? And (2) did the program have any delayed effects on targeted indicators for which no significant inter-group differences emerged immediately after program completion?

Methods

Design and hypotheses

This multisite experimental study was carried out from September 2008 to October 2011 in Quebec, Canada, with a cohort of French-speaking caregivers. The participants were recruited in two metropolitan regions from four cognition (memory) clinics by a designated professional in each clinic, who was blind to the intervention. The participants' relatives had been diagnosed with Alzheimer's disease by geriatricians and neurologists working in the clinics, who were also blind to the intervention. Caregivers in the experimental group (EG) attended our program and those in the control group (CG) received usual care, which consisted of being referred to local community services and follow-up medical visits for dementia medication. The caregivers were assessed two weeks prior to the start of the program (baseline), before being randomized to either group. In order to avoid group imbalance, randomization to the EG or CG was carried out within the two participating regions and stratified according to the two following criteria: kinship tie to cared-for relative (e.g., spouse, daughter or other) and sex of caregiver. These criteria were applied because they have been associated with psychological distress and have been considered in

previous randomized studies, such as the largest U.S. study of caregivers [15,16]. Minimization was used as this technique is particularly suited to the stratified allocation of study participants [17]. Caregivers were also interviewed immediately at program completion (post-test) and six months later (follow-up). Prior to the baseline interview, each caregiver signed a study participation consent form approved by the research ethics committee of the *Institut universitaire de gériatrie de Montréal* (ID MP – IUGM – 08 -0020). The committee approved the multisite project after consulting with the various cognition clinics involved in the study.

We hypothesized that EG caregivers would maintain at follow-up the positive outcomes identified immediately at program completion (post-test). Regarding delayed effects at follow-up, we hypothesized that, EG caregivers would: make more frequent use of stress-management coping strategies; receive support from their family network more often; and have fewer family conflicts regarding the care situation.

Sample

The participants were primary caregivers (spouse or offspring) who self-defined themselves as the main person responsible for a relative aged 65 or older who had been diagnosed with Alzheimer's disease in the past nine months and lived at home. Caregivers who were receiving psychotherapy or participating in a support group at the time of recruitment were excluded. All the caregivers recruited from the cognition clinics (n=167) agreed to receive a phone call from the project coordinator, whose task was to explain the study and solicit their participation. Thirty-four (20%) of the caregivers contacted by the coordinator refused to take part, mainly due to lack of time. Chi-squared analyses of sociodemographic characteristics revealed that men (mostly husbands) constituted a significantly higher percentage of the refusers than of the participants. There were no other significant inter-group differences. Regarding attrition, 19 (24%) caregivers in the EG and 17 (32%) in the CG dropped out of the study between baseline and follow-up for a variety of reasons (Fig. 1). There was no significant difference in attrition rate between the two groups.

Ultimately, 97 caregivers took part in the study, with 61 in the EG and 36 in the CG (Fig. 1). The two

groups were unevenly split deliberately in order to facilitate longitudinal follow-up. Specifically, we planned to subject half of the EG to a booster session of our program and to evaluate its efficacy (study in progress). According to Cohen's criteria [18], our sample size enabled detection of a large program effect with statistical power of 80% and an alpha error of 5%, taking into account a correlation coefficient of 0.5 between measurement times. This calculation was performed using GPower3 statistical software [19].

