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Research Article

Influence of an Evidence Based Psychoeducational Intervention on Caregiving Appraisal - ③

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ABSTRACT

Objectives: The goal of this intervention study was to examine the influence of an individualized evidence based psychoeducational intervention on appraisal of caregivers (CGs).

Method: This pre-post longitudinal study (baseline, six, twelve and 18 months follow-up) was based on a psychoeducational intervention (Progressively Lowered Stress Threshold (PLST) model) and a NYU caregiver intervention with 125 informal caregivers of community dwelling people with dementia (PWD). Statistical analysis consisted of T-test, repeated measures Anova and Linear Mixed Models.

Results: Our findings identified that the intervention generally kept positive appraisal stable except for a decrease noted at 12 months. Negative appraisal experienced a slight decrease at 6 months, increased at 12 months and decreased below baseline levels at 18 months. In the Linear Mixed Models, caregivers' increased reaction to behavioral and psychological symptoms of dementia was associated with negative appraisal over time. Greater positive social support was associated with less negative appraisal over time. Greater negative social support was associated with greater negative appraisal over time.

Discussion: Practitioners need to incorporate specific individualized content to aid adjustment based on PWD and caregiver needs. Booster sessions offering content to decrease caregiver's upset reactions to BPSD, increase positive support, and decrease negative support might be incorporated shortly after 6 months but definitely before 12 months to improve positive appraisal and decrease negative appraisal of caregiving.

Keywords: Alzheimer's disease; Caregiving appraisal; Progressively Lowered Stress Threshold; NYU caregiver intervention

INTRODUCTION

Over 46.8 million people suffer from dementia worldwide [1] and in the US one in eight suffer from Alzheimer's Disease (AD), the sixth leading cause of death [2,3]. Dementia Caregivers (CGs) may experience burden due to the increased Behavioral and Psychological Symptoms of Dementia (BPSD). Apathy, depression, irritability, agitation and anxiety are the most prevalent BPSD [4]. Estimated rates of BPSD have ranged between 61% and 88% for PWD living in the community [5]. In particular, CGs find care tasks difficult because of the unexpected behaviors that may emerge in dementia and that are difficult to manage, a problem that may be a critical predictor of the PWD's institutionalization [6]. Improving targeted care strategies may reduce negative consequences of caregiving, thus delaying more costly nursing home care. Positive aspects of caregiving are of increasing interest in the literature [7]. A better understanding of the full range of the caregiving experience includes greater appreciation for both negative and positive aspects including possible benefits of caregiving. Findings identify that differences by race, gender and caregiving relationship can shape the caregiving experience. For example, Lin, Fee, and Wu [8] identified that wife caregivers were least likely to report positive experiences. Female and adult - child caregivers (e.g., daughter) reported having more negative caregiving experiences compared to male and spouse caregivers. Roth et al. [7] found different risk factors for negative caregiving aspects (PWD problem behavior and increasing dependency) than for positive aspects of caregiving (reciprocal support was helpful for different caregiver subgroups). Despite scientific evidence of positive effects from implementation of psychoeducational service programs, development and testing of caregiver interventions and health care services has lagged behind other research efforts such as those to find a cure for dementia, develop pharmacological interventions or to explore preventive strategies to slow the onset of cognitive decline [9]. The 2017 update of the National Alzheimer's Plan Act (NAPA), calls for ongoing care planning and testing of effective CG interventions that include benefits to PWD as well as listening to the voices of PWD themselves and family members regarding care needs of the dyad [10]. Given the long disease trajectory and the fact that most PWD live and age at home in their communities, implementing approaches to improve outcomes for this population

