

The Conceptual Framework for Development of Quality of Life Assessment in Stroke Patients According to Icf Model: Narrative Review

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Abstract

The incidence of stroke was increasing worldwide. The complications following stroke affected the quality of life (QOL) in stroke patients. The QOL is an important indicator which provided an information of succeed in treatment plan. Since an International Classification of Functioning, Disability and Health (ICF model) was created as a framework for the measurement of functional disability that is utilized among physicians, nurses and rehabilitation-related allied health professionals to develop a more comprehensive treatment plan, it was lacking of QOL assessment aspect. Hence, added QOL assessment in ICF model could be an effective tool which promotes an effective treatment plan. Moreover, no available study which use ICF model outcome able for reflect all domains of QOL in stroke patients. The present study aims to introduce a conceptual framework that is compliant with ICF model for the development of the assessment in which outcome is able to reflect all domains of QOL. Results There were various available QOL assessment such as General HRQOL questionnaire and Specific HRQOL questionnaire. However, among those available QOL assessment tools, they still incomplete to represent the QOL of stroke patients. Therefore, we provided a new conceptual framework for cover all QOL aspects. The information provided in the present study could be beneficial for a healthcare provider in their treatment plan which leads to an effective treatment plan to improved QOL in stroke patients. Conclusion, A conceptual framework for QOL assessment in stroke patients that cover all aspects of life as stated by the ICF model in which measuring outcomes able to aid better treatment planning and yield an effective rehabilitation outcome.

Keywords: Quality of Life, quality of life assessment, stroke, International Classification of Functioning, Disability and Health.

Introduction

The incidence of stroke was dramatically increasing worldwide. According to World Stroke Organization reports, stroke is the second leading cause of deaths worldwide. In 2018, every 80 million people there are 5.5 million people death from stroke. Moreover, it also found that there was 13.7 million people who diagnosed as stroke. Unfortunately, an average of 1 in 4 people aged 25 years old and above and 60 percent of stroke patients have had premature death. (Wiseman, 2018) In Thailand, the high incidence of stroke also reported. Stroke is the first leading cause of death among Thai people. Unfortunately, the number of

diagnosed patients is expected to increase every year. The Strategy and Planning Division of Ministry of Public Health reported the number of stroke patient between 2013 and 2017 and found that new cases which diagnosed with stroke was increased about 4% (293,463 in 2016 to 304,807 in 2017). Regrettably, among those patients, a high mortality has been reported with an average of 30,000 deaths each year distributed in every age group. (Thaincd, 2016).

According to pathophysiology of stroke, stroke is an abnormality of blood vessels which supplies to the brain and result in an inadequate blood supply to brain. The conditions which causes stroke were i) a blockage of blood vessels or Ischemic stroke and ii) a rupture of blood vessels or Hemorrhagic stroke. The following complication of stroke leads to neurological symptoms that last up to 24 hours or

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even death in severe cases (Thongthawee et al., 2018). Interestingly, the previous incidence reported that 20 percent of stroke patients may be fully recovered after an appropriated medical treatment. Moreover, a 30 percent of these patients experience with a physical disability and require constant assisting in daily activities and 50 percent of them may have speech impairment and difficulty communicating with others (Hanchaiphibookul et al., 2011).

Seriously, the complications of stroke most common impacts on physical health which including 1) loss sensation and weakness in affected side, 2) movement and balance problems, 3) difficulty swallowing and 4) speech impediment and communication problems. As the symptoms progress the ability to perform their activities of daily living gradually diminishes and disability appears (Parry, 2004). The mental and emotional effects of stroke range from anxiety, depression, irritability and behavioral changes. Nevertheless, some of the stroke patients may not be able to resume their normal lives, forced to alter the roles and responsibilities they once possessed and becoming dependent on other family members. This shows that stroke can have a profound effect on social aspect which can eventually become long-term effect on the patient's quality of life (QOL) (Seesawang, 2016; Carod-Artal and Egidio, 2009). All of above suggested that the complications after stroke could leads to a poor QOL and cause functional disability. Therefore, an appropriated and earlier QOL assessment could be beneficial for an effective treatment plan.

