Mobile Phone–Based Questionnaire for Assessing 3 Months Modified Rankin Score After Acute Stroke
A Pilot Study

Charith Cooray, MD; Marius Matusevicius; Nils Wahlgren, MD, PhD; Niaz Ahmed, MD, PhD

Background—In many countries, a majority of stroke patients are not assessed for long-term functional outcome owing to limited resources and time. We investigated whether automatic assessment of the modified Rankin Scale (mRS) based on a mobile phone questionnaire may serve as an alternative to mRS assessments at clinical visits after stroke.

Methods and Results—We enrolled 62 acute stroke patients admitted to our stroke unit during March to May 2014. Forty-eight patients completed the study. During the stay, patients and/or caregivers were equipped with a mobile phone application in their personal mobile phones. The mobile phone application contained a set of 20 questions, based on the Rankin Focused Assessment, which we previously tested in a pilot study. Three months after inclusion, the mobile phone application automatically prompted the study participants to answer the mRS questionnaire in the mobile phones. Each question or a group of questions in the questionnaire corresponded to a certain mRS score. Using a predefined protocol, the highest mRS score question where the study participant had answered yes was deemed the final mobile mRS score.

A few days later, a study personnel performed a clinical visit mRS assessment. The 2 assessments were compared using quadratic weighing κ-statistics. Mean age was 67 years (38% females), and median baseline National Institutes of Health Stroke Scale (NIHSS) score was 5 (interquartile range 2–10.5, range 0–23). Median and mean clinical visit mRS at 3 months was 2 and 2.3, respectively. We found a 62.5% agreement between clinical visit and mobile mRS assessment, weighted kappa 0.89 (95% confidence interval 0.82–0.96), and unweighted kappa 0.53 (95% confidence interval 0.36–0.70). Dichotomized mRS outcome separating functionally independent (mRS score 0–2) from dependent (mRS score 3–5) showed 83% agreement and unweighted kappa of 0.66 (95% confidence interval 0.45–0.87).

Conclusions—Mobile phone–based automatic assessments of mRS performed well in comparison with clinical visit mRS and could be used as an alternative in stroke follow-up. 

Key Words: cell phones ■ outcomes research ■ prediction ■ questionnaires ■ stroke

The modified Rankin Scale (mRS) has evolved to become the most widely used primary outcome measure of functional level among stroke patients in clinical stroke trials and long-term routine clinical follow-up. Unfortunately, a majority of stroke patients are not assessed within 3 months by clinical visit mRS in many countries, including Sweden, because of limited resources and time. As a result, long-term routine clinical follow-up data are lacking for many stroke patients.

In contemporary trials and studies, the mRS assessment has been performed in various ways, the main distinction being an unstructured interview versus a structured approach. The Rankin Focused Assessment (RFA) developed by Saver et al is a structured form of the mRS assessment that is brief, practical, and reduces inter-rater variability. We have selected RFA as the base of the mobile phone questionnaire assessed in the present study.

To our knowledge, the role of mobile phone–based questionnaires generating automatic mRS scores without the need to adjudicate healthcare professionals in the assessment of mRS has previously not been tested after acute stroke. Other alternatives to the clinical visit face-to-face interviews, such as telephone-based mRS assessments and postal questionnaires, have been evaluated with mixed results.

We aim to investigate whether automatic assessment of the mRS based on a mobile phone questionnaire may serve an alternative to mRS assessments at clinical visits after stroke.

Methods
Assessment Tool Construction
The RFA formed the basis for the set of questions that were included in the mobile phone application (MA; 5.2 MB). The 20 questions included in the original RFA description were translated into Swedish and incorporated into the MA (see Data Supplement for...
WHAT IS KNOWN

- The modified Rankin Scale is the most widely used instrument for long-term follow-up of patients after acute stroke.
- Normally, modified Rankin Scale is assessed at a clinical visit or by a telephone interview; however, a large number of stroke patients are not assessed for long-term functional outcome owing to limited resources and time.

