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Gender Effects on Components of Burden and Depression among Dementia Caregivers

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Abstract

Objective: Previous literature has examined burden and depression predominately as unitary constructs in relation to dementia caregiving. No studies thus far have examined gender differences in the specific components of burden and depression in dementia caregivers. The current study examined whether empirically-validated dimensions of caregiver burden, as measured by the Zarit Burden Interview (ZBI), and depression, as measured by the Center for Epidemiologic Studies Depression Scale (CESD) differed by gender for dementia caregivers.

Methods: The sample consisted of 211 community-residing dementia caregivers who reported some degree of distress and were enrolled in a longitudinal intervention study. Only baseline functioning was evaluated in this study. Levels of burden were assessed using the ZBI, and levels of depression were assessed using the CESD.

Results: Factor analysis revealed 3 facets of burden: impact of caregiving on caregivers' lives, guilt, and frustration/embarrassment, and 4 facets of depression: depressed affect, somatic and retarded activity, positive affect, and interpersonal feelings. Overall burden (p<.001) and the impact of caregiving on caregivers' life (p<.001) factor were significantly higher in females than in males. Additionally, overall levels of depression (p=.018) and the somatic and retarded activity (p=.018), depressed affect (p=.005), and positive affect (p=.012) factors were significantly higher in females.

Conclusions: Findings suggest that distressed male and female dementia caregivers experience caregiving differently. Results from this study could potentially be used to identify gender-specific interventions related to different subtypes of burden and depression to optimize quality of life for dementia caregivers.

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gender; dementia caregiving; burden; depression	

INTRODUCTION

Many older adults with dementia are cared for at home by their family members; typically adult children or spouses. Although there are positive aspects of the caregiving experience that can buffer the negative effects (Lloyd, Patterson, & Muers, 2014), it often entails emotional, physical, social, and financial burden, which may place added stress on caregivers (Bass et al., 2012, Sörensen, Duberstein, Gill, & Pinquart, 2006; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006; Papastavrou et al. 2007; Molyneux et al. 2008; Kim, Chang, Rose, & Kim 2012). In addition, caregivers have a higher risk of mortality than non-caregivers (Schulz & Beach, 1999). Caregivers who experienced high burden additionally exhibit significantly worse depression scores (Cuijpers, 2005; Epstein-Lubow, Davis, Miller, & Tremont, 2008), reduced functional status, lower life satisfaction, and anxiety (Liu et al., 2016).

Women have typically assumed the caregiver role and provide more family caregiving than men. The proportion of male caregivers, however, is increasing (Baker & Robertson, 2008; Pöysti et al., 2012). In general, female caregivers tend to experience more distress and utilize more services in the community than males. Further, it has been suggested that women are more likely to be exposed to stressors from caregiving and even perceive and cope with these stressors differently than men (Sharma, Chakrabarti, & Grover, 2016). For example, women tend to spend more time providing care, may experience greater levels of mental and physical strain, and experience higher levels of distress. Women caregivers are also more likely to experience stigma (Kahn et al., 2016), task difficulty and negative life changes (Jessup, Bakas, McLennon, & Weaver, 2015), increased guilt (Romero-Moerno et al., 2014), and significantly lower self-esteem (Washington et al., 2015) as compared to male caregivers. Conversely, males tend to experience less emotional distress, physical effects, and psychological effects than females (Gallicchio et al., 2002; Kramer, 2000). Men have been found to approach caregiving in a different way than females in that they are more taskoriented, and as such may not be as emotionally involved or as distressed as females (McFarland & Sanders, 1999). Other research posits that men may not be willing to admit the levels of stress as to not appear weak or vulnerable, and may have support from wives and female family members (Mc Donnell & Ryan, 2011).

This issue of whether men and women differ in their response to caregiving is not entirely clear. Several studies have failed to find significant gender differences on major caregiving outcomes (Serrano-Aguilar PG, Lopez-Bastida J, & Yanes-Lopez V, 2006; Tang et al., 2013; Russell, 2001; Baker, Robertson, & Connelly, 2010). Pöysti and colleagues (2012) did not find significant gender differences in depression, satisfaction with life, or loneliness. However, they did find that burden was significantly lower in males than in females. Similarly, McConaghy and colleagues (2005) failed to find significant differences in satisfaction with life, depression, burden, coping style, and physical health between male and female caregivers. As such, although men are increasingly assuming the caregiver role, the amount of and specific aspects of burden and depression they experience is worthy of additional research.

