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Integration of the Pleasant Events and Activity Restriction Models: Development and Validation of a “PEAR” Model of Negative Outcomes in Alzheimer's Caregivers

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This study examined an activity restriction/pleasurable activities mismatch model for psychosocial and health-related outcomes. A total of 108 spousal caregivers of patients with Alzheimer’s Disease (AD) were assessed for their experience of social and recreational activities over the past month as well as their perception of how restricted they were for engaging in social and recreational activities. Participants were divided into three groups based on their reported activities and activity restriction: HPLR = High Pleasant Events + Low Activity Restriction (i.e., reference group; N = 28); HPHR/LPLR = Either High Pleasant Events + High Activity Restriction or Low Pleasant Events + Low Activity Restriction (N = 43); LPHR = Low Pleasant Events + High Activity Restriction (N = 37). We hypothesized that participants reporting low pleasant events combined with high activity restriction (LPHR) would demonstrate greater disturbance relative to other two groups in multiple outcome domains, including: (a) greater mood disturbance, (b) greater use of negative coping factors, (c) reduced use of positive coping strategies, (d) reduced report of psychological resource factors (e.g., personal mastery, self-efficacy), and (e) increased report of subjective health difficulties (e.g., sleep disturbance). Results generally supported our hypotheses, suggesting that assessment of both constructs is important for best predicting quality of well-being in AD caregivers, and potentially for establishing maximal effect in behavior therapy for caregivers.

Over the next two decades, it is anticipated there will be a rapid increase in the proportion of people aged 65 years and older in the United States. Specifically, the U.S. older adult population is
expected to increase from approximately 35.1 million in 2000 (12.4% of the population) to about 72.1 million (19.3% of the population) in 2030 (U.S. Census Bureau, 2008). Because there is yet no cure for Alzheimer’s Disease (AD), this aging trend will result in a significant increase in the number of individuals with AD as well as those providing them with care (i.e., caregivers). As has been repeatedly shown, taking care of a loved-one with dementia is a highly stressful life circumstance that often results in reduced well-being of the caregiver, particularly an increase in depressive symptoms (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz, O’Brien, Bookwala, & Fleissner, 1995; Schulz & Williamson, 1991). However, other negative outcomes have been noted to result from caregiver stress, including anxiety (Aguglia et al., 2004; Winslow, 1997), anger (Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989), and even societal concerns such as elder abuse (Coyne, Reichman, & Berbig, 1993; Wolf, 1998). Further, negative physical health outcomes have been found to be associated with dementia caregiving, including increased risk for hypertension (Shaw et al., 1999) and cardiovascular disease (Lee, Colditz, Berkman, & Kawachi, 2003; Mausbach, Patterson, Rabinowitz, Grant, & Schulz, 2007). Increased stress and subsequent reduced well-being have been demonstrated in other caregiver populations as well, such as parents caring for a child with a chronic illness. As opposed to dementia caregivers, recent literature has suggested that parental caregivers appear to be most significantly affected by parental distress and caregiver strain as opposed to depressive symptoms (Everhart, Fiese, & Smyth, 2008; Storch et al., 2009). Given the anticipated demographic shifts and consequences associated with caregiving, caregiving presents as a growing public health concern (Talley & Crews, 2007).

There has been much discussion of the circumstances and factors that result in reduced well-being for caregivers (Cooper, Balamurali, & Livingston, 2007; Covinsky et al., 2003; Schulz et al., 1995). The role of pleasant events in caregiver well-being, particularly depression, has received limited attention, despite theoretical and empirical evidence suggesting that a lack of engagement in pleasurable activities plays a prominent role in the onset and maintenance of depression (Lewinsohn, 1974, 1975; Lewinsohn & Amenson, 1978; Mausbach, Patterson, & Grant, 2008). Increasing engagement in pleasurable activities is a hallmark of cognitive-behavior therapy (CBT), and increasing positive events (i.e., behavioral activation) has been shown to effectively reduce depressive symptoms in a variety of populations (Jacobson, Martell, & Dimidjian, 2001; Jacobson et al., 1996), including caregivers (Coon, Rider, Gallagher-Thompson, & Thompson, 1999; Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003). Further, it has been implied that increasing pleasurable activities is related to residual improvements to other outcomes, including cognitive appraisals and self-efficacy (Coon et al., 2003; Jacobson et al., 1996).

