

Measuring health-related quality of life after stroke: A brief tool.

Russell, M., Dempster, M., & Donnelly, M. (2011). Measuring health-related quality of life after stroke: A brief tool. *Applied Research in Quality of Life*, 6(1), 41-51. DOI: 10.1007/s11482-010-9111-9

Published in:

Applied Research in Quality of Life

Document Version:

Early version, also known as pre-print

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Measuring Health-Related Quality of Life After Stroke: A Brief Tool

Mary Russell¹, Martin Dempster², Michael Donnelly¹

¹School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast

²School of Psychology, Queen's University Belfast

Address for Correspondence:

Martin Dempster, School of Psychology, Queen's University Belfast, University Road,
Belfast, UK BT7 1NN

Tel: +44 28 90975547 Fax: +44 28 90664144 m.dempster@qub.ac.uk

Abstract

Routine assessment of health-related quality of life (HRQoL) can be time consuming and burdensome for a person with stroke. Therefore the aim of this study was to develop and test a brief instrument for assessing HRQoL among people with stroke. The Quality of Life after Stroke Scale (QLASS) was constructed from items within the Quality of Life Index-Stroke Version and the Chronic Respiratory Disease Questionnaire. It was administered to 92 people with stroke at 3 points in time: immediately after discharge from hospital, 6 months and 12 months later. Results suggest that the QLASS has 19 items which represent 3 factors: emotional functioning, mastery and fatigue which correlate with valid measures of health status and activities of daily living. The QLASS is proposed as a brief, valid HRQoL tool for use among people with stroke.

Key Words:

quality of life; stroke; questionnaire validity

Introduction

There is a growing consensus that health-related quality of life (HRQoL) is an important healthcare outcome and a key dimension in the assessment of stroke services (Geyh, Cieza, Kollertis, Grimby and Stucki 2007; de Haan, Aaronson, Limburg, Langton and van Crevel 1993; van Gijn 1992). Nevertheless, the routine assessment of HRQoL can prove difficult, as completing lengthy questionnaires regularly can be time consuming for the health professional and perceived as burdensome for the person with stroke. When the HRQoL measure is combined with other questionnaires, as is often the case in research studies, this burden increases.

To avoid this imposition, many studies have focused on the feasibility of using proxy ratings of QoL (Dorman, Waddell, Slattery, Dennis and Sandercock 1997; Mathias et al. 1997; Sneeuw, Aaronson, de Haan and Limburg 1997) but this is clearly not as valid as the person's rating of their own HRQoL (Pickard et al., 2004; Williams et al., 2006). Therefore, there is a need to have available a valid assessment of HRQoL which is brief, so as to reduce the burden of completion of the instrument by the person with stroke.

Some generic health status measures (often referred to in the literature as measures of HRQoL) have been used among people after stroke, for example the Sickness Impact Profile (de Haan, Limburg, van der Meulen, Jacobs and Aaronson 1995), the EuroQol (Dorman, Slattery, Farrell, Dennis and Sandercock 1997, 1998) and the SF36 (Dorman et al. 1998; O'Mahony, Rodgers, Thomson, Dobson and James 1998). However, it is unlikely that generic instruments would be sensitive to detecting change among a specific group of patients (Eurich, Johnson, Reid & Spertus, 2006; Owolabi, 2010). A more sensitive measure

of HRQoL is provided by a condition-specific instrument – an instrument which has been designed to tap into those areas of life which may be affected by a specific condition (Dempster and Donnelly 2000).

There are several stroke-specific HRQoL instruments available: the Burden of Stroke Scale (Doyle, McNeil, Hula and Mikolic 2003), the Stroke Impact Scale (Duncan et al. 1999), the Stroke-Specific Quality of Life Scale (Williams, Weinberger, Harris, Clark and Biller 1999), the Quality of Life Index-Stroke Version (King 1996), the Stroke-Adapted Sickness Impact Profile-30 (van Straten et al. 1997), and the Instrument for Young Hemorrhagic Patients (Hamedani et al. 2001). Although the psychometric properties of these instruments are good, the items contained within each instrument range in number from 30 (Stroke-Adapted Sickness Impact Profile-30) to 78 (Stroke-Specific Quality of Life Scale). The Burden of Stroke Scale, Stroke Impact Scale and Quality of Life Index all contain 64 items and the Instrument for Young Hemorrhagic Patients contains 54 items. The aim of this research was to develop and test a briefer stroke-specific HRQoL questionnaire.

