

QUALITY OF LIFE FOLLOWING LIVER TRANSPLANTATION

By

Joan A. Mesch, R.N., B.S.N.

A Thesis

Presented to

The Oregon Health Sciences University

School of Nursing

in partial fulfillment of the requirements

for the degree

Master of Science

June, 1992

APPROVED:

[REDACTED]

Caroline M. White, DrPH., Professor, Community Health
Care Systems, Thesis Advisor

[REDACTED]

Julia S. Brown, PhD., Professor, Community Health Care
Systems, Reader

[REDACTED]

John R. Crossen, PhD., Assistant Professor, Medical
Psychology, Reader

[REDACTED]

Barbara Gaines, RN, EdD, Associate Professor, Chair
Community Health Care Systems Department, Reader

Acknowledgements

A project like this is never accomplished alone. On this page I wish to recognize a few of those who eased me through the writing of this paper. I will undoubtedly leave out someone, but my brain is still doing the statistics for this project. To all of those I live with, all of those I work with, all of those I work for and all of those who kept me in their hearts and prayers, I express now my sincere thanks.

To my advisors and the readers of this project: Caroline White, Julia Brown, and John Crossen, thank you for your many patient hours of teaching. To the Department of Gastroenterology, OHSU, Emmet Keefe and Kent Benner, thank you for allowing me to analyze the data used in this project. Another thanks to John Crossen for his assistance with the data entry and analysis, and for interpreting and teaching the language of statistics used in this project.

My love to my family. To my son Brian and my husband Denis: I probably could have done this without you, but I would have forgotten why I began this journey.

TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. INTRODUCTION.....	1
Review of the Literature.....	3
Conceptual Framework.....	10
Purpose of the Study.....	13
II. METHODS.....	15
Sample and Setting.....	15
Data Collection Instruments.....	18
Inputs.....	18
Demographic data.....	18
The Chronic Illness Problem	
Inventory (CIPI).....	18
The Shipley Institute of Living	
Scale (SILS).....	21
The Karnofsky Performance Status	
(KPS).....	23
Psychological Mediators.....	25
SCL-90-R.....	25
Quality of Life.....	26
The Quality of Life Scale (QOLS).26	
Design and Procedure.....	29
Analysis.....	30

III. RESULTS.....	31
Descriptive Findings.....	31
Answers to the Research Questions.....	34
Additional Findings.....	37
IV. DISCUSSION.....	43
V. SUMMARY, LIMITATIONS, RECOMMENDATIONS FOR FUTURE RESEARCH, AND IMPLICATIONS FOR CLINICAL PRACTICE.....	48
Summary.....	48
Limitations.....	50
Recommendations for Future Research.....	51
Implications for Clinical Practice.....	52
REFERENCES.....	54
APPENDICES.....	60
A. Chronic Illness Problem Inventory and Summary Sheet.....	61
B. Shipley Institute of Living Scale (SILS) and Scoring Tables.....	67
C. Karnofsky Performance Status.....	78
D. SCL-90-R Scoring Profile and Scoring Guide.....	81
E. Quality of Life Scale (QOLS).....	88
F. Additional Tables Reporting Correlation Coefficients Among Variables.....	91
ABSTRACT.....	101

LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
1	Characteristics of the Sample by Gender.....17
2	Measures Corresponding to the Elements of the Conceptual Framework.....19
3	The Five Domains of Quality of Life and the 15 Associated Components as Described by Flanagan (1982).....27
4	Scores of Liver Transplant Recipients on Selected Standardized Measures of Functioning: Means, Standard Deviations and Ranges.....32
5	Differences in Quality of Life of Transplant Recipients by Gender, Marital Status, Age, Education, and Time Since Transplant: Mean Scores and Standard Deviations on the QOLS.....35
6	Correlations of Scores of Liver Transplant Recipients on "Input" Variables (Demographic Characteristics, CIPI, KPS, SILS) and Quality of Life Scale (QOLS).....39
7	Correlations of Scores of Liver Transplant Recipients on "Input" Variables (Demographic Characteristics, CIPI, KPS, SILS) and the "Psychological Mediator" (SCL-90-R).....40
8	Correlations of Scores of Liver Transplant

Recipients on "Psychological Mediators" (SCL-90-R)
and Quality of Life Scale (QOLS).....41

CHAPTER I

INTRODUCTION

The first liver transplant in humans was performed in 1963 in Denver Colorado (Starzl et al., 1963). After this breakthrough, other centers undertook to provide liver transplant surgery for the treatment of end-stage liver disease. However, in the 1970's the short survival of transplant recipients led to a moratorium on liver transplantation as a broadly available therapy (Fox & Swazey, 1978). During this general moratorium, two centers continued to explore liver transplantation as an experimental therapy for end-stage liver disease, one center at Denver, Colorado, and one center at Cambridge, England (Calne, 1978).

In the early 1980s better surgical techniques, immunosuppressive drug therapy, and better preservation of donor organs improved the survival of liver transplant recipients. In 1983, at the Consensus Development Conference of the National Institute of Health, liver transplantation was no longer designated as an experimental procedure for the treatment of liver disease (Schmid, 1983). Today, liver transplantation is widely available for the treatment of broad categories of liver disease, including parenchymal and

cholestatic diseases, inborn errors of metabolism, and tumors (Starzl, Demetris & Van Thiel, 1989).

The Task Force for Organ Transplantation (1986) estimated that 40 per 1,000,000 people each year in the United States would be affected by liver disease treatable by liver transplantation. In 1990, 2,656 liver transplants were performed in the United States, an increase of 492 transplants over 1989 (UNOS, 1991). With the cumulative increase in the number of survivors, and recognition of the high costs of liver transplantation, the focus of concern has shifted from survival alone to the quality of life after transplantation.

The purpose of this study is to further our knowledge of quality of life as perceived by liver transplant recipients. To that end, their quality of life will be described, and the relationship of selected physical, psychological and social factors to that quality of life will be explored. To make comparisons with other groups more meaningful and to maximize reliability and validity, standardized measures are used throughout. It is hoped that clinicians and program planners will find the knowledge gained from this study useful for planning strategies

to enhance the quality of life of liver transplant recipients.

Review of the Literature

A review of the literature regarding life after liver transplantation indicates that some problems do indeed exist. Tarter et al. (1984) found that ten 3-year survivors of liver transplantation experienced disruption of normal activities. They also experienced psychiatric and social adjustment disturbances, although without disability, in the areas of anxiety, somatic concern, frustration, depression, worry, and social withdrawal. These same authors also found persistent cerebral dysfunction involving hand-to-eye ("visuopractic") coordination.

In a second study, Tarter, Erb, Biller, Switala and Van Thiel (1988) prospectively investigated the neuropsychiatric and psychosocial processes of 112 liver transplant recipients. The authors reported that the recipient's severity of stress was related to his/her health status at the time stress was measured. The spouse's stress was positively correlated with the daily stress of the transplant recipient. Normal daily activities were disrupted. Those who had more than one transplant experienced a less successful

rehabilitation. Problems included social dysfunction, depression, decreased physical activity, economic strain, and insomnia, this latter being positively correlated with anxiety. Persistent cognitive changes were identified in the areas of visuospatial and practic capacities, concentration, and memory. Even so, transplant recipients reported overall improvement relative to their pretransplant status.

In a third study, Tarter, Switala, Arria, Plail and Van Thiel (1991) compared the life quality of 53 liver transplant recipients before and after transplantation with that of a sample of healthy persons from the community. This study supported previous findings that life quality is significantly better after transplantation, but still not equal to that of normal control subjects. Thus, on the assumption that scores in the bottom quartile for the control group indicated impairment with regard to a specific area, it was estimated that 47% of the recipients were impaired in their social interaction and home management after liver transplant. With regard to their recreation, sleep, pastimes and rest, from 43% to 45% were deficient.

Similarly, in a preliminary report of their

prospective study, Kuchler, Kober, Brotsch, Henne-Bruns, and Kremer (1991) described improvement in the quality of life of 47 liver transplant recipients following their transplant. The researchers also reported that females adjusted better than males, but that both sexes experienced persistent anxiety. Moreover, survival was greater among patients with greater social support and less preoperative depression.

Hicks, Larson and Ferrans (1992) used standardized measures to compare the quality of life, mood state and perception of impairment of 17 "short term" (two years or less since transplantation) and 18 "long term" (greater than two years since transplantation) liver transplant recipients. These researchers found significantly greater perception of impairment in the "long term" group using the Sickness Impact Profile (SIP). When compared with renal transplant recipients (SIP, \bar{M} = 5.5%) this liver transplant population reported greater impairment (SIP, \bar{M} = 7%) but less than heart transplant recipients (SIP, \bar{M} = 9.6%). No differences were found between "short" and "long" term groups on the Profile of Mood States or a Quality of Life Index-Liver Transplant version.

Others have reported the experience of liver transplant recipients. Iwatsuki, Shaw, and Starzl (1985) assessed 31 of 33 five-year survivors who received transplants between 1963 and 1984 as "completely rehabilitated". Foley, Davis and Conway (1989) used Likert-type scales to measure the perceived symptom frequency and symptom distress related to both immunosuppressive therapy and transplantation in 45 liver transplant recipients. They also measured the direction and intensity of change in 23 life events to examine the side effects of immunosuppressive therapy. These investigators found that perceived symptom frequency was inversely related to quality of life as measured by two items about "perceived" quality of life and "satisfaction with" quality of life. Likewise, those who perceived negative life changes in the areas of relationships, physical, social and psychological functioning reported a poorer quality of life. Of the 45 transplant recipients, half reported a negative change in financial status. On the basis of their study the investigators stated that they do not believe that immunosuppressive therapy (the form of immunosuppressive therapy is not described in the report) affected the transplant recipients' perception

of quality of life.

Wolcott, Norquist and Busuttil (1989) used several health and psychosocial measures to assess medical, psychological, and social status in 41 liver transplant recipients at least 4 months post transplant. They reported high stress in financial matters and medical treatment. The investigators also noted that the "psychosocial measures showed that there was minimal mood disturbance, high self esteem, and positive life satisfaction except in work, career, and sexual activities" (p. 3565). The transplant recipients also reported little social interaction despite large social networks. Liver transplant recipients in their sample had a lower score on a standardized measure of well-being (Index of Well Being) than a comparison group of renal transplant recipients.

House, Dubovsky and Penn (1983) performed routine psychiatric evaluations on 34 liver transplant recipients, of whom 26 had also been evaluated prior to transplant. All 26 evaluated before transplant exhibited psychiatric problems, as did 34 evaluated after transplant. Both before and after transplant these problems consisted of both psychologic dysfunctions and organic brain syndromes and were more

severe than those exhibited by renal transplant patients.

