Perceived Control, Coping, and Expressed Burden among Spouses of Suspected Dementia Patients: Analysis of the Goodness-of-Fit Hypothesis

Norm O’Rourke*
Simon Fraser University at Harbour Centre

Philippe Cappeliez
University of Ottawa

RÉSUMÉ
L’hypothèse de l’adéquation (goodness-of-fit) avance que la détresse résulte de l’inadéquation entre le choix de stratégies d’adaptation et la capacité subjective de changer les stimuli sources de stress. Les réponses dirigées vers des buts ou d’adaptation active sont considérées comme les plus efficaces dans les circonstances où l’individu croit qu’il peut changer ou contrôler les menaces perçues (par exemple, la stratégie de résolution de problème). Par contre, lorsque les situations stressantes doivent être acceptées, les stratégies de régulation de la détresse seraient de mise (par exemple, les stratégies centrées sur les émotions). Cette étude avec des conjoints de patients présumés déments n’apporte qu’un soutien empirique inconsistant à cette facette de la théorie cognitivo-phénoménologique de Lazarus et Folkman. Cette distinction entre adaptation centrée d’un côté sur les émotions et de l’autre sur les problèmes apparaît moins pertinente que l’effort global d’adaptation relatif au contrôle perçu et au fardeau de l’aidant naturel. De plus, la capacité perçue de contrôler les situations stressantes reliées à la démence apparaît être plutôt indépendante de l’adaptation de l’aidant naturel. Ces résultats sont discutés en termes des demandes uniques et chroniques auxquelles sont confrontés les conjoints de personnes affligées par la démence.

ABSTRACT
The goodness-of-fit hypothesis contends that distress results due to incongruence between choice of coping strategies and perceived ability to change stressful stimuli. Goal-directed or active coping responses are believed to be most efficacious when the individual believes s/he can change or control perceived threats (i.e., problem-focused coping). Instances in which stressors must be accepted, however, would dictate reliance upon strategies to regulate distress (i.e., emotion-focused coping). Inconsistent support for this facet of Lazarus and Folkman’s cognitive phenomenological model was obtained in this study of spouses of suspected dementia patients. The distinction between emotion- and problem-focused coping appears less germane than overall coping efforts relative to perceived control and caregiver burden. In addition, perceived ability to control dementia-related stressors appears to be somewhat independent of coping by caregivers. These findings are discussed in terms of the unique and chronic demands faced by spouses of persons with dementia.

* This article was written with the support of a Social Sciences and Humanities Research Council of Canada (SSHRC) Doctoral Fellowship awarded to the first author.

Manuscript received / manuscrit reçu: 05/09/00
Manuscript accepted / manuscrit accepté: 20/07/01

Keywords: burden, caregivers, control, coping, aging

Mots clés : fardeau, aidants naturels, contrôle, adaptation, vieillissement

Requests for offprints should be sent to: / Les demandes de tirés-a-part doivent être adressées à:
As noted by Kramer and Vitaliano (1994), the stress and coping model has become the dominant paradigm in caregiving research. In large degree, this stems from the observation that distress among caregivers is highly variable. Although faced with similar demands, some caregivers cope effectively whereas others become despondent (Baumgarten, 1989). It therefore would appear logical to conclude that negative outcomes such as depression and burden are attributable largely to caregiver characteristics as opposed to contextual factors (e.g., patient severity, duration of illness).

The cognitive phenomenological model states that negative outcomes occur once demands exceed perceived resources and ability to cope (Lazarus & Folkman, 1984). According to this paradigm, appraisal of threat is variable across situations and individuals. A certain stressor may be deemed innocuous by one person and not another, although the latter may perceive this same stressor as threatening at another time (Folkman & Lazarus, 1980; Stephens & Hobfoll, 1990).

The stress and coping model distinguishes between two separate modes of appraisal. The first (primary appraisal) refers to the evaluation of the potential threats to well-being, whereas secondary appraisal entails response selection. Subjective control is hypothesized to be integral to this process as the perceived ability to manage stressors governs choice of coping strategies. For instance, the belief that an aversive situation can be changed or eliminated should lead to primary reliance upon active coping (i.e., problem-focused coping). In contrast, the belief that one must accept negative events (i.e., no perceived control) should lead to reliance upon emotion-focused coping, in order to mitigate the negative affective consequences of aversive circumstance (e.g., avoidance, wishful thinking, emotional discharge). This description over-simplifies the process, as persons most often employ multiple strategies in response to noxious stimuli. According to the model, however, one type of coping generally predominates as a function of perceived control (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

The cognitive phenomenological model further contends that distress occurs as a result of incongruent matching of coping relative to perceived controllability. For example, predominant reliance upon strategies to directly manage negative events beyond one’s control will likely prove futile. As well, affective management of stressors one could allay with more active coping will also prove unsatisfactory. In this instance, exposure to stressors is prolonged by failing to assert available control (Folkman & Lazarus, 1980).

