

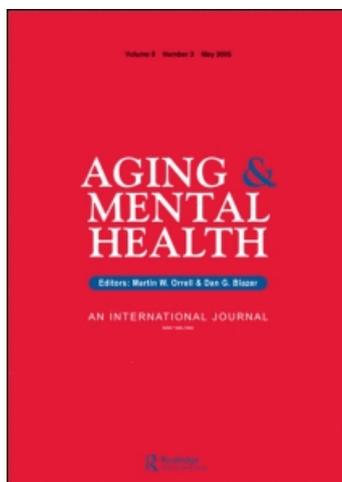
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### The structure of risk factors and outcomes for family caregivers: Implications for assessment and treatment

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## The structure of risk factors and outcomes for family caregivers: Implications for assessment and treatment

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**Purpose:** We examined the associations among risk factors (e.g., behavioral problems, family conflict) and outcomes (e.g., overload, depression) commonly used in the research literature in order to inform the design of caregiver assessment and interventions.

**Methods:** A sample of 67 caregivers caring for a family member in the middle stages of dementia were assessed on 15 risk factors and six outcome measures.

**Results:** Risk factors were at best only moderately correlated with one another, suggesting their relative independence. Outcome measures showed somewhat higher correlations with one another, but participants varied in terms of the number and type of outcomes that were elevated. Multivariate results showed that risk factors differed in their contribution to models, predicting various outcomes.

**Implications:** Caregivers possess unique combinations of risk factors and outcomes that suggest the need for individualized or tailored interventions. Designing an effective caregiver assessment and corresponding targeted intervention requires careful planning and selection of appropriate risk factors and outcomes.

**Keywords:** dementia caregiving; interventions; stress

### Introduction

Understanding the association among risk factors and outcomes commonly used in research on family caregivers can better inform the design of assessment and interventions. Theoretical models have long viewed caregiving stress as a multidimensional, dynamic process (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000; Vitaliano, Maturo, Ochs, & Russon, 1989), where stressors and resources (or lack thereof) act in concert to mediate or moderate outcomes (Lazarus & Folkman, 1984; Pearlin et al., 1990). Stressors experienced by caregivers include the care receiver's functioning, behavior, and emotions (primary stressors), as well as the consequences that care demands have on other areas of the caregiver's life (secondary stressors), such as work or taking care of their own health. In turn, stressors are acted upon by social and psychological resources that can mediate or moderate their effects on outcomes. Caregivers can draw upon these resources to manage the various challenges they face, including subjective dimensions such as the meaning they attribute to the care situation and their own emotions. Together, stressors and resources operate in dynamic interplay to produce outcomes, conceptualized as the consequences of prolonged incumbency in the care role. Outcomes for caregivers include declining mental health (e.g., depressive symptoms) and physical health, as well as feelings of burden and giving up the caregiving role (Aneshensel et al. 1995; Schulz, O'Brien, Bookwala, &

Fleissner, 1995; Vitaliano, Zhang, & Scanlan, 2003). High levels of stressors and low or inadequate resources can be considered together as risk factors for adverse outcomes.

In moving from a theoretical model to an intervention plan, studies typically highlight a specific stress pathway, focusing in on one or two risk factors (e.g., Gitlin, Belle, Burgio, Czaja et al., 2003; Schulz et al., 2000, 2003) and targeting a mediator or moderator of the stress pathway so that its impact on an outcome can be mitigated. One example of a single treatment is training in behavioral management (e.g., Burgio, Stevens, Guy, Roth, & Haley, 2003). As we show with path 'a' in Figure 1, this treatment is hypothesized to help caregivers better manage and thus reduce the frequency of the behavioral and psychological symptoms of dementia (BPSD). In turn, decreasing BPSD is expected to have an effect on an outcome, in this case, by lowering caregivers' depressive symptoms. We illustrate this by the solid path (path b) between the BPSD and the outcome. To the extent that other constructs are measured, they are typically treated as covariates or used to test subsidiary hypotheses. The advantage of implementing this type of single treatment is the ability to determine its impact separate from other types of treatment. By contrast, when multiple treatment components are implemented, it is difficult to determine which parts of the treatment are effective and which have little value.

Despite these advantages, the single treatment design has some potential drawbacks. A major

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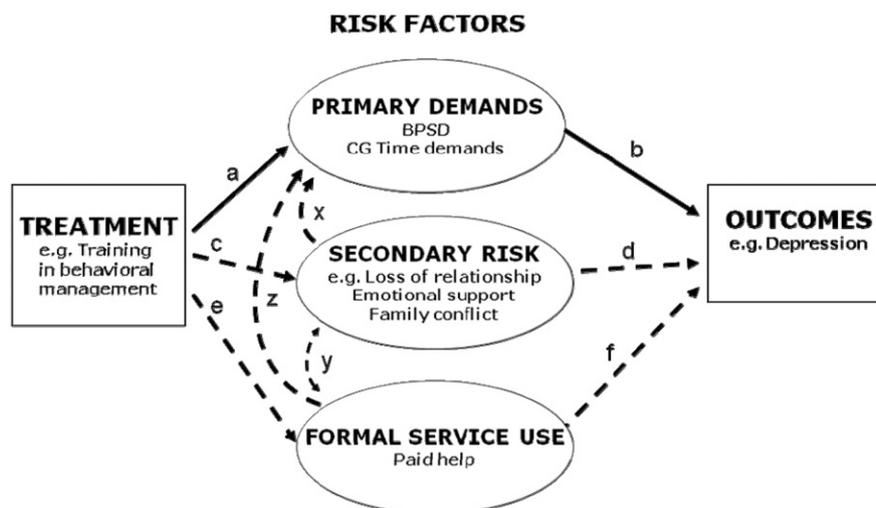


Figure 1. Stress process model showing the effect of treatment on risk factors and outcomes.

