Quality of Life During and After Inpatient Stroke Rehabilitation

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Background and Purpose—Very limited longitudinal data are available that assess the health-related quality of life (HRQOL) of stroke survivors after discharge from inpatient rehabilitation. The purpose of this research was to assess changes in HRQOL during inpatient rehabilitation and again 6 months after discharge.

Methods—This was a prospective study of all eligible patients admitted to an inpatient stroke rehabilitation hospital over a 3-year period. HRQOL was assessed by means of the Medical Outcomes Study 36-item Short Form (SF-36). Dependent t tests were used to compare the scores at admission and discharge and at discharge and 6 months. Changes in HRQOL were calculated for the period of admission to discharge and of discharge to the 6-month follow-up.

Results—Complete data were available for 85 patients. During rehabilitation, there were improvements in all 8 domains of the SF-36, with 5 attaining statistical significance. After discharge, 3 domains continued to improve, with 1 attaining statistical significance. However, there were marked and statistically significant declines in the other 5 domains of the SF-36. Feedback was obtained from a subset of the patients as to the reasons for these declines.

Conclusions—Substantial gains in HRQOL during inpatient stroke rehabilitation may be followed by equally substantial declines in the 6 months after discharge. There is a need for longitudinal research into the HRQOL of stroke survivors and their families, as well as a need to ensure that adequate community services and support are available. (Stroke. 2003; 34:801-805.)

Key Words: outcome ■ quality of life ■ rehabilitation ■ stroke ■ stroke assessment

Stroke survivors make up the largest category of patients in rehabilitation and have the third-highest length of stay in rehabilitation, following spinal cord injuries and brain dysfunction.1 Research evidence indicates that both inpatient and outpatient stroke rehabilitation helps stroke survivors maximize their health-related quality of life (HRQOL), including physical, cognitive, emotional, and social aspects.2 However, less is known about the HRQOL of stroke survivors after discharge from rehabilitation.

Cross-sectional data suggest that HRQOL and well-being after stroke are significantly impaired. A comparison of 5056 community-dwelling seniors and 339 community-dwelling stroke survivors identified lower well-being, greater likelihood of restrictions in both physical and cognitive functions, poorer mental health, and more comorbid conditions in the stroke survivors compared with seniors who had not had a stroke.3 A comparison of 304 survivors of a mild stroke, 184 people who had experienced a transient ischemic attack, and 654 people who had risk factors but no symptoms of stroke or transient ischemic attack indicated that the HRQOL was lowest in the stroke group and that the consequences of even a mild stroke affected all dimensions of health except pain.4 A third study, which examined 50 stroke survivors between 1 and 3 years after discharge, found that overall HRQOL was low and recommended that rehabilitation programs place more emphasis on psychosocial issues that affect stroke survivors’ lives as a whole.5 A fourth study compared the HRQOL of 639 stroke survivors 6 years after the event to that of the general population. Those researchers found that cases had significantly lower scores on physical functioning and general health than controls, although no differences were found in mental health and bodily pain.6 Finally, a study of 46 stroke patients 4 years after the event found that despite a good recovery in terms of hospital discharge, activities of daily living, and return to work, the QOL of 83% of the patients had not returned to the prestroke level.7

Longitudinal data are limited but support the findings of the cross-sectional studies. One study that assessed 63 stroke survivors during inpatient rehabilitation 1 month after stroke and again at home 6 months after the stroke found that functional independence and HRQOL improved over time but that this improvement was strongly correlated with self-care and self-efficacy.8 A second study examined 35 patients at 3, 6, and 12 months after stroke and noted that the patients as a group were depressed and remained so over the course of the study.9 QOL scores were abnormal at 3 months,
and although they improved slightly over the course of the study, they were still highly abnormal after 1 year.

The purpose of this research was to assess the changes in HRQOL during inpatient rehabilitation and again 6 months after discharge. This study would permit a comparison of changes in HRQOL during inpatient rehabilitation with changes in HRQOL in the 6 months after discharge.