is of the utmost importance [11]. Burden has historically been used as an important outcome in many caregiver intervention studies [12]. A more recent caregiving focus is on both positive outcomes (e.g., a feeling of gain or gratification) and negative outcomes (e.g., burden) [13]. In 1995, the National Institute of Nursing Research and the National Institute on Aging established the Resources for Enhancing Alzheimer's Caregiving Health (REACH) project. This project revealed the importance of understanding both the positive and the negative aspects of caregiving and fostered the development of new measures for the positive aspects of caregiving. Thus positive appraisal scales are encouraged for evaluation of at least one outcome in caregiving interventions [14] as measured in this study using the Philadelphia Geriatric Caregiving Appraisal Scales. Home based caregiver and PWD intervention studies can be successful. In an international literature review, Gallagher-Thompson et al. [15] identified 159 non-pharmacological best practices for family caregivers of PWD that are ready to be implemented and enact into dementia policies. Another systematic review of research on home-based interventions designed to improve quality of life for PWD [11] identified key elements of interventions that demonstrated successful outcomes with clinical importance to PWD: theory based, had been pilot tested before implementation, emphasized skill building, and tailored their strategies to identified needs of CGs and PWD. Interventions that were successful in delaying time to nursing home admission also achieved benefits of decreasing BPSD and increasing CG support [16]. No adverse events were reported with any of the non pharmacological interventions; thus they are low to no risk, feasible to implement, and acceptable to PWD and their families [17]. Several multiple component interventions identified in literature reviews were effective in teaching caregivers to cope with high levels of burden and also delayed institutionalization [18,19]. Additionally, when interventions were implemented based on individual needs assessment caregivers received greater benefits [18,3]. Most intervention studies look at outcomes related to reducing negative aspects of caregiving rather than measuring positive aspects associated with caregiving. Additionally, immediate, rather than long term outcomes related to caregiving and its appraisal are their main focus. Thus, the long-term benefits of many caregiver interventions may be difficult to determine. A recent literature review by Gitlin and colleagues [11] identified very few studies (6%) that assessed for long

term benefits, with most studies using a 12 month post- intervention follow up period. The purpose of the current study was to examine the influences of an individualized psychoeducational intervention on both positive and negative appraisal of caregivers of PWD over an 18 month period. The following Research Questions (RQs) were investigated:

RQ1: Which subgroups of caregivers at baseline (race, gender, education, relationship and financial status) reported the highest positive and negative appraisal (as measured by summary negative and positive appraisal scores)?

RQ2: What was the influence of the intervention on positive and negative appraisal over an 18 month period?

RQ3: Which subgroups of caregivers benefitted most from the intervention?

This article on the influence of an individualized psychoeducational intervention on positive and negative caregiving appraisal is one aspect of a larger report on outcomes of the intervention. The larger study has yielded information focused on two outcomes: depression [20] and behavioral symptoms in PWD and symptom response in CGs [21]. Results identified a slight decrease in depression scores over the 18 month followup period ($p = .002$) as well as a significant decrease in frequency of behavioral symptoms between baseline and 6 month followup. Findings reported an overall significant decrease in caregiver reaction to behavioral symptoms from baseline to 18 month followup. The outcome related to caregiving appraisal has not been previously reported.

Conceptual Framework

The first part of the intervention, teaching behavioral management to family CGs, was based on content derived from the Progressively Lowered Stress Threshold (PLST) model and prior national and international research using the model over the past 30 years. The model [22] proposes that because of declines in cognitive and functional abilities, PWD need environmental demands modified, resulting in decreased internal and external stress. Reducing stress caused by these demands can enhance functional adaptive behavior. Interventions based on the PLST model have reduced CG burden, impact and depression [23,24] and enhanced CG satisfaction, as well as reduced behavioral symptoms [25] over time. The PLST model has been identified as one of two effective psychological interventions for the treatment of behavioral symptoms in dementia [26]. Development of the PLST approach was grounded in the stress and coping model [27], suggesting that CG well-being is affected by both primary stressors originating in the illness or care of the PWD (such as Behavioral and Psychological Symptoms of Dementia (BPSD) and environmental stressors. Individualized ongoing plans of care based on the PLST model content provide environmental modifications grounded in Lawton's Person-Environment Fit Model [28] because of declining cognitive/functional abilities. Thus stress is reduced and functional adaptive behavior enhanced. Family conflict is another environmental stressor which illustrates the need for the second component in the current intervention. The second part of the intervention also used an underlying stress process model [29], and was based on the NYU CG intervention [30] that hypothesized that improving family support and decreasing family conflict would improve the CG abilities to withstand difficulties of caregiving and defer the need for institutionalization. Another hypothesized benefit of both parts of the intervention tested here is that through ongoing education and support, the CG's positive appraisal of the PWD will

be enhanced and BPSD exhibited by the PWD minimized, thereby decreasing impact and stress. This decrease should result in improved positive support and appraisal in the caregiving situation. In this study, assessment and support with care planning occurred every 6 months over an 18-month period. The ongoing follow-up and offer to be available as needed resulted in sustained support not only for the primary CG but also for other family members. If caregivers learn active behavioral management strategies that limit negative consequences of BPSD, their perceptions of these symptoms should be less upsetting and less threatening [30]. Thus, the second component was implemented to include family education during at least one 3-4 hour family session focused on education about management of BPSD and encouragement to use community resources. The mobilized family system also enabled increased support when needed across the 18 month follow-up period. The expected outcome of the psychoeducational intervention was that CGs would report less negative appraisal and greater positive appraisal (caregiving satisfaction). The second part of the intervention was based on the New York University Intervention use of family sessions (described in more detail later) reported to be successful increasing social support and in delaying institutionalization [31]. The latter variable was not examined in this study.

