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CHILDREN'S ADJUSTMENT TO A PARENT'S STROKE: DETERMINANTS OF HEALTH STATUS AND PSYCHOLOGICAL PROBLEMS, AND THE ROLE OF SUPPORT FROM THE REHABILITATION TEAM

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Objective: **To investigate the support given to young children of patients with stroke by rehabilitation teams and to identify characteristics of the patients, spouses and children that relate to children's adjustment 2 months after the patient's discharge.**

Subjects and methods: **Seventy-seven children (≤18 years of age) of patients with stroke consecutively admitted to inpatient rehabilitation were included. Adjustment was measured with the Child Behaviour Check List, Child Depression Inventory and Functional Status II. Multilevel regression analyses were conducted to identify determinants of adjustment.**

Results: **Half of the children received some form of support from a rehabilitation team. Receiving more support was related to more severe disability of the parent with stroke, but not to the child's health or behavioural problems at the start of the stroke victim's inpatient stay. At the start of rehabilitation, 54% of the children had subclinical or clinical problems. Children's adjustment 2 months after their parent's discharge was related to the strain on spouses and not to the patients' characteristics or those of the support.**

Conclusion: **The children's adjustment was related to the strain perceived by the healthy parent. There is a need for support that focuses on the experience of children of patients with stroke, regardless of stroke severity.**

Key words: stroke, children's adjustment, support, parental illness.

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INTRODUCTION

Stroke is a chronic condition that may have serious consequences for patients' physical, cognitive and behavioural functioning. However, stroke also affects the patients' families. While rehabilitation professionals are primarily patient-oriented, support for spouses by rehabilitation teams has become more common in recent years. However, it is as yet unusual to provide support for young children when one of their parents has had a stroke.

During the last decade, healthcare research has increasingly paid attention to children whose parents suffer from physical illness, resulting in the publication of 3 reviews (1–3). Armistead et al. (1) noted that the way parents' physical illnesses may affect children's functioning can vary with a number of different dimensions of illness: onset (acute or gradual), course (progressive, constant, episodic), impairments (physical or cognitive) and outcome (morbidity or mortality). Kelley et al. (2) speculated that children of parents with disabilities are at risk for numerous maladies, though few empirical studies have assessed this problem. The review by Korneluk & Lee (3) included 17 studies that evaluated the impact of parents' physical illness on children under the age of 18 years. The authors examined available evidence for the influence of 3 sets of variables: illness variables, individual variables (patient and child characteristics) and family variables. With respect to illness variables, they found that the mere presence of parental illness *per se* did not inevitably lead to child adjustment difficulties. Although there is sufficient evidence showing that children are distressed by their parents' illness, the majority of children of ill parents do not have psychological problems in the clinical range. With respect to the individual variables, adolescents in particular appear at risk for emotional problems when parents fall ill, and this risk is most pronounced for adolescent girls. Only 6 articles have examined family variables, and these studies offer preliminary evidence that variables relating to the family's functioning and coping strategies (marital adjustment, parental depression and parent-child relationships) play a role in the adjustment to parental illness (3).

Nearly all studies among children of parents with chronic illness or disabilities have been done outside the field of medical rehabilitation, though a few studies have been published about spinal cord injury (4, 5) and multiple sclerosis (6–8). In 2000, Teasell et al. (9) stated that the impact of stroke on young children of stroke victims had yet to be studied. Since then, to the best of our knowledge, no study on the impact of stroke on young children has been published.

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A survey among medical rehabilitation specialists in the Netherlands showed that professionals at all rehabilitation centres consider support for children of patients with stroke to be important but difficult to accomplish (10). Insofar as support was available to children, it was incidental and *ad hoc*. In some cases, children were invited for consultation with rehabilitation specialists or social workers. Sometimes they attended a full day (or half day) programme with the patient, giving them an opportunity to witness therapy sessions with their father or mother and to be informed about the parent's disease by different members of the rehabilitation team. However, it is not known how many children have adjustment problems, how many receive some kind of support from the rehabilitation team, whether the children who get support are those that have the greatest difficulties in coping with their parent's condition, and whether the support given makes any difference to the children's adjustment. The purpose of the present study was to examine support and adjustment among children when 1 of their parents has suffered a stroke, and to examine possible determinants. A better understanding of the determinants of children's adjustment might improve the support provided by members of rehabilitation teams.

The study focused on 2 main questions:

- Which children receive support from a rehabilitation team during inpatient rehabilitation after 1 of the parents has suffered a stroke?
- Which determinants can be identified of children's adjustment 2 months after their parent is discharged from inpatient rehabilitation? Determinants investigated included characteristics of patients, spouses and children and of the support received.