WHAT THE STUDY ADDS

- This is the first time a mobile phone application has been evaluated for self-assessment of functional outcome after acute stroke.
- Excellent concordance is seen between clinical in-office assessments by healthcare personnel and mobile phone–based self-assessments.
- The findings suggest the possibility of using the inexpensive mobile phone–based automatic assessment as a new supplementary method for follow-up of acute stroke patients, especially when resources are limited.

English translation of the questions). Where necessary, questions were truncated because of space limitations (100 characters/question) in the MA. The MA, registered name Medipal, has previously been used successfully in nonstroke healthcare mobile phone follow-up studies, and the ease of use of the application has been previously evaluated with positive results. A medical IT company located in Stockholm, Novatelligence, created Medipal. The application was available for the main types of smartphones (Iphone and Android), thereby encompassing a majority of the smartphone types used in Sweden. The questionnaire consists of 20 yes/no questions regarding specific functional items in 5 sections: (1) constant care, (2) basic activities of daily living, (3) instrumental activities of daily living, (4) limitations in participation in usual social roles, and (5) presence of common stroke symptoms. All these 20 questions (4) were added to the MA. Before the present study, a smaller feasibility study with 20 stroke patients was performed with a shorter follow-up time of 6 weeks, indicating good performance, both technically and practically, of the current study design.

Study Size, Population, and Protocol

We did not conduct a formal sample size estimation; however, we decided to collect a total of 50 patients because a systematic review of mRS reliability studies showed a median population size of 47 in previously conducted studies. A flow diagram showing the study population can be seen in Figure. Acute stroke patients (ICD code I61=hemorrhagic and I63=ischemic) admitted to the stroke unit at the Karolinska University Hospital–Solna during the period March to May 2014 were consecutively offered participation in the study, regardless of acute interventions or stroke severity. All acute stroke patients were screened during regular working hours (08.00–17.00) and informed about the study, offered participation, and if included, the MA was installed on the patient’s personal mobile phones. The following inclusion criteria were used:

1. Clinical signs and symptoms concurring with a diagnosis of acute stroke.
2. The patient and/or a close relative/caregiver had an available compatible mobile phone.

3. The patient received an ICD diagnosis of either I61 (hemorrhagic) or I63 (ischemic) at discharge.

The following exclusion criteria were used:

1. Clinical signs and symptoms concurring with a diagnosis of transient ischemic attack.
2. Neither the patient nor a close relative/caregiver had an available compatible mobile phone.

In cases where the patients could not participate themselves, either because of lacking a compatible mobile phone, because of not being able to reliably handle such a device, or because of cognitive symptoms, we included a close relative/caregiver who would answer in the patient’s place. The proxy was only included if the patient and proxy had regular contact, deemed at least weekly, and the proxy had a good insight into the patient’s prestroke functional level and would continue having regular contact with the patient. To maximize response, when possible, we included one such close relative/caregiver in addition to the patient themselves as a safety precaution in case the patient would not answer the questions at follow-up. All study participants were equipped with an instruction sheet containing detailed instructions on how to answer the mobile phone–based mRS questionnaire. During the follow-up period, the study participants were reminded about participation in the study through automatic monthly messages in MA. No instructions were given regarding the questions to be answered in the MA, apart from the written instructions sheet.