The starting point for the development of a HRQoL instrument is to clarify the meaning of HRQoL on which the instrument will be based. This is important as a quick examination of the content of instruments that claim to measure HRQoL will reveal that they do not all tap into the same domains. It is clear, therefore, that different authors are attempting to measure different things with different HRQoL instruments.

In many cases, authors of HRQoL instruments will begin by presenting a definition of HRQoL based on the World Health Organization (WHO) definition of health (Guyatt et al., 1993). The WHO (1958) declared that “health is a state of complete physical, mental and

social wellbeing and not merely the absence of disease or infirmity". This statement introduced the concept of "positive health" and the notion that an assessment of health should include psychological and social factors in addition to the traditional outcomes of mortality and morbidity. There appears to be general agreement that this holistic approach should be applied to health assessment and that any assessment of HRQoL should consider psychological, social and physical issues (Martin & Stockler, 1998). However, these are broad terms and would be difficult to assess comprehensively in a brief HRQoL instrument, particularly one which aims to be condition-specific. Therefore, the working definition for the HRQoL instrument to be developed within the present study was a brief instrument designed to assess the most pertinent psychological, social and physical issues for people who have experienced a stroke.

In terms of the pertinent physical functioning issues for people who have experienced a stroke, one of the important potential consequences of stroke is fatigue. Recent studies have estimated the prevalence rate of fatigue among people after stroke to be between 40% (Morley, Jackson & Mead, 2005) and 57% (Choi-Kwon, Han, Kwon & Kim, 2005), increasing with time to as much as 70% 1 year post-stroke (Schepers, Visser-Meily, Ketelaar & Linderman, 2006). Staub and Bogousslavsky (2001) suggest that even patients with excellent neurological and neuropsychological recovery post-stroke may still experience fatigue. Indeed, fatigue has been shown to be associated with post-stroke emotional health and with limitations on social activities and the reintegration into family, community and working life (Glader, Stegmayr & Asplund, 2002; Ingles, Eskes & Phillips, 1999; Naess, Nyland, Thomassen, Aarseth & Myhr, 2005; van der Werf, van den Broek, Anten & Bleijenberg, 2001). Therefore, recognition of post-stroke fatigue and its consequences may be critical to effective rehabilitation and recovery post-stroke and will have implications for both

psychological and social functioning. Consequently, a conceptualisation of HRQoL in the area of stroke should include physical functioning which focused on fatigue but also considered the social limitations created by fatigue and any physical constraints resulting from stroke.

In terms of psychological functioning, anxiety and depression levels are high in people post-stroke (Astrom, 1996; Barker-Collo, 2007) and anxiety and depression have been shown to impact on social and physical functioning (Naess et al., 2005; Shimoda & Robinson, 1998). Additionally, perceptions of control among people post-stroke have been linked to recovery of physical functioning (Johnston, Morrison, MacWalter & Partridge, 1999). Therefore, it appears that symptoms of anxiety and depression and the issue of perceived control are important issues to address in the HRQoL of people post-stroke.

In summary, then, a review of the literature in the area leads us to believe that HRQoL among people who have experienced a stroke is likely to be influenced to a large extent by their fatigue, the impact of their physical functioning on social functioning, symptoms of depression and anxiety and perceptions of control. Consequently, these are the key issues that a stroke-specific HRQoL instrument should tap in to.

