Long-term outcome after stroke: a disability-orientated approach

J. HOCHSTENBACHI, R. DONDERS, T. MULDER, J. VAN LIMBEEK and H. SCHOONDERWALDT

The impact of stroke on both patients and family is extensive. This study describes the degree of disability experienced by both after stroke, with special emphasis given to psychosocial dysfunction. One hundred and sixty-five patients who suffered a stroke in the past 5 years and their proxies filled in a mail-delivered Sickness Impact Profile (SIP). After each SIP category, a 5-point scale was added to determine the extent to which items in that category were experienced as a problem. Also an inventory was made of desired help. Results showed that stroke has a very high impact on everyday functioning, as indicated by a total SIP score of 20. The results showed that psychosocial disabilities arise independent of the degree of physical disabilities, that these problems are chronic, and that they hinder 52% of patients often permanently. It can be argued that in addition to a motor- or function-orientated approach, psychosocial treatment programmes are urgently needed.

Langzeit-Outcome nach Schlaganfall – Eln behinderungsorientierter Ansatz

Die Auswirkungen eines Schlaganfalls auf Patienten wie Familienangehörige sind weitreichend. Die Studie beschreibt aus der Sicht beider den nach Eintritt eines Schlaganfalls erlebten Grad der Behinderung, wobei insbesondere die psychosozialen Aspekte im Vordergrund stehen.

165 Patienten, die in den vergangenen 5 Jahren einen Schlaganfall erlitten hatten, sowie ihre Angehörigen beantworteten im Rahmen einer postalischen Befragung das Sickness Impact Profile (SIP). Nach jeder SIP-Kategorie wurde eine fünfstufige Skala eingefügt, auf der angegeben werden sollte, in welchem Umfang Items der jeweiligen Kategorie als Probleme erlebt werden. Auch wurde eine Auflistung erwünschter Hilfen erstellt.


Es kann gefolgt werden, daß zusätzlich zu einem motorisch-bzw. funktionsorientierten Ansatz dringender Bedarf für psychosoziale Dehandlung und Intervention besteht.

Le denenir a long terme apres attaque: une approche orientée sur le handicap de situation

Les conséquences d’une attaque à la fois sur le patient et sa famille sont importantes. Cette étude décrit la situation de handicap vécue par les deux à la suite d’une attaque avec une mise en lumière spécifique du dysfonctionnement psychosocial.
165 patients victims d’attaque au cours des cinq dernières années, ainsi que leurs proches ont répondu à une enquête postale par le SIP (Sickness Impact Profile). A chacune des catégories du S.I.P. on a ajouté une échelle à 5 points pour déterminer à quels items de la catégorie correspondaient les problèmes rencontrés. L’inventaire des aides souhaitées était également réalisé.

Les résultats ont montré que l’attaque a de très importantes conséquences sur le fonctionnement de la vie quotidienne comme le prouve le score de 20 obtenu au S.I.P. Les résultats ont aussi montré que la sphère des situations de handicaps psychosociaux est indépendante du degré des incapacités physiques, que ces incapacités sont chroniques et pour plus de 52% des patients définitives.

On peut affirmer qu’en sus des prises en charge sur le plan moteur et fonctionnel, il est urgent d’y adjoindre un programme de traitement psychosocial.

Resultados a largo plazo después del accidente cerebro-vascular: un enfoque orientado a la discapacidad

Este estudio describe el grado de discapacidad experimentado por la familia y el paciente después del accidente cerebro-vascular, a partir del reconocido impacto que tiene sobre ambas partes, poniendo un énfasis particular en la disfunción psicosocial. El método aplicado consistió en hacer contestar una encuesta por correo basada en el Perfil de Impacto de la Enfermedad (PIE) a ciento sesenta y cinco pacientes que sufrieron el accidente cerebro-vascular en los últimos cinco años, así como a sus familiares más próximos. Cada categoría del PIE se completaba con una escala de 5 puntos para determinar hasta qué punto los epígrafes de esa categoría eran experimentados como problema. También se clasificó la ayuda deseadas. Los resultados muestran que el accidente cerebro-vascular tiene un gran impacto en el funcionamiento cotidiano, con un grado 20 en la escala del PIE. Los resultados muestran además que las discapacidades psicosociales se producen con independencia del grado de las discapacidades físicas, que estos problemas son crónicos y que afectan al 52% de los pacientes siempre o casi siempre. Como conclusión se puede argumentar que a un enfoque motorio o funcional se deben añadir urgentemente los necesarios programas de tratamiento psicosocial.