Note: Solid paths indicate the effects of a single treatment design. The dotted paths indicate the multiple influences and reciprocal effects between constructs.

shortcoming of this design is the implicit assumption that all caregivers experience the same risk factors (e.g., behavioral stressors) and, as a result, need the same treatment (e.g., behavioral management). In contrast to this assumption, growing evidence from diverse research areas indicates that multiple risk factors can contribute independently to the same outcome. Outcomes such as depression, falls among the elderly, hypertension, substance abuse, and conduct disorder among children have come to be viewed as having multiple risk factors (e.g., Conduct Problems Prevention Research Group, 2007; Sobell & Sobell, 1999; Tinetti, McAvay, & Claus, 1996). In Figure 1, we illustrate the challenges of accounting for multiple risk factors when planning treatment by the dotted paths between the treatment, risk factors, and outcomes. When the outcome of interest (e.g., depression) is the result of multiple and reciprocal influences among risk factors (paths *x*, *y*, and *z*), the particular risk factors that contribute to depression may differ from one person to the next. For one caregiver, depressive symptoms may be the consequence of being overwhelmed by BPSD (path *a*), and therefore a treatment to reduce BPSD should be helpful. Another caregiver may feel depressed due to a high degree of conflict with family members over how care is being provided (path *d*) or because he lacks formal services (path *f*) or some combination in between. In this case, behavior management treatment is not likely to address this caregiver's conflict with his family (path *c*) or formal service use (path *e*). In fact, a treatment that addresses a risk factor the caregiver does not possess, but fails to target ones that he/she does have is not likely to be effective. In that type of situation, caregivers may show no change as a result of treatment, may fail to comply or withdraw from treatment, or may experience a worsening of symptoms in reaction to the intervention (Bierman, 2002; Collins, Murphy, & Bierman, 2004; Collins, Murphy, Nier, & Strecher, 2005).

Our multivariate perspective of caregiving risk factors can be extended to the conceptualization of outcomes. Following typical public health approaches, most caregiving treatment studies focus on single outcomes (e.g., depression, health symptoms), yet in this population there may be heterogeneity in multiple outcomes. Some caregivers may experience depressive feelings when exposed to chronic stress while others may suffer from worsening health. The pathways to these two outcomes may or may not be similar (i.e., the result of the same or different risk factors), and treatment directed at one might be affected by the presence or absence of the other. A caregiver who is both depressed and in poor health may benefit more from a treatment that addresses a specific need (i.e., relief from stress exposure), rather than from training in a new skill (e.g., behavior management).

The present investigation is an exploratory and descriptive analysis of the association among risk factors and outcomes in a sample of family caregivers of persons with dementia. In conceptualizing this study, we draw upon and extend the Pearlin stress process model of caregiving (Aneshensel et al., 1995; Pearlin et al., 1990) that highlights the multidimensional structure of stress. Whereas Pearlin and colleagues selected variables to test a theoretical model of the stress process, we focus on constructs previously addressed in caregiver treatment studies that could inform the design of caregiver assessment instruments or treatment (e.g., Belle et al., 2006; Burgio et al., 2003; Farran, Loukissa, Perraud, & Paun, 2003; 2004; Mittelman, Roth, Coon, & Haley, 2004; Zarit, Stephens, Townsend, & Greene, 1998). By exploring the associations among risk factors and outcomes, this study examines: (1) potential risk factors that might be most useful when designing a comprehensive assessment for caregivers and targeting a treatment for particular outcomes and (2) whether heterogeneity among caregivers in risk factors and outcomes might

indicate the need for more individualized or tailored treatment protocols.

## Methods

### Sample

The sample consisted of 67 family caregivers of community-dwelling persons with dementia recruited from direct service organizations and research centers in the greater Cleveland metropolitan area (i.e., the Elder Care Services Institute of the Benjamin Rose Institute, the Cleveland Chapter of the Alzheimer's Association, the University Memory and Aging Center of University Hospitals and Case Western Reserve University), and through direct outreach. The project manager called potential participants to explain the study and conduct a brief screening interview to determine eligibility.

Eligibility for the study included being the self-identified primary caregiver for a person with a dementia diagnosis and reporting some degree of care-related stress. Caregivers did not have to live in the same household with the care receiver, but needed to have regular contact and responsibility for care. Care receivers had to live in ordinary community housing, not in specialized housing for older people or for individuals with dementia. Of the eligible caregivers who were contacted, 87% agreed to participate in the study. Sample characteristics are shown in Table 1.

### Procedures

Caregivers who were eligible for the study were interviewed in their homes by a trained interviewer. Interviews lasted on average 2 h (SD = 0.56) and covered a wide range of topics, including sociodemographic characteristics of the caregiver and person with dementia, risk factors and outcomes.

## Measures

### Risk factors

In selecting risk factors we were guided by stress models of caregiving (e.g., Pearlin et al., 1990; Schulz et al., 2000) by studies of the relationship between risk factors and outcomes (e.g., Aneshensel et al., 1995; Schulz et al., 1995), as well as our own prior work (Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Zarit & Femia, 2008). Measures of risk included both stressors and resources that could mediate or moderate the outcomes. Ideally each stressor would be matched to a resource that could potentially reduce or ameliorate the effects of that stressor on an outcome. We found, however, it was not possible to align measures of stressors with specific resources. For example, a stressor such as BPSD might be alleviated by multiple resources, such as caregiver's knowledge and/or skill in managing behavior problems or having time away from the person with dementia. Likewise, a resource such as social support potentially addresses more than

Table 1. Sample baseline characteristics.