Indeed, the issues identified here are not unusual in the conceptualisation of HRQoL among people with a range of chronic illness, particularly cardiovascular illnesses. For example, a series of brief, valid and reliable HRQoL instruments have been developed and adapted by Guyatt and colleagues for use among people with chronic illness. These are: the Chronic Respiratory Disease Questionnaire (Guyatt, Berman, Townsend, Pugsley and Chambers 1987); the Chronic Heart Failure Questionnaire (Guyatt et al. 1989); and the

Quality of Life after Myocardial Infarction Questionnaire (Hillers, Guyatt and Oldridge 1994). Although the content of these instruments differs to some extent, they all include items which address the dimensions of emotional functioning, mastery and fatigue. Given that the items used to indicate “emotional functioning” tap into symptoms of anxiety and depression and the items used to indicate “mastery” could also be labelled “perceived control”, it appears that this existing pool of items could go some way to addressing HRQoL among people after stroke, as conceptualised previously. However, to complete the required pool of items that meets our definition of HRQoL, items which make a broader assessment of physical functioning and its impact on social functioning are required.

The physical functioning subscale of the Quality of Life Index (QLI) (King, 1996) meets this requirement and is brief. Therefore, it was proposed that a new quality of life instrument comprising the 15 items from the Emotional Functioning, Mastery and Fatigue scales developed by Guyatt and colleagues and the 5 items assessing Physical Functioning from the QLI would constitute an appropriate, condition-specific instrument for the assessment of HRQoL among people after stroke. The validity of this hybrid instrument requires investigation.

Method

Patients were recruited who had experienced a stroke during the 4 weeks immediately preceding admission to hospital. Participants were eligible for inclusion in the study if they were not resident in a nursing or residential home and were not cognitively impaired to the extent where they would be unlikely to be able to complete the measures included in the research. The assessment of cognitive impairment was completed using the Abbreviated

Mental Test (Hodkinson, 1972), using a cut-off score of 7/10 (Qureshi & Hodkinson, 1974).

All participants were visited in their own homes and asked to complete the following questionnaires in a one-to-one interview setting: the Barthel Index (Mahoney and Barthel 1965), the Nottingham Extended Activities of Daily Living Scale (Nouri and Lincoln 1987), the Short Form 36 (SF36) (Ware & Sherbourne, 1992), the Stroke Mobility Index and 10 metre walk test (Wade, Collen, Robb and Warlow 1992), the EuroQol (EuroQol Group 1990), and the Quality of Life after Stroke Scale (QLASS).

The QLASS was the name given to the new measure developed for this study. It is constructed from items used in the Fatigue, Emotional Functioning and Mastery scales of questionnaires such as the Chronic Respiratory Disease Questionnaire (Guyatt et al. 1987) and the Physical Functioning scale of the Quality of Life Index – Stroke (King 1996). It contains 20 items, with responses on a 7 point Likert scale.

Participants were asked to complete the instruments at 3 points in time: after discharge from hospital, 6 months and 12 months later. Ethics approval for the research was provided by the University Medical Ethics Committee.

Results

A total of 92 participants provided valid responses at each point in time. Approximately 51% of the sample (47/92) were male and the average age of respondents was 68.4 years (SD = 11.32). Approximately 69% (63/92) of respondents had a family carer. The clinical classification of stroke for the respondents is provided in Table 1. The summary statistics for the instruments administered are provided in Table 2. These results indicate that participants' physical

functioning and social functioning changed significantly from time 1 to time 2 and remained reasonably stable between time 2 and time 3.

A principal components analysis (with oblimin rotation) was conducted on the 20 items from the QLASS. The scree plot suggested a three factor solution, explaining 58.77% of the variance. The factor loadings from the rotated solution are shown in Table 3. The three factors have been labelled (emotional functioning, mastery and fatigue), based on an analysis of their content.

A second factor analysis was conducted on the data collected at time 2 to determine whether or not the factor structure could be replicated. At this time, the 3 factor solution explained 60.18% of the variance. Only one item did not show the same pattern of factor loadings as found at time 1 (see Table 4). This item asks respondents to indicate how much of the time they have felt relaxed and free of tension. At time 1, this item is grouped with other items assessing emotions, but also loads (to a similar degree) on the “fatigue” factor. At time 2, the factor loadings for this item on the factors of “emotional functioning” and “fatigue” are similar to those found at time 1 but the item loads most highly on the “mastery” factor. Given that this item does not consistently load on any factor(s), it may be best to remove it from the questionnaire.