Since stroke affects patients QOL, World Health Organization has developed a conceptualized framework for assessing QOL according to "Global concept of quality of life" that recognizes physical, emotional, social, environmental and personal domain of life (Trevittaya, 2016). There are 2 types of QOL assessment tool used in stroke patients including 1) generic health related quality of life (HRQOL) questionnaire and 2) specific health related quality of life questionnaire. Generic HRQOL questionnaire measures the effects of the disease and symptoms have on patient's QOL by focusing on several influential stroke related factors. Some of the most common generic HRQOL questionnaire used in patients with stroke include 1) Short Form 36 (SF-36) (Brody, 2016) , 2) Nottingham Health Profile (NHP) (Baró et al., 2006), and 3) Sickness Impact Profile (SIP) (Salter et al., 2008). On the other hand, specific HRQOL questionnaire was designed for disease specific assessment therefore (Liddle and McKenna, 2000) the items are tailored

to the symptoms, side effects and impact of a particular disease. The outcome of specific HRQOL questionnaire is able to show the efficacy of a given treatment and its contribution to changes in QOL. Widely used specific HRQOL questionnaires in stroke patients are 1) Stroke Specific Quality of Life Scale (SSQL) (Lin et al., 2011), 2) Stroke Impact Scale (SIS) (Duncan et al., 2001) and 3) Quality of Life Index – Stroke version (Golomb et al., 2001). According to aforementioned could suggested that an effective QOL assessment could lead to an effective therapeutic plan.

Since an International Classification of Functioning, Disability and Health (ICF model) was created as a framework for the measurement of functional disability that is utilized among physicians, nurses and rehabilitation-related allied health professionals to develop a more comprehensive treatment plan, it was lacking of QOL assessment aspect. Hence, added QOL assessment in ICF model could be an effective tool which promotes an effective treatment plan. Moreover, no available study which use ICF model outcome able for reflect all domains of QOL in stroke patients. Therefore, the present study aims to introduce a conceptual framework that is compliant with ICF model for the development of the assessment in which outcome is able to reflect all domains of QOL and potentially lead to an effective treatment plan.

Quality of life assessment in stroke patients

The QOL assessment in stroke patients should be emphasizes and comprehensively. Therefore, World Health Organization has developed a conceptualized framework for assessing QOL as "Global concept of quality of life" that recognizes physical, emotional, social, environmental and personal domain of life (Trevittaya, 2016). Subsequently, "International Classification of Functioning, Disability and Health" (ICF model) was created to standardized the measurement of disease impacts and illness which was published in 2000. The purposes of ICF model is to provide a common language for functional and QOL data collection, which defines health as the dynamic state of complete physical, emotional and social wellbeing (WHO, 2016) The ICF model, covers the physical, emotional, social, environmental and personal factors. Previous study was using this model in applied to QOL assessment in spinal cord injury patients in which results indicated that the assessment was able to comprehensively captured patient's QOL and leads to an effective treatment planning (Post and Noreau, 2005)

The most common quality of life (QOL) assessment in stroke patients is Health-Related Quality of Life (HRQOL), which explicitly measures the effects of disease upon body structure and body function and patient's ability to perform activities. There are 2 types of QOL assessments in stroke patients: 1) Generic HRQOL questionnaire and 2) Specific HRQOL questionnaire (Liddle and McKenna, 2000)

1. Generic HRQOL questionnaire

1.1 Short Form Health Survey (SF-36) assesses the general aspect of QOL. This questionnaire has been widely established in many countries including Thailand. The form consists of 36 items that can be separated into 35 health questions and 1 question about reported health transition. 35 health questions cover 8 health domains including Physical Functioning; Role limitation due to physical problem; Body pain; General Health Perception; Vitality; Social functioning; Role limitation due to emotional problem; and Mental Health. Number of questions varies in different domains and each question will ask patients to recall their health status in past 4 weeks. SF-36 scoring is generated by summing up the scores from 8 domains into 0-100 scale, which a higher score represents better QOL (Brody, 2016). In the past few years there have been multiple studies examining the validity and reliability of QOL instruments and the outcomes have shown that SF-36 is considered to be a highly valid and reliable assessment (Failde and Ramos, 2000; Yu and Tang, 2013; Leurmarnkul and Meetam, 2005).

