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Patterns of relationships between background characteristics, coping, and stroke caregiver outcomes

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Abstract

Purpose—Little is known about mediators of stroke caregiver outcomes or patterns of relationships of outcome predictors. We examined relationships between the variable sets: caregiver and stroke survivor characteristics, coping (proposed mediators), and caregiver outcomes.

Methods—We assessed 253 dyads prior to discharge from acute rehabilitation. Outcomes were depression, anxiety, preparedness, life change, and family functioning. Coping included problem-solving, caregiver appraisal, and unmet resource needs. Multivariate canonical correlation analyses were computed between the sets of variables to identify unique patterns of relationships.

Results—Six patterns of significant relationships were found ($R=.30$ to $.84$, $ps < .01-.02$). The strongest relationship was that between greater threat appraisal and negative life change, greater anxiety, and lower caregiving preparedness ($p < .01$). Caregiver characteristics (nonwhite, spousal caregivers) were related significantly to several outcomes (positive life change, lower anxiety, and less healthy family functioning) ($R=.43$, $p < .01$) and remained significant after controlling for the effect of mediators ($R=.32$, $p < .02$).

Conclusion—Findings suggest various patterns of relationships that provide guidance for individualizing early caregiver intervention. Clinicians can build on caregivers' strengths while identifying threats to adaptation to tailor interventions that promote healthy outcomes.

Keywords

stroke; caregiver; coping; mediator; outcomes

Each year, approximately 795,000 persons in the U.S. experience a new or recurrent stroke.¹ Most return home in the care of a family member. Negative outcomes among stroke caregivers are common during the first months after stroke onset and tend to persist for months or years.²⁻⁵ For instance rates of 30 % to 52% have been reported for depression.^{2-4,6,7} Furthermore, caregiver factors, such as depression, stress, and poor family functioning have been correlated with negative stroke survivor outcomes, including functional recovery and stress.^{2,8-9}

A number of studies have examined variables that are correlated with stroke caregiving outcomes. Variables demonstrating fairly consistent associations with negative outcomes include low social support, dysfunctional problem-solving, negative appraisals, ineffective family functioning, female gender, caregiver health, and survivor function/stroke severity.^{2-4,7,10-13} Moreover, the finding that caregiver family functioning deteriorated significantly during the first months after stroke onset raises concern about the health of the family unit.³ The relationships between variables such as age, race, and relationship to the survivor are inconsistent.^{3,7,10-11,13-16} Coping variables, such as appraisal of caregiving, and problem-solving are potential mediators between caregiver and survivor demographic and illness characteristics and outcomes. Coping variables have been correlated with CG distress and family functioning^{3,11,17-19}, and have mediated relationships between background factors and distress.²⁰⁻²¹ Another potential mediator is unmet needs for information, emotional, social and physical assistance, and other resources.^{5,22-23}

Caregivers report many life changes and have described the early caregiving period when they are dealing with new roles, problems, and responsibilities as most difficult,²² and report feeling unprepared for caregiving.^{22,24} Lower preparedness for caregiving has been correlated with depression or negative mood and stress^{7,9} and improved significantly with a problem-solving intervention.²⁵

Evidence exists that caregiving has negative effects on physical health, including greater risk for coronary heart disease and mortality.²⁶⁻²⁷ Based on reviews of CG health studies, researchers recommended increasing the emphasis on physical health assessment in CG studies.²⁸⁻²⁹ Effects on health have been observed as early as two months after initiating caregiving, when 16% of caregivers reported at least one new or exacerbated health condition.³

Few stroke caregiver studies examined coping processes as mediators or developed profiles or patterns of variables related to adaptation. Knowledge of such patterns and mediators can help to identify caregivers at risk for negative outcomes and potential interventions. The purpose of this study was to assess the relationships between sets of caregiver and stroke survivor characteristics and caregiver coping and outcome variables to identify patterns of adaptation. The research questions were: 1) To what extent do the background-illness characteristics sets relate to the caregiver coping set?, 2) To what extent does the coping variables (mediator) set relate to caregiver outcomes?, and 3) To what extent does the caregiver characteristic set relate to outcomes after controlling for coping?