Individualized Evidence Based Intervention

The aim of the psychoeducational community intervention was to provide support and education to CGs of PWD. Location for the intervention was based upon CG choice and convenience. CGs were provided individualized community education after a baseline assessment of their care situation. The intervention was then individualized to each care situation according to each CG's needs assessed during each interview. Education was provided via a module that included types of dementia, stages, symptoms, behavioral characteristics of each stage, communication, seeking help, and using community resources. Care planning was based upon prioritizing care to address the behavioral symptoms assessed as causing the most upsetting CG reactions. Targeting specific behavioral symptoms for intervention management was described by Gitlin, winter, Dennis, Hodgson and Hauck [32]. Based on PLST content, CGs were taught to decrease stressors that trigger dysfunctional episodes and sudden functional decline related to excess disability. Reduction of these stressors was expected to keep the care recipients below the stress threshold where BPSD occur. As noted earlier, the second component of the intervention included a family meeting which has been previously described [21]. Delivery of the intervention occurred in two phases with education completed first followed by a family session. Both meetings were planned within one month after the baseline interview (care planning with CG planned two weeks after baseline and family meeting planned two weeks after care planning). Ongoing maintenance and support continued after the initial intervention, with results of each subsequent assessment used to develop the 6 month follow-up care plan. Reinforcement thus occurred using an individualized care plan developed every 6 months for each caregiving situation based on behavioral responses identified as most upsetting. All caregivers received all components of the intervention. Follow-up interviews continued every six months for 18 months to reassess BPSD, develop new care plans, and reinforce education according to newly identified behavioral symptoms.

METHODS

Study Design and Eligibility

A caregiver was defined as a person who spent over 4 hours per

week providing unpaid assistance to the PWD. The primary CG self-identified as the person spending the most time caregiving among the care network. CGs were eligible for this study if the PWD had a medical diagnosis of any type of irreversible dementia, resided in a home setting outside of a nursing home facility, and lived within a geographical travel distance not to exceed one hour from the study site. Following approval from the institutional review board, data were collected by trained research assistants who were nurses or social workers employed by the School of Nursing. Subjects were CGs enrolled in a School of Nursing dementia CG program of intervention research. Referrals of CGs for the intervention research program came from a wide network of health providers, physicians, neurology and family practice clinics, support groups and by word of mouth. Caregivers expected to receive an intervention when they called to enroll in the Caregivers Program of Research. This study allowed a practical, “real world” implementation of the intervention as described by Menne, Bass, Johnson, Kearney and colleagues [33] since random assignment and a control group were not possible. The current study evaluated whether a psychoeducational intervention based on PLST content and a family meeting encouraging use of community services improved (1) positive caregiving appraisal and (2) decreased CG negative appraisal. Further exploration of which subgroups of caregivers at baseline reported the most positive and negative caregiving experiences and which caregivers benefitted the most over time after the intervention was of interest. We enrolled N = 125 dyads of caregivers /care recipients with a diagnosis of irreversible dementia and exposed CGs to the individualized psychoeducational intervention. Each caregiver received all components of the intervention. Each outcome was measured at baseline, six, twelve and 18 months follow-up to test whether the psychoeducational intervention improved outcomes over time. Caregiver records included process sheets for random checks to assure that each CG received the same components including assessments, training content, and timeline for collection of data.

Measures

The following instruments were used to measure CG appraisal, CG social support, memory and behavioral problems, and demographics.

Subjective Caregiving Appraisal (Outcomes): A 20 - item subscale of the 28 item Philadelphia Geriatric Center Caregiving Appraisal Scales (PGCCAS) was used to assess caregiving appraisal (burden, perceived negative impact, and satisfaction) from 1 = not at all to 5 = a great deal. One scale (mastery) was dropped in the current study because it was not expected to be a meaningful outcome, as confirmed in a previous study [34]. Caregiving burden is distress linked to caregiving such as worry, fatigue, guilt etc. An item example is “You are very tired as a result of caring for your loved one.” Perceived negative Impact from caregiving is the perception that caregiving has intruded upon social life, work, activities etc. An item example is “You are isolated and alone as a result of caring for your loved one”. Negative appraisal includes the two concepts of caregiving burden and perceived negative impact. On the other hand, satisfaction is the accumulation of things the CG does or feels that provide affirmation and personal satisfaction such as daily uplifting events that occur during the caregiving experience. An item is “Your loved one’s pleasure over some little thing gives you pleasure”. In the current study positive appraisal was conceptualized and measured as caregiving satisfaction (6 items, $\alpha_{\text{baseline}} = .559$) and negative appraisal was conceptualized and measured by burden and impact (14 items, $\alpha_{\text{baseline}} = .920$). The higher the score, the higher level

