Quality of Life Measurements: A Comparison of Self Rating and Spousal Rating

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QUALITY OF LIFE MEASUREMENTS:
A COMPARISON OF SELF RATING
AND SPOUSAL RATING

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THESIS ACCEPTANCE

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Abstract

The purpose of this study is to examine the relationship between self rating and spousal rating of a quality of life questionnaire. This research will be used to determine if a spouse can provide reliable information when a patient suffers from an acquired disability that has an impact on his or her communicative competence. Acquired disabilities such as stroke, dementia or Alzheimer’s disease may require the spouse to make critical treatment choices.

The research study consisted of fifteen (15) couples, married for 10 years or longer, selected from the Greater Lincoln District Sertoma Clubs in Lincoln, Nebraska and the Dundee Presbyterian Church in Omaha, Nebraska. The research study and procedures were presented to the couples, and they voluntarily chose to participate in the study. Following acquisition of informed consent, the subjects met at a study site to complete the Quality of Life Systemic Inventory (QLSI). The couples were randomly divided into two groups. A self rating group, which completed the questionnaire from their own perspective, and a second group, the spousal rating group, completed the questionnaire from their spouse’s perspective.

A Pearson product-moment correlation was calculated on the mean scores obtained from each subject. The means from global and sub scale scores were used. Statistically significant correlations were noted on the global speed portion of the QLSI, however the global state, global goal, and global rank did not evidence statistically significant findings. Specific domains on the QLSI, which found statistically significant correlations, were related to physical health, cognitive-affective functioning, work, and housekeeping. The sub scales that were not found to be statistically significant were those test items related to family and social environment, marital relationship, and leisure. Analysis also revealed that several subjects were perceptive to the importance of specific domains in their spouse’s lives, however this perception did not correlate statistically. The clinical use of the QLSI for proxy examination of quality of life is not supported by the findings of this research.
Acknowledgments

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CHAPTER 1

Introduction

Quality of life (QOL) measures are being used increasingly in the health care profession. These measures can assist with understanding the impact of chronic illnesses, evaluating medical treatments and guiding health care utilizations (Brooks, Gorkin, Schron, Wiklund, Champion, & Ledingham, 1994). Whereas objective procedures measure the presence or absence of a disease, QOL measures account for how disease affects a patient's life.

The current trend toward qualitative issues is due to the fact that advances in medical technology are allowing individuals to live longer lives, although their lives are not necessarily free from illness, disease or disability (Duquette, Dupuis, & Perrault, 1994). Therefore, the goals of medical, pharmacological, and rehabilitative professionals must seek to improve quality of life, not just extend the quantity of life. Completion of a quality of life questionnaire will help health care professionals select and direct treatment options.

To provide the most holistic and comprehensive care, health care professionals must look at evaluating the patient across many domains. The goal of the health care field according to Mosteller & Falotico-Taylor (1989) is “to assess the impact of disease and its management, including interventions on the well being of the patient” (p. 66). For example, in the rehabilitative field of medicine, it has been a traditional scope of practice to view functional levels such as degrees of pain or ability to return to work, as criteria for improvement. This perspective is changing as the field is “widening its approach to a more global personal improvement, such as subjective quality of life in different life domains” (Duquette et al., 1994, p. 106). The responsibility of the health care profession encompasses not only identifying the disease, but also recognizing the ramifications of treatment of the disease on every aspect of the patient’s life. Physical well being, emotional poise, intellectual functioning as well as overall health must be considered when treating an individual.

Quality of life measures come in many forms. An example is a self rating scale. Self rating scales are those which an individual completes by himself or herself, and they include
questionnaires, simple or forced choice checklists, or scaling devices (Gottschalk & Lolas, 1992). A problem arises when an individual is unable to complete a quality of life questionnaire to help direct his or her medical care. Loew & Rapin (1994) feel that QOL is a concept that must be applied by the patients themselves, as ethical issues arise when another individual completes the form. It may be difficult to determine if a proxy examiner has the best interest of the patient in mind. However, other researchers feel that one cannot consider QOL without considering those closest to the patient. Often when an individual becomes disabled, the spouse or a significant other becomes their caregiver (Berdardo & Berdardo, 1992). The patient's overall well being and functioning becomes partially or totally dependent on another person.

A major concern ensues when a patient is unable to complete a QOL questionnaire for himself or herself, due to communicative or cognitive impairment. A concern of Tippett & Sugarman (1996) is that "patients may be unable to understand information provided to them...because of acute illness or cognitive impairment" (p. 32). An individual must possess a functional level of communicative competence to complete a QOL questionnaire.

Communicative competence is defined as "the quality or state of being functionally adequate in daily communication..." (Light, 1989, p. 138). Communication entails both expressing and receiving information. Expressive language is defined as the "use of conventional symbols to communicate one's perceptions, ideas, feelings or intentions to others" and the "ability to communicate via the spoken or printed word" (Nicolosi, Harryman, & Kresheck, 1989, p. 141). Receptive language is defined as "words one understands" which "may be verbal or visual; spoken or written messages received by the individual" (Nicolosi et al., 1989, p. 142). If a patient is unable to express his or her thoughts, feelings or attitudes, or is unable to understand information presented to him or her, completing a quality of life questionnaire will be an arduous and frustrating, if not impossible task.

Spouses or significant others will play a crucial role in helping determine medical interventions and treatment goals for the patient who is communicatively or cognitively impaired.
compromised. The results of this study may help to determine if the spouse can reliably complete a QOL questionnaire for a patient who is communicatively or cognitively impaired.

**Hypothesis**

**Alternate**

The responses obtained from self completion of a quality of life questionnaire will significantly correlate with the responses obtained from the spouse completing the same questionnaire in a proxy fashion.

**Operational Definition of Terms**

**Self Completion**

An individual completes a document by himself or herself from his or her own perspective.

**Quality of Life Questionnaire**

A form which attempts to quantify an individual’s perceptions about happiness of satisfaction within his or her life.

**Proxy**

The representation of an individual by another person on his or her behalf.

**Assumptions, Limitations and Delimitations**

**Assumptions**

One individual will be completing the questionnaire for his or her spouse; therefore it must be assumed that the subjects used in this study will be completing the form from their spouse’s perspective with their spouse’s interest in mind.

**Limitations**

A limitation of this study is the restricted selection of subjects from two organizations in two metropolitan communities. It must be recognized that quality of life perceptions as well views on marriage may vary from region to region, i.e. from rural areas to urban or metropolitan areas.
**Delimitations**

The Quality of Life Systemic Inventory is one of many quality of life questionnaires that can be used to quantify perceptions. The results of this study cannot be generalized to other questionnaires.
CHAPTER 2
Literature Review
Quality of Life Measurements

Introduction

What gives lives meaning or value? What makes people happy or satisfied with their lives? What makes people unhappy or dissatisfied with aspects of their lives? These questions are quite personal and distinctive. Each individual must make judgments about what makes him or her happy, what makes him or her satisfied with life. Until recently, the issue of one's happiness or satisfaction with life was not considered in habilitative or rehabilitative medicine. Current health care trends are focusing on the "consumer" and clinicians and researchers have begun to become more "consumer oriented." These professionals are beginning to develop measurement tools that allow for quantification of medical and therapeutic intervention on a person's quality of life.

Quality of life measures are commonly used when a person is experiencing decreased health status. Quality of life (QOL) measures can assist with understanding the impact of a chronic illness, evaluating medical interventions, and guiding health care utilizations (Brooks et al., 1994). The patient completes the questionnaire that provides personal information that will guide health care professionals to valued treatment options, treatments that will enhance or maintain a desired QOL.

A dilemma arises when the patient has a disability which effects his or her communicative competence, such as a stroke, dementia, or Alzheimer's disease, therefore being unable to assist with evaluating or directing interventions and treatment options. The question must be posed; can the spouse complete the questionnaire for the patient with responses that would be similar to the responses gathered if the patient could fill the questionnaire out himself of herself?
Changes in Health Care

Traditional health care is changing rapidly. The role of the professional as the sole decision maker in patient care is a concept of the past. Patients are gaining autonomy and becoming the primary decision makers for the services and treatments they receive. This is due, in part, to the increasing importance of outcome measures in health care. "Quality of life, a broad multidimensional concept, is increasingly invoked in health care decision making" (Loew & Rapin, 1994, p. 40). No longer are only objective measures, such as those that detect the absence or presence of disease, being used to treat individuals and plan intervention strategies. Subjective tools such as quality of life measures are being utilized to direct the care of the patient.

