

The Post-stroke Psychosocial Environment of Stroke Patients and Their Partners: Some Preliminary Results of a Longitudinal Study

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Most reports on the psychosocial impacts of stroke have been descriptive and anecdotal in nature, or have only gathered information at one point in time, usually months to years after the stroke occurrence (Artes and Hoops, 1976; Buck, 1968; Chwat, Chapey, Gurland, and Pieras, 1980; Fengler and Goodrich, 1979; Kinsella and Duffy, 1978, 1979, 1980; Malone, 1969; Webster and Newhoff, 1981). There has been a lack of prospective information regarding the process of adjustment to stroke over time, and of data which compare pre- and post-stroke social environmental factors related to well-being and successful adaptation for both the individual who has experienced the stroke and his or her primary caregiver.

Nevertheless, previous reports have suggested significant disruption in the amount and quality of social contact and social support following the occurrence of a stroke. In addition, several studies have documented that depression is a frequent problem in persons who have suffered a stroke (Robinson et al., 1985; Robinson and Szetela, 1981). There is some evidence to suggest that the spouses of stroke patients are at high risk for depression as well. At least three previous studies (Artes and Hoops, 1976; Fengler and Goodrich, 1979; Kinsella and Duffy, 1979) have indicated that the partners of aphasic stroke patients, compared with the spouses of those who are not aphasic, are at greater risk for depression and other negative changes.

The purpose of this study was to examine social support and well-being changes related to disabling strokes in a sample of recent stroke patients and their partners. Information was obtained at two points in time -- at four to eight weeks following stroke onset and six months later. The following questions were addressed. 1) In what ways does the social support system change over time as a result of a stroke? 2) What is the impact on the stroke patient and partner of a changing support system? 3) What are the important correlates and predictors of health and well-being outcomes and adaptation at different points in time, and over time? 4) What is the relationship between site of lesion (right or left hemisphere) and well-being outcomes?

METHOD

The Sample. Subjects were 50 individuals who had recently suffered an initial, completed stroke and their partners. Criteria for inclusion in the study were: (1) clinical evidence of a single completed stroke; (2) no

evidence of coexisting terminal illness or rapidly progressive medical disease; (3) the stroke occurred within 8 weeks of the initial interview. Demographic characteristics of the subjects are summarized in Table 1.

Table 1. Demographic characteristics of stroke patients and caregivers in the sample.

	STROKE PATIENTS	CAREGIVERS
AGE		
Mean Age	63.7	62.5
S.D.	9.85	10.7
Range	37-90	36-84
GENDER		
% Male	82	18
% Female	18	82
ETHNICITY		
% Caucasian	94	92
% Black	4	4
% Other	2	4
EDUCATION		
% High School Graduates	76	80
% At least some College	48	40
EMPLOYMENT (PRE-STROKE)		
% Working Full-Time	36	22
% Working Part-Time	12	14

Stroke-Related Data. Information regarding the stroke event was obtained from medical records for all of the stroke patients. CT scan reports were obtained for 48 of the 50 patients. Ninety percent of patients had incurred thromboembolic strokes, and 60% had documented left hemisphere lesions. Stroke-related data are summarized in Table 2.

Data Collection. The primary data-gathering tool was a questionnaire administered during face-to-face interviews. Additional information was obtained from previously developed scales adopted for this study: the CES-D depression scale (Radloff, 1977); the Index of Psychological Well-Being (Berkman, 1971); an optimism scale, the LOT (Scheier and Carver, 1983); an Activities of Daily Living scale, the Barthel Index (Mahoney and Barthel, 1965); and a Caregiver Burden scale adapted from one described by Zarit, Reever, and Bach-Peterson, 1980.

Information collected included demographic, health-related, and stroke-related information, along with detailed information about the subjects' social activities, social networks, social support systems, and marital relationships. The major outcome variables were subjects' scores on the CES-D

depression scale and the Index of Psychological Well-Being, widely-used and psychometrically well-studied instruments. This paper will report only on the correlates and predictors of depression scores at each interview time, and over time.

Table 2. Stroke-related data for the patients in the sample.

	NUMBER	PERCENT
TYPE OF STROKE		
Thromboembolic	45	90
Hemorrhagic	4	8
Lacunar	1	2
SITE OF LESION		
Left Hemisphere	30	60
Right Hemisphere	15	30
Brain Stem	4	8
Bi-hemispheric	1	2

Data were collected over a 21-month period from November, 1983 through July, 1985. Over 80% of the interviews were conducted in subjects' homes. Approximately half the stroke patients were able to participate in the interview process, including 37% of the left-hemisphere damaged subjects. For the remainder, their partners provided information about them. Except for the outcome measures, which tapped current affect and well-being, the Time 1 interview gathered information about the pre-stroke situation. At Time 2, the frame of reference was the time period between interviews.

