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Quality of life and handicap of stroke survivors in Hong Kong

Key Messages

1. Between 3 and 12 months after first disabling stroke, despite having small but significant improvement in basic functional status, quality of life (QOL) deteriorated significantly in terms of psychological health, social relationships, and perceived living environment, which lead to an increased handicap in terms of orientation.
2. Very old (≥ 80 years) stroke patients are at risk of deterioration in handicap with time.
3. The presence of a spouse predicted a significant decline in physical and environmental QOL.
4. Pain in affected limbs was associated with physical QOL and predicted a significant decline.
5. Depressive mood had a significant and generalised adverse effect on QOL and handicap, while disability in basic activities of daily living was primarily associated with physical and psychological decreases in QOL only.
6. Old-age home residence, lack of physical exercise, and the prescription of soft diets or tube feeding were both associated with poor QOL and handicap.
7. For stroke patients who have residual medical and psychosocial problems that result in deteriorating QOL and handicap months after hospital discharge, the day hospital can offer multidisciplinary assessment, rehabilitation, caregiver training, and counselling.

Introduction

Hong Kong has a comprehensive hospital-based rehabilitative service for stroke patients in the acute and sub-acute phases. But once the functional recovery reaches a plateau, patients are discharged with occasional out-patient clinic follow-up. In the longer term, functional level may remain stable.¹ However, if stroke victims cannot adjust socially and psychologically to the disabilities, they may experience great handicap and loss of quality of life (QOL). Handicap refers to the social disadvantages caused by disability, and QOL is the multidimensional subjective experience.

This prospective study examined the changes in handicap and QOL during the first year of stroke patients. The determinants of handicap and QOL and the risk factors of deterioration in these two areas were examined. The hypothesis was that handicap and QOL after stroke improved with time, as psychosocial adjustment took place.

Methods

This study was conducted from September 2001 to August 2003. Patients with acute stroke in Prince of Wales Hospital (PWH) were identified from the stroke registry. Those with significant pre-morbid handicap (Rankin score >2) were excluded. At 3 months after onset of stroke, eligible subjects were formally recruited either at out-patient clinics in PWH or at home. After obtaining written consent, demographic and clinical details were collected from the subjects: age, sex, marital status, old-age home residence, welfare assistance, education, duration of daily physical exercise, pain in affected limbs, prescription of soft diets or tube feeding; functional status—Barthel index (BI; maximum score, 20), Lawton instrumental activity of daily living (IADL; maximum score, 3); mental status—geriatric depression scale (GDS), mini-mental state examination (MMSE); handicap—London handicap scale (LHS); QOL—WHOQOL-BREF (HK).

The LHS was translated into Chinese and had been validated in Hong Kong.² It consists of six questions covering six domains: mobility, physical independence, occupation, social integration, orientation, and economic self-sufficiency, each scoring from 1 to 6. Higher scores point to greater handicap. The total score of all six domains was used to indicate overall handicap level. Family members gave surrogate responses for LHS in the case of subjects could not reliably respond to the questionnaire.

WHOQOL-BREF (HK) is the shortened form of WHOQOL-100, translated into Cantonese.^{3,4} This version includes 28 QOL questions, covering four domains: psychological health, physical health, social relationship, and the environment. The domain scores were transformed to percentage point scores according to a local normogram.

Barthel index has 10 items of activities of daily living (ADL). The total score of 20 indicates full independence in these activities. Lawton IADL has eight items of activities, each scoring from 0 to 3; higher scores indicate greater independence. The average of the item scores was used as the final score. The GDS has 15 items; its Hong Kong Chinese version has been validated and a

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Table 1. Demographic and clinical characteristics of 303 stroke subjects at 3 months

Characteristic	No. (%)
Age (years)	
<70	117 (39)
70-79	122 (40)
≥80	64 (21)
Female	150 (50)
Old-age home	58 (19)
Widowed/single/divorced	119 (39)
Education for <3 years	126 (42)
Comprehensive Social Security Assistance	80 (26)
Physical exercise per day	
≥1 hour	45 (15)
20-59 minutes	119 (39)
<20 minutes	139 (46)
Pain in affected side	
Mild	61 (20)
Moderate/severe	30 (10)
Diet	
Soft/puree	33 (11)
Tube feeding	23 (8)

score of 8 or more indicates depression. The Hong Kong Chinese version of the MMSE has been validated. Out of a maximum score of 30, the optimal cut-off point for dementia varies from 18 in illiterate subjects to 22 among those with more than 2 years of schooling.

All measurements were repeated in the subjects' own homes or in out-patient clinics at 6 and 12 months after onset of stroke. Subjects who had recurrence of stroke or other disabling conditions continued to be followed up.