For SF-36 application in Thailand, the questionnaire has been translated into Thai, which was later re-tested across 448 participants to determine its internal consistency reliability and construct validity. The study revealed that the validity of Thai' SF-36 version was more than 0.70 in all domains (Cronbach's alpha = 0.72-0.86) (Leurmarnkul and Meetam, 2005). Subsequently, 3 items were added to social functioning domain of SF-36 Thai version in 2005 to ameliorate its application among patients with stroke. The inter consistency of the version was re-tested and the results indicated that the questionnaire remained reliable with Cronbach's alpha more than 0.07 in all health domains (Cronbach's alpha = 0.7-0.98). Apart from stroke patients, SF-36 is also used in heart disease patients. SF-36 reliability has been studied in 212 participants who have heart disease. The measure achieved Cronbach's alpha score more than 0.70 and inter-item correlation above 0.4 accounting SF-36 as being a reliable assessment

tool for heart disease population (Krittayaphong et al, 2000).

1.2 Nottingham Health Profile (NHP) was developed to assess the QOL in general population by measuring a person's subjective perception of their own health status. The NHP consist of 38 items questionnaire which could be divided into the following domains: 1) Energy level 2) Emotional reaction 3) Physical mobility 4) Pain 5) Social isolation and 6) Sleep. Test and re-test reliability of NHP was investigated on 58 osteoporosis patients with 4 weeks interval period and 93 peripheral vascular disease patients with 8 weeks interval period. The studies showed that the Cronbach's alpha score were between 0.71 and 0.88 (Coons et al., 2000), which indicated the assessment reliable. The instrument was also reported to have good discriminant validity when the questionnaire was administered to 39 patients with Rheumatoid arthritis and 43 patients with migraine (Golomb et al., 2001).

The Test re-test ability of Nottingham Health Profile was also studied in 74 stroke patients and compared against SF-36. The results show NHP and SF-36 obtained Intra-class Correlation Coefficient value of 0.89 and 0.96 for test re-test reliability and score of 0.89 and 0.92 for inter-rater values, respectively ($p < 0.01$) (Cabral et al., 2012). Unfortunately, NHP has not yet been translated into Thai language.

1.3 Sickness Impact Profile (SIP) is a QOL assessment tool that was intended to measure perceived health status and the impacts the disease have on a person's activity and activities of daily living. The questionnaire consists of 136 questions that can be grouped into 12 dimensions, this include; 1) Ambulation 2) Mobility 3) Body care and movement 4) Communication 5) Alertness behavior 6) Emotional behavior 7) Social interaction 8) Sleep and rest 9) Eating 10) Work 11) Home management and 12) Reaction and pastimes. The test re-test reliability score of SIP is equal to 0.92 (Bowers et al., 2009)

2. Specific HRQOL questionnaire

2.1 Stroke Impact Scale (SIS) is stroke specific QOL assessment tool that outcome able to provide an excellent reflection on patient's recovery overtime. This self-reported instrument has been improved to version 3.0 which currently has 59 items concerning 8 areas including: Strength; Communication; Memory; Emotion; Social participation; Activity of daily living;

Mobility; Hand function; and Composite physical. Summative score ranges from 0 to 100 in which the higher the score indicates the better the QOL. (Duncan et al., 2001)

SIS has been translated into 25 languages and able to achieved excellent validity and reliability. The instrument is able to evaluate QOL and capture the impact stroke has on the patients. SIS version 3.0 was first translated into Thai by Totsaporn Khampolsiri and colleagues. It has been found that the validity and reliability values of the translated version fluctuated from each domain, when administered to 10 participants who were in a QOL improvement program for stroke survivors receiving home health care. (Khampolsiri et al., 2006)