of the perceived negative appraisal (i.e., burden and impact). The six items of the satisfaction subscale were reversely coded. For positive appraisal, the higher the score, the higher level of perceived positive appraisal (i.e. satisfaction). The original PGCCAS four factors were confirmed in two groups, an institutionalized sample (N = 239) and a respite sample (N = 632). Test-retest reliability for 103 CGs of institutionalized people with dementia was between .75 and .78. Validity correlations indicated that subjective burden was highly related to summary burden ratings and significantly associated with all of the other indicators. Data support the validity of the indices as dimensions of caregiving [35].

Predictors: The Revised Memory and Behavior Problems Checklist (RMBPC). The RMBPC was used to identify behaviors of PWD and to determine which behaviors resulted in the most upset reaction for the CG. PWD behavioral symptoms and CG reactions were studied by asking CGs to respond to The Revised Memory and Behavior Problem Checklist (RMBPC) developed by Teri et al. [36]. The RMBPC is a 24 - item CG report measure of the frequency of and reaction to behavioral problems exhibited by the PWD. Three subscale scores and one total score was provided for frequency of behavior problems related to memory loss, depression, and disruption with corresponding measures reported for CG reaction to these three types of problems. CG reaction to PWD behavioral symptoms were scored by the degree to which the behaviors “bothered or upset” the CG: 0 = not at all, 1 = a little, 2 = moderately, 3 = very much, and 4 = extremely. Overall scale reliability for the RMBPC was reported by Teri et al. [36], with total alpha scores of 0.84 for frequency of behavior problems and .90 for corresponding CG upset reaction. Subscale alpha scores ranged from .67 to .89. For this study, one total score of the CG’s reaction score of behavioral symptoms ($\alpha = .862$) was used due to higher correlations between the frequency score and the CG’s reaction score ($r = .732$). Thus the Frequency of Behavioral Problems Scale was excluded.

Social support: The Social Provision Scale (SPS) was used to assess CG perceived social support [37]. The SPS consists of 24 items measuring positive (11 items) and negative (13 items) aspects of six provisions: guidance, reliable alliance, reassurance of worth, attachment, social integration, and opportunity for nurturance, from 1 = strongly disagree to 4 = strongly agree. Item example for perceived social support is “There are people who enjoy the same social activities I do.” Research has supported the reliability and validity of the Social Provisions Scale, as well as the factor structure of the measure. Items on the positive social support subscale were reversely coded. The higher the score, the higher level of the perceived positive social support ($\alpha_{\text{baseline}} = .755$). As for negative social support, the higher the score, the higher level of the perceived negative social support ($\alpha_{\text{baseline}} = .759$). An item example for negative social support is “There is no one I can depend on for aid if I really need it.”

Demographic data: Demographic information was collected at all data collection periods. For CGs, age, length of care (how long have you been a CG?), race (White =1 Black = 0), relationship of CG to CR (Spouse =1, non - spouse = 0), CG employment (Yes =1, No = 0), financial strain (0 = no, 1 = yes), and education (High School or less than high School = 0 more than high school = 1) were included. For CRs, age and gender (Female = 1, Male = 0) were included.

Statistical analysis: Descriptive statistics were used to describe the sample with means and standard deviations for all continuous

variables and frequencies and percentages for all categorical variables. An exploratory factor analysis was conducted for the CG Appraisal Scale to determine number of factors for the 20 - item scale. The items loaded onto two factors (positive appraisal and negative appraisal). Cronbach's alphas were estimated to examine internal consistency and reliability among the CG appraisal scales. To examine differences between demographics and the CG appraisal subscales (i.e., positive and negative appraisal) at baseline, independent t-tests were used. Repeated measures ANOVA was used to examine the effects of interventions on CG appraisal subscales over time and by caregiving group. To evaluate the impact of the intervention and other factors on CG appraisal over time, Linear Mixed Models were developed. First, separate Linear Mixed Models were developed to examine a time effect for the two measures (positive appraisal, and negative appraisal). Post-hoc tests were conducted using Turkey's methods. Second, using all the predictor variables, we developed our full model including CG's relationship to PWD, financial strain, CG reaction on the RMBPC, positive social support, negative social support, and time. When variables (gender, employment, and education) were not significantly associated with appraisals, we removed these variables from the full model to achieve the reduced model (Table 3). All data were analyzed using SPSS version 22 and *p* - values < 0.05 were regarded as statistically significant.

