Patient Dissatisfaction With Acute Stroke Care

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Background and Purpose—Riks-Stroke, the Swedish Stroke Register, was used to explore patient characteristics and stroke services as determinants of patient dissatisfaction with acute in-hospital care.

Methods—All 79 hospitals in Sweden admitting acute stroke patients participate in Riks-Stroke. During 2001 to 2007, 104 876 patients (87% of survivors) responded to a follow-up questionnaire 3 months after acute stroke; this included questions on satisfaction with various aspects of stroke care.

Results—The majority (>90%) were satisfied with acute in-hospital stroke care. Dissatisfaction was closely associated with outcome at 3 months. Patient who were dependent regarding activities of daily living, felt depressed, or had poor self-perceived general health were more likely to be dissatisfied. Dissatisfaction with global acute stroke care was linked to dissatisfaction with other aspects of care, including rehabilitation and support by community services. Patients treated in stroke units were less often dissatisfied than patients in general wards, as were patients who had been treated in a small hospital (vs medium or large hospitals) and patient who had participated in discharge planning. In multivariate analyses, the strongest predictor of dissatisfaction with acute care was poor outcome (dependency regarding activities of daily living, depressed mood, poor self-perceived health).

Conclusions—Dissatisfaction with in-hospital acute stroke care is part of a more extensive complex comprising poor functional outcome, depressive mood, poor self-perceived general health, and dissatisfaction not only with acute care but also with health care and social services at large. Several aspects of stroke care organization are associated with a lower risk of dissatisfaction. (Stroke. 2009;40:3851-3856.)

Key Words: acute stroke care ▪ patient satisfaction ▪ stroke outcome ▪ stroke services

Patient satisfaction with the care they receive is becoming an increasingly important component of health care quality. Dissatisfaction is an adverse outcome of care, sometimes leading to long-lasting frustration for both patients and health care staff. Dissatisfaction is linked to distrust in the health care staff or system, and patients who are discontent are less likely to comply with medical advice and medication.

Previous studies of possible determinants of stroke patient satisfaction/dissatisfaction have mainly focused on late phases after stroke. Emotional stress, depression, and unmet care demands have been found to be associated with dissatisfaction. A small Scottish prospective study on acute stroke care showed that most patients were satisfied and that they were more content with the care than their care givers were. Most dissatisfaction occurred in the areas of information and social advice.

What determines dissatisfaction with acute stroke care has not been explored. To what extent do patient characteristics and outcome contribute, and how much can be ascribed to health care structure and content? We have used data from Riks-Stroke, the national quality register for stroke care in Sweden, to explore determinants of dissatisfaction. The register covers all hospitals in the country admitting acute stroke patients. As in previous articles on the subject, this report on >100 000 patients focuses on patient dissatisfaction rather than satisfaction, because of the disproportionate impact dissatisfaction may have on patients and staff.

Patients and Methods

Riks-Stroke, the Swedish Stroke Register

Riks-Stroke, the Swedish Stroke Register, was initiated in 1994 with the primary aim to monitor and support improvement of quality of stroke care in Sweden. Details on the register and annual reports with open comparisons of processes and results between health care providers and hospitals are available at the Riks-Stroke website (http://www.riks-stroke.org). Riks-Stroke is funded by a grant from The National Board of Health and Welfare and The Swedish Association of Local Authorities and Regions. The register has been approved by the Regional Ethical Review Board at Umeå University and the data-handling procedures have been approved by the National Computer Data Inspection Board.

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3851
Eligibility and Recorded Items
Patients diagnosed with ischemic stroke (ICD-10 code I63), intracerebral hemorrhage (ICD-10 code I61), or unspecified acute cerebrovascular event (ICD-10 code I64) are eligible for registration in Riks-Stroke. Patients with subarachnoidal hemorrhages are not included.

Details on what information is collected in the acute phase of stroke are available at http://www.riks-stroke.org. Three months after stroke, the patients are contacted by staff at the hospital that they have been treated in and are asked to answer a questionnaire either by mail or by telephone. Information on the patients’ living arrangement, dependency in daily living (ADL), satisfaction with care, self-reported depression, and patient-perceived general health are included in this 3-month follow-up. In the follow-up questionnaire 3 months after stroke, the question, “How satisfied or dissatisfied are you with the care provided in hospital?,” had 5 fixed response alternatives (very satisfied, satisfied, dissatisfied, very dissatisfied, uncertain). Analogous questions with the same response alternatives were asked about specific aspects of stroke care, including personal treatment by staff, communication with doctors, information on the disease, rehabilitation, and community support after discharge.