Keywords: stroke; sickness impact profile; cross-sectional study; long-term outcome

Introduction

Much research has been performed so far to describe or predict functional recovery after stroke (Jongbloed, 1986), but less is known about the cognitive, emotional, and behavioural consequences of brain damage. It is only during the last decade that studies have appeared in which these have been described (Miller, 1984; Bleiberg et al., 1985; Prigatano et al., 1986; Prigatano, 1987). The literature on the impact of brain damage on family and friends mentions such consequences as financial problems, work-related problems, decline in physical health, social isolation, role-changes, anger, anxiety, and depression (Lezak, 1978, Klonoff and Prigatano, 1987; Livingston, 1987; Schultz et al., 1988; Brooks, 1991; Williams, 1991). Since the main (therapeutic) focus in rehabilitation (research) is still on the reacquisition of motor skills, little is known about the extent to which these psychological consequences occur, how much of a handicap they are, and to what extent they influence the quality of life.

In the acute post-stroke phase, the main therapeutic bias may be justified by the fact that stroke patients as well as their relatives consider the reacquisition of locomotion capacity to be of the utmost importance. However, after the hospital period, the vast majority of survivors go home, and they are more or less ignorant of the possible psychological and
social consequences of their stroke. This is an important point, since in the stages following the acute phase, these psychosocial variables become increasingly important and play a crucial role in re-establishing the quality of life and in regaining independent living (Ahlsio et al., 1984; Robinson et al., 1985; Niemi et al., 1988; Viitanen et al., 1988; Ogden et al., 1990, Nydevik and Åsberg, 1991; Åström et al., 1992). It can therefore be argued that, until now, too little attention has been devoted to this topic once patients have left the hospital or rehabilitation centre. Home-directed after-care programmes are still very rare in stroke rehabilitation.

The main goal of this study is to establish the degree of physical and psychosocial disabilities, to gain more insight into the quality of life of patients (and their proxies) suffering from the long-term consequences of stroke.

**Methods and subjects**

**Methods**

The perceived disability was assessed by means of the Sickness Impact Profile (SIP). This is a behaviour-based, generic measure of health status, composed of 136 statements or items about health-related dysfunctions, which are grouped into 12 categories. Each of the SIP-items describes changes in behaviour that are attributable to health status. There are three categories in the physical dimension concerning physical dysfunctioning (Ambulation, Mobility and Body care and movement), four in the psychosocial dimension (Social interaction, Alertness behaviour, Emotional behaviour and Communication), and five (Sleep and rest, Home management, Work, Recreation and pastimes and Eating) that are not aggregated in any way except to form the SIP total score (Gilson et al., 1975; Bergner et al., 1976). Respondents were asked to mark only those statements related to their actual health status. Every statement has a given weight, a value proportional to the amount of dysfunction. These weights are summed for each category and for each dimension; the final sum is the total score. The scores are given as a percentage of the maximal dysfunction in each category and have a possible range of 0–100. The higher the score, the greater the dysfunction. A Dutch version, which has been tested for reliability and validity (Jacobs et al., 1990; de Bruin et al., 1992; de Haan et al., 1993), was used in this study. The SIP takes about 30 min to complete, and can be self-administered or used in an interview form. Although for mail-delivered SIPs internal consistency and correlation with criteria are lower, they still deliver reliable data (de Bruin et al., 1992). The use of a surrogate SIP, obtained from proxies, has been evaluated. Results have shown that if the surrogate is a family member who is closely involved in the patient’s care, the use of surrogate SIP total and dimension scores are reliable (McCusker and Stoddard, 1984; Rothman et al., 1991).

Since the SIP has been used for a number of different patient populations (Patrick and Deyo, 1989; de Bruin et al., 1992; König-Zahn et al., 1993), it offers the opportunity to compare the sickness impact of stroke with that of a variety of other diseases. Although the SIP measures the subjective impact of an illness or injury on everyday functioning, it does not provide us with information about the extent of the suffering that is experienced or the extent to which items of a category were felt to be a problem. Therefore after each category, a question (‘To what extent do you experience the marked items as a problem?’) was added. The answer to that question was given on a five-point scale
(‘never’, ‘seldom’, ‘sometimes’, ‘often’, ‘always’). To gain more insight into the
categories for which people wanted help a second question was added ‘Would you like any
help in the area of . . . ?’

Subjects

The inclusion criteria were: having a stroke in the last 5 years, being younger than 75 years
of age at the time of the stroke, living at home, and not suffering from other major physical
diseases or mental disorders. Although it is known that two-thirds of stroke patients are
older than ours, we were interested in the younger group because of their longer life
expectancy and the greater pressure to participate in society, and so it seemed relevant to
analyse the nature and seriousness of the disabilities within this selected group.

