

SHORT REPORT

Effect of experience of severe stroke on subjective valuations of quality of life after stroke

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Abstract

Previous work suggests that the quality of life associated with severe disability after stroke is rated very poorly by members of the public, often as being worse than death. Other evidence suggests that experience of illness alters perceptions of its severity. This was tested for severe stroke. Eleven patients with severely disabling stroke, but able to complete a standard gamble interview, 22 age and sex matched controls, and 20 health professionals participated. A standard gamble interview was carried out to determine the quality of life (utility) associated with three hypothetical scenarios representing mild, moderate, and severe stroke, and current health. A sample was retested for reliability, and comparisons were made with other measures of health status. All three subject groups showed wide variation in the utilities they attached to each of the scenarios. The control subjects' valuations were lower than those of either patients or staff members, especially for moderate stroke (median 0.30, 0.73, and 0.68 respectively). There were weak to moderate correlations between utilities and other measures of health status including the Barthel index ($r=0.51$) and Rivermead mobility score ($r=0.24$). Test retest-reliability was modest (reliability coefficient 0.75), but indicators of the internal validity of the results were good. In conclusion, it cannot be assumed that general population valuations are valid for patient groups. In clinical practice it is unsafe to make any assumption about subjective quality of life after stroke, due to the wide range of valuations given, although many people rate severe and moderate stroke at least as bad as death.

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Information on quality of life is needed for both clinical practice and health policy purposes. Current guidelines suggest that a patient's "best interests" are served if an intervention is likely to lead to "a length and quality of life that would have been acceptable to the patient".¹

Quality of life assessments are also required for clinical trials, cost effectiveness, and decision analyses.²

The views of the general public are often sought in making quality of life assessments.³ In clinical practice, the opinions of the individual patient should have primacy. Patients' values may well differ from the average. Unfortunately, the mental tasks required to make direct estimations of quality of life in individual patients are very taxing, leading to substantial measurement errors. However, if we can demonstrate differences between groups of people (which minimises the effects of random errors), we should be very cautious about extrapolation from the general population to individual patients.

Most patients who survive severe strokes have impairments of language or cognition, making it impossible for them to undertake subjective exercises on estimation of quality of life. We undertook a study of a selected sample of survivors of severe stroke whom we thought would be able to complete measurement interviews.

Methods

SUBJECTS

A cohort of 585 adult survivors of stroke (consecutive hospital admissions) was registered 3 months after their strokes. One hundred and forty five had a Barthel index⁴ less than 11/20, and were followed up for cognitive and communication impairment, depression, and physical and functional recovery. Seventy six survivors were reinterviewed after 12 months (41 had died, 14 refused, 11 moved out of the area, three were too ill).

At the 12 month assessment, 20 patients scored 10/10 on the abbreviated mental test score,⁵ showed no impairment in communication on the Sheffield screening test,⁶ and were thought potentially capable of managing a standard gamble interview.

CONTROLS

Twenty two sex and age (within 5 years) matched controls were recruited from the hospital anticoagulant clinic. At a minimum they were able to walk with the aid of no more than a stick, had no cognitive impairment or depressive illness, and had not had a stroke.

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Table 1 Distribution of utility scores assigned to different health scenarios by study groups