For patients unable to respond themselves, family members or, if the patient was cared for in an institution, staff members were asked to complete the questionnaire.

Coverage and Validations
During the years 2001 to 2007, an average of 23 676 stroke events per year was recorded in the Riks-Stroke register. The coverage, ie, the proportion of acute stroke patients treated in hospital in Sweden that is included in Riks-Stroke, is estimated to be 82%. A detailed case-by-case validation of Riks-Stroke indicates that patients who died early, were not treated in a stroke unit, or were cared for in a nursing home were less likely than others to be included in the register.5,7 The participation rate in the 3-months follow-up has improved from 84.0% of stroke survivors in 2001 to 89.8% in 2007. Validations of the Riks-Stroke data have shown good consistency (>90%) for most items from information in the routine medical records and data entered into the Riks-Stroke database.8

Level of consciousness on admission to hospital is recorded using 3 levels based on the Reaction Level Scale 8,5 and has been validated in the Riks-Stroke setting (available at http://www.riks-stroke.org). Patients with Reaction Level Scale 1 are defined as alert, with Reaction Level Scale 2 to 3 are defined as drowsy, and with Reaction Level Scale 4 to 8 are defined as unconscious. The summarizing Riks-Stroke item ADL dependency (based on responses to 3 questions) has a 92% sensitivity and a 91% when compared with Barthel Index <90% and correlates well with modified Rankin score.9,10

The questionnaire at 3-month follow-up included the questions, “Do you feel depressed” and “How do you assess your general health condition?,” both with 4 fixed response alternatives and an “uncertain” alternative. In relation to Prime-MD, an established instrument to screen for depression,11 the Riks-Stroke assessment of depressive mood has a high specificity (100%) but a low sensitivity (38%).12

Statistical Analyses
To facilitate presentation of results, the responses were dichotomized into “satisfied” and “dissatisfied,” with uncertain responses remaining a separate category. In addition to univariate analyses, a multinomial regression model was applied to assess an association between the predictors and the response. Predictor variables were selected for the model if they had a plausible clinical relationship with the response. Multinomial regression was chosen because the categorical dependent outcome had 3 levels (satisfied, dissatisfied, and uncertain).

Results
Among the 104 876 patients included during the years 2001 to 2007, there were 55 074 (52.5%) men and 49 802 (47.5%) women. Mean age was 72.3 years in men and 76.4 years in women. A diagnosis of intracerebral hemorrhage was recorded in 9.5% of the patients, an ischemic stroke was recorded in 86.3%, and unspecified stroke was recorded in 4.2%. Nonresponders at the 3-month follow-up had the same mean age as responders but were more often ADL-dependent before the present stroke, had on average more severe strokes, and were more often discharged to an institution (Supplemental Table I, available online at http://stroke.ahajournals.org).

Table 1. Proportion of Patients Dissatisfied With In-hospital Acute Stroke Care in Relation to Patient Characteristics, Riks-Stroke Database 2001–2007

<table>
<thead>
<tr>
<th>Item*</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>P, Difference Within Each Item†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabitant, n=55 692</td>
<td>1479 (2.7%)</td>
<td>1549 (2.8%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, n=49 453</td>
<td>1457 (2.9%)</td>
<td>4745 (9.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, n=33 557</td>
<td>912 (2.7%)</td>
<td>2221 (6.6%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No, n=91 620</td>
<td>2112 (2.3%)</td>
<td>4527 (4.9%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
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<tr>
<td>Yes, n=17 353</td>
<td>501 (2.9%)</td>
<td>760 (4.4%)</td>
<td>&lt;0.0001</td>
<td></td>
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</tr>
<tr>
<td>No, n=94 194</td>
<td>2064 (2.2%)</td>
<td>5181 (5.5%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Level of consciousness on admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alert, n=96 664</td>
<td>2632 (2.8%)</td>
<td>5094 (5.3%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drowsy, n=8788</td>
<td>334 (3.8%)</td>
<td>1377 (15.7%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unconscious, 1454</td>
<td>62 (4.3%)</td>
<td>291 (20.0%)</td>
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<td></td>
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<tr>
<td>ADL function at 3 months after stroke</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Independent, n=80 074</td>
<td>1845 (2.3%)</td>
<td>1979 (2.5%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependent, n=23 404</td>
<td>1161 (4.3%)</td>
<td>4684 (18%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place of living 3 months after stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At home, married/cohabitant, n=55 692</td>
<td>1479 (2.7%)</td>
<td>1549 (2.8%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At home, alone, n=49 453</td>
<td>1457 (2.9%)</td>
<td>4745 (9.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In institution, n=19 186</td>
<td>797 (4.2%)</td>
<td>4574 (23.8%)</td>
<td></td>
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</tr>
</tbody>
</table>

*Data missing in <2% for each individual item except smoking. †Not including patients with “uncertain” as response.
Patients who had assistance when responding answered the questionnaire more often than others stated that they were dissatisfied with the care provided (Supplemental Table II, available online at http://stroke.ahajournals.org).

