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Caregiver Reactions to Dementia Symptoms: Effects on Coping Repertoire and Mental Health

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Abstract

Currently, 15 million informal caregivers, most of whom are women, provide care for older adults with dementia (Alzheimer's Association, 2016). Caregiving for these individuals often creates distress and may adversely affect female caregiver's psychosocial and spiritual well-being. Approximately 35% of dementia caregivers complain of health deterioration after initiating caregiving responsibilities as compared to 19% of caregivers of older adults who do not have dementia (Alzheimer's Association, 2016). Persons with dementia exhibit symptoms and behaviors that often are challenging for their caregivers. The way that caregivers react to these symptoms and behaviors may affect their coping repertoire and their mental health. Adequate evaluation of caregiver reactions to symptoms of dementia will provide information useful for developing targeted interventions to promote optimal health of female dementia caregivers and to potentially postpone the need for nursing home or long-term placement of the care recipient.

Dementia Caregiving and its Impact

Dementia caregiving includes not only caring for individuals with dementia but also managing their dementia-related symptoms, such as anxiety, apathy, depression, agitation, wandering, and disruptive behavioral problems (Alzheimer's Association, 2016). The most common of these symptoms are apathy, depression, and agitation (Lyketsos et al., 2000; Lyketsos et al., 2011). These symptoms can occur from the prodromal stage of dementia through the later stages (Lyketsos et al., 2011). The Cache County Study on Memory in Aging found that 61% of dementia patients show one or more disruptive behavioral symptoms (Lyketsos, Steinberg, Tschanz, Norton, Steffens, & Brietner, 2000) that make it difficult for their day to day care and management. Research has indicated that these psychological and behavioral symptoms produce more distress in caregivers (Robinson et al., 2016) than custodial care alone.

Caregivers do not react in the same ways to their care recipient's symptoms. The way informal caregivers react to symptoms of dementia is directly related to their caregiving burden (Alvira et al., 2015; Robinson et al., 2016). Although memory related symptoms occur most often, caregivers show the strongest reactions to depressive (e.g., expression of hopelessness, and threats to self-hurt) and disruptive (e.g., dangerous behaviors, and aggression) (Robinson et al., 2016) symptoms. When these symptoms become unmanageable, some caregivers may opt for institutionalization of their family member with dementia, which could produce post-placement burden among caregivers as they deal with guilt, nursing home staffs, and financial considerations (Gaugler et al., 2011; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010).

Caregivers have developed a coping repertoire and use different methods/skills to manage caregiving burden and to promote their wellbeing. Two such coping mechanisms are resourcefulness and spiritual practices. Research has shown that higher levels of resourcefulness (Zauszniewski, 2016; Zauszniewski, Lekhak, Burant, Variath, & Morris, 2016; Zauszniewski, Musil, Burant, & Au, 2014) and spirituality (Hodge & Sun, 2012; Lopez, Romero-Moreno, Gonzalez, & Losada, 2012; Spurlock, 2005) are associated with lower psychological distress associated with the caregiving burden. However, caregivers may not react to all dementia symptoms in ways that adversely affect their coping repertoire (i.e., resourcefulness or spiritual practices). This study examines the effect of caregiver reactions to dementia symptoms of care recipients on specific coping repertoires (i.e., resourcefulness and spiritual practices) along with consequences of such reactions on indicators of the caregiver's mental health (i.e., perceived stress and depressive symptoms).

Purpose and Research Questions

This study examined associations between caregiver reactions to their care recipients' depressive, disruptive, and memory-related symptoms with their coping repertoire (i.e., resourcefulness and spiritual practices) and with their mental health (i.e., perceived stress and depressive symptoms). The following research questions were addressed:

1. Do caregiver reactions to dementia symptoms of care recipients affect their coping repertoire (i.e., resourcefulness and spiritual practices)?
2. Is the caregiver's coping repertoire (i.e., resourcefulness and spiritual practices) affected differently by their reactions to specific sets of dementia symptoms (i.e., depressive, disruptive, or memory-related)?
3. Do caregiver reactions to dementia symptoms of care recipients affect their mental health (i.e., perceived stress and depressive symptoms)?
4. Is the caregiver's mental health (i.e. perceived stress and depressive symptoms) affected differently by their reactions to specific sets of dementia symptoms (i.e.,

Methods

Design

This descriptive study is a secondary analysis of baseline data obtained from a community-based sample female caregivers of older adults with dementia who participated in a three-wave clinical trial to develop and test interventions to manage stress and promote mental health.