Another theory that has received relatively little attention in the onset and maintenance of depression in caregivers has been the Activity Restriction Model (Williamson, 2000; Williamson & Schulz, 1992, 1995; Williamson & Shaffer, 2000). This model suggests that the stresses of caregiving impede one’s ability to engage in social and recreational activities, and this restriction is then expected to result in downstream mental health consequences, most notably depression. This model has been consistently supported in a number of populations, including pain patients (Williamson & Schulz, 1992), cancer patients (Williamson, 2000; Williamson & Schulz, 1995), and both artery bypass caregivers (Nieboer et al., 1998) and Alzheimer’s caregivers (Mausbach et al., 2008). Whereas pleasant events are observable, measurable behaviors, activity restriction may be differentiated by its emphasis on the cognitive appraisal that one is not able to engage in as much activity as one would like. Indeed, there are a number of theoretical combinations of engagement versus perceived loss of engagement, such that assessment of only one may not be sufficient to predict the entire scope of affective experience. For example, assessment of only pleasant events may not be sufficient because some individuals may engage in a low number of pleasant events yet perceive only a low level of activity restriction. Similarly, assessment of only activity restriction may be insufficient because some individuals may report a high level of activity restriction but engage in a relatively high level of pleasurable activities. Theoretically, assessment of both should allow for maximum prediction of outcomes, such that individuals who report high engagement in pleasant events with low activity restriction should be maximally differentiated from those who engage in low pleasant events with high activity restriction.

The purpose of the current study is to test this integrated Pleasant Events (PE) and Activity Restriction (AR) model (“PEAR” model). Specifically, we hypothesized that caregivers who engaged in a relatively high amount of pleasurable activities combined with low activity restriction would demonstrate the “healthiest” psychosocial outcomes, whereas those who engaged in relatively low levels of pleasurable activities with high activity restriction would demonstrate worsened outcomes. Caregivers...
experiencing high pleasant events with high activity restriction or low pleasant events with low activity restriction were expected to experience reduced well-being, but this reduction was not hypothesized to be as great as those experiencing low pleasant activities with high activity restriction. An additional novel aspect of this study is our emphasis on coping/resource variables as dependent variables. Specifically, Jacobson and colleagues (1996) and Coon et al. (2003) have previously demonstrated that purely behavioral, pleasant-events-based interventions are as effective for changing cognitive outcomes (e.g., negative thinking, self-efficacy) as interventions that focus more heavily on cognitive constructs (e.g., cognitive-behavioral therapy). Based on these previous lines of research, we examined differences in coping/resource variables as a function of varying levels of pleasant events and activity restriction.

**Methods**

**Participants**

Participants were 108 spousal caregivers of patients with probable AD enrolled in the Alzheimer’s Caregiver Project and Pleasant Events Project (PEP) at the University of California, San Diego (UCSD). To be eligible, participants were required to be providing in-home care for a spouse with a diagnosis of probable AD, in generally good health, and at least 55 years of age. By design, participants were excluded if their physical and/or mental health rendered participation very burdensome or introduced confounds that could invalidate the purposes of the study (e.g., serious psychiatric or medical illness). Because an added aspect of the research focused on biological outcomes, additional exclusion criteria included severe hypertension (i.e., 200/120 mm Hg) or treatment with anticoagulant medication. Participants were recruited via referral from the UCSD Alzheimer’s Disease Research Center (ADRC), recommendation of existing participants, and presentations at local caregiver support groups and health fairs. All participants provided written consent before enrolling in the studies, and the research was approved by the UCSD Institutional Review Board (IRB).

**Measures**

All assessments occurred in participants’ homes via a single visit, where research staff interviewed participants with a thorough assessment that included measures of demographic, mood/stress, coping and resource variables, and health factors. Demographic and descriptive information included participant age, gender, educational history, and years caregiving. Specific psychosocial measures included in this study are listed below.

**Care Recipient Functioning**

Three measures were administered to caregivers that assessed their care recipient’s (CR) level of functioning. The first was the Clinical Dementia Rating (CDR) scale (Morris, 1993). This scale required caregivers to report on their loved one’s level of functioning in six domains: (a) memory, (b) orientation, (c) judgment and problem solving, (d) community affairs, (e) home and hobbies, and (f) personal care. Scores on these domains are then used to create a total CDR score ranging from 0 to 3, with higher scores indicating greater dementia severity.