RESULTS

Changes in Subjects' Social Networks and Social Support Systems. This study focused particularly on social network and social support changes related to the stroke. Some predictions regarding negative changes in the structural and interactional aspects of the social networks were confirmed by the data, while others were not. The expected declines in overall network size after the stroke were not found for the caregivers or for the patients when group data were considered. Likewise, data analysis did not reveal any significant declines in the frequency of face-to-face contacts with network members, as had been predicted. Minimal changes over time were seen in the relationship composition of the partners' networks. For the patients, however, the predicted declines in the number and proportion of friends in the network and increases in the number and proportion of relatives in the network were observed at Time 2. These data are summarized in Table 3.

Table 3. Changes in the relationship composition of the stroke patients' social networks from Time 1 to Time 2.

	TIME 1		TIME 2	
	TOTAL #	%	TOTAL #	%
<u>Gender Composition</u>				
Female	234	47	287	53
Male	260	53	254	47
<u>Relationship Composition*</u>				
Friends	192	39	162	30
Other Relatives	80	16	116	21
Neighbors	42	9	61	11
Work Associates	22	4	7	1
Other	4	1	17	3
Total Relatives	234	47	286	53
Total Non-Relatives	260	53	255	47

* For only those relationship categories which showed some change over time.

Some of the predicted changes regarding network social support were confirmed. Caregivers reported both giving and receiving less support from their close network at Time 2, across all types of support, including instrumental assistance, emotional support, and informational support. After the stroke they experienced fewer reciprocal support exchanges with their close networks across all types of support, and fewer confiding relationships in which they were the providers of confiding support. The patients saw themselves as receiving increased instrumental help and less informational help at Time 2. They reported giving less tangible assistance to their network members, but saw themselves as providing more confiding and informational help after the stroke than before. Both patients and caregivers maintained pre-stroke levels of socializing at six months post-stroke.

Prevalence of Depressive Symptoms. Initially, a fairly high proportion (25%) of the group of less communicatively impaired stroke patients (those who were able to complete the outcome measures and the interview) had scores on the CES-D indicative of being at high risk for depression. What was not expected was that almost half of the caregivers (48%) scored above the cutoff level indicating high risk for depression at Time 1. These percentages decreased only slightly at Time 2 (to 23% for the patients and 45% for the partners), and remained considerably higher than the proportion of individuals at risk for depression among the general population of elderly persons. Table 4 summarizes the CES-D results for both the stroke patients and their partners.

Table 4. Scores for stroke patients and caregivers on the CES-D (maximum score = 84).

	TIME 1		TIME 2	
	MEAN	S. D.	MEAN	S. D.
Caregivers	22.7	13.32	20.04	13.23
Patients	17.88	11.91	20.22	15.20
% Caregivers above cutoff score of 23		48		45
% Patients above cutoff score of 23		25		23

Correlates of Depression. Numerous Pearson and Kendall correlation coefficients were computed in order to investigate whether this study confirmed predicted relationships between depression scores and the independent variables. Tables 5, 6, 7, and 8 summarize the correlational relationships between depression score and other variables, for both Time 1 and Time 2. Health status, both objective and perceived, was expected to be strongly and negatively related to depression score. In fact, results of the study confirmed the frequently found negative relationship between health status and depression. For the caregivers, subjective health rating was strongly correlated with depression score, with objective health score also a significant correlate of depression level. These associations were all in the expected direction of poorer health rating being correlated with a higher depression score. For the patients, a higher objective health index score and less optimistic expectations for future health were both correlated with a higher level of depression.

Stroke-related variables proved to be strong correlates of depression. For the caregivers, a higher depression score was associated with greater concern about caring for the patient in the future, a lower level of patient ADL functioning, feeling that they could have done something to prevent the stroke, and a higher overall stroke severity rating.

At Time 2, stroke-related variables continued to be related significantly to depression score. For the caregivers, a greater level of perceived burden, along with increased frequency of negative behaviors and personality traits in the patient and decreased frequency of positive patient behaviors were correlated with higher depression scores. Both the patients' and the spouses' ratings of the patients' functional independence were negatively related to the patients' depression scores.