Conceptual Model

The conceptual model was The Moos and Schaefer Model of Coping with the Crisis of Illness,³⁰ which proposes that background characteristics influence responses to life crises. These factors influence health and well-being outcomes directly and indirectly through mediators, (coping variables) such as cognitive appraisal and coping strategies.

METHODS

The study used a cross-sectional descriptive design. Participants were recruited and assessed during the stroke survivor's acute rehabilitation from four rehabilitation facilities. Caregivers met the following inclusion criteria: aged 21 or older, co-resident and primary caregiver for an adult survivor of a recent stroke who was planning to return home, sufficient hearing to engage in assessments, English speaking, at risk for depression (as measured by a CES-D score greater than 9), and not receiving counseling or attending a support group.

Measures

Background and illness characteristics—Caregiver and survivor demographic and illness data were collected during acute rehabilitation. Variables in the analysis were caregiver race, sex, relationship to survivor, health, age, and prior history of depression. Caregiver physical health was measured using a single item (0=“poor” to 3=“excellent”), which is used widely and has demonstrated validity.^{31–32} Table 1 shows scores and Cronbach alpha for all variables.

Survivor variables included motor and communication and cognitive function, and caregiver-rated cognitive function. The Functional Independence Measure (FIM) was used to assess severity of disability in motor, communication, and cognitive domains, with higher scores representing greater independence.³³ FIM admission scores were used in the analyses. Caregiver perception of cognition was assessed using the Cognitive Status Scale (CSS). Items address recognition, communication, and memory deficits. Higher scores indicate greater impairment. Validity was supported by comparisons with another cognitive test in Alzheimer caregivers.³⁴

Coping Variables

The Social Problem Solving short form scale (SPSI-R) was used to assess problem-solving.³⁵ This instrument contains five subscales that measure problem-oriented (PO) dimensions (positive, PPO and negative, NPO) and problem-solving styles (rational, avoidance, impulsive/careless). Higher scores for NPO, avoidance (APS), and impulsive (IPS) styles reflect more ineffective problem-solving (PS). Higher scores for PPO and rational PS (RPS) indicate more effective problem-solving. The scales have adequate internal consistency. Validity has been supported by correlations with depression and anxiety in the expected directions.³⁵

The Appraisal of Caregiving Scale (ACS) measures benefit, benign, and threat caregiving appraisal.³⁶ Items are rated on a 5-point scale from “strongly disagree” to “strongly agree”. Mean scores are computed by dividing the sum of scale items by the number of items in the scale. Higher scores reflect greater levels of each construct. Reliability, and content and construct validity have been demonstrated.^{36–37} Serial factor analyses of the original items resulted in a 3-factor 27 item solution. Validity was supported by significant correlations in the expected directions between the appraisal scales and caregiving antecedents and outcomes. The ACS has been used in stroke CG samples; alphas ranged from .71(benefit) to .92 (threat).^{19,38}

The 13-item measure, Unmet Resource Needs Inventory (URN) was used to assess knowledge and access to caregiving resources. We developed the scale based on results from a prior study.²² Responses (1=“strongly disagree” to 5=“strongly agree”) are summed, with higher scores indicating greater unmet need. Validity was supported by significant correlations in the expected directions with caregiver depression, preparedness, and anxiety. Results of an exploratory factor analysis using .30 loading criteria indicated a uni-dimensional solution, the construct, unmet resource needs. Excepting a reverse scored item, which was revised, the factor loadings ranged from .30 –.78; explained variance was 35% Alpha coefficient was .84. (King, unpublished data, 2010).

Outcomes—The Centers for Epidemiological Studies–Depression scale (CES-D) was administered to assess the frequency and severity of depressive symptoms experienced during the past week.³⁹ The CES-D is comprised of 20 depressive symptoms which are rated on a scale of 0 = “none” to 3 = “5 to 7 days”. The possible range of scores is 0 to 60; higher scores reflect greater symptom severity. A score of 16 is suggested as the cutoff indicative

of depression. Alpha coefficients in community subjects ranged from .85 to .90.⁴⁰ The CES-D distinguished acutely depressed patients from those who had recovered from depression, and community adults. Strong correlations with a clinical depression rating and other depression scales support validity.^{39,40} The CES-D has been used widely in stroke caregiver studies, and is sensitive to change.^{25,41}