Caregiver	
Relationship (%)	
Husband	16.4
Wife	38.8
Daughter or daughter-in-law	34.3
Son or son-in-law	7.5
Other	3.0
Gender (% female)	74.6
Age (years)	
<i>M</i> (SD)	62.5 (11.6)
Range	41–85
Race (%)	
European American	62.7
African American	35.8
Asian or other	1.5
Ethnicity (% Hispanic)	
	1.5
Education	
High school or less	21.2
Some college/graduate	65.2
More than college	13.6
Income ( <i>Mdn</i> , \$ per year in US dollars)	30,000–39,999
Employment (% yes)	44.8
Care receiver with dementia	
Problem onset [ <i>M</i> , years, (SD)]	6.31 (4.28)
Gender (% female)	56.7
Age (years)	
<i>M</i> (SD)	77.5 (10.1)
Range	51–94
Education	
High school or less	47.0
Some college/graduate	40.5
More than college	10.1
Income ( <i>Mdn</i> , \$ per year in US dollars)	Less than \$10,000

one stressor. Our resulting set of 15 measures of risk was one that would typically be considered for a comprehensive caregiver assessment for research or clinical services, which was consistent with one goal of the study – to inform development of a comprehensive assessment for planning interventions. Following the Pearlin et al. model, we grouped 15 risk factors into three areas (refer also to Figure 1): (1) risks related to primary care demands ('primary demands'), (2) risks related to the spillover of care demands into other areas of the person's life, including roles, relationships, and activities ('secondary risks'), and (3) risks associated with low use of supportive services and barriers to using help ('formal service use'). For conceptual clarity, we have coded stressors and resources so that higher scores always equal higher levels (e.g., more BPSD, more emotional support). Because of the large number of risk measures, we have summarized their characteristics in Table 2. Table 3 shows the means and standard deviation (SD) of scores for risk factors.

### Outcomes

In the stress process model, the criterion for an outcome measure is that it captures the impact that stressors have on caregivers' lives and well-being

Table 2. Description of risk measures and outcomes used in the study.

Measure (reference)	# items	Description	Response format	Reliability ( $\alpha$ )
<b>Primary demands</b>				
1. Activities of Daily Living (ADL) impairment (Lawton & Brody, 1969)	13	The sum of seven instrumental ADLs (shopping for food, cooking, etc.) and six personal ADLs (bathing, dressing, grooming, etc.)	0 = needs no help 1 = needs reminders 2 = needs a lot of help 3 = cannot do without help 0 = 0 h 1 = 1–4 h 2 = 5–8 h 3 = more than 8 hours 0 = did not occur to 4 = occurred every day.	0.92 (acceptable)
2. Caregiver (CG) demands	2	How long during the day can CG stay home alone, and how many hours per day do you spend assisting your CG?	0 = 0 h 1 = 1–4 h 2 = 5–8 h 3 = more than 8 hours 0 = did not occur to 4 = occurred every day.	0.59 (acceptable for a 2-item scale)
3. Frequency of behavior and psychological symptoms of dementia (BPSD) (Weekly Record of Behavior (WRB); Fauth et al., 2006; Femia, Zarit, Stephens & Greene, 2007)	33	(1) In the last week, how frequently did (agitation, mood, communication, etc.) occur?	0 = not upsetting to 4 = extremely upsetting	0.89 (acceptable)
4. Appraisals of BPSD (WRB; Fauth et al., 2006; Femia, et al., 2007)		(2) How stressful was this behavior?	0 = not at all to 3 = completely	0.85 (acceptable)
<b>Secondary risks</b>				
1. Loss (Pearlin et al., 1990)	4	Extent to which CG feel the loss of their relationship with the person with dementia	0 = none of the time to 3 = all of the time	0.68 (acceptable)
2. Dyadic strain (Sebern & Whitlatch, 2007)	8	Tension and frustration CG feels towards the CR over the past month.	1 = none or < once/week to 4 = help everyday; 0 = strongly agree to 3 = strongly disagree	n/a
3. Frequency of informal help	1	Amount of help from family and friends during a typical week	4-point scale ranging from strongly disagree to strongly agree	0.93 (acceptable)
4. Dissatisfaction with informal help	4	Dissatisfaction with the amount of help received	0 = no disagreement to 4 = a lot of disagreement	0.84 (acceptable)
5. Emotional support (Pearlin et al., 1990)	7	Degree to which CGs feel that others understand their situation, have someone to confide in, etc.		

