

Longitudinal Study of Quality of Life Following Stroke

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Abstract

The purpose of this study was to conduct a longitudinal examination of various dimensions of quality of life for patients following their first stroke and to identify variables that predict subsequent quality of life. 121 patients with a first stroke and 121 matched healthy controls from the same community were assessed at baseline and 1 year after discharge from hospital using a self-administered General Quality of Life Inventory.

One year after discharge, the clinical condition of 84% of patients following a stroke had improved or they had fully recovered. However, their quality of life had not reached the level of the healthy controls. Of note was that 16% of patients whose stroke symptoms were unchanged or worse after 1 year of follow-up showed no change in quality of life scores compared with baseline. One year after discharge, family and social support had significantly decreased and self esteem and body image were impaired compared with baseline, particularly for patients experiencing deterioration of their condition.

Multiple stepwise regression analysis showed that quality of life was best predicted by the severity of the stroke, patients' outcome expectancy, their values of need level for life, and potential for neuroticism. Stroke was found to impair most aspects of patients' quality of life. During rehabilitation after stroke, more attention should therefore be paid to adjusting patients' outcomes expectancy and their values of need level for life to a more realistic level and ensuring sufficient psychosocial support as well as active drug and physical therapy.

Key words: Stroke, Quality of life

Introduction

Stroke is a major chronically disabling brain trauma that often radically and permanently changes the lives of patients. Most strokes are not fatal, but the disabilities caused may be profound and lead to severe impairment of quality of life (QOL).¹⁻⁴ Gage et al³ and Solomon et al⁴ reported that the QOL of a patient after a moderate or major stroke is perceived as worse than or equal to death by many patients. Hence, there is a growing consensus that QOL

should be considered as an important index of health care outcome.

However, despite the potential for stroke to affect multiple domains of life and related outcomes, few studies have addressed QOL after stroke. Some reported studies have reached contradictory conclusions.⁵⁻⁷ However, nearly all research into QOL after stroke has failed to include a comparison group of healthy adults.^{4,5,8-12}

Over the years, QOL has been defined in many different ways. A broad consensus has emerged that at least 4 dimensions should be included in a QOL assessment: physical, psychological, social function, and patients' symptoms.^{1,2,13,14} This study, therefore, was undertaken to compare the QOL of patients after stroke with healthy controls, and to prospectively examine the QOL of patients followed up during a 12-month period after discharge from hospital using a multidimensional measure that includes physical health, psychological health, social functioning, and living conditions.^{1,2,14,15}

Methods

Patients

Patients were included in the study as long as the following criteria were met.

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The patients were discharged from hospital within 1 week of improvement in their condition after a first stroke. There were no other neuro-musculoskeletal conditions that would interfere with normal function and the patients had no previous history of psychiatric illness. Cognitive and language functioning was adequate for participation in the study procedures. Patients could read and write Chinese and were well enough to give informed consent. The diagnosis of stroke was confirmed clinically and by computed tomography.

The control subjects were matched in terms of the patients' age groups (<45 years, 45 to 65 years, >65 years), gender, and occupation (manual worker, farmer, office worker, professional, other) by healthy individuals from the same community who had no history of seeking medical attention during the previous year.

Materials

A 64-item self-administered form of the General Quality of Life Inventory (GQOLI) was used (the validity, reliability, and sensitivity have been described in detail elsewhere^{16,17}). The GQOLI assesses physical health, psychological health, social functioning, and living condition dimensions, which are further divided into 16 factors. Each item is rated on a 5-point scale. Higher scores denote better QOL.

The Related Factors of Quality of Life Checklist (RFQC) includes the following 4 variables: hierarchy system of perceived needs for future life, the value of needs, referential standard compared with current life, and neuroticism and extroversion personality traits.¹⁸

The Symptom Checklist for stroke patients includes 15 symptoms related to stroke and side effects of treatment.¹⁷ Each symptom is rated on a 5-point scale with a score of 5 representing a normal condition and 1 representing a severe condition.