Participants also completed the revised Memory and Behavior Checklist (RMBPC) (Roth et al., 2003; Teri et al., 1992), which assesses the extent to which CRs exhibited 24 memory and behavior problems over the past week (e.g., asked the same question over and over; appeared anxious or worried; expressed feelings of hopelessness or sadness about the future). For each problem behavior, caregivers answered using a 4-point Likert scale (0 = never, 1 = 1 to 2 times, 2 = 3 to 6 times, and 4 = daily or more often). For the current study, we used the scoring method described by Roth and colleagues, whereby each of the problem behaviors was recoded as 0 = did not occur in the past week versus 1 = occurred in the past week. The total number of problem behaviors experienced by the caregiver was then created by summing the 24 items. Previous studies indicate this scale has excellent reliability and validity (Roth et al.), and for the present study coefficient alpha was .82.

Finally, participants were asked the extent to which their care recipient was dependent upon them to complete 7 activities of daily living (ADLs; e.g., eating, bathing, dressing) and 8 instrumental activities of daily living (IADLs; e.g., taking medications, using a telephone). Responses were given on a 4-point Likert scale (1 = not at all to 4 = completely). For the purposes of the current study, we summed the total number of ADLs and IADLs that required at least some help (range = 0–15), and coefficient alpha was .91 for the current study.

**Pleasant Events**

The extent to which each participant engaged in various pleasant events was assessed using a modified version of the Pleasant Events Schedule—AD (PES-AD; Logsdon & Teri, 1997). This scale asked participants to indicate how much they engaged in 20 activities (e.g., “shopping or buying things,” “listening to music,” “going on outings”)
over the past month. Response options were 0=not at all, 1=a few times (1–6 times), and 2=often (7 or more times). A summary score was created by adding responses to the 20 items, with higher scores indicating greater engagement in pleasant activities. For the present study, Cronbach’s alpha was .71.

Activity Restriction
To assess activity restriction, participants completed the Activity Restriction Scale (Williamson & Schulz, 1992), which asks participants to indicate how much, in general, they felt restricted from doing 9 activities over the past month: (a) “caring for yourself,” (b) “caring for others,” (c) “doing household chores,” (d) “going shopping,” (e) “visiting friends,” (f) “working on hobbies,” (g) “sports and recreation,” (h) “going to work,” and (i) “maintaining friendships.” Responses ranged from 0=never or seldom did this to 4=greatly restricted. Items were summed to create an overall score, with higher scores indicating greater activity restriction. Cronbach’s alpha for this scale was .76 for the current study.

Mood/Stress Measures
Participants completed the brief version of the Center for Epidemiologic Studies Depression scale (CESD-10; Andresen, Malmgren, Carter, & Patrick, 1994). The CESD-10 contains 10 items that assess how much the participant experienced various depressive symptoms over the previous week. Responses are given on a 4-point Likert scale ranging from 0=rarely or none of the time (<1 day) to 3=most or almost all the time (5–7 days). Scores were summed, and higher scores indicated greater experience of depressive symptoms. Coefficient alpha for this study was .76.

Participants also completed the Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988). The PANAS contains 20 items assessing both positive (10 items) and negative affect (10 items; PA and NA, respectively). PA items reflect the participant’s level of energy, excitement, and enthusiasm (e.g., “determined,” “interested,” “excited”), whereas NA items reflect generalized distress (e.g., “irritable,” “afraid,” “upset”). For both PA and NA scales, items were summed to create an overall score, with higher scores indicating greater experience of PA and NA, respectively. For the present study, Cronbach’s alpha for PA and NA was .88 and .82, respectively.

All participants also completed the Role Overload Scale (Pearlin, Mullan, Semple, & Skaff, 1990), which assesses subjective levels of stress. The scale consists of four statements about participants’ energy level, to which participants indicate how much the statements describes them on a 4-point Likert scale (0=not at all to 3=completely). The four items are summed to create an overall overload score, with higher scores indicating greater stress. For the current study, this scale had adequate internal reliability (alpha = .75).