This recent shift toward qualitative issues is a result of advancing medical technology allowing people to live longer lives, although those lives may not be free from sickness, disease or disability (Duquette et al., 1994). The use of QOL measures can report changes in an individual's attitudes and feelings, whereas conventional, objective methods of health care show changes in clinical arenas only (Wiklund & Karlberg, 1991). For example, an individual suffering from a moderate speech disorder that affects how well he or she is understood, may show measured improvement with therapy over time. However, if that individual does not value, or feel the need for therapy, he or she may want to discontinue therapy, even though the clinician feels it is a necessity. Therefore, QOL measures can serve as the "endpoint" when more objective measures are inconclusive (Wenger, Mattson, Furberg, & Elinson, 1984).

Roles of the Health Care Provider

Health care professionals have an ethical responsibility to study and use QOL measures (Pocock, 1991). The responsibility of these professionals includes the use of a comprehensive approach that would best benefit the patient. This involves evaluating treatments and therapies using clinical, biological, psychological and social criteria (Loew & Rapin, 1994). The professionals must view the patient and his or her lifestyle as well as the illness that affects them.
There are many reasons health care professionals utilize QOL measures. The goal in the health care field, according to Mosteller & Falotico-Taylor (1989), is “to assess the impact of disease and its management, including interventions on the well being of the patient,” (p. 66). QOL measures are a tool that makes this goal attainable.

As QOL measures make reference to health and health care issues, it is important to define health. The World Health Organization (WHO) defines health as “the state of complete physical, mental and social well being and not merely the absence of disease or infirmity” (Mosteller & Falotico-Taylor, 1989, p. 66). This definition implies that health may or may not be a factor in influencing quality of life (Mosteller & Falotico-Taylor, 1989). Although increased physical health status may be a consideration in therapeutic intervention, it is not the sole consideration.

The health care field tends to use QOL measures more frequently to maximize the health component of the measure, consequently, other aspects of the measure, those not related to health issues, are unintentionally minimized (Mosteller & Falotico-Taylor, 1989). The concept of quality of life implies that all components of life such as physical well being, emotional composure, intellectual capacity as well as general health, be considered when determining a person’s quality of life. Therefore, professionals must adjust their roles to accommodate the patient and require QOL measures to encompass all aspects of the patient’s life.

Reasons for this paradigm in health care suggest that “the view that traditional morbidity and mortality measures are insufficient to capture the full impact of medical interventions...” therefore there is an “increasing interest in the measurement of QOL or health status” (Jenkinson, 1994, p. 377). The concept that patient death, relapse or recurrence of disease or disability or “purely biochemical or physiologic measures of disease activity” (Veldhuyzen Van Zanten, 1991, p. 234) disregards variables that can assess the well being of an individual beyond their current health status.
Definitions of Quality of Life

To fully understand QOL measures, quality of life must be adequately defined. The fundamental question surrounding QOL measures is “what gives value to our lives?” (Loew & Rapin, 1994, p. 37). Obviously the answer will be different for everyone, however there are fundamental areas that are key for each person. Operational definitions of QOL are based on the basic process of an individual's pursuit of goals (Duquette et al., 1994). Just as perceptions of life are different, so are the ways in which QOL is defined.

There are many definitions for QOL, however, they do share a common thread, an overall sense of satisfaction, well being or achievement within life. Table 1 contains many current definitions of QOL. All of these definitions may be appropriate or adequate to generally define QOL. Each patient, however, makes the final determination.

Table 1. Definitions of Quality of Life

<table>
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<tr>
<td>Duquette, R.L., Dupuis, G. &amp; Perrault, J.</td>
<td>“A sense of satisfaction and well being that an individual feels about his or her life.” p. 107</td>
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<td></td>
<td>“The degree to which an individual succeeds in accomplishing his desires.” p. 107</td>
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<td>“The extent to which a person's hopes and ambitions are matched and fulfilled by experience.” p. 107</td>
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<td>Bliley, A. V. &amp; Ferrans, C. E.</td>
<td>“A person's sense of well being that stems from satisfaction or dissatisfaction with the areas of life that are important to him or her.” p. 194</td>
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<td>Berdardo, F.M. &amp; Berdardo, D.H.</td>
<td>“Quality of life measures the difference, at a particular moment in time, between the hopes and expectations of the individual and that individual's present experience.” p. 52</td>
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<tr>
<td>Leibowitz, J.M., McClain, J.W., Evans, E.A., Ruma, P. &amp; Rauner, T.</td>
<td>“…quality of life as a measure of the relationship or interaction between the objective environment and the subjective or perceived environment.” p. 341</td>
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<tr>
<td>Grant, M., Padilla, G.V., Ferrell, B.R. &amp; Rhiner, M.</td>
<td>“A personal statement of positivity or negativity of attributes that characterize one's life.” p. 343</td>
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QOL has also been defined as the “distance between the states and goals of an individual in different hierarchically organized life domains” (Duquette et al., 1994, p. 107). Several sources have identified domains assessed when evaluating quality of life. Padilla, Grant, & Ferrell (1992) defined three distinct dimensions of QOL pertaining to psychological, physical, and interpersonal well being. Other domains that are addressed in QOL issues are more general and relate to health and functioning, social aspects, economic variables, psychological concerns, spiritual needs, family, productivity, intellectual capability, emotional stability, and overall life satisfaction (Bliley & Ferrans, 1993; Wenger et al., 1984). Generally, QOL measures account for patients’ experiences regarding emotional, social and physical well being (Brooks et al., 1994). Jeffres & Dobos (1995) cite Campbell and other who have noted that “people’s satisfaction with one domain of life is related to satisfaction with other domains, and one’s satisfaction with life as a whole is a global concept summing up one’s satisfaction across domains” (p. 181). How an individual will respond to each of these areas is variable but dependent on experiences in all domains.

Patient Perspectives

To ensure the effect of an intervention on a patient’s quality of life, it is necessary to look at how a treatment impacts a patient and his or her family in relation to their quality of life (Veldhuyzen Van Zanten, 1991). Many patients with chronic illnesses have accepted that there may not, in fact, be a cure for their disease or disorder. Yet they may be impractical by setting unattainable goals and having unrealistic expectations about treatments and outcomes.

Therefore, a “major goal for patients with chronic conditions is not a cure, but an improvement in function resulting from the reduction in the symptoms or the severity of an illness or a limitation of the progression of a disease” (Wenger et al., 1984, p.1). When the patient begins to accept his or her limitations based on the chronic aspect of the disorder, the ultimate goal of health related intervention becomes increased physical and emotional stability (Wiklund & Karlberg, 1991). Many treatments may not promise a lifestyle that existed prior to the
disease or disability, but enable sufficient modifications in the progression of the illness, which allow the person a sense of well being.

Patient perspectives on the health care they receive may be attained from QOL measures. Not only does completing the questionnaire give health care providers an idea of what gives this particular patient's life value, the actual process of eliciting the information from the patient may contribute to their sense of well being and importance (Pocock, 1991). This information may be utilized by both the patient and the health care providers to make rational and appropriate treatment alternatives (Wenger et al., 1984). Completing the form may be "liberating" to the patient, giving him or her a voice in medical and therapeutic interventions.

Uses of Quality of Life Measures

Quality of life measures have many uses in the health care profession. They may be used to select individuals for a specific type of treatment, or to screen them for staging of the disease or disorder. The measures may indicate disease progression. A major finding when using QOL measures is that it may in fact improve health care professional and patient communication. The patient is allowed to voice concerns and pose questions he or she may not have considered before reading the questionnaire. They are also more involved in the decision making process by which their treatment or therapy is recommended. QOL measures may also be used to assess the quality or appropriateness of health care received (Jenkinson & Crispin, 1994). QOL measures may be utilized to both direct interventions and to analyze them.

Other uses of QOL have been documented. The measures may be used to access the impact of chronic illness on the overall well being of an individual. They may also detect which medical intervention is graded as effective and which treatments are failing. Overall, QOL measures "provide additional information for determining the effects of the disease and its treatment on the patient's life in terms of physical function, social life, overall life satisfaction, outlook on the future, symptoms and depression" (Brooks et al., 1994, p. 438) when clinical trials cannot. Patients themselves are able to monitor progress by being aware of the medical goals
they set prior to the initiation of intervention. Consequently, observation of progress is made possible by completing a QOL questionnaire.

Cost Effectiveness

The use of QOL measurements not only benefits patients, their families, and health care professionals, the measurements are cost effective, which has implications for the public as a whole. Frattali, Thompson, Holland, Wohl, & Ferketic (1995) cite Hosek and colleagues who studied “relationships among the cost of rehabilitative care, functional status, and diagnostic classification and found that functional status, rather than diagnostic classification, is a better predictor of cost” (p. 14). For example, stating that a stroke patient has the potential to return to work following extensive physical, occupational, and speech therapy will be a better predictor of cost than stating merely that the patient suffered a stroke. Measures of functional outcomes, such as QOL measures, are being used to determine costs (Frattali et al., 1995). Also, with proper quantification, “cost effectiveness studies should be able to demonstrate increased measurable outcomes for the same unit of cost” (Tolsma, 1993, p. 12), when compared with traditional health care costs. Individuals can complete QOL questionnaires and strive toward functional, attainable goals with a clearer view of the cost of their treatment. They may also appreciate the cost of their care more when they know the outcome will return them to home or work, and that all the expense was not for tests or procedures that did not directly benefit their rehabilitation.