Within a week after answering the questionnaire, an mRS-certified study personnel who was blinded to the participants’ own ratings rated the patients with a clinical visit mRS assessment. This assessment was performed in 2 parts. The first part consisted of a conventional unstructured interview followed by a second part, where the RFA questionnaire was used in a standard structured manner. An overall assessment of the interview taking into account both parts of the interview was done, and the patients assigned an mRS score by the first rater. The entire interview was filmed and subsequently judged by a second study personnel who was also blinded to the patient’s own rating. The second rater assigned an mRS score according to the same procedure as described for rater 1. The second rater, however, also
rated the 2 parts of the interview separately, generating scores for the 2 parts of the interview separately in addition to an overall interview score. In cases where the first 2 raters ranked the patient differently on the overall interview, a third study personnel viewed the footage, and in collaboration with the first 2 raters, a final score was assigned. Participants’ mobile phone–based questionnaire responses were translated to an mRS score using a predefined protocol. Each question in the questionnaire corresponded to a certain mRS score, starting with the question differentiating between mRS scores 5 and 4, the second question differentiating between mRS scores 4 and 3, questions 3 to 7 for differentiating between mRS scores 3 and 2, questions 8 to 11 for differentiating between mRS scores 2 and 1, and questions 12 to 20 for differentiating between mRS scores 1 and 0. The first question needed to be answered to answer the second question and so on. The entire questionnaire needed to be completed to send in the response. The highest mRS score question where the study participant had answered yes was deemed the final mobile mRS score. In cases where both patient and relative/caregiver sent in MA responses and 2 different mRS scores were obtained for a certain patient, patient scores were used in the subsequent statistical analysis. During the study period, no technical problems were reported, and responses from the study participants were received smoothly after encryption and stored securely in a database. The mobile phone questionnaire responses were first opened after final adjudication of the clinical visit assessment score.

Standard Protocol Approvals, Registrations, and Patient Consents

The local ethics committee at Karolinska Institutet, Stockholm, Sweden, approved the project, including collection of study participants, follow-up, data handling, and analysis. Written informed consent was obtained from all patients. In cases where the patient could not leave informed consent, patients were included after consent given by a close relative or caregiver. In cases where a relative/caregiver participated in the study, informed consent was also required from them.

Statistical Analysis

The main outcome measure was the weighted kappa score (quadratic) for the whole spectrum of the mRS scores (0–5), assigning lower weights to higher discrepancies compared to lesser discrepancies. The quadratic kappa uses a square function to assign the specific weights and has previously been used in the literature.10 The unweighted kappa score was also calculated. In addition, unweighted kappa scores were calculated for various dichotomizations of the mRS. Following standard protocol, a kappa of 0 to 0.2 was considered poor, 0.21 to 0.4 fair, 0.41 to 0.6 moderate, 0.61 to 0.8 good, and 0.81 to 1.00 excellent.11 Percentage agreement was calculated as well.

mRS Concordance Over the Entire Range of Scores

Overall Interview Assessment

In 30 out of 48 patients (mean age 65, 40% females, median baseline NIHSS score 4, IQR 2–13.5), the mRS scores concurred perfectly (total agreement 62.5%). Of the remaining 18 patients, scores differed by 1 level in 16 patients and by 2 levels in 2 patients (mean age 70, 33.3% females, median baseline NIHSS score 7.5, IQR 1.5–9.5). A cross tabulation of the paired ratings is shown in Table 2. The weighted kappa was 0.89 (95% confidence interval 0.82–0.96), and the unweighted kappa was 0.53 (95% confidence interval 0.36–0.70).

Structured Interview

When using the structured RFA judgment, the results were similar to the overall rating (see Table 1).

mRS Concordance Over the Entire Range of Scores, Including the Deceased Patients

In an additional analysis including the 3 deceased patients and assigning them mRS scores 6 in the comparative analysis, the concordance was similar to the overall rating without deceased patients (see Table 1).

mRS Concordance for a Dichotomized Outcome

Overall Interview Assessment

The percentage agreement for the dichotomization separating independent from dependent functional level (mRS 0–2 versus 3–5) was 83.3%, and unweighted kappa score was 0.66 (0.45 to 0.87). Table 3 shows the percentage agreement and kappa score for all possible dichotomizations of the mRS score.