Some literature, however, demonstrates gender differences among caregivers, albeit not regarding specific factors relating to depression and burden. Brown and colleagues (2007), found a gender-specific difference in help-seeking behaviors in husband caregivers. Gender differences also emerge when gender boundaries are crossed and caregivers must take on responsibilities that their spouses previously performed, which may affect personal identity (Calasanti & Bowen, 2006). In addition, male spousal caregivers reported fewer stressors and overall depression than female spouses (Bookwala & Schulz, 2000).

Much of the past literature has examined gender differences in overall levels of depression and burden, and treated these variables as unitary constructs. Recent studies, however, have demonstrated that caregiver burden and depression are multidimensional. To our knowledge, no studies thus far have examined gender differences in specific factors of burden and depression.

The Zarit Burden Interview (ZBI) is a widely used measure of caregiver burden, and consists of questions designed to measure burden associated with both functional and behavioral impairments in care recipients, as well as the effect of caregiving on the caregiver's lives. The ZBI examines burden as a unitary construct, but recent factor analytic studies have revealed a two-factor structure: personal strain and role strain (Bedard et al., 2001; Hebert, Bravo, & Preville, 2000; O'Rourke & Tuokko, 2003); and three-factor structures: embarrassment/anger, dependency, and self-criticism (Flynn-Longmire & Knight, 2011; Knight, Fox, & Chou, 2000), and social consequences for caregivers, psychological burden, and guilt (Ankri et al., 2005). Springate and colleagues (2014) found a 3-factor structure: direct impact of caregiving upon caregivers lives, guilt, and frustration/embarrassment in a sample of dementia caregivers.

The purpose of this study was to examine if a differential relationship exists between the factors of burden and depression and gender in a sample of dementia caregivers. We used previously established factors for the ZBI and the CES-D, as described below (Longmire & Knight, 2010; Springate & Tremont, 2014). Importantly, as the components of these essential variables that are commonly the focus of study outcomes have not yet been examined in by gender in dementia caregiving, findings from this study may help to tailor specific treatment recommendations and support for dementia caregivers.

METHODS

Participants

Participants were enrolled in the Family Intervention: Telephone Tracking- Caregiver (FITT-C) randomized, controlled trial (Tremont et al., 2015). All participants were caregivers for individuals with dementia. Participants underwent a baseline assessment and were assigned to a telephone-delivered caregiver intervention; either the FITT-C or the Telephone Support (control) condition. For complete details of inclusion/exclusion criteria, see Tremont et al, (2013). Briefly, inclusion criteria for the caregivers in the FITT-C study included endorsement of two of nine negative experiences associated with caregiving (e.g., overwhelm, sad mood, family conflict, exhaustion). As such, caregivers were required to experience some level of distress to enter the study. Exclusion criteria for caregivers

consisted of: major medical illness; not primarily English speaking; cognitive impairment; those who were in caregiving role for at least 6 months and who provided at least 4 hours of assistance per day; and no access to a telephone. Inclusion criteria for care recipients in the FITT-C study included formal DSM-IV diagnosis of dementia documented by a neurologist, psychiatrist, or geriatrician; community-dwelling; and no plan for placement in long-term care or for the caregiver to end role within 6 months. Care recipients who were diagnosed with other major medical conditions that affected independent functioning were also excluded. Complete details about the study have been previously published elsewhere (Tremont et al., 2015; Tremont et al., 2013). All study procedures were approved by the Rhode Island Hospital Institutional Review Board.

Measures

Zarit Burden Interview (ZBI): To measure burden, we used the ZBI, which is a 22-item self-report measure that examines burden associated with caregiving. The ZBI measures subjective feelings the caregiver is experiencing related to negative impact of caregiving on physical, emotional, financial, and social functioning (Zarit, Reever, & Bach-Peterson, 1980). The ZBI has shown good internal consistency, validity, and reliability across multiple studies (Flynn-Longmire & Knight, 2011; Knight, Fox, & Chou, 2000; O'Rourke & Tuokko, 2003; Herbert, Bravo, & Preville, 2000).

