Evaluation of Measures Used to Assess Quality of Life After Stroke

Deborah Buck, BA; Ann Jacoby, PhD; Anna Massey, BSc; Gary Ford, FRCP

Background and Purpose—Assessment of quality of life (QOL) after stroke is becoming common with the recognition that evaluation of treatment should include quality as well as quantity of survival. This article will outline the main conceptual and methodological issues in QOL assessment, highlight advantages and disadvantages of measures used in stroke QOL research, and discuss some unresolved issues.

Summary of Review—We undertook a MEDLINE search using the keywords “stroke” and “quality of life” and reviewed 3 key texts on QOL measurement in stroke. Fifteen generic and 10 condition-specific measures used to assess QOL in stroke were identified and evaluated with the following criteria: reliability, validity, responsiveness, precision, acceptability, suitability for proxy respondents, mode of administration, and use of patient-centered approaches in development. Domains covered and level of comprehensiveness varied widely between generic and stroke-specific measures. No stroke-specific instruments used patient-centered approaches in their development. Four stroke-specific measures (Frenchay Activities Index, Niemi QOL scale, Ferrans and Powers QOL Index–Stroke Version, and Stroke-Adapted Sickness Impact Profile [SA-SIP30]) provided evidence of reliability and validity.

Conclusions—The need remains for a patient-centered, psychometrically robust, stroke-specific QOL measure. Patients should be involved in each stage of instrument development. Caution is needed in the selection of an instrument to measure QOL after stroke. Although the Ferrans and Powers QOL Index–Stroke Version, Niemi QOL scale, SA-SIP30, and Sickness Impact Profile come closest to satisfying many of the criteria outlined in this article, the selection of any individual instrument depends on the specific goals and constraints of a particular study. (Stroke. 2000;31:2004-2010.)

Key Words: England ■ psychometrics ■ quality of life ■ stroke outcome

Assessment of quality of life (QOL) in stroke is becoming increasingly common. In this article, we evaluate outcome measures that have been used in stroke QOL research, updating a review by de Haan and colleagues in 1993.1 This takes into account further developments in the area and the increasing need in pharmacological intervention studies for a robust QOL measure. We discuss factors to be considered when QOL measures for stroke are selected on the basis of these evaluations, highlighting some important unresolved issues. We begin with a summary of some of the main conceptual and methodological issues in QOL assessment.

Conceptual Issues in QOL

Impairment, Disability, Handicap, and QOL

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published in 1980.2 It illustrates how disease can engender impairment, defined as a loss or abnormality of psychological, physiological, or anatomic structure or function. Impairment in turn may lead to disability, defined as a restriction or inability to perform an activity in a way considered normal for a human being. Handicap may arise either directly owing to impairments or because of disability after interaction with the physical or social environment. Handicap is defined as a disadvantage that restricts or prevents the performance of a role deemed normal.

QOL is said to lie beyond the disease-handicap continuum.3 Although the ICIDH offers an important theoretical perspective, it neglects wider QOL issues. Although handicap is the most relevant clinical outcome for patients and impairment the least relevant, QOL may be even more pertinent from the patient’s point of view.4

Definitions of QOL

Consensus about the definition of QOL has yet to be reached, but most researchers believe it is multidimensional,5–7 comprising 3 broad “domains”: physical, mental, and social. QOL has recently been defined by the World Health Organization Quality of Life (WHOQOL) Group as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”8

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The Importance of Measuring QOL

There is general agreement that the effects of treatment should be measured in terms of quality as well as quantity of survival. Medical advances may prolong life, but it is important to know the nature of that further life. Without an assessment of QOL, a treatment may be deemed successful despite poor psychosocial functioning or adjustment to illness. For instance, stroke patients who are fully independent according to Barthel Index scores may nevertheless experience limitations in areas such as employment and leisure activities or in emotional adjustment. Alternatively, a treatment beneficial to psychosocial status may be rejected because it fails to improve physical functioning. Medical interventions may be beneficial to patients on impairment or disability measures, but without equally refined QOL measurements, a clear and comprehensive evaluation of their efficacy is not possible. The recent development of thrombolytic and neuroprotective therapies has highlighted the urgent need for improved outcome measures for stroke, including QOL measures.

Methodological Challenges to Assessing QOL

A recent UK National Health Service (NHS) Research and Development Health Technology Assessment (HTA) recommends that a number of criteria should be considered when outcome measures are chosen. These criteria are reliability, validity, responsiveness to change over time, precision, appropriateness, and acceptability.

