Quality of Life of Persons with Spinal Cord Injury Living in Taipei:

A Psychometric study

By

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ABSTRACT

Title: QUALITY OF LIFE OF PERSONS WITH SPINAL CORD INJURY LIVING IN TAIPEI: A PSYCHOMETRIC STUDY

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The purpose of this study was to gather knowledge about implementing the adapted Flanagan Quality of Life Scale (QOLS, 1978), in Chinese spinal cord injured outpatients.

The QOLS was translated into Chinese and the Pearson's correlation coefficients (.84 to .98) were obtained between the English version and the Chinese versions with 59 bilingual people. The internal consistency reliability in the English and Chinese versions both were .88. The content validity of the QOLS was confirmed with 39 spinal cord injury outpatients by asking three open-ended questions about quality of life (QOL). For example, what does QOL mean to you?, what kind of things are important to your QOL?, and has the quality of your life changed over the past year?. Content analysis was used to analyze the qualitative data. 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 organization or public affair". The additional four domains identified by the SCI outpatients were as follows: (1) free of environment barriers, convenient equipment and transportation, (2) psychological adaptation, (3) free of complications and (4) good relationships with caregivers. In addition, the Cronbach's alpha was .85 on the first testing and .83 on the second testing. The test-retest correlation with a two-to-three week interval was .83.

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

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CHAPTER 1

Introduction

Spinal cord injury (SCI) is a catastrophic event. Approximately 1,000 such injuries occur each year in the Republic of China. The annual (1978-1981) incidence of SCI in Taipei, the capital city of the Republic of China, was 14.6 per million population (Chen & Lien, 1985). The mortality rate of SCI has decreased as a result of advances in medical and nursing care. The life expectancy of the individual with SCI is now 30.2 years past the injuries (Burish, 1983). However, most victims face significant unrecoverable paralysis, sensory impairment, and bowel, bladder and sexual dysfunction. For those with quadriplegia, they also may have respiratory compromise, loss of temperature control, circulatory impairment, and other autonomic nervous system dysfunction (Gutierrez, 1993).

In the Republic of China, 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 instruments to measure the quality of life. Therefore, the purpose of this study was to gather further knowledge about implementing the adapted Flanagan Quality of Life Scale (QOLS) in Chinese spinal cord injured outpatients.

CHAPTER 2

Literature Review

Despite the growing recognition of the importance of quality of life (QOL) in health care, there is little consensus regarding its definition. The concept has been defined as happiness, satisfaction, physical function and other factors related to an individual's life or perception of life. Similarly, it has been operationalized with a variety of measures by different investigators (McCauley, 1991). In addition, extreme care must be taken with measures developed in the United States when applied to a population whose native language is not English and whose culture is different. Therefore, the literature review included (1) conceptualizing QOL, (2) QOL in the population with SCI, (3) nursing research on QOL in Taiwan, (4) measurements of QOL, (5) development of the QOLS instrument, and (6) translation issues.

Conceptualizing QOL

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). In the 1960's, QOL for many Americans revolved around a house in the suburbs, an automobile (or two), education for one's children, more and better appliances, and money with which to travel and retire (Alexander, 1981). More recently, there has been consensus that QOL is a broad concept. It has been defined as "a person's sense of well-being, his satisfaction or dissatisfaction with life" (Dalkey & Rourke, 1973), "the degree of need satisfaction with the areas of physical, psychological, and social" (Hornquist, 1982), and "a person's sense of well-being stems from satisfaction or dissatisfaction with the areas of life that are important to him or her" (Ferran & Powers, 1992). Dean (1987), in a review study, 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. For children with cancer, Hinds (1990) also defined QOL as their sense of well-being during the entire experience of cancer.

In regards to the dimensions (domains) of QOL, there is wide variation in the number and type of variables (Table 1) that have been employed in studies of QOL, ranging from a few basic variables to elaborate listings (Flanagan, 1978; Ferrans & Powers, 1985; Frisch, 1992; George & Bearon, 1980).

QOL in people with SCI

Over the past ten years increasing attention has been paid to the QOL of patients with chronic illness. Research on patients with SCI on rehabilitation units or in the community has typically focused on objective measures, such as mortality, morbility, physical functioning, complications, employment, and independent living (Taricco, 1992; Whiteneck, 1992). Little is known of what QOL is to the people with SCI, and what is important to their QOL.

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.

Table 1

Domains of QOL

Author's Name/ Study	Domains of QOL
Flanagan (1978)/ A research approach to improving our QOL	1. Physical well-being & financial security 2. Relationships with other people 3. Social, community, & civic activities 4. Personal development & fulfillment 5. Recreation
George & Bearon (1980)/ QOL in older persons	1. Health & functioning status 2. Social-economic status 3. Life satisfaction 4. Self-concept

(Table continues)

Table 1 (continued)

Domains of QOL

Author's Name/Study	Domains of QOL
Ferrans & Powers (1985)/ QOL Index: Development & psychometric properties	1. Physical health, function & health care; 2. Marriage ; 3. Family; 4. Friends; 5. Occupation; 6. Future retirement; 7. Education; 8. Leisure; 9. Stress; 10. Standard of living 11. Peace of mind; 12. Personal faith; 13. Personal appearance; 14. General happiness & general satisfaction; 15. Life goal

(Table continues)

Table 1 (continued)

Domains of QOL

Author's Name/ Study	Domains of QOL
Fisch & Colleagues (1992)/ Clinical validation of QOL Inventory: A measure of life satisfaction for use in treatment planning & outcome assessment	1. Health; 2. Self-regard; 3. Philosophy of life; 4. Standard of life; 5. Work; 6. Recreation; 7. Learning; 8. Creativity; 9. Social service; 10. Civic action; 11. Love relationship; 12. Friendships; 13. Relationships with children; 14. Relationships with relatives; 15. Home; 16. Neighborhood; 17. Community

Several studies have documented that many people view individuals with physical disabilities as less happy, less satisfied with life, and unable to attain worthwhile existence (Titley & Cooley, 1969).

In the early 1970's, Camerson (1973) used several simple questions to study how much the handicapped enjoyed his or her life. For example, "how has your life been so far?", "how do you expect life to be in the future?" and "how much do you look forward to next month?" In comparing responses of 190 physically disabled persons and 195 physically able-bodied persons, Cameron found that there were no differences between the two groups on ratings of life satisfaction. However, the subjects of this study were not SCI persons.

In a study of life satisfaction of patients with SCI, Carlson (1979) investigated 54 men between ages of 18 and 41 who were paraplegic or quadriplegic. She found that life satisfaction was related to family relationships, intimacy, personal maintenance, general attitude since injury, presentation of self, and stress management. The results also showed that the respondents were generally satisfied with their lives.

Dissatisfaction was frequently greatest in family and other intimate relationships.

In a prominent study in the 1980's, Crewe (1980) investigated 128 SCI people and 66 of their significant others (usually a parent or spouse) by intensive interviews and mailed questionnaires. The interview concerned their experiences about their health, medical treatment, educational and work experiences, social life, sexual and marital adjustment, and their feelings about their disability and about themselves. Crewe also compared the life satisfaction of these 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 Crewe's 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%).

Schultz and Decker (1985) reported on the life satisfaction of 100 older persons with SCI (40 to 73 years age) using the Life Satisfaction Index-A (LSI-A; Adams, 1969). The SCI subjects reported lower scores than those of two reference groups. Over 50% of the participants reported dissatisfaction on five of the 18 scale items. Unfortunately, the nature of these items was not specified. However, they reported four significant variables which affected scores of the LSI-A measure: perceived control, perception of disability as a positive or negative event, social support and satisfaction with the quality and quantity of social contacts.

More recently, in a study conducted in Sweden by Lundqvist (1990) and colleagues, the QOL of 98 individuals with SCI for more than four years was investigated. Four instruments and one QOL rating scale were used to assess their physical, psychological and social well-being. 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.