(continued)

Table 2. Continued

Measure (reference)	# items	Description	Response format	Reliability ( $\alpha$ )
6. Family conflict (Pearlin et al., 1990)	15	Disagreements the CG has with family members over aspects of care.	4-point scale ranging from none of the time to all of the time.	0.89 (acceptable)
7. Health behaviors (Pearlin et al., 1990)	6	How often CGs engage in healthy (enough sleep) or risky behaviors (drink too much alcohol)		0.52 (acceptable for a risk scale)
8. Leisure (Deimling, Bass, Townsend, & Noelker, 1989)	8	Amount of time CG spent on social and leisure activities (visiting with friends, religious activities, etc.)	1 = a lot less time that I'd like to 3 = about the right amount of time	0.78 (acceptable)
<b>Formal service use</b>				
1. Frequency of formal help	1	Amount of paid help during a typical week	1 = none or < once/week to 4 = help everyday;	n/a
2. Sum of CG dissatisfaction with help	4	Dissatisfaction with the amount of help received	0 = strongly agree to 3 = strongly disagree	0.77 (acceptable)
3. Financial strain (Pearlin et al., 1990)	2	Monthly financial strain and whether money spent on caregiving is what the CG can afford.	3-point scale	0.52 (acceptable for a 2-item scale)
<b>Outcomes: Care specific</b>				
1. Role overload (Pearlin et al., 1990; Zarit et al., 1998)	6	In the past week, the extent to which care activities led to CG's feelings of being overwhelmed or exhausted.	0 = none of the time to 3 = all of the time	0.73 (acceptable)
2. Role captivity (Pearlin et al., 1990)	3	In the past week, the extent to which CG believed the care role was involuntary.	0 = none of the time to 3 = all of the time	0.67 (acceptable)
<b>Outcomes: General Well-being</b>				
3. Depressive symptoms (Patient Health Questionnaire, PHQ-9; Spitzer, Korenke, & Williams, 1999)	9	Over the last 2 weeks, how often did CG feel (tired, depressed, poor appetite, etc.)	0 = not at all to 3 = nearly every day.	0.71 (acceptable)
4. Anger (Hopkins Symptoms Checklist, HSC; Derogatis, Lipman, Covi, & Rickles, 1971)	5	Over the last 2 weeks, how often did CG feel (critical of others, annoyed, irritated, etc.)	0 = not at all to 3 = very much	0.82 (acceptable)
5. Positive affect [dementia quality of life instrument (DQoL); Brod, Stewart, Sands & Walton, 1999]	6	Over the last 2 weeks, how often did CG feel happy, joked with others, etc.	0 = never to 3 = very often	0.88 (acceptable)
6. Subjective health (medical outcome studies, MOS; Ware & Sherbourne, 1992)	9	Global subjective health; negative beliefs about one's health; and extent to which health has interfered with CGs everyday activities in the past month.	Varying responses; high scores indicated better subjective health.	0.77 (acceptable)

Note: Items were summed to form total scores. Higher scores indicate more of the construct (i.e., greater dissatisfaction, greater strain, better health, etc.).

Table 3. Descriptive statistics for risk factors and outcomes.

Risk factor	<i>M</i> (SD)	Range	<i>M</i> (SD) risk scores by tertiles		
			Low	Medium	High
<b>Primary demands</b>					
ADL impairment	23.01 (9.28)	4–39	13.23 (4.86)	25.92 (2.38)	34.93 (2.79)
CG demands	3.21 (1.84)	1–6	1.27 (0.45)	3.48 (0.51)	5.67 (0.46)
Frequency of BPSD	53.46 (17.70)	1–88	33.15 (11.88)	52.79 (5.39)	71.83 (7.71)
Appraisal of BPSD	34.75 (20.57)	0–92	14.60 (6.68)	32.50 (5.06)	58.13 (12.69)
<b>Secondary risks</b>					
Loss	7.95 (4.19)	0–12	3.75 (2.01)	8.83 (1.10)	12.81 (1.17)
Dyadic strain	7.12 (3.40)	0–16	3.24 (1.51)	7.26 (0.82)	11.00 (2.05)
Frequency of informal help	2.19 (1.23)	1–4	4.00 (0.00)	2.65 (0.48)	0.93 (0.26)
Dissatisfaction with informal help	5.61 (2.75)	0–9	2.69 (1.38)	6.58 (1.17)	8.65 (0.49)
Emotional support	17.39 (3.91)	5–21	20.61 (0.50)	17.80 (1.15)	12.87 (3.18)
Family conflict	16.03 (11.07)	0–46	4.29 (3.21)	14.64 (3.30)	28.25 (7.04)
Health behavior	10.83 (2.64)	2–13	13.86 (1.01)	11.04 (0.82)	7.86 (1.17)
Leisure	16.04 (4.10)	8–24	20.56 (1.47)	16.09 (1.15)	11.27 (1.75)
<b>Formal service use</b>					
Frequency of formal help	2.28 (1.26)	1–4	4.00 (0.00)	2.70 (0.47)	0.96 (0.19)
Dissatisfaction with formal help	3.97 (2.57)	0–9	2.03 (0.95)	4.31 (0.48)	7.50 (1.47)
Financial strain	1.81 (1.38)	0–5	0.78 (0.42)	2.00 (0.00)	3.94 (0.77)
<b><i>M</i> (SD) outcome scores by tertiles</b>					
Risk factor	<i>M</i> (SD)	Range	Low	Medium	High
<b>Care specific</b>					
Role overload	10.64 (3.30)	2–16	6.44 (1.88)	10.55 (1.15)	14.18 (1.30)
Role captivity	2.32 (2.12)	0–9	0.00 (0.00)	1.36 (0.49)	4.37 (1.84)
<b>General well-being</b>					
Depressive symptoms	6.67 (4.49)	0–20	2.26 (1.57)	5.78 (0.65)	11.19 (3.32)
Anger	6.15 (4.08)	0–18	1.95 (0.90)	5.45 (1.22)	10.83 (2.61)
Positive affect	14.40 (4.43)	4–24	19.13 (2.36)	14.15 (1.65)	9.00 (2.30)
Subjective health	12.82 (3.98)	3–21	16.50 (1.80)	12.78 (3.98)	7.95 (1.94)

(Pearlin et al., 1990). For the study, we investigated two kinds of outcomes: care-specific outcomes and general measures of well-being. Table 2 describes the outcome measures used for the study and Table 3 shows the means and SDs.

