ORIGINAL ARTICLE

Community integration and its relation to quality of life among post-stroke patients

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Abstract:

This study aims to identify the level of participation and activity after stroke (community integration), quality of life (QOL) and to determine whether there is any relationship between the level of participation and activity after stroke and QOL among post-stroke patients. This was a cross-sectional study by using Community Integration Questionnaires (CIQ) and Stroke Specific Quality of Life-12 (SSQOL-12). Participants were 21 men and 13 women attending rehabilitation treatment at National Association of Stroke Malaysia. Thirtyfour post-stroke patients with mean age of 64.5±12.0 years participated in this study. The mean CIQ and SSQOL-12 total scores were 11.9±4.8 and 40.2±5.8 respectively. The level of participation and activity among post-stroke patients was low in this study and QOL was found to be in moderate. A positive correlation was found between the level of participation and activity and QOL among them ($r= 0.42$, $p< 0.05$). Resulst of QOL and degree of participation in the community are the indicator of the successful stroke recovery. A low level of participation, indicating a need for occupational therapy (OT) to be more active in organizing support groups or community-based rehabilitation for post-stroke patients, otherwise, it will lead to worsening function and QOL.

Keywords: Community-based rehabilitation, participation, quality of life, stroke,

1. INTRODUCTION

Stroke remains a significant public health concern worldwide because stroke is the most common cause of neurological disability. Globally, 16.9 million people are estimated experienced stroke annually. In the 5-year study period, the incidence and prevalence of stroke in Malaysia increased dramatically [1]. Almost 60% of patients remain disabled among those who are survived and every year, in Malaysia around 40, 000 become disabled due to stroke [2,3].

Community integration after stroke, which consists of several crucial elements, including participation in activities at home or a setting like home, engagement in productive activities, and establishment and enjoyment of a social network relatively paid the less attention [4]. It is not only by health care teams but researchers also do not focus on participation after stroke. Daily activities is not the only crucial for living but also social roles such as set of rights, duties, expectations, norms and behaviours that a person has to face and fulfil are mainly needed for well-being [5].

Issues revolving around community and role integration can possibly has a huge impact on QOL of the stroke patient and community reintegration decreases so does the post-stroke patients' quality of life [6]. Low level of participation has been associated with feeling of sadness, loss of interest in things persistently, social isolation and deterioration of quality of life [7]. Being able to reintegrate back into the community and re-engage in work and social activities, even in the early phase of the post-stroke conditions is a major key in influencing a greater quality of life [8].

Most of studies about post-stroke rehabilitation were conducted in other countries. Study in Malaysia did not emphasize the relationship between the level of participation, activity, and QOL among post-stroke patients. This led to the researcher to conduct this study with the following objectives to: 1) identify the level of participation and activity after stroke, both in the community and home among post-stroke patients, 2) identify the quality of life among post-stroke patients, 3) determine whether there is any relationship between the level of participation and activity after stroke and quality of life among post-stroke patients.

2. MATERIALS AND METHOD

This was a cross-sectional study. The ethical approval was obtained from the Ethics Committee of Universiti Teknologi Mara (UiTM). Permission to conduct this study was also gained from the National Stroke Association of Malaysia (NASAM).

2.1 Subjects

The subjects in this study were recruited from NASAM. The eligibility requirements included post-stroke patients aged above 18 years old, had first-time post-stroke and more than 6 months as well as able to comprehend in English. Post-stroke patients who suffered from aphasia and psychiatric conditions were excluded from the study. The survey was conducted by distributing the questionnaires to them.

2.2 Instruments

Community Integration Questionnaire (CIQ)

CIQ is used in this study to measure the level of participation and activity after stroke, both in the community and in the home [9]. It comprises 18 questions to assess reduction in handicap or effective role performance in four areas, home integration, social integration, productivity and electronic social networking. Higher scores represent greater levels of community integration. The CIQ-R can be administered via self-completion, face-to-face or telephone interviews.