Table 1. Overall and Structured Assessment Versus Mobile Phone Application (MA)

<table>
<thead>
<tr>
<th>Overall Clinical Assessment vs MA</th>
<th>Structured Assessment vs MA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage Agreement</td>
<td>Weighted Kappa</td>
</tr>
<tr>
<td>Entire range of scores (0–5), excluding dead patients</td>
<td>62.5%</td>
</tr>
<tr>
<td>Entire range of scores (0–6), including dead patients</td>
<td>64.7%</td>
</tr>
<tr>
<td>mRS 0–2 vs 3–5</td>
<td>83.3%</td>
</tr>
<tr>
<td>Patient vs MA</td>
<td>72.7%</td>
</tr>
<tr>
<td>Caregiver vs MA</td>
<td>59.4%</td>
</tr>
</tbody>
</table>

mRS indicates modified Rankin Scale.
Mobile phone–based assessment automatically can be converted into an mRS score without the need for score judgment by a healthcare professional. When analyzing score concordance on an exact score level, our study results are in line with previously conducted studies on mRS rater reliability comparing ratings between healthcare professionals.12,13 It is important to note that our study compares patient/caregiver response assessment with healthcare professionals and cannot directly be compared with previous studies, where assessments have been conducted solely by trained study personal. Excellent agreement is seen for exact score level when analyzing weighted kappa. For the dichotomized analysis separating independent (mRS score 0–2) from dependent functional outcome (mRS score 3–5), we found a good inter-rater variability kappa (0.66). Results were similar comparing the patient/caregiver MA assessment with both the structured interview assessment as well as with the overall interview assessment. Agreement between the 2 clinical raters in the study was excellent, with a weighted kappa of 0.95. For separating excellent outcome defined as mRS score 0–1 versus mRS score 2–5, we found a good kappa score (0.72). For separating mRS score 0–3 versus 4–5, we found an excellent inter-rater variability kappa (0.88). The clinical rationale for using dichotomized outcomes with higher functional deficits as thresholds (mRS threshold 3 or 4) is relevant because hemispherectomies14 and thrombectomy trials15 with severe stroke use these mRS cut offs.

A systematic review on the reliability of the mRS,10 based on 10 studies involving 587 patients, showed an overall inter-rater variability of 0.46 (unweighted kappa) and weighted kappa 0.90 for a traditional mRS assessment over the entire range of scores. Our results, comparing patient and/or caregiver assessments with clinical visit mRS assessments, indicate better inter-rater variability than the combined results from the systematic review.

Alternatives to clinical visit face-to-face interviews for assessing poststroke mRS, such as postal questionnaires and telephone interviews versus face-to-face interviews, have been tested previously.5–7,16 Two of these studies5,16 regarding telephone interviews, showed good results, with weighted kappa results of 0.71 (unweighted kappa 0.41) and 0.82 (unweighted kappa not stated). The third telephone interview study6 demonstrated poorer results, with an unweighted kappa of 0.30 to 0.38 comparing telephone assessments with face-to-face interviews. Most importantly, in these studies, the alternative telephone assessment approach was performed by trained personnel. Postal questionnaires have been widely used in clinical trials, and in one study, a good inter-rater variability was seen when comparing postal questionnaire assessments with telephone assessments.7 However, to our knowledge, postal assessments with mRS scores.

### Table 2. Cross Tabulation of Paired Ratings

<table>
<thead>
<tr>
<th>Clinician Assessment Score (mRS)</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile phone–based assessment score (mRS)</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>1</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

mRS indicates modified Rankin Scale.

### Structured Interview

When using the structured RFA judgment, the concordance was similar to the overall interview assessment.

### mRS Concordance Over the Entire Range of Scores Separating Patient Answers From Caregiver Answers

#### Overall Interview Assessment

In total, 32 responses were collected from caregivers (median NIHSS 7.5, IQR 4–16) and 22 responses from the patients themselves (median NIHSS 2, IQR 0–4). 6 of these also had responses from the respective caregiver. The percentage agreement for the caregiver responses was 59.4%, weighted kappa 0.86 (0.76–0.96), and unweighted kappa 0.51 (0.30–0.71). The percentage agreement for the patient responses was 72.7%, weighted kappa 0.82 (0.70–0.94), and unweighted kappa 0.59 (0.33–0.85).

