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Need for Resourcefulness Training for Women Caregivers of Elders with Dementia

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Abstract

Nearly 10 million American women are caregivers of elders with dementia and may experience overwhelming stress that adversely affects their mental health. Interventions to teach them resourcefulness skills for managing stress can promote optimal mental health and facilitate continued caregiving. However, effectiveness of resourcefulness training (RT) cannot be examined until its need is established.

Purpose—This pilot trial with 138 women dementia caregivers examined the need for RT using subjective and objective data.

Methods—Data were collected before and after RT. Data analysis focused on baseline resourcefulness scores (higher scores = lower need), scores in relation to attrition, correlations among resourcefulness, stress, and depressive symptoms, and post-RT evaluation of need for RT.

Results—Baseline resourcefulness scores were normally distributed and showed 74% of the caregivers had a moderate to high need for RT. Reasons for attrition were unrelated to need for RT, however caregivers who dropped out had resourcefulness scores that averaged two points higher than those who remained in the study. Lower resourcefulness was associated greater stress ($r=-.37$, $p<.001$) and depressive symptoms ($r=-.52$, $p<.001$). Of the 63 caregivers who received RT, 82% ($n=52$) reported a felt need for RT; 94% ($n=59$) believed other caregivers need RT.

Conclusions—The results suggest a substantial need for resourcefulness training in women dementia caregivers and support moving forward to test RT effectiveness for reducing caregiver stress and depressive symptoms.

Individuals, 65 years and older, are the fastest growing population in the United States (United States Census, 2010). Dementia mostly affects older adults and currently it is

estimated that 4.2 million people in the U. S. are suffering from some form of dementia (Hurd, Martorell, & Langa, 2015). The incidence of dementia increases substantially after age 75 and the incidence of dementia is expected to triple by 2050 (Prince, Guerchet, & Prina, 2013). More than 15 million informal caregivers provide care to elders with dementia (Moon & Dilworth-Anderson, 2015). These unpaid caregivers are usually family members, and 65% are women (Bouldin & Andresen, 2010). In 2013, they provided 17.7 billion hours of unpaid care with a monetary value of \$220.2 billion (Moon & Dilworth-Anderson, 2015).

Due to the length and complexity of dementia care, caring for elderly with dementia takes a toll on the physical, emotional, social, spiritual and financial health of the caregivers (Alzheimer's Association, 2015; Kim, Chang, Rose, & Kim, 2012; Sörensen & Conwell, 2011; Vitaliano et al., 2005; Vitaliano, Young, & Zhang, 2004). Further, the outcomes of the caregiving burden and stress, such as increase in depression, fatigue, cardiovascular diseases, are worse in women caregivers than in men (Alzheimer's Association, 2015; Pinquart & Sörensen, 2006; Sörensen & Conwell, 2011; Vitaliano et al., 2004). However, the adverse effects of dementia caregiving on the wellbeing of caregivers may be avoided with appropriate interventions.

Research shows that individuals with greater resourcefulness skills have better capability to deal with stressful situations such as caregiving and thus, have less anxiety and depression and better perceived health (Zauszniewski, 1996, 2006; Zauszniewski, Au, & Musil, 2012; Zauszniewski, Bekhet, Lai, McDonald, & Musil, 2007; Zauszniewski, Eggenschwiler, Preechawong, Roberts, & Morris, 2006). Resourcefulness training, an intervention based on Zauszniewski's Resourcefulness and Quality of Life Theory (2006), has been found to reduce stress, promote health, and facilitate continued caregiving (Zauszniewski, 1997; Zauszniewski, Eggenschwiler et al., 2006; Zauszniewski et al., 2007; Zauszniewski, et al., 2012). However, the need for resourcefulness training in dementia caregivers has not been reported.

The evaluation of need for an intervention can be studied from the perspectives of healthcare providers, family members or intervention recipients (Zauszniewski, 2012). Most importantly, Zauszniewski's model of intervention parameters to be assessed during intervention development suggests it is important to study the need for an intervention, such as resourcefulness training, from the caregiver's perspective because their perceived need is likely to impact their interest and performance of the intervention, and ultimately, its effect on their health.

Purpose and Research Questions

The aims of the pilot study reported here were to determine 1) what percentage of women dementia caregivers scored high on the resourcefulness scale, indicating a low need for resourcefulness training; 2) whether low resourcefulness in women caregivers was associated with greater stress and depressive symptoms; 3) whether women caregivers who dropped out of the study and those who continued differed on measures of resourcefulness, stress, and depressive symptoms; 4) what reasons women caregivers gave for dropping out of resourcefulness training; 5) what percent of women caregivers who completed

resourcefulness training said they believed they needed it; and 6) what percent of women caregivers who completed resourcefulness training believed other women caregivers of elders with dementia would need it.