Coping/Resource Variables
The Revised Ways of Coping Checklist (RWCC; Vitaliano, Russo, & Carr, 1985), a 42-item questionnaire, was used to assess five coping domains. These coping domains are: (a) problem-focused coping (15 items; “Bargained or compromised to get something positive from the situation”); (b) seeks social support (6 items; “Talked to someone who could do something about the problem”); (c) blames self (3 items; “Realized you brought the problem on yourself”); (d) wishful thinking (8 items; “Wished the situation would somehow go away or somehow be finished”); and (e) avoidance (10 items; “Went on as if nothing had happened”). Participants were asked to imagine a specific stressor they experienced during the past month and respond to each item by indicating the extent they used each coping strategy to manage the stressful event. Responses were given on a 4-point Likert scale (0=never used to 3=used a great deal). Previous research has found the RWCC to be reliable and valid for use in caregiving populations (Gallagher-Thompson et al., 2003), and in the current study coefficient alpha was .82 for Problem-Focused Coping,.82 for Seeks Social Support,.61 for Blames Self,.78 for Wishful Thinking, and .66 for Avoidance Coping.

Coping self-efficacy was assessed using the scale developed by Chesney and colleagues (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006). This 13-item scale asks caregivers to indicate how confident or certain they are in performing specific actions in response to life stresses. Responses are given on a 10-point scale (0=cannot do at all to 10=certain can do). The overall scale assesses self-efficacy in three coping domains: (a) self-efficacy for using problem-focused coping (6 items; “Break an upsetting problem down into smaller parts”); (b) self-efficacy for stopping unpleasant thoughts (4 items; “Make unpleasant thoughts go away”); (c) self-efficacy for getting support (3 items; “Get friends to help you with the things you need”). Chesney and colleagues (2006) have reported strong Cronbach’s alpha and test-retest reliability coefficients for all three scales. For the current study, alpha for the problem-focused coping, stopping unpleasant thoughts, and getting support subscales was .87, .90, and .76.
Health Outcomes
Two health outcomes were included in the present study. The first was the caregiver’s perception of his/her overall health, which was assessed using a single item, asking caregivers, “In general, would you say your health is — .” Responses were given on a Likert scale ranging from 0 = poor to 4 = excellent.

Participants also completed the Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989), which consists of 19 questions assessing 7 components of sleep quality: (a) subjective sleep quality, (b) sleep latency, (c) sleep duration, (d) habitual sleep efficiency, (e) sleep disturbances, (f) use of sleep medication, and (g) daytime dysfunction. Each of the seven components is scored on a scale of 0 to 3, and the scores on each domain are then summed to create a global PSQI score, with higher scores indicating worse sleep quality.

Data Analysis
Our first approach to the data was to create three groups reflecting the participants’ engagement in pleasant events and activity restriction. Participants were coded as high or low in engagement in pleasant events and activity restriction, respectively, based on median splits for each scale. Then, three groups were created from these codes: HPLR = high in pleasant events and low in activity restriction (N = 28); HPHR/LPLR = either high in pleasant events and high in activity restriction or low in pleasant events and low in activity restriction (N = 43); and LPHR = low in pleasant events and high in activity restriction (N = 37). HPHR participants (n = 20) were combined with LPLR participants (n = 23) because there was no a priori reason to believe they would differ on any outcome variables. However, to examine this belief we conducted a series of t tests comparing these two subgroups on our 15 outcome variables.

Using this three-group categorization as our primary independent variable, a series of MANO- VAs using Wilks’ criterion was run to test whether these groups significantly differed in the following outcome domains: (a) mood/stress, which consisted of scores on the CESD, Positive Affect, Negative Affect, and Role Overload; (b) positive coping/resource variables, consisting of problem-focused coping, seeks social support, personal mastery, self-efficacy for using problem-focused coping, self-efficacy for stopping unpleasant thoughts, and self-efficacy for obtaining support; (c) negative coping, consisting of blames self, wishful thinking, and avoidance; and (d) health outcomes, which were subjective health rating and PSQI scores. For the mood/stress outcomes, the critical value for alpha was adjusted to .0125 (.05/4 = .0125) to control for familywise error. For positive coping/resource variables, alpha was adjusted to .008. Alpha for negative coping and health outcomes were adjusted to .017 and .025, respectively. To test our hypothesis that a combination of low pleasant events with high activity restriction would result in worsened outcomes, significant omnibus tests were followed by planned comparisons of the LPHR group to our other two group categories, with a significance value of .05 set for these planned comparisons.