Simultaneously, Siösteen (1990) and colleagues conducted a comparative study assessing the QOL of C6 quadriplegics, wheelchair-bound paraplegics and ambulant paraplegics using several instruments as well as a self-perceived overall QOL visual analogue scale. No correlations among severity of disability and level of depression, state of mood or overall QOL were found. An interesting finding was that being able to drive a car, and to manage independent car transfers, was strongly associated with mental well-being and with high QOL. In addition, high social activity was also associated with perceived good QOL.

A descriptive study by Cushman (1992), examined recent functional changes and perceptions regarding the QOL in 43 SCI persons who were 15 years past injury. A global rating of QOL was used to rate the subjects' current QOL relative to that of same age peers. The results showed that neither level nor completeness of injury was a significant factor. The group with lower self reported QOL had lower rates of current employment. However, this did not reach statistical significance. Subjects who were in a preferred current living situation had a significantly better perceived

QOL.

Clayton & Chubon (1994) conducted a study in 100 individuals with SCI to identify issues associated with QOL after SCI. The Life Situation Survey, a subjective indicator of life quality developed to address issues in chronic disability, served as the primary assessment tool. This Likert-type scale is comprised of 20 items, 10 of these items are commonly accepted QOL domains, such as income, health and satisfaction with life role. The other ten items derived through a critical incidents study including mobility, autonomy, egalitarianism and social support. The total scores (89.5) showed that SCI participants perceived and rated their life quality to be somewhat lower than nondisabled (107) and some other chronic disease groups, such as cardiac (93) and rheumatoid arthritis patients (94). Items regarding self-esteem, income, public services and life role were lowest. In addition, income, educational status and social activities were associated with perceived QOL.

In a outcome measure study by Whiteneck (1992), the QOLS & Individual Needs Questionnaire which were developed by Flanagan (1978), and the Life Satisfaction

Index were 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 rasing children was also one of less important area rated by subjects. This result showed that individuals with SCI may experience a shift in priorities, because of their long term physical disability. In addition, the results also revealed significant differences in scores on the Life Satisfaction Index with respect to age. Those under age 50 reported significantly better life satisfaction than the older people.

With another approach, Krause and Dawis (1992) used a longitudinal study design to identify the optimal predictors of life satisfaction among a variety of demographic and adjustment variables. Two hundred and eight-six individuals with SCI were administered the Life Situation Questionnaire in 1985 and 1989.

Multiple regression was used to identify the optimal predictions of 1989 satisfaction from predictor variables taken in 1985 and 1989. Results suggested that psychological adjustment was a better predictor of satisfaction than were demographic and injury-related predictors. This finding also suggested that it was particularly important for professionals to predict long-term outcomes when working with persons with SCI.

In a qualitative descriptive study by Bach (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. The category of independence was also found to be important to people with a variety of chronic illnesses (Burckhardt, 1989). The inner strength or survival category encompassed responses about subjects' control over life, their ability to make the best of what they had and to do with what they had, and their will to live. Assertiveness included speaking up for oneself and asking for assistance when necessary. In fact, these two findings highly reflected the components that are important to a quadriplegic's life.

Taken together, QOL among people with SCI is associated with physical, psychologic, and social well- being, especially related with satisfaction in health status, and relationships with others. Increasingly, QOL assessment has received more attention in rehabilitation. However, most studies have been based on improvised QOL measures, and that has diminished their value. The measures often lack norms and reliability and validity data. Additionally, the diversity of instruments being used severely limits comparison of results from different studies (Clayton & Chubon, 1994).

Nursing research of QOL in Taiwan

A study entitled "what social and health variables account for the variance of life satisfaction in Chinese elderly", conducted by Huang (1988), was the earliest research about QOL in Taiwan. This cross-sectional survey, which investigated the life satisfaction of 501 elderly living in Taipei, measured QOL using a investigator-developed instrument. Structural equation modeling was selected as the multivariate analysis to examine the outcome variable, life satisfaction. The results of this study revealed that nine variables, such as health locus of control, living arrangement, self-rated health...etc, explained 38% of the variance in life satisfaction. Self-rated health was the most critical factor impacting life satisfaction. Perceived social support and living arrangement were found to contribute second and third.

Simultaneously, a study of life quality and associated factors of patients with chronic obstruction pulmonary disease (COPD) was conducted by Hsu (1988). The Sickness Impact Profile, Psycho-Social Assets Scale, Health Locus of Control, and Health Information Scale were used to determine factors related to QOL of 98 healthy comparative group and 98 COPD patients. _t_-test and canonical correlation analysis were used as statistic analysis methods. The results revealed that the QOL of patients with COPD was significantly lower than that of healthy people. The findings also supported that age and severity of disease contributed to lower QOL. Additionally, the psycho-social assets, health locus of control and health knowledge variables explained only 24.2% of the variance in life quality.

To explore the impact of caregiving situations and caregiving strain on the QOL of Chinese caregivers of elderly family members with chronic disease, Liu (1991) investigated 474 family caregivers with several instruments. The results showed that the significant predictors of QOL of the caregivers were family satisfaction, health status of the caregivers, family hardiness, and caregivers' strain. A total of 58% of the variance was explained by these predictors.

More recently, Lin (1993), a physical therapist, conducted a study to assess the QOL of individuals with SCI with a investigator-developed instrument. This instrument encompassed 56 items which included five domains as follows: 1) physical condition,
2) environment or transportation conditions,
3) psychological adjustment, 4) educational condition, and 5) economic condition. The results revealed that the severity of injury and gainful employment were two major factors affecting QOL.

As alluded to above, the measures of QOL used in these studies were usually developed or translated and modified by those researchers. Therefore, the measures often lack norms, reliability and validity data, rendering interpretation of findings tenuous.

Measurements of QOL

Instruments to measure QOL include three different types. For example, there are generic measures, disease-specific measures, and modified generic measures.

Generic measures

These measures may provide operational definitions for several domains summarized by a single index. For example, the Flanagan (1978) QOL scale was developed for a general population, but has been used to compare QOL among four different types of chronic diseases, such as diabetes mellitus, ostomy secondary to colon cancer or colitis, osteoarthritis, and rheumatoid arthritis (Burckhardt, 1989). More recently, Burckhardt (1993) did a comparison among healthy people and six different groups of chronic illness people with the QOL scale. The mean scores of QOL were as follows: healthy comparison group (83.2), ostomy (82.3), rheumatoid arthritis (79.6), osteoarthritis (77.2), COPD (74.2), insulin dependent diabetes (73.7) and fibromyalgia (71.5). Another example is the Quality of Well-Being Scale which has been applied to groups of patients with AIDS, cystic fibrosis, and arthritis (Kaplan, 1989). Likewise, the Life Situation Survey (Chuban, 1987) has been used in a variety of populations, such as students, medium security inmates, end-stage renal disease, spinal cord injury, and mental retardation.

A generalizable quality of life measurement may facilitate comparisons between health care interventions across many fields. However, it may not be able to detect small, but clinically important, differences (Drummond, 1987; Patrick, 1989).

Disease-specific measures

This approach to QOL measurement focuses on specific aspects of health status. For instance, the breast cancer chemotherapy questionnaire (Levine, 1988) was developed for women with stage II breast cancer receiving chemotherapy. The items were generated through a literature review and discussions with medical oncologists, oncology nurses and stage II breast cancer patients. The items included areas of physical, emotional and social well-being, but also included some specific items for cancer patients. For instance, consequences of hair loss, emotional dysfunction, physical symptoms, trouble and inconvenience associated with treatment, fatigue, and nausea. Another example is the chronic lung disease questionnaire, a disease-specific measure of QOL functions on dyspnea, day-to-day activities, fatigue, and areas of emotional dysfunction, such as frustration and impatience (Guyatt, 1987).

Changes in disease-specific measures may be easier to interpret, because they are more specific or more closely associated with changes in clinical measures of disease activity, such as the side effects of chemotherapy effect in cancer patients (Levine, 1988).