In 2015, Granjanagoonchorn A. and Dajpratham P. further examined the validity and reliability of the SIS 3.0 version Thai by comparing the criterion-validity between SIS score in associated domain with outcome measurement of the Barthel Index (BI), Thai Mental State Examination (TMSE), Functional Ambulation Categories (FAC), and Patient Health Questionnaires (PHQ-9). The results indicate that SIS 3.0 version Thai achieved good correlation in the following domains: mobility (0.74 – 0.76); activity of daily living (0.73 – 0.75); social participation (0.53 – 0.68); emotion (0.54), moderate correlation in strength (0.41 – 0.43); communication (0.4), and poor correlation in memory (0.25); hand function (0.19 – 0.25). Moreover, the results of SIS discrimination validity study among stroke patients with various levels of disability according to Modified Rankin Scale were statistically significant in composite physical, social participation, mobility, activity of daily living and communication domain as well as recovery score. While test re-test reliability of the instrument was in excellent level (0.92 – 0.99), acceptable internal consistency in all domains (0.7 – 0.9) except for emotion (0.5) (Garnjanagoonchorn, 2015)

2.2 Stroke-Specific Quality of Life Scale (SSQL)
comprises of 49 questions covering 12 domains namely: Movement; Energy; Upper extremity function; Work; Mood; Self-care; Social roles; Family roles; Vision; Language; Thinking and Personality. SSQL has a reliability score of 0.73 (Abubakar and Isezuo, 2012)

2.3 Quality of Life Index – Stroke version was created by Ferrans & Powers to measure QOL of patients with chronic diseases which has been developed into multiple disease specific versions including stroke. It contains 36 questions consisting of 4 domains: Functional; Financial; Spiritual and Family. The reliability

score of the instrument is equal to 0.91 (Golomb et al., 2001).

Generic HRQOL and specific HRQOL questionnaire that are used to measure QOL of patients with stroke were recruit to use in this study. Considering the properties, it would appear reasonable to conclude that both types of instrument have their advantages and limitations. The outcome of generic HRQOL questionnaire can be used in comparison with general population however, they cannot identify the source of health problem (Duncan et al. 2001). Whereas stroke specific QOL measures are able to distinctly determine the affected areas as well as assessing various aspects of QOL that are related to the pathology of the disease. This allows the reviewer to provide treatment that is tailored to patient's problems. One disadvantage of the specific HRQOL is that the outcome cannot be compared with general population.

Since, the ICF model was created as a framework for the measurement of patient's QOL that is utilized among physicians, nurses and rehabilitation-related allied health professionals to develop a more comprehensive treatment plan. An aforementioned evidence would support that the measuring factors in each measure does not follow the conceptual framework of International Classification of Functioning Disability and Health (ICF Model). In addition, after a careful consideration of each QOL assessment tool used in stroke patients, the evidence suggests that the measures present one limitation that can lead to poor treatment planning, which is the lack of ability to assess all domains of physical, emotional, social, environmental and personal factors.

According to aforementioned information could suggested that an effective QOL assessment could lead to an effective therapeutic plan. Since ICF model was lacking of QOL assessment aspect. Therefore, added QOL assessment in ICF model could be an effective tool which promotes an effective treatment plan. Moreover, no available study which use ICF model outcome able for reflect all domains of QOL in stroke patients for an effective treatment plan.

The concept of quality of life assessment in stroke patients according to ICF model

Nowadays, many researches forcing on QOL assessment. Since QOL assessment is not only affected the quality of life of patients but also the successfulness of treatment plan. Therefore, many health care providers focusing on an effective QOL assessment for their effective treatment goals. In

addition, it is also necessary that allied health professionals such as physical therapists who play a vital role in treating stroke patients to understand the conceptual framework of QOL assessment. However, the assessors have to select the most appropriated instrument that will capture livelihood of the patients.