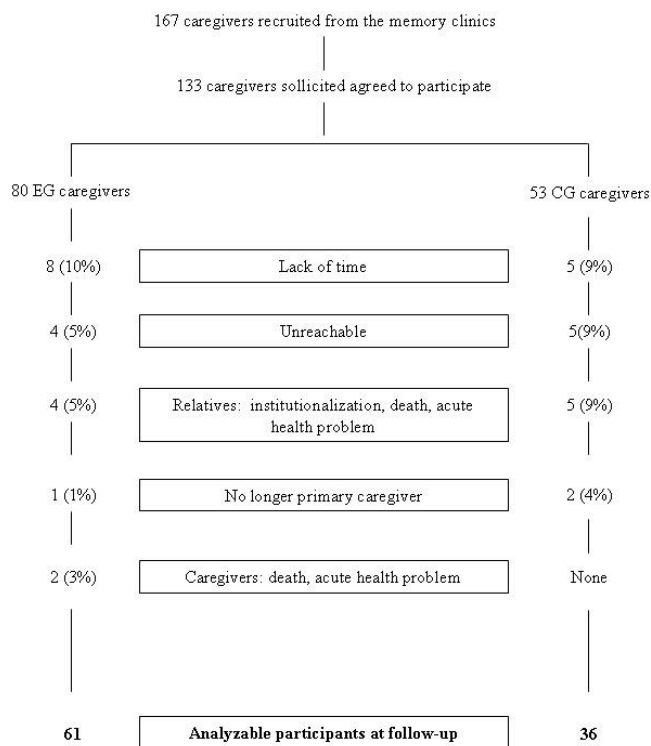


Figure 1. Flow of participants through study

Measurements

All measures used were standardized instruments with proven sensitivity to change over time, which were employed in previous longitudinal studies of caregiving. Their original English-language versions were translated into French following a parallel back-translation procedure [20]. The measures are briefly described below [11].

Preparedness for caregiving. The 8-item Preparedness for Caregiving Scale [21] measures the degree of caregiver preparedness to care for the relative with dementia (e.g., “How well prepared do you think you

are to take care of your family member’s emotional needs?”). The choice of responses ranges from 1 (not at all prepared) to 5 (very well prepared). The baseline alpha coefficient (BAC) was 0.84 with a 95% confidence interval (CI) of 0.78-0.88 and the follow-up alpha coefficient (FAC) was 0.86 (95% CI: 0.81-0.90).

Confidence in dealing with caregiving situations. The Self-Efficacy Scale [22] was used to measure this outcome (BAC of 0.89 with 95% CI: 0.86-0.92; FAC of 0.91 with 95% CI: 0.89-0.94). The scale comprises 15 items on which caregivers rate their level of confidence in dealing with caregiving situations (e.g., dealing with your need to maintain most of your daily activities). The choice of responses ranges from 1 (not at all confident) to 5 (extremely confident).

Self-efficacy. We used the Revised Scale for Caregiving Self-Efficacy [23] for this purpose. Unlike the Kuhn and Fulton [24] measure, this scale evaluates caregiver capacity specifically, in terms of obtaining respite from family and friends (5 items; e.g., asking a friend or family member to stay with your relative for a day when you want to take a break), controlling disturbing thoughts about the caregiver role (5 items; e.g., unfairness of having to manage this caregiving situation), and responding to the relative’s disruptive behaviors (5 items; e.g., responding without raising your voice when your relative interrupts your activities repeatedly). Respondents mark their degree of self-efficacy on an analog scale from 0 (absolutely incapable) to 100 (fully capable). Pearson’s correlation coefficients between the overall scale and the three specific dimensions investigated ranged from 0.68 to 0.75 (BAC for the total scale of 0.86, with 95% CI: 0.82-0.90; FAC of 0.90 with 95% CI: 0.87-0.93).

Planning for relative’s future care needs and knowledge of formal services. We used the Planning for Future Care Needs Scale [24] to assess decisions made by the caregiver in order to meet the ill relative’s future care needs (6 items; e.g., “I have compared different options of help or care in the future and have decided which would work for me and which would not.”). We also used the Knowledge of Services Scale [24] to assess how familiar caregivers were with services (7 items; e.g., “I know which home healthcare agencies are active in my area.”). The choice of responses was the same for the two scales, ranging from 1 (not at all true of me) to 5

(completely true of me). In terms of planning for the relative's future care needs, the BAC reached 0.86 (95% CI: 0.81-0.90) and the FCA 0.85 (95% CI: 0.80-0.90). The BAC for knowledge of services was .89 (95% IC: 0.86-0.92) and the FAC reached 0.90 (95% IC: 0.87-0.93).