On the other hand, although disease-specific instruments may detect the small changes in medical treatment, they do not permit the comparison of groups with different chronic diseases or disabilities. "Inability to make these comparisons decreases the generalizability and usefulness of the measures for evaluating clinical trials that are not disease specific (i.e., many nursing strategies) or for making policy decisions that are cost-effective across groups" (Burckhardt, 1989, p.348).

Modified generic measures

A generic modified instrument, modified for specific populations, is an economic method for developing a suitable instrument. For example, Selby's (1984) QOL measure is used to assess the QOL of patients with breast cancer. One section of the instrument is based on the Sickness Impact Profile (SIP), a global measure of health status developed by Bergner et al (1981). Another example is the study of back pain by Roland et al. (1983). The authors selected 24 of 136 items that they felt were most appropriate for back pain from eight of 12 different SIP categories.

Development of the QOLS instrument

Flanagan's QOLS

This instrument was developed for the general population in the 1970's. Flanagan (1978) began defining the main determinants of QOL and developing procedures for surveying the importance of each component in an empirical manner. 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 from Harlem to retirement communities in Arizona to San Francisco's Chinatown were included. The method selected was the critical incident technique. Subjects were asked questions such as, "Think of the last time you did something very important to you or had an experience that was especially satisfying to you. What did you do or what happened that was so satisfying to you?", "Why did this experience seem so important or satisfying?", "Think of a time you saw something happen to another person that was really harmful or made their life worse in some way. Exactly what happened to this person?", "Why do you feel that this made their life worse?", "What should have happened in this situation?", "Think of a recent time you could not do something you wanted very much to do or could not have something you wanted very much to have. What did you want to do or have that you could not do or have?" Other questions asked for "the biggest change in the quality of your life... in the past 5 years?", "a continuing source of pleasure to you", "a continuing source of trouble to you", "a strong positive emotional impact" and "a strong negative emotional impact". A number of other questions were used to try to include as wide a range of experiences and behaviors as possible.

In all 6,500 critical incidents were collected, each reporting a time when something was actually observed to have a significant effect either positively or negatively on overall quality of life. These incidents were sorted into similar activities and experiences. Through an inductive process of gradual refinement, a set of 15 categories was formulated. (Flanagan, 1978; Flanagan, 1982).

Adapted Flanagan QOLS

In a psychometric study by Burckhardt (1989), 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. For instance, independence, being physically active, ability to care for self, being healthy, having a sense of security, positive interaction and relationships with others, and meaning in life. The participants with osteoarthritis also emphasized freedom from pain, while those with diabetes emphasized being in control. 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. In addition, Burckhardt (1989) used the 7-point Delighted-Terrible scale to measure the degree of satisfaction instead of the original 5-point satisfaction scale. This format was developed by Andrews and Crandall (1976) who found it to be more sensitive and less negatively skewed than a 5-point satisfaction scale.

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.

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

"Comparison of psychometric properties of the source and target language versions provides additional data for assessing equivalence of both versions of the instrument" (Jones, 1987, p. 325). 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. However, finding enough competent bilingual respondents is not easy (Jones, 1987).

An alternate method for assessing the psychometric soundness of the target language version is to administer the two source language forms to monolingual subjects and compare scores from the two source language version and the second source language version (developed through back-translation) (Werner & Campbell, 1970).

The internal consistency of the two versions can be assessed with Cronbach's alpha, item analysis and calculation of the Pearson product moment correlation between total scores, and subset scores of both forms. Cluster analysis or factor analysis can be used for assessing validity (Jones. 1987).

CHAPTER 3

Methods

The purpose of this study was to gather information regarding the validity and reliability of the adapted Flanagan QOLS, translated into Chinese, in Chinese SCI outpatients.

The study included two parts: preliminary work and the main study. The preliminary work will be described first, followed by a description of the main study.

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 (Breslin, 1970; Liu, 1993).

Participants

Translators

The two translators who did with back-translation were from Taiwan. One was a medical student who immigrated after he finished junior high school. The other majored in social sciences and works as a translator in a community church. He immigrated when he was in the sixth year of elementary school.

Bilingual individuals

Six master-educated bilingual individuals who majored in different fields were asked to compare the Chinese version with English version of the QOL scale.

In order to examine the reliability and concurrent validity of the Chinese version, a convenience sample of fifty-nine bilingual persons filled out the Chinese and the English versions of the QOL scale. The criterion for deciding that they were biligual 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 (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 Burckhardt'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 mailed to the selected subjects by the Association. 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 English and Chinese version of QOL scales. The Pearson's correlation coefficients between the English version and the Chinese 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

Republic of China (Taiwan) is a country with a population of 21,000,000 people. There are approximately 3,500,000 people living in the capital city (Taipei) and the surrounding six cities. 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

Since it was the first time home visiting investigation was implemented in this population in Taiwan, the response rate was difficult to estimate. Mailed questionnaires had been found to have a response rate from 50% to 70% (Lan, 1992; Lin, 1993; Shiue, 1992). Because a sample of 20 subjects was desired, the researcher selected 30 subjects from the roster by randomly choosing the first number on the roster and then using a table of random numbers to select the other 29 subjects. The initial response was not sufficient to give 20 subjects, therefore another sampling was done two weeks later.

Each of the potential subjects was sent a letter with information on the study and an invitation to participate. Also included was the consent form (Appendix A). The letter also included a self-addressed, stamped postcard with an identifying code number. If the individual wished to participate or declined to participate, he or she was instructed to return the postcard to the researcher (Appendix F). After two weeks, a second letter was sent to those on the first mailing who had not responded.

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

The Quality of life scale (QOLS)

The QOLS is a 15-item Likert-type scale developed by Flanagan to which a sixteenth item (independence) has been added based on Burckhardt et al's (1989) findings in patients with chronic illness (Appendix B). The scoring format used by Burckhardt and colleagues was developed by Andrews and Crandall (1976). Scores for each item range from 1 (terrible) to 7 (delighted). Psychometric data from Burckhardt et al (1989) showed that the internal consistency reliability coefficient of the QOLS was .86 to .89 over a 6-week period. Test-retest reliability in the same sample was .78 between the first and second measurements (a 3-week interval), and .76 between the first and the third measurements (a 6- week interval).

Open-ended questions

A qualitative method was used to obtain content validity of the QOLS. The author used Burckhardt's (1989) three open-ended questions to identify domains of quality of life and determine the participants' perceptions of the stability of their lives: (1) What does quality of life mean to you? (2) What kinds of things are important to your quality of life? and (3) Has the quality of your life changed over the past year?

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 (Appendix C).

Procedures for data collection

Those willing to participate returned the postcard and the signed consent form to the investigator. The investigator then called the subject and described the purpose of the study and the procedures (Appendix G). An appointment was also arranged between the researcher and the participant at a mutually agreed upon time and place.

Prior to the beginning of the interview and administering of the questionnaire, the researcher read the informed consent with each subject.

The subjects were first asked three open-ended questions about their quality of life. They were then asked to fill out the QOLS. All home visits were conducted by the researcher. The length of home visits ranged from 1 and 1/2 hours to 3 hours including a break as the subject needed, for example, pressure relief from the wheelchair.

The print of the questionnaires was enlarged for the quadriplegic individuals. The researcher provided assistance to the quadriplegics in filling out the questionnaires as needed.

Each participant was sent a thank you card for participating in the study one week after the home visit.

Subjects who were willing to participate in a retest received the questionnaire or were visited by the researcher again two weeks later.

Protection of human subjects

The rights of the human subjects were protected according to federal guidelines as monitored by the Oregon Health Sciences University Committee on Human Research. The study was considered exempt from review by the committee.

The consent form was sent with an introductory letter, so that the subject would have better understanding of their rights.

The identity of all subjects participating in this study was kept confidential by using a coding system. All completed questionnaires were kept in a locked cabinet. The data in the computer were protected.