The conceptual framework of QOL assessment in stroke patients is based on a "Global and Dynamic Concept" that aimed to investigate the impacts of diseases or illnesses on health condition, which has been developed into ICF codes. World Health Organization implemented the ICF codes in 2000, with the objective to provide a standard definition for health and documentation. According to ICF, definition of health is 'A state of complete physical, mental, and social well-being not merely the absence of disease and infirmity'. The model facilitates the communication in clinical practice and social workplace as ICF provides a common language enables the data to be compared internationally (Failde and Ramos, 2000). This was accomplished by appointing codes for every component of QOL including body function/structure, activities, social participation and environmental factors that affect human lives.

The ICF model has shifted the perspective of disability from medical aspect towards social aspect, because disability is not only caused by physical illness but also integration between physical abnormalities and unsupported environmental factors that compel people with disability to live differently. Therefore, applying ICF model to the assessment and data collection will yield a more comprehensive outcome that contains

information of the illness, effects of the disease and environmental factors which can be used as a guideline for recovery planning to improve the patient's QOL.

The idea of ICF codes into health and QOL assessment was initiated by Post M, De Witte L and Schrijvers A (Post and Noreau, 2005). The ICF codes involve 5 health components, that act as a framework allowing the instrument to reflect the impact of the disease and the problem patients have within each component. The five interconnecting components of ICF (Figure 1) include:

1. Body Function/Structure: body function covers the physical and psychological function of a person, while structure represents the anatomy of the body such as organs, limbs and other parts. Deterioration at a body function or structure level is considered to be impairment.
2. Activities: work or activities of daily living that is different to each person. Any changes or discontinuation of the activity that occurs due to the disease is known as activities limitation.
3. Participation: is the ability to engage with others or take part in social activities whereas alteration or avoidance of social activities is identified as participation restriction.
4. Environmental factors: are external factors that have an impact on patient's environment such as surrounding of patient's accommodation, culture and perspective of people in the community.
5. Personal factors: are personal lifestyle and individual factor excluding health such as gender, nationality, age, physical activity level, education and social status.

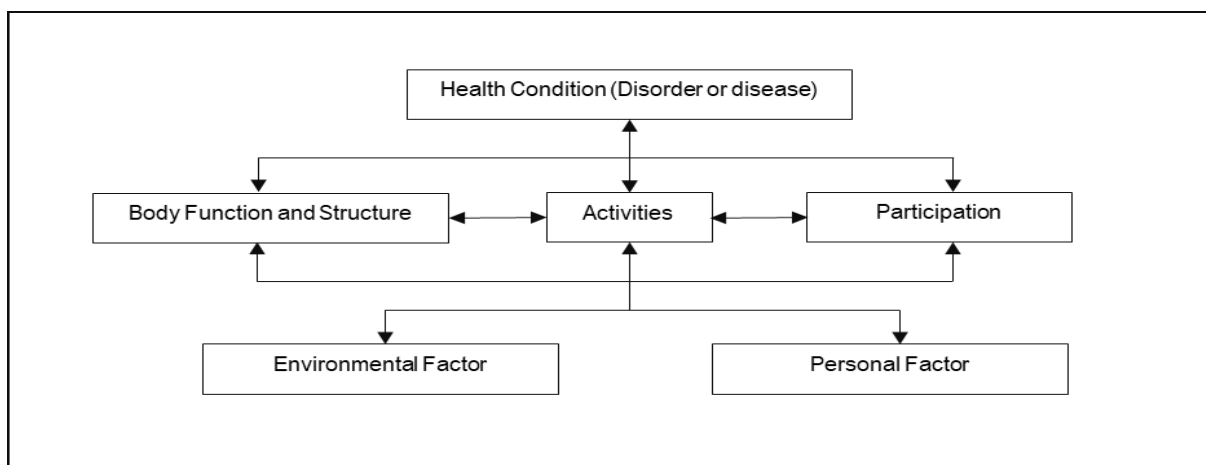


Figure 1. The International Classification of Functioning, Disability and Health (ICF). Reprinted from International Classification of Functioning, Disability and Health: ICF. Geneva, Switzerland: World Health Organization; 2001 with permission of the World Health Organization.

