

Implementing the Adapted Flanagan Quality of Life Scale in Persons with Spinal Cord Injury Living in Taipei: A Psychometric study

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Abstract

Purpose: The purpose of this study was to gather knowledge about implementing the adapted Flanagan Quality of Life Scale (QOLS, 1987), in spinal cord injured (SCI) outpatients in Taiwan.

Methods: The study was a non-experimental psychometric assessment design. In the preliminary stage, a number of translations and back-translations were carried out to ensure a refined and accurate Chinese-language version QOLS. Fifty-nine bilingual persons examined the reliability and concurrent validity of the Chinese version. In the main study, content analysis was used to analyze the qualitative data in order to assure the content validity.

Results: Pearson's correlation coefficients between the English and Chinese (E & C) versions were 0.84 to 0.98. The internal consistency reliability in the E & C versions both was 0.88. The content validity of the QOLS was confirmed with 39 SCI outpatients by asking three open-ended questions about quality of life (QOL). All the major components of the QOL identified in the QOLS were also identified by SCI outpatients as components of their QOL except item #8 "participating in organization or public affairs". The additional four domains identified by the SCI outpatients were as follows: (1) freedom from environment barriers, convenient equipment and transportation, (2) psychological adaptation, (3) freedom from complications and (4) good relationships with caregivers. In addition, Cronbach's alpha was 0.85 on the first testing and 0.83 on the second testing. The test-retest correlation with a two-to-three week interval was 0.83.

Conclusions: Overall, the reliability and validity of the Chinese version of adapted Flanagan QOLS were high. The additional four domains may be added to the adapted Flanagan QOLS when implemented with the SCI outpatients.

Key Words : quality of life (QOL); spinal cord injured (SCI); Flanagan Quality of Life Scale (QOLS)

Introduction

Spinal cord injury (SCI) is a catastrophic event. Approximately 1,000 such injuries occur each year in Taiwan. (Chen & Lien, 1985). The mortality rate of SCI has decreased as a result of advances in medical and nursing care. However, most victims face significant unrecoverable paralysis, sensory impairment, and bowel,

bladder and sexual dysfunction (Gutierrez, Young, & Vulpe, 1993).

In Taiwan, only some individuals with SCI have been treated at rehabilitation centers, and little is known about how they perceive the quality of their lives after they return home. There is a lack of appropriate

Chinese instruments to measure the quality of life (QOL). Therefore, the purpose of this study is to gather information regarding the validity and reliability of the adapted Flanagan QOLS, which translated into Chinese, and implementing in Chinese SCI outpatients.

Literature Review

The literature review included (1) conceptualizing QOL, (2) QOL in the population with SCI, and (3) translation issues.

Conceptualizing QOL

In a review study, Dean (1987) found that a variety of terms equated with QOL, such as life satisfaction, well-being, health, happiness, value of life, adjustment, meaning of life and functional status.

Although many determinants or indicators have been suggested as standards for life quality, an agreed on definition to guide research is lacking (Ferrans & Power, 1985). "There is not yet a universally agreed upon definition of quality of life, nor is there a standard for its measurement" (Ferrans, 1990, P. 248). Therefore, prejudice and questions raised.

QOL in the population with SCI

It is generally agreed that a certain level of physical and material well being, safety and health is necessary as the basis for a fully satisfying life. However, the disabled patient, such as the SCI person, has lost the physical capacity for the necessary responses to establish and maintain the relationships, interactions, and participation that healthy persons have. Therefore, prejudice and questions arise.

In a prominent study in the 1980's, Crewe (1980) compared the life satisfaction of 128 SCI outpatients to those cited in Flanagan's (1978) national study of persons without disabilities. Crewe found that the

participants in the Flanagan's study were more likely to report greater satisfactions in all areas. The largest discrepancies between Crewes and Flanagan's samples were for financial-material well-being (48% to 74%), sexual relationships with spouse (40% to 84%) and employment-work (39% to 79%). Less striking differences were noted on the item pairs health-health and personal safety (63% to 86%) and social-socializing (68% to 73%).