Time Trends

The proportion of patients who were dissatisfied with acute stroke care decreased slightly from 3.5% in 2001 to 2.8% in 2007 ($P<0.0001$). In parallel, the proportion stating that they were uncertain about satisfaction declined from 8.4% to 5.6%.

Associations to Patient Characteristics and Outcome

The proportion of patients expressing dissatisfaction with hospital stroke care was similar in women (2.9%) and men (2.8%), whereas the proportion of “uncertain” responses was higher among women (7.8% vs 5.2%; $P<0.0001$). The proportion of dissatisfied patients was relatively high (>5%) in patients younger than 35 years of age. It declined steadily with increasing age ($P<0.0001$; Figure 1). At older than age 80, the proportion of “uncertain” responses increased steeply, reflecting the fact that many elderly stroke patients responded by proxies.

In univariate analyses, level of consciousness on admission to hospital was strongly associated with satisfaction/dissatisfaction with care during the hospital stay (Table 1). Dissatisfaction also correlated strongly with outcome 3 months after stroke. Thus, patients who were dependent in primary ADL functions were twice as likely as independent patients to be dissatisfied with the care they had received in hospital, as were patients who were in institutional care compared to living at home (Table 1). Low mood and poor self-assessed health also had a strong relationship to dissatisfaction (Figure 2). Thus, the proportion of patients that were dissatisfied with care during the hospital stay increased from 1.6% in patients who never/almost never felt depressed to 11.3% higher in patients who stated that they always felt depressed. Similarly, the proportion of dissatisfied patients ranged from 1.3% (in patients who assessed their general health as very good) to 12.1% (very poor general health).

A multinomial logistic regression model was used to identify independent predictors of “dissatisfied” and “uncertain” responses. Several of the associations identified in univariate analyses were replicated (Table 2). Thus, among patient characteristics at stroke onset that emerged as inde-
dissatisfied patients (rs correlation between length of hospital stay and proportion of care if they had been admitted to a general ward rather than A higher proportion of patients were dissatisfied with their Associations to Stroke Care Structure dissatisfied with acute in-hospital care (Table 2). perceived were all, independent of each other, associated with ADL-dependent, feeling depressed, and having poor self-independent predictors of dissatisfaction were low age and living alone. Several indicators of poor outcome at 3 months after stroke emerged as strong predictors of dissatisfaction. Being ADL-dependent, feeling depressed, and having poor self-perceived were all, independent of each other, associated with dissatisfaction with acute in-hospital care (Table 2).

Associations to Stroke Care Structure

A higher proportion of patients who were dissatisfied with their care if they had been admitted to a general ward rather than to a dedicated stroke unit (Table 3). There was a very weak correlation between length of hospital stay and proportion of dissatisfied patients (r = 0.096).

If the patients experienced that they had participated actively in planning of treatment and rehabilitation after discharge, the likelihood of being dissatisfied was lower than if they had not participated (Table 3).

In the regression model with patient characteristics also included, being treated in a small vs a medium or large hospital was significantly associated a low proportion of dissatisfied patients. None of the other of the variables reflecting type of stroke services provided remained as being independently associated with dissatisfaction. However, the proportion of patients who responded “uncertain” was significantly lower among patients treated in a stroke unit vs other types of wards (Table 2).