Stroke severity was defined in terms of level of handicap assessed by the Clinical Rating Scale for Handicap in Nervous System Functioning (CRSH) (Edinburgh and Scandinavian research criteria).¹⁹ Higher scores denote greater stroke severity or poorer functioning.

Outcome variables were identified according to the sum of the changed values of scores on the CRSH and the Global Function Rating Scale (global function is rated on a 7-point scale, whereby 1 represents normal and 7 represents death) 1 year after discharge compared with baseline. Outcomes of stroke were divided into 4 grades of deterioration, no change, improvement, and recovery.¹⁹

Statistical Analysis

The investigators requested patients to complete all the instruments at 2 points in time — 1 week before discharge from hospital (average, 37.9 days after the stroke occurred) and 1 year after discharge. The healthy controls were assessed for baseline data with the GQOLI and RFQC.

During the 1-year period after discharge, patients received stroke rehabilitation and prophylactic therapy such

as antihypertensive agents, aspirin, and physical therapy. Patients were asked not to use alcohol and cigarettes.

Results

Demographic Characteristics

128 patients and 128 matched controls were assessed for baseline data before discharge from hospital. The controls were assessed throughout the study enrolment period. At the second data collection period (1 year after discharge from hospital), 7 patients (5.5%) had withdrawn from the study. Therefore, the sample reported here represents 94.5% of the 128 patients and their matched controls who entered the study.

The mean age of the 121 patients who completed the 1-year follow-up was 60.4 ± 8.1 years (range, 35 to 85 years). The average duration of illness (from stroke to predischARGE evaluation) was 79.6 ± 82.5 days (range, 20 to 167 days) and the mean duration of admission of hospital was 37.9 ± 28.2 days (range, 18 to 64 days). The mean score of the CRSH was 4.7 ± 3.9 (range, 2 to 9). Sixty three patients were male (52.1%) and 58 were female. Fifty six patients had a haemorrhage-type stroke (46.3%), and the remaining 65 had an infarction-type stroke.

Quality of Life

At baseline, the scores for the physical health dimension were significantly lower for the patients than the controls for the 4 factors (Table 1). With the exception of self esteem and body image factors, the scores for the psychological health dimension and other factors were significantly lower for the patients than the controls.

With regard to the social functioning dimension, the scores for the social support and communication factors were notably higher for the patients than the controls and the scores for the recreation and working factors of the social functioning dimension were lower for patients than controls. There were no significant differences in the scores for marriage and family relationship factors between the 2 groups. On the other hand, the score for income and consuming factor of living conditions dimension was significantly lower for the patients than the controls.

The patients were divided into 2 groups according to stroke type to compare the quality of life between these groups. At baseline, no significant difference was found between patients with haemorrhage- and infarction-types of stroke for almost all factors of the GQOLI, with the exception of cognitive functioning. For this factor, the score was significantly lower for patients with haemorrhage-type stroke (9.67 ± 2.14) than for those with infarction-type stroke (12.19 ± 2.08 ; $t = 4.39$; $p < 0.01$).

One year after discharge, the scores for positive and negative feelings were lower for the patients with haemorrhage-type stroke (10.12 ± 2.03) than for those with infarction-type stroke (12.78 ± 2.34 ; $t = 2.48$; $p < 0.05$). There was no significant difference between the 2 groups for the other factors.

Table 1. Inter-group comparison of scores for the factors and dimensions of the General Quality of Life Inventory (± SD).