Seventy-six subjects from the Department of Neurology of University Hospital
Nijmegen formed the total pool of patients who met the criteria. In addition, 188 patients
(and their proxies) were approached via the Centre for Rehabilitation at the Sint
Maartenskliniek in Nijmegen. These patients were drawn at random from the total pool of
stroke patients available at that centre. This resulted in 264 patients and their proxies,
drawn from two groups, who were approached with mail-delivered SIPs. These two groups
were selected since it was expected that the group from the University Hospital would
show the normal heterogeneous mix, with some patients going home (having few or no
physical impairments) and others being admitted to a rehabilitation centre, and the group
from the rehabilitation centre would have more serious physical impairments compared to
the patients who went home. The latter aspect is relevant since it enables us to study the
relationship between physical and psychosocial disabilities.

Fifty-eight questionnaires were not completed properly and were excluded, 21 patients
did not respond, eight refused to cooperate, and 12 had died. Of the remaining 165
patients, there were 88 men and 77 women. Their mean age at the time of their stroke was
54 years (S.D. = 13, range 16–73); 61% were younger than 70. At the time of completing
the questionnaire, the mean age was 57 (S.D. = 13, range 20–74). After discharge from
the hospital, 103 patients went to a rehabilitation centre, 42 went directly home, and 20
went home by a circuitous route (usually a nursing home).

The distribution over time was as follows: 14.5% (n = 22) had had their stroke less than
a year before, 24.3% (n = 37) between 1 and 2 years, 29.6% (n = 45) between 2 and 3
years, 17.1% (n = 26) between 3 and 4 years, and 14.5% (n = 22) more than 4 years
before. For 13 patients, the exact onset of the stroke was not known. There were 66
patients (40%) with a left-hemisphere lesion, 87 (52.7%) with a right-hemisphere lesion,
and 12 (7.3%) whose lesion side was unknown.

The home situation of 129 patients was known: 14% lived alone, 76% lived with their
spouse and/or children, 4.7% lived in a nursing home, and 5.3% lived with other relatives
or friends. For 163 proxies the relationship with the patient was known: 70.6% were a
partner, 13.5% a child, 5.5% a parent, 3.7% another relative, and 6.8% were a friend.

Data analysis

The data were analysed by means of (multivariate) analysis of variance, Student’s t-tests,
and Pearson correlation coefficients.
Results

General results

Figure 1 shows the scores for the different SIP categories for all patients and proxies for the two dimensions (physical and psychosocial) as well as the overall SIP score. Since only 19 subjects were working, the category Work has been excluded from the overall score. Most problems are experienced in the categories ‘Home management’, ‘Recreation and pastimes’, ‘Alertness behaviour’, and ‘Ambulation’. No significant difference existed between the mean category scores of patients and proxies ($F(11, 152) = 1.106; p = 0.36$). Therefore, only the scores of the patients will be mentioned.

For all categories, no significant effect existed for age ($F(44, 494) = 1.35; p = 0.071$), and gender ($F(11, 125) = 1.19; p = 0.30$). The analysis revealed a significant effect for lesion side ($F(11,125) = 3.20; p = 0.001$). ‘Communication’ was the only category for which the lesion side showed a significant effect ($F(1, 151) = 9.99, p < 0.001$). As would be expected, patients with left-hemisphere lesions had a significantly higher score (20) than patients with a right-hemisphere lesion (12).

Length of post-stroke period: a cross-sectional analysis

In order to study the effect of the length of the post-stroke period, five separate groups of patients were formed. The SIP scores on the physical and psychosocial dimension for the different post-stroke period groups are shown in Table 1. The results indicated no significant difference between the time groups ($F(4, 145) = 0.33, p = 0.86$), or between the psychosocial and the physical scores ($F(1,145) = 0.43 p = 0.51$). However, there was a significant interaction ($F(4, 145) = 3.18, p = 0.015$). In this case, this means that the differences between the psychosocial and the physical scores decline when more time has elapsed since the onset of the stroke. This effect is primarily caused by the difference in the early post-stroke group ($p = 0.0064$). The other differences were not significant ($p > 0.06$).

The effect of discharge placement: home or rehabilitation centre

To unravel the effect of discharge placement on the SIP scores pertaining to the physical and psychosocial dimensions, two groups were examined. One group consisted of patients who went directly home after being discharged from hospital (HOME group, $n = 42$) while the other consisted of patients who were admitted to a rehabilitation centre (REHAB group, $n = 103$). Table 2 shows the effect of discharge placement after the hospital period on SIP scores for the psychosocial and physical dimensions, and the overall score. The results showed a significant difference between the REHAB group and the HOME group on the physical dimension ($t(115.1) = -5.52, p < 0.000$). However, no significant difference existed in the psychosocial functioning of the two groups ($t(143) = -1.32, p = 0.19$). Furthermore, there is only a moderate relation between the physical and the psychosocial dysfunctioning ($r = 0.50, p = 0.000$).