Table 3. Proportion of Patients Dissatisfied With In-hospital Acute Stroke Care in Relation to Stroke Care Structure, Riks-Stroke Database 2001–2007

<table>
<thead>
<tr>
<th>Item*</th>
<th>N</th>
<th>Dissatisfied %</th>
<th>N</th>
<th>Uncertain %</th>
<th>P, Difference Within Each Item*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital size, N of stroke patients per year</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Large; ≥500, n=29 918</td>
<td>994 (2.7%)</td>
<td>2,151 (5.8%)</td>
<td>&lt;0.0001</td>
<td></td>
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</tr>
<tr>
<td>Medium; 300–499, n=32 415</td>
<td>983 (2.6%)</td>
<td>1,473 (3.9%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Small; &lt;300, n=42 521</td>
<td>979 (2.0%)</td>
<td>2,974 (6.1%)</td>
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<td></td>
</tr>
<tr>
<td>Treated in</td>
<td></td>
<td></td>
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<tr>
<td>Stroke unit, n=76 309</td>
<td>1,932 (2.5%)</td>
<td>4,527 (5.9%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General ward, n=14 486</td>
<td>516 (3.5%)</td>
<td>1,262 (8.7%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, n=14 081</td>
<td>504 (3.5%)</td>
<td>954 (6.7%)</td>
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<td></td>
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<tr>
<td>Follow-up within 3 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital out-patient clinic, n=13 903</td>
<td>244 (1.8%)</td>
<td>343 (2.5%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary health care, n=13 294</td>
<td>231 (1.7%)</td>
<td>529 (4.0%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None planned, n=21 096</td>
<td>642 (3.1%)</td>
<td>1,162 (5.5%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient participation in planning of treatment and rehabilitation after discharge†</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, n=32 242</td>
<td>742 (2.3%)</td>
<td>2,410 (7.5%)</td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No, n=4235</td>
<td>132 (3.1%)</td>
<td>417 (9.8%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*SNot including patients with “uncertain” as response. †Of patients who knew that they had been subject to structured planning.

Satisfaction With Global Acute Stroke Care in Relation to Satisfaction With Individual Components of Stroke Care
The main outcome variable in this article is global satisfaction with acute in-hospital stroke care. The Riks-Stroke follow-up questionnaire also includes questions on satisfaction with specific components of acute care and support after discharge from hospital.

Patients who were dissatisfied with global in-hospital stroke care were also more likely to be dissatisfied with individual aspects of stroke care, in as well as out of hospital. Thus, global dissatisfaction with acute care was closely linked to dissatisfaction with personal treatment by staff (Cronbach alpha=0.69), communication with doctors (0.62), information on the disease (0.63), rehabilitation (0.61), and community support after discharge (0.64). Community support after discharge was the most frequent single domain causing dissatisfaction (5% dissatisfied).

Discussion

This study shows that patient dissatisfaction with in-hospital care for acute stroke is closely related to poor functional outcome, low mood, and poor self-perceived general health at 3 months after stroke. In addition, organization of stroke services is of importance for patient satisfaction. Patients who have been treated in a large hospital, have not had access to stroke unit care, and have not had an outpatient follow-up after discharge are more likely to be dissatisfied with their care. Patients who are dissatisfied with acute stroke care are often also dissatisfied with rehabilitation and community support after discharge.

Limitations and Strengths

It has been shown that informal care givers of stroke patients are more likely than the patients themselves to be dissatisfied with acute stroke management and stroke rehabilitation. We chose to include also seriously affected patients to cover the entire spectrum of stroke severity. It should, however, be observed that the responses regarding the most disabled patients may have been influenced by the assisting persons.

Twenty-nine percent of the follow-up data were obtained by telephone and face-to-face interviews (Table 2). In some instances, the interviewer may have been involved in the acute care. This may have caused more positive responses than if there had been an independent interviewer.

The low proportion of patients who were dissatisfied with acute stroke care (2.7% in 2007) is consistent with the 3% dissatisfaction rate among patients hospitalized for acute stroke in Scotland. Questions on general satisfaction with health care may have a low sensitivity compared to comprehensive multidimensional instruments to measure patient satisfaction. The proportion of patients responding that they were uncertain about their satisfaction with in-hospital care was consistently 2- to 3-times higher than the proportion being straightforward about their dissatisfaction. “Uncertain” responses probably hide a considerable number of patients that are actually dissatisfied. With these considerations in mind, the absolute levels of dissatisfaction should be regarded with great caution. Instead, we have focused on relative
differences in the proportion of dissatisfied patients. For most variables, the multinomial logistic model showed good consistency regarding predictors of dissatisfaction vs uncertainty.

Previous descriptive and analytic studies of stroke patient satisfaction have been performed in acute hospital, rehabilitation hospital, and outpatient settings, sometimes using comprehensive and well-validated questionnaires or a qualitative research approach. The single question used as the main outcome variable in this study has not been tested for test–retest repeatability or other clinimetric characteristics. However, the very large numbers in Riks-Stroke serve to reduce the likelihood of chance findings by high intra-individual variability. With the large numbers, the problem is rather to sort out what differences that are meaningful to patients (and the health care system) among those who emerge as highly statistically significant. The response rate in this study (87%) is very high. For instance, in a large US nationwide survey of patients’ perception of hospital care, 36% of the patients who were invited to participate chose to do so.