Reliability and Validity

Evidence of reliability and validity is vital for QOL measures, as with any outcome measures, to ensure confidence in their scientific robustness. Reliability is the extent to which measurements for the same individual on separate occasions or by different observers produce similar results. Validity is the extent to which an instrument measures what it is meant to measure. One of the most meaningful indications of validity is the extent to which the relevant patient group was involved in generating the content of a measure. Thus, the determination of crucial domains for specific conditions should be through patient-centered methods. For stroke, Duncan and colleagues in the United States recently found that 8 key areas (strength, hand function, activities of daily living, mobility, communication, memory, emotion, and social participation) emerged as the key areas from the patient’s perspective. Similarly, Williams et al. reported that patients identified 12 key domains (mobility, energy, upper-extremity function, work/productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality).

Responsiveness of a Measure

Depending on the requirement of the study, a responsive QOL measure may be needed. Such a measure will be able to detect even small differences within an individual over time. Use of unresponsive measures in intervention studies (for example, those concerned with within-patient differences over time) would fail to detect whether such changes had occurred, thus resulting in misleading findings.

Precision

Precision is concerned with the number and accuracy of distinctions made by a measure, that is, precision of response categories or of numerical values. Also important to precision is the capacity of a measure to report the most favorable or poorest health states (in other words, the extent of floor and ceiling effects).

Appropriateness

In the evaluation of outcome measures for use in clinical trials, the HTA report emphasizes that any measure used should match the specific purpose and questions of the trial. Similarly, the content of a measure used to assess QOL in stroke should reflect the aims of the study and consider the nature of the patient group.

Acceptability

Acceptability and average completion times need to be considered in any outcome measure but especially for use in stroke given the potential cognitive problems and feelings of tiredness that may be experienced after stroke. Previous response rates (to the measure overall and to individual items) should also be examined. However, acceptability of a measure is best determined by pretesting with patients in terms of wording, response options, and general layout.

In addition to the above criteria recommended in the HTA report, a number of other issues of particular relevance to stroke populations should be addressed: suitability of a measure for use with proxy respondents, intended mode of administration of the measure, and whether the measure is generic or stroke specific.

Proxy Respondents

Use of proxies (asking a relative or close friend to answer questions as he or she believes the patient would) is important given the difficulties that some people with stroke may have in communicating or understanding research questions. The use of proxies where necessary may be preferable to excluding more severe cases from trials, particularly because such individuals are likely to have a markedly reduced QOL.

Mode of Administration: Self- Versus Interviewer-Administered

Self-administered measures tend to be less resource intensive than interviewer-administered measures. However, physical difficulties that limit ability to complete a questionnaire or cognitive or linguistic problems that affect concentration or understanding may render self-completion an arduous if not impossible task for some people. Interviewer-administered questionnaires may also be problematic to apply, because some stroke patients will be unable to respond in an interview setting owing to speech problems. Thus, given the range of impairments often experienced after stroke, it is important to establish whether a QOL measure can be both self- and interviewer-administered.

Generic Versus Condition-Specific Measures

In generic QOL measures, certain domains will be key for all patient groups, but there may also be an absence of areas that
are specific to a particular condition. Although generic measures enable comparisons between groups with a diverse range of illnesses, they cannot focus on the problems of a specific condition and may not be sensitive to important changes in QOL.

**Review of Outcome Measures Used in Stroke**

A MEDLINE search and a review of 3 key texts identified 15 generic measures used in stroke QOL research and 10 condition-specific measures (although not all were stroke specific). The MEDLINE search was undertaken in October 1999 using the keywords “stroke” and “quality of life.” No limit was put on the year of publication, but published language was limited to English only. This generated 351 articles. However, many of these were not relevant for the purposes of the present article, mainly because the article was not primarily about stroke. Thus, a total of 49 articles were consulted for the evaluation exercise. (A full list of the relevant articles consulted is available from the authors on request.) This evaluation was not intended as a full systematic review but rather to demonstrate the variety of measures used in the assessment of QOL after stroke.

The identified measures were evaluated in terms of criteria recommended by the UK HTA report. We have included additional evaluation criteria that are important for stroke populations (suitability for use with proxy respondents and mode of administration), as outlined above. Given the essential differences between generic and condition-specific measures, as highlighted earlier, we evaluated each type separately. Two of the present authors undertook independent evaluations of the measures identified. There were few discrepancies, but when they arose, the issue was discussed and agreement achieved between the evaluators.