Coping strategies. The Carers' Assessment of Managing Index [25] was used to assess the frequency of utilization (1 = never/almost never to 4 = very often/always) of three coping strategies: problem solving (14 items; e.g., "Thinking about the problem and finding a way to solve it"), reframing (14 items; e.g., "Realizing that the person you care for is not to blame for the way they are"), and managing symptoms of stress (9 items; e.g., "Setting a little free time aside for yourself"). Some items were removed (one each for problem solving and reframing and five for managing stress) to obtain a BAC of 0.70 (95% CI: 0.60-0.78) and a FAC of 0.81 (95% CI: 0.81-0.75) for problem solving. The BAC and FAC for reframing were 0.77 (95% CI: 0.69-0.83) and 0.81 (95% CI: 0.75-0.86), respectively. For stress management, the BAC was 0.48 (95% CI: 0.29-0.63), but the FAC reached 0.73 (95% CI: 0.62-0.81).

Informal social support. In order to determine the frequency of support from family, friends and neighbors that was received by caregivers (excluding the relative with dementia), we used the 27-item Inventory of Socially Supportive Behaviors [26]. This instrument covers emotional support (e.g., expressing interest in caregiver), informational support (e.g., indicating a person to see in order to obtain help), and instrumental support (e.g., providing caregiver with transportation). A total score is obtained by averaging out the ratings for individual items (ranging from 1 never/almost never to 4 very often/always). The BAC was 0.86 (95% CI: 0.81-0.90) and the FAC reached 0.87 (95% CI: 0.83-0.91) for the whole scale.

Family conflicts. The Family Caregiver Conflict Scale [27] measures the level of conflict between caregivers and family members. The 15-item instrument (BAC of 0.90 (95% CI: 0.87-0.93) and FCA of 0.92 (95% CI: 0.89-0.94) assesses disagreements over general aspects of caregiving (e.g., disagreements about some family members not doing their share to help for the relative with relative with dementia). Respondents indicate on an analog scale from 1 (not at all true) to 7 (very true) the degree to which each of the disagreements described applied to their situation

since diagnostic disclosure. The total score is obtained by averaging out the ratings for individual items (range 1 to 7).

Psychological distress. We used the Psychological Distress Index, an adapted version of the Psychiatric Symptom Index [28], to measure psychological distress. Both the French and English versions of this 14-item instrument have demonstrated sound psychometric properties [29]. Respondents rate how often (0=never to 3=very often) they felt distressed in the past week (e.g., "feeling tense or under stress"). The BAC was 0.91 (95% CI: 0.88-0.93) and the FAC was 0.88 (95% CI: 0.84-0.91).

Finally, in addition to providing sociodemographic data, caregivers completed the 8-item Cognitive Status Scale developed by Pearlin et al. [30] who reported a correlation of 0.65 between caregiver scale ratings and the Mini Mental State Examination [31] completed by professionals. Some studies have demonstrated the validity of family information regarding a relative's cognitive status [32,33]. The level of cognitive impairment of a cared-for relative is gauged on a possible score range of 0 (low) to 32 (high). The BAC was 0.77 (95% CI: 0.71-0.82) and FAC reached 0.79 (95% CI: 0.71-0.85).

Procedure

Most caregivers were interviewed by the same person at baseline, post-test and follow-up, usually at the caregiver's home. Interviews took an average of 60 to 90 minutes to complete. The interviewers received two days' training, which involved use of a guide designed by the researchers and active training methods (e.g., role playing).

To blind the interviewers to caregiver group assignment, participants were randomly assigned to the EG or CG only after the baseline interviews. At post-test and follow-up, caregivers were instructed by the project coordinator not to reveal their group assignments. The six specialized nurse clinicians who implemented the program had experience in individual intervention and knowledge of issues regarding family caregivers and care for IWD. Workbooks were developed for clinicians and caregivers; these contained documents and exercises to help put the intervention strategies discussed during each session into practice.

Program implementation fidelity was verified by two researchers using audio recordings of the sessions [11]. The clinicians also had to complete a logbook after each session to make sure the program was applied as planned. Content analysis of these logbooks was carried out independently by one researcher and the project coordinator, and revealed that the program was implemented in accordance with the initial plan.