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.

In addition, the interview contained the three open-ended questions which allowed the subjects freedom to respond. Information obtained from these questions was used to confirm the content validity of the QOLS.

The interview data were recorded and analyzed by the researcher. 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.

CHAPTER 4

Results

Results include preliminary work and the main study. Results of the preliminary work encompass translation issues, and reliability and concurrent validity of the QOLS in the Chinese version. Characteristics of SCI participants, content validity and test-retest reliability of the QOLS in the Chinese version were included in results of the main study.

The preliminary work

Translation and wording issues

Two back-translation were compared to the original QOLS in Appeddix D and E.

Several wording issues were discussed as follows:

(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.

Reliability and validity

The internal consistency reliability in the English and Chinese versions both were .88. The Pearson's correlation coefficients in terms of concurrent validity of English and Chinese versions were .84 to .98 (Table 2).

Table 2

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 & qe16	.92		

Total e & c: Pearson's correlation between the English version and the Chinese version (total 16 items).

qe1 & qc1: Pearson's correlation between item #1 of the English version and the Chinese version, etc.

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.

With respect to education, the minority of the sample (8%) had graduated from 4-year colleges. Forty-one percent had graduated from either a vocational school or private college. Eighteen percent had graduated from high school and 32% had less than a high school education.

Eleven (50%) of the 22 subjects in the study were currently employed. Four (18%) were self-employed and seven (32%) had remained jobless since their injuries.

As for religion, the majority were Buddhist (46%), 27% had no religion, 9% were protestant, 9% were Taoism, and 9% were other religions.

With respect to the information on the spinal cord injury, the most common cause was motor vehicle accidents (50%), followed by falls (23%), occupational accidents (9%), diving accidents (5%), sports accidents (4%) and other causes (9%).

Eight (37%) were complete quadriplegia, two (9%) were incomplete quadriplegia, eight (36%) were complete paraplegia, four (18%) were incomplete paraplegia. Nineteen of 22 were wheelchair bound. The rest needed devices for walking for short distances. They still needed a wheelchair when they went out.

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).

To assess the degree to which the sample was representative of the SCI Association of R. O. C. members, a comparison was made based on a nationwide survey (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 3.

Interview content analysis

To gather content validity of the QOLS, a total 39 subjects were asked three open-ended questions about quality of life. Twenty of the 39 were asked by mail in the preliminary study. Twenty two subjects were interviewed by the researcher in the main study. There were three subjects who were in both groups, and data from both their interview and mailed questionnaires were used.

The sixteen quality of life components are described first, followed by the other findings. The definition of each item was based on Flanagan's (1978, item 1-15), and Burckhardt's (1989, item 16) studies.

1. Material well-being and financial security. Having good food, home, possessions, comforts, and expectations of these for the future.

> *" To me, having a job and a stable income are important to my quality of life".*
>
> *"The meaning of quality of life is that I will not feel insufficient in materials in my daily life".*
>
> *"I think financial subsidy is the most important thing on my life".*
>
> *"With a warm home, a car and free of worry about money".*
>
> *"I felt better last year because I had more income".*

Table 3

Gender distribution, types of lesion, and causes of SCI in the report of the SCI Association of R. O. C. and the present study

	The Report of SCI Association of R. O. C.	The present study
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%

2. Health and personal safety. Enjoying freedom from sickness, possessing physical and mental fitness, avoiding accidents and other health hazards.

> *"The most important thing to my quality of life is health, especially for the individual with spinal cord injury. Maintaining body functions is very important".*
>
> *"The change of my life in the past year was that I used to walk a short distance with crutches before the surgery. Now, I am totally wheelchair bound. I have to make many adjustment again".*

3. Relations with spouses, or significant others. The relationship involves love, companionship, sexual satisfaction, understanding, communication, appreciation, devotion, and contentment.

> *"After I was injured, I finally realized the importance of my family- my husband and kids. other than that, nothing is more important for me".*
>
> *"I got married last year. I feel so good. I feel stable and content. It is good to know that you have someone supporting you in any situation".*
>
> *"My girlfriend left me. I feel lonely".*

4. Having and raising children. This relationship involves watching their development, spending time with them and enjoying them. Also included are things like molding, guiding, helping, appreciating, and learning from them and with them.

> *"To me, I already have a stable job and income, what is more important now is raising my daughter".*
>
> *"I wish I could do something for my son. You know, I wish I could take him out for shopping, picnic and sight-seeing".*
>
> *"My first priority is my kids. I hope that I can take them out to travel. Well, I can not take them out, but they are quite understanding".*

5. Relations with parents, siblings or other relatives. In these relations, one experiences communicating with or doing things with them, visiting, enjoying, sharing, understanding, being helped by and helping them. The feeling of belonging and having someone to discuss things with is a large component.

> *"I am the person who takes family and work seriously. To me, chatting with my family everyday is the meaning of quality of life, not having good*

> *food or nice clothes".*
>
> *"Living with my family, I can have invaluable love and perfect care. We are interdependent and support each other".*
>
> *"Harmony in the family and love between family members are the most important things to my quality of life".*
>
> *"Living in modernized society, if I was not injured, I would not have much time to be with my parents. Now, I can watch television with them and explain the news to them. I think that it is bliss to me to have the opportunity".*

6.Relationship with close friends. In these relationships one shares activities, interests and views. Important aspects of these relationships involve being accepted, visiting, giving and receiving help, love, trust, support, and guidance.

> *"After being injured, I was feeling really down. I refused to see my friends, but they did not forsake me. Not only did they come and visit me, they also asked for my input in situation they have encountered. I gave advice as I did before I was injured. When they took according to my advice*

and succeed, I feel especially happy, because I feel useful".

"I still keep in touch with my school friends and would sometimes drive to the beach".

"Friends are important to me. I always share my worry with my friends".

7. Activities related to helping or encouraging other people (other than relatives or close friends). This can be done through one's efforts as an individual or as a member of some organization, such as a church, club, or volunteer group that works for the benefit of other people.

"Helping those who are newly injured is one of important things to me".

"I started sharing my successful experiences with other individuals with spinal cord injuries. I hope that it is helpful to them".

8. Activities relating to local and national governments. It includes staying informed through the media, participating by voting and through other communications, having political, social, and religious freedom.

There were no examples from this group of patients that fit this domain.

9. Learning-attending school, improving understanding, getting additional knowledge. It is an intellectual development through activities in or out of school.

"To live is to have a goal. For me, my goal is to continue my computer education and to fulfill my dream of acquiring a degree".

"I wish I could go back to school, but you know that is impossible...it is just a dream for me".

"I love to travel. It can increase my knowledge and enrich my view".

10. Understanding yourself-knowing your assets and limitations-knowing what life is about. This may involve developing and gaining orientation and purpose for one's life. It also includes becoming more mature, experiencing personal growth and development, and realizing the ability to influence the course of one's life significantly.

"I started to listen to Buddhist tapes and study Buddhist books. It is helpful. I think that I can get more understanding about the meaning of life".

"The meaning of quality of life? It depends on what you want and what you need. You've got to understand yourself first".

<u>11. Work-job or in home.</u> This includes having interesting, challenging, rewarding, worthwhile work in a job or home. It also includes doing well, using one's abilities, learning and producing, obtaining recognition, and accomplishing on the job.

"I just got a job. I can get contentment and accomplishment from my job. I think that it is the biggest change in the past year".

"To me, quality of life is work. If I can do it well, then I will feel good. But if not, I will feel stressed".

"If I am alive, why not make life happier. My biggest joy is when I finish a hard project. I would feel that I am so good".

<u>12. Expressing yourself creatively.</u> It includes showing ingenuity, originality, imagination in music, art, writing, handicrafts, drama, photography, practical or scientific matters, or everyday activities.

"I am glad that I have been involved in painting,

writing and calligraphy during the last year".

<u>13. Socializing-meeting other people, doing things, parties, etc.</u>

"I have participated in the organization and social events over the past year. It increases my social network and enhances my interpersonal relationship with others".