METHODS

Subjects

Patients with stroke consecutively admitted to 9 Dutch rehabilitation centres (see acknowledgements) between April 2000 and July 2002 were included in the FuPro-Stroke cohort (11). The inclusion criteria for patients were: first-ever stroke, supratentorial and one-sided lesion and age over 18 years. Exclusion criteria for patients were: disabling co-morbidity (pre-stroke Barthel Index (BI) below 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 below 16 and/or having a very serious chronic illness. If the couple had young children (4–18 years) who were living at home, these children were also invited to take part in the study. Exclusion criteria for children were: having a serious chronic illness and having serious behavioural problems before the parent's stroke, for which professional help from a psychologist or psychiatrist had been obtained.

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 of the couples had young children (aged 18 years or under). Three families refused to participate with their children, and 1 family had already been receiving professional help for their child's behavioural problems before the stroke. A total of 82 children of 55 patients participated in the first assessment, of whom 77 also participated in the second assessment. We had to exclude 2 children because their parents were excluded from the FuPro study due to recurrent stroke, and 3 children refused further participation.

Procedure

At the start of the inpatient rehabilitation process, 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. With the exception of children between the ages of 4 and 7 years, spouses and children individually completed a series of pencil-and-paper questionnaires. For children between 4 and 7, we used parent-report measures only. All spouses and children were interviewed by the same researcher at home about 2 months after the patients had been discharged from the rehabilitation centre (second assessment). The medical ethics committees of the University Medical Centre Utrecht and the participating rehabilitation centres approved the study, and informed consent was obtained from all participating patients, spouses and children.

Measures

Patients with stroke. Data on age, gender, type of stroke, hemisphere involved and length of stay at the rehabilitation centre were obtained from medical files. Disability of the patients with stroke was assessed with the BI at the start of the rehabilitation. The reliability and validity of the BI for this patient group are well-documented (12). The ability to communicate was determined by observation, on a scale ranging from 1 (no communication) to 5 (normal communication), based on the Utrecht Communication Observation (UCO) (13, 14). Cognitive impairments were assessed with the widely-used Mini-Mental State Examination (MMSE) screening test (15). Patients were recorded as being cognitively impaired if their MMSE score was 23 or less, or their UCO score was 3 or less (communication at best possible by guessing and questioning).

Spouses. Data on age, gender, employment and educational level were documented in the first assessment. At follow-up, depression was measured using the Goldberg Depression Scale (GDS) (16). This scale consists of 9 questions with yes or no answers, each "yes" adding 1 point to the total score. A total score of 2 or higher indicates clinically important disturbance. The GDS has good specificity (93%) and sensitivity (82%) (17). Perceived strain was measured with the Caregiver Strain Index (13 items) (18). This short instrument is the most commonly used burden scale for caregivers in stroke research. It has dichotomous item scores that can be summed to a total score. A score of 7 or higher indicates serious strain (19).

Children. Data on age, gender, family situation and school level were documented at the first assessment. We examined adjustment by assessing behavioural problems, depression and health status at both interviews. The Child Behaviour Check List (CBCL) (20) is a standardized parent-report measure for children aged 4–18 years, which asks parents to rate their children's behavioural problems on a 3-point scale as 0 (not true), 1 (somewhat/sometimes true) or 2 (very/often true). Items were summed to obtain a total score for internalizing symptoms (i.e. withdrawn, somatic complains, and anxiety/depression) and externalizing symptoms (i.e. delinquent and aggressive behaviour). The raw scores were transformed into standardized *t*-scores to compare the scores of boys and girls and younger (< 12 years) and older children. Following Achenbach's recommendations, *t*-values were used as cut-off scores to mark the 3 problem areas of "clinical" (64 and over), "subclinical" (between 60 and 63), and "normal" (59 and below). Depression was measured with the Child Depression Inventory (CDI) (21). The CDI is a 27-item self-report measure designed to assess a variety of symptoms of depression among children aged between 8 and 18 years. Each item consists of 3 sentences that describe a range from non-distressed to severe and clinically significant symptoms. A total score of 20 or over indicates clinical depression, those between 13 and 19 sub-clinical depression (21). We used the 14-item parent-report version of the Functional Status (FS-II) (22) to assess the children's health status. The FS-II was developed for children aged between 0 and 16 years, and consists of 14 items such as fatigue, sleep disturbance, energy and intractable behaviour (0 = never, 1 = sometimes, 2 = almost always). To assess any unfavourable changes in the children's social activities we asked about changes in school records (lower), sports activities (less), holidays (none), household activities (more) and helping to assist the stroke patient. The number of "yes" scores gave the Social Change Score (SCS), ranging from 0 to 5. In the second assessment, we asked the children about the support they had received from the rehabilitation team during the period of inpatient rehabilitation. Three types of support were distinguished: (1) 1 or more consultations with the rehabilitation specialist; (2) and/or the social worker; (3) and/or attending 1 or more full-day therapies. By adding the "yes" answers, we constructed a score for the support received from the rehabilitation professionals, ranging from 0 (no support) to 3 (much support), a score of 3 meaning that the child had had all possible contact moments with members of the rehabilitation team.