Methods

This was a prospective study of all eligible patients admitted to an inpatient stroke rehabilitation program in a Canadian rehabilitation hospital between February 1998 and March 2001. The hospital serves a large geographic area of southeastern Ontario, with a population of ~300,000 residents, of which ~45% are rural. Fifteen beds are available for inpatient stroke patients, and rehabilitation is provided by a multidisciplinary team. Additional details regarding the program are available elsewhere. The research was approved by the Queen’s University and Affiliated Teaching Hospitals Health Sciences Human Research Ethics Board, and participants provided informed consent.

HRQOL was assessed by means of the Medical Outcomes Study 36-item Short Form (SF-36), which is a self-administered questionnaire containing 36 items that, when scored, yield 8 domains. The physical functioning domain assesses limitations in physical activities such as walking and climbing stairs. The role physical and role emotional domains measure problems with work or other daily activities as a result of physical health or emotional problems. Bodily pain assesses limitations resulting from pain; vitality measures energy and tiredness. The social functioning domain examines the effect of physical and emotional health on normal social activities, and mental health assesses happiness, nervousness, and depression.

The general health perceptions domain evaluates the personal opinion of one’s health compared with that of one’s peers, as well as the expectation of changes in health. All domains are scored on a scale from 0 to 100, with 100 representing the best possible health state.

Two summary scores can also be derived. However, they were not used in the present study because they represent summaries of the domain scores and we wanted to assess changes in the individual domains. Although stroke-specific HRQOL measures are now available, they were not available when the study was initiated, which led to the use of the more generic SF-36 in this study. The SF-36 has been validated for use in stroke patients, and the problem of missing data encountered in a previous study of older stroke patients was not encountered in the present study.

Patients were eligible if they were considered able to comprehend the information, consent process, and the questions contained within the SF-36. The program social worker (J.V.) identified all consecutive patients, and a study volunteer approached these patients between 3 and 5 days after admission. The study was described as one that measured QOL from a health perspective, and they were told that if they consented, they would complete it right away, a few days before they left the hospital, and 6 months after their discharge by means of a mailed questionnaire and telephone follow-up. The SF-36 was administered with the aid of the volunteer so that those who experienced difficulty reading or writing could dictate their responses to the volunteer. Proxy responses from relatives or significant others were not accepted.

A small amount of additional information was collected by means of chart review. This included age, sex, side of stroke, and discharge disposition to allow us to examine differences on the basis of these factors.

Analyses included descriptive statistics (mean, SD, frequencies), independent t tests to compare the outcomes of nonrespondents with those who participated fully, and paired t tests to compare the 8 domains of the SF-36 from admission to discharge and from discharge to the 6-month follow-up. Change scores were calculated in such a way that positive change scores indicated improvement and negative change scores indicated deterioration.

Results

Data were collected for 255 patients at admission, 197 at discharge, and 85 at the 6-month follow-up. Forty-eight patients were not yet eligible for the 6-month follow-up, and 2 were still in hospital at the time that the study closed, but there were no more resources available to continue the follow-up.

The available number of patients who could have been included at the time of follow-up was therefore 205, for a response rate of 41.5%. Reasons for loss to follow-up at both discharge and 6 months include the fact that patients were not always willing to participate beyond the admission questionnaire, some patients were discharged when the volunteer was not available, and a number who were eligible for the 6-month follow-up did not return the survey despite telephone calls to remind them.

To assess the generalizability of the results, we compared the baseline SF-36 scores of those for whom we had complete data (n=85) with the scores of those for whom we did not (n=170). We found only 1 statistically significant difference in HRQOL between the 2 groups. The mean role physical score of the group for whom we had complete data was 6 points lower than the score for the group for whom we did not have complete data, indicating that at least for this domain, those for whom we had complete data had poorer scores. There were no differences in the percentage of men versus women, the percentage of left versus right hemisphere strokes, or the mean ages between the 2 groups. There were differences in the discharge destination, however. Of those with complete data, only 5.9% were discharged to a nursing home, whereas of those with incomplete data, 22.4% were discharged to a nursing home (P<0.01). This suggests that these results may be more representative of stroke survivors who return to the community.

The age of the sample ranged from 33 to 92 years, with a mean of 69.6 years and an SD of 11.8 years. Mean length of stay was 41.9 days, with an SD of 28.1 days. Table 1 describes additional characteristics of those for whom we had complete data.