Methods

Design and sample

This community-based study involved a convenience sample of women caregivers of elders with dementia. The study was the first phase of the larger study in where women caregivers were randomly assigned to resourcefulness training (RT) or usual care. To be eligible for the study women caregivers had to be aged 21 years and older and currently providing supervision/direct care for a minimum of 4 hours per day for at least 6 months for an elder with dementia. Data were collected in three face-to-face interviews spaced 6 weeks apart using structured instruments, and from written journals (RT-EW and EW) and digital voice recordings (RT-VD and VD) completed during the intervention. Prior to recruiting the study participants, approval was obtained from the University Institutional Review Board. Flyers describing the research were posted in community health centers, churches, and places of business (e.g., grocery stores, department stores, restaurants, coffee houses, bookstores, libraries, etc.) and given to support groups for women caregivers of elders with dementia.

The initial sample included 138 women caregivers. However, 12 withdrew from the study after the first, baseline data collection, before receiving either the RT or the comparison (expressive disclosure) intervention. The sample of 126 was considered sufficient for examining descriptive statistics, including frequencies and percentages, and for identifying moderate correlations ($r=.50$) between resourcefulness and perceived stress and depressive symptoms at a significance level of $\alpha=.05$, and power of $B = .80$ (Cohen, 1992).

Resourcefulness Training Intervention

Of the 126 women caregivers who completed the parent study, 32 were randomly assigned to receive resourcefulness training (RT). The RT intervention was delivered by a trained interventionist who taught resourcefulness skills in a single 40-minute session and this was followed by a 4-week period during which caregivers used either a daily written journal or a digital voice recorder to reinforce the RT skills they were taught. During the 4 weeks, intervention providers had weekly telephone contact with the caregivers. The RT took place between the baseline data collection and the second data collection. Measures of resourcefulness, perceived stress, and depressive symptoms were completed before and after the intervention.

Instruments

The women caregivers completed a self-report demographic questionnaire and measures of resourcefulness, perceived stress, and depressive symptoms before and after the intervention. The demographic questionnaire asked about age, race/ethnicity, marital status, education, income, and number of health problems, using a checklist of 10 leading health problems experienced by women: heart disease, cancer, stroke, respiratory disease, diabetes,

hypertension, osteoporosis, kidney disorders, mental disorders, and HIV/AIDS (United States Department of Health and Human Services, 2003).

Resourcefulness—Resourcefulness was measured by the 28-item Resourcefulness Scale (RS; Zauszniewski, Lai, & Tithiphontumrong, 2006), which contains 16 items reflecting personal resourcefulness and 12 items reflecting social resourcefulness. Sample personal and social resourcefulness items are: “If I find it difficult to concentrate on a task, I divide it into smaller parts” and “When it is hard for me to make a decision, I ask someone to help me think things through.” Item responses are made on a 6-point Likert scale, from extremely non-descriptive of the respondent’s behavior (0) to extremely descriptive (5). Scores range from 0 to 140, with higher scores indicating greater resourcefulness (Zauszniewski, Lai, et al., 2006). A Cronbach’s alpha of .83 has been reported (Zauszniewski, Lai, et al., 2006). In this sample Cronbach’s alpha was .81. Construct validity has been supported by confirmatory factor analysis to verify the presence of substantially correlated subscales reflecting personal and social resourcefulness ($r = .41, p < .001$) (Zauszniewski, Lai, et al., 2006).

Perceived Stress—Perceived stress was measured by the 14-item Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) on which items are rated on a 5-point Likert scale from “never” to “very often.” Higher scores, after reversing scores on seven items phrased in the opposite direction, indicate greater perceived stress. Internal consistency estimates for the PSS, as indicated by Cronbach’s alpha, have ranged from .84 to .87 (Cohen et al, 1983; Cohen & Williamson, 1988). Test-retest reliability has been reported with a correlation of .85 (Cohen et al, 1983; Cohen & Williamson, 1988). Construct validity has been demonstrated through predictive relationships with theoretically related constructs including self-assessed health, health service use, health behaviors, help-seeking behavior, and salivary cortisol (Schwartz & Dunphy, 2003; Wright et al., 2004). In this sample, Cronbach’s alpha was .83.

Depressive Symptoms—Depressive symptoms were measured by the 20-item Center for Epidemiological Studies – Depression Scale (CES-D; Radloff, 1977) on which items are rated on a 5-point scale from “rarely” to “always.” Higher scores, after reversing scores for four items phrased in a positive direction, indicate greater depressive symptoms (Radloff, 1977). The CES-D has widely reported validity and has been standardized for a variety of ages and races/ethnicities (Radloff, 1977). In studies of healthy elders, Cronbach’s alphas have ranged from .80 to .88 (Lewinsohn, Seely, Roberts, & Allen, 1997; Zhang, Sun, Kong, & Wang, 2012). In this sample, Cronbach’s alpha was .87.

