

When a Parent Has a Stroke

Clinical Course and Prediction of Mood, Behavior Problems, and Health Status of Their Young Children

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Background and Purpose—The purpose of this research was to describe the clinical course of children's functioning (depression, behavioral problems, and health status) during the first year after parental stroke and to determine which patient-, spouse-, or child-related factors at the start of inpatient rehabilitation can predict children's functioning after parental stroke at 1-year poststroke.

Methods—Interviews with 82 children (4 to 18 years of age) and their parents (n=55) shortly after admission to a rehabilitation center, 2 months after discharge from inpatient rehabilitation, and 1 year after stroke. Depression was assessed using the Children Depression Inventory, behavioral problems with the Child Behavior Check List, and health status with the Functional Status II. Potential predictors were gender and age (child), activities of daily living disability and communication ability (patient), and spouse's depression and perception of the marital relationship.

Results—At the start of the stroke patient's rehabilitation, 54% of the children had ≥ 1 subclinical or clinical problems, which improved to 29% 1 year after stroke. Children's functioning 1 year after stroke could best be predicted by their functioning at the start of rehabilitation. Spouse depression and perception of marital relationship were also significant predictors. A total of 28% to 58% of the variance in children's functioning could be explained.

Conclusions—Children's functioning after parental stroke improved during the first year after stroke. Identifying children at risk for problems 1 year after stroke requires assessment of children's functioning and the healthy spouse's depressive symptoms and perception of the marital relationship at the start of rehabilitation. This demonstrates the need for a family-centered approach in stroke rehabilitation. (*Stroke*. 2005;36:2436-2440.)

Key Words: family health ■ longitudinal studies ■ stroke

Stroke is a chronic condition that may have serious consequences for a patient's physical, cognitive, and behavioral functioning. A stroke, however, not only affects the patient but also the spouse and children. Research on the consequences of parental physical illness on children's functioning¹⁻³ suggests that child adjustment difficulties may be more closely related to stress associated with the illness than to illness severity indices. Armistead et al.² introduced the term "disrupted parenting" as a key mechanism for explaining child problem behavior. Disrupted parenting is defined as reduced parental support or neglect of the child. It might result indirectly from parental physical illness because of changed family routines, parental absence, depression, stress, and conflicts between parents or between parents and children. One recent study⁴ showed that a chronic health condition in the father was strongly related to more behavioral problems in his children.

A recent cross-sectional study⁵ showed that half the children of stroke patients reported behavioral problems or depressive feelings at the start of inpatient rehabilitation. Significant relations were found between these symptoms and the spouse's burden and depression, whereas relations with measures of physical, cognitive, and communication disabilities of the stroke patient were insignificant.

No longitudinal follow-up or prognostic study of the impact of stroke on young children has been published to date. Prospective studies are necessary for revealing changes in children's functioning and predictors of children's long-term functioning after parental stroke. Early identification of children at risk for depressive, behavioral, or health problems and knowledge of relevant predictors might enable professionals to provide effective support to children and their families.

Therefore, the aim of this study was to answer the following research questions: (1) what is the course of children's func-

Received June 26, 2005; final revision received August 6, 2005; accepted August 16, 2005.

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Stroke is available at <http://www.strokeaha.org>

DOI: 10.1161/01.STR.0000185681.33790.0a

tioning (depression, behavior problems, and health status) during the first year after parental stroke; and (2) which factors, measured at the start of inpatient rehabilitation, can predict children's functioning at 1 year after stroke?

Methods

Subjects

Stroke patients consecutively admitted to 9 Dutch rehabilitation centers between April 2000 and July 2002 were included in the FuPro-Stroke cohort.⁶ Inclusion criteria for patients were first-ever stroke, supratentorial and 1-sided lesion, and age >18 years. Exclusion criteria for patients were prestroke Barthel Index (BI) <18 and inability to speak Dutch. If the patient had a spouse, he or she was also asked to participate in the study. Exclusion criteria for spouses were BI of the spouse <16 and/or having a very serious chronic illness. If the couple had young children (4 to 18 years of age) who were living at home, these children were also invited to participate in the study. Exclusion criteria for children were having a serious chronic illness and having behavioral problems for which professional help had been obtained before the parental stroke.