In a study conducted in Sweden by Lundqvist (1991) and colleagues, the QOL of 98 individuals with SCI for more than four years was investigated. The QOL ratings in the SCI group were an average of 25% lower than the reference population. Urinary incontinence, infection, and autonomous dysreflexia were related to inhibited self-care performance. However, severe pain was the only complication that related to lower QOL scores.

In a outcome measure study by Whiteneck et al. (1992), the QOLS & Individual Needs Questionnaire which were developed by Flanagan (1978), was used to measure the QOL of individuals with SCI for more than 20 years. Approximately 75% of 282 subjects rated their current QOL as either good or excellent on a 5-point QOL scale. They also rated the areas important to their QOL, such as expressing themselves, reading, and listening to music. Regarding how well they felt their needs were met in each of these areas, the results showed that having and raising children was the least well met. However, having and raising children was also one of less important are rated by subjects. This result showed that individuals with SCI may experience a shift in priorities, because of their long term physical disability.

In a qualitative descriptive study by Bach & McDaniel (1993), the focus group technique was used to gather information from 14 quadriplegics about what constituted components of QOL for them. The

information was categorized into eight categories. Five of eight categories were similar to those identified in Flanagan's study, such as health; finances; job and productivity; relationships with significant others, family members and friends; and level of activity. The other three categories were independence, inner strength or survival, and assertiveness.

Taken together, QOL among people with SCI is associated with physical, psychological, and social well being, especially related with satisfaction in health status, and relationships with others.

Translation Issues

Potential problems regarding translation of an instrument to a different language can be minimized by careful translation, back-translation, and administering two versions of the instrument to bilingual people to obtain reliability and validity (White & Elander, 1992).

Translation and back-translation To assure greater comparability in translated instruments, Breslin (1970) has suggested a series of steps to provide adequate translation: (1) If it is anticipated that the original work will be translated, use simple language; (2) Secure competent translators who are familiar with the topics; (3) Use two bilingual translators, one to translate from the original language, and the other to translate back to the original language without having seen the English version; and (4) In addition to the two translators, have a group of individuals refine both translations. In addition, items with apparent discrepancies between the two language versions should be modified and the back-translation cycle repeated until the investigator is satisfied with the equivalence of forms (Jones, 1987; White & Elander, 1992).

Assessment of psychometric equivalence The ideal means of comparing the psychometric properties of the source and target language versions of the instrument is to administer both versions to bilingual

subjects. The two versions of the questionnaire should demonstrate a high correlation. (Jones, 1987).

Methods tion

The study included two parts: preliminary work and the main study. Data were collected between April 10, 1994, and September 15, 1994, at Portland (U.S.A.) and Taipei (Taiwan).

Preliminary work

The preliminary work included: (1) translating the QOL scale into Chinese, (2) examining the reliability and concurrent validity of the Chinese version of the QOL scale using fifty-nine bilingual individuals, and (3) obtaining content validity by asking twenty SCI outpatients three open-ended questions about their QOL.

Instrument translation

The translation procedures were as follows: (1) The researcher translated the English version into a Chinese version. (2) Six bilingual individuals were asked to compare the English version with the Chinese version and record their recommendations concerning the Chinese version. (3) Two bilingual individuals back translated the Chinese version into the English version, and (4) A native English speaker compared the back-translations with the original English version to ensure that these two scales were asking the same questions. If any of the questions did not match the criteria, then procedures 1-3 were repeated.

Participants

Translators: The two translators who did with back-translation were from Taiwan when they finished junior high school. One is a medical doctor. Another majored in social sciences and works as a translator in a community church.

Bilingual individuals: Six master-educated bilingual individuals who majored in different fields were asked to compare the Chinese version with English version of the QOLS. In order to examine the reliability and concurrent validity of the Chinese version, a convenience sample of fifty-nine bilingual persons filled out the E & C versions of the QOLS. The criterion for deciding that they were bilingual was that they had at least two years of college education. The instruments were administered in random order to control for possible order effects. The participants ranged in age from 20 to 52 years old (mean=30.4, S.D.=6.8). Six (10%) were college graduates with associate degrees. Twenty-eight (47%) were college graduates with baccalaureate degree. Sixteen (27%) were graduates with master's degrees. One (2%) was still in the doctoral program. Eight (14%) were physicians.