Consequently, data collected at a third point in time were subjected to analysis by Cronbach’s alpha, to determine the internal consistency of the scales after this item was removed. The results were Emotional Functioning: 0.87; Mastery: 0.83; Fatigue: 0.88. The analysis also indicated that the alpha values could not be improved by removing any of the items.

To further examine the construct validity of these factors, correlations were conducted between the three newly created factors on the QLASS and the previously validated measures of health status and physical functioning (SF-36, Barthel Index, Nottingham Extended ADL Index, Euroqol, Mobility Index). The resulting correlation coefficients are presented in Table 5. Coefficients underlined in Table 5 highlight the relationships which would be expected to be strongest in the particular row. This expectation is met in all cases. In addition, the criterion scales which most closely resemble the factors of the QLASS are the SF36 Mental Health scale (resembling Emotional Functioning on the QLASS) and the SF36 Energy/Vitality scale (resembling the Fatigue scale on the QLASS) and the magnitude of the correlation coefficients is highest for these relationships.

To examine the sensitivity to change of the QLASS factors, we calculated a standardised response mean ($(\text{mean1} - \text{mean2}) / \text{SD of change scores}$) for the change between times 1 and 2. The participants in the study were deemed to change significantly on most assessment instruments between time 1 and time 2. Therefore, we would expect that the QLASS emotion and mastery scales would be sensitive to this change. Given the lack of significant change on the SF36 energy/vitality scale, it was expected that the QLASS fatigue scale would have a low SRM. The SRM value for the QLASS emotional scale is higher than that for similar scales (SF36 role emotional and SF36 mental health) and the SRM for the QLASS fatigue scale is higher than that for the SF36 Energy/Vitality scale. The SRM for the QLASS mastery scale is lower than the SRM for other instruments that measure more specific types of physical functioning or social functioning.

To examine the stability of responses over time, we estimated test-retest reliability using the intraclass correlation coefficient (ICC) between times 2 and 3. The ICC scores for

the QLASS scales compare well with the commensurate scales on other instruments. Again, the more focused measures of types of physical functioning are more stable over time than the QLASS mastery scale.

Conclusions

The research aimed to develop a brief, valid stroke-specific HRQoL instrument. The QLASS is a 19 item instrument which has a 3 factor structure and this has been confirmed over time. Furthermore, the factor structure is similar to the factor structure found for other brief HRQoL instruments developed by Guyatt and colleagues (Guyatt et al. 1987; Guyatt et al. 1989; Hillers, Guyatt and Oldridge 1994).

Further evidence for construct validity of the QLASS is provided by the correlations of appropriate direction and magnitude with valid measures of health status and activities of daily living (without correlating to the extent that they appear to be measuring the same thing). This correlational analysis also shows that each of the factors underlying the QLASS has a similar correlation coefficient with general health status, which suggests that each domain (emotional functioning, mastery and fatigue) contributes in a similar fashion to perception of overall health status.

The responsiveness over time and stability over time of the QLASS emotion and fatigue scales are similar to similar previously validated scales. However, the QLASS mastery scale has a lower level of responsiveness and stability than other more focused scales. This is not surprising. The QLASS mastery scale is an attempt to capture the extent to which limitations in physical functioning of stroke survivors impact on their social

functioning. Scales which measure specific aspects of physical functioning, such as activities of daily living, are essentially health status assessments which ignore the interplay between physical and social functioning and, therefore, are more likely to be sensitive to changes in physical functioning. Yet, as an assessment of HRQoL, we believe that the QLASS offers something different –

an indication of the extent to which changes in physical functioning have an important impact on the life quality of the stroke survivor. Consequently, instruments which tap into physical or social functioning only are not good comparators for the QLASS mastery scale, but we are not aware of any scale which aims to achieve something similar. This demonstrates the added value of a scale such as the QLASS. It is conceptually different from most existing HRQoL scales used among people with stroke.