	Patients (n = 121)	Controls (n = 121)	Paired t test
Physical health dimension	44.15 ± 8.58	56.42 ± 8.71	9.84*
Sleep and energy	11.75 ± 2.61	13.61 ± 2.72	4.75*
Pain and discomfort	10.06 ± 2.89	13.73 ± 2.74	9.78*
Eating and sexual function	11.33 ± 2.31	14.12 ± 3.17	6.71*
Sensory and motor function	11.45 ± 2.75	13.81 ± 2.41	5.73*
Psychological health dimension	51.44 ± 6.29	57.87 ± 8.72	5.64*
Positive and negative feelings	11.96 ± 2.20	14.61 ± 2.91	6.85*
Cognitive function	11.81 ± 2.96	13.78 ± 3.12	4.32*
Self-esteem and body image	14.15 ± 1.84	14.21 ± 2.16	0.20
Level of psychological stress	13.05 ± 2.65	14.98 ± 2.96	4.58*
Social function dimension	51.17 ± 6.66	54.92 ± 5.89	5.17*
Social support and communication	15.33 ± 1.70	14.69 ± 2.37	2.07†
Recreation	11.70 ± 2.54	13.17 ± 2.12	4.19*
Work	9.51 ± 2.34	12.21 ± 1.96	8.34*
Marriage and family relationship	14.52 ± 2.40	14.78 ± 2.21	0.43
Living conditions dimension	51.88 ± 6.45	53.92 ± 8.17	1.85
Housing	15.31 ± 3.02	15.60 ± 4.91	0.47
Income and consuming	11.89 ± 2.21	14.67 ± 2.91	6.91*
Community service	11.73 ± 3.15	11.98 ± 3.10	0.21
Living environment	12.48 ± 2.84	13.10 ± 3.70	1.25

* $p < 0.01$; † $p < 0.05$.

Patients were then grouped according to the outcome assessment of stroke 1 year after discharge. For the patients whose condition deteriorated, the scores for positive and negative feelings, self esteem and body image, social support and communication, and marriage and family relationship factors were lower 1 year after discharge than they were before discharge (Table 2).

For the patients who improved or recovered, the scores for the self esteem and body image, and social support and

communication factors remained significantly lower despite the improvement in physical function during the follow-up period. Furthermore, the scores for the remaining factors of the QOLI and Symptom Checklist (except for marriage and family relationships) significantly increased by the end of the year compared with baseline, although the scores for most of the factors of the QOLI for the patients who improved or recovered had still not reached the normal level of the matched controls.

Table 2. Intra- and intergroup comparison of the change values of scores for the General Quality of Life Inventory and Symptom Checklist between before discharge and 1 year after discharge (± SD).

	1 vs 3* (n=19)	1 vs 5* (n = 19)	2 vs 4* (n = 102)	2 vs 6* (n = 102)
Physical health dimension	-1.67 ± 0.91	-15.7 ± 4.51†	+7.13 ± 1.73†	-4.27 ± 1.46†
Sleep and energy	-0.27 ± 0.38	-3.56 ± 1.09‡	+0.87 ± 0.47‡	-1.09 ± 0.87‡
Pain and discomfort	+1.01 ± 0.98	-3.48 ± 1.09‡	+2.03 ± 0.88†	-1.82 ± 1.01†
Eating and sexual function	-1.78 ± 1.12	-4.12 ± 1.09†	+1.77 ± 0.79†	-1.12 ± 0.67†
Sensory and motor function	-0.65 ± 0.67	-4.16 ± 1.61†	+2.12 ± 1.08†	-0.39 ± 1.01
Psychological health dimension	-9.86 ± 1.87†	-17.98 ± 5.76†	+1.11 ± 1.72	-5.39 ± 1.83†
Positive and negative feeling	-3.57 ± 1.81‡	-6.09 ± 2.67†	+0.98 ± 0.72‡	-1.69 ± 1.09†
Cognitive function	+0.37 ± 1.16	-3.41 ± 0.98*	+1.17 ± 0.57†	-1.08 ± 0.61†
Self esteem and body image	-4.89 ± 1.18†	-4.93 ± 1.28†	-2.07 ± 1.02†	-2.23 ± 1.10†
Level of psychological stress	-1.53 ± 1.79	-3.25 ± 0.76‡	+0.96 ± 0.65‡	-1.12 ± 1.09‡
Social function dimension	-5.28 ± 2.99	-10.38 ± 3.02†	+0.62 ± 0.41	-3.61 ± 1.76†
Social support and communication	-4.14 ± 1.97†	-3.78 ± 1.09‡	-1.13 ± 0.71†	-0.31 ± 0.49
Recreation	+1.76 ± 1.79	+0.75 ± 0.96	+1.31 ± 0.77†	-0.26 ± 0.31
Work	+0.97 ± 0.78	-3.89 ± 1.13‡	+1.77 ± 0.91†	-1.15 ± 0.95‡
Marriage and family relationship	-3.97 ± 1.61‡	-3.79 ± 1.09‡	-0.18 ± 0.48	-0.19 ± 0.63
Total scores on Symptom Checklist	-3.68 ± 2.87		+8.36 ± 2.21†	