### Results

**Generic Measures**

Nine of the 15 generic measures or approaches identified were used to measure poststroke QOL in only a single study and/or they tapped only 1 domain of QOL (Karnofsky Performance Status Scale, Life Satisfaction Index Nottingham version, Geriatric QOL Questionnaire, Functional Life Scale, Hospital Anxiety and Depression scale, and various utility approaches [visual analogue scale, standard gamble technique, time trade-off, and global scale]). Moreover, little information is available about their psychometric and other properties. Unlike standardized, indirect measures of utility such as the EuroQol, London Handicap Scale (LHS), and Health Utilities Index (HUI), the other utility measures are direct measures of personal preference regarding health states. They were developed for health economic evaluations and derived from a specific body of economic/decision theory. In the interests of brevity and focus, these measures will be excluded from our main evaluation because we are concerned only with standardized descriptive measures, both generic and condition specific, used in the assessment of QOL after stroke.

Tables 1, 2, and 3 list the remaining 6 generic measures identified as having been used in stroke QOL research. Each measure was systematically evaluated in terms of its performance in stroke populations, by the criteria outlined above. The Sickness Impact Profile (SIP) and Nottingham Health Profile (NHP) were the only 2 generic measures to exhibit all 3 psychometric properties of reliability, validity, and responsiveness. The NHP, SIP, and HUI were developed by use of patient-centered methods. Suitability for use with proxy respondents in stroke studies is evident for the SIP, EuroQol, and HUI. The MOS 36-Item Short Form Health Survey (SF-36) and most of the other generic measures, can be either self- or interviewer-administered. The LHS is a self-completion-only measure.

In terms of acceptability, the levels of comprehensiveness and number of items varied widely between measures. Although coverage is broad in some of the generic QOL measures, certain issues relevant to stroke, such as concentration and memory, are not covered at all. Average completion times ranged from 2 to 30 minutes. Overall response rates to the measures in stroke populations were acceptable in most cases, although a wide range was found for the EuroQol and SF-36. Response rates to individual items were good for the HUI and LHS, moderate for the SF-36, but not known for the other generic measures. Evidence of acceptability in terms of pretesting with stroke patients exists only for the HUI.

The level of precision (in terms of the number of response categories and evidence of floor or ceiling effects) also varies
widely between measures. The SIP and NHP have only 2 response categories, for example, whereas the SF-36 has a combination of between 2 and 6 response categories depending on the domain, and the LHS has 6 response categories. Floor and ceiling effects in stroke populations are not known for most of the generic measures identified, but the SF-36 has high ceiling effects on some domains.

Condition-Specific Measures
The MEDLINE search identified 10 condition-specific measures that had been used in stroke QOL research. However, 3 of these (the Heart Patients Psychological Questionnaire,22,25 the Multi-Dimensional Health Locus of Control Scale,22 and the Life Orientation Test22) were not developed to be stroke specific, and an additional MEDLINE search found little information about these measures. Therefore, we focused only on the 7 identified measures that were designed to be stroke specific (Tables 4, 5, and 6). All but 1 of these measures (the Frenchay Activities Index [FAI])35 had been used in only 1 reported study. Although we did not focus on generic measures, which were used in only 1 reported study, the stroke-specific measures warrant further attention.

Information about the domains covered and the psychometric and other properties of the stroke-specific measures are outlined

<table>
<thead>
<tr>
<th>TABLE 2. Generic Outcome Measures Used in Stroke QOL Research: Description of Domains and Acceptability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measure</strong></td>
</tr>
<tr>
<td>SIP</td>
</tr>
<tr>
<td>NHP</td>
</tr>
<tr>
<td>MOS SF-36</td>
</tr>
<tr>
<td>EuroQol (utility)</td>
</tr>
<tr>
<td>HUI (HUI 2/HUI 3 combined version)</td>
</tr>
<tr>
<td>LHS (utility)</td>
</tr>
</tbody>
</table>

| **Measure** | **No. of Items** | **Average Completion Time** | **Response Rates (of Measure)*** | **Response Rates (of Items)*** | **Pretesting With Stroke Patients†** |
|---------------------------------------------------------------|
| SIP | 136 | 20–30 min | 83–98% | Not reported | No |
| NHP | 38 | 5–10 min | 72–89% | Not reported | No |
| MOS SF-36 | 36 | 5–10 min | 63–83% | <75% for all items in role-physical and role-emotional scales | No |
| EuroQol (utility) | 6 | 2–3 min | 63–80% | Not reported | No |
| HUI (HUI 2/HUI 3 combined version) | 9 | 20 min | 95% | 95% Provided complete and evaluable responses | Yes |
| LHS (utility) | 6 | Not reported | 67–79% | 5% Returned incomplete | No |

*In studies of stroke populations.
†For acceptability, clarity, etc.