The ICF model was adapted by Post M, De Witte L and Schrijvers A for its application in measuring QOL in spinal cord injury (SCI) patients (Post and Noreau , 2005). The instrument was to assess satisfaction in life or QOL as well as impact the

disease has on each domain of patient’s life. They modified conceptual framework for QOL assessment in SCI was illustrated in Figure 2 which shows the assessment framework that integrates the component of physical, emotional, social, environmental and personal factors.

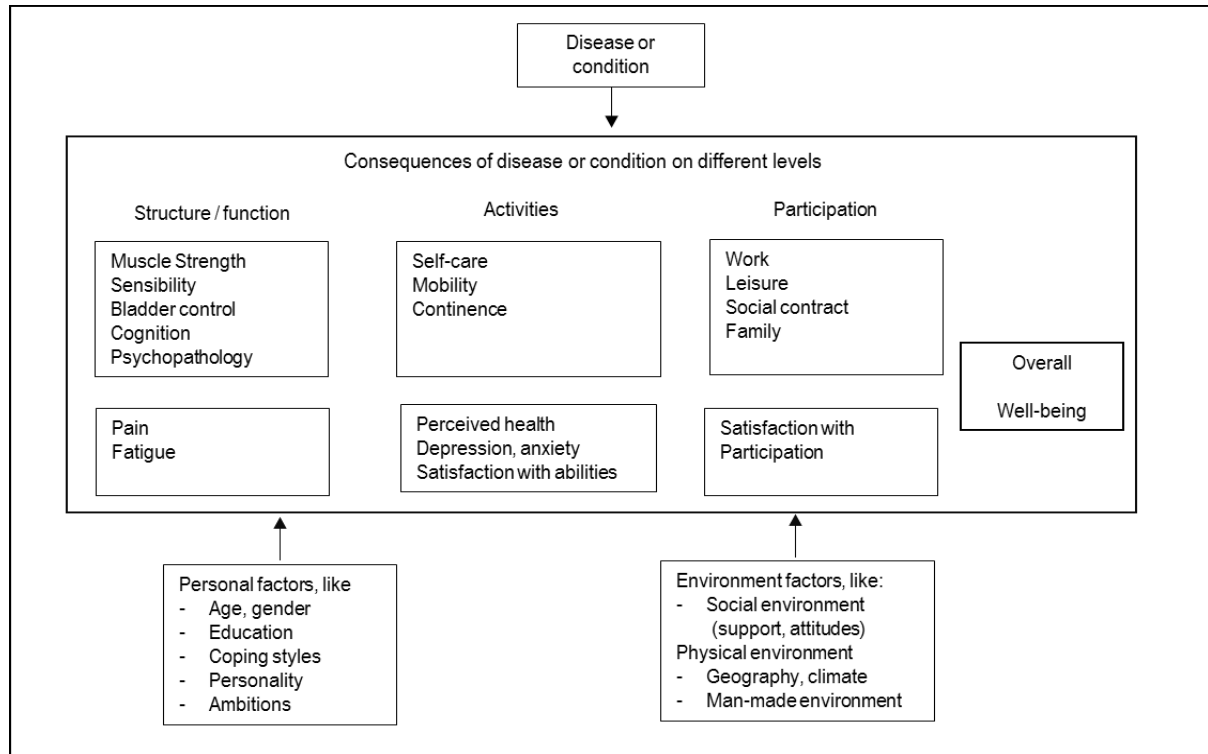


Figure 2. An ICF-based model of quality of life. Adapted with permission form Post MWM, de Witte LP, Schrijvers AJP (Post and Noreau, 2005).

Nonetheless, following a thorough examination of QOL assessment tools in stroke patients often found that majority of the instruments focus on measuring the limitation of body function/structure, activities, social participation but lack the inclusion of the environmental and

personal factor.