Statistics

Descriptive statistics were used to describe characteristics of the children and their parents (patients and spouses). We used Pearson correlations to assess the relationships between the 4 measures of children's outcomes at 2 months after patients' discharge from the rehabilitation centre. These analyses were conducted using SPSS 11.0. The other analyses used multilevel techniques to deal with multiple predictors in a dependent structure (23). A unique feature of multilevel analysis is that it works with a statistical model designed for nested data. Our data did indeed have a nested structure with a 3-level hierarchy, the lowest level being the individual level of the children (1st level), nested in families (2nd level) which were in turn nested in rehabilitation centres (3rd level). The dependent variable was measured at the lowest level and the independent variables at all existing levels.

To answer the first research question, i.e. which children obtained support, univariate analysis was applied to examine the relation between "support from the rehabilitation team" and the independent children's and parents' characteristics at baseline. The second research question regarded possible determinants of the children's functioning 2 months after the patients' discharge. The number of families ($n = 51$) and children ($n = 77$) included in this study allowed for 4 independent variables in the multilevel regression analyses. For this reason, we first performed univariate analyses. Based on the results of the univariate analysis and the theoretical considerations, 4 variables were selected to be entered in the multiple regression analysis. The analyses were performed using MlwiN (24).

RESULTS

Half of the children were girls, and mean age was 13 years (Table I). Four children were under 8 years of age. One in 4 were attending primary school, while the others were attending secondary school or vocational education. At the first assessment, subclinical or clinical range behavioural problems were present in 53% of the children, with 30% showing internalizing symptoms, 17% externalizing symptoms and 14% depressive symptoms. The patients were relatively young (mean age 46 years) and, according to their Barthel Index scores, moderately disabled at the start of inpatient rehabilitation. On average, admission to the rehabilitation centre was about 1 month after stroke, and patients remained at the centre for about 3 months. One in 4 patients had communication problems (UCO < 5). Spouses were also relatively young, and more than half of them had a paid job for more than 20 hours a week.

Support

About half of the children (54%) obtained at least 1 type of support from the rehabilitation team: 23%, 15% and 16% of the children had 1, 2 or all 3 types of contact with the team, respectively. These percentages were lower than expected and therefore we looked the percentage of children with behavioural problems that had at least 1 type of support. Of the children with deviant scores on the CBCL scales for internalizing and externalizing behaviour or CDI, 65%, 75% and 62% had had at least 1 type of support from the rehabilitation team, compared with 46%, 46% and 52% of the children without deviant scores on the scales. These differences in percentages are not statistically significant.

Table I. *Baseline characteristics of children and their parents*

Characteristics	
Children n = 77	
Gender (girls)	53%
Mean age, years (SD)	13.4 (3.1)
First child in family	39%
School type	
primary education	25%
lower vocational education	20%
secondary education	20%
pre-university education	12%
intermediate vocational education	21%
Mean CDI (SD)% ≥13	6.5 (5.7) 14%
Mean CBCL int (SD)% ≥60	51.7 (11.4) 30%
Mean CBCL ext (SD)% ≥60	49.1 (10.9) 17%
Median FS-II (IQR)	85.7 (17)
Patients n = 51	
Gender (women)	51%
Mean age, years (SD)	45.5 (6.0)
Stroke	
infarction	71%
hemisphere (left)	60%
Mean LOS in days (SD)	99 (58)
Mean Barthel Index (SD)	14.0 (4.7)
Median UCO (IQR)	5 (1)
Cognitively impaired (yes)	36%
Spouses n = 51	
Gender (women)	49%
Mean age, years (SD)	44.4 (5.6)
Employed for more than 20 hours/week	69%
Educational level (high*)	23%

CDI = Child Depression Inventory; CBCL int. = Child Behaviour Check List internalizing; CBCL ext. = Child Behaviour Check List externalizing; FS-II = Functional Status; IQR: interquartile range; LOS = length of stay, in days; UCO = Utrecht Communication Observation.