<table>
<thead>
<tr>
<th>TABLE 3. Generic Outcome Measures Used in Stroke QOL Research: Precision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measure</strong></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>SIP</td>
</tr>
<tr>
<td>NHP</td>
</tr>
<tr>
<td>MOS SF-36</td>
</tr>
<tr>
<td>EuroQol</td>
</tr>
<tr>
<td>HUI (HUI 2/HUI 3 combined version)</td>
</tr>
<tr>
<td>LHS</td>
</tr>
</tbody>
</table>

*In studies of stroke populations.
†Scores of 0–100 are generated for each domain.
‡Six “levels” for each dimension.
in Tables 4, 5, and 6, which use the same evaluation criteria as Table 1, 2, and 3. Four of the measures (the FAI, the Niemi QOL scale,36 the Ferrans and Powers QOL Index–Stroke Version,37 and the 30-item Stroke-Adapted SIP [SA-SIP30] 38) exhibit both reliability and validity. Only the FAI has been shown to be responsive to change. Only the FAI has evidence of suitability for use with proxy respondents, and only the FAI and SA-SIP30 can be both self- and interviewer-administered. None of the stroke-specific measures used patient-centered methods in their development.

As with the generic measures identified, stroke-specific instruments varied immensely in terms of their coverage and number of items. Average completion time was known only for the FAI (3 to 5 minutes). Overall response rates to the measures in field tests were acceptable where this information was known. Response rates to individual items were good for the Ferrans and

### TABLE 4. Stroke-Specific Outcome Measures Used in Stroke QOL Research: Psychometric and Other Properties

<table>
<thead>
<tr>
<th>Measure</th>
<th>Evidence of</th>
<th>Mode of Administration</th>
<th>Use of Patient-Centered Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAI</td>
<td>Yes</td>
<td>Self or interview</td>
<td>No</td>
</tr>
<tr>
<td>Niemi QOL Scale (4 years after stroke)†</td>
<td>Yes</td>
<td>Interview</td>
<td>No</td>
</tr>
<tr>
<td>Ferrans and Powers QOL Index–Stroke Version (QLI)†</td>
<td>Yes</td>
<td>Interview</td>
<td>No</td>
</tr>
<tr>
<td>Viitanen Life Satisfaction Interview (for long-term survivors)†</td>
<td>No</td>
<td>Interview</td>
<td>No</td>
</tr>
<tr>
<td>Stroke Rehabilitation Outcome Study†</td>
<td>No</td>
<td>Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Ahlsio QOL interview†</td>
<td>No</td>
<td>Interview or self</td>
<td>No</td>
</tr>
<tr>
<td>SA-SIP30†</td>
<td>Yes</td>
<td>Interview or self</td>
<td>No</td>
</tr>
</tbody>
</table>

*Evidence of proxy agreement on total scores, although on some individual items, agreement was poor.
†Measure was only used in 1 reported study.
‡Evidence is for original, generic version.

ADL indicates activities of daily living.

For acceptability, clarity etc.

This measure was only used in 1 reported study.

Clarity of wording was examined in development of original QLI and SIP.

### TABLE 5. Stroke-Specific Outcome Measures Used in Stroke QOL Research: Description of Domains

<table>
<thead>
<tr>
<th>Measure</th>
<th>Appropriateness</th>
<th>Acceptability</th>
<th>Pretesting With Stroke Patients*</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAI</td>
<td>3 Domestic chores; outdoor activities; leisure and work</td>
<td>15 3–5 min 75–86% Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Niemi QOL Scale† (4 years after stroke)</td>
<td>4 Working conditions; activities at home; family relationships; leisure activities</td>
<td>58 Not reported 97% Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Ferrans and Powers QOL Index–Stroke Version (QLI)†</td>
<td>4 Health and functioning; socioeconomic; psychological/spiritual; family</td>
<td>38 Not reported 71% 99–100%</td>
<td>No‡</td>
</tr>
<tr>
<td>Viitanen Life Satisfaction Interview† (for long-term survivors)</td>
<td>7 Life in general; self-care ADL; leisure; togetherness–friends; togetherness–family; marriage; sexuality</td>
<td>7 Not reported 89% Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Stroke Rehabilitation Outcome Study†</td>
<td>3 Level of satisfaction with life in general; no. of person-to-person contacts; active participation in the community</td>
<td>6 Not reported Not reported Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Ahlsio QOL interview†</td>
<td>Not clear but includes global QOL</td>
<td>Not clear Not reported 98% Not reported</td>
<td>No</td>
</tr>
<tr>
<td>SA-SIP30†</td>
<td>8 Body care and movement; social interaction; mobility; communication; emotional behavior; household management; alertness behavior; ambulation</td>
<td>Not clear Not reported Not reported</td>
<td>No‡</td>
</tr>
</tbody>
</table>

ADL indicates activities of daily living.