The generalisations that can be made from this study are limited in terms of the population of inference. Our sample was restricted to stroke survivors who were not extremely cognitively impaired and was also heterogeneous in terms of the classification of stroke that had been experienced by participants. Our sample was too small to conduct any subgroup analysis of these stroke categories, even though it is a relatively large sample for research conducted within this population.

The conceptualisation of HRQoL used in this research was also limited. Given the desire to develop a brief HRQoL assessment, we restricted ourselves to the pertinent issues likely to impact on the life quality of a stroke survivor, as suggested by previous research. As such, there are issues which may have been important to participants in the research but which were not addressed by the questionnaire. This is a problem particular to all questionnaires with predetermined items and suggests the need for a more individualised

approach. However, in this case, pragmatism was considered to be of utmost importance, given the characteristics of the population.

In summary, this research suggests an alternative, brief instrument for assessing HRQoL among people with stroke, which will assist clinicians wishing to complete routine assessments of HRQoL and provide a useful tool to be used in research studies within this population.

References

- Astrom, M. (1996) Generalized anxiety disorder in stroke patients. *Stroke*, 27, 270-275.
- Barker-Collo, S.L. (2007) Depression and anxiety 3 months post stroke: Prevalence and correlates. *Archives of Clinical Neuropsychology*, 22, 519-531.
- Choi-Kwon, S., Han, S.W., Kwon, S.U. & Kim, J.S. (2005) Poststroke fatigue: characteristics and related factors. *Cerebrovascular Diseases*, 19, 84-90
- Dempster, M. & Donnelly, M. (2000) Selecting a measure of health-related quality of life. *Social Work in Health Care*, 32, 45-56.
- Dorman, P.J., Slattery, J., Farrell, B., Dennis, M. & Sandercock, P. (1997) Is the EuroQol a valid measure of health-related quality of life after stroke? *Stroke*, 28, 1876-1882.
- Dorman, P.J., Slattery, J., Farrell, B., Dennis, M. & Sandercock, P. (1998) Qualitative comparison of the reliability of health status assessments with the EuroQol and SF-36 questionnaires after stroke. *Stroke*, 29, 63-68.
- Dorman, P.J., Waddell, F., Slattery, J., Dennis, M. & Sandercock, P. (1997) Are proxy assessments of health status after stroke with the EuroQol questionnaire feasible, accurate and unbiased? *Stroke*, 28, 1883-1887.
- Doyle, P.J., McNeil, M.R., Hula, W.D. & Mikolic, J.M. (2003) The Burden of Stroke

Scale (BOSS): Validating patient-reported communication difficulty and associated psychological distress in stroke survivors. *Aphasiology*, 17, 291-304.

Duncan, P.W., Wallace, D., Lai, S.M., Johnson, D., Embretson, S. & Laster, L.J. (1999) The stroke impact scale version 2.0. Evaluation of reliability, validity and sensitivity to change. *Stroke*, 30, 2131-2140.

Eurich, D.T., Johnson, J.A., Reid, K.J. & Spertus, J.A. (2006) Assessing responsiveness of generic and specific health related quality of life measures in heart failure. *Health and Quality of Life Outcomes*, 4: 89.

EuroQol Group. (1990) EuroQol – A new facility for the measurement of health-related quality of life. *Health Policy*, 16, 199-208.

Geyh, S., Cieza, A., Kollertis, B., Grimby, G. & Stucki, G. (2007) Content comparison of health related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): A systematic review. *Quality of Life Research*, 16, 833-851.

Glader, E., Stegmayr, B. & Asplund, K. (2002) Poststroke Fatigue: A 2-year follow-up study of stroke patients in Sweden. *Stroke*, 33, 1327-1333.

Guyatt, G.H., Berman, L.B., Townsend, M., Pugsley, S.O. & Chambers, L.W. (1987) A measure of quality of life for clinical trials in chronic lung disease. *Thorax*, 42, 773-778.