Variations of Quality of Life Measures

Eliciting the information from QOL measures may be obtained many ways. Measurement of quality of life status may be acquired via self rating scales and external ratings, those completed by individuals other than the patient. Self ratings may include questionnaires, simple or forced choice checklists or scaling devices (Gottschalk & Lolas, 1992). Some researchers feel that QOL is a concept that must be applied to the measurement by the patients themselves, as an ethical conflict is apparent (Loew & Rapin, 1994). It may be assumed that the spouse or significant other does not truly know what the patient values in life, therefore, there is
an inconsistency. When the patient is unable to complete a QOL measure, perhaps due to a decrease in communicative competence, the caregiver may in fact be completing the form with his or her own best interest at heart, and not the best interest of the patient.

Many argue, however, that one may not consider QOL without considering the spouse or significant other, due to the fact that if the patient becomes disabled, it is the person closest to the patient that becomes the caregiver (Berdardo & Berdardo, 1992). After an individual is sent home following a debilitating illness, it is the spouse, significant other, or family member that supervises the individual and provides physical, social, and emotional support. Therefore, the QOL of an individual is intertwined with that of the family (Berdardo & Berdardo, 1992).

It may also be noted that increasing the patient's quality of life may reduce it for another person (Berdardo & Berdardo, 1992). For example, a patient who goes home may be dependent on his or her spouse, the caregiver, for some activities of daily living. Social interactions may be limited to family and close friends depending on the extent of the disability. The caregiver also must provide emotional support for the spouse as he or she is coping with a new disability. The caregiver no longer has an independent lifestyle; he or she must live within the schedule of the spouse, providing many of his or her cares and needs. Therefore, quality of life of the caregiver may very well be diminished.

Some researchers suggest that people other than the patient may ascertain functional capacity. A significant other filling out the form may "validate" the patient's self report (Wenger et al., 1984). This procedure allows the professional to obtain more information for the increased likelihood of appropriate and adequate treatment. Researchers may also wish to compare raters' scores for appropriateness of response (Mosteller & Falotico-Taylor, 1989). The notion of multiple reports would appear to increase the likelihood of comprehensive care.

Perceptions, Expectations, and Quality of Life

For many people, the old adage "you do not know what you have until it is gone" is quite relevant. Bliley & Ferrans (1993) discovered that "the relationship between health and QOL was most pronounced in persons whose health prevented them from performing desired activities" (p.
Perceptions of QOL can begin to change as an individual's health affects his or her most valued life domains.

Loew & Rapin (1994) noticed a trend that elderly people perceive QOL to be influenced by their attitude toward health. However, it is dually noted that "perceived QOL does not seem to decrease with aging in a parallel fashion to the decrease in functional capacities" (Loew & Rapin, 1994, p. 40). As people age, their perceptions and outlooks about health and life begin to accommodate an increased awareness of mortality. As a general rule, the elderly are more willing to accept a disability, therefore their subjective QOL ratings will be influenced by this attitude (Loew & Rapin, 1994).

A major area of concern is the expectations of health care providers in comparison to the patients they treat. As stated above, elderly people seem to adjust their QOL as they age. Loew & Rapin (1994) discovered that the elderly population tends to have lower expectations of their health than the young doctors, nurses and health care professionals treating them. This chasm of expectations can be easily bridged by QOL outcome measures. The patient can state exactly what is important to him or her, and the health care professionals can use the report as a guide by which to treat the individual. This protocol would reduce confusion and frustration, while increasing communication between the patient and the multitude of professionals treating him or her.

**A Distinct Quality of Life Measure**

An example of a QOL measure is the Quality of Life Systemic Inventory (QLSI). This inventory is a subjective, global questionnaire. It is made up of four distinct portions involving 30 different life domains, such as sleep and rest, family life, and work. First, the QLSI allows the patient to indicate the state where he or she is at a distinct point in time in reference to an ideal situation. Then, the questionnaire permits the patient to identify a personal goal in relation to their current state and the ideal. Next, the QLSI requires the individual to indicate the speed of improvement, deterioration, or if there is no change in his or her life. Finally the questionnaire allows the patient to prioritize the importance of life domains. As most inventories emphasize
performance in life domains separating happiness and satisfaction, the QLSI treats happiness and satisfaction as the same entity. The QLSI is a personalized inventory (Duquette et al., 1994).

QLSI Standardization Information

The primary objective of standardization was to validate the QLSI in its capacity to measure quality of life as it relates to reaching personal goals within life domains. One hundred and seventy one normal subjects (95 males and 76 females) with a mean age of 43.6 from the Montreal Heart Institute Cardiac Prevention and Rehabilitation Center were given the QLSI in a test-retest reliability design. The initial testing comprised of evaluating the subjects with the QLSI (Duquette et al., 1994), the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbauch, 1961), the STAI anxiety (Speilberger, Gorsuch, & Lushene, 1970), the Sheerer and Maddux self-efficacy scale (Sheerer & Maddux, 1982), the Buss and Durkee hostility profile (Buss & Durkee, 1957), the Derogatis Stress Profile (Derogatis, 1980), and the Marlowe and Crowne social desirability scale (Crowne & Marlowe, 1960). Two weeks later at re-evaluation, the subjects were given only the QLSI (Duquette et al., 1994).

Statistical analysis involved test-retest reliability with repeated ANOVA’s for each QLSI score of goal, gap and conflict. Concurrent validity was measured by using stepwise multiple regressions between QLSI scores and the scores received from questionnaires measuring hostility, anxiety, depression and self-efficacy. Finally a correlation matrix was computed from the scores of the QLSI and the Marlowe and Crowne social desirability scale (Duquette et al., 1994).

The results of the study indicated test-retest reliability with reliability coefficients as follows, goal: .858; gap: .838; and conflict: .858. Stability was noted due to low variance measurements. The QLSI scores indicated that when assessing concurrent validity there is a certain amount of variance when compared to other psychological measures (inward hostility: $r^2=.17$; anxiety: $r^2=.35$; depression: $r^2=.26$; self-efficacy: $r^2=.05$; stress: $r^2=.18$), therefore, it is observed that the QLSI captures information much different from the depression, anxiety, stress
and hostility measures used in this study. Interscore correlations between QLSI scores were observed to be very low (gap-goal \( r = .293, p = .01 \); gap-conflict \( r = .172 \); goal-conflict \( r = .155 \)), showing the different capacity of each dimension. Finally, it was indicated that the QLSI scores are not strongly influenced by social desirability as all correlations were below .25 (Duquette et al., 1994).

The QLSI is a distinct and personalized quality of life measure. Results of validation indicate that the test is stable, the three QLSI scores are quite distinct and social desirability does not have an impact on the measurement tool. The QLSI is currently being used with cardiovascular, diabetic and AIDS patients and is continuing to be validated (Duquette et al., 1994).

Language

Quality of life and Language

A degree of communicative skill must be present to complete a QOL questionnaire. Communication consists of expressive and receptive language. Nicolosi et al. (1989, p. 141) defines expressive language as the “use of conventional symbols to communicate one’s perceptions, ideas, feelings or intentions to others” and the “ability to communicate via the spoken or printed word. Receptive language is defined as "words one understands" which “may be verbal or visual; spoken or written messages received by the individual” (Nicolosi et al., 1989, p. 142). Completing a quality of life questionnaire independently requires functional expressive and receptive language skills.

Concerns regarding completion of QOL measures also involve cognitive skills. Cognitive processes can be described as skills relating to memory, attention, concentration, judgment, reasoning, and problem solving (Nicolosi et al., 1989; Tomblin, Morris, & Spriestersbach, 1994). The patient must be able to attend and concentrate on the task at hand, often for many minutes and possibly even for an hour when completing a questionnaire. The individual must also be able to make judgments about his or her life and provide insight into
specific circumstances that determine QOL issues. The patient must have adequate cognitive linguistic skills to accurately complete a QOL measurement.

It has been determined that an appropriate level of language and cognitive skills must be present in order to complete a QOL questionnaire, but many times a disease or disorder is inhibiting these skills and does not allow the patient to complete the form himself or herself. If there is impairment within the expressive or receptive language structure or the patient is cognitively compromised, the patient's QOL must be ascertained by another individual.

Communicative Competence

Competence can be defined as "the quality of state of being functionally adequate in daily communication..." (Light, 1989). To further understand functionality, Webster's Dictionary (1984) defines functional as an ability to perform or operate. An individual that is communicatively competent can perform various speech and language tasks in many different environments effectively. Light (1989) also states an important point, that communicative competency is ever changing; it is not a static concept, much like QOL. When an individual suffers from a particular disorder that inhibits his or her communicative competence or cognition, most likely it is their spouse that will become their caregiver. The caregiver then becomes responsible for daily communication and decision making.