Relation to Patient Characteristics
Our results indicate an improvement in patients’ perception of acute stroke care over time. This parallels the improvement in other quality indicators observed in Riks-Stroke both as to processes (adherence to recommendations in the Swedish national guidelines) and outcome, eg, proportion of ADL-independent patients 3 months after stroke (annual reports from Riks-Stroke).

Whether the patients are satisfied with the care they are provided is largely a result of the balance between expectations and the quality of care actually provided. In stroke rehabilitation, conflicting views between patients and the treating team about realistic aims are clearly associated with patient dissatisfaction. When Pound et al found that women and elderly people were more likely to express satisfaction with their care, they speculated that this may be attributable to low expectations. It is then interesting that, after adjustment for covariates, we found no major differences between men and women in Riks-Stroke (and this study).

Our observation that the proportion of dissatisfied patients declines with age is consistent with one but not the other of the previous 2 stroke studies that were large enough to analyze the relationship with age. At ages older than 80 years, the low proportion of patients expressing dissatisfaction may be ascribed to a high proportion of “uncertain” responses, conceivably attributable to cognitive impairments (and thus a high proportion of responses by proxies) and ambivalence accompanying depressive mood.

ADL function at 3 months was strongly linked to satisfaction with in-hospital care. The association with functional outcome has been evident in some but not all previous studies on patient satisfaction with stroke care. Our results also indicate that depressive mood and poor self-perceived general health 3 months after stroke are, independent of each other and independent of ADL function, strong predictors of dissatisfaction. This is in line with a previous observation on an impact of emotional distress and depressive mood. The very strong association with mood in the present study (Figure 2) was possibly an effect of a high specificity but low sensitivity for depression of the single question on depressive mood used in the Riks-Stroke follow-up questionnaire.

Relations to Organization of Stroke Services and Processes
In univariate analyses, patients treated in dedicated stroke units were less likely to be dissatisfied (and to be uncertain) than patients treated in general wards or other types of wards. This is in agreement with results from a randomized controlled trial and a national stroke audit, both performed in the UK. Greater patient satisfaction should be added to the list of benefits provided by stroke unit care.

In multivariate analyses that included adjustments for differences in stroke outcome at 3 months, the associations with stroke units and outpatient follow-up no longer remained significant. It should, however, be noted that multiple logistic regression models may underestimate the effects of individual predictors when they are correlated. Stroke unit care is associated with improved functional outcome and adjustment for outcome may result in underestimates of the actual effect of stroke unit care (downward bias attributable to over-adjustment). Along the same line of reasoning, because discharge planning and structured follow-up after discharge are often parts of the stroke unit concept, their effects may be underestimated in a regression model. Therefore, information emerging from univariate analyses on the effects of different types of stroke services on patient satisfaction should also be regarded as relevant.

Both in univariate and multivariate analyses, dissatisfaction with acute care was significantly less common in patients treated in small rather than medium or large hospitals. This is an observation that is not unique to stroke care. For instance, in a recent survey of 4000 hospitals in the United States, patients treated in small hospitals more often rated their global satisfaction as high compared with patients in treated in larger hospitals.

Clinical Implications
A major finding of this study is that the great majority of stroke patients are satisfied with the acute in-hospital care they receive. In the minority of patients who are dissatisfied, our results support the contention that dissatisfaction with in-hospital acute stroke care is only a part of a more extensive complex comprising depressive mood, poor self-conceived general health, and dissatisfaction with health care and social services at large. It may be that, in many patients, poststroke depression is a significant component of this complex. If this is so, then early detection and successful treatment of depression could help to alleviate patients’ dissatisfaction with stroke care. Because patient dissatisfaction is closely associated with poor functional outcome, successful early functional rehabilitation is also likely to reduce patient dissatisfaction after stroke.

We also emphasize that health care professionals and decision-makers have important tasks to improve patient–staff communication, competence, structures, and processes to lessen the risk for the patient being dissatisfied with the care that is provided. We highlight the potential for reducing patient dissatisfaction by structural measures, such as access
to care in a stroke unit, patient involvement in discharge planning, and systematic follow-up after discharge.

Disclosures
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