Center for Epidemiology Studies Depression Scale (CES-D): To assess depression, we used the 20-item CES-D self-report inventory, which measures symptoms associated with depression. This measure has adequate reliability and validity (Radloff, 1977).

Statistical Analysis

We compared men and women on demographic and dementia severity characteristics. A principal component factor analysis (PCA) using Oblimin rotation was performed to examine the factor structure of the ZBI and the CES-D in our sample. For the ZBI, we set the fixed number of factors to three and for the CES-D, set the fixed number of factors to four to replicate previous factor analyses (Longmire & Knight, 2010; Springate & Tremont, 2014). Regression-based factor scores were also generated. One-way analyses of variance (ANOVA) were performed to examine the relationship between caregiver's gender and differences in ZBI and CES-D factors. All analyses were performed using SPSS 21.0.

For the present study, we used a previously validated three-factor solution of the ZBI that was derived from a sample of dementia caregivers that closely align with our population (Springate & Tremont, 2014). The factors were: direct impact of caregiving upon caregivers lives, guilt, and frustration/embarrassment. To examine depression, we used the Center for Epidemiologic Studies- Depression Scale (CES-D). We used four previously validated factors: depressed affect, somatic and retarded activity, positive affect, and interpersonal feelings (Longmire & Knight, 2010).

RESULTS

For the current study, 211 participants completed baseline assessments. Demographic characteristics are presented in Table 1. The study sample had a mean age of 62.79(SD=12.77) years, a mean education level of 14.92(SD=2.61) years, and a gender distribution of 77.7% female. The majority (96.2%) were Caucasian. The sample had a mean CES-D score of 16.09(SD=10.16) and a mean ZBI score of 38.61(SD=14.30). Men and women did not significantly differ in demographic characteristics (age, education, and ethnicity). There were no group differences in severity of dementia or frequency of behavior problems.

Overall, 90% of caregivers reported clinically significant burden (ZBI $\,$ 21) and 47% reported clinically significant depression (CES-D $\,$ 16) at baseline. Chronbach's alpha of the ZBI ($\alpha = 0.90$) and the CES-D ($\alpha = 0.89$) indicated good internal reliability.

For the ZBI, 3 factors were extracted (Table 2). The first factor, accounting for 38.5% of the variance, described the impact of caregiving on caregivers' lives (e.g., social life decreasing, health suffered, lost control of life, and feeling stressed and strained). The second factor, accounting for 10.16% of the variance, described feelings of guilt (e.g., feeling like they should be doing more for care recipient, feeling uncertain around recipient, feel they could be doing a better job caring for recipient). The third factor, accounting for 8.44% of the variance, reflected feelings of frustration and embarrassment (e.g., feeling embarrassed over recipient's behavior, feelings uncomfortable having people over).

On the ZBI total score, women reported a significantly higher level of burden compared to men (F=11.288, p=.001). Of the 3 factor scores generated from the ZBI, only the first factor (impact of caregiving on caregivers' lives) was significantly different by caregiver gender, with women scoring significantly higher on this factor than men (F=17.225, p<.001). There were no significant gender differences with the guilt or frustration/embarrassment factors.

PCA for the CES-D revealed 4 factors of depression (Table 3). The first factor, depressed affect (e.g., feeling depressed, lonely, sad, or fearful, crying spells), accounted for 33.43% of the variance. The second factor, accounting for 8.43% of the variance, reflected somatic and retarded activity (e.g., poor appetite and sleep, talked less than usual, difficulty getting going). The third factor, positive affect (e.g. feeling hopeful, happy, and enjoying life), accounted for 7.27% of the variance. The fourth factor, accounting for 5.83% of the variance, reflected interpersonal feelings (e.g., believing people were unfriendly).