### Analysis procedures

Given the small sample size relative to the number of variables, certain types of multivariate analyses (e.g., latent models) were not possible; hence, the goal of the study was descriptive and exploratory rather than predictive or seeking causative explanations. The analyses proceeded in several steps where first we examined the correlations among risk factors, among outcomes, and then between risk factors and outcomes. We also wanted to extend these bivariate analyses by dividing scores into those indicating, on average, a high-risk or poor outcome. To do that, we divided each risk factor and outcome measure into high, medium, and low scores using a tertile split based on the distribution of scores on each measure. Table 3 shows the mean scores on each risk and outcome variable for caregivers who fell in each tertile for that variable. As a last step, we conducted a series of multiple linear

regressions using the risk factors as independent variables to predict each of the six dependent variable outcomes. To reduce the number of predictors in each regression model, we simultaneously entered only those risk factor variables with a significant zero order correlation with the dependent measure.

### Results

#### Correlations among risk factors

As shown in Table 4, correlations among the 15 risk factors were mainly in the low to moderate range (0.2–0.4). Only 3 of the 15 risk factors showed high associations with each other. Frequency and appraisal of BPSD were highly correlated ( $r=0.76$ ,  $p<0.001$ ). This finding is expected, because the measures are partly dependent on one another. The greater the frequency of BPSD, the more upsetting and stressful the behavior was for the caregiver. Both of these measures were highly and positively correlated with dyadic strain ( $r=0.64$ ,  $p<0.001$  for frequency and  $0.68$ ,  $p<0.001$  for appraisal). At a lower magnitude, frequency of BPSD was correlated with dissatisfaction with informal help ( $r=0.35$ ,  $p<0.05$ ), family conflict ( $r=0.48$ ,  $p<0.05$ ), and health behavior ( $r=-0.26$ ,  $p<0.05$ ).

Table 4. Correlations among risk factors.

Risk factors	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
<b>Primary demands</b>															
1. ADL impairment	–														
2. CG demands	<u>0.62</u>	–													
3. Frequency – BPSD	–0.04	0.08	–												
4. Appraisal – BPSD	–0.22	–0.16	<u>0.76</u>	–											
<b>Secondary risks</b>															
5. Loss	<u>0.40</u>	0.18	0.20	0.23	–										
6. Dyadic strain	–0.06	0.00	<u>0.64</u>	<u>0.68</u>	<u>0.26</u>	–									
7. Freq. informal help	0.20	0.12	–0.11	–0.16	0.02	–0.24	–								
8. Dissat. informal help	<u>0.25</u>	0.11	<u>0.35</u>	<u>0.39</u>	0.22	<u>0.34</u>	<u>–0.26</u>	–							
9. Emot. support	–0.21	<u>–0.24</u>	–0.10	–0.21	–0.18	<u>–0.26</u>	<u>0.14</u>	<u>–0.32</u>	–						
10. Family conflict	–0.08	–0.08	<u>0.48</u>	<u>0.29</u>	0.11	<u>0.29</u>	–0.07	<u>0.39</u>	0.05	–					
11. Health behavior	0.16	0.14	<u>–0.26</u>	<u>–0.26</u>	–0.08	<u>–0.27</u>	0.14	–0.12	0.20	<u>–0.34</u>	–				
12. Leisure	–0.07	–0.05	<u>–0.15</u>	<u>–0.20</u>	–0.03	<u>–0.21</u>	<u>0.31</u>	<u>–0.40</u>	<u>0.27</u>	<u>–0.11</u>	0.14	–			
<b>Formal service use</b>															
13. Frequency of formal help	<u>0.40</u>	<u>0.26</u>	–0.23	<u>–0.27</u>	0.04	<u>–0.29</u>	0.01	0.13	–0.05	–0.07	<u>0.26</u>	0.04	–		
14. Dissatisfaction formal help	–0.19	–0.05	0.20	<u>0.25</u>	–0.00	0.19	0.21	0.19	–0.06	0.23	–0.12	–0.13	<u>–0.49</u>	–	
15. Financial strain	0.03	0.05	0.13	<u>0.22</u>	0.08	–0.03	0.14	0.20	–0.08	0.08	–0.00	–0.21	<u>–0.02</u>	<u>0.39</u>	–

Note: Underlined values indicate significance ( $p < 0.05$ ).

Appraisal of BPSD showed a low correlation with the frequency and dissatisfaction with formal help, indicating that caregivers who rated BPSD as more stressful were those who had less formal help and were more dissatisfied with the amount of formal help that they received ( $r = -0.27, p < 0.05$  for frequency of formal help and  $r = 0.25, p < 0.05$  for dissatisfaction with formal help). The associations among the remaining risk factors were low to moderate at best.

**Caregiver patterns of risk factors**

By dividing the 15 risk factor scores into tertiles, we were able to examine further the relation among risk factors and determine if caregivers with elevated scores on one risk measure (as indicated by a score in the highest tertile) tended to have high scores on all of the risk measures, or if the pattern of risk scores were more heterogeneous. Results showed that caregivers had a mean of nearly four risk variables ( $m = 3.79$ ;  $SD = 2.44$ ) on which scores were in the highest tertile. However, results also indicated that caregivers were actually quite heterogeneous in terms of their patterns of elevated scores. At the extremes, one caregiver showed one risk factor in the medium tertile and 14 in the low range, while two caregivers had scores on 10 risk factors in the highest tertile, and three or four in the medium category. The remaining 64 caregivers were spread along the full continuum of possible scores, showing high risk in some areas and low or medium risk in other areas. Highlighting this heterogeneity, no two caregivers showed the same combination of elevated risk factors.