Statistical analysis

Descriptive statistics (means, standard deviations, and percentages) were calculated in order to create a profile of the participants in the EG and CG. The sociodemographic equivalence of the two groups was then tested by running chi-squared tests on categorical variables and Student's *t*-tests on continuous variables. Student's *t*-tests were also used to determine whether outcome variables at baseline for participants in the EG were equivalent to those in the CG. When data were not normally distributed, Mann-Whitney tests were performed but the statistical conclusions remained unchanged. The homogeneity of variance was also tested and Welch's correction was applied in the case of psychological distress, as the variances were not homogeneous.

The research hypotheses were tested through repeated-measures analyses of covariance (ANCOVA). The participants' baseline results were considered as covariables in these analyses. When the Group x Time interaction terms were significant, a simple effects analysis was conducted for the group at each time to detect any significant mean change between post-test and follow-up. This approach enabled identification of differences in effects at post-test and follow-up, i.e., whether a non-significant finding at post-test became significant at follow-up (delayed effect) and whether a significant difference at post-test was no longer present at follow-up (failed maintenance of effect).

When the interaction terms were not significant, main Group and Time effects were examined. A significant Group effect indicated that inter-group mean differences were the same at both times (post-test and follow-up). In other words, the results of these analyses indicated persistent effects. A significant Time effect reflected changes over time in both groups.

Prior to running the repeated-measures ANCOVA, the homogeneity of variance-covariance matrices was assessed with Box's *M* test. Results revealed all variances and covariances to be homogeneous, except for knowledge of services and reframing. However, this test is sensitive to violations of the normality postulate. A parallelism test was also carried out to verify the homogeneity of the regression slopes for the two groups. No significant differences emerged, except for knowledge of services. In this case, the parallelism test provided significant results. Therefore, this covariable was divided into three categories (low, moderate, high) at baseline in a way that facilitated having a sufficient number of participants in each cell, as suggested by Tabachnick and Fidell [34]. The presence of outliers was checked using both univariate (*z*-scores) and multivariate (Mahalanobis distance) approaches. When remote values were deemed significant ($p < 0.001$), ANCOVA was repeated excluding the data regarding participants considered to be extreme cases. As the statistical conclusions remained unchanged for all variables, only the results for all participants are presented. The correlations among outcome variables proved moderate (coefficients did not exceed 0.50), except for confidence in dealing with caregiving situations and preparedness for caregiving ($r = 0.65$, $p < 0.001$), the coping strategies of problem solving and reframing ($r = 0.65$, $p < 0.001$), and knowledge of services and planning for relative's future care needs ($r = 0.64$, $p < 0.001$).

Results

Regarding the sociodemographic characteristics of the sample, women represented approximately 80% of the caregivers in both groups and the mean age was around 60 (Table 1). In terms of kinship with the cared-for relative, roughly 35% of the caregivers were spouses (mostly wives) and over 40% were daughters. The average time elapsed since dementia diagnosis was nearly four months. In both groups, the cared-for relatives were mostly women in their 80s. The IWDs in the CG were older than those in the EG (Table 1). Based on caregiver self-reporting, the cognitive impairment of the IWDs was no more than moderate (Table 1).

Comparisons at baseline revealed no significant mean differences between outcomes variables among EG and CG participants (Table 2).

Table 1. Comparison of sociodemographic characteristics of participants in experimental and control groups at baseline

Variable	Experimental group (n = 61)	Control group (n = 36)	Chi ²	t-test
Caregivers				
Women (%)	82.0	80.6	0.03	
Mean age in years (SD)	59.57 (11.94)	61.22 (12.45)		- 0.65
Mean no. of years of education (SD)	13.11 (3.37)	14.42 (4.02)		- 1.71
Kinship tie to ill relative (%)			2.40	
Wife	29.5	27.8		
Husband	8.2	5.6		
Daughter	49.2	41.7		
Son	6.6	11.1		
Other	6.6	13.9		
Living with relative (%)	50.8	50.0	0.01	
Mean number of months since diagnosis (SD)	3.42 (2.69)	3.47 (2.57)		0.09
Cared-for relatives				
Women (%)	57.4	69.4	1.40	
Mean age in years (SD)	78.84 (7.21)	81.94 (6.11)		- 2.17*
Mean cognitive impairment score (SD)	7.97 (4.39)	9.39 (5.39)		- 1.41

* p ≤ 0.05

Results indicated many persistent program effects, one concerned knowledge of services. As mentioned earlier, knowledge of services was divided in three categories at baseline because the parallelism test proved significant (see Covariate x Group, Table 3).