#### Structured Interview

The concordance for caregiver and patient responses analyzed separately were similar compared with the overall interview assessment (see Table 1).

### mRS Concordance Between Rater of the Clinical Visit mRS Assessment and Subsequent Rater of Video Footage

The percent agreement between the 2 raters was 79% (38/48), weighted kappa 0.95 (95% confidence interval 0.92–0.99), and unweighted kappa 0.74 (95% confidence interval 0.59–0.88).

### Discussion

To our knowledge, no study has been published to date aiming at investigating the assessment of mRS using mobile phone technology. Our study for the first time shows a role of mobile phone–based questionnaires for automatic assessment of mRS after stroke, which performed good to excellent compared with clinical visit mRS assessments. This is an important knowledge because routine follow-up after stroke is lacking in many countries, and this type of assessment may be used as an alternative to clinical in-office interviews, which may be difficult for patients or healthcare personal because of administrative barriers, traveling difficulties, resource limitations, or economic factors. Additionally, this novel form of assessment requires practically no time or resource allocation from the healthcare system because the patient/caregiver responses automatically can be converted into an mRS score without the

### Table 3. Percentage Agreement and Kappa for Different Dichotomizations of mRS

<table>
<thead>
<tr>
<th>mRS Cutpoint</th>
<th>Percentage Agreement</th>
<th>Kappa</th>
<th>Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–1 vs 2–5</td>
<td>87.5%</td>
<td>0.72</td>
<td>Good</td>
</tr>
<tr>
<td>0–2 vs 3–5</td>
<td>83.3%</td>
<td>0.66</td>
<td>Moderate</td>
</tr>
<tr>
<td>0–3 vs 4–5</td>
<td>95.8%</td>
<td>0.88</td>
<td>Excellent</td>
</tr>
<tr>
<td>0–4 vs 5</td>
<td>95.8%</td>
<td>0.83</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

mRS indicates modified Rankin Scale.
assessments have not been validated against clinical visit face-to-face interviews, despite their wide use. Our alternative assessment, a mobile phone–based questionnaire answered by either the patient themselves or a close relative/caregiver, with the response automatically translated into an mRS rating, resulted in an excellent weighted kappa value of 0.89 when compared with clinical visit face-to-face interviews. Note that in the present study, the mRS scores based on the answers in the mobile phone questionnaire were assessed manually; however, the translation from questionnaire to mRS score is extremely straightforward and could easily be automatized. Only 15 out of totally 89 patients (17%) could not participate in the study because of lacking access to a compatible mobile phone, suggesting a high penetration of compatible mobile phone use in the general Swedish population, in all age groups.

Our study has certain limitations. The analysis is based on answers from patients in some cases and from close relatives/caregivers in other cases. This variability could potentially affect the interpretation of results. Patients participating and answering by themselves were younger (55 versus 73) and had milder strokes (median NIHSS 2 versus 7.5) compared with answers received from caregivers, illustrating the greater need of proxy assistance in the case of older and sicker stroke survivors. However, this in fact reflects the real-life clinical situation. Older patients and patients with moderately severe strokes may have difficulties using mobile phones during the acute phase, either because of unfamiliarity with the electronic devices or because of physical/cognitive barriers, and our results clearly illustrate the need of using the proxy option to maximize follow-up data. Nonetheless, kappa values for the caregiver and patient responses analyzed separately were similar and therefore suggest the feasibility of using caregiver responses as a proxy for patient responses. In certain cases, it would be more suitable to use the caregiver response rather than the patient response because the latter sometimes would not be reliable (eg, for patients with anosognosia, impressive dysphasia). These decisions need to be made individually for each patient in the acute setting. Using help from close relatives or caregivers ensured that all willing patients were able to be included and maximized our follow-up data. Even in clinical follow-up, assessments of mRS information is often needed from caregivers, especially in the case of severely affected stroke patients. Eleven patients dropped off during the study period, the missing outcome data potentially affecting the main results; however, a sensitivity analysis using multiple imputation showed only a marginal change in both the weighted and unweighted kappa for the main analysis when imputing outcome data for the missing patients.