A total of 338 patients were included in the FuPro study, of whom 68% had a spouse. Of these spouses, 211 (92%) participated in the present study. Fifty-nine couples had young children. Three families refused to participate with their children, and 1 family received professional help for their child's behavioral problems before the stroke. A total of 82 children of 55 families participated in the first assessment (T1), of whom 77 also participated in the second (T2) and 71 in the third assessment (T3). Seven children were excluded because their parents were excluded from the FuPro study because of recurrent stroke (4×) or divorce (3×), and 4 children refused additional participation.

Procedure

At the start of inpatient rehabilitation, patients, spouses, and children were invited by their rehabilitation specialists to participate in the study. The first assessment was conducted as soon as possible after informed consent had been given. Spouses and children individually completed a series of pencil-and-paper questionnaires in a face-to-face interview. For children aged 4 to 7 years, we used parent-report measures only. The same researcher interviewed all of the spouses and children at home ≈2 months after the patients had been discharged from the rehabilitation center (second assessment) and 1 year after stroke (third assessment). The medical ethics committees of the University Medical Centre Utrecht and the participating rehabilitation centers approved the study, and informed consent was obtained from all of the participating patients, spouses, and children.

Measures

Behavior problems of the child were assessed using the Child Behavior Check List (CBCL),⁷ a parent-report measure for children aged 4 to 18 years. Items were summed to obtain scores for internalizing symptoms (ie, withdrawn somatic complaints and anxiety/depression) and externalizing symptoms (ie, delinquent and aggressive behavior). Raw scores were transformed into T scores that are standardized for gender and age. Cutoff scores of T values were used to mark behavior as "clinical," indicating a need for professional help (≥64); "subclinical," indicating considerable problems just outside the clinical range, 60 to 63; and "normal" (≤59).⁷ Depression was measured using the Child Depression Inventory (CDI).⁸ The CDI is a 27-item child self-report measure for children aged 8 to 18 years. A total score of ≥20 indicates clinical depression, and scores between 13 and 19 indicate subclinical depression.⁸ We used the 14-item parent-report version of the Functional Status (FS-II)⁹ to assess the child's health status. The FS-II was developed for children aged 0 to 16 years and consists of 14 items, like fatigue, sleep disturbance, energy, and intractable behavior. The FS-II score has a range of 0 to 100; a higher score indicates better health status.

Independent Variables

Patient data on age, gender, type of stroke, hemisphere involved, and length of stay at the rehabilitation center were obtained from medical records. Demographic variables of the spouse and the child were documented at the first assessment.

Stroke Patients

Disability was assessed using the BI.¹⁰ The ability to communicate was rated on a scale from 1 (no communication possible) to 5 (normal communication), based on the Utrecht Communication Observation (UCO).¹¹ The BI and the UCO score were assessed at admission and at 1 year after stroke.

Spouses

Depression was measured using the Goldberg Depression Scale (GDS).¹² This consists of 9 questions with yes or no answers. A total score of ≥2 indicates a clinically important disturbance.¹³ The perception of marital relationship between the spouse and patient was assessed using the 17-item Interactional Problem Solving Inventory (IPSI).¹⁴ The IPSI has a total score range of 17 to 85, with a higher score indicating more harmony. The GDS and IPSI were assessed at all 3 of the measurements.