Guyatt, G.H., Eagle, D.J., Sackett, B., Willan, A., Griffith, L., McIlroy, W., Patterson, C.J., & Turpie, I. (1993) Measuring quality of life in the frail elderly. *Journal of Clinical Epidemiology*, 46, 1433-1444.

Guyatt, G.H., Nogradi, S., Halcrow, S., Singer, J., Sullivan, M.J. & Fallen, E.L. (1989) Development and testing of a new measure of health status for clinical trials in heart failure. *Journal of General Internal Medicine*, 4, 101-107.

de Haan, R.J., Aaronson, N., Limburg, M., Langton Hewer, R. & van Crevel, H. (1993) Measuring quality of life in stroke. *Stroke*, 24, 320-327.

de Haan, R.J., Limburg, M., van der Meulen, J.H.P., Jacobs, H.M. & Aaronson, N.K. (1995) Quality of life after stroke. *Stroke*, 26, 402-408.

Hamedani, A.G., Wells, C.K., Brass, L.M., Kernan, W.N., Viscoli, C.M., Maraire, J.N., Awad, I.A. & Horwitz, R.I. (2001) A quality of life instrument for young hemorrhagic stroke patients. *Stroke*, 32, 687-695.

Hillers, T.K., Guyatt, G.H. & Oldridge, N. (1994) Quality of life after myocardial infarction. *Journal of Clinical Epidemiology*, 47, 1287-1296.

Hodkinson, H. (1972) Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age and Ageing*, 1, 233-238.

Ingles, J.L., Eskes, G.A. & Phillips, S.J. (1999) Fatigue after stroke. *Archives of Physical Medicine and Rehabilitation*, 80, 173-178.

Johnston, M., Morrison, V., MacWalter, R. & Partridge, C. (1999) Perceived control, coping and recovery from disability following stroke. *Psychology & Health*, 14, 181-192.

King, R.B. (1996) Quality of life after stroke. *Stroke*, 27, 1467-1472.

Mahoney, F.I. & Barthel, D.W. (1965) Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, 14.

Martin, A.J., & Stockler, M. (1998) Quality of life assessment in health care research and practice. *Evaluation & the Health Professions*, 21, 141-156.

Mathias, S.D., Bates, M.M., Pasta, D.J., Cisternas, M.G., Feeny, D. & Patrick, D.L. (1997) Use of the Health Utilities Index with stroke patients and their caregivers. *Stroke*, 28, 1888-1894.

Morley, W., Jackson, K. & Mead, G.E. (2005) Post-stroke fatigue: An important yet neglected symptom. *Age and Ageing*, 19, 84-90.

Naess, H., Nyland, H.I., Thomassen, L., Aarseth, J. & Myhr, K.M. (2005) Fatigue at long-term follow-up in young adults with cerebral infarction. *Cerebrovascular Diseases*, 20, 245-250.

Nouri, F. & Lincoln, N.B. (1987) An extended activities of daily living scale for stroke patients. *Clinical Rehabilitation*, 7, 233-238.

O'Mahony, P.G., Rodgers, H., Thomson, R.G., Dobson, R. & James, O.F.W. (1998) Is the SF-36 suitable for assessing health status of older stroke patients? *Age & Ageing*, 27, 19-22.

Owolabi, M.O. (2010). Which is more valid for stroke patients: generic or stroke-specific quality of life measures? *Neuroepidemiology*, 34, 8-12.

Pickard, A.S., Johnson, J.A., Feeny, D.H., Shuaib, A., Carriere, K.C. & Nasser, A.M. (2004) Agreement between patient and proxy assessments of health-related quality of life after stroke using the EQ-5D and Health Utilities Index. *Stroke*, 35, 607-612.

Qureshi, K. & Hodkinson, M. (1974) Evaluation of a 10 question mental test of the institutionalized elderly. *Age and Ageing*, 3, 152-157.

Schepers, V.P., Visser-Meily, A.M., Ketelaar, M. & Lindeman, E. (2006) Poststroke fatigue: Course and its relation to personal and stroke-related factors. *Archives of Physical Medicine and Rehabilitation*, 87, 184-8.