* Senior secondary education, university preparatory education, higher professional education or university.

Univariate relationships between characteristics of children and their parents and support

We first tested the adequacy of a 3-level model. At the highest level, there was no significant variance, meaning that families that received care from the same rehabilitation centre were not more alike than families from different rehabilitation centres. At the family level, there was a significant variance, with children within 1 family being more alike than children in different families. We therefore decided to use a 2-level regression model, accounting for dependency at the individual and family levels. The support score only correlated significantly with the patients' BI ($r = -0.263$, $p = 0.04$) (Table II). More support was given to children with a more disabled parent. We found no correlations between support and any of the children's or spouses' characteristics.

Children's adjustment

There were moderate but significant correlations between all the measures of children's health status and their psychological

Table II. *Univariate correlation coefficients between baseline characteristics of children (*n = 70*) and their parents (*n = 55*) and support measured 2 months after discharge of the parent with stroke from clinical rehabilitation; multilevel analysis*

Characteristics	Support	*p*-value
Child		
gender	0.150	0.10
age	−0.056	0.58
CDI	0.00	1.0
CBCL int.	0.108	0.32
CBCL ext.	0.123	0.24
FS-II	−0.082	0.49
Patient		
Barthel Index	−0.263	0.04*
UCO	−0.225	0.10
Cognitive imp. (yes)	0.143	0.25
Spouse		
gender	−0.138	0.31

CDI = Child Depression Inventory; CBCL int. = Child Behaviour Check List internalizing; CBCL ext. = Child Behaviour Check List externalizing; FS-II = Functional Status; UCO = Utrecht Communication Observation.
*$p < 0.05$.

functioning (Table III). The CBCL external and CBCL internal behaviour scores were strongly correlated.

Univariate multilevel analyses were applied first (Table IV). All outcome measures of children's health and psychological functioning showed significant correlation coefficients with the spouses' caregiver strain and depression. The gender of the healthy spouse appeared to be insignificant. Further significant correlations were found between the children's age, gender and support score and the CBCL internal score, between the children's age and the CBCL external score and between Social Change Score and the CDI. No other significant correlations were found between any patient or children's variables and the children's health (FS II); nor were any significant correlations found between any outcome measures and patient characteristics. Because of the small data set, only 4 independent variables could be included in the multivariate analysis. Since there was a very strong correlation between the spouses' GDS and CSI scores ($r = 0.73$, $p = 0.000$) we included only the CSI. We also included children's age and gender, and their support score. The multiple regression analyses (Table V) showed that caregiver strain was a significant determinant of the children's functioning 2 months after their parents' discharge. Further, gender (female) and age (younger) were predictors of CBCL internal and CBCL external behaviour problem scores, respectively.

Table III. *Pearson correlations between children's outcome measures 2 months after discharge of the parent with stroke from clinical rehabilitation*

Two months after patients' discharge	CDI	FS II	CBCL ext.	CBCL int.
CDI	1			
FS II	−0.272*	1		
CBCL ext	0.332**	−0.428**	1	
CBCL int	0.335**	−0.534**	0.609**	1

CDI = Child Depression Inventory; FS-II = Functional Status; CBCL int. = Child Behaviour Check List internalizing; CBCL ext. = Child Behaviour Check List externalizing.
*$p < 0.05$, **$p < 0.01$.

Table IV. *Univariate correlation coefficients between independent variables and children's outcome measures 2 months after patient's discharge, multilevel analysis*

Determinants	CBCL int. coefficient	CBCL ext. coefficient	CDI coefficient	FS-II coefficient
Child				
Age	−0.231*	−0.230*	0.114	0.104
Gender (girls)	0.196*	0.111	0.057	0.052
SCS	0.069	0.078	0.213*	−0.02
Support score	0.212*	0.170	0.010	−0.05
Patient[a]				
BI	0.077	0.008	0.022	−0.02
UCO	0.104	0.113	0.200	0.14
Cognitive imp. (yes)	−0.140	−0.009	0.004	−0.106
Spouse				
Gender (women)	0.029	−0.027	0.016	−0.125
GDS	0.369**	0.062	0.225*	−0.272*
CSI	0.349**	0.316**	0.285*	−0.569**

[a] Assessment of the patient at admission for inpatient rehabilitation.
CBCL int. = Child Behaviour Checklist internalizing; CBCL ext. = Child Behaviour Checklist externalizing; CDI = Child Depression Inventory; FS-II = Functional Status II; SCS = Social Change Score; BI = Barthel Index; UCO = Utrecht Communication Observation; GDS = Goldberg Depression Scale; CSI = Caregiver Strain Index.
*$p < 0.05$, **$p < 0.01$.