Results

Three hundred and three subjects were recruited 3 months

after onset of stroke. The baseline demographics and clinical characteristics of the subjects are shown in Table 1. Six patients had another stroke and 10 were admitted to old-age homes between 3 and 12 months' follow-ups.

The functional status, handicap, mood, and QOL scores of all subjects 3 to 12 months after stroke are shown in Table 2. At 3 months, 139 (46%) subjects had full BI scores of 20; 73 (24%) were dependent (BI <15). Ninety-four (36%) of 263 subjects had GDS scores of 8 or over, indicating clinically significant depression.

The QOL data were available in 247 (82%) subjects. The ones with missing QOL data had greater age (median, 80 vs 71 years in those with QOL data) and GDS (11 vs 5), lower MMSE (10 vs 25) and BI (6 vs 20). All differences were highly significant ($P < 0.001$, Mann-Whitney U test).

There was a significant improvement in BI and MMSE. But there was a significant increase in GDS, and QOL in terms of social relationships and environment decreased. There was no significant change in total LHS, but handicap in terms of mobility and social integration decreased, while handicap in terms of orientation increased.

Most of the follow-up visits at 6 and 12 months were conducted in the subjects' own homes. Six subjects dropped out at 6 months, and 31 more dropped out at 12 months: 16 died, two suffered from terminal illness, seven moved to Mainland or overseas, seven lost contact, four refused to cooperate, two were in hospital. When compared with those with complete data, the dropout subjects had greater age (median, 77 vs 72 years; $P = 0.011$, Mann-Whitney U test) and lower BIs (17 vs 19, $P = 0.005$).

Table 2. Changes in functional status, mood, handicap, and quality of life in the first year of stroke

Parameter	3 months (T_3)		6 months (T_6)		12 months (T_{12})	
	No.	Score [†]	No.	Change ($T_6 - T_3$) [†]	No.	Change ($T_{12} - T_3$) [†]
Barthel index (max, 20)	303	19 (15, 20)	297	0 (0, 0)	268	0 (0, 1.0) [‡]
IADL (max, 3)	303	1.1 (0.1, 1.4)	297	0 (-0.1, 0)	268	0 (-0.1, 0.1)
MMSE (max, 20)	285	24 (19, 28)	271	0 (-1, 2)	251	0 (-2, 2) [§]
GDS (max, 15)	263	5 (2, 10)	254	0 (-1, 2)	227	1 (-1, 2) [§]
WHO QOL (max, 100)						
Physical	247	56 (44, 69)	237	0 (-7, 6)	213	0 (-9.5, 7.0)
Psychological	247	56 (44, 70)	237	0 (-7, 6)	213	0 (-12, 6) [‡]
Social	247	69 (56, 75)	237	0 (-6, 0)	213	0 (-12, 0) [§]
Environmental	247	69 (63, 75)	237	0 (-12, 0)	213	0 (-12, 6) [§]
LHS domain (max, 6)						
Mobility	303	3 (1, 3)	296	0 (0, 0)	268	0 (-1, 0) [§]
Independence	303	3 (2, 4)	296	0 (0, 0)	268	0 (0, 0)
Occupation	303	3 (1, 5)	296	0 (0, 0)	268	0 (0, 1)
Social integration	303	2 (1, 3)	296	0 (0, 0)	268	0 (-1, 0)
Orientation	303	2 (1, 3)	296	0 (0, 0)	268	0 (0, 1) [§]
Economic	303	2 (2, 4)	296	0 (0, 0)	268	0 (0, 0)
Total LHS (max, 36)	303	16 (11, 20)	296	0 (0, 0)	268	0 (-2, 2)

* IADL denotes instrumental activity of daily living, MMSE mini-mental state examination, GDS geriatric depression scale, WHO QOL World Health Organization-Quality of Life Questionnaire (abbreviated Cantonese version), and LHS London handicap scale

[†] Values shown as median (25th, 75th percentile)

[‡] $P < 0.05$, Friedman test

[§] $P < 0.005$, Friedman test

Table 3. Estimated effect on London handicap scale score (LHS) and quality of life (QOL) domain percentage scores due to independent factors on multilevel multivariate analysis*