Scenario	Study group	Percentage (No) assigning utility score				Median (interquartile range) utility score	Significance of difference (Kruskal-Wallis) χ^2 (df)
		≤ 0.1	0.1–0.5	0.5–0.9	≥ 0.9		
Current health	Patients	18 (2)	18 (2)	18 (2)	46 (5)	0.70 (0.48–0.98)	11.8(2);p=0.003
	Controls	5 (1)	18 (4)	36 (8)	41 (9)	0.85 (0.53–0.98)	
	Staff	0	0	5 (1)	95 (19)	0.98 (0.98–0.98)	
Mild stroke	Patients	18 (2)	9 (1)	18 (2)	55 (6)	0.93 (0.50–0.98)	1.1(2);p=0.56
	Controls	5 (1)	23 (5)	32 (7)	41 (9)	0.78 (0.48–0.98)	
	Staff	0	5 (1)	50 (10)	45 (9)	0.88 (0.75–0.98)	
Moderate stroke	Patients	27 (3)	18 (2)	9 (1)	46 (5)	0.73 (0.03–0.98)	5.5(2);p=0.25
	Controls	41 (9)	27 (6)	14 (3)	18 (4)	0.30 (0.01–0.63)	
	Staff	10 (2)	15 (3)	60 (12)	15 (3)	0.68 (0.41–0.78)	
Severe stroke	Patients	46 (5)	18 (2)	18 (2)	18 (2)	0.40 (0.48–0.98)	2.8(2);p=0.25
	Controls	68 (15)	14 (3)	5 (1)	14 (3)	<0 (<0–0.48)	
	Staff	45 (9)	30 (6)	25 (5)	0	0.14 (<0–0.45)	

Twenty health professionals were also interviewed, 10 of them twice, 6 months apart, to assess the test-retest reliability of the interview.

INTERVIEWS

Interviews took place in the patients' homes, the anticoagulant clinic for controls, and hospital offices for staff. The standard gamble test was used. For a given state of health, this proposes a hypothetical treatment which could restore perfect health, but at risk of instant death. The subject is asked to choose between living in the state of health described, or taking a chance on returning to perfect health by undergoing the hypothetical treatment. The chance of death associated with the treatment is varied, starting with the extremes (100% and 0%), and iterating in a "ping-pong" fashion towards the point when the subject is unable to choose between the options. At this point, the chance of success of the treatment represents the utility of the health state under test. Utilities conventionally have a value of 1.0 for perfect health and 0 for death.

All participants were given six descriptions of health states, including mild, moderate and severe strokes,⁷ their current state of health, perfect health, and death. They were asked to rank the descriptions in order of preference. Using previously tested visual aids, to help convey the idea of probabilities, standard gambles were performed for the three stroke scenarios and current health, in random order. Interviews were abandoned if the participant clearly could not comprehend the task. Utilities were measured to ± 0.025 only.

Ethics committee approval was granted, and all participants gave consent.

ANALYSIS

Distributions of utility scores, and proportions rating the stroke scenarios as bad as or worse than death, were compared between groups for each scenario. Test-retest reliability was assessed using the methods of limits of agreement⁸ and the reliability coefficient (intraclass correlation coefficient).⁹

SAMPLE SIZES

Available numbers gave 65% power to detect a 1 SD (about 0.25) difference in mean utility, and 30% power to detect a 20% absolute

difference in the proportion rating severe stroke worse than death.

Results

STUDY POPULATIONS

Sixteen of the 20 patients agreed to take part, and 11 successfully completed interviews. The mean age of patients and controls was 71 years (range 62–89); 36% were women. The mean age of staff was 34 years (range 24–55); 60% were women. The patients' median Barthel index (out of 20) was 9 (range 0–10) 3 months after stroke and 16 (range 5–19) at 12 months.

Distributions of utility scores are given in table 1. The groupings represent very good utilities (>0.9), very bad utilities (<0.1), and low and high midrange scores (0.1–0.5 and 0.5–0.9, respectively). All the distributions were highly skewed. All groups showed variation in utilities across the entire range possible (0.0–1.0) for each of the stroke scenarios. In general, stroke scenarios were rated highest by the patients, and lowest by the controls, with health professionals intermediate. The mild stroke scenario was rated as almost perfect health by most of the patients. Differences were most pronounced for the moderate stroke scenario where median utilities were 0.725 for the patients and 0.68 for staff, compared with 0.30 for the controls ($p=0.06$). The patients rated the severe stroke scenario with a relatively benign median utility of 0.4, compared with <0 for the controls and 0.14 for the health professionals. More controls (12, 55%) rated severe stroke worse than death, than did patients (four, 36%), or staff (seven, 35%) (χ^2 , $p=0.012$).