Results
A breakdown of caregiver and care recipient characteristics is presented in Table 1, as are ANOVA and chi-square comparisons of these characteristics by study group for linear and categorical variables (e.g., CDR score), respectively. For these comparisons we ran ANOVAs and chi-square tests. Caregivers were primarily elderly, female, and well-educated. Care recipients were generally in Stage 1 or Stage 2 of AD and required a significant level of assistance with ADLs/IADLs. As expected, significant differences were found for our three groups on the AR and PE scales. Overall means for AR were higher than seen in older cancer patients (Williamson & Schulz, 1995) but similar to a previous study of Alzheimer caregivers (Mausbach et al., 2008). Our mean sample PES-AD score was very similar to that observed by Searson and colleagues (2008), who assessed both Alzheimer’s patients and their caregivers.

Univariate ANOVAs indicated significant group differences in age, CDR total scores, and ADLs/IADL. Specifically, HPLR participants were significantly older than HPHR/LPLR participants. Also, compared to HPHR/LPLR and LPHR caregivers, HPLR participants were significantly more likely to be caring for a CR in Stage 1 and reported helping their CRs with fewer ADLs/IADLs.

Preliminary Analyses
We proposed that, theoretically, participants who were high in PE and high in AR should not differ from those low in PE and low in AR on any of our outcome variables. To test this, we conducted a series of t tests with an adjusted critical value of α < .003 to control for multiple testing (i.e., .05/15 = .003). Results of these tests indicated that these groups were not significantly different from one another on any of our 15 outcome variables.
We then proceeded to conduct our MANOVA analyses using the three-group categorization. The first MANOVA tested group differences in mood/stress outcomes. Results of this analysis indicated a significant main effect of group, $F(8, 204) = 7.63, p < .001$. Univariate ANOVA analyses for the variables are presented in Table 2.

Table 2: Univariate Tests Comparing Three Groups on Primary Outcomes

<table>
<thead>
<tr>
<th>Variable</th>
<th>HPLR (N=28)</th>
<th>HPHR/LPLR (N=43)</th>
<th>LPHR (N=37)</th>
<th>F, $\chi^2$</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood/Stress Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Coping/Resource Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SE Problem-Focused Coping</td>
<td>47.82 ± 10.74 [44.11-51.54]</td>
<td>44.02 ± 8.91 [41.03-47.02]</td>
<td>40.30 ± 10.37 [37.07-43.53]</td>
<td>4.62</td>
<td></td>
</tr>
<tr>
<td>Negative Coping Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blames Self</td>
<td>1.53 ± 1.50 [0.85-2.22]</td>
<td>1.74 ± 1.66 [1.19-2.30]</td>
<td>2.92 ± 2.18 [2.33-3.51]</td>
<td>5.91</td>
<td></td>
</tr>
<tr>
<td>Health Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective Health Rating</td>
<td>2.68 ± 0.61 [2.34-3.02]</td>
<td>2.51 ± 1.08 [2.24-2.79]</td>
<td>2.24 ± 0.89 [1.95-2.54]</td>
<td>1.91</td>
<td></td>
</tr>
</tbody>
</table>

Note: HPLR=High Pleasant Events+Low Activity Restriction; HPHR/LPLR=Either High Pleasant Events+High Activity Restriction or Low Pleasant Events+Low Activity Restriction; LPHR=Low Pleasant Events+High Activity Restriction. ADL=Activities of Daily Living; IADL=Instrumental Activities of Daily Living; RMBPC=Revised Memory and Behavior Problem Checklist. Cells with different superscripts denote significant differences.
the individual dependent variables (and differences between groups) are presented in Table 2, and effect sizes are presented in Table 3. As seen in the Table, ANOVAs for all four variables were significant. For all four outcomes, specific planned comparisons indicated that LPHR participants were significantly different compared to HPLR participants. Specifically, LPHR participants had significantly higher scores for depressive symptoms, negative affect, and role overload, and significantly lower scores for positive affect. Perhaps most importantly, LPHR participants scored significantly higher than the HPHR/LPLR group in depressive symptoms, negative affect, and role overload, and scored significantly lower in positive affect. These latter findings, in which LPHR participants were significantly more distressed than HPHR/LPLR participants, suggests the utility of an integrated model rather than a single one.