DISCUSSION

We found that only half of the children had had 1 or more types of supportive contact with a rehabilitation team. Support received during inpatient rehabilitation did not correlate with the children's or spouses' characteristics, but there was a significant negative correlation with the stroke patients' BI

Table V. *Regression coefficients (B) between independent variables and children's outcome measures 2 months after patient's discharge, multilevel multiple regression analysis*

Determinants	CBCL int. coefficient	CBCL ext. coefficient	CDI coefficient	FS-II coefficient
Child				
Age	−0.074	−0.806*	−0.117	0.164
Gender (female)	3.223*	1.808	1.224	0.660
Support score	0.925	0.780	−0.123	−0.262
Spouse				
CSI	1.005**	0.845*	0.409**	−1.660***

CBCL int. = Child Behaviour Checklist internalizing; CBCL ext. = Child Behaviour Checklist externalizing; CDI = Child Depression Inventory; FS-II = Functional Status II; CSI = Caregiver Strain Index.
*$p < 0.05$, **$p < 0.01$, ***$p < 0.000$.

scores. Apparently, the rehabilitation teams did not pay more attention to children who had adjustment problems, as has been suggested in the literature (3, 25). The significant relationship between child support and the patients' BI might indicate that team members do pay extra attention to children who have a seriously disabled parent, perhaps because they expect these children to have more adjustment problems than children of less seriously disabled parents. However, another explanation may be that seriously impaired patients stay in inpatient rehabilitation for longer, which simply increases the opportunities for contact between the teams and the children.

The second aim of the present study was to investigate the determinants of children's adjustment. We did not find a correlation between stroke severity (physical and cognitive disability, communication problems) and psychosocial problems among the children. Our multiple regression analysis showed a significant correlation between the caregiver strain perceived by the healthy parent and all child outcome measurements. This is in line with other studies (1, 3, 26) that have examined the role of family functioning and parental illness and reported preliminary evidence that variables relating to the functioning of the family and the non-ill parent play a role in determining children's adjustment to parental illness. It is likely that the spouses' burden relates to disruption of parenting, for example because family routines change or because the parent has less time to support a child, is absent or suffers from depression (1). We found a correlation ($r = 0.73$) between strain and depression among the healthy parents. Other studies also found significant correlations between CSI and measures of carer mood (0.51–0.72) and negative affect (0.56–0.66) (19). However, spouses might also experience additional strain and emotional distress when their children do not cope well. In addition, emotionally distressed parents might report increased distress in their children more readily than non-distressed parents, although the literature (3) provides no evidence to support the hypothesis that parents suffering from a disorder over-report problems in their children.

Like others (1, 3, 27) we found some indications that individual characteristics (age and gender) of the children moderate the impact of parental illness. Support given by the rehabilitation teams did not correlate with children's adjustment. In the present study, support meant having contact with members of the rehabilitation team, and thereby receiving additional information, having the opportunity to express concerns and ask questions (by consulting rehabilitation specialists and social workers) and greater access to the parent (by attending a full-day therapy programme). It is possible that the amount of support thus received was too small to be effective. Further research should clarify whether a more intensive child support programme might yield positive effects on child adjustment.

Our study had several limitations, which should be considered in order properly to interpret our results. Firstly, since our sample was small, longitudinal studies with larger sample sizes are needed to confirm our results. Such larger studies would also allow more variables to be entered in the model. Secondly, our sample was selected, in that we only included children when one of their parents had had a stroke and had been selected for inpatient rehabilitation, and we only included children from two-parent families. This makes the generalizability of the model to children of one-parent families or patients not selected for rehabilitation debatable. Thirdly, we used only an overall support score, which is a rough measure that provides little information about the relevance of various support aspects to the children. The timing and content of the support given to children and the need for support felt by children should be examined in greater detail in order to identify crucial support elements that could be tested in intervention studies.

On the basis of our findings, we recommend supporting not only the children of severely disabled parents, but also the children of depressed and stressed non-ill parents. In addition, one should support both parents, to improve their competence to participate in family life, to inform them about children's behaviour and self-expression and to assist them in supporting their own children and to maintain the children's schedule and routine activities.

In conclusion, the existing literature has emphasized the importance of focusing on the entire family system in cases of parental illness. Half of the children in our study may be regarded as having adjustment problems. Our study shows that child adjustment is related to the burden on the non-ill parent, and that the support offered to children is not related to children's or spouses' characteristics at the start of inpatient rehabilitation. The rehabilitation teams were found to provide support to only half of the children; those with the most disabled parents.

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