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ORIGINAL REPORT

LONG-TERM OUTCOME IN CHILDREN OF PATIENTS AFTER STROKE

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Objective: **To investigate the long-term effects on children of parental stroke, with respect to care-giving tasks, children's behavioural problems and stress, and to study the relationship between stress and child, patient and partner characteristics.**

Subjects: **A total of 44 children (age range 10–21 years) were assessed 3 years after parental stroke.**

Main measures: **Behavioural problems were assessed with the Child Behaviour Check List and the Youth Self-Report. Stress was measured using the Dutch Stress Questionnaire for Children.**

Results: **Most children (66%) assisted their parent in self-care or mobility. Some of the children (31%) experienced behavioural problems. The results showed that 37.5% of younger children show externalizing problems on the Child Behaviour Check List. Stress was significantly related to female gender of the child, and to depression, limitations in extended activities of daily living and life satisfaction of the patient.**

Conclusion: **Most children do well 3 years after parental stroke. However, some children of patients after stroke have behavioural problems and need attention in clinical practice.**

*Key words: s*troke, children's adjustment, parental illness.

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INTRODUCTION

Stroke is one of the leading causes of disability in Western countries. The number of patients in the Netherlands surviving a stroke is predicted to rise to 150,000 by 2020 (1). Previous studies have shown that, after rehabilitation, 62% of stroke patients were still dependent for activities of daily living (ADL) and 32% were inactive in instrumental ADL 3 years post-stroke (2). Data were comparable to a recent study, in which 37% of the stroke patients were inactive in instrumental ADL one year post-stroke (3). Another study found that although the majority of patients were discharged home after inpatient rehabilitation, 26% still received physiotherapy and 40% received home care 5 years post-stroke (4). As these figures indicate, many stroke patients have lifetime disabilities, which have serious consequences for their physical, cognitive and behavioural functioning.

In addition to the direct consequences for the patient, the patient's family will also be affected (5). Korneluk & Lee (6) reviewed studies on children living with a parent with physical illness and concluded that, 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. They also concluded that adolescents in particular appear to be at risk for emotional problems when parents fall ill, and this risk is most pronounced for adolescent girls. Armistead et al. (7) noted that the way in which 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). Most research has focused on children of patients with cancer (8–13), multiple sclerosis (14–16) and spinal cord injury (17, 18). Few studies have been carried out on outcome for children with a parent who has had a stroke. From these studies we learn that more than 50% of the children had subclinical or clinical problems at the start of the parental rehabilitation (19). A subsequent longitudinal study showed that child functioning improved over the first year after stroke (20). To date, no publications are available about the outcome of children and adolescents living at home with a parent who is more than one year post-stroke. The aim of this explorative study was to examine the long-term consequences on children of parental stroke. The study focused on care-giving, behavioural problems and stress in children 3 years after parental stroke. In addition, the relationship between stress of the child, and child, patient and partner characteristics was investigated.

METHODS

Subjects were the children of patients after stroke included in the Functional Prognosis after Stroke (FuPro-Stroke) study (21, 22). All patients after stroke had been admitted to 1 of 9 participating rehabilitation centres. Inclusion criteria were: age over 18 years, first-ever stroke and a supratentorial lesion located on one side. Exclusion criteria were: a pre-stroke Barthel Index (BI) below 18 and insufficient command of Dutch. If the patient had a spouse he or she was asked to participate in the study. Exclusion criteria for spouses were BI < 18 and/or having a serious chronic illness. If the couple had children between 4 and 18 years

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of age living at home, the children were also asked to participate. Exclusion criteria for children were: having a serious chronic illness or having behavioural problems for which professional help had been obtained before the parental stroke.

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. Other assessments followed at about 2 months after the patients had been discharged from the rehabilitation centre, 1 year and 3 years post-stroke. All assessments were conducted by an independent research assistant. The present analyses focused on outcome at 3 years after the parental stroke. 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

Demographic characteristics of the children, patients and partners were assessed.

Care-giving characteristics

The children were asked if they had to assist the stroke patient by helping them with ADL (i.e. dressing, washing, eating, toileting, transferring in and out of the wheelchair) or if they had to perform household activities (i.e. cleaning, cooking, buying groceries). Both scores were dichotomized into assisting the parent (1) or not (0), and into performing household activities (1) or not (0). The children were also asked if they experienced positive changes in their relationship with their parent due to their parent's stroke. The changes we asked the children about were: more intense family relationship, feeling more important, feeling more needed, having more responsibility, being more matured, parents spending more time with the children, and parents being more positive.