Family functioning was assessed using the 12-item General Functioning Scale of the McMaster Family Assessment Device (FAD).⁴² The scale assesses overall health of family functioning with a range of scores from 1="healthy" to 4="unhealthy". A cut-off of 2.0 distinguishes healthy from unhealthy family functioning.⁴³ Concurrent and predictive validity, internal consistency reliability, sensitivity, and specificity have been demonstrated in various samples.⁴³ The FAD has been used in stroke studies, was sensitive to change, and predicted depression or lower mental health.^{3, 13, 17, 44}

Anxiety was measured using the 5-item Tension-Anxiety subscale of the Profile of Moods Scale short form (POMS).⁴⁵ This 5-point response scale describes feelings ranging from mild to intense. Higher scores reflect greater anxiety. Internal consistency reliability, predictive, construct, and divergent and convergent validity have been demonstrated.⁴⁵⁻⁴⁷ Reliabilities ranged from .73 to .93 depending on the population studied.

Caregiver Preparedness was assessed using the Preparedness for Caregiving Scale (PCS).⁴⁸⁻⁴⁹ Higher scores represent greater preparedness. Validity and internal consistency reliability, tested with multiple samples have been demonstrated. The PCS is an 8-item, 5-response option scale (0="not at all prepared" to 4="very well prepared"). Responses are summed and divided by the number of items; the potential range of scores is 0-4. Alpha coefficients range from .67 to .92.⁴⁹ Preparedness has been a significant predictor of CG role strain or stress,^{9, 48} and was sensitive to change in stroke CG studies.^{25,41}

Perception of Life Change was measured using the Bakas Caregiving Outcomes scale (BCOS), which measures change in social functioning, subjective well-being, and somatic health.^{19,38} The 15-items with a 7-point response set, 1 = "Changed for the Worst" to 7 = "Changed for the Best" are summed for an overall score that reflects CG life change. Higher scores represent more positive change. Construct validity was supported by a uni-dimensional factor analysis solution and prediction of the BCOS by stress and coping variables. Criterion validity was supported by significant correlations with a well-being measure. Internal consistency reliability is strong.³⁸

Procedures

Institutional Review Board approval was provided by each site. Informed consent was obtained prior to screening caregivers for inclusion criteria and collecting data. Functional status was retrieved from the survivor's medical record.

Analysis

All statistical analyses were conducted using SPSS 13.0 (SPSS, Inc., Chicago, IL). Prior to undertaking the primary analyses the distributions of each variable were examined for suitability in multivariate analysis, and the existence of outliers was evaluated. Mean (SD) or frequencies (%) were used to describe participant characteristics.

Canonical correlation (CC) was used to assess the relationship between sets of patient or caregiver variables and sets of nine coping and five outcome variables. CC is the optimal correlation between sets of multiple variables. The sets are created using weighted composites (canonical variates) for each relationship set that maximize the relationship between the variables. The CC analyses enabled assessment of multidimensional

relationships to identify patterns of unique associations between the variable sets. The first canonical variate in a set accounts for the greatest variance. The maximum number of canonical variates that can be computed is dependent on the smallest number of variables in either set.⁵⁰ As suggested by Pedhazur (1982)⁵¹ an a priori cutoff for canonical coefficients was selected at 0.30 to identify meaningful correlations, that explain more than 9% of variance between canonical variables and study variables.⁵⁰ The sample size for this study (253 subjects for 15 variables) exceeded the suggested requirement of a 10:1 ratio of number of subjects for each independent variable.⁵⁰

Based on the conceptual model, we tested the mediational role of the coping variables. Each variable set was separately correlated with the other sets. If meaningful correlations existed between all sets, a mediational analysis examined the proportion of variance that coping variables (i.e., proposed mediators) accounted for in the relationship between caregiver or survivor characteristics and outcomes.

The survivor variable set included: caregiver-rated cognitive status, FIM motor and communication and cognitive function. This variable set was not related to potential mediators; thus further analyses were not computed. The caregiver characteristic set was comprised of six variables (Table 1). Nine mediator variables included three appraisal scales, five problem-solving scales; and unmet resource needs (Table 1). Finally, five outcomes were included. Assumptions for within-set multicollinearity were evaluated and no two variables within any set were too highly correlated ($r's \leq 0.60$) for canonical analysis.