Shimoda, K. & Robinson, R.G. (1998) Effect of anxiety disorder on impairment and recovery from stroke. *Journal of Neuropsychiatry and Clinical Neuroscience*, 10, 34-40.

Sneeuw, K.C.A., Aaronson, N.K., de Haan, R.J. & Limburg, M. (1997) Assessing

quality of life after stroke. The value and limitations of proxy ratings. *Stroke*, 28, 1541-1549.

Staub, F. & Bogousslavsky, J. (2001) Fatigue after stroke: A major but neglected issue. *Cerebrovascular Diseases*, 12, 75-81.

Van der Werf, S.P., van den Broek, H.L.P., Anten, H.W.M. & Bleijenberg, G. (2001) Experience of severe fatigue long after stroke and its relation to depressive symptoms and disease characteristics. *European Neurology*, 45, 28-33.

Van Gijn, J. (1992) Measurement of outcome in stroke prevention trials. *Cerebrovascular Diseases*, 1992, 2(suppl 1), 23-34.

Van Straten, A., de Haan, R.J., Limburg, M., Schuling, J., Bossuyt, P.M. & van den Bos, G.A. (1997) A stroke-adapted 30 item version of the Sickness Impact Profile to assess quality of life (SA-SIP30). *Stroke*, 28, 2155-2161.

Wade, D.T., Collen, F.M., Robb, G.F. & Warlow, C.P. (1992) Physiotherapy intervention late after stroke and mobility. *British Medical Journal*, 304, 609-613.

Ware, J.J. & Sherbourne, C.D. (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*, 30, 473-483.

Williams, L.S., Bakas, T., Brizendine, E., Plue, L., Tu, W., Hendrie, H. & Kroenke, K. (2006) How valid are family proxy assessments of stroke patients' health-related quality of life? *Stroke*, 37, 2081-2085.

Williams, L.S., Weinberger, M., Harris, L.E., Clark, D.O. & Biller, J. (1999)
Development of a stroke specific quality of life scale. *Stroke*, 30, 1362-1369.

World Health Organization (1958) *The First Ten Years of the World Health Organization*. Geneva: World Health Organization.

Table 1

Bamford Classification of Stroke

	N	%
Total Anterior Circulation Syndrome (TACS)	20	21.7
Partial Anterior Circulation Syndrome (PACS)	30	32.6
Posterior Circulation Syndromes (POCS)	7	7.6
Pure Motor Stroke (PMS)	13	14.1
Pure Sensory Stroke (PSS)	15	16.3
Ataxic Hemiparesis (AH)	1	1.1
Sensory-motor stroke (SMS)	6	6.5
Total	92	100.0

Table 2

Change over time for Comparison Instruments

	Time 1	Time 2	Time 3	p	SRM	ICC
	Mean(SD)	Mean(SD)	Mean(SD)		(T2-T1)	(T2-T3)
Barthel	13.96 (3.60)	17.30 (3.30)	17.57 (3.53)	<.001	1.05	0.94
Nottingham ADL	5.70 (5.26)	9.65 (6.42)	9.86 (6.35)	<.001	0.75	0.92
Mobility Index	3.63 (1.53)	5.23 (1.15)	5.33 (1.11)	<.001	1.11	0.85
Timed walk	17.22 (5.11)	24.70 (18.32)	20.70 (11.86)	.079	0.41	0.80
EuroQol	60.25 (16.17)	67.12 (16.33)	67.27 (20.01)	.005	0.40	0.59
SF36 physical func	18.17 (19.60)	32.28 (29.27)	34.00 (31.36)	<.001	0.53	0.93
SF36 role physical	11.52 (28.85)	26.12 (38.05)	26.40 (38.50)	<.001	0.39	0.45
SF36 role emotional	60.30 (44.06)	71.91 (42.61)	67.42 (43.80)	.156	0.21	0.44
SF36 social func	30.89 (33.41)	49.67 (35.40)	51.04 (37.95)	<.001	0.48	0.74
SF36 mental health	65.67 (23.56)	68.66 (20.32)	68.40 (18.53)	.371	0.12	0.76
SF36 energy/vitality	43.74 (21.70)	43.63 (21.00)	45.38 (22.48)	.737	0.004	0.81
SF36 pain	79.55 (28.58)	72.28 (33.02)	73.41 (32.58)	.083	0.25	0.68
SF36 general health	69.53 (18.83)	66.74 (21.30)	65.93 (24.46)	.242	0.15	0.74
QLASS Emotional	4.80 (1.47)	5.29 (1.22)	5.35 (1.28)	.003	0.37	0.67
QLASS Mastery	3.95 (1.96)	4.36 (1.31)	4.44 (1.36)	.015	0.27	0.79
QLASS Fatigue	3.91 (1.53)	4.10 (1.56)	3.96 (1.68)	.639	0.11	0.75