"I started to visit my friends".

"I felt better last year because I had more opportunities to go out with friends".

"To me, quality of life is environment free of barrier, because I like to go out to meet new friends".

<u>14. Reading, listening to music, or observing entertainment.</u> It is a kind of passive recreation.

"I feel life is very carefree, because throughout a day I either watch TV or get on my power wheelchair and go out or have meals with friends".

"TV is another good partner to me".

"I think my life is quite stable and peaceful... drawing, reading and listening to the radio on special topics are my daily routine".

"Listening to music and reading my favorite books

are my daily life".

15. Participating in active recreation.

"Now I feel that I have more stamina than before. I am glad that I am even able to do some exercise after work".

"Go outside and enjoy the sunshine and flowers".

"I was a very active person who loved the outdoors. I used to go hiking with my family on the weekends before I was injured. Now, I can not hike anymore, but I am still looking for alternative recreation (outdoors)".

16. Independence, doing for yourself.

"To me, the more I can take care of myself, the higher quality of life I will have".

"If someone can not take care of himself or herself, what the quality of life in there?"

"To me, quality of life is that I can take care of my activities of daily living. Everyone has their own pride and wants to be free, and have no need to depend on other people's help".

"Dependence will cause frustration. I personally do not like to depend on other people if I can do it by myself".

"I got a job last year. My family is really happy for me, because I am able to be independent".

Other findings

1. Barrier-free, convenient equipment and transportation.

"I have easy access to transportation, so I can go places".

"An environment with very few barriers is very important to the individual with SCI. Now I can not even leave the building".

"I have a modified vehicle. Now, I can go somewhere, when I want to go".

"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".

"Peace of mind".

"Psychological well-being. Psychological health".

"A healthy attitude".

"Living with self-esteem and respect. We are just

like the normal person. We just have some dysfunction in our bodies".

<u>3. Free of complications.</u>

"Free of pressure sores".

"Free of fear of having complications".

"I always get urinary tract infections. It really bothers me a lot".

<u>4. The relationship with caregivers (family members or attendants).</u>

"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 does not 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 correlations of .83 and Cronbach's alpha of .85 on the first testing and .83 on the second testing.

CHAPTER 5

Discussion, Implications, & Summary

Discussion

All the major components of quality of life identified for the general population in the QOLS were identified by these SCI outpatients as components of their quality of life except item #8 "Participating organization or public affair" which was not found in the interview data. Nineteen categories emerged from the data. Fifteen categories are similar to the domains of the QOLS. 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. In Chinese culture, people are used to taking care of themselves and their families rather than participating in government and public affairs. On the other hand, a qualitative study by Bach (1993), the interview result did not reveal this category either.

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, and relationships with family, significant others and friends. They may have physical and psychological difficulties in participating and caring about being involved in public affairs.

In addition, for item 12 "expressing yourself creatively" just one statement was found on content analysis. This may be due to needs differences. It may also be due to having physical difficulties in performing the activities in this item.

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. Especially with respect to the architectural barriers, this finding is consistent with the context of the Republic of China health care system where the rights of disabled patients are still largely neglected and where compliance with laws on architectural barriers are seldom enforced (Wu, 1992). Consequently, the disabled person's autonomy and independence appear to be threatened by architectural barriers (Taricco, 1992). Additionally, community reintegration which is accompanied by a perceived high QOL is also impeded by architectural barriers (Krause & Dawis, 1992).

The category of psychological adaptation also has been reflected in the literature regarding QOL in SCI population. In the early 1980's, Tucker (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. Furthermore, Wright (1983) believed that adjustment to disability required value change. Not only is the meaning which the individual attaches to the disability, in need of change or modification, but he or she also needs to change his or her attitudes about what is meaningful in life. Taken together, the degree of adjustment with disability will affect the perception of one's QOL.

The occurrence of complications decreasing the QOL of SCI individuals has been reported by several investigators (Eisenberg & Saltz, 1990; Lundqvist, 1991). Furthermore, in the long run, complications affect not only one's QOL but also the mortality rate, for instance, respiratory infection, renal death, and septicemia due to pressure sores. In one study, genitourinary disorders (renal failure and pyelonephritis) accounted for 49% of the deaths occurring between ages of 30 and 39 (Whiteneck, 1992).

In Decker's (1989) findings, 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. Furthermore, a study of well-being in 100 middle-aged and elderly SCI persons (Decker & Schulz, 1985) found that long-term coping was facilitated by the presence of a primary support person or caregiver.

Overall the QOLS is a reliable and valid generic measure. In addition, it is also an easy tool to administer and understand. As alluded to above, a generic measure may facilitate comparisons between health interventions across many groups. It is especially important to the diversity of SCI population and rehabilitation population. However, the limitation is that it may miss concerns of particular interest to the study participants. Therefore, adding some disease-specific items may increase the content validity when applying this instrument in spinal cord injury population. Additional studies are needed to determine the validity of including these four additional domains in further quality-of-life 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.

Implications for nursing

Most commonly, outcome measurements in rehabilitation are judged in terms of functional outcomes. For example, "is the individual able to put clothes on?", and "can he or she transfer from bed to wheelchair independently and safely?". However, these limited- focus approaches ignore the holistic nature of human-beings and rehabilitation nursing. Indeed, satisfying relationships and a meaningful interaction with the social and physical environment are much more important than the ability to transfer and dress independently. Fortunately, there is increasing attention on QOL assessment in the rehabilitation field. Clayton & Chubon (1994) have suggested that "potential uses include measurement of rehabilitation progress and program outcome, identification of factors that underlie differences in the life quality of persons with disability, long-term monitoring of the status of individuals with disabilities, and rating the life quality of various disability groups to establish priorities for program development and allocation of resources" (p. 633).

Regarding the four additional domains, it is important for nurses working at the rehabilitation unit to understand what is important to individuals with SCI. With respect to "environment free of barrier, convenient equipment, and transportation", this finding broadened the view of the rehabilitation nurse in considering how environment barriers affect the disabled individual. In fact, Trieschmann (1980) and DeJong (1984) have addressed this issue by saying that accessibility of the environment greatly raises a person's ability to resume a productive life in community. In addition, in an independent living program evaluation study, Tate and colleagues (1992) reported that 69 SCI participants demonstrated a significantly lower level of psychological distress one year post-injury. At this point, intervention strategies must be increasingly directed to removing and coping with environmental barriers and community reintegration. The rehabilitation program may focus on negotiating community barriers, such as how to order care buses, how to get a modified automobile, how to modify home environment, and how to get convenient equipment. In addition, accompanying the patient to the community, the real world, should be implemented when the patient is still hospitalized. The most important notion to the rehabilitation nurse is that we have the awareness and responsibility to advocate for the rights of the disabled individuals and to assist persons with SCI and other disabling conditions to gain full access to life opportunities by minimizing barriers to work, education, etc. This notion must be disseminated from the rehabilitation professionals.

In regard to "free of complications", patient education programs about pressure sores prevention and bladder training may have to be evaluated. A study to gather further information about why patients so easily get pressure sores and urinary tract infections when they are at home should be conducted.

There can be problems regarding psychological adaptation and relationships between the SCI individual and the caregiver. The rehabilitation nurse may establish a support group of well-adapted SCI individuals and their caregivers with newly injured SCI patients and their caregivers. This could facilitate psychological adaptation of newly injured SCI patients and their caregivers. Furthermore, the objectives of the rehabilitation should also include facilitation of the adaptation of the family or the primary caregiver.

Summary

Approximately one thousand new SCI cases occur each year in the Republic of China. Most victims face unrecoverable physical disability and multiple systems dysfunctions, such as bowel, bladder and sexual dysfunctions. However, little is known about how they perceive the quality of their lives when they return home. There is a lack of appropriate instruments to measure QOL. Therefore, the purpose of this study was to gather knowledge about implementing the adapted Flanagan (1978) QOLS in Chinese SCI outpatients.