Results

Sample Characteristics

The sample recruited was 362 rsurvivor-caregiver dyads. Of these, 80 (22%) were ineligible; 29 (10%) of 282 eligible caregivers did not complete data collection, and 18 (5%) of survivors did not consent or functional data were not available. The final sample was 253 caregivers and 235 survivors. Most caregivers were Hispanic or Caucasian White (69%), 26% were Black, 7% were Hispanic, 4% were Asian and 3% were either Pacific islander, unknown, or more than one race. Among survivors, 72% were Hispanic or Caucasian White, 24% were Black, 8% were Hispanic, 3% were Asian, and 1% were more than one race, Table 1 shows caregiver and survivor characteristics and measures. Whereas the majority of caregivers were female, most survivors were male. Caregiver distress was high; 74% reported scores indicative of possible depression (CES-D ≥ 16); 37% reported ineffective family functioning, and 27% were moderately to extremely anxious.

Caregiver Models

Table 2 shows the variable sets, six canonical variates (CV) with their canonical coefficient, CV correlations, and percent variance explained by the canonical correlations. Figure 1 illustrates the relationships between the variable sets and provide the CV. Results are presented for the three research questions.

1. Relationship between caregiver characteristics and coping—Caregiver characteristics were related to patterns of coping variables in two meaningful ways that were significant (Figure 1). The first relationship, canonical variate 1 (CV1) ($R = .50, p < .01$) indicated that caregivers with more benign, less threatening appraisals, as well as more unmet resource needs were more likely to be nonwhite, older, and in poorer health. The second relationship, CV2 ($R = .45, p < .01$) revealed that younger non-white caregivers in better health viewed the stroke as less threatening, yet more distressing (less benign), and

reported greater benefit appraisals than other caregivers. These caregivers perceived problem-solving positively and less negatively, and used avoidance problem-solving more than other caregivers.

2. Relationship between coping variable set and outcomes—Three patterns of significant relationships between coping and outcome sets were observed (Figure 1). The first relationship, CV3 ($R = .84, p < .01$) indicated that caregivers with higher threat appraisal experienced greater negative outcomes, including negative life change, greater anxiety, and felt less prepared for caregiving. For the second relationship, CV4 ($R = .49, p < .01$), the significant coping findings were characterized by caregivers having higher levels of distress appraisals (a less benign view), while simultaneously holding stronger benefit appraisals, combined with a mixed orientation to solving problems. They had a positive orientation despite a negative view of problem-solving and reported high unmet needs. This pattern was associated with greater depression and anxiety. At the same time, their life changes tended to be positive; family functioning was healthy and they felt prepared for caregiving. The third relationship, CV5 ($R = .30, p < .02$) indicated less threatened individuals who saw more benefit in caregiving, used less rational problem-solving, had high unmet needs, and were unprepared for caregiving, had less healthy family functioning, but they experienced positive life change.

3. Relationship between caregiver characteristics set and outcomes—Nonwhite spousal caregivers were more likely to experience less anxiety, positive life change, and less healthy family relationships, CV6 ($R = .43, p < .01$; Figure 1). This relationship remained significant after controlling for mediators (coping variables) ($R = .32, p < .02$), indicating that caregiver characteristics play a unique role in achieving outcomes.

Discussion

The caregivers in this study were quite distressed, as noted by the high rates of possible depression (74%), anxiety, and unhealthy family functioning. However, these rates may not be representative of all new stroke caregivers because the study eligibility criteria included risk for depression.

Findings suggest that certain background variables and mediators may be important factors in initial adjustment of caregivers. Race, health, age, and relationship to survivor were significant in the caregiver characteristic sets that either were related to mediators or outcomes, and three coping sets were related to outcomes. Unlike other studies, health was not related to outcomes, but was related to mediators.^{3,16} This difference may be due to health being combined with other variables in this study.

The CV1 cluster of characteristics and relationships suggest under-resourced, nonwhite, older, sicker caregivers who perhaps cope by perceiving less threat in a resigned way (“I can only do what I can do”). These caregivers may distance themselves from the events, leading to a view of the situation as rather benign or neutral instead of distressing, which may be a way of coping with a difficult situation. On the other hand, they may be resilient and may have mastered coping with stressful events with few resources. Others have reported that Black caregivers tend to view caregiving as less stressful than White caregivers.^{20,52} When initiating the caregiving role, these individuals might be empowered by educating them on resources.