Stroke Specific Quality of Life -12 (SSQOL-12)

SSQOL-12 consists of 12 questions from physical and psychosocial dimensions to be used with patients with ischemic stroke and intracerebral hemorrhage. SS-QOL-12 can be administered by face to face interview or self-administer by the participants. The higher the score indicates better quality of life among stroke patients. SS-QOL-12 have good criterion validity for all items that were selected from the original version [10]. In the development sample, the item domain correlations of the selected items were very high between 0.85- 0.95.

2.3 Data Analysis

The data were analyzed using the Statistical Program for Social Sciences version 21 (SPSS-21). Descriptive statistics were used to analyze the characteristics of the subjects and reported in the frequency and percentage. In order to describe the distribution of the data, a mean (standard deviation – SD), Pearson r (to determine relationship) were conducted. The Pearson correlation was conducted to determine the relationship of between the community integration and quality of life post-stroke patients.

3. RESULT

3.1 Demographics

The demographic background of participants are depicted in Table 1. Overall, there were n = 34 participants in total; which 21 (61.8%) were male and 13 (38.2%) were female. Most of them were Chinese 30 (88.2%). Other ethnic came from 3 (8.8%) Malay and only 1 (2.9%) Indian. The participants consisted of more Buddha religion 24 (70.6%) compared to Christian, Islam, and no religion which shared the same number 3 (8.8%) and only 1 (2.9%) Hindu.

For marital status, 26 (76.5%) were married and 4 (11.8%) were single and divorce respectively. In this study have similar proportions of pre-stroke occupation where 17 (50%) employed and unemployed. For post-stroke occupation, only 3 (8.8%) were continued employed and the balanced were 31 unemployed (91.2%). For the educational level, majority were secondary higher (SPM) 21 (61.8%) followed by tertiary, secondary lower and primary level, 7 (20.6%), 3 (8.8%) respectively. Among the total number of participants, 21 (61.8%) experienced right site lesion, whereas 13 (38.2%) left site lesion. Moreover, most of the participants in this study 19 (55.9%) had ischemic stroke and 15 (44.1%) of the participants had haemorrhagic stroke.

For medication, majority of the participants 31 (91.2%) were taking medications for stroke whereas 3 (8.8%) not taking any medication. Based on the study, all participants 34 (100%) had undergone rehabilitation program likes occupational therapy, physiotherapy and speech therapy.

Table 1: Demographic profile of participants (n = 34)

Characteristic		n	%
Gender	Male	21	61.8
	Female	13	38.2
Ethnicity	Chinese	30	88.2
	Malay	3	8.8
	Indian	1	2.9
	Others	0	0
Religion	Islam	3	8.8
	Hindu	1	2.9
	Buddha	24	70.6
	Christian	3	8.8
	No religion	3	8.8
Marital status	Single	4	11.8
	Married	26	76.5
	Divorced	4	11.8
Educational qualification	Primary	3	8.8
	Secondary lower (PMR, SRP)	3	8.8
	Secondary higher (SPM)	21	61.8
	Tertiary (University level)	7	20.6
Occupation	Pre stroke:		
	Employed	17	50.0
	Unemployed	17	50.0
	Post-stroke		
	Employed	3	8.8
	Unemployed	31	91.2
Site of lesion	Right	21	61.8
	Left	13	38.2
Stroke subtypes	Ischemic stroke	19	55.9
	Hemorrhagic stroke	15	44.1
Medication	Yes	31	91.2
	No	3	8.8
Treatment	Had undergone rehabilitation programme (PT/OT/ST)	34	100.0
	Never undergone a rehabilitation programme	0	0

3.2 Community Integration

Table 2 below showns the mean and standard deviation for variables in community integration. Based on CIQ, the scores for home integration are 2.41 (2.36) out of 12, social integration 5.38 (1.94) out of 10, productivity 2.06 (0.69) out of 7 and electronic social network 1.97 (1.53) out of 6 respectively. The mean for the total CIQ for all 34 post-stroke patients in this study was 11.88 (10.12) out of 35 with the highest score of 24 and the lowest score of 3 out of 35.