For the caregivers, higher pre-stroke levels of social activity and social support were associated with lower Time 1 depression scores. For the patients, several aspects of conjugal support, both positive and negative, were correlated with Time 1 depression score.

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 Table 5. Correlations with CES-D for caregivers.

Level of Optimism	-.537 ***
Subjective Health Rating	-.445 ***
Concern About SV Future Care	.432 **
Barthel Index Score (ADL'S)	-.415 **
Could Have Done Something to Prevent Stroke	.406 **
Amount of Long-Term Illness Support	-.388 **
Proportion of NW Providing Long-Term Illness Support	-.365 **
Total # of Volunteer Organizations	-.353 **
Level of Education	-.335 *
Acknowledged Mental Health Problem	.320 *
Number of Information Support Exchanges	-.313 *
Stroke Severity Rating	.307 *
Proportion of NW Sharing Hobbies and Interests	-.283 *
Objective Health Rating	.273 *
Number of Network Members Sharing Hobbies and Interests	-.262 *
Site of Lesion	.256 *
Proportion of Reciprocal Confiding Rel.	-.246 *
Patient Perceived Less Help Than Expected	.523 **
Patient's Level of Optimism	-.414 *

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 Note: NW = network

* = p < .05
 ** = p < .01
 *** = p < .001

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 Table 6. Correlations with CES-D for patients, Time 1 (N = 25).

Patient Variables

Frequency of Pre-Stroke Marital Disagreement	.479 **
Level of Optimism	-.414 *
Objective Health	.388 *
Could Have Done Something to Prevent the Stroke	.377 *
Expectations of Future Health	.368 *
Concern About Future Care	.359 *

Caregiver Variables

Partner Likely to Share Concerns	.354 *
Partner's Rating of Marital Disagreement Frequency	.407 *

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 * = p < .05
 ** = p < .01

Table 7. Correlations with CES-D for caregivers, Time 2.

Presence of Mental Health Problems	.571 ***
Level of Perceived Caregiver Burden	.498 ***
Level of Optimism	-.413 **
Objective Health Rating	.400 **
Number of NW Members Do Not Get Along With	.394 **
Network Density	-.383 **
Average Frequency of Face-To-Face NW Contacts	.381 **
Stability of Personality and Behavior in Patient	-.331 *
Subjective Health Rating Change, Time 1 to Time 2	.321 *
Number of Organizational Memberships	-.307 *
Increased Negative Behaviors and Personality Traits in Patient	.269 *
Marital Happiness Rating	-.266 *
Decreased Positive Behaviors and Personality Traits in Patient	.265 *
Likelihood of Patient Confiding in Partner	-.259 *
Amount of Network Overlap	.253 *
Number of Task Exchanges	.249 *

* = p < .05

** = p < .01

*** = p < .001

Table 8. Correlations with CES-D for patients, Time 2.

Presence of Mental Health Problems	.783 ***
Number of NW Members Less Help Than Expected	.686 ***
Frequency of Pre-Stroke Marital Disagreement	.574 **
Level of Optimism at Time 2	-.570 **
Number of NW Members Providing Transportation	.516 **
Level of Optimism at Time 1	-.509 **
Proportion of NW Providing Transportation	.495 **
Proportion of NW Who Appreciate Patient's Situation	.482 **
Number of NW Members Who Appreciate Patient's Situation	.471 **
Satisfaction With Amount of NW Contact	-.454 *
Change in Employment Status	.448 *
Proportion of Friends in NW	.394 *
Objective Health Rating	.389 *
Change in Subjective Health Rating, Time 1 to Time 2	.372 *
Barthel Index Rating (ADL'S)	-.354 *
Could Have Done Something to Prevent Stroke	.352 *
Partner's Rating of Frequency of Pre-Stroke Marital Disagreement	.4941 **
Partner's Rating of Barthel Index	-.410 *

* = p < .05

** = p < .01

*** = p < .001

At Time 2, both positive and negative aspects of social network relationships were reflected in the correlations of these variables with depression. For the patients in particular, those who had previously been more socially integrated before the stroke, and who retained more friends in their network at Time 2, were more likely to have higher depression scores, contrary to our predictions. Also, higher reported levels of certain types of instrumental assistance after the stroke were related to higher patient depression scores at Time 2. While it is possible that this relationship between levels of instrumental support and depression may simply be indicative of the relationship of both higher levels of support and depression score to the severity of the stroke disability, it also is possible that inappropriate levels of support were responsible for the correlation between support levels and depression.