*For acceptability, clarity etc.
†This measure was only used in 1 reported study.
‡Clarity of wording was examined in development of original QLI and SIP.


**TABLE 6. Stroke-Specific Outcome Measures Used in Stroke QOL Research: Precision**

<table>
<thead>
<tr>
<th>Measure</th>
<th>No. of Response Categories</th>
<th>Weighting of Response Categories</th>
<th>Floor/Ceiling Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAI</td>
<td>4</td>
<td>Not reported</td>
<td>Not reported*</td>
</tr>
<tr>
<td>Niemi QOL Scale† (4 years after stroke)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Ferrans and Powers QOL Index—Stroke Version (QLI)†</td>
<td>6</td>
<td>Yes</td>
<td>Not reported</td>
</tr>
<tr>
<td>Viitanen Life Satisfaction Interview†</td>
<td>6</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Stroke Rehabilitation Outcome Study†</td>
<td>Varies: 1 item has 4, 4 items are raw figures based on no. of social contacts, 1 item not clear</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Ahlsio QOL Interview†</td>
<td>Not clear but includes visual analogue scale</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>SA-SIP30†</td>
<td>2</td>
<td>Not reported‡</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

*But has comment that it “appears to have none.”
†Measure was only used in 1 reported study.
‡But weighting is for original, generic version.

Powers QOL Index—Stroke Version but were not reported for the FAI, the Niemi QOL Scale, the Viitanen Life Satisfaction interview, the Stroke Rehabilitation Outcome Study, the Ahlsio QOL interview, or the SA-SIP30. Acceptability of these stroke-specific measures was not pretested with patients. Precision is difficult to assess for the stroke-specific measures. Where information was available, the number of response categories varied from 2 to 6, and floor or ceiling effects were not reported for any of these measures.

**Discussion**

This article updates earlier reviews of generic and condition-specific measures for use in assessing QOL after stroke. To describe their performance and properties as they relate to stroke specifically, we considered only those measures that have been (rather than measures that could be) applied in this particular clinical population.

The limitations of this evaluation should be acknowledged. It is based on a MEDLINE search and 3 key texts in the area of QOL measurement in stroke. Resources were not available to review the “gray” literature. Our search may also have been constrained because some relevant studies did not use the term “quality of life.” Our search was therefore not necessarily exhaustive.

**The Measures**

Although we have identified a number of generic scales used to assess QOL in stroke, many are of limited value in assessing stroke interventions owing to their lack of responsiveness to changes in QOL. Moreover, such measures would not be adequate because they do not reflect the concerns of stroke patients themselves. In stroke rehabilitation, for example, where the reduction of handicap tends to be the main objective, the outcome measure used should be one developed to focus on issues of handicap. Many patients and healthcare providers, however, also require information on whether that reduction is associated with corresponding improvements in QOL.

We have also identified several stroke-specific measures used to assess QOL, but the psychometric testing of many of these has either been incomplete or absent. The FAI is the only stroke-specific measure that can be used to successfully assess QOL with proxy respondents when necessary. However, this measure, despite its use to measure QOL, was developed to assess premorbid levels of lifestyle activities and is therefore not comprehensive as a QOL measure. The issue of proxy measures is critical for this condition, because people with cognitive and language problems are often unable to respond to research questions, and their experiences are as important as those of people without cognitive impairments. The incorporation of proxy information may also increase the size and representativeness of the sample. However, good patient-proxy agreement is to a large extent dependent on the reliability of the measures used.

Finally, none of the stroke-specific instruments identified cover all issues thus far found to be appropriate to people who have had a stroke. This could be a reflection of the fact that none have used a patient-centered approach in their development. We believe that to ensure that all pertinent issues are detected, a patient-centered approach should be adopted in the development of any condition-specific measure, and rigorous psychometric testing is essential.

**Conclusions**

Improved methods to measure QOL in stroke are required. QOL measures must be valid, reliable, responsive, and comprehensive. The importance of involving patients at every stage of measure development has been stressed in a recent UK NHS HTA report. This involvement should incorporate the use of qualitative research methods, such as in-depth interviews, to ascertain the breadth and depth of the impact of stroke on QOL. Such knowledge can then inform the content of any subsequent outcome measure. Patients should also be involved in confirming the content and testing of the response categories and overall format of any new measure. In the United States, Duncan et al and Williams et al have recently undertaken patient-centered exercises to develop measures of the impact of stroke. In the United Kingdom, the present authors are developing a stroke-specific, patient-centered QOL measure that is currently being tested for validity and reliability.
Acknowledgments

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References

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