This goodness-of-fit hypothesis was examined in a study by Vitaliano, DeWolfe, Maiuro, Russo, and Katon (1990) that included spousal caregivers of persons with dementia (n = 101). Participants were grouped into separate categories on the basis of perceived control of the stressor reported as most disturbing (i.e., high and low perceived control). Coping strategies were compared between groups relative to depressive affect. Among spousal caregivers, correlations for depression and problem-focused coping were significantly different between groups reporting changeable versus not changeable stressors (Z = 2.25, p < 0.01). Although response levels for emotion-focused coping were higher among caregivers reporting stressors as beyond control, correlation differences did not achieve statistical significance (Z = -1.44, ns). These findings thus provided inconclusive support for the goodness-of-fit hypothesis. The interrelation between problem-focused coping and perceived control led to the hypothesized association with caregiver depression. This result did not emerge, however, with respect to control and emotion-focused coping.

The current study reassessed the goodness-of-fit hypothesis among caregivers with a multivariate analytic strategy. Instead of grouping spouses in one of two control categories on the basis of response to one dichotomous variable, cluster analysis was used to classify participants simultaneously on the basis of perceived control and emotion- and problem-focused coping. In keeping with the stress and coping model, it was hypothesized that distinct groupings would emerge in which incongruence between perceived control and coping responses would be significantly associated with caregiver dysphoria. More precisely, it was assumed that greater dysphoria would be evident among participants presenting as reliant upon problem-focused coping along with low perceived control and also by those reliant upon emotion-focused cop-
ing and high reported control. Negative affect within this sample was measured as caregiver burden.

Vitaliano et al. (1990) did not report whether or not control and coping were related to dementia severity and illness duration. At this point, one can only speculate whether illness severity and duration of patient symptoms affect choice of coping strategies and perceived ability to control dementia-specific stressors. As stated by Niederehe and Funk (1987), it is reasonable to expect greater reliance upon problem-focused coping by caregivers early in the disease process, whereas patient deterioration and greater familiarity with role demands lead to reliance upon emotion-focused strategies at later stages. Preliminary support for this assertion is provided in a study by Kileen (1990). The relationship between illness severity and duration of symptoms, on the one hand, and perceived control and choice of coping strategies, on the other, was examined in the current study.

Method

Participants

For this study, 50 spouses were recruited over a 1-year period (20 men, 30 women). The average age of participants was 68.5 years (SD = 9.57). Couples had been married an average of 40.7 years (SD = 12.0). This sample represents consecutive admissions to the Clinic for Alzheimer Disease and Related Disorders, UBC Hospital (Vancouver Hospital and Health Sciences Centre). This tertiary diagnostic facility receives physician referrals from all regions of British Columbia. As part of a structured 2-day assessment, community-dwelling patients and their caregivers meet with health care professionals from various disciplines (neuropsychology, geriatric medicine, neurology, speech pathology, psychiatry, social work).

Caregivers were asked to complete a series of measures at the time their spouse underwent neuropsychological testing. Participants entered an office to individually complete questionnaires. Each was provided with the telephone extension of the first author should s/he have any questions while completing questionnaires. During data collection, only 3 respondents sought clarification.

Upon completion, participants were requested to place questionnaires within the envelope provided, seal it, and deposit the package within a strongbox located in the room. This means of data collection was chosen to reduce potential confounding of responses as a function of the demand requirements of face-to-face interviews. According to Paulhus (1991), distortion of responses due to impression management is less likely when research participants are provided anonymity. Each set of questionnaires was coded so that responses could be cross-matched with patient data.

Measures

Coping Responses Inventory

The Coping Responses Inventory (CRI) from the Health and Daily Living Form (Moos, Cronkite, & Finney, 1990) was adapted for the current study. This scale was developed to assess generalized coping across situations. Instructions for the current study, however, were rewritten to prime participants to consider the most stressful aspect of their marriage over the past year. Four examples of stressors common to caregivers were provided (e.g., “Answering the same question repeatedly”; “Loss of relationship with spouse”). Respondents were requested to circle the example or write in the stressor most salient to them. In the majority of cases, stressors pertained to their role as caregiver or to a specific aspect of the disease process.