Sample

A convenience sample of 138 female caregivers was recruited using flyers describing the parent study that were posted in community health centers, churches, and places of business (e.g., grocery stores, department stores, restaurants, coffee houses, bookstores, and libraries) and were distributed to support groups for female caregivers of older adults with dementia. Eligibility for the study included: female gender, age of 21 years and older, and current supervision or direct care for an elderly person with dementia, for a minimum of 4 hours per day and for at least 6 months. The sample size of 138 was considered sufficient for descriptive and regression analyses using 3 predictors (caregiver reactions to three sets of dementia symptoms) on resourcefulness, spiritual practices, perceived stress and depressive symptoms at a significance level of $\alpha=.05$, and power of $B = .80$ (Cohen, 1992).

Demographic characteristics of the sample are reported elsewhere in detail (Zauszniewski et al., 2015) and briefly summarized here. Ages of the female caregivers ranged from 25 through 89 years ($M = 56$ years). More than half were Caucasian (54%); 38% were African American; 8% reported other or mixed races/ethnicities. Forty-five percent were married or partnered, and 55% were unmarried (e.g., single, divorced, separated, or widowed). Nearly 60% had an Associate Degree or higher. Yet, of those reporting their annual household income, 56% reported an income less than \$30,000. The women reported good health, but hypertension (29%), osteoporosis (19%), respiratory disorders (12%), and diabetes (9%) were among conditions reported most frequently. The majority of care recipients (i.e., older adults with dementia) were female (72%) and their ages ranged from 65 through 100 years ($M = 82$ years).

Procedures

Data used for this secondary analysis were collected during face-to-face interviews using structured instruments (described below). Approval was obtained from the University Institutional Review Board.

Instruments

Following the completion of a self-report demographic questionnaire (i.e., age, race/ethnicity, education, income, general health, and characteristics of care recipient), the female caregivers completed measures of caregiver reactions to dementia symptoms (depressive, disruptive, or memory-related), caregiver coping repertoire (resourcefulness and spiritual practices), and caregiver mental health (perceived stress and depressive symptoms).

Caregiver reactions to symptoms of dementia were captured by the 24-item Revised Memory and Behavior Problems Checklist, which provides scores for the caregiver's reaction to symptoms consistent with dementia, including depressive, disruptive, and memory-related symptoms (Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992). Items are rated on a 5-point scale ranging from "not at all" (0) to "extremely" (4) bothersome. Internal consistency for caregiver reaction to dementia symptoms was established by Cronbach's alphas ranging from .87 to .90 (Robinson et al., 2016; Teri et al., 1992). Cronbach's alphas for the three subscales range from .77 to .86 (depressive symptoms), .70 to .76 (disruptive symptoms) and .76 to .79 (memory-related symptoms), (Robinson et al., 2016, Teri et al., 1992). Alphas for the analyses reported here were .88, .78, .86, and .79, for the total scale, and memory-related, depressive, and disruptive symptoms, respectively. Construct validity has been established through correlations with measures of caregiver depression and burden with all subscales significantly correlated with caregiver depression or burden (r 's = .29, .31, and .26; p 's < .01) (Teri et al., 1992). In addition, factor analysis confirmed three first-order factors, consistent with three subscales (Teri et al., 1992).