Pennington (1989), who is himself a liver transplant recipient and a physician, uses four paradigm cases to describe life after liver transplantation. Stressed in each of the cases was the financial burden precipitated by the high cost of medications, loss of job due to liver disease, and inability to obtain a job after transplant. In two cases the transplant recipient was considered permanently disabled by both former and potential employers. In two cases marital status affected access to financial assistance. One of these couples chose to divorce to relieve the financial burden. Pennington concludes that although liver transplant recipients are physically and mentally capable, economic and social pressures exert great hardship after transplantation.

In summary, this review of the literature indicates that liver transplant recipients report that overall quality of life is better after than prior to transplant. Liver transplant recipients also report more psychosocial distress and disruption of daily activities than does a normal population. Some liver transplant recipients demonstrate persistent cognitive

deficits in the areas of coordination, concentration, and memory. Distress has been reported in the forms of anxiety, depression, somatic concern, frustration, insomnia, social isolation, sexual relationship disturbances, financial difficulty, and disruption of work and career. On measures of perceived impairment, mood states and quality of life, no statistical difference was described between transplant recipients less than two years and those greater than two years from transplantation. Finally, the experience after liver transplantation may be different for men than for women.

The research about life after liver transplantation is characterized by certain limitations. Samples are generated from populations of patients served by one, or at the most two, transplant programs. The samples in many instances are small. A variety of strategies have been used to assess quality of life and the variables thought to be associated with it. The predominant strategy has been to use quantitative instruments, only a few of which were standardized. Not always are the scores of patients reported with study results, making it difficult to

assess investigator claims regarding quality of life and other issues. The absence of scores also makes it difficult to incorporate the findings into clinical protocols or practice.

Conceptual Framework

Over the past three decades, many scholars have attempted the difficult task of defining and measuring the concept of "quality of life" (e.g., Andrews, 1986; Campbell, Converse, & Rodgers, 1976; Flanagan, 1978). Their efforts have indicated the complexity and multidimensionality of the concept. Generally, the term has been taken to refer not to "objective indicators" of an individual's condition, but to the individual's own subjective sense of well-being, happiness, and satisfaction with various aspects of life. From extensive qualitative research Flanagan (1978) identified the critical aspects of quality of life as; physical and material well-being, relationships with other people, social, community and civic activities, personal development and fulfillment, and recreation.

A 15-item instrument was developed by Flanagan (1982) based on these critical aspects of quality of life. Flanagan used this instrument to assess both the

importance to the individual of each aspect, as identified by the 15 items, and the individual's degree of satisfaction with that aspect, using 5-point rating scales. Flanagan's instrument (1982) was modified by Burckhardt, Woods, Schultz & Ziebarth (1989) and then psychometrically evaluated on a sample of patients with arthritis. Quality of life was rated on a 7-point scale for each item in the five domains of Flanagan's original scale (1982). It is Burckhardt's modification of Flanagan's instrument that is used in the present research to measure quality of life of liver transplant recipients.

Burckhardt (1985) has developed a conceptual model, derived from the cognitive framework advanced by Lazarus and Cohen (1976, cited in Burckhardt, 1985) to explain adaptive outcomes. Lazarus and Cohen theorized that inputs to the person (the physical environment, the social environment, demographic characteristics, and particular adaptive problems) are psychologically processed and cognitively appraised by the person. These inputs in interaction with the individual's internal psychological processes (individual internal operations) then result in "adaptive outcomes", which Burckhardt calls "quality of life." Burckhardt (1985)

found support for this model using path analysis in a sample of patients with arthritis.

In common with Lazarus and Cohen's theory, Burckhardt's model conceives of the quality of life of patients with arthritis as determined by a number of physical, psychological and social factors. These factors are separated into "inputs" and "mediators". The "mediators" (perceived support, negative attitude, self esteem, and internal locus of control) intervene to mute, exacerbate or otherwise influence the impact of the "input" factors (e.g., disease related factors, and demographic and social factors) on the "outcome" (i.e., quality of life).

The present research into the quality of life of liver transplant recipients employs Burckhardt's (1985) conceptual model. It also uses her measure of quality of life. However, the other measures are different. In this study the "inputs" include demographic characteristics, time since liver transplant, cognitive ability, problems of daily living, and a rating of global performance. The psychological processes of the individual is represented by a multidimensional measure of psychological disturbance, and is considered a "psychological mediator." It is theorized that the

interaction between these "inputs" and "psychological mediators" determine the "quality of life" of liver transplant recipients.

Purpose of the Study

The purpose of this study is to describe the perceived quality of life of liver transplant recipients and to explore the effects of selected physical, psychological and social factors on that quality of life. To that end, answers are sought to the following questions:

- 1) Does the quality of life after liver transplantation differ for men and women?
- 2) Does the quality of life after liver transplantation differ for those who are married and those who are not?
- 3) Does the quality of life after liver transplantation differ by age of the recipient?
- 4) Does the quality of life after liver transplantation differ by education of the recipient?
- 5) Does the quality of life after liver transplantation differ by time since transplant?

In addition to answering these questions, the relationships among the "inputs", "psychological mediators" and outcome variable, "quality of life," posited by the conceptual framework will be examined. Burckhardt (1985) found that psychological mediating factors contributed directly to quality of life, whereas age, gender, severity of pain and impairment due to arthritis, economic status and social network (inputs) indirectly affected quality of life through the mediating psychological factors. In line with those findings, one would expect to find the "inputs" to be related to the "psychological mediators" and the "psychological mediators" to be related to "quality of life". The "inputs", on the other hand, may or may not be related to "quality of life." Understanding the relationships between the variables provides information to health care providers about the dynamics that influence quality of life.

CHAPTER II

METHODS

Sample and Setting

The sample includes 48 orthotopic liver transplant recipients followed in a gastroenterology clinic from September 1990 to June 1991 for routine health screening and blood tests. Prior to their clinic visits, a member of the health care team contacted 57 liver transplant recipients by telephone and assessed their global performance using the Karnofsky Performance Status (KPS) (Karnofsky & Burchenal, 1948).

Of the 57 patients assessed by the KPS, 49 subsequently completed the other measures (86%). One of those 49 was too young to include in this research (15 years old) and was therefore excluded. Hence there are 48 transplant recipients for whom data were sufficiently complete to allow analysis. The 8 adult liver transplant recipients (5 males, 3 females) who did not complete the other instruments had similar ratings of global performance to the other 48, with mean KPS scores of 81.3 (range= 70-95) and 84.0 (range= 40-100) respectively.

Thirty (62%) are male, and 18 (38%) are female.

Three transplant recipients (6%) required more than one transplant. Twenty-four (50%) were transplanted at this center. Twenty-four (50%) were transplanted at six other centers and were followed at this clinic. Most had survived more than one year (n=29).

For the purpose of describing the attributes of the sample and relating those to the major points of the study, the sample was divided into groups. The sample was divided into 3 age groups; those 40 years old and younger, those 41 to 55, and those 56 years old and older. The sample was also divided to compute differences related to educational background; those who had less than 12 years of education, those who completed 12 years of education, and those who completed more than 12 years of education. In order to determine the differences related to the time since transplantation the sample was divided into three groups; those less than 12 months post-transplant ("recovering"), those between 12 months and 24 months ("transitional phase"), and those greater than 24 months ("recovered"). Table 1 describes the characteristics of this sample by gender and by age, education, time since transplant and marital status.

Table 1

Characteristics of the Sample by Gender.

Characteristics	Male (n=30)	Female (n=18)	Total (N=48)
Age (Years)			
22-40	12	5	17
41-55	11	10	21
56+	7	3	10
Mean	45.0	47.9	46.1 yrs.
SD	11.2	9.2	10.2
Range			22-64 yrs.
Education (Years)			
< 12	3	2	5
= 12	6	9	15
> 12	21	7	28
Mean	13.8	13.2	13.6
SD	2.3	2.5	2.4
Range			9-18 yrs.
Time Since Transplant (Months)			
< 12	15	4	19
12-24	8	6	14
> 24	7	8	15
Mean	17.1	22.1	19.0
SD	15.2	15.7	15.4
Range			2-67 mos.
Marital Status			
Married	24	13	37
Nonmarried	6	5	11

Data Collection Instruments

The conceptual framework provides a basis for clustering the measures into three groups. Table 2 names the measures for each of the clusters of the conceptual framework; inputs, psychological mediators, and quality of life. Each is described below.

Inputs

Demographic data were extracted from the patient records. These data include: recipient's gender, age in years to the nearest birth date, number of years of education, marital status and the time since last transplant. In order to standardize the measures of age and time since transplant, the date of administration of the Karnofsky Performance Status (Karnofsky & Burchenal, 1948) was used to calculate these variables. In real time this date was spread over the testing period (September, 1990 to June, 1991) and in some cases (e.g., when instruments were completed at home) the dates of completion of different instruments may have varied up to two months.

The Chronic Illness Problem Inventory (CIPI) is a self-administered inventory consisting of 65 questions. It is designed to rate 18 dimensions (Kames, Naliboff, Heinrich & Schag, 1984) including problems with: sleep,

Table 2

Measures Corresponding to the Elements of the
Conceptual Framework.

Inputs	Psychological Factors	Quality of Life
Demographic Data	SCL-90-R:	Quality of Life
Age		Scale
Gender	Global Severity Index (GSI)	(QOLS)
Education (yrs.)		
Marital status		
Time since transplant (9mos.)	Positive Symptom Total (PST)	
Shipley (SILS): estimated IQ Abstraction Quotient	9 Dimensions: somatization obsessive- compulsive interpersonal sensitivity	
Chronic Illness Problem Inventory (CIPI): sleep eating finances employment medications cognitive physical appearance body deterioration sex activities of daily living inactivity social activity contact with family/friends assertion medical interaction marital difficulty marital overprotection nonmarried relationships	depression anxiety hostility phobic anxiety paranoid ideation psychoticism	
Karnofsky Performance Status (KPS)		

eating, finances, employment, medications, cognitive, physical appearance, body deterioration, sex, activities of daily living, inactivity, social activity, contact with family and friends, assertion, medical interaction, marital difficulty, marital overprotection, and nonmarried relationships (see Appendix A). The severity of symptoms is rated from 0-4, ("not at all" to "very much"). Each dimension is scored by adding the rating of the items in each dimension (2-5 items per dimension) and dividing by the number of items in that dimension. There is no overall score for the instrument.