SCI subjects: To assess content validity, the investigator used Burckhard, woods, Schultz & Ziebarth's (1989) three open-ended questions: (1) What does quality of life mean to you? (2) What kinds of things are important to your quality of life? (3) Has the quality of your life changed over the past year? Letters containing these three questions were mailed to individuals with SCI living in Taiwan.

A total of forty-eight individuals with SCI were randomly selected from a roster provided by the SCI Association in Taipei. The three questions were sent to the selected subjects. Twenty of the 48 (42%) responded and shared their views on the quality of life.

Data analysis

Cronbach's alpha was used to assess the internal consistency reliability in the E & C version of QOL scales. The Pearson's correlation coefficients between the E & C version were used to determine the concurrent validity. Content analysis was used to assess the content validity.

The main study

Design

The design of the study was a non-experimental psychometric assessment design. The major purpose of the main study was to collect further data on the content validity of the questionnaire, as well as to assess its test-retest reliability in the target population.

Setting and Subjects

The target population was individuals with SCI who were members of the SCI Association in Taiwan. The accessible population was members of the SCI Association who live in Taipei. The membership of the Association was approximately 1,100 people, of whom 311 individuals live in the city of Taipei and six surrounding cities.

Inclusion criteria The criteria for inclusion in this study were (1) individuals with a medical diagnosis of SCI, (2) eighteen years of age and above, (3) individuals who are able to read and understand the questionnaires, and (4) individuals without other diseases that affected their functional status and quality of life, for example, congestive heart failure, chronic obstruction pulmonary disease, or rheumatoid arthritis.

Sampling The sampling of the study is a convenience and on-purpose sampling.

Response rate A total of 107 letters were mailed to potential subjects through systemic sampling from the roster. Two letters were returned. One was undeliverable. The other was returned due to death of the subject. Of the remaining 105, 35 (33%) postcards with signed consent forms were returned. Eleven (11%) postcards were returned declining to participate. Of the thirty-five who were interested in participating, 13 were excluded. Two declined when the researcher contacted them on the phone. One was rehospitalized due to a pressure sore. One was hospitalized for a urinary tract

examination. Two had SCI and head injuries. One had a C3-4 injury and was too weak to talk very much. Four were not able to read the questionnaires. Two were unavailable due to vocational rehabilitation.

Measurements Flanagan developed the Quality of life scale (QOLS) for the general population in the 1970's. Nearly 3,000 people encompassing three different age groups (30, 50, and 70 years of age), varying races, and backgrounds, representing all areas of the country. Subjects were asked questions about QOL. In all 6,500 critical incidents were collected and sorted into similar activities and experiences. Through an inductive process of gradual refinement, a set of 15 categories was formulated. (Flanagan, 1978; Flanagan, 1982).

The Adapted Flanagan QOLS In a psychometric study by Burckhardt et al. (1989), the internal consistency reliability coefficient of the QOLS was 0.86 to 0.89 over a 6-week period. Test-retest reliability in the same sample was 0.78 between the first and second measurements (a 3-week interval), and 0.76 between the first and the third measurements (a 6-week interval). In addition, three open-ended questions were used to identify domains of QOL of persons with chronic illnesses, including diabetes mellitus, ostomy, osteoarthritis, and rheumatoid arthritis. The interview results revealed that the four groups of subjects used very similar terms to describe the areas that were important to their QOL. The prominent finding was that "independence, being able to do for oneself" was mentioned by all four of the different groups of patients as one important component of their QOL. Therefore, a sixteen item "independence, being able to do things for oneself" was added to the Flanagan QOLS. Burckhardt et al. (1989) also used the 7-point Delighted-Terrible scale to measure the degree of satisfaction instead of the original 5-point satisfaction scale. Andrews and Crandall (1976) who found it to be more sensitive and less negatively skewed than a 5-point

satisfaction scale developed this format.