Variable [†]	Total LHS	QOL domains			
		Physical	Psychological	Social	Environmental
6 months					-2.8 (-1.2, -4.4)
12 months	0.3 (0.2, 0.4)			-2.5 (-0.7, -4.3)	-1.8 (-0.2, -3.4)
Female		-5.0 (-2.6, -7.4)			
Old-age home	6.7 (5.7, 7.7)				-5.3 (-1.5, -9.1)
Education					
None [‡]					
Primary	-2.0 (-0.9, -3.1)				
Secondary	-3.4 (-2.2, -4.7)				
Welfare assistance					
None [‡]					
CSSA		-4 (-0.6, -7.4)	-4.2 (-0.8, -7.6)		
DA		-4.6 (-1.4, -7.8)	-3.4 (-0.4, -6.8)		
OAA					
Diet					
Normal [‡]					
Soft/tube-fed		-4.2 (-0.8, -7.6)			
Pain in affected side					
No [‡]					
Mild					
Moderate/severe		-4.9 (0.9, -8.9)			
Physical exercise					
≥1 h/day [‡]					
20-59 min/day	-1.0 (-0.2, -1.7)				
<20 min/day			-3.1 (-0.1, -6.1)	-3.9 (-0.9, -6.9)	
Barthel index	0.01 (0, 0.001)	1.2 (0.8, 1.6)	0.6 (0.4, 0.8)		
GDS	0.3 (0.2, 0.4)	-1.8 (-1.4, -2.2)	-2.6 (-2.4, -2.8)	-1.2 (-0.8, -1.6)	-2.0 (-1.6, -2.4)

* Values are shown as coefficient (95% confidence intervals); non-significant factors were left blank, non-significant factors examined were as follows: age, sex, marital status, Instrumental Activities of Daily Living, mini-mental state examination, National Institutes of Health Stroke Scale on admission

[†] CSSA denotes Comprehensive Social Security Assistance; DA disability allowance, OAA old-age assistance, and GDS geriatric depression scale

[‡] Reference category

On multilevel multivariate regression analysis of all data collected at all three time points, the significant independent determinants of total LHS scores and the four domains of WHOQOL are shown in Table 3. Twelve months after stroke was associated with a small significant decrease in social and environmental QOL and a small increase in total LHS. Geriatric depression scale was associated with all QOL domains and LHS, while BI was associated with physical and psychological QOL, and minimally with LHS.

At 12-month follow-up, QOL data were available in 213 subjects, and total LHS scores were available in 263 subjects. Among those with available data, 53 (25%), 65 (31%), 58 (27%), 57 (27%) subjects declined by 8 percentage points or more in physical, psychological, social, and environmental domain scores, respectively. Fifty-four (17.8%) had total LHS score increased by 3 points or more. The significant factors to predict decline in QOL and handicap are shown in Table 4. No covariate was associated with decline in social QOL.

Discussion

This prospective cohort study showed that after the first 3 months of a stroke, QOL deteriorated significantly in terms of psychological health, social relationships, perceived living environment, and increased handicap related to orientation. Aged 80 years or more was predictive of an increase in

handicap. Being married and pain were associated with a significant decrease in QOL. Depression had a negative effect on all four domains of QOL and handicap, while the negative effect of physical disability as reflected by BIs was primarily in physical and psychological QOL. Lack of physical exercise, need for soft diets or tube feeding, old-age home placement were other potentially modifiable QOL and handicap factors.

The cohort had a wide range of disability, but nearly half of the subjects were independent in terms of basic ADL. Approximately 12% of subjects were unable to respond to the QOL questionnaire. Those who could not be assessed for QOL were older and had more severe strokes. The dropout rate was 12%. The dropouts tended to be older and more severely disabled. The outcomes of those who completed the study would therefore be biased towards the more favourable.

There was a reduction in mobility handicap with time, but handicap in terms of orientation increased. Handicap in terms of orientation may be countered by better access to information, eg going out, recourse to telephones, newspapers, radios, television, and the internet. Special attention should be paid to the very old (≥80 years) stroke patients who were more likely to have significant increases in handicap with time. Diminished social network, and visual and hearing loss are probable contributory factors.

Table 4. Variables at 3 months associated with significant decline in quality of life (QOL) and increase in handicap at 12 month*

Variable [†]	Decline in QOL			Increase in London handicap scale score, n=54
	Physical, n=53	Psychological, n=65	Environmental, n=57	
Age (years)				
<70 [‡]				
70-79				
≥80				4.39 (1.56, 12.37)
Married				
No [‡]				
Yes	3.05 (1.22, 7.63)		2.87 (1.12, 7.35)	
Pain				
No [‡]				
Mild	2.60 (1.03, 6.53)	2.81 (1.16, 6.77)		
Moderate/severe		5.36 (1.46, 19.68)	6.85 (1.73, 27.16)	
GDS				
<8 [‡]				
≥8	0.30 (0.12, 0.73)	0.30 (0.13, 0.69)	0.22 (0.09, 0.56)	
MMSE				
≥20 [‡]				
<20			3.34 (1.05, 10.57)	

* Values are shown as odds ratio (95% confidence intervals) on multiple logistic regression; non-significant odd ratios were not shown; non-significant variables included education, old-age home residence, prescription of soft diets or tube feeding, Barthel index group

[†] GDS denotes geriatric depression scale; and MMSE mini-mental state examination

[‡] Reference category

Formal and informal caregivers should take a proactive role in helping these disabled older people to maintain connections with their outside world.