Communicative Continuum

If a deficit in communicative competence can be determined, the deficit is identified along a continuum ranging from impairment, disability or handicap, as defined by the World Health Organization. The first area is that of impairment, defined as an abnormality of structure or function at the organ level (Frattali et al., 1995). Impairment involves the disease or disorder itself and not the ramifications of the anomaly. An individual can function quite independently with an impairment.

The second area is that of a disability. Disability is the functional consequence of an impairment affecting performance of daily tasks (Frattali et al., 1995). Therefore, a disability will affect the patient at home, work, school and or in social settings. It is not only measured by
difficulties experienced by the patient, but the difficulty that the communicative partners may have. Often with proper intervention, a disability can be reduced with the use of compensatory strategies, leaving the individual to function with little, if any, assistance from others.

The third area is a handicap, which results in social, economic or environmental disadvantages resulting from impairment or disability (Frattali et al., 1995). A handicap goes beyond the impact on daily living activities into domains that are novel and unfamiliar. Not only is the patient affected by an impairment or disability, he or she has a loss of opportunity that would not have existed if the disease or disorder was not present. A handicapping condition is not remediated by compensatory strategies; it is a consequence of environmental and social factors.

Goals for Evaluation

When evaluating individuals for areas of deficits, it is crucial to view the entire communicative continuum via the assessment. Traditional tools for assessment focus on the level of impairment (Frattali et al., 1995). These tools are often referred to as objective measures.

Functional assessment tools are designed for disability (Frattali et al., 1995). These tests encompass rating scales completed by significant others and health care professionals. Because an individual's daily life is affected, those closest to the patient and those working with the patient provide information to develop compensations to overcome or lessen the disability.

Using handicap inventories or quality of life scales to evaluate handicapping conditions can allow an individual to assess the level of satisfaction within areas of his or her life and consequently prioritize these areas. These measures can also allow individuals to increase their awareness of lost opportunities in these specific life areas. Their treatment and care can focus on areas of greatest significance and importance, thus minimizing the effects of the environment on all of the life's domains.

The goal of comprehensive assessment is to evaluate levels of impairment, disability and handicap (Frattali et al., 1995). This assessment will involve many individuals with much
expertise, such as the patient, his or her family, and many health care professionals. Utilizing objective assessment, subjective testing and broad QOL evaluation may provide the most extensive information for the best treatment options, and enhance overall communication.

Continuing Research

Further research is needed to determine who can provide reliable patient information when the patient himself or herself is unable. Age, gender, and relationship to the patient are all factors that may influence these results. The patient's socio-economic status (SES) also has implications regarding cost effectiveness and the use of QOL measures. An examination of QOL measurements themselves should be undertaken to best quantify patient and proxy reports.

First, the age of a couple may indicate generational views on medical and rehabilitative treatments, communication styles between partners, or traditional roles of partners in a relationship. Further research should delineate the ages of couple, possibly to seeking subjects in only one decade.

Second, men or women may be more perceptive to their spouses wants or needs. Seeking a possible link to gender specific perceptions should be evaluated. This may indicate who may be a better source of information for proxy reports.

Third, examining who might be a more accurate proxy examiner must be assessed. A spouse may be more or less reliable than a parent or an adult-child, or a significant other may be a more reliable source of information than a sibling. Much research is needed to determine the variables that influence the reliability of proxy reporters in QOL issues.

Fourth, further research must examine the impact of SES status on proxy reporting of QOL measurements. The effectiveness of secondary reporting on QOL questionnaires may have cost reducing implications for medical and rehabilitative treatments, especially for those individuals in lower economic status. This may allow persons who would not have been able to afford medical or rehabilitative treatments to seek life enhancing, cost effective treatments.

Finally, the use of different and varied QOL questionnaires must be examined. Scales that rank or prioritize life information may prove more reliable than those questionnaires which
elicit open responses. Questionnaires that select specific diseases or impairments, such as stroke and speech disorders may be more useful and reliable to patients and their families than general life questionnaires. These types of questionnaires can itemize particular life domains that are affected by the specific impairments. For example, a questionnaire which is stroke specific would focus on issues of functional independence in areas such as walking or being mobile, communication, returning to work, or participating in hobbies. Research into this area may actually require the development of new functional QOL questionnaires. Continued research into the use of QOL questionnaires and proxy reporters is essential for the ongoing pursuit of excellence in the medical and rehabilitative fields.
CHAPTER 3
Methodology

Subjects

Population
The population for this study consists of individuals married 10 (ten) years or longer without any significant medical problems which inhibit communication or cognition. The population includes those individuals living independently with their spouses.

Sample
The subjects for this study included 15 individuals and their spouses. These couples had no significant medical problems, which inhibited communication or cognition such as a previous stroke or dementia. The individuals were ambulatory and living independently with their spouse.

Research Design
Subjects were randomly assigned to a self rating group or a spousal rating group. The self rating group was asked to complete the quality of life questionnaire for themselves. The spousal rating group was asked to complete the questionnaire from their spouse's perspective. Results were calculated following questionnaire completion.

Study Procedures
Each subject completed the Quality of Life Systemic Inventory (QLSI). One individual (Subject A) completed the questionnaire for himself or herself. The spouse (Subject B) also completed the QLSI for Subject A. Questionnaire completion occurred in one setting of approximately 1 hour. Preferential setting was implemented and the subjects were not allowed to converse regarding the questionnaires contents before or during QLSI administration and completion.

Pearson's correlation coefficient was calculated using the subjects' mean scores from global and sub scale domains to determine the significance of self rating and spouse rating of their partner. Presentation of the questionnaire was randomized by order. An alternating order
of completion, such as a male completing self evaluation and then a female completing self evaluation was used to prevent habitualization.

Data was analyzed following testing procedures. Comparisons of overall global scores and sub scores were made between the subject and his or her spouse. The means of each subjects' scores were used to complete the correlations. A graphic comparison of the mean scores was also presented.

**Instrumentation**

**Basic Concepts of The Quality of Life Systemic Inventory**

The Quality of Life Systemic Inventory (QLSI) was developed by Gilles Dupuis of the Montreal Heart Institute to quantify the impact of the environment on life domains. According to Dupuis, Perrault, Lambany, Kennedy, & David (1989), the term quality of life (QOL) can be divided into the four basic concepts of goals, control, negative and positive feedback loops and hierarchical order. These concepts are believed to work in concert to achieve a sense of happiness and satisfaction within a person's life.

**Goals**

First, setting goals is the basis of all human behavior. Dupuis et al. (1989) states that "our behaviors are controlled by our goal setting and are always goal directed" (p. 38). As individuals begin to set goals they act and react within the environment to reach those goals, often times losing and gaining control over their lives in the process.

**Control**

The second concept of control is closely linked to setting goals. Dupuis et al. (1989) cites Powers stating that an existing definition of control is "the attainment and maintenance of the desirable preselected state through actions on the environment" (p. 38). As individuals begin to set goals, they will realize that there is a gap between where they are now in a given situation, and where they would like to be. The concept of control is the effort a person uses to reduce that gap and attain their goal. The environment will have an impact on this progression, and may assist with increasing or decreasing the gap. An individual will feel more in control
when the gap is narrowing and the attainment of a goal is at hand. The feeling of being out of control is more evident when the gap between a person's present state and a goal is wide (Dupuis et al., 1989). Therefore, the attainment of a goal is dependent on factors in the environment. These environmental influences may increase or decrease the control a person has on his or her life.

**Negative and Positive Feedback Loops**

The ever changing gaps between an individual's present state and a goal, and the implications on a person's attitudes can be illustrated in the third concept of the QLSI, negative and positive feedback loops. A negative feedback loop reduces the gap between the present state and the goal, and consequently, the person is in a more satisfied state of mind. Positive feedback loops are those which increase the gap between present state and the goal. These loops may occur when a person sets goals too high and continually fails to make the smallest advance toward the goal. Feelings of failure and frustration often accompany positive feedback loops. The concept of feedback loops is the "cornerstone" of the QLSI (Dupuis et al., 1989). An individual's advancement or retreat towards or away from a particular goal will affect his or her perception of life satisfaction in a particular domain. Feelings of success will fuel a positive sense of life satisfaction, while constant failure will present a decrease in happiness or satisfaction in life.