Table 2 describes the changes in scores from admission to discharge and from discharge to the 6-month follow-up. During rehabilitation, there were improvements in all 8 domains of the SF-36, although only 5 were statistically significant.
significant. After discharge, 1 domain continued to show statistically significant improvement (role physical functioning), and 2 showed nonsignificant improvement (physical functioning and vitality). However, there were marked and statistically significant declines in the other 5 domains of the SF-36 in the 6 months after discharge.

These data are also portrayed in the Figure, along with the age-adjusted normative data for the sample. The normative data indicate that there are substantial differences between the stroke survivors and their peers in most of the SF-36 HRQOL domains.

The side of stroke had little impact on HRQOL scores. Role emotional functioning was significantly different at admission, with patients with left hemisphere stroke functioning more poorly than those with right hemisphere stroke ($P<0.05$), but these differences were no longer present at discharge. At discharge and at the 6-month follow-up, there were no differences between those with a left hemisphere and those with a right hemisphere stroke. There were insufficient data to assess the impact of a stroke on both sides or strokes that could not be categorized as right versus left.

Sex had an impact over time. There were no differences between men and women at admission. However, differences began to emerge at discharge, with women scoring more poorly on physical functioning ($P<0.05$), vitality ($P<0.01$, and mental health ($P<0.05$). At the time of the 6-month follow-up, there were no longer significant differences between men and women in physical functioning, but the differences in vitality and mental health became more pronounced ($P<0.01$ and $P<0.001$, respectively).

The relatively low number of stroke survivors discharged to an institution in the current sample (5 of 85) prohibited statistical comparison of the 2 groups. However, an examination of the mean values revealed that both groups improved during inpatient rehabilitation and that both groups had a similar pattern of improving in some domains and dropping substantially in others after discharge. Inpatient improvements in those who would eventually be discharged home were stronger than those of the patients discharged to an institution.

Finally, age was not a limiting factor for stroke rehabilitation. A comparison of the scores of those less than or equal to the mean age versus those older than the mean age indicated that the older patients had better scores on bodily pain and general health perceptions than the younger group at the time of admission ($P<0.05$ in both cases). At discharge, these differences had disappeared, but the younger patients were doing better than the older ones in the vitality domain ($P<0.05$). No differences were significant at the time of the 6-month follow-up, suggesting that age was not a significant factor in assessments of changes in HRQOL during and after stroke rehabilitation.

### TABLE 2. Changes in SF-36 Scores From Admission to Discharge and From Discharge to 6-Month Follow-Up (n=85)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in SF-36, admission to discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>17.26 (25.1)</td>
<td>$P&lt;0.001$</td>
</tr>
<tr>
<td>Role Physical</td>
<td>3.57 (20.6)</td>
<td>ns</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>6.35 (56.8)</td>
<td>ns</td>
</tr>
<tr>
<td>Vitality</td>
<td>4.64 (24.4)</td>
<td>ns</td>
</tr>
<tr>
<td>Mental Health</td>
<td>6.76 (20.4)</td>
<td>$P&lt;0.01$</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>13.83 (46.5)</td>
<td>$P&lt;0.01$</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>8.10 (36.7)</td>
<td>$P&lt;0.05$</td>
</tr>
<tr>
<td>General Health Perceptions</td>
<td>4.51 (18.0)</td>
<td>$P&lt;0.05$</td>
</tr>
<tr>
<td>Change in SF-36, discharge to 6-month follow-up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>0.95 (27.2)</td>
<td>ns</td>
</tr>
<tr>
<td>Role Physical</td>
<td>13.16 (35.2)</td>
<td>$P&lt;0.001$</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>-23.8 (52.2)</td>
<td>$P&lt;0.001$</td>
</tr>
<tr>
<td>Vitality</td>
<td>2.32 (23.6)</td>
<td>ns</td>
</tr>
<tr>
<td>Mental Health</td>
<td>-10.43 (21.3)</td>
<td>$P&lt;0.001$</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>-9.67 (40.9)</td>
<td>$P&lt;0.05$</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>-21.19 (35.2)</td>
<td>$P&lt;0.001$</td>
</tr>
<tr>
<td>General Health Perceptions</td>
<td>-12.46 (21.7)</td>
<td>$P&lt;0.001$</td>
</tr>
</tbody>
</table>

Positive change scores reflect improvement while negative change scores indicate decline. Items in bold indicate declines.