The CIPI was developed as a screening tool for use with patients with chronic pain and other chronic health problems. Kames et al. (1984) report that agreement between the CIPI and complete psychological evaluation at the Pain Management Center, UCLA, was 72% in terms of absence of a specific problem, and 80% in terms of the presence of a specific problem, thus providing a measure of criterion validity. Test-retest reliability was adequate ranging from .69 to .97 with a mean of .87. Internal consistency of the revised CIPI for 18 scales using Chronbach's coefficient alpha, had a range of .78 to .98, and a mean of .85.

The CIPI yields profiles by which to make comparisons among patients with a specific health problem and among groups of patients with different health problems. The mean scores of pain patients on each of the 18 dimensions have been graphed for comparison with chronic illness groups (obesity, pain, and chronic respiratory patients). The CIPI has also been used with groups of patients with tinnitus (Harrop-Griffiths, Katon, Dobie, Sakai & Russo, 1987; Sullivan et al., 1988) and sickle cell anemia (Barrett et al., 1988).

The Shipley Institute of Living Scale (SILS) is a commonly used, brief (20 minutes), cognitive function screening test (see Appendix B) that assesses breadth of vocabulary and level of abstract reasoning (Zachary, 1986). The SILS was originally standardized using a normative sample of students from fourth graders to undergraduates. The revised SILS was restandardized using a broader age range ($M = 34.9$) of psychiatric patients. The test and its scoring are described in full in the administration manual.

The SILS is a self-administered, 60-item multiple-answer and item-completion test. A Verbal Score is obtained by assigning one point for each correct answer

and one point for every four unanswered items on the verbal portion of the test. An Abstraction Score is obtained by assigning two points for each correct answer on the abstract reasoning portion of the test. A Total Score is obtained by summing the Verbal and Abstraction Scores and this sum is then transformed into a T-score. The Total Score is entered into a mathematical formula to obtain an estimate of the Wechsler Adult Intelligence Scale-Revised version (WAIS-R), full scale IQ score.

The SILS provides two scores that contrast the Vocabulary Score with the Abstraction Score, only one of which is used in this study because the other has limitations (Zachary, 1986). The underlying assumption in contrasting the Vocabulary and Abstraction scores is that mental function, as measured by vocabulary (mental content) and abstraction (mental process), should be approximately equal. Therefore, those who have intellectual impairment will show a discrepancy between vocabulary skills and abstract thinking.

The Abstraction Quotient (AQ) of the SILS is a description of over-all cognitive function developed by Mason and Ganzler (1964). The AQ is a standard score (M=100, S.D.=15) based on the difference between the

obtained abstraction score and a "predicted abstraction score". The "predicted abstraction score" was determined by Mason and Ganzler (1964) by means of a linear regression of the Abstraction Scores of 198 VA patients, nonprofessional staff and volunteers on their vocabulary scores. The tables for deriving the AQ are provided in Appendix B.

The SILS appears to be reasonably reliable and valid (Zachary, 1986). Split-half reliability using the Spearman-Brown computational formula on a sample of 322 Army recruits was .87 for Vocabulary, .89 for Abstraction and .92 for the Total Scores. Test-retest reliability coefficients for the Total Scores of several groups of female nurses and undergraduate students at intervals between 2 and 16 weeks were between .62 and .82. The SILS derives its validity from the Wechsler Intelligence Test, and has many of the same capabilities and limitations.

The Karnofsky Performance Status (KPS) (Karnofsky & Burchenal, 1948) is a widely used 10-point rating of the patient's global functional performance (see Appendix C). A rater scores the percent of the patient's functioning based on the verbal anchors for each of the 10 ordered categories. In general, 80-100%

is considered normal functioning with no special care needed; 50-70% represents inability to work, but ability to function otherwise with varying degrees of assistance; and below 50% designates the need for institutional care.

Grieco and Long (1984) obtained an interrater reliability coefficient of .86 using the Spearman Rank Correlation when raters used the same data sources to score the functional performance of 30 individuals from five different in-patient and out-patient populations at a V.A. Medical center in Florida. Concurrent validity is indicated by correlations of .68 to .96 between the KPS scores and scores on three other measures of patient quality of life. A test of the discriminant validity of five different quality of life measures (including the KPS) on five groups of patients demonstrated that the KPS possessed the maximum discriminatory power.

With the present sample, the KPS was determined by a single rater. The rater based each rating on an interview protocol to elicit responses related to employment, ability to carry out normal activities, and pretransplant status (see Appendix C). Since the KPS was rated by the same rater using the same criteria

internal consistency can be expected (Grieco & Long, 1984). No intra-rater reliability was calculated with this sample.

Psychological Mediators

The SCL-90-R, developed by Derogatis (1983), is also a commonly used self-administered, psychological screening tool that assesses psychological disturbance (see Appendix D). It is based on the Hopkins Symptom Checklist. The SCL-90-R measures 9 dimensions of psychological disturbance, namely, somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Each dimension is measured on a 5-point scale of distress (0-4), with the higher scores indicating greater distress. The sum of the scores is divided by the number of items answered for each of the dimensions, thus adjusting for any missing items.

A Global Severity Index (GSI) is calculated by adding the scores (that can vary from 0-4) for all nine dimensions and the additional items and dividing by the number of items answered. The Positive Symptom Total (PST) can vary from 0-91. The PST is the total number of items with a score other than zero.

Internal consistency for the 9 dimensions using coefficient alpha is between .77 and .90. Test-retest reliability of 94 patients at a 1-week interval was between .80 and .90 for the 9 dimensions. Several studies of validity have indicated the sensitivity of the SCL-90-R in predicting clinical psychological distress/disturbances (Derogatis, 1983).

Quality of Life

The Quality of Life Scale (QOLS) was developed by Burckhardt (1985). Fifteen items are identical to those in an instrument developed by Flanagan (1982). That instrument was the outcome of research by Flanagan and psychologist colleagues who used a critical incident technique to analyze 3000 interviews of men and women across the United States. Flanagan and his colleagues identified 15 components of quality of life clustered into 5 domains (Flanagan, 1978)(see Table 3).

Burckhardt (1985; 1988; Burckhardt, Woods, Schultz & Ziebarth, 1989; C.S. Burckhardt personal communication, January 28, 1992) used Flanagan's instrument to study the quality of life of chronically ill patients, substituting a 7-point rating scale ("terrible", scored 1, to "delighted", scored 7) for Flanagan's 5-point rating scale to assess

Table 3

The Five Domains of Quality of Life and the 15
Associated Components as Described by Flanagan
(1982).

Domain	Component
A. Physical and material well-being	1. Material comforts; desirable home, food, conveniences, security
	2. Health and personal safety
B. Relationships with other people	3. Relationships with relatives
	4. Having and rearing children
	5. Close relationship with spouse or member of the opposite sex
	6. Close friends, sharing views, interests, activities
	7. Helping and encouraging others
C. Social, community and civic activities	8. Participating in local and governmental affairs
	9. Learning, attending school improving understanding
D. Personal development and fulfillment	10. Understanding yourself and knowing your assets and limitations
	11. Work that is interesting rewarding and worthwhile
	12. Expressing yourself in a creative manner
	13. Socializing with others
	14. Reading, listening to music, watching sports, other entertainment
E. Recreation	15. Participation in active recreation

satisfaction (Burckhardt et al., 1989). Also, the QOLS does not assess the importance of each item to the individual's perception of quality of life. Based on the findings of her research Burckhardt et al. (1989) added another component, namely, independence, or the ability to do for oneself.

The scores of each of the 16 items in Burckhardt's instrument are summed to provide a total score which can range from 16 to 112. Missing items are given a mean score. The internal consistency reliability coefficient of the 16-item scale was .86 in a study of 94 fiber myalgia patients (C.S. Burckhardt, communication January 28, 1992). The internal consistency reliability coefficient of the 15-item scale was also high (Burckhardt et al., 1989), ranging from .84 to .92 for four groups of chronically ill patients tested across a 6-week time period at two week intervals. The test-retest reliability coefficients at two 3-week intervals using the subjects in the above four groups were .78 and .84.

Sensitivity of the instrument with the chronic illness groups is inferred because one group (ostomy) had a significantly higher mean score than the other group (diabetics) independent of the demographic

characteristics of the two groups. Convergent validity is inferred based on significant correlation coefficients between the QOLS and other measures related to quality of life (Burckhardt et al., 1989). That Flanagan used inductive reasoning to develop his scale (1982) offers evidence of construct validity.

Design and Procedure

The design of this study is cross sectional and correlational. The data used in this investigation had been previously collected for the purpose of the clinical evaluation of liver transplant recipients and for preliminary planning of their treatment. Measures were chosen by health care providers to evaluate broad dimensions of the transplant recipient's status after transplantation. The measures were self-administered and took a relatively short time to complete. Whenever possible the instruments were completed during regularly scheduled clinic visits; otherwise they were completed by the recipient at home and returned to the clinic. Some dimensions of the instruments overlap, but none of the dimensions are identical.

Protection of confidentiality for the subjects was provided through assignment of a code number to each individual and entering the data into the computer

according to the assigned code number. This study involves the analysis of the grouped clinical data described above. Hence, although the study was reviewed and approved by the Oregon Health Science University Committee on Human Research no special consent from the patient was required to carry out the analysis of these data.

Analysis

Quality of Life Scale scores were the dependent variables. T-tests were used to identify if there were differences by gender and marital status (research questions 1 and 2). Analysis of variance was used to see if there were differences by age, education and time since last transplant (research questions 3, 4 and 5). To describe the relationships among the measures data for the entire sample were aggregated for correlational analysis. Because of the large number of comparisons being made and therefore the increased probability of obtaining significant differences or significant relationships by chance alone, the p-value to determine significance was set at .01 or less.

CHAPTER III

RESULTS

Descriptive Findings

The demographic data and months since liver transplant for this sample have been described earlier (see Table 1). The liver transplant recipients in this study were predominantly male (n=30; female, n=18) with a mean age of 46. More than half had completed high school; almost two thirds (n=29) were more than one year since transplant; 77% were married at the time of the study.

Five standardized measures were used to assess aspects of the liver transplant recipient's physical, psychological, and social functioning following transplant: Chronic Illness Problem Inventory, Shipley Institute of Living Scale, Karnofsky Performance Status, SCL-90-R and the Quality of Life Scale. In general, this population of liver transplant recipients report that they are doing well. The means, standard deviations and ranges for each of the standardized measures are presented in Table 4.

The scores reported on the CIPI by this liver transplant population have means approximately equal to

Table 4

Scores of Liver Transplant Recipients on Selected
Standardized Measures of Functioning: Means,
Standard Deviations and Ranges.