RESULTS

Study population description

Descriptive analysis results appear in table 1. The mean age of caregiver participants was approximately 67 years. On average, participants had provided 3 years of caregiving and they provided 30 hours per week (*SD* = 16, 94 range from 4 to 70 hours) of care. Over half of CGs were female and most CGs were White. Four fifths (82%) of the participants were spouse CGs and others consisted of offspring (18%), and friends (.5%). Less than one fifth (17.2%) of the CGs reported financial strain. Approximately one third (29.4%) of the study population had a high school education or less. The mean age of the care recipients with dementia was approximately 78 years and more than two fifths (42.9%) of them were female. Participant attrition was quite high over the 18-month data collection period. Most attrition occurred from PWD institutionalization (*n* = 38) or death (*n* = 20). The next largest attrition occurred between enrollment and baseline (*n* = 15) possibly because caregivers decided they were not ready to actively engage in a skills based intervention. Some of these caregivers noted they were looking for respite volunteers to give them a break from caregiving. Referrals were made to community resources for these stressed caregivers. For a more in depth explanation about attrition, see Robinson, et al. [22].

RQ1: Which subgroups of caregivers at baseline reported the highest positive and negative appraisal?

Table 2 provides the demographic characteristics and their associations with the two caregiver appraisal subscale scores (positive and negative appraisal) at baseline. Independent t-test indicated that there were no subgroup differences in either subscale except for financial strain and education, which approached significance (*p* = .06). Caregivers who were facing financial strain due to caregiving reported significantly higher negative appraisal scores compared to caregivers not facing financial strain. Caregivers who had received a high school education or more showed higher positive appraisal scores compared to caregivers who had less than a high school education (*p* = .06) (see Table 2).

RQ2: What was the influence of the intervention on positive and negative appraisal over an 18 month period?

To visualize high and low points of positive and negative appraisal, the means are first identified at each time point to examine differences over the four time points. Positive appraisals (satisfaction with caregiving) increased very little after baseline (*M* = 30.1, *SD* = 5.705; 6 months *M* = 30.45, *SD* = 5.73) with some decrease in positive appraisal occurring at 12 months (*M* = 26.45, *SD* = 5.69). However, by the 18 month time point (*M* = 30.20, *SD* = 4.83) means returned to

Table 1: Baseline Demographic Characteristics Caregivers (N = 125).

	Total
	n (%) or Mean (SD)
CG Age	66.65 (12.43)
Years of Caregiving	3.2 (2.66)
CG Gender – Female	88 (68.8)
CG Race – White	118 (92.9)
CG Relationship to Patient	
Spouse	105 (82)
Other*	23 (18)
CG Employed – Yes	33(26)
CG Facing financial strain?	
Yes	22 (17.2)
CG Education Level	
≤ High School	37 (29.4)
CR AGE	77.95 (8.22)
CR Gender (Female)	85 (42.9)

Table 2: Baseline Appraisal Scores by Demographic Characteristics (N = 125).

	Positive Appraisal		Negative Appraisal	
	<i>M</i> (<i>SD</i>)	<i>p</i>	<i>M</i> (<i>SD</i>)	<i>p</i>
Gender				
Female	30.33 (5.8)	0.51	25.65 (9.39)	0.59
Male	29.53 (5.4)		24.59 (9.43)	
Race				
White	30 (5.3)	0.27	25.16 (9.43)	0.43
Black	32 (7.89)		27.90 (8.73)	
Relationship of Caregiver to PWD				
Spouse	30.08 (5.28)	0.936	26.06 (9.34)	0.10
Non Spouse	30.08 (5.83)		22.33 (9.34)	
Employed				
Yes	30.22 (5.88)	0.89	22.97 (9.6)	0.09
No	30.06 (5.7)		26.97 (8.41)	
Facing financial strain?				
Yes	29.20 (5.61)	0.40	29.67 (10.5)	.012
No	30.33 (5.77)		24.25 (8.71)	
Education Level				
≤ High School	30.13 (5.61)	0.06	25.11 (9.4)	0.144
Higher than High School	22.5 (7.78)		35 (8.48)	

Note: *M* = Mean; *SD* = Standard Deviation



Table 3: Linear Mixed Model Results for Positive Appraisal, and Negative Appraisal.