SF-36 scores at admission, discharge, and the 6-month follow-up.
Discussion

Inpatient rehabilitation has a strong, positive impact on HRQOL, as expected. This is consistent with a large body of literature that supports the effectiveness of rehabilitation on physical, cognitive, emotional, and social aspects of a patient’s function and well-being. However, the finding that significant improvements during inpatient rehabilitation may be followed by equally significant declines in the 6 months after discharge suggests that patients may not do well when they return to their own environment.

To some extent, this results because adaptation to stroke involves much more than just physical function, and a return to one’s prestroke environment may serve as a reminder of the degree of loss of function and independence. One cross-sectional study found that poor mental health and physical and cognitive difficulties were associated with a reduced sense of well-being, but social supports and educational resources moderated the impact of poor functional status. A second cross-sectional study found that the most significant predictors of HRQOL included marital status, quality of social support, functional status, and depression.

Given these results, we thought it was important to obtain feedback from the patients and their caregivers to see whether these findings were consistent with their experience. Fifteen stroke survivors and 7 caregivers responded to our invitation to review the results. The 2 groups were separated after the results were presented to them to obtain independent feedback. Comments about the study and the SF-36 were generally positive, and none felt that it had been burdensome or difficult. Not all agreed with the results of the study, but they were aware that they, as a group, probably represented a subset of patients who had achieved greater improvement than those who were unable to attend or who were uninterested in attending.

In separate discussions, the stroke survivors focused on issues surrounding their independence, usefulness, self-care, and socializing and felt that the decline in HRQOL, for some domains, was likely related to comorbid conditions, reduced energy levels, limited social life, and unrealistic expectations of recovery after stroke. Their recommendations included having faith; having the option of participating in group exercises at the rehabilitation hospital, a local gym, or a health club; and above all, having realistic expectations and information on the potential for mood disorders and depression after stroke.

The caregiver group focused on different issues. They indicated that they needed much more information, particularly at the time that the stroke survivor was discharged into their care. They identified issues of funding for special needs, the need for additional therapy for the stroke survivor, and the need for access to qualified help. They thought that the decline in HRQOL was related to older age (which the data did not support), lack of social support, changing roles within the marital relationship, and the mood of the stroke survivor. Their recommendations included having faith, having access to support groups, having access to exercise options such as swimming pools, and having support from service clubs.

Age was not a significant factor in this sample, which is supported by other research into the effect of age on functional outcomes and subjective well-being after stroke. The side of stroke also had little impact on the HRQOL outcomes assessed in this study. Sex had little effect initially, but women achieved less improvement in the vitality and mental health domains 6 months after discharge than men.

Discussion in the focus group centered on the traditional role of women in the home and the difficulties that they may have encountered in maintaining that role after discharge. One previous study found that women had a higher subjective well-being than men after stroke, although the time that had elapsed since the stroke was not clear. Both those who were eventually discharged home and those who were institutionalized had improvements in HRQOL, but the improvements for those discharged home were greater.

There are a number of limitations of this study, which must be taken into account when these results are interpreted. Additional clinical information such as stroke severity and comorbid conditions would have been very useful in the interpretation of the results. The sample was relatively small, and follow-up was limited by several factors. The use of multiple comparisons is an additional weakness, but the sample size did not permit more sophisticated approaches such as the Bonferroni procedure for multiple comparisons.

However, the results suggest that substantial gains in HRQOL during inpatient rehabilitation may not be sustained after discharge. In fact, the inpatient gains may be followed by significant declines after discharge. Caregiver HRQOL was not directly assessed, but the focus groups also identified a significant caregiver burden. This is supported by a body of research that identifies adjustment difficulties, depression, deterioration in health, and greater use of healthcare resources among caregivers. There is evidence that social resources and support, realistic expectations, additional knowledge, education, and counseling may help to alleviate the burden of stroke on both the patient and the caregiver in the months after discharge from a rehabilitation program.

These results suggest that there is a clear need for longitudinal research into the HRQOL of stroke survivors and their caregivers to adequately assess the burden of illness and the burden of care after discharge from inpatient rehabilitation. Additional knowledge will allow healthcare providers to ensure that adequate community support is made available to facilitate reintegration of the patient into their family and social roles.

Acknowledgments

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References

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