Women scored significantly higher than men on overall level of depression (F=5.400, p=. 021). Of the 4 factor scores generated from the CES-D, depressed affect (F=10.945, p=. 001), somatic and retarded activity (F=5.646, p=.018), and positive affect (F=8.797, p=. 003) significantly differed by gender, with women scoring higher on these factors than men.

DISCUSSION

Our study identified significant gender differences in dimensions of caregiver burden and depression. Specifically, we found that women reported a significantly higher level of overall burden and the ZBI factor of impact of caregiving on caregivers' lives. There were no

significant gender differences with the guilt or frustration/embarrassment factors. In addition, women scored significantly higher than men on overall level of depression, and the CES-D factors of depressed affect, somatic and retarded activity, and positive affect. Findings from this study shed light on factors to attend to when working with both male and female caregivers to optimize well-being, and suggest caregiver interventions specifically tailored to gender may be particularly effective in reducing symptoms of burden and depression. Specifically, the impact that the caregiving experience is having on the caregivers' lives, depressed affect, and somatic activity should be targeted in females. Past studies (Elliot, Burgio, & DeCoster, 2010; Schulz et al., 2003; Tremont et al., 2015) used risk assessment approaches to tailor interventions. Future interventions might incorporate results from the present study and specifically tailor interventions to male and female caregivers.

One explanation for the gender differences seen herein may be related to the stress-coping theory (Papastavrou et al., 2009). Studies have determined that women use more ineffective coping styles (e.g., fantasy, denial, escape, avoidance) more frequently than men, who tend to use effective coping strategies (e.g., problem-solving, acceptance, distancing) (Sharma, Chakrabarti, & Grover, 2016). The disparity of coping strategies could explain the higher levels of burden and depression among women. As such, a focus of therapy or treatment for burden in female dementia caregivers could focus on effective coping strategies aimed the impact of caregiving on caregivers' lives. Specifically, as questions from this factor reflect a change in the caregivers' lifestyle, treatment focused on rebuilding social networks, resuming leisure activities and hobbies, regaining control of their lives, and having time to focus on themselves may be particularly beneficial to female dementia caregivers.

In terms of depression, treatment in female caregivers should be focused on both depressed affect (alleviating low mood, feelings of failure, loneliness, and sadness) and somatic and retarded activity (low appetite, everything is effortful, restless sleep, unable to "get going). Interestingly, females were also significantly higher than males on positive aspect factor of the CES-D. As such, treatment aimed at bolstering positive thoughts (feeling hopeful about the future, feeling happy, and enjoying life) may have an added beneficial effect on female caregivers' mood. This could be particularly useful as previous studies have shown that positive aspects of caregiving buffer negative caregiving consequences and moderate treatment effects, and that positive and negative aspects work independently of each other (Lloyd, Patterson, & Muers, 2014; Tarlow et al., 2004).

In sum, it appears females may experience caregiving in more emotional ways than men, who may be experiencing negative effects of caregiving in different ways (poor health, poor sleep). Even though we required the caregivers have some level of distress prior to entering the study, men are not reporting as much burden and depressive symptoms as women. Therefore, the typical measures to assess negative aspects of caregiving may not capture males' experiences and may be more sensitive to the type of experience female caregivers are undergoing. Future studies could explore this in greater detail and detect and assess the ways in which distress manifests in male caregivers.

Limitations of this study include a predominantly Caucasian, female caregiver population, who are caring for patients with dementia. Thus, to generalize our findings to caregiving populations, the effect of gender on factors of caregiver burden and depression should be replicated in more diverse populations. Furthermore, as the ZBI and CES-D are self-report measures, there are some concerns that participants may exaggerate or under-report their perceived level of burden or depression to either make their situation seem worse or minimize their problems, which could result in a response-bias. However, the ZBI and CES-D have previously established reliability and validity.

Nevertheless, these results have important implications for our understanding of specific dimensions of burden and depression among dementia caregivers. Taken together, the caregiving experience and negative effects from caregiving may differ according to gender, which is consistent with other studies illustrating gender differences in caregiver burden and depression (Jessup, Bakas, McLennon, & Weaver, 2015; Kahn et al., 2016; Romero-Moerno et al., 2014; Washington et al., 2015). In addition, results of this study suggest that although the ZBI and the CES-D are typically utilized as a unitary measure of burden and depression, they likely reflect several different dimensions of these factors. Further, there are significant gender differences on the factors of burden, depression, and on relationship satisfaction, which have implications for the assessment and treatment of these outcomes in dementia caregivers. Given the complexity of these two constructs, targeted intervention approaches that may impact specific dimensions of burden and depression according to gender may be a useful line of future research.