Table 3
Factor loadings for QLASS at time 1

	Component		
	Emotion	Mastery	Fatigue
Feel discouraged/down in the dumps	.776		.313
Upset, worried, depressed	.775		
Restless, tense, uptight	.764		
Upset or scared	.692		
Feeling of fear/panic	.600		
Felt frustrated/impatient	.573	.300	.474
Felt embarrassed/stroke	.510	.377	
Feel relaxed/tension free	<u>.492</u>		<u>.472</u>
Amount of control		.788	
Able get around		.775	
Ability do things for self		.762	
Go places outside home		.738	
Complete control of stroke	.376	.583	
Happy, satisfied, pleased	.514	.536	
Feel confident/Sure		.463	
Able to speak		.406	
Low in energy			.865
How much energy			.856
Worn out/sluggish			.815
Fatigue over 2 weeks			.804

KMO = 0.862; Bartlett's test of sphericity: $\chi^2 = 1076.25$, $p < .001$

Factor loadings less than an absolute value of 0.3 have been suppressed.
 Factor loadings in bold indicate the factor to which each item was attributed.

Table 4
Factor loadings for QLASS at time 2

	Component		
	Emotion	Mastery	Fatigue
Discouraged/down dumps	.767		
Upset.worried,depressed	.760		
Restless,tense,uptight	.727		
Upset or scared	.702		
Feeling of fear/panic	.639		
Felt frustrated/impatient	.578	.409	
Felt embarrassed/stroke	.710		
Feel relaxed/tension free	<u>.394</u>	<u>.506</u>	<u>.447</u>
Amount of control		.735	
Able get around		.770	
Ability do things for self		.745	
Go places outside home		.743	
Complete control of stroke	.387	.483	
Happy,satisfied,pleased	.458	.567	
Feel confident/Sure	.316	.396	
Able to speak		.478	
Low in energy			.879
How much energy			.862
Worn out/sluggish	.301		.846
Fatigue over 2 weeks			.844

KMO = 0.871; Bartlett's test of sphericity: $\chi^2 = 1142.35$, $p < .001$

Factor loadings less than an absolute value of 0.3 have been suppressed
 Factor loadings in bold indicate the factor to which each item was attributed

Table 5
Relationship between QLASS Factors and measures of health status

	Emotional	Mastery	Fatigue
Barthel	.336	<u>.471</u>	.181*
Nottingham ADL	.394	<u>.610</u>	.293
Mobility Index	.302	<u>.416</u>	.132*
Timed walk [†]	-.242*	<u>-.511</u>	.022*
EuroQol	.472	.594	.390
SF36 physical functioning	.434	<u>.654</u>	.398
SF36 role physical due/physical problems	.201*	<u>.336</u>	.315
SF36 role emotional	<u>.333</u>	.280	.222
SF36 social functioning	.503	<u>.620</u>	.451
SF36 mental health	<u>.723</u>	.522	.401
SF36 energy/vitality	.448	.479	<u>.833</u>
SF36 pain	.384	.329	.311
SF36 general health	.385	.360	.341

[†] n = 35

* p > .05