Spiritual practices were measured by the 10-item Spiritual Perspectives Scale (SPS; Reed, 1987) that reveals the extent to which individuals hold certain spiritual beliefs (6 items) and participate in spiritual activities (4 items). Thus, the SPS provides a single score but captures both beliefs (e.g., life perspective, and meaning) and behaviors (e.g., praying, and meditating) that are measured on 6-point scales ranging from "strongly disagree" to "strongly agree" (for beliefs) or from "not at all" to "about once a day" (for behaviors). Higher composite scores indicate a higher level of spirituality. Internal consistent reliability estimates have ranged from .91 to .95 (Dailey & Stewart, 2007; Jesse & Reed, 2004; Reed, 1987). The Cronbach's alpha in the study sample was .93. Evidence for construct validity has been found with correlations in the predicted directions with measures of life satisfaction, spiritual practices, church attendance, religiosity, psychological distress, depression, anxiety, and stress (Daily & Stewart, 2007; Jesse & Reed, 2004; Humphreys, 2000; Reed, 1987). In addition, factor analysis revealed a two-factor solution that reflected spiritual beliefs and behaviors (Daily & Stewart, 2007).

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 et al., 2006). A Cronbach's alpha of .83 has been reported (Zauszniewski 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 et al., 2006).

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.” After reversing scores on seven items phrased in the opposite direction, higher scores 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). In this sample, the Cronbach’s alpha was .83. Test-retest reliability has been reported with a correlation of .85 (Cohen et al, 1983; Cohen & Williamson, 1988). Evidence for 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).

Depressive Symptoms were measured by the well-known 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.” After reversing scores for four items phrased in a positive direction, higher scores 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). In this sample, the Cronbach’s alpha was .87.

Data Analysis

To address the research questions, the data analysis involved the use of linear and multiple regression. Linear regression was used in research questions 1 and 3, where the effect of a single independent variable (i.e., the composite score for all dementia symptoms) on a single dependent variable (e.g., resourcefulness) was examined. Four linear regressions were performed. Multiple regression was used for research questions 2 and 4, where the effects of three independent variables (depressive, disruptive, and memory-related symptoms) on a single dependent variable (e.g., depressive symptoms) were examined. Four multiple regressions were performed.

Results

Reactions to dementia symptoms: Effects on caregiver coping repertoire

To determine whether caregiver reactions to dementia symptoms of care recipients affected their coping repertoire, separate analyses were conducted for resourcefulness and spiritual practices. Two linear regressions were used to test if caregiver reactions to dementia symptoms had effects on their resourcefulness and spiritual practices. The results showed that caregiver reactions to dementia symptoms (composite score) explained 32.4% of the variance of resourcefulness (adjusted $R^2 = .32$, $F(3,137) = 22.87$, $p < .001$) and 10.1% of the variance of spiritual practices (adjusted $R^2 = .10$, $F(3,137) = 6.11$, $p < .001$).

Reactions to depressive, disruptive, and memory-related symptoms: Effects on coping repertoire

To investigate whether the caregiver’s coping repertoire (i.e., resourcefulness and spiritual practices) is affected differently by their reactions to specific sets of dementia symptoms (i.e., depressive, disruptive, or memory-related), separate analyses were conducted for

resourcefulness and spiritual practices. The findings from the two multiple regression analyses revealed that, of the three sets of dementia symptoms, caregiver reactions to depressive symptoms were the only reactions that significantly affected their spiritual practices ($B = -.40$, $p < .02$). However, caregiver reactions to both the depressive and disruptive symptoms significantly affected their resourcefulness ($B = -.57$, $p < .02$ and $B = -1.04$, $p < .001$, respectively). However, caregiver reactions to memory-related symptoms of dementia in their care recipients had no effect on their resourcefulness or spiritual practices. (See Table 1).

Reactions to dementia symptoms: Effects on caregiver mental health

To establish whether caregiver reactions to dementia symptoms of care recipients affected their mental health, separate analyses were conducted for perceived stress and depressive symptoms. Two linear regressions were used to test if caregiver reactions to dementia symptoms had effects on their perceived stress and depressive symptoms. The results showed that caregiver reactions to the dementia symptoms (composite score) explained 19.0% of the variance of perceived stress (adjusted $R^2 = .19$, $F(3,137) = 11.74$, $p < .001$) and 23.1% of the variance of depressive symptoms (adjusted $R^2 = .23$, $F(3,137) = 14.68$, $p < .001$).