Other measures of RT Need—In addition to the demographic questionnaire and scales measuring perceived stress, depressive symptoms, and resourcefulness, we tracked attrition and asked the caregivers who withdrew from the study their reason for doing so, in order to determine whether or not their reasons reflected a perception of little need for the intervention. Then, at the end of the study, we asked the caregivers who received RT whether they believed they needed the intervention and whether they felt that other caregivers of elders with dementia might need the intervention.

Results

Sample characteristics

The initial sample consisted of 138 women caregivers who met the study criteria. Of those 138, 9% (n = 12) withdrew from the study after the baseline data collection interview. Therefore, 91% (n = 126) of the caregivers remained.

Ages of the caregivers ranged from 25 to 89 years with an average age of 56 years. The sample was 54% Caucasian, 38% African American, and 8% other/mixed races/ethnicities; 27% were single, 45% were married/cohabitating; 4% were separated; 18% divorced; and 6% were widowed. In terms of education, 1% had completed junior high school, 10% had completed high school or G.E.D., 30% had completed some college, 12% had completed as associate degree, 27% had a bachelor's degree, 17% had a master's degree, and 3% had a doctorate. Of those who reported their income (9% did not), 56% reported an income < \$30,000, 25% reported an income between \$30,001 and \$50,000, and 19% reported an income > \$50,001. Overall, the study participants were in good health; the most frequently reported health problems were hypertension (29%), osteoporosis (19%), respiratory disorders (12%), and diabetes (9%). Caregivers reported most of their elderly care recipients were women (72%); 28% were men. Care recipient ages ranged from 65 to 100 with an average age of 82 years. Caregivers spent between 4 and 24 hours a day in caregiving with an average of 14 hours. The length of time they had been caregiving ranged from 6 to 276 months (23 years), with an average time of 55 months (4 to 5 years)

Baseline resourcefulness

Scores on the Resourcefulness Scale (RS) were examined at baseline for all the women caregivers initially enrolled in the study, including the 12 who later withdrew. The possible range of scores on the RS is from 0 to 140. To determine caregiver's need for resourcefulness training, we used the levels of need for resourcefulness training used in our previous research (Zauszniewski, et al., 2012): the possible RS range was divided into five levels of need based on a mean score of 87 obtained in previous research (Zauszniewski, Lai, et al., 2006) and allocating 20 points to each need level, ranging from very low to very high need. Table 1 shows the RS score ranges at baseline with corresponding level of need, along with the percentage and number of caregivers who fell in each level of need. Based on their scores on the RS at the beginning of the study, 74% of the caregivers who enrolled in the study had a moderate to very high need for resourcefulness training.

Correlates of resourcefulness

At baseline, we also examined correlations between resourcefulness scores and measures of perceived stress and depressive symptoms. Our assumption was that if resourcefulness scores were significantly associated with perceived stress and depressive symptoms, resourcefulness training would be needed to provide caregivers with personal and social resourcefulness skills to reduce their stress and minimize their depressive symptoms. We conducted this analysis for the total sample of caregivers (N=138), but also conducted separate analyses for those who subsequently withdrew from the study and compared them to those who completed the study. Table 2 shows the correlations between resourcefulness,

perceived stress, and depressive symptoms for the total sample, those who withdrew, and those who completed the study.

As shown in Table 2, correlations between resourcefulness and perceived stress and between resourcefulness and depressive symptoms were significant and in the expected direction, and they were moderate to large in strength. Lower resourcefulness was associated with greater perceived stress and more depressive symptoms in the total sample of caregivers; however, the correlations were stronger among those who dropped out of the study.

Reasons for withdrawing

Among the 12 caregivers who withdrew from the study after baseline data were collected, 4 dropped out before the intervention phase of the study; and 8 dropped out during the 4-week intervention. Table 3 shows the baseline resourcefulness scores by reason for attrition. Scores for the 12 caregivers who withdrew from the study ranged from 44 to 119, with an average of 83.25, suggesting a moderate need for resourcefulness training. Although no caregivers stated that they wished to withdraw from the study because they felt they did not need the intervention, 3 said that they lost interest; it is not known whether their diminished interest came about because they felt they did not need the intervention. Their baseline RS scores averaged 67.67, indicating a somewhat high need for resourcefulness training.

Four caregivers cited being too busy as their reason for withdrawing. All 4 dropped out during the intervention phase. Their baseline RS scores averaged 90.75, indicating a moderate need for resourcefulness training. Finally, 5 women caregivers were lost to follow up because of phone disconnection. Four were lost before the intervention phase and 1 was lost during the intervention phase. Their baseline RS scores averaged 86.60, indicating a moderate need for resourcefulness training.