**Hierarchical Order**

Finally, to maintain control of multiple loops in many of life's domains, a hierarchical order must be established within a person's life. Prioritizing life's domains decreases the high levels of conflict, which may arise in many domains at one time. When an individual creates priorities, emphasis of control is placed on only a few domains instead of many, therefore decreasing frustration and depression (Dupuis et al., 1989). The expression "spreading oneself too thin" is applicable to explain the concept of priorities. If every life domain is a priority, then the individual donates time and effort to all life areas viewed as essential. He or she may feel exhausted, frustrated, and out of control, therefore perceiving less satisfaction with life. A
person who prioritizes only a few life areas can maintain control more efficiently by exerting the
most effort in those areas viewed as essential. The other "less important" life areas can then be
supplemented as needed. The individual who is able to prioritize life domains will most likely
have a higher perceived level of life satisfaction.

Having considered these concepts, Dupuis et al. (1989) developed an operational
definition for the QLSI: "quality of life, at a given time, is a state that corresponds to the level
attained by a person in the pursuit of hierarchically organized goals" (p. 40). Quality of life will
change constantly as an individual attempts to achieve a goal or goals in his or her life.

QLSI Design

In order to evaluate quality of life, information was needed to determine an individual's
present state in each life domain, the goal of that domain and how important each domain is to
the individual. The QLSI distinguishes a total of 30 life domains (Dupuis et al., 1989) (see Table
2). The QLSI then divides these 30 domains into seven sub scales (see Table 3). The sub scale

Table 2. Domains for the QLSI

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sleep</td>
</tr>
<tr>
<td>2.</td>
<td>Physical Capacities</td>
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<tr>
<td>3.</td>
<td>Alimentary Habits</td>
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<tr>
<td>4.</td>
<td>Physical Pain</td>
</tr>
<tr>
<td>5.</td>
<td>General Physical</td>
</tr>
<tr>
<td>6.</td>
<td>Relaxation</td>
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<tr>
<td>7.</td>
<td>Active Leisure</td>
</tr>
<tr>
<td>8.</td>
<td>Outdoor Entertainment</td>
</tr>
<tr>
<td>9.</td>
<td>Interaction with My Children</td>
</tr>
<tr>
<td>10.</td>
<td>Interaction with My Family</td>
</tr>
<tr>
<td>11.</td>
<td>Interaction with My Friends</td>
</tr>
<tr>
<td>12.</td>
<td>Social Support</td>
</tr>
<tr>
<td>13.</td>
<td>Type of Task at Work</td>
</tr>
<tr>
<td>14.</td>
<td>Efficacy at Work</td>
</tr>
<tr>
<td>15.</td>
<td>Interaction with My Work Colleagues</td>
</tr>
<tr>
<td>16.</td>
<td>Work Physical Environment</td>
</tr>
<tr>
<td>17.</td>
<td>Interaction with My Work Superiors</td>
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<tr>
<td>18.</td>
<td>Unemployment Situation</td>
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<tr>
<td>19.</td>
<td>Financial State</td>
</tr>
<tr>
<td>20.</td>
<td>Home Care Routines</td>
</tr>
<tr>
<td>21.</td>
<td>Efficacy in Home Care Routines</td>
</tr>
<tr>
<td>22.</td>
<td>Heavy Work Around the House</td>
</tr>
<tr>
<td>23.</td>
<td>Intellectual functioning</td>
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<tr>
<td>24.</td>
<td>Self Esteem</td>
</tr>
<tr>
<td>25.</td>
<td>State of Mind</td>
</tr>
<tr>
<td>26.</td>
<td>capacity to Share Emotions</td>
</tr>
<tr>
<td>27.</td>
<td>Couple's Interaction</td>
</tr>
<tr>
<td>28.</td>
<td>Sexual Relations</td>
</tr>
<tr>
<td>29.</td>
<td>Life Environment</td>
</tr>
<tr>
<td>30.</td>
<td>Social Acceptance</td>
</tr>
</tbody>
</table>
Table 3. Sub scale categorization

<table>
<thead>
<tr>
<th>Sub Scale</th>
<th>Life Domain</th>
<th>Number of Test Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub Scale A</td>
<td>Physical Heath</td>
<td>5</td>
</tr>
<tr>
<td>Sub Scale B</td>
<td>Cognitive – Affective Functioning</td>
<td>4</td>
</tr>
<tr>
<td>Sub Scale C</td>
<td>Family and Social Environment</td>
<td>6</td>
</tr>
<tr>
<td>Sub Scale D</td>
<td>Marital Relationship</td>
<td>2</td>
</tr>
<tr>
<td>Sub Scale E</td>
<td>Leisure</td>
<td>3</td>
</tr>
<tr>
<td>Sub Scale F</td>
<td>Work</td>
<td>7</td>
</tr>
<tr>
<td>Sub Scale G</td>
<td>Housekeeping</td>
<td>3</td>
</tr>
</tbody>
</table>

Headings are listed from A to G and include physical health, cognitive-affective functioning, family and social environment, marital relationship, leisure, work, and housekeeping (Dupuis et al., 1989). These sub scale domains are used to categorize the questions on the testing form, and each sub scale has a determined number of test items.

The first portion of the questionnaire uses a state-goal dial (see Figure 1). This dial includes the concept of an ideal goal, personal goal, and a present state. The ideal goal can be derived as the “perfect situation, which is always desirable, but not necessarily attainable” (Dupuis et al., 1989, p. 41). The personal goal represents contentment, but not total satisfaction. The present state is the individual’s current situation within the specified domain (Dupuis et al., 1989, p. 41). The individual must examine his or her current state in a particular domain, and where he or she would like to be in the future. These concepts are visually represented on the state-goal dial.

The individual is to draw a line representing the current state of performance in a given life domain, and draw a line representing a personal goal. The person’s state and personal goal may be identical if they are content with the current situation in the specified life domain. If the current state and personal goal are not the same a gap between the two will be evident. If a person feels that he or she is in the ideal situation, or his or her goal is the ideal, then the person marks the circle at the top of the dial (Dupuis et al., 1989). The gap, in less than ideal situations, may be small indicating near achievement and increased control, or the gap may be large, showing less progress toward the goal and subsequently a lack of control in the life domain.
The next portion of the questionnaire involves evaluating the stability of the gaps, whether they are changing or not, in negative feedback loops or in positive feedback loops. A "speed dial" much like those in automobiles is used to assess if the current state is changing (see Figure 2). An individual checks whether the situation is steady, improving or deteriorating. Next, the person draws a line indicating at what speed the change is taking place (Dupuis et al., 1989). The rate of personal change may be slow, which is indicated to the left of the arch, or the rate of change may be fast, indicated to the right of the arch. Slow improvement may indicate better control over a domain, whereas fast deterioration may signify a lack of control. No change or a steady indication may be perceived as good, bad, or indifferent, depending on the goal the person has set and how important it is.

Finally, the individual must rank on a 7 point Likert scale how important each of the domains is in his or her life. The Likert scale contains numbers from 1 to 7 (see Figure 3). Number 1 indicates an "essential" ranking of a domain. Number 4 indicates a "moderately important" ranking, and a number 7 rating indicates a domain which is "not important at all" (Dupuis et al., 1989). Prioritizing life domains allows an individual to maintain appropriate control of his or her life and therefore, maintain an adequate level of happiness or satisfaction.
Scoring

The state-goal dial and the speed dial are types of visual analog scale. The state-goal dial is divided into 20 segments and the speed dial is divided into 8 segments. Each segment on each of the dials was given a value according to an “exponential curve based on the formula of uncertainty progression” (Dupuis et al., 1989, p. 42). This concept was utilized due to the fact that the larger the gaps in the state-goal dial, the more likely an individual is to have unpredictable events occur during progression toward the goal. A patient suffering from a debilitating stroke will serve as an example. Immediately following the stroke the patient is unable to walk. The distance between the patient's present state, being unable to walk at all, and his or her goal, being able to walk without assistance is large. Many unpredictable events may occur from the time of insult to the time the patient begins to walk again, therefore the gap on the state-goal dial is large and will generally decrease slowly.

The same concept was used when assessing rapid deterioration on the speed dial, however, when improvement was seen on the speed dial, a decrease in the unpredictable events was noted. Conversely, as a situation improves rapidly, reducing the gap, a negative exponential was used due to the reduced uncertainty within the situation (Dupuis et al., 1989). If the stroke patient noted above was unable to walk following a stroke, but set a goal to walk with moderate assistance, instead of independently, the gap between the present state and goal would be smaller. This illustrates the reduced likelihood of unexpected events, which may occur during recovery.
Finally, within the ranking portion of the test, a negative exponential curve was used. The reason for this approximation is based on the premise that "the more important a life domain, the more uncertainty linked to a gap will have a negative impact on the patient's life" (Dupuis et al., 1989, p. 42). Number 1 on the Likert scale is listed as "essential" and is valued at 2, number 4 is labeled "moderately important" and is given a value of .82 and number 7 is "not important" and has a value of .15. The gap between the state and goal is multiplied by one of these values, according to the rank assigned by the individual (Dupuis et al., 1989).