A summary of the details of each QOL assessment tool in stroke patients by S. Geyh et al the components could be distinguished based on ICF model in the Table 1 below.

Table 1. The table displays classification of the components in quality of life assessment tools in stroke patients based on ICF model (Geyh et al., 2007).

Quality of life assessment tools	International Classification of Functioning, Disability and Health Domain				
	Body Function / Structure	Activities	Participation	Environment Factor	Personal Factor
Nottingham Health Profile (NHP)	✓	✓	✓	✓	-
Short Form Health Survey (SF-36)	✓	✓	✓	-	-
Sickness Impact Profile (SIP)	✓	✓	✓	✓	-
Stroke Impact Scale (SIS)	✓	✓	✓	-	-
Stroke-Specific Quality of Life Scale (SSQL)	✓	✓	✓	-	-
Quality of Life Index – Stroke version	✓	✓	✓	✓	-

The distinguished data of QOL assessment tools in stroke patients obtained from review in comparison with the ICF model (Table1) provides indisputable evidence that most measures failed to include environmental and personal factors, which have been found to correlate with decreasing time patients spent in recovery.

Due to the aforementioned reason, when assessing QOL in stroke patients, healthcare professionals must take environmental and personal factors into consideration. This can be achieved by incorporating quality assessment through an interview by assigning questions regarding the residential environment, household atmosphere, pre-stroke personality and behavior for instances. Alternatively, the clinical evaluators could explore the possibility to construct an instrument that measures all 5 components of the ICF model in which outcome can be used in conjunction with baseline testing in order to design an appropriate treatment plan accordingly.

Guidance for the application of ICF model on the quality of life assessment in stroke patients within the scope of rehabilitation

The priority of providing rehabilitation services is to assess the patient's quality of life (QOL) therefore, to incorporate the ICF model into the measures the following guidelines may be considered:

1. Apply the ICF model as a guideline for problem evaluation to procure a better rehabilitation outcome in stroke patients.

A crucial factor physiotherapist/occupation therapist must consider when assessing QOL in stroke patients is to establish the framework that complement the disease timeline. On the one hand, during recovery phase the instrument should measure the physical capability and ability to perform activities of daily living. On the other hand, when patients are returning to society the assessment should capture the activities, social participation, environmental and personal factors that are conducive to the activities and lifestyles of the patients. As a consequence, this will allow for data collection that is consistent in each patient and enables the information to be utilized in a long-term treatment planning.⁹ In order to measure all components of QOL as established by the ICF model, the physiotherapists/occupational therapists should consider developing an inclusive QOL instrument that measures all component of the ICF model and combine the measuring outcome with the baseline test results to construct an effective treatment plan that is individualized to

each stroke patient.

2. Apply the ICF model for research and development of quality of life assessment in stroke patients to procure a better rehabilitation outcome.

The previous literature reviews and evidences suggested that the available QOL assessment tools in stroke patients have no instrument to measure all domains of the ICF model. Therefore, future research was recommended that researches be conducted to develop an instrument that measures all relevant aspects and further examine its validity in comparison with other available standardized QOL measures in stroke patients such as SIS, which will permit physiotherapists, occupational therapists or physiatrists for international comparison of both the treatment and assessment outcomes. An example of a local study that assessed validity and reliability of a QOL assessment following international research standards is a study by Granjanagoonchorn A and Dajpratham P, an investigation of validity and reliability of the SIS 3.0 Thai version. The criterion validity of the study was compared with the outcome of standard measures including Barthel Index (BI), Thai Mental State Examination (TMSE), Functional Ambulation Categories (FAC), and Patient Health Questionnaires (PHQ-9) (Garnjanagoonchorn, 2015)

Conclusion

The present study suggested a conceptual framework for QOL assessment in stroke patients that cover all aspects of life as stated by the ICF model in which measuring outcomes for a better treatment planning and leads to an effective rehabilitation outcome. The present study also provided guidance for future research and development of ICF based QOL assessment in stroke patients to achieve international standard.

Disclosure

The authors declare that they have no conflict of interest

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