The demographic questionnaire As for the general background, each of the respondent was asked to fill out a personal demographic questionnaire to provide social demographic information and disease related information.

Data analysis

Descriptive statistics were used to analyze the demographic data and characteristics of the study subjects. Cronbach's alpha was used to determine internal consistency reliability. Pearson's correlation coefficient was used for description of level of correlation between test and retest.

The procedure of the content analysis (1) In each case, I visit the client in person at home, tape-record the whole conversation process, and lay out every detail as individual report. After categorized each case by inductive method, I compared it to the QOLS of Flanagan's. (2) Each case was discussed with my colleagues who hold the master degree of nursing. (3) The whole reports, including original tape-record conversation, were translated into English by three bilingual Chinese-American. My two thesis advisors checked the final English version. (4) To avoid the categorization bias, each case were reviewed again after one month.

The principle of content analysis is to identify themes, patterns, similar words, and context. The major components of QOL identified by the individuals with spinal cord injury were then compared with the QOLS.

Results

The preliminary work

Translation and wording issues (1) With respect to describing the degree of satisfaction, it was hard to find a series of adjectives such as delighted, pleased, and

terrible in Chinese wording. Therefore, the researcher adapted "very satisfied" instead of "delighted", "satisfied" instead of "pleased", and "very dissatisfied" instead of "terrible". (2) In item 10 "understanding yourself-knowing your assets and limitation-knowing what life is about", the term of "strength" or "advantage" was used to replace the term "assets" in the Chinese version. (3) In item 5 "close relationships with spouse or significant other", the term "close relationship" nearly equals to sexual intimacy in Chinese. However, since close relationships in English may include love, understanding, communication and appreciation, the researcher used "relationships with spouse or significant other" rather than "close relationships with spouse or significant other". (4) In item 8 "participating in organizations and public affairs", a few bilingual subjects asked what this item exactly meant. Therefore, one example "vote" was added in Chinese version in order to be easily understood. (5) For item 15 "participating in active recreation", two examples, exercise and picnic, were added in the Chinese version.

Table 1 : The Pearson's Correlation Coefficients of the English and Chinese versions of the QOLS

Item	data	Item	data
Total e & c	.95	qe1 & qc1	.96
qe2 & qc2	.91	qe3 & qc3	.92
qe4 & qc4	.98	qe5 & qc5	.95
qe6 & qc6	.91	qe7 & qc7	.90
qe8 & qc8	.93	qe9 & qc9	.88
qe10 & qc10	.87	qe11 & qc11	.92
qe12 & qc12	.91	qe13 & qc13	.87
qe14 & qc14	.84	qe15 & qc15	.93
qe16 & qc16	.92		

Total e & c: Pearson's correlation between the E & C version (total 16 items).

qe1 & qc1: Pearson's correlation between item #1 of the E & C version, etc.

Reliability and validity The internal consistency reliability in the E & C versions both were 0.88. The Pearson's correlation coefficients in terms of concurrent

validity of E & C versions were 0.84 to 0.98 (Table 1).

The main study

Subject characteristics

The sample consisted of twenty-two individuals with spinal cord injury living in Taipei. Of the twenty-two respondents, 15 (68%) were male and seven (32%) were female. Participants' ages ranged from 21 to 45 years old, with a mean of 32.5 years old (SD=7.4). Thirteen (59%) were unmarried, five (23%) were married, three (14%) divorced and one (4%) separated. Nineteen (86%) lived with family, two (9%) lived alone, and one (5%) lived in a nursing home. The range of time between the individual's injury and the interview was 2 years to 18 years (mean = 7 years; mode = 5 years). Age at the time of injury ranged from 10 to 42 years old (mean = 25.5 years old).