To summarize the correlations, predicted relationships were found between health status and depression score, and between stroke-related variables and CES-D score. Some of the expected relationships between social network and support factors and depression were confirmed, while others were not. A number of negative network impacts on the patients and the caregivers were suggested by the correlations.

Predictors of Depression. For the caregivers, a series of hierarchical regression analyses explored the best predictors of depression score at Time 1, Time 2, and over time. Variables were chosen for inclusion in the regression equation based on a model of the impacts of stroke developed for the study, and on the strength of each variable's correlation with depression score. Tables 9, 10, and 11 summarize the results of the regression analyses.

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Table 9. Hierarchical regression for CES-D, Time 1, for caregivers.

DEPENDENT VARIABLE CES-D				
	MULTIPLE R	R2	R2 CHANGE	SIMPLE R
Subjective health rating	.455	.207	.207	-.455
Barthel Index Score	.588	.346	.139	-.426
Concern regarding future care	.635	.403	.057	.432
Proportion instrumental task assistance (pre-stroke)	.659	.435	.032	-.314
Proportion reciprocal confiding (pre-stroke)	.685	.470	.035	-.211

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Table 10. Hierarchical regression for CES-D, Time 2, for caregivers.

DEPENDENT VARIABLE CES-D, TIME 2				
	MULTIPLE R	R2	R2 CHANGE	SIMPLE R
Objective health rating	.403	.162	.162	.403 *
Perceived caregiver burden	.667	.445	.283	.502
Marital happiness rating	.670	.449	.004	-.281
Density of Network	.702	.493	.043	-.360
Proportion of NW providing instrumental help	.703	.494	.001	-.081

* Higher objective health score indicates poorer health.

Table 11. Hierarchical regression for CES-D, Time 1 and Time 2, for caregivers.

DEPENDENT VARIABLE CES-D, TIME 2				
	MULTIPLE R	R2	R2 CHANGE	SIMPLE R
CES-D, Time 1	.552	.305	.305	.552
Subjective health, Time 1	.554	.307	.002	-.204
Subjective health, Time 2	.559	.313	.006	-.185
Barthel Index, Time 1	.596	.355	.043	-.051
Barthel Index, Time 2	.607	.369	.013	-.088
Proportion reciprocal confiding, Time 1	.618	.382	.012	-.334
Proportion reciprocal confiding, Time 2	.672	.452	.070	-.341
Perceived caregiver burden	.784	.614	.162	.496

As has been found in many previous studies, the best predictor of caregiver depression score at Time 1 was subjective health rating. The patient's level of ADL functioning, concern about being able to care for the patient in the future, and the proportions of instrumental task assistance and reciprocal confiding within the pre-stroke network were also independently predictive of depression score.

The strongest predictor of depression score at Time 2 was the degree of perceived caregiver burden. Objective health rating and network density also added to the explained variance in caregiver depression score.

Finally, a change-focused regression analysis approach, as described by Cronbach and Furby (1970), was employed in order to investigate the relative contributions of key variables over time to the prediction of caregiver depression score at Time 2. In this approach, variables are entered into the regression equation in a specified order, such that the effects of a particular variable at Time 1 are accounted for immediately before the effects of that variable at Time 2 are measured. The order in which variables are entered into the regression equation has the effect of controlling for the initial levels of the predictor variables when looking at the effects of changes in those variables over time.

Table 11 summarizes the results of the change-focused regression analysis of Time 2 depression score on several key predictor variables. The level of depressive symptomatology at Time 1 was the best predictor of Time 2 depression score, as was expected. After controlling for subjective health and the patient's level of ADL functioning at Time 1 as well as changes in these variables over time, perceived caregiver burden at Time 2 was a strong predictor of depression score. The proportion of reciprocal confiding exchanges with the network at Time 2 and the patient's level of ADL functioning at Time 1 contributed to predicting Time 2 depression scores as well.

CLINICAL IMPLICATIONS

The findings of this study have implications for clinicians dealing with stroke patients and their families, and for those planning and developing intervention programs. First, this study clearly confirms that depression is not an infrequent or isolated occurrence even in a sample of relatively independently functioning stroke patients who are living at home. While a number of recent studies have suggested that depressive symptoms are neither recognized nor treated as frequently as they should be in people who have suffered strokes (Robinson, 1986), this information needs to be more widely disseminated.