Behavioural problems and stress

Behavioural problems were determined by the Child Behaviour Check List (CBCL) (23, 24) for children between 4 and 16 years. The CBCL is a standardized parent-report measure, which asks parents to rate their children's behavioural problems. Children 17 years or older filled out the Youth Self-Report (YSR) (25, 26) to assess behavioural problems. The YSR is a parallel version of the CBCL, to be filled out by older children themselves. Both measures use the same scoring system on a 3-point scale as 0 (not true), 1 (somewhat/sometimes true) or 2 (very/often true). Items of both measures were summed to obtain a domain score for internalizing symptoms (i.e. withdrawn, somatic complaints and anxiety/depression) and externalizing symptoms (i.e. delinquent and aggressive behaviour) and a total score. The total score is the summation of internalizing, externalizing and other problems. The raw scores were transformed into standardized T scores reflecting a mean population distribution of mean 50 and standard deviation (SD) 10. These T scores were used to indicate behavioural functioning in the "clinical" (64 and over), "sub-clinical" (between 60 and 63), and "normal" range (59 and below).

The *amount of stress* experienced by the child was assessed by the Dutch Stress Questionnaire for Children (Stress Vragenlijst voor Kinderen (SVK)) (27). This self-report measure consists of 19 questions that focus on how the child had felt in the previous 3 months. Scores range from 17 to 68; a higher score indicates more stress. Internal consistency reliability of the measure has been tested in children with a parent who survived a stroke (Cronbach's $\alpha = 0.78$) and in children of parents with Parkinson's disease (Cronbach's $\alpha = 0.83$) (28).

Determinants of stress

SVK scores for the child were related to measures indicating functioning of the patient after stroke and the partner. We chose to use only the SVK scores for these analyses because the SVK was available for all children, while CBCL and YSR scores were available only for some of the children, dependent on their age. Patient variables were depression (Centre for Epidemiologic Studies Depression Scale CESD) (29), cognitive function (Mini Mental State Examination MMSE) (30), independence in ADL (BI) (31) and extended ADL (EADL) (Frenchay Activities Index, FAI) (32), mobility (Rivermead Mobility Index, RMI) (33) and life satisfaction (Life Satisfaction Questionnaire, LiSat-9) (34). MMSE, CESD and LiSat-9 were assessed only in communicative patients. Partner characteristics were: depression (Goldberg Depression Scale, GDS) (35), care-giving burden (Caregiver Strain Index, CSI) (36,37) and life satisfaction (total score LiSat-9). In addition, the partner completed the Interactional Problem Solving Inventory (IPSI) (38), which reflects perception of marital status.

Statistics

Although most data were normally distributed, we chose to report descriptives by median values and interquartile ranges (IQR) for child, patient and partner data, since the number of participants was low. Correlation coefficients were used to examine relationships between children's stress scores and behavioural problems and between children's stress scores and patient and partner variables. Non-parametric Spearman correlations and Mann-Whitney *U* tests for score differences between subgroups were used and multivariate analyses were omitted due to small numbers of children in this explorative study. All statistics were conducted using SPSS version 13.

RESULTS

Descriptives

In the present analyses data for 44 children of 29 patients were included. The mean age of the children was 16 years (SD = 3), age range 10–21 years, and 59% of the children were girls. Median scores of the SVK, CBCL and YSR are reported in Table I.

Patients were relatively young, with a mean age of 47 years (SD = 5) and 43% were men (Table II). Twenty-one percent of the patients had communication problems. At 3 years post-stroke most patients (64%) were independent in ADL (BI ≥ 19). Twenty-one percent of the patients showed depressive symptoms (CESD ≥ 16). Only 9% of the patients had a paid job 3 years post-stroke, compared with 65% before the stroke.

One partner did not complete the assessment. The mean age of the remaining 28 partners was 47 years (SD = 5) and 57% were women (Table II). Of the partners, 27% had completed higher education. In total, 54% of the spouses showed depressive symptoms (GDS ≥ 2).

Table I. *Stress and behavioural problems of children 3 years after parental stroke*

Characteristics	Median (IQR)	% in sub-clinical or clinical range
SVK total score	34.5 (10.8)	NA
T score CBCL internalizing	46.0 (16.5)	12.5
T score CBCL externalizing	47.0 (27.3)	37.5
T score CBCL total	45.0 (25.8)	25.0
T score YSR internalizing	52.0 (9.0)	13.4
T score YSR externalizing	50.0 (11.0)	6.7
T score YSR total	51.0 (14.0)	6.7

SVK $n = 44$; CBCL $n = 24$, YSR $n = 15$.
IQR: inter-quartile range; NA: not applicable; SVK: Stress Questionnaire for Children; CBCL: Child Behaviour Check List; YSR: Youth Self-Report.