Table 2 : Gender distribution, types of lesion , and causes of SCI In the report of the SCI Association of R.O.C. the present study

	The Report of SCI The present study Association of R. O .C.	
Gender		
Male	85.6%	68.2%
Female	14.4%	31.8%
Types of Lesion		
Quadriplegia	31%	45.5%
Paraplegia	69%	54.5%
Causes of SCI		
Traffic	48%	50%
Fall	15%	22.7%
Occupation	12%	9.1%
Sports	5%	4.5%
Stabbing or Gun	4%	0%
Others	9%	9.1%

To assess the degree to which the sample was representative of the SCI Association of R. O. C., a comparison was made based on a nationwide survey (Wu, 1992). Subjects in the present study were younger at the time

of injury (25.5 y/o to 27.3 y/o), fewer were male (68% to 86%), and more quadriplegics participated in the study (46% to 31%). A detailed comparison is illustrated in (Table 2).

Interview content analysis

Nineteen categories emerged from the data. Fifteen categories are similar to the domains of the QOLS. All the major components of QOL identified for the general population in the QOLS were identified by these SCI outpatients as components of their QOL except item #8: "Participating in organization or public affairs". The other categories were as followed: (1) Barrier-free, convenient equipment, and transportation. "An environment with very few barriers is very important to the individual with SCI. Now I can not even leave the building". "I felt better last year, because I felt more comfortable in my living environment. I modified some equipment". "Now, we have care buses. It increases our outside activities and leisure life". (2) Psychological adaptation: "Accept disability and live with hope are important to my QOL". "Psychological well-being and a healthy attitude are important to my QOL". (3) Freedom from complications: "Free of pressure sores". "Free of fear of having complications". "I always get urinary tract infections. It really bothers me a lot". (4) The relationship with caregivers (family members or attendants): "These two years I have had this attendant. He would massage me and exercise my arm and leg muscles. He helped a lot. Before he came, my life was dull, but because of his help in getting in and out of bed, I get to go out more often". "In the past year, we hired a maid for twenty-four hours. Now there is always someone around which makes me feel safer". "During the day my brother would go to work, and at night he would bring back food for me. We would chat and then he would help me get in bed, and later on at night he would reposition me. He doesn't complain and give me a great source of support. Without him, I can not

imagine what my life would be like".

Reliability of the QOLS

The QOLS was administered to 22 subjects initially and 14 of the subjects participated in the retest two to three weeks later. Support for reliability was provided by test-retest correlation of 0.83 and Cronbach's alpha of 0.85 on the first testing and 0.83 on the second testing.

Discussio

The possible reasons for not finding any examples of item #8 are interview skills, cultural differences and needs differences. The author did not approach the role of civic participation in QOL of individuals with SCI when interviewed. On the other hand, according to the Maslow's (1970) hierarchy of needs model, another interpretation is that these subjects may still be struggling in pursuing their basic needs, such as physical and material well-being, job and financial security. They may have physical and psychological difficulties in participating and caring about being involved in public affairs. In a qualitative study by Bach & McDaniel (1993), the interview result did not reveal this category either.

It was not surprising to find that "free of environment barriers, convenient equipment, and transportation", "psychological adaptation", "free of complications" and "good relationships with caregivers" are important to QOL. In truth, these four categories are related to the impact of disability on their lives. Due to the limitation of the body function, individuals with SCI must depend on special equipment and cars to access places that they want to go. They also have to rely on the caregiver to help them in their activities of daily living. Decker, Schultz and wood (1989) found that the caregiver not only provides physical assistance with activities of daily living, but also the cognitive and

affective needs of the SCI persons. The relationship between the SCI individual and the caregiver is especially important to quadriplegics.

The category of psychological adaptation also has been reflected in the literature regarding QOL in SCI population. In the early 1980's, Trisechmann (1980) addressed the fact that emotional adjustment is the key to rehabilitation of the patient. Krause and Dawis (1992) also found that psychological adjustment was a better predictor of satisfaction than demographic and injury-related predictors.

Several investigators (Eisenberg & Saltz, 1990; Lundqvist, et. al., 1991) have reported the occurrence of complications decreasing the QOL of SCI individuals.

There are several disadvantages of this study. First, most of the cases are located at the metropolitan areas of Taipei. The patient who lived in rural area may be overlooked. Second, all responders are the members of Chinese association of SCI. There are still many outpatients are not listed as member of Chinese association of SCI. Finally, the overall responding rate seems lower than expected.