Positive Coping/Resource Variables

Results of the MANOVA for positive coping/resource variables was also significant, F(12, 200) = 3.08, p = .001. Specific planned comparisons (see Table 2) again indicated significant main effects for personal mastery (p < .001) and self-efficacy for obtaining social support (p < .001). No significant main effects were found for the positive coping variables problem-focused coping (p = .923) or seeks social support (p = .745), or for self-efficacy for using problem-focused coping (p = .012) and self-efficacy for stopping unpleasant thoughts (p = .013). Specific comparisons of the groups again indicated that LPHR participants had significantly lower personal mastery and all three self-efficacy variables than HPLR participants. As seen in Table 3, effect size differences between the LPHR and HPHR/LPLR groups were small-to-medium on all three forms of self-efficacy.

Negative Coping Variables

As with our two previous analyses, a significant main effect of group was found for negative coping variables, F(6, 206) = 4.93, p < .001, with all three ANOVAs also demonstrating a main effect of group (see Table 2). Planned comparisons of groups indicated again that LPHR was significantly higher than HPLR on all negative coping variables. Further, planned comparisons indicated that LPHR was significantly higher than HPHR/LPLR on all negative coping variables.

Health Variables

MANOVA results of health variables indicated the main effect of group was significant, F(4, 208) = 3.21, p = .014. Univariate ANOVA results for our two health variables indicated a significant main effect of group for PSQI scores (p = .004) but not for subjective health ratings (p = .153). Planned comparisons for PSQI scores were consistent with our previous findings, such that the LPHR group reported significantly worse sleep quality than both other groups.

Discussion

In this study, we hypothesized that caregivers engaging in a relatively low number of pleasurable activities with high appraisal of activity restriction would report significantly worsened psychosocial outcomes relative to those engaging in more pleasant activities with low activity restriction. We further examined psychosocial outcomes for those with either low PE or high AR. Our findings confirmed this hypothesis, such that significant differences existed between caregivers reporting simultaneous high PE and low AR (HPLR) compared to those reporting low PE and high AR (LPHR) across several psychosocial and health outcomes relevant to dementia caregiving. Specifically, our results indicated that caregivers in the LPHR group reported more depressive symptoms, negative affect, and overload and less positive affect compared to caregivers who are less restricted and frequently engage in pleasant events. Furthermore, caregivers in the LPHR group also reported significantly reduced use of positive coping (i.e., personal mastery and all three self-efficacy variables) compared to HPLR participants. Similar

Table 3

<table>
<thead>
<tr>
<th>Variable</th>
<th>LPHR vs. HPLR</th>
<th>LPHR vs. HPHR/LPLR</th>
</tr>
</thead>
<tbody>
<tr>
<td>CESD</td>
<td>1.07</td>
<td>0.70</td>
</tr>
<tr>
<td>NA</td>
<td>0.99</td>
<td>0.72</td>
</tr>
<tr>
<td>PA</td>
<td>-0.58</td>
<td>-0.47</td>
</tr>
<tr>
<td>Role Overload</td>
<td>2.04</td>
<td>0.90</td>
</tr>
<tr>
<td>Problem-focused Coping</td>
<td>0.01</td>
<td>0.09</td>
</tr>
<tr>
<td>Seeks Social Support</td>
<td>0.20</td>
<td>0.10</td>
</tr>
<tr>
<td>Personal Mastery</td>
<td>-1.20</td>
<td>-0.90</td>
</tr>
<tr>
<td>SE Problem-focused Coping</td>
<td>-0.71</td>
<td>-0.39</td>
</tr>
<tr>
<td>SE Stopping Unpleasant Thoughts</td>
<td>-0.72</td>
<td>-0.39</td>
</tr>
<tr>
<td>SE Obtaining Social Support</td>
<td>-1.03</td>
<td>-0.49</td>
</tr>
<tr>
<td>Blames Self</td>
<td>0.74</td>
<td>0.62</td>
</tr>
<tr>
<td>Wishful Thinking</td>
<td>1.16</td>
<td>0.83</td>
</tr>
<tr>
<td>Avoidance Coping</td>
<td>0.85</td>
<td>0.51</td>
</tr>
<tr>
<td>Global PSQI</td>
<td>0.87</td>
<td>0.49</td>
</tr>
<tr>
<td>Subjective Health Rating</td>
<td>-0.57</td>
<td>-0.27</td>
</tr>
</tbody>
</table>

Note: HPLR = High Pleasant Events + Low Activity Restriction; HPHR/LPLR = Either High Pleasant Events + High Activity Restriction or Low Pleasant Events + Low Activity Restriction; LPHR = Low Pleasant Events + High Activity Restriction. A negative value reflects that the LPHR group has a lower mean score on the specific variable.
result emerged for negative coping variables. Finally, LPHR caregivers reported significantly more sleep disturbance compared to HPLR caregivers.