The CRI was initially validated among a sample of more than 1,800 late-middle-aged and older adults (Moos & Schaefer, 1993). According to Kramer and Vitaliano (1994), responses to the CRI possess adequate validity as compared to measures of depressive affect, life satisfaction, and health outcome. Internal consistency of responses for separate coping constructs has been reported as ranging from 0.60 to 0.83 among a randomly derived sample of 405 adults (M = 39.4 years of age; Holahan & Moos, 1990). To address study hypotheses, the two emotion-focused subscales were combined for this study (affective regulation and emotional discharge; e.g., “I got busy with other things to keep my mind off the problem”, “I somehow let my feelings out”, respectively) as were the two problem-focused subscales (information seeking and problem solving; e.g., “I talked with a friend about the problem”, “I took things a day at a time, one step at a time”, respectively). In contrast to other coping instruments, it was unnecessary to compute relative scores for coping responses (see Vitaliano, Maiuro, Russo, & Becker, 1987) as the CRI is divided evenly between items measuring emotion- and problem-focused coping.

Coping measures have been adapted repeatedly in caregiving research (Brashares & Catanzario, 1994; Lutzky & Knight, 1994). Respondents were next asked to indicate how often they had used 40 separate means of coping to contend with the specified stressor. Four separate alternatives were provided for each response, ranging from no (0) to yes, fairly often (3). Higher response totals suggest greater reliance upon specific coping strategies.
In the Vitaliano et al. (1990) study, appraised changeability was recorded as a single, dichotomous item. In contrast, caregivers in the current study provided responses regarding their ability to control the reported stressor using a 5-point scale. Response alternatives ranged from not at all (0) to a great deal (4). Although appraisal again was measured by a single question, additional response alternatives allowed for increased measurement sensitivity (i.e., ordinal versus dichotomous scoring).

A similar item measured the degree of subjective distress caused by the reported stressor. This item may be interpreted as a measure of primary appraisal (i.e., degree of perceived threat to well-being). Responses were provided along a 5-point ordinal scale with scores ranging from no distress (0) to very distressing (4).

**Burden Interview**

The Burden Interview (BI; Zarit, Orr, & Zarit, 1985) was specifically developed for family caregivers of dementia patients. This instrument presents respondents with a series of 22 statements. The degree to which caregivers endorse each is rated along a 5-point scale. Response alternatives range from never (0) to nearly always (4), with higher totals indicating greater burden. Although two BI subscales exist (personal strain and role strain), BI scores are most often reported as a combined total due to high correlation between subscales (e.g., r = 0.75; Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994). Of further note, no definitive cut-off score has yet been established above which caregiver burden is deemed to be suggestive of psychopathology (e.g., clinical depression).

Internal consistency of responses to the BI has been reported as ranging from \( \alpha = 0.88 \) (Hassinger, 1986) to \( \alpha = 0.94 \) (O’Rourke & Wenaus, 1998). Zarit and Zarit (1990) report test-retest reliability as \( r = 0.71 \) (no time interval specified).

**Functional Rating Scale**

The Functional Rating Scale (FRS; Tuokko, Crockett, Beattie, Horton, & Wong, 1986) was developed to quantify patient impairment across cognitive and functional domains (memory, social/occupational, home and hobbies, problem solving, personal care, affect, language, orientation). This measure provides a cumulative rating of dementia severity, while recognizing uneven rates of decline across neurodegenerative disorders (i.e., global versus circumscribed deficits). FRS scores range from 8 to 40, with higher totals suggestive of greater impairment.

FRS scores were obtained during the interdisciplinary team meeting in which patient diagnoses were deter-
Due to unequal group membership (a function of hierarchical cluster formation), discriminant function analysis was also performed. Ninety-four per cent of caregivers were appropriately classified ($\chi^2[3, N=50] = 76.8, p < 0.01$) within their respective groupings. This finding further supports the viability of these clusters as distinct subsets within the derived sample.

These three clusters were labelled as low coping-moderate control ($n = 21$), moderate coping-high control ($n = 22$), and high coping-low control ($n = 7$). Table 1 presents descriptive data for each grouping and for the full sample. These labels are based upon mean differences for perceived control, emotion- and problem-focused across clusters, and overall sample means. Moderate mean levels approximate the sample mean, whereas high and low coping and control levels are respectively greater or less than sample means.