**Correlations among outcome measures**

Correlations among the six outcome variables fell for the most part in the moderate range between  $-0.48$

and  $0.60$ . All but one correlation (subjective health and anger,  $r = -0.17$ ) reached statistical significance (Table 5). Subjective health had the lowest correlations with the other measures, while depressive symptoms had the highest associations, particularly with role overload ( $r = 0.60, p < 0.05$ ) and role captivity ( $r = 0.56, p < 0.05$ ).

We considered the number of outcomes on which caregivers had scores in the highest tertile (indicating an adverse outcome). Results showed that caregivers had, on average, two outcome measures on which scores fell in the highest tertile ( $SD = 1.65$ ). At the extremes, one caregiver was in the lowest tertile (i.e., best outcome) on all six outcome variables, and one caregiver was in the highest tertile on all six. Most caregivers, however, were clustered around the mean, but with considerable between-person variability on which outcomes measures had elevated scores. In sum, we found that for both risk factors and outcomes, the pattern of elevated scores showed a high degree of heterogeneity across caregivers.

**Correlation of risk factors with outcomes**

Table 6 shows the correlations between risk factors and outcomes together. Some risk factors had moderate to high associations with most or all of the outcome measures, particularly, the frequency and appraisal of BPSD, dyadic strain, dissatisfaction with informal help and family conflict. Emotional support showed consistent correlations with four of the six outcomes, but the magnitudes of the coefficients were only in the low range ( $r = -0.34$  to  $0.31$ ). Other risk factors shared statistical variance with one or two specific outcomes, rather than with most or all of the outcomes. Caregiver demands were significantly correlated only with positive affect ( $r = -0.30, p < 0.05$ ), and leisure was

Table 5. Correlations among outcomes.

Risk factors	1	2	3	4	5	6
<b>Care specific</b>						
1. Role overload	–					
2. Role captivity	<u>0.52</u>	–				
<b>General well-being</b>						
3. Depressive symptoms	<u>0.60</u>	<u>0.56</u>	–			
4. Anger	<u>0.46</u>	<u>0.45</u>	<u>0.51</u>	–		
5. Positive affect	<u>–0.48</u>	<u>–0.50</u>	<u>–0.49</u>	<u>–0.47</u>	–	
6. Subjective health	<u>–0.31</u>	<u>–0.26</u>	<u>–0.43</u>	<u>–0.17</u>	<u>0.35</u>	–

Note: Underlined values indicate significance ( $p < 0.05$ ).

Table 6. Correlations between risk factors and outcomes.

Risk factors	Outcomes					
	Role overload	Role captivity	Depressive symptoms	Anger	Positive affect	Subjective health
<b>Primary demands</b>						
1. ADL impairment	0.11	–0.08	–0.07	–0.12	–0.23	0.03
2. CG Demands	0.13	–0.16	–0.04	0.11	<u>–0.30</u>	–0.08
3. Frequency – BPSD	<u>0.46</u>	<u>0.44</u>	<u>0.56</u>	<u>0.46</u>	<u>–0.39</u>	–0.17
4. Appraisal – BPSD	<u>0.49</u>	<u>0.54</u>	<u>0.63</u>	<u>0.50</u>	<u>–0.40</u>	–0.11
<b>Secondary risks</b>						
5. Loss	<u>0.22</u>	<u>0.29</u>	0.21	0.05	<u>–0.40</u>	0.01
6. Dyadic strain	<u>0.46</u>	<u>0.54</u>	<u>0.55</u>	<u>0.58</u>	<u>–0.46</u>	<u>–0.33</u>
7. Frequency informal help	–0.14	–0.16	–0.12	–0.17	<u>0.15</u>	<u>0.13</u>
8. Dissatisfaction informal help	<u>0.39</u>	<u>0.42</u>	<u>0.30</u>	<u>0.35</u>	<u>–0.33</u>	–0.09
9. Emotional support	<u>–0.20</u>	<u>–0.27</u>	<u>–0.22</u>	<u>–0.30</u>	<u>0.33</u>	<u>0.13</u>
10. Family conflict	<u>0.47</u>	<u>0.31</u>	<u>0.45</u>	<u>0.38</u>	<u>–0.25</u>	<u>–0.24</u>
11. Health behavior	<u>–0.46</u>	<u>–0.46</u>	<u>–0.54</u>	<u>–0.27</u>	<u>0.37</u>	<u>0.31</u>
12. Leisure	<u>–0.35</u>	–0.05	–0.22	–0.07	<u>0.07</u>	<u>0.14</u>
<b>Formal service use</b>						
13. Frequency formal help	–0.06	–0.10	<u>–0.26</u>	–0.13	0.08	0.15
14. Dissatisfaction formal help	0.16	0.10	<u>0.08</u>	0.20	–0.05	–0.01
15. Financial strain	0.18	–0.04	–0.21	0.16	–0.00	0.11
16. Total of high-risk scores	<u>0.68</u>	<u>0.70</u>	<u>0.71</u>	<u>0.72</u>	<u>–0.66</u>	–0.15

Note: Underlined values indicate significance ( $p < 0.05$ ).

correlated with only role overload ( $r = -0.35, p < 0.05$ ). Four risk factors [activities of daily living (ADL) impairment, frequency of informal help, dissatisfaction with formal help, and financial strain] showed no significant associations with any of the six outcome variables. The number of risk factors that were elevated (scores in the highest risk tertile) had consistently high correlations with all the outcomes, except subjective health. The magnitude of these correlations was higher than for any individual risk factor. Finally, the total number of risk factors with elevated scores and total number of outcomes with elevated scores were strongly correlated ( $r = 0.68, p < 0.001$ ).