Measure	Mean	(SD)	Range
Chronic Illness Problem Inventory (CIPI)			
Sleep	0.9	(1.0)	0-4
Eating	1.2	(1.1)	0-4
Finances	1.2	(1.2)	0-4
Employment	1.1	(1.2)	0-4
Medications	0.3	(0.5)	0-4
Cognitive	1.0	(1.1)	0-4
Physical appearance	0.8	(0.9)	0-4
Body deterioration	0.7	(0.9)	0-4
Sex	1.0	(1.0)	0-3.5
Activity	0.8	(0.8)	0-4
Inactivity	0.6	(0.7)	0-3
Social interaction	0.5	(0.8)	0-3.7
Family & friends contact	0.8	(0.9)	0-3.2
Assertion	1.2	(1.3)	0-4
Marital	0.6	(0.9)	0-3.2
Marital overprotection	0.5	(0.7)	0-2.3
Nonmarried relations	2.1	(1.4)	0-4
Shipley Institute of Living Scale (SILS)			
IQ	107	(12)	69-125
AQ	108	(14)	65-135
Karnofsky Performance Status (KPS)			
	84	(14)	40-100
SCL-90-R			
Global Severity Index	0.6	(0.5)	0-2.2
Somatization	0.8	(0.6)	0-2.5
Obsessive-compulsive	0.8	(0.8)	0-3.5
Depression	0.7	(0.7)	0-2.8
Anxiety	0.5	(0.5)	0-2.5
Hostility	0.4	(0.4)	0-1.5
Phobic Anxiety	0.2	(0.4)	0-1.7
Paranoid Ideation	0.3	(0.4)	0-1.3
Psychoticism	0.3	(0.4)	0-2.4

Table 4 (continued)

SCL-90-R			
Positive Symptom Total (PST)	30	(18)	3-71
Quality of Life Scale (QOLS)	81	(15)	52-109

Note: The range of possible scores is 0-4 for each CIPI dimension; 0-100 for the KPS; 0-4 for each dimension of the SCL-90-R and the GSI; 0-91 for the PST; 16-112 for the QOLS.

1 with the range 0-4 ("not at all", 0 to "very much", 4). Of the 18 dimensions, 11 have scores across the range of severity. The Karnofsky Performance Status (KPS) scores also have a wide range (40-100). The mean score on the KPS (84) falls within the range "normal functioning" (80-100), indicating the majority of this population is able to function independently.

The Shipley Institute of Living scores also have a wide range. The means for the two measures (estimated IQ = 107 and the Abstraction Quotient = 108) are near the normalized score (100) indicating verbal and abstract reasoning skills are normal. The Quality of Life Scale has a wide range of scores, but unlike the other instrument scores the median (83) and mean (84) are approximately equal indicating less positively skewed scores. The scores of the SCL-90-R reflect generally low rating of psychological distress; unlike the other measures, for 8 of the 9 dimensions, the highest score was less than 3 (out of a possible 4).

Answers to the Research Questions

The mean scores and standard deviations on the Quality of Life Scale scores as affected by gender, marital status, age, education and time since transplantation are described in Table 5.

Table 5

Differences in Quality of Life of Transplant
Recipients by Gender, Marital Status, Age, Education,
and Time Since Transplant: Mean Scores and Standard
Deviations on the QOLS. #

Group	Mean	QOLS (SD)
Gender		
Men (n=30)	79.3	(14.2)
Women (n=18)	85.0	(15.0)
Marital Status		
Married (n=37)	82.9	(14.6)
Nonmarried (n=11)	76.1	(14.0)
Age (Years)		
22-40 (n=17)	79.3	(14.3)
41-55 (n=21)	80.8	(14.6)
56+ (n=10)	86.0	(15.6)
Education (Years)		
< 12 (n=5)	70.8	(20.7)
12 (n=15)	80.3	(14.7)
> 12 (n=28)	83.9	(12.9)
Time Since Transplantation (Months)		
< 12 (n=18)	79.4	(14.5)
13-24 (n=16)	80.3	(14.3)
> 24 (n=14)	85.4	(15.6)
Total Sample	81.3	(14.6)

Research Question 1: Does the quality of life after liver transplantation differ for men and women? No statistically significant difference was observed between the mean Quality of Life Scale (QOLS) scores of men ($n = 30$) and women ($n = 18$), $t(46) = 1.30$, $p < .20$.

Research Question 2: Does the quality of life after liver transplantation differ for those who are married and those who are not? No significant difference was observed between the mean QOLS scores for those who were married ($n = 37$) and those who were not ($n = 11$), $t(46) = 1.38$, $p < .17$.

Research Question 3: Does the quality of life after liver transplantation differ by age of the recipient? The sample was divided into three age groups (22-40, 41-55, and 56+). Analysis of variance did not reveal significant differences in the mean scores on the QOLS between age groups; $F(2, 45) = 0.68$, $p < .51$.

Research Question 4: Does the quality of life after liver transplantation differ by education of the transplant recipient? The sample was divided into three groups based on the education of the transplant recipient (less than 12 years, 12 years, and greater than 12 years). Analysis of variance did not reveal

significant differences in the mean scores on the QOLS based on educational background $F(2, 45) = 1.80, p < .18$.

Research Question 5: Does the quality of life after liver transplantation differ by time since transplant? Again, the sample was divided into three groups based on the time since the last transplant until the date of rating the Karnofsky Performance Status (less than 12 months, 12 to 24 months, and greater than 24 months). Analysis of variance did not reveal significant differences in the mean scores on the QOLS between groups based on the time since transplant $F(2, 45) = 1.93, p < .16$.

In summary, no statistically significant differences were found in the mean scores on a global measure of quality of life within this group based on gender, marital status, age, education or time since transplant.

Additional Findings

The conceptual framework of Burckhardt (1985) was employed as a means for clustering the measures and to explore the relationships among them (see Table 2). Correlational analyses were performed between the "inputs" and the "psychological mediators"; the "psychological mediators" and "quality of life;" and

Table 6

Correlations of Scores of Liver Transplant Recipients
on "Input" Variables (Demographic Characteristics,
CIPI, KPS, SILS) and Quality of Life Scale (QOLS).

Input Variables	Pearson's r with QOLS
<u>CIPI</u>	
Sleep	-.24
Eating	-.35*
Finances	-.28
Employment	-.53**
Medications	-.34*
Cognitive	-.32
Physical appearance	-.48**
Body deterioration	-.39*
Sex	-.42*
Activities of daily living	-.53**
Inactivity	-.63**
Social activity	-.61**
Family/friends contact	-.67**
Assertion	-.42**
Medical interaction	-.19
Marital difficulty	-.39*
Marital overprotection	-.07
Nonmarried relationships	-.23
KPS	.46**
SILS AQ	-.07
SILS estimated IQ	.16
Age	.26
Gender	.19
Marital status	-.20
Years of education	.26
Time Since Transplant	.28

* p significant at ≤ 0.01

** p significant at ≤ 0.001

Table 7

Correlations of Scores of Liver Transplant Recipients
on "Input" Variables (Demographic Characteristics, CIPI,
KPS, SILS) and the "Psychological Mediator" (SCL-90-R).

Input Variables	Pearson r with SCL-90-R	
	GSI	PST
CIPI		
Sleep	.60**	.45**
Eating	.40*	.40*
Finances	.45**	.38*
Employment	.47**	.54**
Medications	.48**	.52**
Cognitive	.70**	.70**
Physical appearance	.38*	.59**
Body deterioration	.65**	.53**
Sex	.34	.54**
Activities of daily living	.57**	.52**
Inactivity	.47**	.57**
Social activity	.57**	.58**
Family/friends contact	.55**	.59**
Assertion	.56**	.59**
Medical interaction	.42**	.36*
Marital difficulty	.48**	.57**
Marital overprotection	.44*	.48**
Nonmarried relationships	.57	.60
KPS	-.40*	-.50
SILS AQ	-.10	-.07
SILS estimated IQ	-.28	-.26
Age	-.09	-.31
Gender	.04	.09
Marital status	.23	.23
Years of education	-.11	-.13
Time Since Transplant	-.22	-.17

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table 8

Correlations of Scores of Liver Transplant
Recipients on "Psychological Mediator" (SCL-90-R) and
Quality of Life Scale (QOLS).

Psychological Mediators	Pearson's r with QOLS
<u>SCL-90-R</u>	
GSI	-.56**
PST	-.63**
Somatization	-.44**
Obsessive-Compulsive	-.34*
Interpersonal sensitivity	-.54**
Depression	-.58**
Anxiety	-.39*
Hostility	-.46**
Phobic anxiety	-.57**
Paranoid ideation	-.42**
Psychoticism	-.51**

* p significant at ≤ 0.01

** p significant at ≤ 0.001

CIPI and the KPS) (see Table 6). All but two of the 18 CIPI dimensions (problems with sex and nonmarried relationships) and the KPS ("inputs") correlated significantly with the "psychological mediator," SCL-90-R, GSI. The KPS (input) did not correlate significantly with the "psychological mediators," SCL-90-R, PST, interpersonal sensitivity, anxiety, and paranoid ideation (see Table 7 and Appendix F, Tables F3, F5, and F8). All but one of the dimensions of the CIPI (nonmarried relationships) correlated significantly with the "psychological mediator," SCL-90-R, PST. Mean scores of problems with nonmarried relationships did not correlate significantly with the QOLS or any of the "psychological mediators" except interpersonal sensitivity (see Table F3, Appendix F).

CHAPTER IV

Discussion

This study used standardized instruments to quantitatively describe the quality of life and physical, psychological, and social experience of 48 liver transplant recipients who were from 2 to 64 months post-transplant. On the basis of the transplant recipients' reports of daily living, cognitive function, psychological function, global performance status, and perceived quality of life, this population reports they are generally doing well.

Liver transplant recipients in other studies (Foley et al., 1989; Hicks et al., 1992; & Wolcott et al., 1989) also report they are doing generally well. Hicks et al.(1992) and Wolcott et al. (1989) however, report that liver transplant recipients score lower on functional impairment instruments than renal transplant recipients and House et al. reports psychologic impairment in all post-liver transplant recipients. Compared to three different groups of chronic pain patients (Kames et al., 1984), this group of liver transplant recipients reported less severe problems in 16 dimensions of the CIPI (all except financial problems and nonmarried relationships). Comparison

with respiratory patients (Kames et al., 1984), indicates these liver transplant recipients reported they are having as many or fewer problems in 9 dimensions of the CIPI, but they reported more problems on the other 9 dimensions (eating, finances, employment, cognitive ability, physical appearance, inactivity, assertion, medical interaction, and nonmarried relationships).

On the CIPI the nonmarried liver transplant recipients describe more problems with relationships (meeting, having a close relationship with a member of the opposite sex) than pain respiratory and obese patients (Kames et al., 1984). Still, no significant correlation was observed in this study between the quality of life of those who were married and those who were not.