Caregivers' perceived need for resourcefulness training

After the intervention, we asked caregivers who received the RT whether they thought they needed RT and whether they felt that other caregivers of elders with dementia would need RT. Of the 63 caregivers who received RT, 52 (82%) felt they needed the intervention, and 59 (94%) felt that other dementia caregivers would also need it. The resourcefulness scores of caregivers who did not think they needed RT ($n=11$) ranged from 39 to 102 ($M=79.55$; $SD=20.77$). These baseline scores suggested a very high need for 1, a somewhat high need for 4, a moderate need for 3, and a somewhat low need for RT for 3.

Discussion

The data from this study showed a significant need for resourcefulness training for women caregivers of elders with dementia. About 30% of the caregivers had a high need for resourcefulness skills and around 45% were in moderate need of these skills. Moreover, the inverse relationships between resourcefulness and depressive symptoms and stress among these caregivers suggest that low resourcefulness poses a risk to the psychological wellbeing of women dementia caregivers. Previous studies have also shown high risk of depression and stress among individuals with low resourcefulness, which are indicators of high need for resourcefulness training (Chen, Chen, & Chu, 2014; Peterson, 2013; Zauszniewski, Bekhet,

& Suresky, 2009; Zauszniewski, et al., 2012; Bekhet, Zauszniewski, & Matel-Anderson, 2012).

Assessing the need for an intervention from the intervention recipient's perspective is critical because their perceived need for the intervention will likely affect their future use of that intervention and, hence, their health (Bekhet et al, 2012; Zauszniewski, 2012). In this study, a large majority of the women who completed the RT felt that they needed this training. Over 90% also believed that other dementia caregivers would benefit from the training. Only 9% of caregivers withdrew from intervention group and they showed moderate to high need for resourcefulness training. Baseline resourcefulness was more highly correlated with stress and depressive symptoms among caregivers who withdrew than among those who remained in the study. However, the number of caregivers who withdrew was very small.

This is one of the few studies to have examined whether participants feel need for intervention and also scores their actual need (Bekhet et al, 2012; Zauszniewski, et al., 2012). Eleven caregivers felt they did not need the RT, but only 3 scored low on need on the resourcefulness scale at baseline. Thus, participants' perception of need may not always match objective indicators. However, on the whole, this study found a high resemblance between self-appraised and objectively evaluated need for resourcefulness. Similar studies on grandmother caregivers (Zauszniewski, et al., 2012) and older adults (Bekhet, et al., 2012) indicate that most of the participants' perceived need match with their need for RT and they recommended similar training for people in the similar situations.

In the study reported here, we measured the need of intervention by evaluating the baseline resourcefulness skills and caregivers' responses for perceived need post-intervention. Since we added an objective indicator, it helped us to corroborate the objective data with subjective data providing validity to the perceived need of the intervention (Zauszniewski, et al., 2012). In this study only a few caregivers scored high in resourcefulness scale, showing major need for resourcefulness training in this population. The results replicates the findings of other studies on resourcefulness training among older adults (Bekhet, et al., 2012) and grandmother caregivers (Zauszniewski, et al., 2012). The findings from this study indicate that we should move forward to test the effectiveness of resourcefulness training for women dementia caregivers.

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Table 1

Baseline scores on the Resourcefulness Scale (RS) and corresponding level of need for resourcefulness training (N=138)

RS score range	% of Caregivers	Level of need for RT
119 to 140	4% (<i>n</i> = 5)	Very low need
98 to 118	22% (<i>n</i> = 31)	Somewhat low need
77 to 97	44% (<i>n</i> = 60)	Moderate need
56 to 76	26% (<i>n</i> = 36)	Somewhat high need
0 to 55	4% (<i>n</i> = 6)	Very high need

Table 2

Correlations between resourcefulness and perceived stress and depressive symptoms

Variable	Correlations with Resourcefulness		
	Withdrawn from study (n = 12)	Remained in study (n = 126)	Total sample (N = 138)
Perceived stress	-.44 *	-.36 **	-.37 **
Depressive symptoms	-.77 *	-.49 **	-.52 **

*
p < .01**
p < .001

Table 3

Reasons for caregivers' attrition and baseline resourcefulness score

# Caregivers	Reason for attrition	Baseline RS score
5	Unable to recontact	<u>M</u> = 86.60 (moderate need)
4	Too busy	<u>M</u> = 90.75 (moderate need)
3	Lost interest in participation	<u>M</u> = 67.67 (somewhat high need)
All (<u>n</u> =12)		<u>M</u> = 83.25; <u>SD</u> = 20.28