In contrast, the CV2 relationships suggest a younger, more positive nonwhite group, who nonetheless may not be directly confronting the tasks of their caregiving role. They may employ less adaptive emotional defenses, such as avoidance or denial. Encouraging them to

take early preventive action to address problems may help avoid unnecessary long-term complications

The CV3 relationships suggest that caregivers who initially approach their role in a highly threatened manner are likely to feel immediate distress, be pessimistic about their future and be less confident in managing care. This relationship may represent overwhelmed caregivers who need time and support to accept new responsibilities. They may be helped by skill building related to specific caregiving tasks, whether that involves life skills, or specific caretaking skills.

CV4 caregivers indicate mixed, at times conflicted coping. They may be more ambivalent individuals, who are experiencing internal distress despite acknowledging assets in their situation. Their tendency to think positively may be protective of some aspects of life, such as family functioning and life change. Despite appearing competent, they may reveal inner turmoil when their wellbeing is more directly addressed. They may require monitoring to promote adaptation while assuming full caregiving responsibility.

The 5th CV profile of mixed positive and negative characteristics and relationships suggests they may be using inadequate coping, as they view their situation in an unusually positive manner, despite acknowledging deficits in resources, skills and support. This group may also need education on caregiving challenges and resources to help anticipate and prevent stress complications.

CV6 represents non-white spousal caregivers, who experience positive life change, are less anxious, but report more unhealthy family functioning. The finding of more positive life change in these caregivers is consistent with studies that compared positive perceptions of Black and Caucasian caregivers.^{20,21} Researchers recently reported lower levels of anxiety among Black caregivers. In that study, lower anxiety, together with religiosity and lower socioeconomic status in Black caregivers partially mediated the relationship between race and positive aspects of caregiving.²¹

Non-White, spousal caregivers also reported poorer family functioning. Stroke may disrupt intimate spousal relationships, contributing to altered family functioning. Most family functioning items are based on communication and behaviors. These caregivers may not have learned communication strategies for aphasia or cognitive impairments. They may be helped by teaching appropriate communication and behavior management, facilitating identification of alternative supports and building on their positive perceptions. Similar to our findings of coping variables as mediating the effect of caregiver characteristics on outcomes, a mediational effect for coping on well-being in Black dementia caregivers has been reported.²⁰ These researchers suggested that cultural differences may contribute to racial variation in coping. For instance, Black caregivers commonly viewed caregiving as expected while White caregivers tended to view caregiving as disrupting lifestyle. Future research is needed to better understand the mechanisms underlying cultural factors that influence differences in perceptions about caregiving.⁵³

Findings provide evidence of the variety of patterns of adaptation in early caregiving and underscore the complexity of caregiver adaptation soon after the onset of a stroke in the family. As such, it informs the need for a flexible approach, tailored to the individual's perceptions and emotional state. However, threat appraisal appears to be an overarching variable in understanding outcomes, suggesting a more universal area for early intervention. For example, soliciting and addressing the new caregiver's fears, and assessing their likelihood and management may reduce distress.

A limitation of this study is the cross-sectional design. We did not account for prior caregiving history which might bear on emotional reactions and perceptions in this new role. Other limitations include pre-selection of the sample on depression and exclusive use of self-report measures, which might restrict the range of relationship patterns.

Despite these limitations, profile assessment adds to understanding the diversity of caregiver adaptation and how the relationship patterns might inform choices for intervention and identify at risk subgroups.

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Figure 1.

Pattern of relationships among caregiver characteristics, coping variables, and outcomes. The numbers, 1 through 6 within the circles, are canonical variates or CV1 through CV6. The relationships represented by the CVs are as follows. CV1: characteristics with coping, CV2: characteristics with coping, CV3: coping with outcomes, CV4: coping with outcomes, CV5: coping with outcomes, and CV6: characteristics with outcomes. Most multiple R values are significant at the $p < 0.006$ level. Dotted line represents the caregiver characteristics-outcomes relationship after controlling for coping (mediators) on each variable. The remaining association ($R = 0.32$) was significant ($p = 0.016$).