Simple effects analysis revealed that EG caregivers with little and moderate knowledge at baseline had better knowledge of services at program completion (post-test) and at six-month follow-up compared with those in the CG (F=12.97, p<0.001 and F=7.20, p<0.01, respectively). These differences explained 13 % and 7% of the variance, respectively, as gauged by the eta-squared value (data not shown). EG caregivers also showed better planning for the future care needs of relatives than CG caregivers (F=4.27, p<0.05 for group effect). These differences explained 4% of the variance as measured by the eta-squared value. There was also a time effect: regardless of group, caregivers demonstrated better planning for future care needs of relative at follow-up (F=10.57, p<0.01). This effect accounted for 10% of the variance (see Table 3).

The other persistent effects concerned the coping strategies of reframing and psychological distress (Table 3). At program completion and six months later, EG caregivers made greater use of reframing and experienced less psychological distress than CG

caregivers (4% and 5% of the variance explained respectively). EG caregivers also tended to report greater self-efficacy in their caregiver role at post-test and follow-up (inter-group mean difference, p=0.06, and 4% of the variance explained by the group effect).

Results also revealed non-persistent program effects on preparedness for caregiving and confidence in dealing with the caregiving situation (significant Group x Time interaction terms; F=8.79, p<0.01, and F=5.86, p<0.05, respectively, see Table 3). The simple effects analyses for the groups at each time indicated that preparedness and confidence decreased significantly between program completion and follow-up for the EG (F=20.93, p<0.001, and F=13.10, p<0.001, respectively: data not shown). Although there were no significant changes for the CG, the significant inter-group mean differences observed at post-test were not significant at follow-up for these two variables. The intervention had no significant effect on the coping strategies of problem solving; means at post-test and follow-up were nearly the same for both groups (Table 3).

Table 2. Comparison of outcome variables for participants in experimental and control groups at baseline

Outcome variable (possible range)	Experimental group M (SD)	Control group M (SD)	t-test
Preparedness for caregiving (8-40)	25.43 (6.44)	26.97 (6.87)	-1.11
Self-efficacy (0-100)	70.64 (14.88)	71.48 (15.45)	-0.26
Confidence in dealing with caregiving situations (15-75)	47.54 (9.75)	51.00 (9.86)	-1.68
Knowledge of formal services (7- 35)	19.21 (8.06)	20.69 (8.41)	-0.86
Planning for relative's future care needs (6-30)	15.23 (6.61)	15.19 (7.16)	0.02
Coping strategies (1-4)			
Problem-solving	2.83 (0.40)	2.89 (0.46)	-0.65
Reframing	2.83 (0.42)	2.97 (0.42)	-1.60
Stress management	2.64 (0.56)	2.80 (0.54)	-1.37
Informal support (1-4)	1.64 (0.35)	1.71 (0.35)	-1.03
Family conflicts (1-7)	2.21 (1.18)	2.10 (1.19)	0.44
Psychological distress (0-100)	24.98 (19.44)	18.92 (14.04)	1.78 ^a

a Welch's correction was applied as the assumption of homogeneity of variance was violated

Table 3. Comparison of outcome variables for participants at post-test and follow-up: ANCOVA results