### Regressions of risk factors and outcomes

As a last step, we conducted a series of multiple linear regressions using the risk variables as independent predictors and each of the six outcomes as the

dependent variables. Because frequency and appraisal of BPSD were partly dependent on one another, we used only appraisals in the regressions. As noted, to reduce the number of variables in each regression, only those risk factors that had a significant zero-order correlation with the particular outcome measure under consideration were included in that regression. Results of these analyses are shown in Table 7. The resulting set of predictive risk factors varied by each outcome variable. Turning first to the two care-specific outcomes, overload was significantly predicted by family conflict and health behavior ( $\beta = 0.24$  and  $0.25$ , respectively,  $p < 0.05$ ), while role captivity was predicted only by health behavior ( $\beta = 0.31, p < 0.01$ ). Turning to the three affect measures, (1) depressive symptoms were significantly predicted by appraisal of BPSD ( $\beta = 0.37, p < 0.001$ ), family conflict ( $\beta = 0.20, p < 0.05$ ), and health behaviors ( $\beta = 0.33, p < 0.001$ ); (2) anger was predicted by dyadic strain ( $\beta = 0.35, p < 0.01$ ), and (3) positive affect was predicted by

Table 7. Regressions of risk factors and outcomes (standardized estimates).

Independent variables (risk factors)	Dependent variables (outcomes)					
	1. Overload	2. Captivity	3. Depressive symptoms	4. Anger	5. Positive affect	6. Subjective health
1. ADL impairment	–	–	–	–	–	–
2. CG demands	–	–	–	–	–0.30**	–
3. Frequency BPSD	–	–	–	–	–	–
4. Appraisal BPSD	0.21	0.21	0.37**	0.14	–0.15	–
5. Loss	–	0.12	–	–	–0.21*	–
6. Dyadic strain	0.11	0.21	0.15	0.36*	–0.18	–0.25*
7. Frequency – informal help	–	–	–	–	–	–
8. Dissatisfaction – informal help	0.07	0.20	–0.01	0.03	–0.06	–
9. Emotional support	–	–0.03	–	–0.16	0.06	–
10. Family conflict	0.24*	–0.01	0.20*	0.23	–0.04	–0.10
11. Health behavior	–0.25*	–0.31**	–0.33***	–0.02	0.27*	0.21
12. Leisure	–0.19	–	–	–	–	–
13. Frequency – formal help	–	–	–0.02	–	–	–
14. Dissatisfaction – formal help	–	–	–	–	–	–
15. Financial strain	–	–	–	–	–	–
Model	9.37***	8.19***	13.42***	7.31***	6.29***	4.35*
<i>F</i>						
Adjusted <i>R</i> <sup>2</sup>	0.43	0.43	0.54	0.36	0.39	0.13

Note: – = Variable not entered into the regression.

\*\*\*, \*\* and \* represent  $p < 0.001$ ,  $p < 0.01$  and  $p > 0.05$ , respectively.

caregiver demands ( $\beta = -0.30$ ,  $p < 0.01$ ), loss ( $\beta = -0.21$ ,  $p < 0.05$ ), dyadic strain ( $\beta = -0.18$ ,  $p < 0.05$ ), and health behavior ( $\beta = -0.27$ ,  $p < 0.05$ ). Lastly, only dyadic strain emerged as a significant predictor for subjective health ( $\beta = -0.25$ ,  $p < 0.05$ ).

## Discussion

The purpose of the present study was to explore the heterogeneity among caregivers in risk factors and outcomes, which could inform the design of a comprehensive caregiver assessment as well as the selection of an appropriate treatment. Our results provide evidence that risk factors in a sample of family caregivers were generally independent of one another and that caregivers were heterogeneous in their patterns of risk scores. These results are consistent with analyses conducted by Pearlin and his colleagues (Aneshensel et al., 1995), who found that the association among stressors and resources both at baseline and in longitudinal analyses were low to moderate at best (Aneshensel et al., 1995). In the present study, the exception was a cluster of three measures that were highly associated with one another, frequency and appraisal of BPSD and dyadic strain. The high degree of overlap among these three measures was not surprising given that they all revolve around behavioral and emotional problems that result from dementia. For the other risk factors, the degree of their association with one another was low to moderate at best, indicating that a caregiver who possesses a high level of one risk factor may or may not experience a high level of another risk factor. Caregivers also varied

in the number and type of risk factors on which they had elevated scores (i.e., falling in the highest tertile). Although all of these caregivers shared the common experience of dementia caregiving, each experienced and reacted to the stressors and resources somewhat differently.

This study also examined the associations among widely used caregiving outcome measures and found that these measures had somewhat higher correlations with each other than did risk factors, although the relation of the affective and care-specific measures to subjective health was surprisingly low. As with risk factors, caregivers showed variability in the number of outcome measures on which they had elevated scores. In other words, some caregivers might have an elevated score for one domain (depression), but not another (anger), while other caregivers might show the opposite pattern. Taken together, these findings on risks and outcomes provide further evidence for the heterogeneity in a caregiver's experience of a relative's dementia.