Problem intensity

The extent to which people experienced the items marked in an SIP-category as a problem was measured by the additional question ‘To what extent do you experience ... as a problem?’ The scores on the five-point scale were correlated with the SIP category scores;
Fig. 1. Mean SIP scores of 165 stroke patients and their proxies.
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Table 1. SIP scores on the physical and psychosocial dimension of five separate patient groups differing in post-stroke period

<table>
<thead>
<tr>
<th>Post-stroke period (years)</th>
<th>Physical dimension</th>
<th>Psychosocial dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 (n = 22)</td>
<td>23 (S.D. = 17)</td>
<td>15 (S.D. = 11)</td>
</tr>
<tr>
<td>1-2 (n = 37)</td>
<td>17 (S.D. = 16)</td>
<td>18 (S.D. = 16)</td>
</tr>
<tr>
<td>2-3 (n = 45)</td>
<td>15 (S.D. = 14)</td>
<td>19 (S.D. = 15)</td>
</tr>
<tr>
<td>3-4 (n = 26)</td>
<td>20 (S.D. = 15)</td>
<td>20 (S.D. = 18)</td>
</tr>
<tr>
<td>&gt; 4 (n = 22)</td>
<td>22 (S.D. = 15)</td>
<td>20 (S.D. = 15)</td>
</tr>
</tbody>
</table>

Table 2. The effect of discharge placement on the psychosocial and the physical dimension, and the SIP total score

<table>
<thead>
<tr>
<th></th>
<th>Rehab group</th>
<th>Home group</th>
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<tbody>
<tr>
<td>Psychosocial</td>
<td>20 (S.D. = 16; n = 103)</td>
<td>16 (S.D. = 14; n = 42)</td>
</tr>
<tr>
<td>Physical</td>
<td>22 (S.D. = 16; n = 102)</td>
<td>10 (S.D. = 10; n = 42)</td>
</tr>
<tr>
<td>Total</td>
<td>22 (S.D. = 13; n = 102)</td>
<td>14 (S.D. = 11; n = 42)</td>
</tr>
</tbody>
</table>

this correlation is highly significant for all categories (all $p < 0.001$). Since not all respondents filled out every additional question, the assessment scores are known for 120 patients and proxies for the physical dimension, and 95 patients and 94 proxies for the psychosocial dimension.

Figure 2 shows to what extent patients and proxies assessed physical and psychosocial functioning as a problem. For the sake of clarity, the first two possibilities on the five-point scale (‘never’ and ‘seldom’) have been combined. As can be expected, the physical assessment scores are high: 72 patients (60%) and 46 proxies (38%) are often or always hindered by the patient’s physical problems. The psychosocial scores are also high, for patients as well as their proxies; 49 patients (52%) and 35 proxies (37%) are often or always hindered by the psychosocial problems which have risen as a consequence of the stroke.

Table 3 shows that, roughly speaking, a quarter of the respondents wanted help for behaviours in the categories which constitute the psychosocial dimension: ‘Alertness behaviour’, ‘Emotional behaviour’, ‘Communication’, and ‘Social interaction’.

Discussion

As mentioned in the Introduction, recovery from stroke until now has been primarily measured in terms of the performance of sensorimotor skills and seldom in terms of psychosocial functioning. The aim of this study was to describe disabilities experienced by both patients and proxies.

An overall SIP score of 20 showed that stroke, indeed, has an extremely high subjective impact on everyday functioning when compared to the scores of the general population or other patient populations. Note that in the general population the mean overall scores on the SIP range from 1.2 to 4.5 (Konig-Zahn et al., 1993). Comparison with scores from the elderly (SIP = 7) (Schuling et al., 1993) or with patients with other serious diseases (for
instance, kidney transplants. SIP = 5.5; myocardial infarction with cardiac arrest, SIP = 10.3) shows that only a few diseases result in a similar or higher SIP score (König-Zahn et al., 1993). For example, three studies of chronic obstructive lung disease report SIP scores of 14.5, 22.2, and 24, whereas studies of chronic pain SIP report scores of 18.7, 23.8 and 30.4 (König-Zahn et al., 1993). Although some caution is necessary since the studies mentioned differ in methodology, it will nevertheless be clear that the stroke scores are relatively high. It is important, however, to make some remarks on this study.
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Table 3. The help that patients and proxies desire in the category forming the psychosocial dimension