Table 2: Community integration score

No	Variables	Mean (SD)
1)	Home Integration	2.41 (2.36)
2)	Social Integration	5.38 (1.94)
3)	Productivity	2.06 (0.69)
4)	Electronic Social Network	1.97 (1.53)
5)	Community Integration	11.88 (4.77)

3.3 Quality of Life

Table 3 shows the mean and standard deviation for variables in quality of life. Based on SSQOL-12, the scores for physical dimensions are 24.91 (4.14) out of 30 and psychosocial dimensions are 15.26 (4.19) out of 30 respectively. The total mean for SSQOL-12 for all 34 post-stroke patients in this study was 40.18 (5.77) with a higher score of 49 and the lowest score of 26 out of 60.

Table 3 Quality of life score

No	Variables	Mean (SD)
1)	Physical dimensions	24.82 (4.08)
2)	Psychosocial dimensions	15.21 (4.13)
3)	Quality of Life	40.03 (5.77)

3.4 Relationship between the level of participation and QOL

Table 4. reveals the correlations of the level of participation and activity and quality of life among post-stroke patients. The correlation coefficient between the level of participation and activity and quality of life is equal to 0.415 in statistical sample and the significance level equal to 0.015, the hypothesis of existed correlation can be accepted with the confidence of 95%. In other words, there is a significant direct correlation between the level of participation and quality of life. Correlation is an effect size so can verbally describe the strength of the correlation using the guide that Evans (1996) suggests for the absolute value of r: .40-.59 “moderate”.

There was a positive correlation between the electronic social network component in CIQ and physical domain in SSQOL-12, r (34) = .032, p<0.05. For the variables of total CIQ and physical domain in SSQOL also shown that there was a positive correlation (r (34) = .407, p< 0.05).

Table 4. Relationship between level of participation and QOL

No	Variables Pearson (*r*) Sig. Value (*p*)		SSQOL-12: Physical domain	Total SSQOL-12
1)	**CIQ: ESN**	*r*	0.369	0.285
		p	0.032*	0.102
2)	**Total CIQ**	*r*	0.407	0.415
		p	0.017*	0.015*

* Correlation is significant at the 0.05 level (2-tailed)

ESN= Electronic Social Network

4. DISCUSSION

4.1 Level of participation and activity after stroke

The findings of the study revaled that the majority of the participants are low in overall community integration. The mean total CIQ score is way far from the normative data made by the authors of the questionnaires [11]. Apart from it is a normative data, there also may be some reasons for the differences in the results such as the different of study context and culture.

In this study, most participants preferred relying on others in home integration. It is observed and stated that more than 90% of stroke survivors received care from their kin [12]. In Malaysian culture, most of the 60 years old and above citizen stayed together with their children. Some household hired a maid to help and taking care of their disabled parents and the consequences are it will make the parents become more dependent and relying on others.

The restrictions in participation and activity also can be related to a low physical functioning especially stability level. The occurrence of trips is one of the most frequent happen in stroke patients particularly when they are walking outside in the community and public. Stroke survivors had low to moderate level of reintegration into everyday activities and only 10% of the study participants were able to achieve full integration after rehabilitation [13].

4.2 Quality of life among post-stroke patients

This study found that the majority of the participants are at a moderate level of quality of life-based on their mean and standard deviation. This may be due to the background of the participating were from urban areas which are in Petaling Jaya and Penang. The participants in this study were also from a moderate educational background and they had awareness about stroke rehabilitation. Moreover, majority of them stayed with their children who mostly received high school education and university and the children will have awareness towards a better quality of life for their parents. Besides, most of them are capable in terms of financials and because the house is located in urban areas, there is a lot of facilities provided and easily reached.

The findings of this study are supported by a survey among stroke survivors in Korea; which concluded that people in urban areas are more satisfied in QOL compared with those

in rural areas [14]. All post-stroke survivors in this study had a stroke for more than 6 months so most of them showed moderate in QOL where they can adapt to their life. This finding is in agreement with the previous study where the result showed improvements in QOL a year after stroke [15]. In contrast to this current finding, a study based in Hong Kong stated that QOL at a 3-month follow-up which is in an acute state was higher than the chronic state [16].

4.3 Relationship between the level of participation and activity and quality of life

This study found that there is a significant correlation between the level of participation and activity and quality of life among post-stroke patients. This finding is in agreement with a previous study which found that as the level of participation improves, so does the QOL among post-stroke patients [6]. Participants with better social participation were reported to have higher QOL [17, 18]. In a large observational study, the result showed the physical functioning, optimism and social support related to well-being, and it was correlated significantly with the meaning of life [19].