The QOLS was translated into Chinese. The translated version was found to have high reliability and concurrent validity. Content analysis of three open-ended questions about QOL revealed that all the major components of the QOL identified in QOLS were also identified by SCI outpatients as components of their QOL except item #8 "participating organization or public affair". An additional four domains found were categorized as follows: (1) free of environment barriers, convenient equipment and transportation, (2) psychological adaptation, (3) free of complications, and (4) good relationships with caregivers. Test-retest reliability of the QOLS was high in the Chinese version.

Overall, the Chinese version of the QOLS is suitable for use in further studies. These studies may repeat the Flanagan (1978) and Whiteneck (1992) studies by asking participants to rate the importance of each domain to their QOL in order to detect whether their needs are being met.

Overall, the research findings can assist rehabilitation nurses to understand what components are important to the SCI population. In addition, professionals must have greater insight into rehabilitation and adjustment to disability as a lifelong process. The patient's care does not cease at discharge. The rehabilitation professionals must work with patients to face, evaluate, redefine, and readapt to problems that are lifelong.

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APPENDIX A

OREGON HEALTH SCIENCES UNIVERSITY

Consent Form

Title:

Quality of life of persons with spinal cord injury living in Taipei: A psychometric study.

Principal investigator:

Shan-Huan Han BSN RN. Graduate student, School of Nursing, Oregon Health Sciences University, Portland, Oregon.

Faculty Advisor:

Carol S. Burckhardt, R.N., Ph.D., Professor, School of Nursing, Oregon Health Sciences University, Portland, OR. Telephone: 503-494-3895.

Purpose:

To investigate quality of life of persons with spinal cord injury living in Taipei.

Procedures:

If I agree to participate, I will be interviewed for approximately 1-1 1/2 hours by the investigator named above. I will answer questions about the following: my personal information (gender, age, level of injury, time since injury, education, occupation, employment status, health insurance, living arrangement, religion, marital status) and answer or fill out the Quality of Life Scale.

Risks:

There are no known risks of participation in this study.

Benefits:

I may not personally benefit from participation in this research study, but the knowledge gained from the study may benefit future spinal cord injured persons by improving the understanding of this population.

Confidentiality:

All of my answers will be seen only by the investigator and used only for research purposes. The published report of the research will not show my individual results, but will show data that are combined with those of other participants.

Costs:

There are no costs involved in participating in this research study.

Questions:

The investigator, Shan-Huan Han will answer any of my questions (about these questionnaires). I can contact her at 0021-503-224-2792 (USA) or 2173924 (Taipei, July-September).

Right to refuse or withdraw:

My participation in this study is completely voluntary. I am free to refuse to participate or withdraw from the study at any time.

I have read this form or my family has read it to me. If I can't write by myself, my family may represent me to sign this consent form.

Signature: ______________________ Date: __________

Signature of investigator:

____

APPENDIX B

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 vigorous.........	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 assets and 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

生活品質問卷調查

日期：

編號：

請閱讀每題並圈選最能表達您目前滿意度的號碼. (7是很滿意，1是非常不滿意)

請回答每題，即使您目前沒有參與這項活動，仍請您表示您對沒參與這項活動的意見. (滿意或是不滿意).

	很滿意	滿意	大部份 滿 意	部有	大部份 不滿意	不滿意	非常 不滿意
1. 物質上的舒適性-家，食物，便利的用物設備，財物保障.	7	6	5	4	3	2	1
2. 健康-身體強健有活力.	7	6	5	4	3	2	1
3. 與父母，兄弟姊妹和親戚的關係--互相溝通，拜訪，幫忙.	7	6	5	4	3	2	1
4. 擁有並扶養小孩	7	6	5	4	3	2	1
5. 與配偶或重要他人的關係	7	6	5	4	3	2	1
6. 與好朋友的關係	7	6	5	4	3	2	1
7. 幫忙及鼓勵他人，參加義務工作，給予他人建議.	7	6	5	4	3	2	1
8. 參與組織社團，公共事務 (如：投票).	7	6	5	4	3	2	1

	很滿意	滿意	大部份滿意	都有	大部份不滿意	不滿意	非常不滿意
9. 學習-- 上學，或不斷增進理解力，獲得更多的知識.	7	6	5	4	3	2	1
10. 瞭解自己-- 知道自己的優點和限制，知道生活是什麼.	7	6	5	4	3	2	1
11. 工作--在外工作，或在家工作.	7	6	5	4	3	2	1
12. 有創意的表達自己	7	6	5	4	3	2	1
13. 社交--跟他人接觸，從事活動，聚會等.	7	6	5	4	3	2	1
14. 閱讀，聽音樂，觀賞娛樂節目.	7	6	5	4	3	2	1
15. 參與動態性消遣活動（如:運動，郊遊..）	7	6	5	4	3	2	1
16. 獨立自主，為自己做，盡力自我照顧.	7	6	5	4	3	2	1

APPENDIX C

PERSONAL INFORMATION QUESTIONNAIRE

ID:
Date:

1. Age: (birthday:____ ____ ____)
(1) 16-20; (2) 21-25; (3) 26-30; (4) 31-35; (5) 36-40
(6) 41-45; (7) 46-50; (8)51-55; (9)56-60; (10) 61-65
(11) 66-70; (12) 71-75 ( )
2. Gender: (1) male (2) female ( )
3. Education: (1) none; (2) elementary; (3) junior high school ; (4) senior high school; (5) technical school; (6) associate college; (7) college; (8) master (9) Ph. D. (10) others ( )
4. Marital status: (1) single; (2) married; (3) separated; (4) divorced; (5) widowed ( )
5. Employment status: (1)part-time; (2) full time; (3) self-employed ; (4) retired (5) unemployed; ( )
If your answer is (4) or (5), please skip No.6
6. Occupation: (1) unskilled ; (2) skilled blue collar; (3) white collar;
7. Health insurance: (1) none; (2) private; (3) family (4)government; (5)labor; (6) farmer/fisher (7) free ( )
8. Living arrangements: (1) with family; (2) without family ( )
If your answer is (1), please skip No.9
9. Living arrangement: (1) living alone at apartment (2) living alone at private foster home; (3) others ( )
10. Religion: (1) Protestant; (2) Catholic; (3) Buddhist (4) Taoism; (5) other; (6) None ( )
11. Level of injury: (1) complete quadriplegic; (2) incomplete quadriplegic; (3) complete paraplegic (4) incomplete paraplegic ( )
12. Onset time: ____ ____ ____.
13. Time since injury (1)less than 6 months; (2) 6-12 months; (3) 1-2 years; (4) 2-3 years; (5) 3-4 years; (6) 4-5 years (7) 5-10 years; (8) 10-15 years; (9) 15-20 years; (10) more than 20 years. ( )
14. Do you have any complications from your SCI
(1) Yes; (2) No ( )
If Yes, what are they? Please specify ____________________

個人資料問卷調查表

編號:
日期:

1. 年齡:　　　　(生日:　　年　　月　　日)
(1) 18-20　(2) 21-25　(3) 26-30　(4) 31-35　(5) 36-40
(6) 41-45　(7) 46-50　(8) 51-55　(9) 56-60　(10) 61-65
(11) 66-70　(12) 71-75 歲　　(　　)

2. 性別: (1) 男　　(2) 女　　(　　)

3. 教育程度: (1) 無　(2) 小學　(3) 初中　(4) 高中　(5) 高職
(6) 專科　(7) 大學　(8) 碩士　(9) 博士　(10) 其它　　(　　)

4. 婚姻狀況: (1) 單身　(2) 已婚　(3) 分居　(4) 離婚　(5) 鰥居　　(　　)

5. 工作狀況:(1) 無　(2) 退休　(3) 半天班　(4) 全天班　(5) 自營業　　(　　)
如您有工作，則工作是
____

6. 健康保險: (1) 無　(2) 私人保險　(3) 公保　(4) 勞保　(5) 眷保
(6) 農/漁 保　(7) 福保　(8) 其它　　(　　)