	Positive Appraisal				Negative Appraisal			
	Est (SE)	p	Est (SE)	p	Est (SE)	p	Est (SE)	p
Relationship to PWD								
Spouse	- .75 (1.03)	.46	.76 (1.03)	.46	-2.67 (1.60)	.096	-2.82 (1.59)	.077
CG Financial Strain								
No	1.18 (.87)	.18	-1.18 (.88)	.18	-2.26 (1.37)	.100	-1.63 (1.38)	.238
PWD's Memory and Behavior Problems	0.07 (.02)	.76	.006 (.02)	.79	.06 (.036)	.078	.104 (.037)	.004
CG Social Support –Positive at baseline	.027 (.09)	.76	-	-	-.73 (.137)	<.001	-	-
-CG Social Support-Negative at baseline	na	na	-.021 (.08)	.87	na	na	.67	<.001
Follow-up time								
Baseline versus 18-months	-.15 (1.28)	.90	.16 (1.28)	.90	2.95 (1.99)	.14	2.60 (1.99)	.19
6-months versus 18-months	.21 (1.28)	.87	.210 (1.29)	.87	2.57 (2.00)	.20	2.15 (2.00)	.28
12-months versus 18-months	- 4.05 (1.37)	.004	-4.05 (1.38)	.004	6.84 (2.16)	.002	6.45 (2.15)	.003

Note: Each mixed model controlled for the year CG entered into the study. Est = Estimate; SE = Standard Error

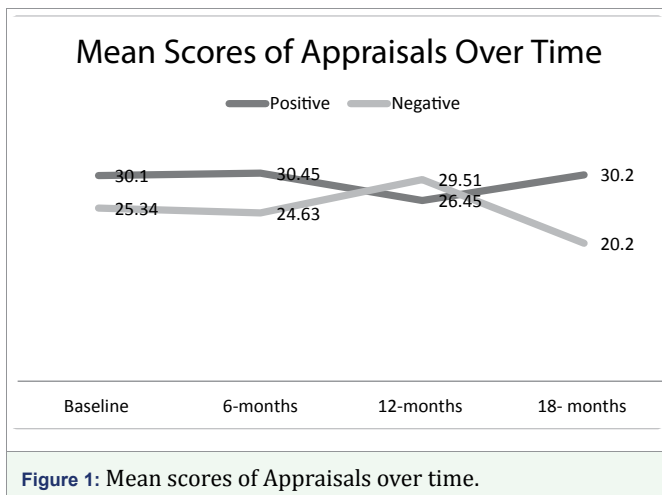


Figure 1: Mean scores of Appraisals over time.

baseline levels. The ANOVA results for positive appraisals identified that there were significant differences in positive appraisals over the four (baseline, 6, 12, 18 months) time points ($F(3,213) = 4.879, P = .001$ see Figure 1). A post hoc test (Tukey HSD) indicated that the positive appraisals at baseline differed significantly at 12 months as well as 6 months from 12 months. However, there was no difference between the 18 month time point and others. Thus, the intervention did not improve positive appraisal during the 12 month follow-up period, but by 18 months positive appraisal had returned to baseline levels (See Figure 1). For negative appraisals (high scores indicates higher burden and higher negative impact), at each time point means are identified in figure 1. For negative appraisals, ANOVA indicated that significant differences occurred over the four (baseline, 6, 12, 18 months) time points ($F(3, 213) = 3.648, p = .013$, see Figure 1). A posthoc test (Tukey HSD) indicated that the negative appraisals at 6 months ($M = 24.64, SD = 9.65$) differed significantly from 12 months ($M = 29.51, SD = 9.77$) and again at 12 months from 18 months ($M = 20.2, SD = 9.13$). Between measurements at baseline and post intervention at 6 months, negative appraisal was reduced (lower scores equal lower burden), but by 12 months negative appraisal (burden) had increased. Negative appraisal fell again below baseline levels at 18 months, although there was no statistically significant difference between baseline and 18 months.

RQ3: Which subgroups of caregivers benefitted most from the intervention?

Approximately 74% ($n = 94$) of CGs had at least one follow-up measurement and were included in the Linear Mixed Models. Results of the Linear Mixed Model indicated a significant time effect for negative appraisal ($p = .013$), and positive appraisal ($p < 0.001$). When including demographic variables (relationship to PWD, CG financial strain due to caregiving), caregiver reaction to the PWD's memory and behavior problems, as measured by the RMPBC, and both negative and positive social support aspects at baseline in the model, none of them were significantly associated with positive appraisal. As seen in table 3, CG reaction to PWD memory and behavioral problems, and positive and negative social support at baseline were significantly associated with negative appraisal over time. CGs who reported higher scores in reaction to PWD's memory and behavioral problems, lower positive and higher negative social support had higher negative appraisal over time. Finally, results identified that the only significant effects were for time between 12 and 18 months which resulted in the expected direction for both types of appraisals when positive appraisal significantly increased and negative appraisal significantly decreased.