This study draws from and builds upon both Lewinsohn’s model of depression (Lewinsohn, 1974, 1975) and the Activity Restriction Model (Williamson, 2000; Williamson & Schulz, 1992; Williamson & Shaffer, 2000). Specifically, we found that in a sample of spousal AD caregivers, a combination of the two theoretical models (i.e., behavioral activation, activity restriction) was significantly better in detecting compromised psychological outcomes than one theory alone. While Table 2 clearly shows that the effects for low engagement in PE or high AR are in the expected direction, in many cases it was not until both were considered that the effects were significantly different from those of caregivers who engaged in a high level of PE combined with low AR. Perhaps more importantly, comparisons between LPHR participants and those in the HPHR/LPLR group indicated many significant results. For example, LPHR participants reported significantly higher depressive symptoms, negative affect, and overload, and greater use of all forms of negative coping assessed in this study. Further, LPHR participants reported significantly lower personal mastery and self-efficacy for obtaining social support. It is these significant findings that emphasize support of our PEAR model, suggesting that integrating “objective” frequency of pleasant events and the “subjective” experience of feeling restricted from engaging in social and recreational activities, indeed, provides optimal predictive utility. Therefore, outcomes related to caregiver health and well-being may be more appropriately studied by simultaneous, rather than independent, consideration of these factors.

These findings suggest potential mediating variables for both cognitive-behavioral and behavioral activation interventions. That is, while both interventions work to increase engagement in pleasurable activities as a means of reducing depressive symptoms, few studies have examined the construct of activity restriction in caregiving samples as an additive factor for the effectiveness of these interventions. Indeed, activity restriction is theoretically more relevant to caregiving than noncaregiving populations because of the role of caregiving stress in “preventing” caregivers from engaging in certain pleasurable activities. Furthermore, caregivers may have a clinically different presentation to noncaregivers, whereby they might make therapeutic-limiting statements such as, “I can’t do more activities because I have to care for my husband.” Presentation of this type of statement in a therapeutic context might raise the importance for clinicians to assess activity restriction at various points during therapy to monitor progress toward potential for improved psychosocial outcomes.

Our model was based on merging Lewinsohn’s model of depression (Lewinsohn, 1974, 1975) with the Activity Restriction Model (Williamson & Shaffer, 2000) with a concentrated focus on PE and AR. While the results of this study suggest that a behavioral treatment program focused on increasing PE and decreasing AR would theoretically decrease depression and improve various psychosocial outcomes in AD caregivers, future research might benefit from examining externalized outcomes (e.g., anger/hostility), particularly since these may predict certain outcomes for the AD patient (e.g., placement in nursing homes; Pillemer & Suitor, 1992). In addition, further work might examine the externalizing factor of emotional expression in caregivers and its effect on caregivers’ psychological disturbance. Indeed, future research might assess how PE and AR predict externalized emotion such as anger/hostility or expressed emotion. Understanding these relationships might have implications for downstream health outcomes as well. Indeed, Shaw et al. (2003) found that the suppression of hostile emotions (low emotional expression) was associated with short-term increases in resting diastolic blood pressure (BP), suggesting expressed emotion may play a role in coping with the constant demands of caregiving. These findings suggest that taking the degree of emotional expression into account when examining caregivers’ overall health is a reasonable route for continued exploration.