Statistical Analysis

The research questions were answered using multilevel analysis, also named hierarchical linear modeling.¹⁵ This is a type of regression analysis that is suitable for longitudinal data with a hierarchical nature (measurements within children, children within families, and families within rehabilitation centers), because it corrects for the violation of independence assumption of normal (nonhierarchical) regression analysis. The numbers of observations per individual may vary. Similar to ordinary linear regression, a regression equation is obtained. For each predictor, a regression coefficient B is estimated and tested for significance, and the amount of explained variance by all of the predictors together is computed. To identify differences between T1 and T2 and T2 and T3 (the first research question), the outcome variables were related to time, which was entered into the analyses as a categorical predictor variable, that is, converted into dummy variables with the second measurement as a reference (dummy T1–T2: T1=1, T2=0, and T3=0; dummy T2–T3: T1=0, T2=0, and T3=1). To answer the second question of the prediction of children's functioning at 1 year after stroke, all of the children who performed T3 measurements were included. The number of families (n=55) and children (n=82) included in this study allowed for a maximum of 6 independent variables in the analyses. Variables were chosen that were most relevant in earlier cross-sectional analyses.⁵ Independent variables were age and gender (child), BI and UCO (patient), and GDS and IPSI (spouse). All 4 of the outcome variables at T3 were analyzed twice: with the outcome variable measured at T1 as predictor (to correct outcome differences for baseline differences) and without. Because it is not common practice to assess or screen children of stroke patients, analyses without the assessment of children's functioning are more useful in practice. A backward elimination technique was used to filter significant main relationships ($P \leq 0.05$). The analyses were performed using MlwiN.¹⁶

Results

Participants

Half of the children were girls, and the mean age was 13 years (Table 1). Four children were <8 years of age. The patients were relatively young (mean age 46 years) and moderately disabled (mean BI 13) at the start of inpatient rehabilitation. On average, admission to the rehabilitation center was ≈1 month after stroke, and patients remained at the center for ≈3 months. Sixty-six percent of the spouses had a paid job for >20 hours a week.

TABLE 1. Baseline Characteristics of Children and Their Parents

Characteristics	Totals
Children (n=82)	
Gender, girls	51%
Mean age, y (SD)	13.3 (3.2)
First child in family	39%
School type	
Primary education	25%
Junior general secondary education	20%
Senior general secondary education	20%
Preuniversity education	12%
Intermediate vocational education	21%
Patients (n=55)	
Gender, women	51%
Mean age, y (SD)	45.5 (6.0)
Stroke infarction	71%
Hemisphere, left	57%
Mean length of stay in days (SD)	99 (57)
Spouses (n=55)	
Gender, women	49%
Mean age, y (SD)	44.6 (5.5)
Employed for >20 hours/week	66%
Educational level, high*	27%

*Senior general secondary education, preuniversity education, higher professional education, or university.

Changes Over Time

At the first assessment, 54% of all children showed ≥ 1 behavior problem or depression, and, for 21%, these scores were within the clinical range. Thirty percent showed internalizing symptoms, 18% showed externalizing symptoms, and 13% showed depressive symptoms (Table 2). At the second and third assessment, the proportion of children with ≥ 1 of these problems was 23% (12% clinical range) and 29% (20% clinical range), respectively. Between T1 and T2, the

internalizing behavioral problems, depression, and health status scores improved ($P<0.001$). Between T2 and T3, we did not find significant differences, but the percentage of children with subclinical or clinical scores on depression and internalizing behavior problems increased, and there was a decreasing trend in health status ($P=0.06$). Externalizing problem behavior did not change significantly between T1 and T2 or between T2 and T3.

Stroke patients improved significantly on the BI and UCO score between T1 and T3. The spouse's depressive symptoms decreased significantly between T1 and T2, but not between T2 and T3 (Table 2). Spouse perception of the marital relationship did not change between T1 and T2 but decreased significantly between T2 and T3.