Bivariate analyses indicated that multiple risk factors were associated with each outcome measure. This finding was only partly supported by the multivariate analyses, in part, because of the small sample size. We also found in both the bivariate and the multivariate analyses that different combinations of risk factors predicted each outcome. It is noteworthy that there were strong associations between the number of elevated risk factors and the six outcome measures, suggesting that the *total number* of risks may be a more significant indicator of adverse outcomes for caregivers than *elevated* scores on any particular risk. Surprisingly, ADL impairment, frequency of informal help, dissatisfaction with formal help, and financial

strain showed no significant associations with any of the six outcome measures, and thus, may represent different dimensions of problems that are independent of a caregiver's affective status and health.

The risk factor with the most consistent relation across all the outcome measures was the caregiver's health behavior. Behavioral and psychological symptoms of persons with dementia are generally considered the most important risk factors for caregivers, and have been targeted most often in interventions. The current findings suggest that how caregivers manage their own health may have considerable consequences for stress-related outcomes. Health behaviors could have a direct, protective effect on caregivers' health and well-being, that is, caregivers who take better care of themselves may experience fewer negative outcomes, despite the level of other care-related stressors. It is also possible that health behaviors may have a mediating influence on outcomes. Specifically, care-related stressors may impinge on the time that caregivers have for managing their own health, which, in turn, leads to poorer outcomes (Son et al., 2007). We should also consider the possible reciprocal role of outcomes on health behaviors. In particular, caregivers who have higher depressive symptoms may be more likely to decrease health promoting activities such as exercise, and increase potentially harmful behaviors such as overeating. Whatever the specific pathway, health behaviors require more attention. In particular, interventions that specifically address these behaviors may prove very effective.

Taken together, these findings on the heterogeneity among risk factors and outcomes suggests the need for adaptive or tailored interventions for caregivers, that is, where the specific treatment components that are delivered to a particular individual or family are determined based on an assessment of risk factors and outcomes (Collins et al., 2004; 2005; Conduct Problems Prevention Research Group, 2007; Sobell & Sobell, 1999; Tinetti, McAvay, & Claus, 1996). The REACH II study of family caregivers of people with dementia (Belle et al., 2006) indirectly addressed these complexities. For REACH II, treatment components were assigned based on caregiver scores for three risk factors (health behaviors, social support, and distress in managing problem behaviors) and two outcomes (i.e., depression, burden). In contrast to prior caregiving interventions that have largely employed components focused on single risk factors, the findings of REACH II were generally positive. It is likely that other studies, notably the NYU caregiver interventions (Mittelman et al., 2004), accomplished the same results as an adaptive design because they allowed experienced clinicians to draw upon multiple treatment components as needed (see Zarit & Femia, 2008, for a review). **Still, the question remains if outcomes for both REACH II and the NYU caregiver intervention might have been improved further with more specific targeting of risk factors and outcomes.** The potential

for replication would also be enhanced with more explicit rules for assigning treatment.

The present findings also suggest that when designing an intervention, it may be important to consider the impact of the number of risk factors or outcome measures with high scores, as well as potential interactions among outcomes. For example, a caregiver who has a high rate of depressive symptoms *and* is in poor health may need a treatment approach that emphasizes relief from caregiving responsibilities. Another caregiver who has depressive symptoms but is in good health may benefit from interventions that increase his/her activity and involvement, such as learning new skills for managing stressors.

Although the findings of our study are encouraging, they are also limited by several factors. The sample size is relatively small, which hampered our ability to observe in greater detail the multivariate relationships among risk factors and outcomes. In addition to obtaining greater clarification of main effects, we were not able to test for interactions that could explore the consequences of various combinations of risk factors. A larger sample size would also make it possible to determine the presence of subgroups of caregivers with distinct patterns of risk factors and outcomes. Another limitation is the cross-sectional nature of the data. Additional waves of data would allow us to examine changes over time in levels of risk factors and outcomes, and possibly also in the relations among them. Finally, the findings may be limited in their generalizability to only caregivers of persons with dementia in the middle stages of the illness where behavioral problems play such a prominent role in the daily experience of caregivers. For other types of caregivers and for dementia caregivers dealing with early or late-stage issues, the relationships between risk factors and outcomes might be different.

The lessons to be taken away from the findings in this study are twofold. First, assessments of caregivers need to be multidimensional. No single measure can adequately capture the full range of risks and outcomes or the variability from one person to the next. A consensus conference led by the Family Caregiver Alliance (FCA) outlined a multidimensional strategy and recommended specific domains and constructs that should be covered in a systematic caregiver assessment (FCA, 2006a, 2006b), many of which were included in the present study (e.g., BPSD, support, services, etc.). This type of approach could lead to more systematic development of care plans for caregivers and accommodate individual differences in caregivers' needs for services and support (Farran et al., 2003, 2004). It is also consistent with developments in other clinical areas, such as palliative care, which emphasize individualized assessment and treatment (e.g., Diwan, Hougham, & Sachs, 2004; Rodin, Lo, Mikulincer, Donner, Gagliese, & Zimmermann, 2009).

Second, it is not sufficient to assume that everyone will benefit in the same way from a single type of intervention, such as providing more informal or

formal help to a caregiver or training a caregiver on a singular set of skills. Caregiver interventions may be improved by adopting a strategy of assessing a wider array of risk factors and outcomes, determining a caregiver's individual need for intervention based on that assessment, and providing a multicomponent treatment program that can address the caregiver's specific risks and be modified to adapt to the caregiver's changing risk profile. New research designs (e.g., Collins et al., 2004, 2005) make it possible to explore these types of tailored treatments for caregivers in a systematic and rigorous manner.

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