Variable	Experimental group		Control group		Covariate	F-ratio			Eta-squared		
	Post-Test	Follow-Up	Post-Test	Follow-Up		Group x Time	Group	Time	Group x Time	Group	Time
Preparedness for caregiving					66.63***	8.79**	12.39***	3.35	0.09	0.12	-
M	30.75	29.44	27.17	28.47							
SD	5.19	5.14	7.32	6.45							
Self-efficacy					103.86***	1.03	3.65 [†]	0.68	-	0.04	-
M	70.94	66.82	66.12	64.55							
SD	12.20	14.51	17.53	19.09							
Confidence in dealing with caregiving situations					.56***	5.86*	6.03*	0.34	0.06	0.06	-
M	54.79	51.39	51.22	51.06							
SD	8.39	9.78	10.48	10.64							
Knowledge of formal services					105.69***	0.61	19.02***	0.04	-	0.17	-
M	26.46	26.21	22.94	23.58							
SD	5.24	6.04	8.09	8.16							
Planning for relative's future care needs					88.28***	1.01	4.27*	10.57**	-	0.04	0.10
M	18.26	19.67	15.89	18.36							
SD	6.02	5.78	7.20	6.84							
Problem solving					91.23***	0.25	1.84	2.69	-	-	-
M	2.93	2.77	2.86	2.75							
SD	0.38	0.43	0.54	0.53							
Reframing					98.76***	1.96	4.09*	0.03	-	0.04	-
M	3.05	2.94	2.97	2.97							
SD	0.36	0.43	0.41	0.46							
Stress management					71.74***	0.18	0.31	0.54	-	-	-
M	2.87	2.71	2.91	2.78							
SD	0.52	0.68	0.60	0.60							
Informal support					44.18***	0.00	1.50	1.94	-	-	-
M	1.69	1.72	1.67	1.69							
SD	0.33	0.39	0.36	0.35							
Family conflicts					131.38***	0.00	0.56	2.07	-	-	-
M	1.94	2.08	1.96	2.11							
SD	1.14	1.22	1.20	1.13							
Psychological distress					60.78***	0.18	4.03*	3.68	-	0.05	-
M	18.42	19.09	20.24	20.70							
SD	16.41	14.99	15.94	14.88							

[†] $p \leq 0.059$, * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Finally, the hypotheses concerning delayed effects were not supported. Indicators that were not significant at post-test (i.e., stress-management coping strategies, frequency of informal support and conflicts over the care situation) were not significant at follow-up either (Table 3).

Discussion

The aim of this study was to evaluate whether positive effects observed at completion of the LBFC program persisted and whether delayed effects emerged at follow-up six-months later. Regarding persistent effects, the results indicated that the LBFC program provides sustained benefits. Compared with the CG caregivers, those in the EG who began with little or moderate knowledge continued to have more knowledge of available services, to have more plans for their relative's future care needs, to resort more

frequently to the coping strategies of reframing, and to experience less psychological distress. EG caregivers also tended to continue to perceive greater self-efficacy regarding their caregiver role (inter-group mean difference close to significance level, $p=0.06$).

These significant findings can be explained by the specific characteristics of the program. Using a temporal approach to caregiving, the program focuses on a particular point in time: the onset of the caregiver career. It also employs an inductive approach to identify the specific needs of caregivers from their own perspective during the transition period of role acquisition. Despite the fact that the program is comprised of seven sessions, the retention rate was high (only three caregivers (5%) in the EG dropped out), which suggests that the program engages caregivers by focusing on issues that are important to them. One of our more salient findings is that caregivers in the EG experienced less psychological distress at post-test and follow-up than those in the CG. This is particularly interesting because many

psycho-educational intervention programs have not produced such an effect [35]. The timeliness of our intervention might explain this finding. Offering early intervention at the outset of the care trajectory rather than when caregivers are burned out, might make it easier to provide relief from psychological distress. The frequent use of reframing strategies might also have contributed to reducing levels of distress. The findings do not allow us to determine whether reframing precedes or follows psychological distress. However, from a theoretical point of view, there are reasons to believe that the use of the emotion-focused strategy of reframing is helpful for managing feelings of distress. According to stress theory [36,37] and cognitive-behavioral models of depression [38], reframing strategies (cognitive restructuring) can replace negative thoughts that generate painful emotions detrimental to caregivers' psychological well-being with more positive thoughts that attenuate painful emotions. For example, in our program, caregivers are invited to focus on the abilities of their relatives and to spend pleasant moments with them, rather than dwell on their disabilities. They are also encouraged to view their relatives' disturbing behavior as a consequence of their illness rather than as an expression of ill will or stubbornness. The finding that EG caregivers continued to have more knowledge about available services does not necessarily mean that these caregivers will actually use these services. Indeed, it has been shown that use of support groups by caregivers of demented relatives was not associated with knowledge of services or counseling [39,40].