Table 1

Descriptives: Patient-Caregiver Characteristics, Coping and Outcome variables, and Scale Alpha Coefficients

Variables	Possible Range	Mean (SD)	N (%)	Alpha
Patient characteristics (N =235)				
Age	22. – 93	61.2(14.5)		
Sex: male			141(60)	
FIM motor	13 – 79	30.8(14.8)		.92
FIM communication-cognitive	5 – 35	16.5(7.8)		.97
Cognitive status (CSS)	0 – 30	8.4(6.9)		.86
Caregiver characteristics (N=253)				
Health:	0 –3	1.8(.69)		
Sex: female			201(79)	
Race: White			175(69)	
Relationship: spousal			160(63)	
Age	21 – 85	54.5(14.4)		
Prior psych treatment: No			224(88)	
Mediator Measures				
Positive problem orientation (PPO)	0 – 20	12.9(3.7)		.71
Negative problem orientation (NPO)	0 – 20	5.2(4.3)		.83
Rational problem solving (RPS)	0 – 20	11.9(3.9)		.81
Avoidance problem solving (APS)	0 – 20	4.0(3.8)		.80
Impulsive problem solving (IPS)	0 – 20	4.2(3.5)		.72
Threat appraisal	1 – 5	2.8(.71)		.89
Benign appraisal	1 – 5	2.7(.75)		.74
Benefit appraisal	1 – 5	3.6(.63)		.79
Unmet resource needs (URN)	13 – 65	33.3(7.6)		.84
Outcome Measures				
Depression (CES-D)	0 – 60	22.9(9.6)		.91
Family functioning (FAD)	1 – 4	1.9(.4)		.83
Anxiety (POMS)	0 – 20	7.2(4.6)		.83
Caregiver preparedness (PCS)	0 – 4	2.5(.73)		.84
Perception life change (BCOS)	15 – 105	54.6(11.1)		.87

Note. A higher value represents more positive score for the FIM, Health, PPO, RPS, benign and benefit appraisals, PCS, and BCOS. A lower value represents more positive scores for CSS, NPO, APS, IPS, threat appraisal, URN, CES-D, FAD, and POMS.

Table 2

Canonical Correlation Analysis Summary

Variable Set	CV1 C Coeff	CV2 C Coeff	CV3 C Coeff	CV4 C Coeff	CV5 C Coeff	CV6 C Coeff
Caregiver characteristics						
Health	-.36*	.54*				.19
Sex	.20	.29				.29
Race	-.72*	-.40*				-.71*
Relationship	.29	.17				.49*
Age	.36*	-.66*				-.08
Prior psych treatment	.16	-.06				-.26
Coping						
Threat	-.35*	-.36*	.54*	-.14	-.36*	
Benign	.66*	-.51*	-.29	-.32*	-.04	
Benefit	.00	.54*	-.20	.43*	.57*	
Positive PO	.06	.36*	-.04	.42*	.00	
Negative PO	-.04	-.38*	.24	.76*	.10	
Rational PS	-.09	.03	.01	.05	-.31*	
Impulsive PS	-.05	.06	.12	.10	-.04	
Avoidance PS	.27	.48*	-.10	.05	.27	
Unmet resource needs	.61*	.11	.08	-.43*	.86*	
Canonical correlation	.50*	.45*				
% variance explained	25%	20%				
Outcomes						
Life change			-.36*	.60*	.96*	.51*
Depression			.05	.48*	.18	.20

Variable Set	CV1 C Coeff	CV2 C Coeff	CV3 C Coeff	CV4 C Coeff	CV5 C Coeff	CV6 C Coeff
Family functioning			.20	-.34*	.56*	.65*
Anxiety			.46*	.74*	.04	-.47*
Caregiver preparedness			-.33*	.35*	-.52*	.29
Canonical correlation			.84*	.49*	.30*	.43*
% variance explained			71%	24%	9%	18%
Canonical correlation						
% variance explained						

* $p < .05$ significant relationships.

Note. CV = canonical variates; also shown in Figure 1. The CV, such as CV1 is comprised of the variables in the respective column. For instance, CV1 includes the caregiver characteristics and mediational variables in column one.

Note. C Coeff = canonical coefficient, PO = problem orientation, PS = problem-solving,