House et al. (1983) reported persistent organic brain syndromes after transplant. Similarly, Tarter et al. (1984, 1988) reported cognitive problems with coordination, concentration and memory. These same functions were not measured in this study, but the numbers with low cognitive skills as measured by verbal (IQ) and abstract reasoning (AQ) skills were few (IQ < 90, n = 1; AQ < 90, n = 5). In addition, quality of

life was not related to the educational background of the transplant recipient.

The mean score on the Karnofsky Performance Status (84) was within the range of normal functioning, with 79% scoring between 80 and 100, 17% between 50 and 70, and 4% less than 50. Mean score of 84 for the liver transplant recipients contrasts favorably with those reported by Grieco and Long (1984) for patients with stroke ($\bar{M} = 39.5$), dialysis ($\bar{M} = 51$), pain ($\bar{M} = 62$), and psychiatric outpatient ($\bar{M} = 75$).

Comparisons with normal and psychiatric outpatient populations can be made based on the mean scores of the SCL-90-R (Zachary, 1986). Male and female responses using this instrument are reported separately. Both men and women liver transplant recipients reported more psychological distress than a normal population in all dimensions except paranoid ideation (male liver transplant recipients reported less distress than a normal population). However, in comparison to outpatient psychiatric populations, both male and female liver transplant recipients reported less distress in all dimensions, except somatic concerns for which both men and women had slightly higher scores. Although Kuchler et al. (1991) reported

women experience less depression and better quality of life than men, this research did not support those findings. T-Scores for both men and women in this sample of liver transplant recipients is 61 and 60 respectively. There were also no significant differences in the quality of life scores of the men and women in the sample.

The Quality of Life Scale developed by Burckhardt (1985) employed to measure quality of life in this study included one additional item, independence, being able to do for one self. Other populations, those with chronic illness, were studied using the 15-item scale. Even so, comparisons indicate that liver transplant recipients are within the range of the scores of those other populations (ostomy group, $\bar{M} = 82.3$ on the 15 item QOLS; diabetes group, $\bar{M} = 74.1$ on the 15 item QOLS; the liver transplant recipients, $\bar{M} = 81$ on the 16 item QOLS).

Unlike the findings of Wolcott et al. (1989), quality of life was not affected by the age of the transplant recipients. However, the age range in this study was truncated at the upper limit by the selection process for liver transplantation at most transplant centers and was truncated at the lower limit by the

selection process for this research. It is possible that if older and younger transplant recipients were included in this study differences in quality of life might be found in relation to age.

Additionally, the relationships between the elements of the measures were explored. Correlational analysis indicated that psychological distress and global performance were very closely related to quality of life. Of the 18 dimensions of the CIPI, 16 were significantly related to the global measure of psychological function (problems with sex and nonmarried relationships were not significantly related). However, problems with sex were significantly related to quality of life. Health care providers could expect to find a negative impact on quality of life if problems in these areas were reported. Problems with non-married relationships, verbal and abstract reasoning, and the demographic "inputs" were not related to either psychological function or quality of life.

CHAPTER V
SUMMARY, LIMITATIONS, RECOMMENDATIONS FOR
FUTURE RESEARCH, AND
IMPLICATIONS FOR CLINICAL PRACTICE

Summary

As the number of liver transplant survivors increases and the availability of liver transplantation makes it a widespread intervention for the treatment of liver disease, the quality of life of liver transplant recipients becomes increasingly important. This study describes the experience of 48 orthotopic liver transplant recipients (30 men and 18 women, age 22-64) after transplantation. This study answers questions related to the quality of their lives and explores the nature of quality of life through correlational analysis of the elements of several instruments. The measures were clustered based on a conceptual framework previously employed to test the relationships among multiple variables and the measure of quality of life used in this study. All of the instruments used in this study were standardized and scores were based on the transplant recipient's own report of his/her experience.

Quality of life within this population of liver

transplant recipients did not systematically vary in relationship to gender, marital status, age, education or time since transplant. Quality of life is related to physical, psychological, social, and global performance measures. Although some liver transplant recipients report severe problems, more frequently they report that they have few physical, psychological, social, and global performance problems. Their self-reported quality of life was higher than reports from other chronic illness groups.

Questions still linger regarding the true nature of quality of life for this population. Alternative reasons for reporting high quality of life might include: a sense of renewed hope; a personal investment in a positive outcome possibly combined with shifting values to ensure a positive outcome; improvement when compared to life prior to transplant. Positive ratings of quality of life and alternative reasons for reporting positive outcomes illustrate the need for health care practitioners to cautiously interpret the problems experienced by liver transplant recipients as they relate to quality of life. The individual's perception of his/her problems may differ from health care providers' and others' perceptions, of these

problems as they relate to perceived quality of life.

The conceptual framework provided a means of clustering the elements of the measures for systematic analysis of the interrelationships among the elements and for a more meaningful analysis of the factors related to quality of life of liver transplant recipients. Adaptive problems, as measured by the CIPI and the KPS were generally related to the "psychological mediators," as measured by the SCL-90-R and the "psychological mediators" were closely related to "quality of life," as measured by the QOLS. These findings provide preliminary data regarding the nature of quality of life for liver transplant recipients.

Limitations

Several possible limitations of this study should be recognized. The population studied was a sample of convenience, limiting generalization of the results. The relationships among the elements of the standardized measures would be better described through multiple regression path analysis, which was beyond the scope and sample size of this pilot project. Correlational analysis limits the interpretation of the results. Response bias may be inherent to the political and/or personal nature of liver transplant

recipients' responses about the quality of their lives. In spite of these limitations this study adds to the general knowledge about the post-liver transplant experience.

Recommendations for Future Research

The effect of time and the interrelationship between other life variables for transplant recipients as it relates to quality of life requires further study. A qualitative prospective research design would provide the richness to capture the experience of liver transplant recipients. Alternatively, a prospective longitudinal design using quantitative and/or qualitative measures could be employed to study this complex subject.

The role the of significant others and how they effect the liver transplant experience is unclear and requires further study. The study of how the perceptions of health care providers, family, and members of the community differ or are similar to the transplant recipients' perceptions would further our understanding of the political and personal nature of liver transplantation and clarify areas for continuing education.

Implications for Clinical Practice

The findings from this research provide some basis for clinical intervention and decision making with regard to liver transplant recipients. Because of perceived or identified patient needs and efficiency considerations, clinicians often group patients with like characteristics for therapy. This research revealed an absence of differences among groups of transplant recipients based on gender, marital status, age, educational background, or time since transplant. Consequently, it may not be necessary, or even beneficial to provide separate clinical interventions based solely on these characteristics.

The liver transplant recipients in this study generally reported that they are psychologically, socially, physically and globally doing well. Conversely, some transplant recipients also reported severe problems and every problem was experienced by one or more transplant recipient. Health care practitioners and researchers should verify and cautiously interpret how problems after transplantation affect quality of life.

Other researchers have reported altered cognitive abilities related to concentration, memory, and

References

- Andrews, F.M. (Ed.) (1986). Research on the quality of life. Ann Arbor MI: University of Michigan.
- Barrett, D.H., Wisotzek, I.E., Abel, G.G., Rouleau, J.L., Platt, A.F. Jr., Pollard, W.E. & Eckman, J.R. (1988). Assessment of psychosocial functioning of patients with sickle cell disease. Southern Medical Journal, 81(6), 745-750.
- Burckhardt, C.S. (1985). The impact of arthritis on quality of life. Nursing Research, 34(1), 11-16.
- Burckhardt, C.S. (1988). Quality of life for women with arthritis. Health Care for Women International, 9, 229-238.
- Burckhardt, C.S., Woods, S.L., Schultz, A.A. & Ziebarth, D.M. (1989). Quality of life of adults with chronic illness: a psychometric study. Research in Nursing and Health, 12, 347-354.
- Calne, R.Y. (1978). Hepatic transplant. Surgical Clinics of North America, 58(2), 321-333.
- Campbell, A., Converse, P.E., & Rodgers, W.L. (1976). The quality of American life. New York: Russell Sage Foundation.

- Derogatis, L.R. (1983). SCL-90-R administration, scoring & procedures manual-II, for the revised version and the other instruments of the psychopathology rating scale series. Maryland: Clinical Psychometric Research, Inc.
- Flanagan, J.C. (1978). A research approach to improving our quality of life. American Psychologist, 33, 138-147.
- Flanagan, J.C. (1982). Measurement of the quality of life: current state of the art. Archives of Physical Medicine and Rehabilitation, 63, 56-59.
- Foley, T.C., Davis, C.P. & Conway, P.A. (1989). Liver transplant recipients Self-report of symptom frequency, symptom distress, quality of life. Transplantation Proceedings, 21(1), 2417-2418.
- Fox, R. & Swazey, J. (1978). The courage to fail (2nd ed.). Chicago: University Press.
- Grieco, A. & Long, C.J. (1984). Investigation of the Karnofsky Performance Status as a measure of quality of life. Health Psychology, 3(2), 129-142.
- Harrop-Griffiths, J., Katon, W., Dobie, R., Sakai, C., & Russo, J. (1987). Chronic tinnitus: association

- with psychiatric diagnoses. Journal of Psychosomatic Research, 31(5), 613-621.
- Hicks, F.D., Larson, J.L., & Ferrans, C.E. (1992).
Quality of life after liver transplant. Research in Nursing and Health, 15, 111-119.
- House, R., Dubovsky, S., & Penn, I. (1983).
Psychiatric aspects of hepatic transplantation. Transplantation, 36(2), 146-150.
- Iwatsuki, S., Shaw, Jr., B.W. & Starzl, T.E. (1985).
Five year survival after liver transplantation. Transplantation Proceedings, 17(1), 259-263.
- Kames, L.D., Naliboff, B.D., Heinrich, R.L., Schag, C.C. (1984). The chronic illness problem inventory: problem-oriented psychosocial assessment of patients with chronic illness. International Journal of Psychiatry in Medicine, 14(1), 66-75.
- Karnofsky, D.A. & Burchenal, J.H. (1948). The clinical evaluation of chemotherapeutic agents in cancer. In C.M. McLeod (Ed.), Evaluation of chemotherapeutic agents (pp. 191-205). New York: Columbia Press.
- Kuchler, T., Kober, B., Brotsch, D., Henne-Bruns, D. & Kremer, B. (1991). Quality of life after liver