Although our model posits that the combined experience of disengagement from pleasant events and the subjective appraisal of being restricted from activities optimally impact caregiver mood, coping resources, and health, it is important to note that the cross-sectional design of this study precludes causal inferences. It is possible that caregivers who experience higher levels of mood disturbance, poor coping strategies, and/or more disturbed sleep may also be inclined to engage in less pleasant activity, and vice versa. However, theoretically the constructs of pleasurable activity and activity restriction precede psychosocial outcomes in time, and treatment of psychosocial outcomes involves first making an impact on these constructs. Therefore, although our model is not causal in nature, there may be implications for future studies to test our model therapeutically to reduce activity restriction and increase pleasant events to determine if this produces improved psychosocial outcomes.
It is noteworthy that HPLR participants were disproportionately providing care for care recipients in the early stages of AD. That is, relative to the remaining participants, those in the HPLR group were caring for individuals who demonstrated better cognitive functioning (as measured by CDR scores) and required help with fewer ADL/IADLs. Consistent with the Activity Restriction Model, this may suggest that primary stressors precede reductions in PE and increases in AR, which in turn result in downstream consequences to one’s psychological well-being (e.g., increased depressive symptoms, reduced self-efficacy, etc). This may lay the groundwork for examining mediation models, in which changes in care recipient functioning can be associated with PE and AR, which in turn can be associated with these downstream outcomes.

Due to the design of the study, we were restricted to studying spousal caregivers of patients with AD. Therefore, it is unclear how these results generalize to other caregiver relationships (e.g., adult children, grandchildren) or to caregivers of other forms of dementia or disability. While some studies show similar levels of care-related strain between spouse and nonspouse caregivers (Deimling, Bass, Townsend, & Noelker, 1989), others show that spouse caregivers experience more caregiving-related burden than nonspouse caregivers (Draper, Poulos, Poulos, & Ehrlich, 1996). Still other studies suggest that dementia caregiving is associated with greater burden than nondementia caregiving (Ory et al., 1999). Although we are not able to determine from our current dataset, it is possible that greater burden in spouse caregivers or dementia caregivers is due to increased activity restriction with low levels of pleasurable activities. There have also been studies demonstrating ethnic differences in caregiver depression. Future studies may examine potential spouse/nonspouse or dementia/nondementia caregiving differences to our present findings.

We did not examine the role of various demographic characteristics on group differences (e.g., gender and ethnicity) in our study, and so it is unclear whether or not our model applies differently to male and female caregivers, or caregivers of other ethnic groups. Previous research, for example, has found that males and females differ in various caregiving outcomes (DeVries, Hamilton, Lovett, & Gallagher-Thompson, 1997), as do African-American (Haley et al., 2004) and Hispanic caregivers (Coon et al., 2004). How our model applies to these populations is unclear, but would be an interesting future direction for research.

This study examined the relations between AR/PE and caregiver outcomes, but we do not know how a combination of these constructs relates to care recipient outcomes. However, it is likely that high PE with low AR is related to improved outcomes in care recipients as well. Indeed, Teri and colleagues (Teri & Gallagher-Thompson, 1991; Teri & Logsdon, 1991; Teri, Logsdon, Uomoto, & McCurry, 1997) have demonstrated that increased PEs among caregivers and care recipients have beneficial effects on the well-being of the opposing dyad. Future research should examine the role of high PE and low AR on care recipient mood and well-being, as well as reductions in other outcomes (e.g., elder abuse; institutionalization).

Many caregivers may believe that self-sacrifice is admirable for good caregiving. However, these findings suggest that extreme self-sacrifice, to the point of sacrificing (or restricting) one’s own pleasurable activities, may have detriments to caregiver well-being. If indeed such restriction results in negative outcomes to caregiver and care recipient well-being, caregivers may need clinicians (e.g., physicians, psychologists, social workers) to point out how these sacrifices may result in these negative consequences.

These findings imply that PE and AR provide the most useful information when considered concurrently, and therefore, future caregiving research would benefit from the construction and validation of a single scale that assesses both constructs simultaneously. This may take the form of asking participants how restricted they feel with regard to engaging in specific activities followed by the frequency with which they engage in those activities.

In sum, building on the behavioral activation and Activity Restriction models, we find that a combination of high activity restriction with low engagement in pleasant events was associated with significant detriments to caregiver well-being relative to low activity restriction with high engagement in pleasant events. These detriments encompassed multiple domains of caregivers’ lives, including mood/stress, coping, and health outcomes. Behavioral treatments for caregivers often incorporate increasing pleasurable activities, but perhaps do not consider caregivers’ appraisals of activity restriction. These findings suggest that monitoring, as well as active attempts to reduce caregiver’s sense of activity restriction, may be warranted as a component of behavior therapy for caregiving stress.

References


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