RELIABILITY OF STANDARD GAMBLE UTILITY MEASUREMENT

The mean test-retest difference for measurements was small (0.034). The range of differences, however, was large (-0.60 to $+0.55$). The limits of agreement (within which 95% of retest values are likely to fall) was 0.34 (figure 1). The reliability coefficient overall was 0.75, representing moderate reliability.

INTERNAL VALIDITY OF THE RESULTS

For each group the median utilities for mild, moderate, and severe stroke, fell in the expected order, and current health was rated as

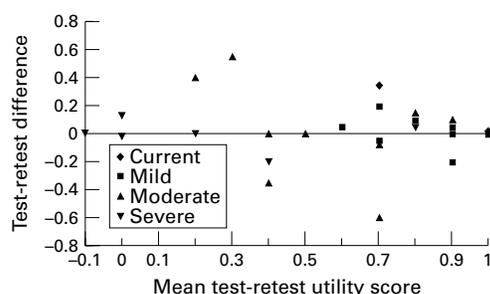


Figure 1 Bland-Altman plot illustrating test-retest reliability of the standard gamble method. The different symbols represent measurements on each of the four scenarios tested.

better than the mild stroke scenario for the control and staff groups. The median utility for current health decreased as expected from staff (0.975), to controls (0.85), to patients (0.725).

ASSOCIATION BETWEEN STANDARD GAMBLE UTILITIES AND OTHER HEALTH STATUS MEASURES

The correlation coefficient with the Barthel index was 0.65 (p=0.04), Rivermead mobility score 0.34 (p=0.34), hospital anxiety and depression score (HADS) anxiety score -0.38 (p=0.28), HADS depression score -0.13 (p=0.72), and Rivemead motor score 0.12 (p=0.7). These are around the expected strength, and are consistent with the standard gamble method being valid.

Discussion

This small group of patients initially had severe strokes. By the time of their interviews five of them had Barthel scores of 17/20 or more. Using the standard gamble, nearly half rated the utility of their current health state to be greater than 0.9, that is, nearly perfect (and comparable with the controls). The group we interviewed were survivors, some of whom had made a reasonable recovery, which may have influenced their opinions. Although they are probably not representative of all patients with acute, severe stroke, they are probably more representative than general population samples. “Utilities” quantify the desirability, value, or worth of a state of health. Standard gamble is a difficult technique for subjects, but it is the “gold standard” for this type of measurement, and it mimics the decision patients have to take in deciding to undergo thrombolytic therapy for acute stroke. There was no consensus on the utility of the stroke scenarios. Lack of consensus has important implications for assumptions about patients’ willingness to take risks, and for the use of “average” utility scores in health policy analyses. Although most patients perceived survival with a severe stroke as comparable with death, a minority disagreed, assigning high utilities.

In previous studies, severe strokes have been rated uniformly undesirable by non-disabled

patients referred for carotid duplex scans,¹⁰ and with atrial fibrillation.^{7 11 12} These studies also reported great variation between respondents in their valuations of scenarios.

It is plausible that from the standpoint of experience of severe stroke, moderate stroke might not seem that bad, supporting the assumption that subjective experience does alter the perceived desirability of a given state of health. Several previous studies have considered this issue for a range of diseases, with divergent results.¹³⁻¹⁶

Our conclusions are uncertain because of the small numbers in this study—patients with severe stroke able to do standard gamble interviews are rare. It is not safe to conclude, however, that the experience of severe stroke has no effect on the valuation given to hypothetical scenarios describing moderate or severe stroke. This uncertainty should be reflected in sensitivity analyses carried out in health economic evaluations. In the clinical situation we can give no advice about “best interest” when considering life sustaining therapies for patients moribund after severe strokes. In some patients “best interest” will be served by intervention; in a larger number it will be not.

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