- transplantation: Can a psychosocial support program contribute? Transplantation Proceedings, 23(1), 1541-1544.
- Mason, M.F. & Ganzler, H. (1964). Adult norms of the Shipley Institute of Living Scale and Hooper Visual Organization Test based on age and education. Journal of Gerontology, 19, 419-424.
- Pennington, J.C. (1989). Quality of life following liver transplantation. Transplantation Proceedings, 21(3), 3514-3516.
- Schmid, R. (1983). National Institutes of Health statement: liver transplants. Hepatology, supplement, 109-110.
- Starzl, T.E., Demetris, A.J. & Van Thiel, D. (1989). Liver transplantation (first of two parts. The New England Journal of Medicine, 321(15), 1014-1022.
- Starzl, T.E., Marchioro, T.L., Von Kaulla, K.N., Hermann G., Brittain, R.S. & Waddell, W.R. (1963) Homotransplantation of the liver in humans. Surgery, Gynecology and Obstetrics, 117(6), 659-676.
- Sullivan, M.D., Katon, W., Dobie, R., Sakai, C., Russo, J. & Harrop-Griffiths, J. (1988). Disabling

- tinnitus. Association with affective disorder. General Hospital Psychiatry, 10(4), 285-291.
- Tarter, R.E., Erb, S., Biller, P.A., Switala, J. & Van Thiel, D.H. (1988). The quality of life following liver transplantation: A preliminary report. Gastroenterology Clinics of North America, 17(1), 207-217.
- Tarter, R.E., Switala, J., Arria, A., Plail, J., & Van Thiel, D. (1991). Quality of life before and after orthotopic hepatic transplantation. Archives of Internal Medicine, 151, 1521-1526.
- Tarter, R.E., Van Thiel, D.H., Hegedus, A.M., Schade, R.R., Gavalier, J.S. & Starzl, T.E. (1984). Neuropsychiatric status after liver transplantation. Journal of Laboratory and Clinical Medicine, 103(5), 776-782.
- Task Force for Organ Transplantation (1986). Organ transplantation: Issues and recommendations. Maryland: U.S. Department of Health and Human Resources.
- Unos releases 1990 transplantation statistics. (1991. April 22). UNOS News Release. ✓
- Wolcott, D., Norquist, G. & Busuttill, R. (1989). Cognitive function and quality of life in adult

liver transplant recipients. Transplantation
Proceedings, 21(3), 3563.

Zachary, R.A. (1986). Shipley Institute of Living
Scale, revised manual. California: Western
Psychological Services.

Appendix A
Chronic Illness Inventory
and
Summary Sheet
(Kames et al., 1984)

PROBLEM INVENTORY

NAME: _____ DATE: _____
SEX: _____ BIRTHDATE: _____

INSTRUCTIONS

The following questionnaire is a list of statements that describe the situations and experiences of individuals who have a chronic illness.

Read each statement using the numbered descriptions at the top of the page, decide HOW MUCH EACH STATEMENT APPLIES TO YOU. Enter the number associated with the description in the box next to the statement. Do not skip questions.

When you are deciding whether a statement applies to you, THINK OVER THE PAST SEVERAL MONTHS. If the statement is true of your experience, then select the description: "a little," "a fair amount," "much," or "very much," and enter the number representing the statement in the box. If the statement is not true and has not applied to you in the past several months, enter "0" representing "not at all." See the examples below.

Examples:

HOW MUCH DOES IT APPLY TO YOU:

- 0 = NOT AT ALL
- 1 = A LITTLE
- 2 = A FAIR AMOUNT
- 3 = MUCH
- 4 = VERY MUCH

I have difficulty driving (2)

I have difficulty talking to
my children about my illness (4)

We are interested in knowing all about your experience, so do not hesitate to endorse a statement even though it only applies to you a little.

Thank you.

Please indicate HOW MUCH EACH STATEMENT APPLIES TO YOU by entering the appropriate number in the box to the right of each statement. Select the number that best describes your experience during the PAST SEVERAL MONTHS.

HOW MUCH DOES IT APPLY TO YOU

0 = NOT AT ALL

1 = A LITTLE

2 = A FAIR AMOUNT

3 = MUCH

4 = VERY MUCH

HOW MUCH DOES IT APPLY TO YOU

0 = NOT AT ALL

1 = A LITTLE

2 = A FAIR AMOUNT

3 = MUCH

4 = VERY MUCH

- | | |
|--|---|
| 1. I have difficulty falling asleep () | 11. I need to use too many medications () |
| 2. I have difficulty staying asleep () | 12. I am afraid I may become or already am dependent on medications () |
| 3. My appetite is poor () | 13. I have difficulty concentrating () |
| 4. I have difficulty maintaining proper weight () | 14. I have difficulty remembering () |
| 5. I am unable to pay my bills () | 15. I have difficulty thinking clearly () |
| 6. I have some financial worries () | 16. I am uncomfortable with how I look () |
| 7. I am not able to work () | 17. I feel I am looked down upon because I look physically disabled () |
| 8. I lose too much work time because of my health () | 18. I do not feel attractive () |
| 9. I have difficulty finding a new job () | 19. I feel my body is generally deteriorating () |
| 10. I am not able to perform all of my duties at work because of my health () | 20. I fear I will never be healthy again () |

HOW MUCH DOES IT APPLY TO YOU

- 0 = NOT AT ALL
- 1 = A LITTLE
- 2 = A FAIR AMOUNT
- 3 = MUCH
- 4 = VERY MUCH

HOW MUCH DOES IT APPLY TO YOU

- 0 = NOT AT ALL
- 1 = A LITTLE
- 2 = A FAIR AMOUNT
- 3 = MUCH
- 4 = VERY MUCH

- | | |
|---|--|
| <p>21. I do not have confidence my body will work right when I need it to ()</p> | <p>31. I have difficulty with transportation ()</p> |
| <p>22. I worry about not being able to care for myself ()</p> | <p>32. It is hard for me to get out of the house very much ()</p> |
| <p>23. I have no other problems beside my medical problem ()</p> | <p>33. My problem is more serious than others with a similar illness ()</p> |
| <p>24. I do not have much interest in sex ()</p> | <p>34. I have difficulty figuring out what to do each day ()</p> |
| <p>25. My physical problem makes sex difficult and/or uncomfortable ()</p> | <p>35. I do not have enough activities to occupy my time ()</p> |
| <p>26. I do not often engage in sex ()</p> | <p>36. I am sitting or lying down most of the day ()</p> |
| <p>27. My partner and I do not often embrace, kiss or touch ()</p> | <p>37. I have difficulty enjoying time with relatives and/or friends ()</p> |
| <p>28. I have difficulty bending, lifting or carrying ()</p> | <p>38. I have problems in planning social activities because I do not know how I will feel ()</p> |
| <p>29. I have difficulty walking and/or moving around ()</p> | <p>39. I have difficulty going out to dinner, movies and other activities ()</p> |
| <p>30. I have difficulty doing household chores ()</p> | <p>40. Family or friends do not come over to visit often ()</p> |

HOW MUCH DOES IT APPLY TO YOU

0 = NOT AT ALL

1 = A LITTLE

2 = A FAIR AMOUNT

3 = MUCH

4 = VERY MUCH

HOW MUCH DOES IT APPLY TO YOU

0 = NOT AT ALL

1 = A LITTLE

2 = A FAIR AMOUNT

3 = MUCH

4 = VERY MUCH

- | | |
|--|--|
| <p>41. I do not get along well with my family ()</p> <p>42. I do not have many close friends ()</p> <p>43. It has been difficult to maintain old friendships ()</p> <p>44. I find it difficult to meet new friends ()</p> <p>45. It is difficult for me to ask family or friends for help when I need it ()</p> <p>46. It is difficult for me to tell others when I am upset ()</p> <p>47. It is difficult for me to tell others when I cannot do something ()</p> <p>48. No one believes my problem is real ()</p> <p>49. I have difficulty getting information from my doctor about my illness ()</p> <p>50. I have difficulty telling doctors when I am dissatisfied ()</p> | <p>51. I have had to see many doctors and try a lot of different treatments for my problem ()</p> <p>52. I feel doctors have not taken my problem seriously ()</p> <p>53. I have never received the proper treatment for my problem ()</p> <p>54. No treatment has ever helped my problem ()</p> <p>The next eight questions (55-62) apply to individuals who are MARRIED or IN A SERIOUS RELATIONSHIP</p> <p>If you are not married and/or do not have a steady ongoing relationship, please skip to question #63 and answer the remaining questions.</p> <p>55. My partner and I have difficulty talking about important matters ()</p> <p>56. My partner and I have difficulty talking about feelings ()</p> <p>57. My partner and I have so much time together that we get on each others nerves ()</p> |
|--|--|

HOW MUCH DOES IT APPLY TO YOU

- 0 = NOT AT ALL
1 = A LITTLE
2 = A FAIR AMOUNT
3 = MUCH
4 = VERY MUCH

HOW MUCH DOES IT APPLY TO YOU

- 0 = NOT AT ALL
1 = A LITTLE
2 = A FAIR AMOUNT
3 = MUCH
4 = VERY MUCH
-

58. My partner and I are not getting along as well as we used to ()
59. My partner expects me to do more than I am capable of ()_____
60. My partner won't let me do activities that I am capable of doing ()
61. My partner spends too much time taking care of me ()
62. My partner worries about me too much ()_____

The remaining questions are for individuals who are NOT MARRIED or ARE NOT INVOLVED IN A STEADY ONGOING RELATIONSHIP

63. I have difficulty meeting opposite sex companions ()
64. I have difficulty developing a close relationship with a person of the opposite sex ()
65. I am afraid to initiate a sexual relationship with someone ()_____

You are finished. Thank you.

CHRONIC ILLNESS PROBLEM INVENTORY

Summary Sheet:

E _____ Date: _____
 _____ Birthdate: _____

SCALE	SUM	MEAN	PROBLEM SEVERITY				
			0	1	2	3	4
SLEEP	___/2=___						
EATING	___/2=___						
FINANCES	___/2=___						
EMPLOYMENT	___/4=___						
MEDICATIONS	___/2=___						
COGNITIVE	___/3=___						
PHYSICAL APPEARANCE	___/3=___						
BODY DETERIORATION	___/4=___						
SEX	___/4=___						
ACTIVITIES OF DAILY LIVING	___/5=___						
INACTIVITY	___/3=___						
SOCIAL ACTIVITY	___/3=___						
FAMILY/FRIENDS CONTACT	___/5=___						
ASSERTION	___/3=___						
MEDICAL INTERACTION	___/5=___						
MARITAL DIFFICULTY	___/5=___						
MARITAL OVERPROTECTION	___/3=___						
NONMARRIED RELATIONSHIPS	___/3=___						
ILLNESS FOCUS	___/4=___						

Appendix B
Shipley Institute of Living Scale
and
Scoring Tables
(Zachary, 1986)

SHIPLEY INSTITUTE OF LIVING SCALE

Administration Form
Walter C. Shipley, Ph.D.