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Table 1.

Caregiver Sample Characteristics

Variable	Mean (SD)	Range
Total Sample (n)	211	
Women: n (%)	164 (77.7)	
Age (years)- Total Sample	62.79 (12.77)	25.00-91.00
Females	61.55 (12.21)	25.00-91.00
Males	67.09 (13.82)	38.00-86.00
Education (years)	14.92 (2.61)	8.00-20.00
Females	14.84 (2.56)	8.00-20.00
Males	15.19 (2.81)	8.00-20.00
Ethnicity: n (% Caucasian)- Total Sample	203 (96.2)	
Females	158 (96.3)	
Males	45 (95.7)	
ZBI Total Score- Total Sample	38.61(14.3)	4.00-77.00
Females	40.34 (13.69)	4.00-72.00
Males	32.57 (14.87)	6.00-77.00
CES-D Total Score- Total Sample	16.09(10.16)	0.00-47.00
Females	16.98 (10.06)	0.00-47.00
Males	12.96 (9.98)	0.00-45.00

Notes: ZBI= Zarit Burden Interview; CES-D = Center for Epidemiology Studies Depression Scale

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Table 2Principal Components Analysis Factor Loadings- ZBI

ZBI Items		Factor Loadings		
	1	2	3	
Do you feel that you don't have as much privacy as you would like, because of your relative?	.764			
Do you feel that your social life has suffered because you are caring for your relative?	.823			
Do you feel your health has suffered because of your involvement with your relative?	.760			
Do you feel that you have lost control of your life since your relative's illness?	.811			
Do you feel that because of the time you spend with your relative you don't have enough time for yourself?	.809			
Overall, how burdened do you feel in caring for your relative?	.764			
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	.742			
Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	.600			
Do you feel strained when you are around your relative?	.665			
Do you wish you could leave the care of your relative to someone else?	.641			
Do you feel uncertain about what to do about your relative?		.626		
Do you feel you should be doing more for your relative?		.904		
Do you feel you could do a better job in caring for your relative?		.835		
Do you feel angry when you are around your relative?			.678	
Do you feel that your relative asks for more help than he/she needs?			.743	
Do you feel embarrassed over your relative's behavior?			.698	
Do you feel uncomfortable about having friends over because of your relative?			.607	
Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?			.648	
Eigenvalue	6.937	1.828	1.519	
% Variance	38.537	10.158	8.440	
Cumulative Variance	38.537	48.696	57.136	

Notes: Extraction Method: Principal Component Analysis.

Rotation Method: Direct Oblimin with Kaiser Normalization

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Table 3
Principal Components Analysis Factor Loadings- CES-D

CES-D Items	Fac	Factor Loadings		
	1	2	3	4
I felt that I could not shake off the blues even with help from my family or friends	.718			
I felt depressed	.777			
I thought my life had been a failure	.596			
I felt fearful	.604			
I felt lonely	.614			
I had crying spells	.685			
I felt sad	.836			
I was bothered by things that usually don't bother me		.566		
I did not feel like eating; my appetite was poor		.690		
I had trouble keeping my mind on what I was doing		.530		
I felt that everything I did was an effort		.689		
My sleep was restless		.444		
I talked less than usual		.707		
I could not get "going"		.618		
I felt that I was just as good as other people			.604	
I felt hopeful about the future			.682	
I was happy			.812	
I enjoyed life			.828	
People were unfriendly				.656
I felt that people disliked me				.738
Eigenvalue	6.686	1.687	1.454	1.166
% Variance	33.428	8.433	7.268	5.828
Cumulative Variance	33.428	41.862	49.129	54.957

Notes: Extraction Method: Principal Component Analysis.

Rotation Method: Direct Oblimin with Kaiser Normalization