Recently, outcome measurements are the main stream in the health program. To SCI people, the outcome measurement in the rehabilitation programs is in terms of functional outcomes. For example, "Can the patient transfer from bed to wheelchair independently and safely?" However, these limited-focus approaches ignore the holistic nature of human-beings. The Chinese version QOLS could be used as one of the outcome measurement instruments for the SCI patients.

Overall, the Chinese version of QOLS is a reliable and valid generic measure. Adding some disease-specific items may increase the content validity when applying this instrument in SCI population. Additional studies are needed to determine the validity of including these four additional domains in further QOL research with

this population. Further study could repeat Flanagan's (1978) study and Whiteneck's (1992) study with asking participants to rate the importance of each domain to their QOL in order to detect whether their needs are met.

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APPENDIX A

QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts-home, food, conveniences,Financial security	7	6	5	4	3	2	1
2. Health-being physically fit and igorous.....	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives- communicating, visiting, helping.....	7	6	5	4	3	2	1
4. Having and rearing children.....	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other.....	7	6	5	4	3	2	1
6. Close friends.....	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice...	7	6	5	4	3	2	1
8. Participating in organizations and public affairs.....	7	6	5	4	3	2	1
9. Learning- attending school, improving understanding, getting additional knowledge.....	7	6	5	4	3	2	1
10. Understanding yourself- knowing your assetsand limitations- knowing what life is about.....	7	6	5	4	3	2	1
11. Work- job or in home.....	7	6	5	4	3	2	1
12. Expressing yourself creatively.....	7	6	5	4	3	2	1
13. Socializing- meeting other people, doing things,parties , etc...	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment.....	7	6	5	4	3	2	1
15. Participating in active recreation.....	7	6	5	4	3	2	1
16. Independence, doing for yourself.....	7	6	5	4	3	2	1

Flanagan 生活品質量表應用於臺北地區 脊髓損傷患者之探討

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摘 要

目的：本研究目的在探討修改後之 Flanagan 生活品質量表應用於臺灣脊髓損傷患者時量表之信、效度。

方法：研究設計是屬非實驗、psychometric 評量。研究分兩部份，第一部份在經由量表之翻譯、反翻譯循環後得到中文版之 Flanagan 生活品質量表，並透過 59 位會中英文之普通個案填寫中英文版之 Flanagan 生活品質量表以檢視其內在一致信度、皮爾森相關係數及建構效度。第二部份則是利用訪談住在臺北縣市的脊髓損傷出院患者，收集其對生活品質之感受、想法，並將資料分析後與 Flanagan 生活品質量表之各項目做比較，以印證其內容效度。

結果：研究結果顯示皮爾森相關係數在中、英文版各項目是 0.84 至 0.98。內在一致信度在兩種版本均是 0.88。內容效度則經由郵寄及親自訪談共 39 位脊髓損傷者三個開放式問題如：(1)對您而言生活品質是什麼？(2)什麼事情對您的生活品質而言是重要的？(3)在過去的一年裡，您的生活品質有什麼樣的變化？資料分析結果顯示大部份在 Flanagan 生活品質量表中定義的生活品質項目，均有在與脊髓損傷患者的訪談中被提到，除了第 8 題："參與組織社團，公共事務"這一項。在分析訪談資料中，另外還有四個新的項目相關於脊髓損傷患者之生活品質：(1)無障礙環境、便利的設施與交通；(2)心理的調適；(3)沒有因脊髓損傷而相關的合併症；(4)與照顧者之間有良好的關係(尤以四肢癱瘓的頸髓損傷者為主)。另外，Cronbach alpha 值於第一、二次測試分別為 0.85 及 0.83，經 2-3 週間隔後再測信度為 0.83。研究結果顯示 Flanagan 生活品質量表中文版是一信效度均不錯的生活品質量表，但若應用於脊髓損傷患者則建議添加上面提到的四個新項目。

關鍵詞：生活品質(Quality of Life; QOL)、Flanagan 生活品質量表(Quality of Life Scale; QOLS)、脊髓損傷(Spinal Cord injured; SCI)

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