The scoring of the QLSI is complex and detailed. Due to the number of subjects in this study who did not complete the questionnaire in its entirety, the scoring methods developed by the author of the QLSI were not used. An attempt was made to use the author's scoring procedure, however results were obviously skewed. There were signs of high correlations based on the fact the subjects did not complete all portions of the questionnaire. Therefore, the raw data obtained from the subjects was collected and analyzed.

Data Analysis

A one-tailed, Pearson product-moment correlation was performed to examine the relationship between the responses obtained from self raters and spousal raters. A .05 level of significance was used for this study. Mean scores were utilized in the statistical analysis and these scores were obtained from global state, global goal, global, speed, and global rank portions of the test. Correlations were also calculated between the means on the state sub scales, goal sub scale, speed sub scales, and rank sub scales.
CHAPTER 4

Results and Discussion

Statistical Analysis

Results

The results of this study were analyzed to determine if a self rater and spousal rater could complete the same quality of life questionnaire, from the same perspective with similar outcomes. Results were calculated from mean scores acquired from self raters and spousal raters. The mean scores were obtained from the global state scores, global goal scores, global speed scores, and global rank scores. These scores are the combinations of mean scores from each of seven sub scales on the QLSI. Correlations were also tabulated for the mean state scores, goal scores, speed scores, and rank scores from each individual sub scale.

After scoring the QLSI for each subject, all raw data was recorded into Microsoft Excel. Statistical procedures included tabulating the mean (M) and standard deviation (SD) of each global and sub scale score and calculating the correlation (r) between the self raters' scores and the spousal raters' scores. A one-tailed, Pearson product-moment correlation was performed to examine the relationship between self rater and spousal rater responses. An alpha level of .05 was established for all statistical tests.

Tables 4-8 display the mean and standard deviation of global and sub scale scores. Also represented in the tables is the number of subjects who completed each portion of the test. Fifteen couples completed the QLSI, although six couples did not complete the test in its entirety. Information obtained from completed portions of each subjects' questionnaire was analyzed.
### Table 4. A Global Comparison of Self Raters and Spousal Raters on the QLSI

<table>
<thead>
<tr>
<th>QLSI Global Scores</th>
<th>Self</th>
<th></th>
<th>Spousal</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>State</td>
<td>6.81</td>
<td>1.73</td>
<td>15</td>
<td>6.75</td>
</tr>
<tr>
<td>Goal</td>
<td>4.33</td>
<td>1.29</td>
<td>12</td>
<td>4.28</td>
</tr>
<tr>
<td>Speed</td>
<td>0.29</td>
<td>0.72</td>
<td>14</td>
<td>0.45</td>
</tr>
<tr>
<td>Rank</td>
<td>2.77</td>
<td>0.60</td>
<td>15</td>
<td>2.68</td>
</tr>
</tbody>
</table>

### Table 5. A Sub Scale Comparison of Self Raters and Spousal Raters on the State Portion of the QLSI

<table>
<thead>
<tr>
<th>State Sub Scale Scores</th>
<th>Self</th>
<th></th>
<th>Spousal</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>Physical Health (SS A)</td>
<td>6.33</td>
<td>1.87</td>
<td>15</td>
<td>7.27</td>
</tr>
<tr>
<td>Cognitive-Affective Functioning (SS B)</td>
<td>7.01</td>
<td>2.11</td>
<td>15</td>
<td>6.53</td>
</tr>
<tr>
<td>Family and Social Environment (SS C)</td>
<td>6.56</td>
<td>2.11</td>
<td>15</td>
<td>6.35</td>
</tr>
<tr>
<td>Marital Relationship (SS D)</td>
<td>7.67</td>
<td>3.03</td>
<td>15</td>
<td>6.97</td>
</tr>
<tr>
<td>Leisure (SS E)</td>
<td>7.18</td>
<td>2.48</td>
<td>15</td>
<td>7.2</td>
</tr>
<tr>
<td>Work (SS F)</td>
<td>6.39</td>
<td>2.20</td>
<td>15</td>
<td>6.44</td>
</tr>
<tr>
<td>Housekeeping (SS G)</td>
<td>7.56</td>
<td>2.39</td>
<td>15</td>
<td>6.52</td>
</tr>
</tbody>
</table>
Table 6. A Sub Scale Comparison of Self Raters and Spousal Raters on the Goal Portion of the QLSI

| Goal Sub Scale Scores          | Self          | Spousal        |
|-------------------------------|---------------|----------------|-----------------|-----------------|-----------------|-----------------|----------------|-----------------|----------------|----------------|----------------|----------------|
|                               | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  |
| Physical Health (SS A)        | 3.60| 1.15| 11 | 4.78| 2.07| 11 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Cognitive-Affective Functioning (SS B) | 4.02| 1.67| 12 | 3.79| 2.30| 12 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Family and Social Environment (SS C) | 4.47| 1.46| 11 | 4.62| 1.96| 11 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Marital Relationship (SS D)   | 4.50| 1.82| 12 | 3.71| 1.91| 12 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Leisure (SS E)                | 4.17| 1.23| 11 | 4.74| 2.32| 11 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Work (SS F)                   | 4.30| 1.84| 11 | 4.05| 1.98| 11 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Housekeeping (SS G)           | 4.56| 1.45| 11 | 4.97| 2.43| 11 |     |     |    |     |     |    |     |     |    |     |    |    |     |

Table 7. A Sub Scale Comparison of Self Raters and Spousal Raters on the Speed Portion of the QLSI

| Speed Sub Scale Scores         | Self          | Spousal        |
|-------------------------------|---------------|----------------|-----------------|-----------------|-----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|
|                               | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  | M  | SD  | N  |
| Physical Health (SS A)        | .28| .98  | 14 | .3 | .81  | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Cognitive-Affective Functioning (SS B) | .38| 1.58| 14 | .66| 1.42 | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Family and Social Environment (SS C) | .20| .55  | 14 | .53| .83  | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Marital Relationship (SS D)   | .46| .84  | 14 | .71| 1.72 | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Leisure (SS E)                | .20| 1.18 | 14 | .26| .46  | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Work (SS F)                   | .14| .89  | 13 | .48| 1.75 | 13 |     |     |    |     |     |    |     |     |    |     |    |    |     |
| Housekeeping (SS G)           | .77| 1.36 | 14 | .64| 1.07 | 14 |     |     |    |     |     |    |     |     |    |     |    |    |     |
Table 8. A Sub Scale Comparison of Self Raters and Spousal Raters on the Rank Portion of the QLSI

<table>
<thead>
<tr>
<th>Rank Sub Scale Scores</th>
<th>Self</th>
<th>Spousal</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>N</td>
</tr>
<tr>
<td>Physical Health (SS A)</td>
<td>2.55</td>
<td>.48</td>
<td>15</td>
</tr>
<tr>
<td>Cognitive-Affective Functioning (SS B)</td>
<td>1.98</td>
<td>.51</td>
<td>15</td>
</tr>
<tr>
<td>Family and Social Environment (SS C)</td>
<td>2.69</td>
<td>.88</td>
<td>15</td>
</tr>
<tr>
<td>Marital Relationship (SS D)</td>
<td>2.43</td>
<td>.56</td>
<td>15</td>
</tr>
<tr>
<td>Leisure (SS E)</td>
<td>3.51</td>
<td>1.12</td>
<td>15</td>
</tr>
<tr>
<td>Work (SS F)</td>
<td>2.86</td>
<td>.88</td>
<td>15</td>
</tr>
<tr>
<td>Housekeeping (SS G)</td>
<td>3.55</td>
<td>1.05</td>
<td>15</td>
</tr>
</tbody>
</table>

Correlations of Global State and Sub Scale Scores

Global score correlations between self raters and spousal raters are displayed in table 9. The global state score $r = .285$, was not found to be statistically significant. The global state score represents how an individual is feeling regarding his or her life satisfaction or happiness in all domains of life at a specific point in time in reference to an ideal. The ideal designates the ultimate goal of being perfectly happy in a life situation (Duquette et al., 1994). The mean of spousal rating subjects was 6.75 (SD = 2.19) and the mean of self rating subjects was 6.81 (SD = 1.73). The difference of the means indicated that spousal raters judged their spouse to be closer to the ideal state than their spouses rated themselves. A correlation of the means across all sub scales of the QLSI can be found in Table 10. The correlation of sub scale means for the state portion of the questionnaire found only the cognitive-affective functioning $r = .496$ sub scale, sub scale (SS B), was statistically significant. The remaining six sub scales were not found to be statistically significant.
Table 9. A Comparison of QLSI Global Scores

<table>
<thead>
<tr>
<th>QLSI Global Scores</th>
<th>df</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>13</td>
<td>.285</td>
</tr>
<tr>
<td>Goal</td>
<td>10</td>
<td>-.002</td>
</tr>
<tr>
<td>Speed</td>
<td>12</td>
<td>.607*</td>
</tr>
<tr>
<td>Rank</td>
<td>13</td>
<td>.340</td>
</tr>
</tbody>
</table>

*p < .05.