DISCUSSION

This study examined the influence of an individualized, psychoeducational intervention on outcomes of CG positive and negative appraisal. Expected outcomes of the two component intervention were that CGs would report less negative appraisal and greater positive appraisal. These outcomes were not achieved to the extent hoped for. Findings indicate the intervention generally kept positive appraisal stable and slightly decreased negative appraisal for CGs over the follow-up period, with different time peaks noted for each type of appraisal. Positive appraisal remained remarkably stable at 6 months but a moderate decrease occurred at 12 months, although by end of follow-up positive appraisal rose back to baseline levels. Negative appraisal had significant differences across time as it peaked at 12 months but had a dramatic decline at 18 months. The significant increase in positive appraisal and decrease in negative appraisal between 12 and 18 months may indicate a possible delayed effect of the intervention or possibly CG comfort/increased expertise with the caregiving role. However, without a control/comparison group it is

impossible to determine the “natural history” of caregiver appraisal over time. That is, it may be that positive appraisal naturally tends to diminish over time due to the ongoing challenges of the caregiving experience, the progressive nature of dementia and associated behavioral and psychological problems, and caregivers taking on a more demanding role [38]. Others report the influence of burden on positive aspects of caregiving over time [39]. Thus, the finding of relative stability for this variable in our study may, in fact, represent a good outcome. Basic content of the PLST training program taught CGs to recognize triggers contributing to anxiety/distress in the PWD, and to intervene before stress increased to dysfunctional levels, thus preventing development of unmanageable behaviors. Theoretical expectations of the intervention were that caregivers’ positive appraisal of the PWD would be enhanced and BPSD minimized, thus decreasing impact and stress. This decrease was expected to result in improved positive support and positive appraisal in the caregiving situation. Positive appraisal did begin to increase at 6 months but experienced a moderate drop at 12 months, possibly because of CG discomfort in planning for satisfying activities and events, as endorsed in the PLST model. Positive appraisal again increased to baseline levels at 18 months. These findings suggest a need for greater reinforcement (booster sessions) of the intervention beginning before the 12 month period and continuing throughout the 18 month period and perhaps even throughout the entire trajectory of the disease process, as care recipient and caregiver needs change over time. If desired, additional family meetings might be offered with an emphasis on mobilizing the family network to increase positive support for the PWD-caregiver dyad. Findings from the Linear Mixed Models data are among the most important in this study: as caregiver reactions to BPSD increased and negative social support increased so did negative appraisal of the caregiving experience increase over time. Our findings are consistent with [40] who reported similar risk factors for negative caregiving experiences (increased care recipient problem behavior and increased dependency), as well as for positive caregiving experiences (increased help offered for the care recipient). Similarly, previous research by our team profiling caregiver service use identified that care recipient problem behaviors was strongly associated with use of services. Thus, services targeted to caregivers coping with increased reactions to memory and behavioral problems in the PWD may facilitate their ability to maintain care at home [41]. Greater levels of negative social support and lower levels of positive social support at baseline were significantly associated with negative appraisal. Roth et al. [7] examined positive aspects of caregiving and determined that differences occurred across gender and relationship groups. Reciprocal help for the care recipient increased positive appraisal for wife, daughter and son caregivers but not for husband caregivers. These findings underscore the need to tailor services according to the unique needs of each caregiver subgroup. Independent T Tests identified caregivers who faced financial strain had significantly greater negative appraisal at baseline; however, when adding other demographic variables in the linear mixed model, the relationship disappeared. These findings on financial strain reinforce the need for additional research that better captures the results of financial strain related to negative caregiving experiences. CGs under financial strain may be so stressed by efforts to meet budgetary needs that their capacity to cope with caregiving stress is compromised. As distress from financial strain was identified to be a predictor of institutional placement [42], providers must emphasize CG financial status as part of a comprehensive assessment and assist CGs who have money issues by immediately making referrals for