Predictive Models

Internalizing problem behavior and spouse depression at T1 were significant predictors of internalizing problem behavior at T3 (47% explained variance; Table 3a). Externalizing problem behavior and age at T1 predicted externalizing problem behavior at T3 (40% explained variance). Children's depression at T3 was predicted by children's depression, gender, and BI of the parent with stroke at T1 (58% explained variance). Health status at T3 was predicted by health status, spouse depression, and spouse perception of marital relationship at T1 (28% explained variance). The same analyses without the T1 child-functioning scores revealed that depression of the healthy parent at T1 was a significant predictor of all of the outcome scores (Table 3b). The spouse's perception of the marital relationship was a significant predictor for children's health status and internalizing problem behavior. The explained variance was between 19% and 22%.

Discussion

This is the first study of the course of children's functioning after parental stroke. Children's functioning improved between admission of the stroke patient in the rehabilitation center and 2 months after discharge of inpatient rehabilitation, except for externalizing problem behavior. In the period

TABLE 2. Scores of the Child Adjustment Measures, Stroke Patient Variables (BI and UCO), and Healthy Parent Variables (GDS and IPSI) at T1, T2, and T3

Variables	T1		T2		T3		P Value T2–T3	
	Mean (SD)	% ≥ 1	Mean (SD)	% ≥ 1	Mean (SD)	% ≥ 1		
Dependent variables								
CBCL int median (IQR) % ≥ 60	54 (17)	30%	48 (22)	10%	§	48 (17)	16%	NS
CBCL ext median (IQR) % ≥ 60	51 (17)	18%	49 (19)	15%	NS	48 (14)	15%	NS
CDI median (IQR) % ≥ 13	5 (6)	13%	3 (5)	7%	§	3 (6)	12%	NS
FS-II median (IQR)	86 (16)		93 (12)		§	89 (18)		NS
Independent variables								
BI median (IQR)	13 (8)					19 (2)		*§
UCO median (IQR)	5 (1)					5 (0)		*‡
GDS median (IQR)	3 (4)		0 (4)		†	2 (5)		NS
IPSI median (IQR)	71 (14)		68 (17)		NS	63 (21)		†

Multilevel analysis.

Int indicates internalizing; ext, externalizing.

*P value change between T1 and T3; † $P<0.05$; ‡ $P<0.01$; § $P<0.001$.

TABLE 3a. Results of the Multilevel Analysis to Predict CBCL Score, CDI Score, and FS-II at T3 Using Dependent and Independent Variables Measured at T1 as Predictors

T1	CBCL int T3 B (95%-CI)	CBCL ext T3 B (95%-CI)	CDI T3 B (95%-CI)	FS-II T3 B (95%-CI)
CBCL int T1	0.64 (0.45, 0.83)‡	Not entered	Not entered	Not entered
CBCL ext T1	Not entered	0.50 (0.27, 0.72)‡	Not entered	Not entered
CDI T1	Not entered	Not entered	0.62 (0.46, 0.77)‡	Not entered
FS-II T1	Not entered	Not entered	Not entered	0.25 (0.03, 2.75)*
Age child	...	-0.72 (0.00, -1.44)*
Gender child	3.02 (1.33, 4.71)‡	...
UCO
BI	-0.21 (-0.03, -0.39)*	...
GDS	1.01 (0.04, 1.98)*	-1.81 (-0.05, -3.12)†
IPSI	0.26 (0.00, 0.52)*
Expl variance	47%	40%	58%	28%

TABLE 3b. Results of the Multilevel Analyses to Predict CBCL Score, CDI Score, and FS-II at T3 Using Independent Variables Measured at T1 (Without the CBCL, CDI, and FS-II Scores at T1)

T1	CBCL int T3 B (95%-CI)	CBCL ext T3 B (95%-CI)	CDI T3 B (95%-CI)	FS-II T3 B (95%-CI)
Age child	...	-1.28 (-0.57, -2.00)‡
Gender child	3.16 (0.86, 5.46)†	...
UCO
BI	-0.31 (-0.07, -0.55)*	...
GDS	2.22 (0.93, 3.51)‡	1.28 (0.16, 2.41)*	0.59 (0.07, 1.11)*	-2.31 (-0.98, -3.64)‡
IPSI	-0.27 (-0.01, -0.55)*	0.32 (0.05, 0.59)*
Expl variance	19%	20%	19%	22%

Int indicates internalizing; ext, externalizing; B, regression coefficient; Expl variance, % of the variance of the dependent variable that is jointly explained by the predictor variables in the analysis.