Table II. Patient and partner variables 3 years post-stroke

Characteristics	*n*	
Patient		
Male	29	43%
Communication problems	29	21%
Mean age, years, (SD)	29	47.4 (5.0)
Median MMSE (IQR)	21	28.0 (3.0)
Median CESD (IQR)	21	7.0 (14.5)
Median BI (IQR)	29	19.0 (2.0)
Median FAI (IQR)	16	26.0 (16.0)
Median RMI (IQR)	29	12.0 (3.0)
Median LiSat (IQR)	19	4.2 (1.2)
Partner		
Male	28	57%
Mean age, years, (SD)	28	47.8 (5.3)
Median GDS (IQR)	28	2.5 (5.8)
Median CSI (IQR)	28	6.5 (6.0)
Median LiSat (IQR)	28	4.3 (1.2)
Median IPSI (IQR)	26	57.5 (26.8)

n: number of available data; SD: standard deviation; IQR: interquartile range; MMSE: Mini Mental State Examination (range 0–30); CESD: Centre for Epidemiologic Studies Depression Scale (range 0–60); BI: Barthel Index (range 0–20); FAI: Frenchay Activities Index (range 0–45); RMI: Rivermead Mobility Index (range 0–15); LiSat: Life Satisfaction Questionnaire (range 1–6); GDS: Goldberg Depression Scale (range 0–9); CSI: Caregiver Strain Index (range 0–13); IPSI: Interactional Problem Solving Inventory (range 17–85).

Care-giving activities

These data show that all children conducted one or more household activities, such as cooking, cleaning their room and buying groceries. In addition, most children (66%) assisted the parent who had had the stroke. The main activity was helping the parent eating (e.g. cutting meat) (39%), pushing the wheelchair (34%) and assisting the parent while dressing (16%).

The children also described some positive changes 3 years after parental stroke. Most children reported that they felt more needed (56%), they had more responsibilities (72%) and that they felt more mature (81%). A smaller proportion of children stated that parents spent more time with them (24%) and that their parents were more positive (43%).

Behavioural problems

At 3 years after parental stroke, 13% of the children showed sub-clinical or clinical internalizing symptoms on the CBCL (12.5%) or YSR (13.4%) and 26% showed sub-clinical or clinical externalizing symptoms on the CBCL (37.5%) or YSR (6.7%). CBCL scores were higher than YSR scores. Table I shows median scores and percentages of sub-clinical and clinical symptoms for CBCL and YSR separately. The proportion of children with one or more behavioural problems was 31% (42% for children under 17 year of age and 18% in the older group). CBCL and YSR scores were not related to age or gender of the children.

Stress

The median score on the SVK was 34.5 (IQR = 10.8) (Table I). Girls showed significantly higher stress scores compared with boys (mean SVK 37.0 vs 31.4; $p = 0.018$). Age did not significantly correlate with stress. Stress scores for children who assisted the parent after stroke and those who did not were not significantly different.

Strong significant correlation coefficients ($p < 0.05$) were found between SVK stress scores and internalizing ($r = 0.62$), externalizing ($r = 0.66$) and total T scores ($r = 0.72$) of the YSR. However, no significant correlations were found between stress scores and CBCL scores.

Stress related to patient and partner characteristics

Stress, experienced by the child was significantly ($p < 0.05$) related to depressive symptoms ($r = 0.456$), extended ADL ($r = –0.741$) and life satisfaction ($r = –0.471$) of the patient. Partner characteristics were not significantly related to experienced stress of the child (Table III).

DISCUSSION

This explorative study is the first to assess long-term outcome (> 1 year) in children after parental stroke. The results indicate that all children conducted household activities and two-thirds of the children conducted care-giving activities, but care-giving was not significantly related to stress experience. Overall, few children showed behavioural problems compared with normal values. Stress experience was related to female gender of the child, to depression, EADL limitations and life satisfaction of the patient, but not to partner variables.

Perceived positive changes

We asked the children if they experienced positive changes, which was an important feature of this study. Research into positive changes relating to care-giving is rare. In our study, children felt more needed and that they had more responsibilities, which they experienced as a positive change. Another study on multiple

Table III. *Spearman correlation coefficients between Stress Vragenlijst voor Kinderen (SVK) stress scores and patient and partner variables*

	Spearman correlation coefficient	*p*-value
Patient characteristics		
Depression (CESD)	0.456	0.038
Cognitive status (MMSE)	–0.165	0.476
ADL independence (BI)	–0.166	0.388
EADL independence (FAI)	–0.741	0.001
Mobility (RMI)	–0.192	0.317
Life satisfaction (LiSat)	–0.471	0.042
Partner characteristics		
Depression (GDS)	–0.013	0.949
Impact care-giving (CSI)	0.163	0.407
Life satisfaction (LiSat)	–0.305	0.114
Marital status (IPSI)	–0.018	0.929

CESD: Centre for Epidemiologic Studies Depression Scale; MMSE: Mini Mental State Examination; BI: Barthel Index; FAI: Frenchay Activities Index; RMI: Rivermead Mobility Index; LiSat: Life Satisfaction Questionnaire; GDS: Goldberg Depression Scale; CSI: Caregiver Strain Index; IPSI: Interactional Problem Solving Inventory; ADL: activities of daily living; EADL: extended ADL.

sclerosis (MS) concluded that children caring for a parent with MS also reported benefits (16). These results indicate that it is important to study not only adverse effects, but also possible positive changes due to caring for a parent. It is, however, not known whether these changes occurred solely due the parental stroke and additional tasks, or whether they were also due to the fact that the children became older. Furthermore, the questionnaire did not distinguish between no change or negative change. Data for norm groups are, unfortunately, not available.