Reactions to depressive, disruptive, and memory-related symptoms: Effects on mental health

To examine whether the caregiver's mental health (i.e., perceived stress and depressive symptoms) is affected differently by their reactions to specific sets of dementia symptoms (i.e., depressive, disruptive, or memory-related), separate analyses were conducted for perceived stress and depressive symptoms. The findings from the two multiple regression analyses revealed that, of the three categories of dementia symptoms, caregiver reactions to both the depressive and disruptive symptoms significantly affected their perception of stress ($B = .24$, $p < .03$ and $B = .31$, $p < .03$, respectively) and their depressive symptoms ($B = .36$, $p < .02$ and $B = .49$, $p < .01$, respectively). As with the indicators of the caregiver coping repertoire, caregiver reactions to memory-related symptoms of dementia in their care recipients had no effect on the two mental health indicators - - perceived stress and depressive symptoms. (See Table 2).

Discussion

This is the first study to examine associations between caregiver perceptions of symptoms of dementia exhibited by their care recipients and aspects of their own coping repertoire and mental health. Caregiver reactions to dementia-related symptoms of care recipients may have a substantial impact on their ability to cope with caregiving stress and their mental health (Robinson, 2001). However, it is most likely a reciprocal relationship, such that a caregiver's lack of coping skills, elevated level of distress, or feelings of depression influence how they react when faced with their family member's symptoms of dementia (Liu, Buckwalter, & Burgener, 2014).

The findings from this study suggest that strategies that caregivers might use for managing caregiver stress, including resourcefulness and spiritual practices, may be diminished, overpowered, or perhaps rendered ineffective when a caregiver is overwhelmed by symptoms expressed by their care recipient who has dementia. Yet, it may also be true that if a caregiver lacks a coping repertoire of resourcefulness or spiritual practices or is highly stressed or depressed, they may perceive the symptoms of dementia expressed by their family member as more bothersome (Campbell, Rowe, & Marsiske, 2011). Thus, while the cross-sectional nature of this study, which contained simultaneous measurement of all study variables, does not allow for determining causality, the results indicate a substantial association between the caregiver's reactions to dementia symptoms and their resourcefulness, spiritual practices, perceived stress, and depressive symptoms.

Of the three groups of symptoms associated with dementia, depressive, disruptive, and memory-related, the depressive symptoms expressed by family member with dementia had the greatest impact on the caregivers. More specifically, associations were found between female caregiver's reactions to depressive symptoms expressed by family members with dementia and their coping repertoire and mental health. That is, as the female caregivers reported feeling more troubled when care recipients appeared sad, tearful, or worried, or expressed feeling worthless, hopeless, or lonely, or talked about wanting to harm themselves or to die, they also reported using fewer coping strategies, including fewer resourcefulness skills and spiritual practices, and poorer mental health, indicated by greater stress and more frequent depressive symptoms of their own. The findings in relation to the caregiver's coping repertoire are consistent with cognitive-behavioral and resourcefulness theories that suggest that one's behaviors (e.g. coping strategies) are affected by thoughts, feelings, and perceptions (Corcoran, 2011; Zauszniewski, 2016, 2017). Associations between caregiver reaction to symptoms of depression in care recipients and their own depressive symptoms have also been reported in other studies of female caregivers, including studies by Ornstein (2013), who did not differentiate between male and female caregivers, and by Lee (2017) who noted a somewhat stronger relationship in daughters versus daughters-in-law.

Reactions of the female caregivers to disruptive symptoms of dementia expressed by family members, such as argumentativeness, irritability, verbal aggression or threats, loudness, or destructiveness, were also found to be strongly related to lower resourcefulness, greater stress, and more frequent depressive symptoms. However, reactions to disruptive symptoms were unrelated to the caregiver's spiritual practices. In the absence of empirical studies of caregiver reactions and coping or resourcefulness, theoretical knowledge of resourcefulness provides support for the relationship between process regulators that may include thoughts, feelings, and perceptions and the use of resourcefulness skills (Zauszniewski, 2016, 2017). Associations between caregiver reaction to their care recipient's disruptive symptoms and their stress have been reported in previous research. Alvira and colleagues (2015) reported a significant association between caregiver reactions to behavioral symptoms of dementia (agitation, irritability, disinhibition, and aggression) and caregiver stress), conceptualized as burden in a study that compared in-home caregivers and those with institutionalized family members; correlations were stronger for the in-home caregivers. Fauth and colleagues (2006) also reported greater stress in caregivers of persons with dementia who expressed

disruptive behaviors, particularly in caregivers of younger versus older persons with dementia.