The fact that almost half the spouses remained at high risk for depression at six to eight months after the stroke points up the need for treating the partner as well as the patient. Caregiver support groups have become increasingly available in recent years, but the need for specific outreach to distressed caregivers by health-care professionals should be recognized.

Furthermore, depression scores in this sample of caregivers and patients fluctuated as much as 30 points in either direction over time. An initial assessment that the patient and the caregiver are doing well or poorly may not be predictive of how they will be coping in six months or a year's time. Subgroups of stroke patients and partners can be clinically at risk for depression at different points in time. Some exhibit high levels of depressive symptomatology immediately after the stroke which decrease over the next six months to normal levels. For others, normal immediately post-stroke depression scores increase to high-risk levels as time progresses. It will be important for targeting and timing appropriate referral and treatment that we be able to predict these differences.

While stroke patient and partner depression scores do not correlate immediately after the stroke, they become more closely associated after six months' time. These results appear to demonstrate the importance of each dyad member's effect on the partner. Discrepancies in affect or in perceptions of the stroke were related to high depressive symptom scores and

increases in depression scores over time. It may be that early intervention for the dyad member who appears to be most at risk will circumvent some later problems for both individuals.

Finally, in our data there were some hints of differential changes over time depending on which hemisphere was damaged by the stroke. For example, the caregivers of stroke patients with left hemisphere damage showed a greater decrease in satisfaction with the amount and quality of social contacts than did caregivers of persons with right hemisphere lesions. On the other hand, the site of lesion being in the right hemisphere was predictive of a higher negative well-being score for the caregiver over time.

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DISCUSSION

- Q: When you take measures that were developed for other populations and apply them to a unique one, you always wonder about their validity and reliability with the populations they were developed for, and then you have further speculations about their reliability and validity with a unique population. Do you have any thoughts about that?
- A: The major outcome variables or dependent measures used in the study, including the CES-D depression scale, have been studied extensively in terms of their psychometric properties, with both general community and clinical samples, including age groups comparable to those in our study. Reliability and validity data were available on all of the dependent measures. We investigated the internal consistency of the measures for our sample as an indicator of reliability, and found the alpha levels to be very high - comparable to those reported in the literature for the particular measure in question. With regard to the validity of the CES-D as a measure of depression in a stroke patient sample, we particularly chose the CES-D because it has been found to be less "loaded" with somatic complaint items than other depression scales. Finally, in obtaining interview information, one must be concerned about the possibility of obtaining "socially desirable" responses - the tendency to respond in what the person perceives as the way you want them to respond. As a control on this, we included a social desirability scale as part of the battery. We found that our sample did not give a high number of socially desirable responses, nor did the social desirability measure correlate significantly with other measures.
- Q: It seems that the thrust of this study is to look at predictors. I think that if you want to get at cause, you need a model. What you have here are a lot of variables and a lot of data, and what you're hoping to come up with are some relationships. I wonder if you might do better to have a model of cause, and then look at the components of that model and how they relate to one another so that you're testing a model and not allowing many variables to lead you to make some causal inferences without an underlying theory.
- A: I agree. At the beginning of the study, we developed a model of adaptation to stroke based on a literature review and our clinical experience. Variables chosen for the hierarchical regression analyses were selected based on this model, as well as on the strength of

correlations with the dependent measure. We plan to statistically test the model further using time-lag analyses and other causal modeling procedures utilizing a third data point, as we have also collected information at one year post-onset of the stroke.

Q: You said that you were surprised that the social networks of your patients did not seem to become reduced after the stroke, and you hadn't expected that. In the patients that I've worked with, that seems like it's the number one complaint - they say they become isolated. Do you think that your results were influenced by the fact that a relatively high percentage of your sample of patients were not working at the time of the stroke?

A: I was surprised that for the structural network measures, such as the size of the network, expected declines were not seen for either the patients or the caregivers. There was some evidence, however, that for some patients at least, a sense of isolation may have been developing. We looked at the distribution of change in the size of the social network over time, and there were almost a quarter of the patient sample who did have decreases in the size of their reported network which were more than one standard deviation from the mean change score for network size. Also, at Time 2 the patients' networks contained more family member names, while both the number and proportion of friends declined. Finally, results of correlational analyses suggested that those patients who had been more socially active before the stroke, and who still reported a large proportion of friends in their networks at Time 2, were more likely to have higher depression and negative well-being scores at Time 2. These results taken together suggest that measures such as a count of the number of persons reported in the network are not very sensitive to the degree of isolation many stroke patients may feel.