Behavioural problems

Mean scores of the CBCL and the YSR did not differ much from those of the normal population. Compared with the previous study conducted one year post-stroke, slightly more children showed externalizing symptoms in the present study (15% vs 26%) but slightly less showed internalizing symptoms (16% vs 13%). Overall the proportion of children with one or more symptoms was 31%, comparable to 29% one year post-stroke. CBCL scores in the present study were slightly lower compared with those of Dutch children who cared for a parent with cancer (12). The CBCL and YSR have been developed and are used as parallel (parent and child) versions of the same measure. CBCL externalizing and total scores were higher than YSR externalizing and total scores, suggesting more behavioural problems in younger children than in older children. However, the pattern of correlations of both scores with the child-reported stress scores, non-significant for the CBCL and strongly significant for the YSR, suggest that both scores are not comparable. The data suggest that parents might be poor raters of their children's feelings, but with the present data we are unable to answer this question (12).

Stress

We used the SVK since this instrument included positively worded items next to the negatively worded items that make up the stress score (e.g. Do you like playing computer games?) which might make this measure more acceptable to children. Girls showed significantly more stress than boys. This is in line with previous measurements of our study in which a different measure, the Child Depression Inventory was used (20). Also, a study in a subset of the children included in the present study combined with children having a parent with Parkinson's disease, suggested that being a girl was significantly related to stress (28). This is also in line with the conclusion of Korneluk & Lee (6).

Stress, and patient and partner variables

Besides child characteristics we also related patient and partner variables to distress of the child. Depressive symptoms, impairments in EADL and life satisfaction of the patient were significantly related to stress. Previous studies in the same cohort showed distinct results concerning the role of patient characteristics. One study showed no relationship between distress of the children and patient variables, while distress of the children was related to depression of the partner and quality of the marital relationship between both parents (19). In contrast, in the second study it was suggested that functional status (BI) was an independent predictor for child distress over time (20). The patient characteristics that were significantly related to stress in the present study have not been included in the previous studies. We found relationships between children's stress scores and patient FAI scores, but not with patient BI scores. The most probable reason for this difference is the ceiling effect of the BI. The actual score range in this study was limited (15–20; 63.6% of patients scoring 19–20 and 45.5% of patients scoring 20). A maximum BI score moreover does not indicate absence of problems and in patients after stroke living in the community, EADL problems measures might be better indicators of functioning. In line with the present finding that patient characteristics are important determinants, Visser et al. (9) showed that physical functioning and mental health of the patient was related to emotional and behavioural problems (CBCL) in children with a parent with cancer. It was advised to take patient characteristics into account when assessing vulnerability of children.

Besides using different patient variables we also used a different outcome measure for assessing stress in the children, which might explain different results, especially concerning the importance of partner characteristics. In addition, the number of participants was much smaller in the present study, which makes it harder to detect significant differences.

Limitations

Some limitations apply to this study. Although the data are unique, it is a small dataset, which makes generalizability of the results more difficult. Due to the small number of children included, we were unable to conduct multivariate analyses. Future research using larger study groups is necessary to identify risk factors for stress and behavioural problems in children with a parent who has had a stroke. Furthermore, some selection bias occurred because this study was part of a larger research project in which patients with, for example, second stroke and partners from, for example, separated couples were excluded. A final potential limitation is that we included more than one child from the same family, thereby violating the assumption of statistical independence of observations. However, we included a maximum of 2 children from the same family in the analysis and did that for 15 families (compared with 14 families with one child). Since we did not include more than 2 children from the same family we expect that the bias towards large families will be small.

In conclusion, most children do well 3 years after parental stroke. Parental stroke does not, by definition, result in more behavioural problems or stress. However, our data also indicate that individual outcome is varied and that some of the children (31%) do experience problems. Our results suggest that 37.5% of younger children show externalizing problems on the CBCL. It is important to realize that individual differences are large and that, despite a favourable outcome for the group as a whole, a proportion of the children of patients after stroke will need attention in clinical practice. Physicians and other care professionals need to include these children in their assessment and care, which requires a family centred approach in which not only the patient receives care, but also the partner and the children.

More research is needed, especially on the causal relationships between outcome and different determinants to gain further insight into risk factors related to negative outcome. This may help to identify the children who need extra attention and care.

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