7. 居住情形: (1) 和家人同住　(2) 沒和家人同住　　(　　)
如您沒和家人同住，則您是　(1) 自己住公寓　(2) 住安養中心　(3) 其它　　(　　)

8. 宗教信仰: (1) 無　(2) 基督教　(3) 天主教　(4) 佛教　(5) 道教
(6) 其它　　(　　)

9. 脊髓損傷的程度: (1) 四肢完全癱瘓　(2) 四肢不完全癱瘓
(3) 下肢完全癱瘓　(4)下肢不完全癱瘓　　(　　)

10. 受傷時間: 民國　　　年

11. 受傷多久: (1) 少於 6 個月　(2) 6-12 個月　(3) 1-2 年　(4) 2-3 年
(5) 3-4 年　(6) 4-5 年　(7) 5-10 年　(8) 10-15 年　(9) 15-20 年
(10) 20 年以上　　(　　)

12. 您有任何因脊髓損傷而引起的合併症麼?
(1) 有　　(2) 沒有　　(　　)
如果有，請寫明:
____

APPENDIX D

Back-translation:(A)

QUALITY OF LIFE QUESTIONNAIRE

Please read each question and circle the number indicative of your degree of satisfaction (7: very satisfaction; 6: satisfaction; 5: mostly satisfaction; 4: mixed; 3: mostly dissatisfaction; 2: dissatisfaction; 1: very poor).

1. Material comfort- family, food, convenience of material uses, financial security.
2. Health- bodily health and level of activity.
3. Relationship with parents, siblings and other relatives- visits, communication, support.
4. Children to support.
5. Relationship with spouse or partner.
6. Relationship with friends.
7. Helping and encouraging others, participation in public work, lending advice
8. Participating in public service.
9. Learning- school, gaining analytic understanding or knowledge.
10. Understanding yourself- knowledge of your strengths and limitations. Understanding of life.
11. Work- at the office or at home.
12. Express yourself creatively.
13. Social contact- with others, involvement in social activities.
14. Reading, listening to music, viewing other entertainment.
15. Involvement in active entertainment.
16. Independent, work for self

APPENDIX E

Back-translation: (B)

Survey on the Quality of Life

Please read each item and chose the number which represent your degree of satisfaction (7: very satisfaction; 6: satisfaction; 5: mostly satisfaction; 4:mixed; 3: mostly dissatisfaction; 2: dissatisfaction; 1: very dissatisfaction.

1. Comfort from material things- family, food, convent facility, and in regard to financial stability.
2. Health: comfort of the body, full of energy.
3. Relationship with parents, siblings, and relatives: communication, visitation, help.
4. Having and rearing children.
5. Relationship with your partner, or significant other.
6. Relationship with your best friend.
7. To encourage others, to do volunteer work, and give advice.
8. Engaging with social and public service.
9. Studies: going to school, increase knowledge, gain more knowledge.
10. Understand yourself- know your strength, limit of your ability, know what is the meaning of life.
11. Occupation- working at home or at work.
12. Have creative expression of oneself.
13. Socializing- involvement with fellowships, engaging in activity.
14. Reading, listening to music, watching entertaining programs.
15. Participating in active recreation.
16. Independent, being able to do one's own work.

APPENDIX F

Letter of introduction to subjects.

No.:

Dear:

My name is Shan-Huan Han. I was a nurse and worked on a rehabilitation floor with spinal cord injured patients for two years before I went to study in U.S.A.

Because little is known about spinal cord injured persons' quality of life, I would like to visit you at your home and ask you fill out the quality of life scale and a personal information questionnaire, such as age, gender, education, religion, martial status, employment status, occupation, and injury information.

Please read the consent form I have enclosed. If you decide to participate in the study, please return the respondent sheet, signed consent form and write down your phone number. I will call you and set time to visit you. If you do not want to participate, please also return the respondent card.

If you have any question about the home visit or the study, please feel free to call me (2173924). Thank you for reading my letter.

Sincerely,

Shan-Huan Han

( ) I would like to participate in your study. Please call me at ________________

Name: ________________

( ) I would not participate in your study.

APPENDIX G

TELEPHONE CHECKLIST

1. Thank the subject for returning the respondent sheet.
2. Ask the subject whether he/she understands the procedure.
3. Ask the subject whether he/she is above 16, without any disease that affects his/her QOL other than SCI.
4. Ask the subject what a good time is for him/her.
5. Ask the subject how to get to his/her home.

APPENDIX H

This MRP is a part of a larger study. The purpose of the larger study is to get knowledge about implementing three instruments (the QOLS, Norbeck Social Support Questionnaire-NSSQ, and the revised Jaloweic Coping Scale-RJCS) in the Chinese SCI outpatients. Therefore, the subjects were asked several questions about their coping, social support, and QOL, then three instruments were filled out.

In 1992, the RJCS had already been translated into Chinese by Ruey-Shien, Chen. Cronbach's alpha on the Chinese RJCS (CRJCS) was reported as .94 for both the overall Use score and the Effectiveness score on older Chinese immigrants (N=31).

The author administered the CRJCS to healthy bilingual people (N=50) and SCI outpatients (N=22). The results showed that Cronbach's alphas were .90 (N=50) and .90 (N=22) for the overall Use score; .92 (N=50) and .91 (N=22) for the overall Effectiveness score.

The NSSQ was translated by the author in the preliminary work of this study. The Pearson's correlation coefficients in each item of NSSQ between the English version and the Chinese version were from

.97 to .99 (N=50).

In the 22 SCI outpatients, the Pearson's correlation coefficients between the two affect items was .99; between the two affirmation items was .96; and between the two aid items was .90.

The Chinese versions of RJCS and NSSQ are attached on the following pages.

號碼:________

日期:________

札氏壓力應付量表

這份問卷是希望了解您應付緊張與壓力的方法,以及您如何處理壓力下的情況,這份問卷列出了不同應付壓力的方法,有些人使用很多不同的方法應付壓力,有些人只使用少數幾種.

對每一個應付壓力的方法,您會被問及兩個問題:

A.使用這個方法的機會有多少?
請圈選出您使用這個方法的多寡,每個數字的意義如下:

0.從未使用
1.很少使用
2.有時使用
3.經常使用

B.如果您曾使用這個方法,它的效果如何?
請您圈選出它的幫助有多大?

0.沒有幫助
1.有一點幫助
2.相當有幫助
3.很有幫助

* 如果您沒有使用過這種方法,B 的部份就不用回答

應付方法	A.使用這種應付方法的機會有多少？				B.如果曾使用過這個方法,它多有效？			
	從未使用	很少使用	有時使用	經常使用	沒有幫助	有一點幫助	相當有幫助	很有幫助
1. 為難題擔憂	0	1	2	3	0	1	2	3
2. 盼望事情會好轉	0	1	2	3	0	1	2	3
3. 吃的或吸煙比平常多	0	1	2	3	0	1	2	3
4. 想出種種方法來處理這個情況	0	1	2	3	0	1	2	3
5. 告訴自己情況可能比現在更糟	0	1	2	3	0	1	2	3
6. 運動或活動筋骨	0	1	2	3	0	1	2	3
7. 試著跳開難題一段時間	0	1	2	3	0	1	2	3
8. 發怒洩憤	0	1	2	3	0	1	2	3
9. 預期最壞的情況可能會發生(做最壞的打算)	0	1	2	3	0	1	2	3
10.試著將難題拋置腦後而想些別的事情	0	1	2	3	0	1	2	3
11.向家人或朋友傾訴難題	0	1	2	3	0	1	2	3
12.因為怎麼做都無濟於事所以接受這個情況	0	1	2	3	0	1	2	3
13.試著客觀地從各個不同的角度來看難題	0	1	2	3	0	1	2	3
14.夢想過更好的生活	0	1	2	3	0	1	2	3
15.與專家討論難題(如醫生,護士,牧師,老師,諮商人員)	0	1	2	3	0	1	2	3
16.試著掌握情況	0	1	2	3	0	1	2	3
17.禱告求神保佑	0	1	2	3	0	1	2	3
18.試著脫離這個情況	0	1	2	3	0	1	2	3
19.不洩漏自己的感受	0	1	2	3	0	1	2	3