The QOL of the stroke subjects was worse in the physical and psychological domains. When compared with BIs, depression had a more generalised effect on QOL and handicap. Depression was present in over one third of our subjects. Antidepressants for post-stroke depression are effective in improving mood, functional recovery, and reducing mortality in the long term.⁵ It is therefore very important to actively look for post-stroke depression and initiate antidepressants.

We hypothesised that QOL would improve with time, as psychosocial adjustment took place. However, this was not the case in our cohort. The decline in QOL was primarily in the environmental and social domains. The decline in environmental QOL is consistent with an increase in handicap related to orientation. Apart from depression, the other important determinant of environmental QOL, residence in an old-age home was also associated with handicap. There is much that old-age home operators can do to improve the environment and quality of care. Access to outside information and communication with family members and friends are important.

The two main predictive factors were pain and being married. Pain in the affected limbs was a determinant of physical QOL, but more importantly predictive of decline in all except social domains of QOL. A painful shoulder, thalamic pain, and spasticity pain are amenable to medical treatments. It was surprising that having a spouse should be associated with a decline in environmental as well as physical domains. How the spouses viewed and managed the stroke patients' disabilities or illness might have a

significant influence on their QOL. For example, the spouse caregivers may overprotect stroke patients, making them feel physically inadequate and restrict their living environment. Psychosocial support and education of family caregivers, particularly the spouse caregivers, should be part of the continuing care of stroke patients.

The decline in social QOL was not associated with a significant change in handicap in terms of social integration. In addition, none of the baseline variables could predict the decline in social QOL. It is possible that we have missed some important variables relevant to this domain of QOL, eg stigma,⁶ or self-esteem.⁷

No or minimal physical exercise was associated with social and psychological QOL decline. The psychosocial benefits of physical exercises in disabled people are well recognised.⁸ In those who are immobile, resistance or passive exercises are feasible and may be beneficial. Group exercises when supervised by allied health professionals may confer health benefits in chronic stroke subjects.⁹

It was unexpected that depression as indicated by high GDS was associated with reduced risk of decline in psychological as well as physical and environmental QOL. Rather than suggesting that depressed stroke patients improved with time, this suggested that depression after stroke could develop late, as the overall trend was an increase in GDS. Therefore doctors and other health care professionals who look after stroke patients should be vigilant for the late development of depression, and initiate appropriate treatment.

The prescription of soft diets and tube feeding was associated with poor physical QOL. The discomfort of tube feeding is well known. Even soft and puree diets limit the

choice of foods, and are associated with under-nutrition because of loss of appetite. The recovery of swallowing ability after stroke can be delayed.¹⁰ The need for tube feeding and soft diets should be regularly reviewed.

Based on our study findings, many stroke patients have residual medical and psychosocial problems, resulting in deterioration in QOL and handicap, months after hospital discharge. For these patients, day hospital can offer multidisciplinary assessment, rehabilitation, caregiver training, and counselling.

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References

1. Sim TC, Lum CM, Sze FK, Or KH, Sum C, Woo J. Outcome after stroke rehabilitation in Hong Kong. *Clin Rehabil* 1997;11:236-42.
2. Lo R, Harwood R, Woo J, Yang F, Ebrahim S. Cross-cultural validation of the London Handicap Scale in Hong Kong Chinese. *Clin Rehabil* 2001;15:177-85.
3. Leung KF, Tay M, Cheng S, Lin F. Hong Kong Chinese version World Health Organization Quality of Life—Abbreviated version. Hong Kong: Hospital Authority; 1997.
4. World Health Organization. Development of the WHOQOL-BREF from the WHOQOL-100. Geneva: WHO; 1997.
5. Robinson RG. Poststroke depression: prevalence, diagnosis, treatment, and disease progression. *Biol Psychiatry* 2003;54:376-87.
6. Van Wylen MD, Dykema-Lamse J. Feelings group for adult day care. *Gerontologist* 1990;30:557-9.
7. Lau A, Chi I, McKenna K. Self-perceived quality of life of Chinese elderly people in Hong Kong. *Occup Ther Int* 1998;5:118-39.
8. Lee DT, Lee IF, Mackenzie AE, Ho RN. Effects of a care protocol on care outcomes in older nursing home patients with chronic obstructive pulmonary disease. *J Am Geriatr Soc* 2002;50:870-6.
9. Lai JC, Woo J, Hui E, Chan WM. Telerehabilitation—a new model for community-based stroke rehabilitation. *J Telemed Telecare* 2004;10:199-205.
10. Lee JS, Tse SL, Tsze SC, Kwok T. Protein malnutrition is adversely associated with swallowing recovery in tube-fed older people. *J Am Geriatr Soc* 2004;52:1588-9.