* $P < 0.05$; † $P < 0.01$; ‡ $P < 0.001$.

between 2 months after discharge from inpatient rehabilitation and 1 year after stroke, we found no significant differences in problem behavior, depression, and health status, but there was a trend of decreased functioning. The same course was observed for depression of the spouse: in the first period, a significant improvement occurred, but in the second period, there was a trend of more depressive symptoms. The quality of the marital relation as perceived by the healthy spouse also decreased in the second period. According to Rolland,¹⁷ diseases with an acute onset, such as a stroke, require the family to accomplish several adaptations in a short period of time. The high percentage of children with clinical and subclinical problems directly after parental stroke might reflect psychotrauma as a consequence of parental stroke and family crisis. The family tries to find a new balance, and, after a period of absence (inpatient rehabilitation), the stroke patient comes home. An increase of child problems in the T2 to T3 period can be expected, because the family will realize that at least some of the changes will be permanent and that they have to reorganize family routines. Although our results showed a trend in this direction, the differences were not significant. This might be because our data set was too small or the follow-up period too short.

The second aim of the study was to examine predictors for children's functioning 1 year after stroke at the start of the

rehabilitation. Children's functioning at T1 was the most important predictor of functioning at T3. This result may suggest an enduring impact of parental stroke on a child's functioning. The predictive power (amount of explained variance) of the models including children's functioning at T1 was considerable and much larger than that of the models without this information. Identification of children at risk for long-term problems is, therefore, best done by screening children for these problems in the early phase of stroke. Ensuring that these children obtain information about the consequences of stroke and its impact on the family and advice about how to deal with their feelings might support the adjustment process. At a later stage, children with persisting adjustment problems can be given professional help if needed.

Without the children's functioning scores at T1, depression of the healthy parent was clearly the most important early predictor of children's adjustment. Other authors also found a negative relation between parental depression and CBCL scores.^{18,19} Vandervalk et al.²⁰ found a similar negative relation between quality of the marital relationship and children's emotional adjustment. Like others,^{1,2} we found some indications that individual child characteristics (age and gender) moderate the impact of parental illness. The seriousness of the stroke appears to be of minor importance.

Our study has several limitations. First, our sample size was small. A larger study is, therefore, needed to confirm our results and to allow more variables (like being the oldest child, having siblings, and parental loss of income) to be entered in the multivariate analyses. Second, we only included children who lived in 2-parent families with a parent who had been selected for inpatient rehabilitation and who was moderately disabled. This limits the generalizability of our results. However, this is the first longitudinal study on this topic and, because it might have implications for practical care, additional research is merited.

Based on our findings, we advise a family-centered approach in stroke care in which attention should be given to children's adjustment. Support programs for the whole family^{21,22} are available, and their effects on children's functioning should be evaluated in future research.

Acknowledgments

This project was undertaken as part of the "Functional prognostication and disability study on neurological disorders" funded by the Netherlands Organization for Health Research and Development (Registration number: 014-32-042). We thank the rehabilitation centers that participated in this study: De Hoogstraat, Utrecht; Rehabilitation Center Amsterdam, Amsterdam; Heliomare, Wijk aan Zee; Blixembosch, Eindhoven; Rijndam, Rotterdam; Trappenberg, Huizen; Sint Maartenskliniek, Nijmegen; Leijpark, Tilburg; and De Vogellanden, Zwolle.

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Stroke. 2005;36:2436-2440; originally published online October 6, 2005;
doi: 10.1161/01.STR.0000185681.33790.0a

Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 0039-2499. Online ISSN: 1524-4628

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