* Key: 1 = the scores on QOL at 1 year postdischarge in the deterioration and no change patient group; 2 = the scores on QOL at 1 year postdischarge in the improved and recovered patient group; 3 = the scores on QOL at pre-discharge in the deterioration and no change patient group; 4 = the scores on QOL at pre-discharge in the improved and recovered patient group; 5 = the scores on QOL of controls matched with deterioration and no change patient group; 6 = the scores on QOL of controls matched with the improved and recovered patient group.
† $p < 0.01$; ‡ $p < 0.05$.

Hierarchy System of Needs and Referential Standard of Life

Each patient was asked to choose 1 to 3 items representing their main needs or desires in life and 1 referential standard for life. At baseline, the responses indicated that the highest priority needs or desires for life among the patients were good physical health (88.8%), wealth (27.0%), and realisation of self worth (14.6%). However, among the control group, the highest priority needs or desires for life were wealth (44.4%), happy family and marriage (39.3%), and good physical health (27.1%). The means of values of need level for overall life were 2.73 ± 1.56 for the patients and 3.24 ± 2.11 in the controls ($t = 3.27$; $p < 0.01$).

Forty one percent of the patients compared their present life with an 'ideal self standard for life', 37.0% with 'previous self conditions', and 21.4% with 'conditions of other people', while only 14.7% of controls compared their present life with 'ideal self standard for life', and 36.4% with 'previous self conditions', although 48.9% of controls compared their life with 'conditions of other people'. There were significant differences between the patients and the controls ($\chi^2 = 8.57$; $DF = 2$; $p < 0.025$).

Multiple Regression Analysis of Factors Affecting Quality of Life

According to the theoretical possibility and the results of the univariate analyses, the change values (between 1 week before discharge and 1 year after discharge) of each dimension in GQOLI and Symptom Checklist as dependent variables (Y) were selected. The independent variables were age (X_1), sex (X_2), severity of stroke at baseline (X_3), stroke type (X_4 — the values of the variables were coded as 1 for haemorrhage-type stroke and 2 for infarction-type stroke), duration of illness (X_5 — from stroke to predischage evaluation), patients' expectancy for outcome of stroke at baseline (X_6), patients' values of need level for overall life at baseline (X_7), reference standard of life at baseline (X_8 — the values of the variables were coded for 'conditions of other people' as 1 for no and 2 for yes), neurotic personality (X_9), and extrovert personality (X_{10}). As shown in Table 3, quality of life was best predicted by the severity of stroke, patients' expectancy value for stroke outcome, patients' values of need level for overall life, and Eysenck's neuroticism personality scale.

Discussion

From this study, it can be seen that patients with stroke continue to report substantial impairment for most areas of QOL, including physical health, psychological health, social functioning, and income and consuming factors of the living conditions dimension when compared with healthy controls, despite the results of clinical examination and CRSH evaluation showing that their clinical conditions had improved at discharge. One year after discharge, the clinical conditions of most patients (84.3%) had further improved or they had fully recovered according to the evaluation of outcome criteria. However, most aspects of physical and psychological health dimensions and working conditions of the social dimension of QOL had not reached the normal level of healthy controls, although their scores on most factors of QOLI had risen significantly compared with baseline levels of QOL before discharge.

It was striking that, at baseline, patients did not experience more marriage and family relationship impairment and they received more social support and communication than healthy controls (Table 1). However, 1 year after discharge, the scores for social support and communication, and marriage and family relationship factors for patients whose condition deteriorated were significantly lower than for healthy controls. For the patients whose condition improved or who recovered, these factors decreased to normal.

One explanation considered for the decrease of social and family support over time is the long-term duration of stroke and the family burden of caring for the patients. At the time of onset of first stroke, the cohesion among family members may increase due to stress.²⁰ During the short hospital admission period (mean, 37.63 ± 28.16 days), patients may have perceived more physical and psychosocial support.