Published by



Name: _____ Sex: M F Age: _____
Education: _____ Usual Occupation: _____ Today's Date: _____

Part I

Instructions: In the test below, the first word in each line is printed in capital letters. Opposite it are four other words. Circle the one word which means the same thing, or most nearly the same thing, as the first word. If you don't know, guess. Be sure to circle the one word in each line that means the same thing as the first word.

EXAMPLE:

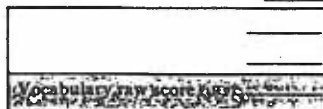
LARGE red big silent wet

- | | | | | |
|-----------------|-------------|------------|------------|-------------|
| (1) TALK | draw | eat | speak | sleep |
| (2) PERMIT | allow | sew | cut | drive |
| (3) PARDON | forgive | pound | divide | tell |
| (4) COUCH | pin | eraser | sofa | glass |
| (5) REMEMBER | swim | recall | number | defy |
| (6) TUMBLE | drink | dress | fall | think |
| (7) HIDEOUS | silvery | tilted | young | dreadful |
| (8) CORDIAL | swift | muddy | leafy | hearty |
| (9) EVIDENT | green | obvious | skeptical | afraid |
| (10) IMPOSTOR | conductor | officer | book | pretender |
| (11) MERIT | deserve | distrust | fight | separate |
| (12) FASCINATE | welcome | fix | stir | enchant |
| (13) INDICATE | defy | excite | signify | bicker |
| (14) IGNORANT | red | sharp | uninformed | precise |
| (15) FORTIFY | submerge | strengthen | vent | deaden |
| (16) RENOWN | length | head | fame | loyalty |
| (17) NARRATE | yield | buy | associate | tell |
| (18) MASSIVE | bright | large | speedy | low |
| (19) HILARITY | laughter | speed | grace | malice |
| (20) SMIRCHED | stolen | pointed | remade | soiled |
| (21) SQUANDER | tease | belittle | cut | waste |
| (22) CAPTION | drum | ballast | heading | ape |
| (23) FACILITATE | help | turn | strip | bewilder |
| (24) JOCOSE | humorous | paltry | fervid | plain |
| (25) APPRISE | reduce | strew | inform | delight |
| (26) RUE | senator | lament | dominate | cure |
| (27) DENIZEN | dispossess | inhabitant | fish | atom |
| (28) DIVEST | charm | intrude | rally | pledge |
| (29) AMULET | untidy | orphan | dingo | pond |
| (30) INEXORABLE | dried | involatile | rigid | sparse |
| (31) SERRATED | moldy | notched | armed | blunt |
| (32) LISSOM | mitigate | loose | supple | convex |
| (33) MOLLIFY | appropriate | direct | pertain | abuse |
| (34) PLAGIARIZE | brush | intend | revoke | maintain |
| (35) ORIFICE | maniacal | hole | building | lute |
| (36) QUERULOUS | outcast | curious | devout | complaining |
| (37) PARIAH | waken | priest | lentil | locker |
| (38) ABET | rashness | ensue | incite | placate |
| (39) TEMERITY | vain | timidity | desire | kindness |
| (40) PRISTINE | | sound | first | level |

DO NOT WRITE IN THIS AREA

Turn over this sheet and continue with Part II when instructed to do so.

Copyright © 1939 by The Institute of Living, The Neuro-Psychiatric Institute of the Hartford Retreat.
Copyright © renewed 1967 by Barbara Shipley Bayle.
Not to be reproduced in whole or in part without written permission of Western Psychological Services.
All rights reserved. 1456789 Printed in U.S.A.



Part II

Instructions: Complete the following by filling in either a number or a letter for each dash (____). Do the items in order, but don't spend too much time on any one item.
EXAMPLE: A B C D E

- (1) 1 2 3 4 5 ____
- (2) white black short long down ____
- (3) AB BC CD D ____
- (4) Z Y X W V U ____
- (5) 12321 23432 34543 456 ____
- (6) NE/SW SE/NW E/W N/ ____
- (7) escape scape cape ____
- (8) oh ho rat tar mood ____
- (9) A Z B Y C X D ____
- (10) tot tot bard drab 537 ____
- (11) mist is wasp as pint in tone ____
- (12) 57326 73265 32657 26573 ____
- (13) knit in spud up both to stay ____
- (14) Scotland landscape scapegoat ____ cc
- (15) surgeon 1234567 snore 17635 rogue ____
- (16) tam tan rib rid rat raw hip ____
- (17) tar pitch throw saloon bar rod fee tip end plank ____ meals
- (18) 3124 82 73 154 46 13 ____
- (19) lag leg pen pin big bog rob ____
- (20) two w four r one o three ____



Summary Scores
V: Raw ____ T ____ A: Raw ____ T ____ Total: Raw ____ T ____
CQ: ____ AQ: ____ Est. IQ: ____



Table B
Conceptual Quotient Conversions

Vocabulary Raw Score	Abstraction Raw Score																				
	40	38	36	34	32	30	28	26	24	22	20	18	16	14	12	10	8	6	4	2	0
32	115	111	106	102	97	93	88	84	80	76	73	70	68	65	62	59	56	53	50	47	44
31	117	115	108	103	99	94	90	85	81	78	74	72	69	66	63	60	57	54	51	48	45
30	120	116	111	106	102	97	92	88	84	80	77	74	71	68	65	62	58	55	52	49	46
29	124	118	113	108	104	99	94	89	85	81	78	75	72	69	66	63	59	56	53	50	47
28	125	120	115	110	105	100	96	91	87	83	79	76	73	70	67	64	60	57	54	51	48
27	128	123	118	113	108	103	98	93	89	85	81	78	75	72	69	66	62	59	56	52	49
26	130	125	120	115	110	105	100	95	91	87	83	80	76	73	70	67	63	60	57	53	50
25	133	128	123	118	112	107	102	97	92	88	84	81	78	75	72	68	64	61	58	55	51
24	137	131	126	121	115	110	105	99	95	91	87	83	80	77	73	70	66	63	59	56	52
23	141	135	130	125	119	114	108	103	98	94	90	86	83	79	76	72	68	65	61	58	54
22	145	140	135	129	124	118	112	106	101	97	93	89	86	82	79	75	71	67	64	60	56
21	151	145	139	133	127	121	115	110	104	100	96	92	88	85	81	77	73	69	66	62	57
20	154	148	142	136	130	124	118	112	107	101	98	94	90	87	83	79	74	71	67	63	59
19	158	151	145	139	133	127	121	115	109	105	100	96	92	89	85	81	76	72	69	65	60
18	164	158	151	145	138	132	126	119	113	109	104	100	96	92	88	84	79	75	71	67	62
17	171	164	158	151	144	137	131	124	118	113	108	104	100	96	92	87	82	78	74	70	65
16	178	171	164	157	150	143	137	130	123	118	113	109	104	100	96	91	86	82	77	73	68

Note. Quotients obtained from Vocabulary scores below 23 are of doubtful validity. CQs based on vocabulary scores below 16 are not provided.

Table C-1
 Predicted Abstraction Scores Based on Age,
 Education, and Vocabulary Raw Scores

Vocabulary Raw Score	Educational Level									
	8	9	10	11	12	13	14	15	16	17
Ages 25-29										
16	9	10	10	11	12	13	14	14		
17	10	11	11	12	13	13	14	15		
18	11	12	13	13	14	14	15	16		
19	12	13	14	14	15	16	16	17		
20	13	14	15	15	16	17	17	18		
21	14	15	16	16	17	18	18	19	20	
22	16	16	17	17	18	19	19	20	21	
23	17	17	18	19	19	20	20	21	22	
24	18	18	19	20	20	21	22	22	23	
25	19	19	20	21	21	22	23	23	24	
26	20	20	21	22	22	23	24	24	25	
27	21	22	22	23	24	24	25	25	26	
28	22	23	23	24	25	25	26	27	27	
29	23	24	24	25	26	26	27	28	28	
30	24	25	25	26	27	27	28	29	29	
31	25	26	26	27	28	28	29	30	30	
32	26	27	28	28	29	30	30	31	31	
33	27	28	29	29	30	31	31	32	33	
34	28	29	30	30	31	32	32	33	34	
35	29	30	31	31	32	33	33	34	35	
36	31	31	32	33	33	34	34	35	36	
37	32	32	33	34	34	35	36	36	37	
38	33	33	34	35	35	36	37	37	38	
39	34	34	35	36	36	37	38	38	39	
40	35	36	36	37	37	38	39	39	40	
Ages 30-34										
16	8	8	9	10	10	11	12	12	13	
17	9	9	10	11	11	12	13	13	14	
18	10	11	11	12	13	13	14	14	15	
19	11	12	12	13	14	14	15	16	16	
20	12	13	13	14	15	15	16	17	17	
21	13	14	14	15	16	16	17	18	18	
22	14	15	16	16	17	17	18	19	19	
23	15	16	17	17	18	19	19	20	20	
24	16	17	18	18	19	20	20	21	22	
25	17	18	19	19	20	21	21	22	23	
26	19	19	20	20	21	22	22	23	24	
27	20	20	21	22	22	23	23	24	25	

Table C-1 (Continued)
 Predicted Abstraction Scores Based on Age,
 Education, and Vocabulary Raw Scores

Vocabulary Raw Score	Educational Level									
	8	9	10	11	12	13	14	15	16	17
28	21	21	22	23	23	24	25	25	26	
29	22	22	23	24	24	25	26	26	27	
30	23	23	24	25	25	26	27	27	28	
31	24	25	25	26	26	27	28	28	29	
32	25	26	26	27	28	28	29	30	30	
33	26	27	27	28	29	29	30	31	31	
34	27	28	28	29	30	30	31	32	32	
35	28	29	30	30	31	31	32	33	33	
36	29	30	31	31	32	33	33	34	34	
37	30	31	32	32	33	34	34	35	36	
38	31	32	33	33	34	35	35	36	37	
39	32	33	34	34	35	36	36	37	38	
40	33	34	35	35	36	37	37	38	39	
Ages 35-39										
16	6	7	8	8	9	10	10	11	12	
17	7	8	9	9	10	11	11	12	13	
18	8	9	10	10	11	12	13	13	14	
19	9	10	11	12	12	13	14	14	15	
20	10	11	12	13	13	14	15	15	16	
21	12	13	13	14	14	15	16	16	17	
22	13	14	14	15	16	16	17	17	18	
23	14	15	15	16	17	17	18	19	19	
24	15	16	16	17	18	18	19	20	20	
25	16	17	17	18	19	19	20	21	21	
26	17	18	19	19	20	20	21	22	22	
27	18	19	20	20	21	22	22	23	23	
28	19	20	21	21	22	23	23	24	25	
29	20	21	22	22	23	24	24	25	26	
30	22	22	23	23	24	25	25	26	27	
31	23	23	24	25	25	26	27	27	28	
32	24	24	25	26	26	27	28	28	29	
33	25	25	26	27	27	28	29	29	30	
34	26	26	27	28	28	29	30	30	31	
35	27	28	28	29	30	30	31	31	32	
36	28	29	29	30	31	31	32	33	33	
37	29	30	30	31	32	32	33	34	34	
38	30	31	31	32	33	33	34	35	35	
39	31	32	33	33	34	34	35	36	36	
40	32	33	34	34	35	36	36	37	37	

Table C-I (Continued)
Predicted Abstraction Scores Based on Age,
Education, and Vocabulary Raw Scores

Table with 2 columns: Vocabulary Raw Score (8-16) and Educational Level (8-16). Sub-section: Ages 40-44. Rows 16-25 and 26-35.