A study based in Canada also found that the greatest deterioration in QOL was related to declining participation in leisure activities as well as unproductivity [20]. Poor social roles, work, and productivity indicated that most post-stroke patients did not have meaningful activity and did not get back to work after stroke gave an impact on QOL. Majority of the stroke survivors that had been working before the stroke attack did not continue and resume their work after that and those who are returning to work usually worked in a week about only one to sixteen hours [21]. By looking at the levels of unemployment, this statement holds true as the post-stroke patients' QOL was poor especially in the work and productivity domains [22].

5. CONCLUSION

The level of participation and activity is lower among the participants in this study because they were dependent on the carers and physical limitations due to the medical conditions and age factor. Moderate level of QOL was shown by the participants because of the sample taken from urban areas which might contribute to the findings. The positive correlation was also found between the level of participation and activity and QOL among post-stroke patients. It is believed that the findings from this study would be beneficial when planning appropriate care or rehabilitation programs to improve the participation and QOL of patients with stroke in Malaysia. From this findings, the therapist needs to emphasize not only the physical stage of the patients which act as a barrier to get a better quality of life to post-stroke patients; but also psychosocial aspects including the emotional part that play an important role in stroke rehabilitation.

5.1 Limitation of the study

This study possesses certain limitation. First, this study had a small sample size. Secondly, patients who had severe language or cognitive impairment were excluded in the present study, leading to some bias against patients who could not express their views. Moreover, this study is based on patients experience from one organization only. This study was also involving patients from urban areas only.

5.2 Recommendations

There is a limited study of the level of participation and QOL that have been conducted in Malaysia, more study about these should be conducted so that appropriate intervention and management of the problem can be provided by the health provider thus can help the post-stroke patient to improve their quality of life in Malaysia. In the future, it is recommended to assess and explore the satisfaction of participation as well, so we can know more details on what post-stroke patients felt. To make a stronger generalizations, the study group should be larger and participants should be from different healthcare settings that provide different management such as patients that attend rehabilitation service from non-government organizations (NGOs) and also hospital should be interviewed. Moreover, it is best to conduct both in urban and rural areas to know the differences between the two settings.

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REFERENCES

[1] Aziz, Z. A., Lee, Y. L., Ngah, B. A., Sidek, N. N., Looi, I., Hanip, M. R.,& Basri, H. B. (2015). Acute stroke registry Malaysia, 2010-2014: results from the national neurology registry. *Journal of Stroke and Cerebrovascular Diseases, 24*(12), 2701–2709

[2] Manaf, H., Justine, M., Omar, M., Md Isa, K. A., & Salleh, Z. (2012). Turning Ability in Stroke Survivors: A Review of Literature. *ISRN Rehabilitation, 2012*, 1–8. https://doi.org/10.5402/2012/284924

[3] NASAM (2018). http://www.nasam.org/english/prevention-what_is_a_stroke.php.

[4] Pang, M. Y. C. (2013). Community reintegration after stroke. *Hong Kong Physiotherapy Association*, 1013-7025. http://dx.doi.org/10.1016/j.hkpj.2013.07.002

[5] Desrosiers, J., Noreau, L., Rochette, A., Bourbonnais, D., Bravo, G., & Bourget, A. (2006). Predictors of long-term participation after stroke. *Disability and Rehabilitation, 28*(4), 221–230. https://doi.org/10.1080/09638280500158372

[6] Kusambiza-Kiingi, A., Maleka, D. & Ntsiea, V. (2017). Stroke survivors' levels of community reintegration, quality of life, satisfaction with the physiotherapy services and the level of caregiver strain at community health centers within the Johannesburg area. *African Journal of Disability, 6*(0), a296. https://doi. org/10.4102/ajod.v6i0.296

[7] Wood, J. P., Connelly, D. M., & Maly, M. R. (2010). Getting back to real living': a qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation, 24*, 1045–1056