As time passes, the long-term burden of taking care of a patient with stroke could impair family cohesion. Family caregivers have to work and pay the family expenses as well as caring for these chronically disabled patients. Meanwhile, the family carers may have less support and intimacy, including a low-quality sexual life (Tables 1 and 2), from the patient than before the onset of the stroke. This could subsequently lead to a decrease in the carers'

Table 3. Standardised regression coefficients of significant ($p < 0.01$) independent variables for predicting the quality of life after stroke.

Y	X_3	X_6	X_7	X_9	R^2	F
Physical health dimension	0.3350	-0.2272			0.4366	4.30*
Psychological health dimension	0.3145	-0.2234	-0.2904	-0.2745	0.4166	3.97*
Social function dimension			-0.3584		0.3962	3.71*
Symptom checklist	0.4042	-0.2982			0.4572	4.56*

Abbreviations: Y = dependent variables; X = independent variables; X_3 = severity of stroke at baseline; X_6 = patients' expectancy for outcome of stroke at baseline; X_7 = patients' values of need level for overall life at baseline; X_9 = neurotic personality.

* $p < 0.01$.

support for the patients. On the other hand, the long duration and chronicity of stroke results in negative feelings and low self esteem for patients,^{5,7,8,12,21} which may impair patients' perceptions of the perceived social and family support.

Another important finding from this study was that the patients did not exhibit more self esteem and body image impairment compared with healthy controls at baseline. However, the score for this factor of QOL increasingly lowered over time. At 1 year after discharge, all patients had a lower self esteem and body image than healthy controls. Some researchers have reported that normal self esteem and body image in stroke patients may be related to neurological disturbances in terms of neglect of body contour, impaired awareness of the disease,⁷ and enjoyment of increased social support after stroke.²¹

In this study, we also found that the scores for social support and communication, and marriage and family relationship factors were parallel with the score for the self esteem and body image factor. Therefore, it is further identified that social and family support plays a critical role in promoting patients' behavioral change and psychological adjustment for coping with stroke.⁷

How can QOL of patients be improved after stroke? As seen in Table 2, one year after discharge, patients whose conditions improved or who were rehabilitated reported significant improvements for nearly all aspects of QOL; whereas the patients whose conditions deteriorated or did not change evaluated their QOL as lower for some aspects or unchanged for others.

Most importantly, as expected, the multiple regression analysis also demonstrated that among all the independent variables, severity of the stroke was a key predictor, being positively related to the physical and psychological health dimensions of QOL. These findings suggest that severity of stroke — mainly the severity of neurological deficits and physical disability — is closely linked with QOL, although it is not the only factor affecting QOL. Another important factor related to QOL was level of needs for overall life.

Calman suggested that QOL was the gap or disparity between one's needs and achievements.²² Thus, the narrower the gap, the higher the quality of life perceived. Specifically, when disease is severely experienced by an individual, almost all aspects of life become health-related. In this study, 88.8% of patients regarded 'good physical health' as their main need in life compared with 27.1% of healthy controls. Obviously, on the one hand, improving the therapeutic effects can lessen the gap and therefore improve patients' QOL, while, on the other hand, lowering the value of needs level for life may be an important way to improve QOL. From our multiple regression analysis (Table 3), we found that higher self evaluations of QOL, especially with regard to psychological health, were related to a lower expectancy for outcome of stroke or lower need level for overall life. After having a stroke, patients may consciously adjust their needs and decrease the value of need level for life in order

to cope with the stress of stroke and thus keep their subjective life perception on a psychologically bearable level. Indeed, this study found that the value of need level for overall life for the patients was significantly lower than that for the controls.

In summary, in the process of a patient's rehabilitation after stroke, in addition to receiving active drugs and physical treatment, more attention should be paid to adjusting a patient's expectancy for outcome of stroke or need for overall life to a more realistic level. Sufficient psychosocial support, enabling patients to be realistic in their self evaluation of their post-stroke restrictions and increasing their chances of fulfilling their responsibilities and enjoying life to the full, is essential.

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