Another limitation is that the study is single center and consists of a relatively small study cohort. Important to note, however, is that our study cohort is of equal size to the median of several previously conducted studies on mRS inter-rater variability. We did not perform a formal power calculation for estimating the required sample size, but the results of our study are interesting and should lead way to further expanded studies, including larger groups of patients from a multicenter setting.

The mobile application has room for certain improvement. Our mobile application did not include an option for score of deceased patients (score 6), which is standard for the mRS score, and in its present form used information from patients in first hand and from caregivers in cases where patients did not answer, whereas the standard RFA assessment on which the MA is based encourages use of multiple information sources, including the patient, family/caregivers, direct assessment by physical examination, and the medical record. Some of these issues may easily be overcome if we incorporate the question whether patients are Alive as a first question and encourage that the mobile application questionnaire be answered together with a relative or caregiver (in an additional analysis, including the deceased patients, the results as expected improved).

Conclusions

Novel automatic mobile phone–based questionnaire assessments of mRS at 3 months after acute stroke performed good to excellent in this study in comparison with clinical visit physician-based mRS assessments. These findings imply that mobile phone–based questionnaires with subsequent automatic mRS assessment may serve a supplementary role to clinical visit assessments, especially in settings where clinical visit follow-up assessments are scarce because of economic and time-restricting factors.

Acknowledgments

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Disclosures

Dr Wahlgren has received expenses from Boehringer Ingelheim for his role as member of the Steering Committee in relation to the European Cooperative Acute Stroke Study III trial with alteplase and served as a consultant to Thrombogenics as chairman of the Data and Safety Monitoring Board. Safe Implementation of Treatments in Stroke International (chaired by Dr Wahlgren) received a grant from Boehringer Ingelheim and Ferrer for the SITS Monitoring Study/The SITS International Stroke Thrombolysis Register. His institution has also received grant support toward administrative expenses for coordination of the European Cooperative Acute Stroke Study III trial. Dr Wahlgren has also received lecture fees from Boehringer Ingelheim and Ferrer. Dr Ahmed is an employee of Safe Implementation of Treatments in Stroke International, which received a grant from Boehringer Ingelheim and Ferrer for the SITS Monitoring Study/The SITS International Stroke Thrombolysis Register. The other authors report no conflict.

References


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MA questions (Yes/No options)

1) Is the person bedridden or restricted to a wheelchair, unable to self-propel without assistance?
2) Is another person’s assistance essential for walking?
3) Is assistance absolutely essential for preparing a simple meal?
4) Is assistance absolutely essential for basic household chores?
5) Is assistance absolutely essential for looking after household expenses?
6) Is assistance absolutely essential for driving a car, for public transport or for ordering and using a cab?
7) Is assistance absolutely essential for local shopping?
8) Has the new stroke substantially reduced the person’s ability to work or study?
9) Has the new stroke substantially reduced the person’s ability to look after family?
10) Has the new stroke substantially reduced the person’s regular free-time activities by more than one half as often?
11) Are the patient’s work, family, and/or social/leisure activities reduced by any other reason than the new stroke?
12) Does the patient have any symptoms resulting from the new stroke?
13) Does the person have difficulty reading or writing as a result of the new stroke?
14) Does the person have difficulty speaking or finding the right word as a result of the new stroke?
15) Does the person have problems with balance or coordination as a result of the new stroke?
16) Does the person have visual problems as a result of the new stroke?
17) Does the person have numbness in any body-part as a result of the new stroke?
18) Does the person have weakness or loss of movement of any body-part as a result of the new stroke?
19) Does the person have difficulty with swallowing as a result of the new stroke?
20) Does the person have any other symptoms related to the new stroke?