financial counseling or legal services [43]. The original PLST investigation in an earlier controlled trial reported a much stronger impact on caregiving appraisal in the desired direction. Effectiveness of a similar PLST - based caregiver intervention comes from a large (N = 241 caregiving dyads), experimental, multi-site, longitudinal (baseline -12 months), R01 NIH-funded study that also examined outcomes from four factors of the Philadelphia Geriatric Center Caregiving Appraisal Scale (mastery, burden, satisfaction, and impact) over time. Findings from this investigation, conducted by co - author Buckwalter and colleagues, determined that over time the PLST - based intervention had a positive impact on caregivers in the experimental group for impact, burden and satisfaction, but had no effect on mastery, when measured against outcomes for caregivers in the comparison group. Stolley et al. [34] concluded that the PLST based intervention helped to increase positive appraisal and decrease negative appraisal of the caregiving situation. In contrast, findings from our study demonstrated minimal effect on appraisal over time. What might have influenced differences between the two studies? Perhaps the most important factor may be that the current study had more PWDs who were in the late stages of disease progression than the previous PLST - based intervention study, as evidenced by the high attrition rates due to institutionalization and death. Caregivers had to have at least two waves of data to be included in the data analysis. Over the 18 month data collection period, data from 42% of participants who were ill enough to be institutionalized or die were included in our final analysis. Those providing care in the later stages of the disease were likely taking on a more demanding role such as providing more assistance with ADLs, which first [38] showed was linked to increased depression, psychological distress, impaired self-care and poor self-reported health. Further, the PLST model is most effective in the early-mid stages of the disease, and is not targeted to caregiving dyads in the late stages of dementia, during which PWD are often too ill, and caregivers too stressed, to benefit as much from proposed strategies. Our results may also illustrate the complexity of translating a Randomized Controlled Trial (RCT) into a real life community intervention. Mittelman and Bartels [44] acknowledged a similar difficulty in translating their RCT, including higher attrition rates along with more CGs who did not complete the required counseling sessions. Fifty five per cent discontinued counseling before completion of all six counseling sessions in contrast to a 98% completion rate reported in their RCT. These authors suggested that a CG intervention is less likely to be fully implemented when provided outside of a controlled research study. Other similarities and differences are noted between the two PLST-based studies. Participants were similar in terms of caregiver age, sex, spousal relationship, and ethnicity, although caregivers in the Buckwalter’s study [34] were slightly better educated and had provided caregiving services for a longer period of time (52 months vs 38 months). The original PLST RCT had a larger sample size, nearly double that of the current study. Similarly, financial burden had a statistically significant and unique effect on perceived burden at baseline and burden scores worsened as financial burden increased over time. The effect of history, a threat to internal validity, might be another explanation for differences in outcomes, as the original PLST intervention occurred in the 1990s. In the ensuing twenty years, CG education and support have become more accessible primarily through work of the Alzheimer’s Association and professional gerontology societies and agencies. The major weakness of this study was that a Random Controlled Trial (RCT) was not implemented because the School of Nursing’s Caregivers Program of Research (CPR) was a program of

intervention research. Enrolled caregivers were similar to clients seeking assistance with their caregiving situation. Referrals were made to the CPR with CGs expecting to participate in an intervention. Thus, this study used a non-RCT design for building evidence. Pre-post longitudinal designs may need to be used as reasonable evidence to guide CG interventions, although as noted earlier, without a control/comparison group we cannot know if, without the intervention, positive appraisal scores might have declined more and negative appraisals might have increased more than with implementation of the intervention. Exclusive reliance on randomized controlled trials as the only source of evidence for effectiveness of non-pharmacological interventions excludes much of the available evidence [45] and makes translation and dissemination of knowledge about successful CG interventions [46] more difficult. Future strategies may be better able to link intervention booster sessions more closely to disease progression and unmet needs of both the PWD and CGs. Interventions focused on individualized concerns of CGs about their reactions to BPSD may be important to develop and test. Additionally, use of a control group is needed to help identify whether the 18 month trajectory of positive and negative appraisals resulted from the intervention or from other factors such as adjustment of the CG to the caregiving situation over time. Research using a 24-month follow-up period would help to determine if the decrease in negative caregiver appraisal noted at 18 months in this study continued over time. Finally, future community based research using the PLST-based intervention may wish to exclude participants in the later stages of disease due to high attrition and failure to benefit from strategies associated with the model. In conclusion, this study examined the influence of a psychoeducational intervention on caregiver appraisal over an 18-month period. Findings demonstrated that rather than increasing, as expected, positive appraisals remained stable, and negative appraisals decreased slightly over the study period, most dramatically at the 18-month point. Importantly, CG reaction to BPSD in care recipients was associated with negative appraisal, and positive social support was negatively associated with negative appraisal, while negative social support was positively associated with negative appraisal. These findings suggest development and testing of interventions targeted to caregiver social support as well as reactions to BPSD may help increase satisfaction and decrease burden associated with the caregiving experience.

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