Correlations of Global Goal and Sub Scale Scores

The global goal score, \( r = -.002 \), was also not found to be statistically significant. The global goal score satisfaction in a particular area of life, it does not necessarily signify the ideal. It is a goal that a person would consider "acceptable or satisfactory" (Duquette et al., 1994). The global goal score includes the means of all sub scales. Once again, the spousal raters (\( M = 4.28, SD = .90 \)) perceived their spouses, the self raters (\( M = 4.33, SD = 1.29 \)), set goals closer to the ideal than actuality. A correlation of the means across all sub scales on the goal section of the QLSI found only one sub scale that was statistically significant. The work sub scale \( r = .531 \), SS F was sound to be statistically significant, while the other six sub scale scores were not.

Correlations of Global Speed and Sub Scale Scores

The correlation for the global speed score \( r = .607 \) was statistically significant. The speed score indicates at what speed the subject is improving or deteriorating in a specific life domain or whether there is no change at all (Duquette et al., 1994). The global speed score indicates change or lack of change in all sub scale domains. Only 14% of the spousal rating subjects (\( M = .45, SD = .77 \)), perceived an increase or decrease in the spouse's QOL when the self rater (\( M = .29, SD = .72 \)), indicated the opposite. In other words, 86% of spousal raters judged increases and decreases in the changes of their spouses QOL with the same awareness that their spouse had indicated. Sub scale comparisons on the speed portion of the QLSI presented the most statistically significant correlations. The physical health sub scale \( r = .538 \), SS A, the
Table 10. A Comparison of Correlation Coefficients of Self Raters and Spousal Raters

<table>
<thead>
<tr>
<th>Sub Scale</th>
<th>State df</th>
<th>r</th>
<th>Goal df</th>
<th>r</th>
<th>Speed df</th>
<th>r</th>
<th>Rank df</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Health (SS A)</td>
<td>13</td>
<td>.433</td>
<td>9</td>
<td>.095</td>
<td>12</td>
<td>.538*</td>
<td>13</td>
<td>.322</td>
</tr>
<tr>
<td>Cognitive-Affective Functioning (SS B)</td>
<td>13</td>
<td>.496*</td>
<td>10</td>
<td>.120</td>
<td>12</td>
<td>.581*</td>
<td>13</td>
<td>.136</td>
</tr>
<tr>
<td>Family and Social Environment (SS C)</td>
<td>13</td>
<td>.152</td>
<td>9</td>
<td>.317</td>
<td>12</td>
<td>.019</td>
<td>13</td>
<td>.361</td>
</tr>
<tr>
<td>Marital Relationship (SS D)</td>
<td>13</td>
<td>.251</td>
<td>10</td>
<td>-.228</td>
<td>12</td>
<td>.311</td>
<td>13</td>
<td>.192</td>
</tr>
<tr>
<td>Work (SS F)</td>
<td>13</td>
<td>.284</td>
<td>9</td>
<td>.531*</td>
<td>11</td>
<td>.529*</td>
<td>13</td>
<td>-.243</td>
</tr>
<tr>
<td>Housekeeping (SS G)</td>
<td>13</td>
<td>.146</td>
<td>9</td>
<td>.369</td>
<td>12</td>
<td>.585*</td>
<td>13</td>
<td>.682**</td>
</tr>
</tbody>
</table>

*p < .05. **p < .01.

cognitive-affective functioning sub scale \( r = .581 \), SS B, the work sub scale \( r = .529 \), SS F, and the housekeeping sub scale \( r = .585 \), SS G, were all found to be statistically significant. The remaining three sub scales, family and social environment \( r = .019 \), SS C, marital relationship \( r = .311 \), SS D, and leisure \( r = .104 \), SS E, were not found to be significant.

Correlations of Global Rank and Sub Scale Scores

The global rank score \( r = .340 \) was not found to be significant. The global rank scores are those that indicate the importance of specific life domains (Duquette et al., 1994). The global rank scores include all life domains. Subjects consistently ranked items from one to four on a seven point Likert scale. Subjects did choose ranking of 5, 6, and 7, but with much less frequency than 1-4 rankings. Individual means of subject rankings ranged from 1.83 to 3.86. The mean for all self raters was 2.77 (SD = .60) while the mean for all spousal raters was 2.68 (SD = .59). The distribution of the means on the ranking portion of the test, according to Duquette et al. (1994) may indicate that the subjects value too many domains as being "essential" and "important," thus creating conflicts and increased pressure within their lives. The ranking portion of the QLSI found only one sub scale that was statistically significant, which was the
housekeeping sub scale $r = .682, p < .01, SS G$. Once again, the remaining six sub scales were not found to be statistically significant.

**Discussion**

The purpose of this study was to determine if a proxy examiner (spousal rater) of a quality of life questionnaire could complete the form with similar results to those obtained from a his or her partner (self rater). The Quality of Life Systemic Inventory was utilized during this study. Global state, goal and rank scores were not found to be statistically significant. Several reasons may account for these results. First, an individual's present state of happiness or satisfaction with life is not necessarily a "visible" quality. Often, many people do not discuss all areas of their lives on a daily basis. For example, work, family, or a person's physical heath may not be discussed unless a change has occurred. Therefore a person's present state is not totally defined until an event has transpired which defines his or her present state in relation to the change.

Second, goal setting may be very similar to the concept of a person's state, which is it is not highly "visible" or perceptual unless there is a concurrent change to ascribe a means of comparison. In relation to aspiring to a goal, goal setting is a very personal process. Others may be aware of an individual's personal goal, yet not really know exactly where those goals are set until there is progression or regression to or from the goal.

Finally, the subjects tended to favor the Likert responses listed from "essential" to "important" on the ranking portion of the QLSI. This would indicate that many of the subjects valued too many of their life domains. Subsequently, conflicts will arise according to Dupuis et al. (1989). Statistically, the rankings of the subjects were not significant; however, a graphic comparison of the means of couples scores (Appendix A) indicated a perception of trends in all life domains. Couples were able to perceive domains that were more important or less important, across all domains, however the subjects and their spouses indicated this trend statistically different from one another.
The global speed portion of the QLSI was found to be statistically significant. The improvement, deterioration, or lack of change in a particular area of life is measured on the speed portion of the questionnaire. Increased perception to these characteristics may be due to the overt signs of success and failure, change from the current state, or movement toward or away from a valued goal in a person's life. For example, as an individual moves away from a predetermined goal, feelings of frustration and anger will surface (Dupuis et al., 1989). These emotions can be readily apparent to a spouse or other family members. Decreased physical health and its impact on a person will be highly observable. Increased satisfaction with work may also be a very observable condition, evidenced with increased communication based on a promotion or raise at work. Also, no change in a situation may be outwardly observable, as no discussion of events is warranted, and no concern in a particular area is needed.

Examining each of the seven sub scales indicated that certain life domains, such as physical health, cognitive-affective functioning, work, and housekeeping were the most correlated of the seven sub scales. With regard to issues of physical health, cognitive-affective functioning, and work, changes in each of these areas are readily and easily observed. Illness, a decrease or increase of physical functioning, changes in memory, changes in happiness about oneself, and changes at work, if not blatantly obvious, generally warrant communication between spouses regarding overall changes in life. This may indicate why these sub scales correlated most often. In reference to the housekeeping correlations, this may be explained by general role definitions in the household. Often times it is one spouse who does the housekeeping consistently. Therefore the sub scale of housekeeping can be quite predictable.

The remaining three sub scales that did not correlate among couples were family and social environment, marital relationship, and leisure. Family and social relationships as well as a person's marital relationship are very personal and private life domains. Also, the control for family and marital relationships lies in all parties involved. For example, a husband may feel as though he is in complete control at his job, because he is the boss. However at home, consideration for his spouse must be made, and decisions regarding their home and family must
be made jointly. Decreased communication in these areas of life may be magnified by a need to be gracious, and not hurt the ones that are loved the most. Therefore, expectations and perceptions may be quite different between spouses who do not regularly discuss wants, needs, and expectations.

Similar to family and marital relationships, leisure issues did not correlate significantly on any sub scale. These issues can be variable with respect to changing needs for leisure time, and actually obtaining that time. Considering work and family schedules, an individual may get plenty of leisure time one week, but not enough the next. Predictability of leisure time may be more difficult than actually perceiving one's needs for that time. This may be the reason for decreased perceptions by spousal raters.