Although memory-related symptoms of dementia that include trouble remembering, repetitive questions, losing things, forgetfulness, difficulty with concentration are more frequently reported by caregivers than symptoms in the other two domains (i.e. depressive or disruptive) (Nogales, 2015), the reaction of the female caregivers to memory-related symptoms of dementia was not found to be related to their coping repertoire (resourcefulness and spiritual practices) or mental health (perceived stress or depressive symptoms). These findings are in contrast with a caregiver study (77% women) by Robinson and colleagues (2001) where memory-related symptoms, as compared with depressive and disruptive symptoms of dementia, were found to have the greatest correlation with the impact on caregiving. In addition to the overall impact of caregiving being most highly correlated with the caregiver's reaction to memory-related symptoms of dementia in that study, the two specific indicators of caregiving impact with the highest associations with memory-related symptoms were economic cost and physical and emotional health.

Recommendations

Further research is needed to examine the effects of caregiver perceptions of symptoms expressed by family members with dementia, particularly studies exploring the effects of dementia symptoms on caregiver coping strategies. Indeed, family caregivers may benefit from interventions comprised of resourcefulness training or support for spiritual practices to strengthen their coping repertoire and promote their mental health. However, their perception of the caregiving situation, including their reaction to symptoms of dementia must be taken into account. In addition, future interventions must be tailored to acknowledge differences that may exist across dementia caregivers, including differences by living/care arrangements, gender, role/relationship, and age of care recipient.

Implications

The findings from this study are relevant for psychiatric and mental health nurses who encounter family caregivers of persons with dementia in professional practice settings or in the community. Knowing that a caregiver's reaction to depressive and disruptive symptoms of dementia expressed by their family member can adversely affect their coping ability and mental health, educational and support groups for dementia caregivers should be designed to: 1) provide information on the possible range of dementia symptoms; 2) include strategies for increasing caregiver awareness of their reactions to the dementia symptoms expressed by their family member, especially the depressive and disruptive symptoms; and 3) assess the effects of the caregiver reactions on their overall mental health.

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Table 1.

Caregiver reactions to dementia symptoms and their coping repertoire (resourcefulness and spiritual practices)

N = 138	Resourcefulness				Spiritual Practices			
Caregiver Reactions to	B	SE B	β	Part r	B	SE B	β	Part r
Depressive Symptoms	-.57 *	.23	-.24 *	-.17 *	-.40 *	.17	-.25 *	-.19 *
Disruptive Symptoms	-1.04 ***	.29	-.12 ***	-.25 ***	-.18	.22	-.09	-.07
Memory-related Symptoms	-.44	.26	-.12	-.12	-.17	.20	-.07	-.07
Adjusted R ²	.32				.101			
F	22.87 ***				6.11 ***			

Notes:

*
p<.05,**
p<.01,***
p<.001

Table 2.

Caregiver reactions to dementia symptoms and their mental health (perceived stress and depressive symptoms)

N = 138	Perceived Stress				Depressive Symptoms			
Caregiver Reactions:	B	SE B	β	Part r	B	SE B	β	Part r
Depressive Symptoms	.24 *	.11	.23 *	.17 *	.36 *	.14	.26 *	.19 *
Disruptive Symptoms	.31 *	.14	.23 *	.17 *	.49 **	.18	.28 **	.20 **
Memory-related Symptoms	.15	.13	.09	.09	.03	.16	.02	.02
Adjusted R ²	.19				.23			
F	11.74 ***				14.68 ***			

Notes:

*
p<.05,**
p<.01,***
p<.001