Our results also reveal non-persistent program effects on certain outcomes. Preparedness to provide care and confidence in dealing with caregiving situations diminished for EG caregivers. It may be that deciding how much to do for a cared-for person and how to provide emotional support grows more difficult and painful over time. With regard to the coping strategy of problem solving, mean scores were similar for the EG caregivers at post-test and follow-up. EG caregivers might have put reframing into practice more than problem solving in order to attenuate the emotional turmoil associated with finding out that their relatives had Alzheimer's disease.

Regarding delayed effects, we found no evidence of change at follow-up in terms of stress-management coping strategies, informal support, and family conflicts over care situations. The low alpha

coefficients, particularly at baseline, might explain the results regarding stress-management coping strategies. With regard to informal support, it is possible that caregivers do not feel the need to call upon family or friends early in the trajectory or are reluctant to ask others for help for fear of being perceived as incompetent [41]. These findings suggest that greater emphasis should be placed on these skills, or that a different approach should be used to develop them. This issue warrants further exploration. As caregivers reported few family conflicts at baseline, a ceiling effect might have been involved here; this meant that EG caregivers had little room for making significant improvement from the start. Indeed, at the outset of the caregiving career, caregivers may simply have very few conflicts with family members.

Overall, it is difficult to compare our results with the literature because other intervention studies did not specify where caregivers were in their caregiving trajectory [13,14,16,42]. An international meta-review of interventions for caregivers [43] revealed that these had a modest effect on various indicators of caregiver health and quality of life.

Our study had some limitations. It focused exclusively on caregivers who had been informed of the diagnosis by geriatricians or neurologists working in memory clinics. Role transition may differ for caregivers informed in a different manner. Furthermore, the reception of the diagnosis constituted an inclusion criterion for the study. Although this criterion normally marks the official start of the caregiving trajectory, some caregivers might delay seeking a diagnosis because they fear learning that their relative does indeed have Alzheimer's disease. In such cases, the role of caregiver might be assumed well before an official diagnosis is formulated. The standard deviation for the cognitive impairment score suggests that the relative's impairment might have been greater at the start of the study for some caregivers. Finally, despite the fact that there was no significant difference in attrition rate between the two groups, the uneven number of participants in the EG and CG may have influenced the results. Despite these limitations, the study was conducted with caregivers recruited through different memory clinics and in different geographical regions, thereby increasing the chances of forming a diversified sample and improving the generalizability of the findings.

Our intention was to give due consideration to novice caregivers whose needs for support are overlooked. We too frequently assume that novices face fewer demands than caregivers further along the caregiving career trajectory, because relatives require much more assistance with daily living activities as their condition worsens. This focus on the functional state of the relative means that novice caregivers' needs, which are primarily emotional rather than instrumental, do not receive sufficient attention [41,44]. Given the persistent effects of the program, we believe that this innovative intervention offers concrete avenues for implementing new practices to support caregivers following diagnostic disclosure. In their critique of the UK National Strategy consultation document [45], Stokes et al. [44] recommended that specialized care managers should follow up on caregivers after diagnosis disclosure. They underlined that the role of health practitioners following diagnosis consisted of much more than merely "signposting people to services" [44] and that caregivers require emotional support. In this regard, some authors have reported a lack of supportive follow-up after diagnosis [7,46]. Health professionals should seek to identify caregivers who seem reluctant to receive support, as these could be the ones who will struggle most with the caregiver role transition. Given that more men than women refused to participate in this study, health professionals should also pay special attention to male caregivers, who may see accepting support as an admission that they lack the competence to fulfill their new role as a caregiver [47,48].

Overall, our program proposes concrete steps to help novice caregivers acquire the skills and knowledge to cope with caregiving situations with greater predictability while minimizing emotional turmoil.

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