The observation graphic trends cannot be ignored in this research. Several couples, although their scores were not statistically significant, were able to predict value trends of their spouse. For example, a spousal rater may have indicated that his or her spouse's physical health was closer to ideal than his or her satisfaction with work. This trend was echoed by the self rater, but on a different value system. Spousal raters were, in several instances, perceptive to specific life domains in relation to the other domains.
CHAPTER 5
Summary and Conclusions

Summary

Quality of life (QOL) is a broad concept that entails a person’s happiness or satisfaction with life. Assessing an individual’s QOL is subjective and complex. It involves examining each particular area of one’s life and making decisions about contentment and issues of improvement. It may not be difficult for a person to evaluate his or her own QOL, but assessing the QOL of an individual who has decreased communicative or cognitive functioning may be quite difficult.

An individual who has suffered a stroke, dementia, or Alzheimer’s disease may not be able to evaluate his or her QOL to direct the medical and rehabilitative treatments imposed on him or her. Therefore it is imperative that another individual assess his or her QOL. This proxy assessment may ensure functional, valuable, and comprehensive medical and rehabilitative care.

The purpose of this research study was to examine the correlation of spouses’ perceptions on their partners QOL. Fifteen couples volunteered to participate in a one time research study. The subjects completed the Quality of Life Systemic Inventory (QLSI) in a setting of approximately one hour. The QLSI is a comprehensive QOL questionnaire, which evaluates a person’s present state, a selected goal, the speed to which that goal is being reached or not reached, and the ranking of importance of life domains. Several of the domains, which are addressed in the QLSI, include physical health, marital relations, work, and leisure.

The study consisted of self raters, those who completed the questionnaire from their own perspective, and spousal raters, the partner who completed the questionnaire from their spouse’s perspective. One subject was completing the form for himself or herself, and their spouse was completing the form for them also. Results were calculated at the completion of the study.

A one-tailed, Pearson product-moment correlation was utilized to compare self raters and spousal raters scores during data analysis, with a .05 level of significance established.
Global state, global goal, and global rank scores were not shown to be statistically significant. The global speed score did, however, indicate statistical significance.

Individual sub scale scores were correlated with significant findings in the state portion of the QLSI in the sub scale of cognitive-affective functioning. In the goal portion of the test, the work sub scale, sub scale F, was found to be significant. The speed portion of the questionnaire evidenced the most statistically significant sub scale scores. These scores were the physical health sub scale, cognitive-affective functioning sub scale, work sub scale, and housekeeping sub scale. The rank portion of the QLSI indicated one sub scale score, housekeeping, that was significant at the .01 level.

Conclusions

The clinical use of the QLSI for proxy examinations is not supported by the results of this study. The only global portion of the questionnaire that was statistically significant related to changes in specific life domains. Three out of four global scores did not find statistically significant correlations. Also, of the seven sub scales on the QLSI, only four were found to be statistically significant, and of those four sub scales, none of them were significant across all portions of the questionnaire.

It must be noted, however, the sub scales that did correlate significantly may be valuable for professionals in the rehabilitation field. The physical health sub scale, cognitive-affective functioning sub scale, and the work sub scale can all be interpreted as functional outcomes for patients who are suffering from debilitating disabilities such stroke or Alzheimer's disease. These particular life domains are those which may be the most important to patients recovering from debilitating disabilities, those which will prioritize the importance of walking again, the value of remembering grandchildren's names, or determining a much needed return to work.

Also, the graphic display of individual couple's scores shows a trend in perceptions among self raters and spousal raters. This is shown in the graphic display of mean scores in Appendix A. The subjects showed a common trend among couples, although their scores were not statistically significant. Although they are not on the same value system, the spousal rater is
able to predict increases or decreases in his or her partners perceived QOL. A spousal rater may be aware of the importance of specific life domains in his or her partner’s life, but the spousal rater may not be cognizant of the specific value to which his or her partner places on each of those domains. The results of this preliminary study indicate the need for more research to be done in this arena.

Further Research

The use of a less comprehensive QOL questionnaire will be needed for continued research in this area. The QLSI is a complex and lengthy form. It was administered in two small group settings, and not all of the subjects completed the form in its entirety. The directions were complex enough that individual sessions for questionnaire completion would be recommended if the questionnaire was used in future research. Also, because several of the subjects did not complete the form entirely, the author’s scoring could not be used due to skewing of the data. Less complex and more disease or impairment specific forms should be used in the future for information to be gained regarding proxy reporting.

The ages of the subjects in this study were heterogeneous, ranging from the third decade to the seventh decade. However, 50% of the subjects who participated in this study were 60 years old or older. Generational views on marriage, family, and housekeeping for example, may have played a role in the results of this study. Also, the notion that open communication and a change in traditional roles between spouses may not be expressed in these generational differences. Further research may be designed to delineate age cohorts and examine specific and singular decades.

Implications

This research was intended to determine the reliability of proxy examinations for spouses who have suffered disease or disability, which has rendered them communicatively or cognitively compromised and unable to complete a QOL questionnaire for themselves. This research, although preliminary, has implications that are vital for patients, their families, and professionals in the medical and rehabilitative fields of medicine, and the impact is threefold.
First, proxy QOL assessments can be cost effective. The life domains that are valued most highly or considered to most important to the patient's quality of life are treated. The areas of that person's life that are not as important are not treated directly, or may be given minimal support. Therefore the need for extensive treatments that are not desired or valued by the patient are eliminated, thus eliminating the added cost.

Second, completing a QOL form may increase the likelihood of appropriate, adequate, and comprehensive care. Often in the rehabilitation field, several professionals are exerting their opinions of expertise, and the patient can be left confused and may feel he or she does not have a voice to express his or her wants and needs in the medical or rehabilitation process. When a patient is communicatively compromised, the voice that is often exerted is that of the patient's spouse. The ideal, valued outcome of proxy QOL examination is that all the professionals involved hear the patient's voice, via his or her spouse. This proxy QOL evaluation will hopefully increase communication between all health care providers, the patient, and family members and allow them to monitor functional, meaningful progress across all disciplines.

Finally, and possibly most importantly, utilizing QOL questionnaires to evaluate the happiness and satisfaction in the lives of individuals with communicative or cognitive impairments, allows them to be a part of primary decision making in the course of their medical and rehabilitative treatments. Using the results from a proxy completion of a QOL questionnaire may enhance or augment meaningful and functional treatments. The objectives of treatments will be based on the value that the patient has in particular life areas or life functions.

Quality of life evaluation can limit handicapping conditions that actually lessen life satisfaction or happiness. It has the potential to reduce the costs in medical and rehabilitative treatments, and subsequently reduce unwanted treatments. QOL assessment can allow all parties to communicate and collaborate for needed treatments. It can give patients and their families independence of decision making and allow them to spend time in valued treatments, and not just treatments that the health care professionals see as valuable. Completion of QOL
questionnaires may re-establish a sense of value and dignity to a person who has suffered from a disease or disability, and provide confidence in the patient and his or her family that their most important needs and wants will addressed.
Appendix A

Graphic Representation of Mean Scores of Subjects
A Graphic Comparison of Global Scores on the QLSI per Couple

Couple 1

Couple 2

Couple 3

Couple 4

Couple 5
A Graphic Comparison of Global Scores on the QLSI per Couple

Couple 6

Couple 7

Couple 8

Couple 9

Couple 10
A Graphic Comparison of Global Scores on the QLSI per Couple

Couple 11

Couple 12

Couple 13

Couple 14

Couple 15
A Graphic Comparison of State Sub Scale Scores on the QLSI per Couple

Couple 1

Couple 2

Couple 3

Couple 4

Couple 5
A Graphic Comparison of State Sub Scale Scores on the QLSI per Couple
A Graphic Comparison of State Sub Scale Scores on the QLSI per Couple

Couple 11

Couple 12

Couple 13

Couple 14

Couple 15
A Graphic Comparison of Goal Sub Scale Scores on the QLSI per Couple
A Graphic Comparison of Goal Sub Scale Scores on the QLSI per Couple

Couple 6

Couple 7

Couple 8

Couple 9

Couple 10
A Graphic Comparison of Goal Sub Scale Scores on the QLSI per Couple

Couple 11

Couple 12

Couple 13

Couple 14

Couple 15
A Graphic Comparison of Speed Sub Scale Scores on the QLSI per Couple

Couple 1

Couple 2

Couple 3

Couple 4

Couple 5
A Graphic Comparison of Speed Sub Scale Scores on the QLSI per Couple

Couple 6

Couple 7

Couple 8

Couple 9

Couple 10
A Graphic Comparison of Speed Sub Scale Scores on the QLSI per Couple

Couple 11

Couple 12

Couple 13

Couple 14

Couple 15
A Graphic Comparison of Rank Sub Scale Scores on the QLSI per Couple

Couple 1

Couple 2

Couple 3

Couple 4

Couple 5
A Graphic Comparison of Rank Sub Scale Scores on the QLSi per Couple

Couple 6

Couple 7

Couple 8

Couple 9

Couple 10
A Graphic Comparison of Rank Sub Scale Scores on the QLSI per Couple

Couple 11

Couple 12

Couple 13

Couple 14

Couple 15
References