Table 1: Descriptive Features of the Full Sample and Three Caregiver Groupings

<table>
<thead>
<tr>
<th>Variable</th>
<th>Full Sample (N= 50)</th>
<th>Low Coping, Moderate Control (n = 21)</th>
<th>Moderate Coping, High Control (n = 22)</th>
<th>High Coping, Low Control (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>$SD$</td>
<td>$\alpha$</td>
<td>$F(2,47)$</td>
</tr>
<tr>
<td>CRI Problem-Focused Coping</td>
<td>31.5</td>
<td>6.49</td>
<td>0.73</td>
<td>45.8**</td>
</tr>
<tr>
<td>CRI Emotion-Focused Coping</td>
<td>24.3</td>
<td>4.67</td>
<td>0.56</td>
<td>31.3**</td>
</tr>
<tr>
<td>Perceived Control</td>
<td>2.14</td>
<td>1.25</td>
<td>—</td>
<td>1.32</td>
</tr>
<tr>
<td>Functional Rating Scale</td>
<td>22.7</td>
<td>6.42</td>
<td>0.92</td>
<td>2.77</td>
</tr>
<tr>
<td>Duration (months) of Symptoms</td>
<td>65.8</td>
<td>42.1</td>
<td>—</td>
<td>0.74</td>
</tr>
<tr>
<td>Distress of Reported Stressor</td>
<td>2.66</td>
<td>1.44</td>
<td>—</td>
<td>0.26</td>
</tr>
<tr>
<td>Zarit Burden Interview</td>
<td>24.7</td>
<td>15.8</td>
<td>0.94</td>
<td>3.41*</td>
</tr>
</tbody>
</table>

* $p < 0.05$
** $p < 0.01$

CRI = Coping Responses Inventory; Functional Rating Scale = dementia severity.

Of note, reported family income ($\chi^2[10, n = 46] = 16.1, ns$), duration of patient symptoms ($F[2,47] = 0.74, ns$), and dementia severity ($F[2,47] = 2.77, ns$) did not differ across the three groups. These results stand in contrast to the hypothesis that caregiver coping strategies differ as a function of patient impairment and illness duration (Niederehe & Funk, 1987). This finding is in accord, however, with a fundamental contention of the cognitive phenomenological model, as few stressors appear predictive of coping across individuals and contexts (Lazarus & Folkman, 1984).

Despite the apparent similarity across groups in terms of role demands, caregiver burden was significantly elevated for the high coping-low control cluster ($F[2,47] = 3.41, p < 0.05$). Perceived control was low among these participants, yet they appeared relatively reliant upon problem-focused coping. Elevated burden for this grouping is consistent with the goodness-of-fit hypothesis (i.e., dysphoria resulting from incongruence between perceived control and coping style).

Within each cluster, relative reliance upon emotion-focused coping was low as compared to problem-focused coping, irrespective of perceived control. As evident from Table 1, emotion- and problem-focused coping appeared to increase in tandem across groups. This finding suggests that the distinction between emotion- and problem-focused coping may not be germane to this sample. Rather, overall effort to cope in situations perceived as beyond control appears predictive of caregiver burden.

Also of note, distress due to reported stressors did not differ across groups ($F[2,47] = 0.26, ns$), despite the significant correlation between distress and caregiver burden ($r[50] = 0.50, p < 0.01$). This counter-intuitive finding suggests that the three groups did not differ as a function of subjective appraisal but as an aggregate of perceived control and coping response. In other words, burden differences are not due solely to the relative distress of reported stressors. Once the correlation between control and burden is partialled out, distress no longer correlates significantly with caregiver burden ($r = -0.09, ns$). Group differences, therefore, appear attributable to secondary appraisal or perceived control rather than primary appraisal (i.e.,...
initial interpretation of threat to well-being). This reflects the idiosyncratic nature of caregiver reactions to role demands.

Although the findings suggest significant burden differences across groups, the unequal distribution of participants is problematic. Despite statistical significance, this result should be viewed with caution given that only 7 of 50 caregivers fell within the high coping-low control cluster. To further assess the overall contribution of independent variables to prediction of caregiver burden, multiple regression was performed to assess if the combination of coping and control allows for a significant increase in observed variance in caregiver burden. A hierarchical regression equation was computed in which control, emotion- and problem-focused coping were entered as a first step ($R^2 = 0.19, p < 0.05$).