<table>
<thead>
<tr>
<th>Categories</th>
<th>Patients</th>
<th>Proxies</th>
</tr>
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<tr>
<td>Alertness behaviour</td>
<td>27.3% n = 143</td>
<td>26.9% n = 130</td>
</tr>
<tr>
<td>Emotional behaviour</td>
<td>22.4% n = 143</td>
<td>25% n = 140</td>
</tr>
<tr>
<td>Communication</td>
<td>25.4% n = 126</td>
<td>23.8% n = 126</td>
</tr>
<tr>
<td>Social interaction</td>
<td>22.1% n = 140</td>
<td>26.7% n = 131</td>
</tr>
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</table>

Generalizing the results to the total stroke population is not possible, since the sample of patients is relatively young. Furthermore, patients who went to a rehabilitation centre are not representative, since in The Netherlands only a small minority of stroke patients receive a structured rehabilitation programme.

For the stroke patients in this study, the highest scores were found in the categories ‘Home management’, ‘Recreation and pastimes’, ‘Alertness behaviour’, and ‘Ambulation’. Generally this agrees with other studies using the SIP at 26 weeks (Schuling et al., 1993), 6 months (de Haan et al., 1994), and 9 months after stroke (Nydevik and Åsberg, 1991), or at 1 year after completing the rehabilitation period (de Witte et al., 1987).

The fact that no significant difference for gender (Labi et al., 1980; Ahlsio et al., 1984; Jongbloed, 1986; Niemi et al., 1988; Nydevik and Åsberg, 1991) or lesion side (Kotila et al., 1984; Robinson et al., 1985; Schulz et al., 1988; de Haan et al., 1994) was found is also in accordance with other investigations. The general effect of age is still unclear, since an age-related increase in the incidence of other diseases or an age-related reduction of social activities may function as confounding factors (Labi et al., 1980; Jongbloed, 1986; Niemi et al., 1988; Nydevik and Åsberg, 1991). However, in our study these confounding factors play a minor role because of our selection criteria used. Furthermore, other researchers found no relationship with age (Ahlsio et al., 1984; Schulz et al., 1988).

Since this was a cross-sectional study, no direct conclusions about the time path can be drawn. The fact is, however, that no differences were found between the scores of the different time groups. No difference was found either between the psychosocial and the physical scores over the different time groups. But there was a significant interaction caused by a substantially larger difference between the psychosocial and the physical scores in the first time-group compared to the others. During this period, physical problems seem to be more overt than psychosocial ones. A plausible explanation for this discrepancy may be that, in this phase, stroke victims are still primarily focused on regaining physical abilities. Although this emphasis on the physical aspects is understandable, it may lead to an underestimate or even neglect of the cognitive, emotional, and behavioural disorders. Furthermore, for the majority of patients and proxies it takes time to accept the chronic nature of the stroke-induced effects (Brooks, 1991) and to realize the impact of these effects on psychosocial functioning. For patients admitted to a rehabilitation centre, it is even harder to be aware of the psychosocial consequences, since they are treated in a more or less protected environment, characterized by a high degree of structure and predictability. The fact that even patients who suffered their strokes a long time previously still show a considerable amount of disabilities, implicates chronicity.

The relative independence of psychosocial problems in relation to physical problems is interesting and deserves some comment. The REHAB group is more physically impaired than the HOME group. It could therefore be expected that the psychosocial problems in the
REHAB group would be larger than those in the HOME group, because a relationship between the degree of physical and of psychosocial disabilities seemed plausible. The present study, however, shows that the psychosocial problems are more or less independent of the seriousness of the physical problems. This is a very interesting point, since it indicates that functional recovery measures which are limited to physical recovery *per se* are not accurate predictors of psychosocial functioning after stroke. This is also shown by the moderate degree to which the physical dimension score of the SIP predicts the psychosocial one.

Finally, it should be recalled that a quarter of the people indicated that they would like to receive help for their psychosocial problems. In reality this number may be even higher, since a relevant number of responders indicated that they could not imagine what kind of help this would be, and so left the question unanswered.

**Concluding remarks**

The fact that the physical and psychosocial problems of stroke survivors are relatively independent of each other needs to be taken into consideration to improve treatment programmes. Indeed, the data clearly reveal that there are chronic psychosocial problems which form a real burden for all involved. It can therefore be argued that what is needed is an integrated rehabilitation approach in which motor, cognitive, perceptual, and psychosocial aspects are united into a coherent behaviour-oriented approach to enhance the quality of life for both patients and their families. The present paper attempts to contribute to such a development, but there is still a long way to go.

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**References**


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