[8] Tse, T., Yusoff, S. Z., Churilov, L., Ma, H., Davis, S., Donnan, G. A., Carey, L. M.,& the START research team. (2017). Increased work and social engagement is associated with increased stroke-specific quality of life in stroke

survivors at 3 months and 12 months post-stroke: a longitudinal study of an Australian stroke cohort. *Topics in Stroke Rehabilitation*. DOI: 10.1080/10749357.2017.1318339

[9] Muller, M., Toth-Cohen, S., & Mulcahey, M. J. (2014). Development and Evaluation of a Hospital-Based Peer Support Group for Younger Individuals with Stroke. *Occupational Therapy In Health Care, 28*(3), 277–295. DOI: 10.3109/07380577.2014.919551

[10] Post, M. W. M., Boosman, H., Zandvoort, M. M. V., Passier, P. E. C. A., Rinkel, G. J. E., & Visser-Meily, J. M. A. (2011). Development and validation of a short version of the Stroke Specific Quality of Life Scale. *Neurol Neurosurg Psychiatry, 82*, 283-286. doi:10.1136/jnnp.2009.196394

[11] Callaway, L., Winkler, D., Tippett, A., Migliorini, C., Herd, N. & Willer, B. (2014). The Community Integration Questionnaire-Revised (CIQ-R). Melbourne, Australia: Summer Foundation Ltd.

[12] Suttiwong, J., Vongsirinavarat, M., & Hiengkaew, V. (2018). predictors of community participation among individuals with first stroke: a Thailand study. *Annals Of Rehabilitation Medicine, 42*(5), 660–669. doi:10.5535/arm.2018.42.5.660

[13] Olaoye, O. A., Adejumobi, A. S., Olasusi, A. O., Aladesuyi, O. B., & Emechete, A. A. I. (2017). Relationship between community integration and life satisfaction among stroke survivors dwelling in rural communities of Southwest, Nigeria. *J Environ Occup Sci, 6*(1), 19-26. DOI: 10.5455/jeos.20170416072212

[14] Jun, H. J., Kim, K. J., Chun, I. A. (2015). The relationship between stroke patients' socio-economic conditions and their quality of life: the 2010 Korean community health survey. *J Phys Ther Sci, 27*, 781–4.doi:10.1589/jpts.27.781

[15] Chuluunbaatar, E., Chou, Y.-J., & Pu, C. (2016). Quality of life of stroke survivors and their informal caregivers: A prospective study. *Disability and Health Journal, 9*(2), 306–312. doi:10.1016/j.dhjo.2015.10.007

[16] Kwok, T. L. R., Wong, E., Wai-Kwong, T., Mok, V., Kai-Sing, W. (2006). Quality of Life of Stroke Survivors: A 1-Year Follow-Up Study. *Archives of Physical Medicine and Rehabilitation, 87*(9): 1177-82

[17] Howitt, S. C., Jones, M. P., Jusabani, A., et al. (2011). A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. *J Neurol, 258*, 1422–30.doi:10.1007/s00415-011-5948-6

[18] Wang, R., & Langhammer, B. (2017). Predictors of quality of life for chronic stroke survivors in relation to cultural differences: a literature review. *Scand J Caring Sci*, doi: 10.1111/scs.12533

[19] Shao, J., Zhang, Q., Lin, T., Shen, J., & Li, D. (2014). Well-being of elderly stroke survivors in Chinese communities: mediating effects of meaning in life. *Aging & Mental Health, 18*(4), 435-443

[20] Edwards, J. D, Koehoorn, M., Boyd, L. A., & Levy, A. R. (2010). Is health-related quality of life-improving after stroke? A comparison of health utilities indices among Canadians with stroke between 1996 and 2005. *Stroke, 41*, 996–1000

[21] Van der Zee, C. H., Visser-Meily, J. M. A., Lindeman, E., Jaap Kappelle, L., & Post, M. W. M. (2013). Participation in the Chronic Phase of Stroke. *Topics in Stroke Rehabilitation, 20*(1), 52–61. doi:10.1310/tsr2001-52

[22] Ntsiea, M.V., Van Aswegen, H. & Lord, S., (2015). The effect of a workplace intervention program on return to work after stroke: A randomised controlled trial'. *Clinical Rehabilitation, 29* (7), 663–673. https://doi.org/10.1177/0269215514554241