To assess the interaction between coping and perceived control, the product of combined coping and perceived control was added as a final step ($\Delta R^2 < 0.005, ns$). The interaction between coping and control fails to account for additional variance in caregiver burden ($F[4,44] = .21, ns$). This suggests that the combined effect of these variables is unable to account for additional variance over and above their additive effect. Again, contrary to the goodness-of-fit hypothesis, there would appear to be no discernible interaction between coping and perceived control relative to caregiver burden.

**Table 2: Correlation Coefficients and Hierarchical Regression Analysis of Caregiver Burden**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Burden (DV)</th>
<th>Problem</th>
<th>Emotion</th>
<th>$B$</th>
<th>$SE B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem</td>
<td>0.36 **</td>
<td>-0.13</td>
<td>0.70</td>
<td>-0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion</td>
<td>0.46 **</td>
<td>1.10</td>
<td>0.80</td>
<td>0.31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>-0.26</td>
<td>-9.16</td>
<td>15.31</td>
<td>-0.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping × Control</td>
<td>0.12</td>
<td>0.26</td>
<td>0.53</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** $p < 0.01$  

$R^2 = 0.19$ for control and coping strategies ($p < 0.05$).  
$\Delta R^2 = 0.004$ subsequent to inclusion of combined coping × control.  
$DV =$ dependent variable; Problem = problem-focused coping; Emotion = emotion-focused coping; Control = perceived control.

**Discussion**

As with the findings of Vitaliano et al. (1990), results of the current study provide inconsistent support for the goodness-of-fit hypothesis. Although caregivers who reported high reliance upon problem-focused coping and low perceived control presented as most distressed, emotion-focused coping was relatively low across groups. This includes those who reported lower levels of emotion-focused coping, moderate control, and relatively little distress. Implicit among the initial hypotheses, it was assumed that at least one grouping of participants would present as relatively reliant upon emotion-focused coping. This was not the case, as problem-focused coping was predominant in each grouping.

This finding is notable given that problems reported by caregivers of persons with dementia are generally not amenable to change (e.g., loss of companionship, repeated questioning, wandering, sleep disturbance). For this study, participants were primed to report stressors specific to being married to someone with pronounced memory impairment; thus the majority reported stressors attributable to the disease process as opposed to situations in which they could exercise greater control. In contrast to the assumption that caregivers accept role demands as outside of their control and thereby turn to emotion-focused strategies, caregivers recruited for this study reported a notable degree of control ($M = 2.14$ on a 4-point scale). This suggests that perceived control and coping are both idiosyncratic phenomena, only determined partially by situational factors (see Gignac & Gottlieb, 1996). This observation is in accord with the findings of Parker, Endler, and Bagby (1993), who stated that distinctions among coping strategies are highly variable. For instance, the factor structure of coping measures has been shown to differ markedly across populations and time. Similarly labelled subscales are often composed of differing items that may load on separate and theoretically distinct factors.

This may suggest that coping needs to be examined from a fresh perspective. Consistent with the findings of this study, categorization of responses may be less relevant on an individual basis than overall coping response. This may require that coping be redefined in order to achieve greater consistency across individuals and groups. For instance, the cognitive phenomenological model as originally formulated by Lazarus...
and coping defined more recently (e.g., relationship-focused coping; DeLongis & O’Brien, 1990).

Various limitations of this study must be acknowledged. For instance, the cross-sectional design precludes conclusions regarding causation. Although coping and perceived control appear associated with caregiver burden, the direction of this relationship cannot be determined. As well, implicit within the cognitive phenomenological model is the notion that appraisal of controllability precedes selection of coping responses. As a function of outcome, appraisal may change and choice of coping strategies be modified (i.e., causation among model variables need not be unidirectional). Data derived at one point in time do not allow these possibilities to be assessed. Longitudinal study would be a better means by which to compare chronologically distinct processes (i.e., measure perceived control at the onset of the stressor and coping responses at a later date). Furthermore, the sample size recruited for the present study was small. Despite results suggesting significant differences across groups, restricted samples limit ability to generalize findings. This limitation was addressed somewhat by hierarchical regression which provided results compatible with the cluster analysis; however, the combined sample remains limited even when treated as a single grouping.

Despite these caveats, there is consistency between current findings and the initial Vitaliano et al. (1990) study. Replication of discrepant results raises concern regarding the goodness-of-fit hypothesis. As applied to this population, failure to provide concordant findings may indicate revisions are required to this facet of the stress and coping model. It appears that not relative reliance upon one type of coping strategy per se but overall coping and control are associated with dysphoria among caregivers. Further research is required across populations to clarify the interrelation between coping and perceived control.

References