應付方法	A.使用這種應付方法的機會有多少？				B.如果曾使用過這個方法,它多有效？			
	從未使用	很少使用	有時使用	經常使用	沒有幫助	有一點幫助	相當有幫助	很有幫助
20.告訴自己難題是他人的過錯造成的	0	1	2	3	0	1	2	3
21.看看會發生什麼事	0	1	2	3	0	1	2	3
22.希望獨處以思考問題	0	1	2	3	0	1	2	3
23.聽天由命,因為事情看來已經絕望	0	1	2	3	0	1	2	3
24.將自己的情緒發洩在別人身上	0	1	2	3	0	1	2	3
25.試著改變情況	0	1	2	3	0	1	2	3
26.試著身心放鬆的技巧使自己放鬆	0	1	2	3	0	1	2	3
27.試著多了解難題	0	1	2	3	0	1	2	3
28.比平時睡得多	0	1	2	3	0	1	2	3
29.試著一步一步地處理問題	0	1	2	3	0	1	2	3
30.試著避免難題干擾,使生活儘可能如常	0	1	2	3	0	1	2	3
31.回想自己過去如何處理其它難題	0	1	2	3	0	1	2	3
32.告訴自己不用擔心,因為一切事情都會解決(船到橋頭自然直)	0	1	2	3	0	1	2	3
33.試著想出權宜之計	0	1	2	3	0	1	2	3
34.喝點兒酒讓自己好過些	0	1	2	3	0	1	2	3
35.讓時間處理這個難題	0	1	2	3	0	1	2	3
36.試著做些自己喜歡的事情來分散注意力	0	1	2	3	0	1	2	3
37.告訴自己"任何事不管多困難,我都能處理"	0	1	2	3	0	1	2	3

應付方法	A.使用這種應付方法的機會有多少？				B.如果曾使用過這個方法,它多有效？			
	從未使用	很少使用	有時使用	經常使用	沒有幫助	有一點幫助	相當有幫助	很有幫助
38.訂定行動的計劃	0	1	2	3	0	1	2	3
39.試著保持幽默感	0	1	2	3	0	1	2	3
40.暫時不理困難,以後再說	0	1	2	3	0	1	2	3
41.雖然百感交集,但試著控制自己	0	1	2	3	0	1	2	3
42.和有過類似遭遇的人討論難題	0	1	2	3	0	1	2	3
43.在腦海中預演該做些什麼事	0	1	2	3	0	1	2	3
44.試著讓自己保持忙碌	0	1	2	3	0	1	2	3
45.學習新的事物以處理難題	0	1	2	3	0	1	2	3
46.做一些平時不會做,衝動冒險的事情	0	1	2	3	0	1	2	3
47.想一些生命中美好的事情	0	1	2	3	0	1	2	3
48.試著忽略或避開難題	0	1	2	3	0	1	2	3
49.與其它有類似遭遇的人做比較	0	1	2	3	0	1	2	3
50.試著往好處想	0	1	2	3	0	1	2	3
51.責怪自己落入這樣的情況下	0	1	2	3	0	1	2	3
52.喜歡獨自解決難題	0	1	2	3	0	1	2	3
53.服用藥物以減輕緊張	0	1	2	3	0	1	2	3
54.試著看"這個情況"的光明面	0	1	2	3	0	1	2	3
55.告訴自己這個難題沒什麼大不了	0	1	2	3	0	1	2	3

應付方法	A.使用這種應付方法的機會有多少？				B.如果曾使用過這個方法,它多有效？			
	從未使用	很少使用	有時使用	經常使用	沒有幫助	有一點幫助	相當有幫助	很有幫助
56.獨處,不想與人接觸	0	1	2	3	0	1	2	3
57.試著改進自己,使自己能更好的處理這個情況	0	1	2	3	0	1	2	3
58.希望難題會消失	0	1	2	3	0	1	2	3
59.倚靠別人幫忙解決	0	1	2	3	0	1	2	3
60.告訴自己只不過是運氣不好而已	0	1	2	3	0	1	2	3

社會支持問卷調查

請於開始前閱讀本頁所有說明.

請於右邊列出您生活中每位重要的人,考慮所有能給予您支持或對您很重要的人.

請寫下他的姓名與您的關係,並參考以下的例子.

名字	關係
1.明	朋友
2.雄	哥哥
3.珍	媽媽
4.彥	朋友
5.何先生	鄰居

請用下表幫您考慮哪些對您重要的人,並儘量寫下來.

例如:
-配偶或伴侶
-家人或親戚
-朋友
-同事和同學
-鄰居
-醫護人員
-輔導員或治療師
-牧師/神父/宗教人士
-其它,請註明________________

您不一定要填滿24個空格,但請儘量寫下生活中對您重要的人.

當您寫好名單後,請翻到第二頁.

名單

號碼:______
日期:______

名字	關係
1.________	1.________
2.________	2.________
3.________	3.________
4.________	4.________
5.________	5.________
6.________	6.________
7.________	7.________
8.________	8.________
9.________	9.________
10.________	10.________
11.________	11.________
12.________	12.________
13.________	13.________
14.________	14.________
15.________	15.________
16.________	16.________
17.________	17.________
18.________	18.________
19.________	19.________
20.________	20.________
21.________	21.________
22.________	22.________
23.________	23.________
24.________	24.________

0= 一點也沒有
1= 一點點,有些
2= 普通
3= 蠻多
4= 非常多

第三題:
您對這人有多信賴?

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______
11. ______
12. ______
13. ______
14. ______
15. ______
16. ______
17. ______
18. ______
19. ______
20. ______
21. ______
22. ______
23. ______
24. ______

[13-15]

第四題:
這人對您的作法或想法,有多少程度的同意或支持?

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______
11. ______
12. ______
13. ______
14. ______
15. ______
16. ______
17. ______
18. ______
19. ______
20. ______
21. ______
22. ______
23. ______
24. ______

[16-18]

請翻下一頁.

第七題:
您認識這人有多久?

1=少於六個月
2=6到12個月
3=1到2年
4=2到5年
5= 多於5年

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________
16. ____________________
17. ____________________
18. ____________________
19. ____________________
20. ____________________
21. ____________________
22. ____________________
23. ____________________
24. ____________________

第八題:
您多久與此人聯絡一次?
(電話,拜訪,或寫信)
1.一年一次或更少
2.一年數次
3.每月一次
4.每週一次
5.每天一次

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________
16. ____________________
17. ____________________
18. ____________________
19. ____________________
20. ____________________
21. ____________________
22. ____________________
23. ____________________
24. ____________________

請翻下一頁.

第九題:
在過去的一年裏您曾因搬遷,換工作,離婚,分居,對方過世,或其它原因而失去任何重要的關係嗎? [57]

———— 0.沒有

———— 1.有

如回答"有" 請繼續回答下面 2題:

9a.請從以下各項中,指出哪些人現在已不再與您聯絡:
(請指出數目,例 4 人　家人或親戚)

——— 配偶或伴侶 [58]
——— 家人或親戚 [59=60]
——— 朋友 [61-62]
——— 同事或同學 [63-64]
——— 鄰居 [65-66]
——— 醫護人員 [67]
——— 輔導員或治療師 [68]
——— 牧師/神父/宗教人士 [69]
——— 其它,請註明____________________ [70]

9b.總之,這些已無法再聯繫的人曾給您多重要的支持?

——— 0.一點也沒有

——— 1.一些

——— 2.普通

——— 3.蠻多

——— 4.非常多