Table with 2 columns: Vocabulary Raw Score (8-16) and Educational Level (8-16). Sub-section: Ages 45-49. Rows 16-25 and 26-36.

Table C-I (Continued)
Predicted Abstraction Scores Based on Age,
Education, and Vocabulary Raw Scores

Table with 2 columns: Vocabulary Raw Score (8-16) and Educational Level (8-16). Sub-section: Ages 50-54. Rows 16-25 and 26-35.

Table with 2 columns: Vocabulary Raw Score (8-16) and Educational Level (8-16). Sub-section: Ages 55-59. Rows 16-25 and 26-31.

table continued on next page...

Table C-1 (Continued)
Predicted Abstraction Scores Based on Age,
Education, and Vocabulary Raw Scores

Vocabulary Raw Score	Educational Level									
	8	9	10	11	12	13	14	15	16	
32	19	19	20	20	21	22	22	23	24	
33	20	20	21	22	22	23	23	24	25	
34	21	21	22	23	23	24	25	25	26	
35	22	22	23	24	24	25	26	26	27	
36	23	23	24	25	25	26	27	27	28	
37	24	25	25	26	27	27	28	28	29	
38	25	26	26	27	28	28	29	30	30	
39	26	27	27	28	29	29	30	31	31	
40	27	28	28	29	30	30	31	32	32	

Ages 60-64

16	0	1	1	2	3	4	5	5	6
17	0	0	1	2	3	4	5	6	6
18	1	2	2	3	4	5	6	7	7
19	1	2	3	4	5	6	7	8	8
20	4	5	6	6	7	8	9	9	10
21	5	6	7	7	8	9	9	10	11
22	6	7	8	8	9	10	10	11	12
23	8	8	9	10	10	11	11	12	13
24	9	9	10	11	11	12	13	13	14
25	10	10	11	12	12	13	14	14	15
26	11	11	12	13	13	14	15	15	16
27	12	13	13	14	14	15	16	16	17
28	13	14	14	15	15	16	17	17	18
29	14	15	15	16	16	17	18	18	19
30	15	16	16	17	17	18	19	19	20
31	16	17	17	18	18	19	20	20	21
32	17	18	18	19	19	20	21	21	22
33	18	19	20	20	21	22	22	23	23
34	19	20	21	21	22	23	23	24	25
35	20	21	22	22	23	24	24	25	26

Table C-1 (Continued)
Predicted Abstraction Scores Based on Age,
Education, and Vocabulary Raw Scores

Vocabulary Raw Score	Educational Level									
	8	9	10	11	12	13	14	15	16	
36	22	22	23	23	24	25	25	26	27	
37	23	23	24	25	25	26	27	27	28	
38	24	24	25	26	26	27	28	28	29	
39	25	25	26	27	27	28	29	29	30	
40	26	26	27	28	28	29	30	30	31	

Ages 65-69

16	0	0	0	1	1	2	3	3	4
17	0	0	1	2	2	3	4	4	5
18	1	2	2	3	3	4	5	5	6
19	2	3	3	4	4	5	6	6	7
20	3	4	4	5	5	6	7	7	8
21	4	5	5	6	7	7	8	9	9
22	5	6	6	7	8	8	9	10	10
23	6	7	8	8	9	10	10	11	11
24	7	8	9	9	10	11	11	12	13
25	8	9	10	10	11	12	12	13	14
26	9	10	11	11	12	13	13	14	15
27	11	11	12	13	13	14	14	15	16
28	12	13	13	14	14	15	15	16	17
29	13	13	14	15	15	16	16	17	18
30	14	14	15	16	16	17	17	18	19
31	15	16	16	17	17	18	18	19	20
32	16	17	17	18	18	19	19	20	21
33	17	18	18	19	20	20	21	22	22
34	18	19	19	20	21	21	22	23	23
35	19	20	20	21	22	22	23	24	24
36	20	21	22	22	23	23	24	25	25
37	21	22	23	23	24	25	25	26	27
38	22	23	24	24	25	26	26	27	28
39	23	24	25	25	26	27	27	28	29
40	25	25	26	27	27	28	28	29	30

Table C-2
Abstraction Quotient Conversions

Predicted Abstraction Score	Observed Abstraction Score										
	0	2	4	6	8	10	12	14	16	18	20
0	100	104	107	111	115	118	122	126	129	133	137
1	98	102	106	109	113	117	120	124	128	131	135
2	96	100	104	107	111	115	118	122	126	129	133
3	94	98	102	106	109	113	117	120	124	128	131
4	93	96	100	104	107	111	115	118	122	126	129
5	91	94	98	102	106	109	113	117	120	124	128
6	89	93	96	100	104	107	111	115	118	122	126
7	87	91	94	98	102	106	109	113	117	120	124
8	85	89	93	96	100	104	107	111	115	118	122
9	83	87	91	94	98	102	106	109	113	117	120
10	82	85	89	93	96	100	104	107	111	115	118
11	80	83	87	91	94	98	102	106	109	113	117
12	78	82	85	89	93	96	100	104	107	111	115
13	76	80	83	87	91	94	98	102	106	109	113
14	74	78	82	85	89	93	96	100	104	107	111
15	72	76	80	83	87	91	94	98	102	106	109
16	71	74	78	82	85	89	93	96	100	104	107
17	69	72	76	80	83	87	91	94	98	102	106
18	67	71	74	78	82	85	89	93	96	100	104
19	65	69	72	76	80	83	87	91	94	98	102
20	63	67	71	74	78	82	85	89	93	96	100
21	61	65	69	72	76	80	83	87	91	94	98
22	59	63	67	71	74	78	82	85	89	93	96
23	58	61	65	69	72	76	80	83	87	91	94
24	56	59	63	67	71	74	78	82	85	89	93
25	54	58	61	65	69	72	76	80	83	87	91
26	52	56	59	63	67	71	74	78	82	85	89
27	50	54	58	61	65	69	72	76	80	83	87
28	48	52	56	59	63	67	71	74	78	82	85
29	47	50	54	58	61	65	69	72	76	80	83
30	45	48	52	56	59	63	67	71	74	78	82
31	43	47	50	54	58	61	65	69	72	76	80
32	41	45	48	52	56	59	63	67	71	74	78
33	39	43	47	50	54	58	61	65	69	72	76
34	37	41	45	48	52	56	59	63	67	71	74
35	35	39	43	47	50	54	58	61	65	69	72
36	34	37	41	45	48	52	56	59	63	67	71
37	32	35	39	43	47	50	54	58	61	65	69
38	30	34	37	41	45	48	52	56	59	63	67
39	28	32	35	39	43	47	50	54	58	61	65
40	26	30	34	37	41	45	48	52	56	59	63

table continued on next page...

Table C-2 (Continued)
Abstraction Quotient Conversions

Predicted Abstraction Score	Observed Abstraction Score									
	22	24	26	28	30	32	34	36	38	40
0	141	144	148	152	155	159	163	166	170	174
1	139	142	146	150	153	157	161	165	168	172
2	137	141	144	148	152	155	159	163	166	170
3	135	139	142	146	150	153	157	161	165	168
4	133	137	141	144	148	152	155	159	163	166
5	131	135	139	142	146	150	153	157	161	165
6	129	133	137	141	144	148	152	155	159	163
7	128	131	135	139	142	146	150	153	157	161
8	126	129	133	137	141	144	148	152	155	159
9	124	128	131	135	139	142	146	150	153	157
10	122	126	129	133	137	141	144	148	152	155
11	120	124	128	131	135	139	142	146	150	153
12	118	122	126	129	133	137	141	144	148	152
13	117	120	124	128	131	135	139	142	146	150
14	115	118	122	126	129	133	137	141	144	148
15	113	117	120	124	128	131	135	139	142	146
16	111	115	118	122	126	129	133	137	141	144
17	109	113	117	120	124	128	131	135	139	142
18	107	111	115	118	122	126	129	133	137	141
19	106	109	113	117	120	124	128	131	135	139
20	104	107	111	115	118	122	126	129	133	137
21	102	106	109	113	117	120	124	128	131	135
22	100	104	107	111	115	118	122	126	129	133
23	98	102	106	109	113	117	120	124	128	131
24	96	100	104	107	111	115	118	122	126	129
25	94	98	102	106	109	113	117	120	124	128
26	93	96	100	104	107	111	115	118	122	126
27	91	94	98	102	106	109	113	117	120	124
28	89	93	96	100	104	107	111	115	118	122
29	87	91	94	98	102	106	109	113	117	120
30	85	89	93	96	100	104	107	111	115	118
31	83	87	91	94	98	102	106	109	113	117
32	82	85	89	93	96	100	104	107	111	115
33	80	83	87	91	94	98	102	106	109	113
34	78	82	85	89	93	96	100	104	107	111
35	76	80	83	87	91	94	98	102	106	109
36	74	78	82	85	89	93	96	100	104	107
37	72	76	80	83	87	91	94	98	102	106
38	71	74	78	82	85	89	93	96	100	104
39	69	72	76	80	83	87	91	94	98	102
40	67	71	74	78	82	85	89	93	96	100

Table D-2
Estimated WAIS-R Full Scale IQ from *Shipley* Total Score Stratified by Age

Total	16-17	18-19	20-24	25-34	35-44	45-54	55-64	65-69	70-74
80	131	129	126	123	121	123	127	133	139
79	129	128	125	121	120	122	126	132	138
78	128	126	124	120	119	121	125	131	137
77	127	125	123	119	118	120	124	130	136
76	126	124	122	118	117	119	123	129	135
75	125	123	120	117	116	118	122	128	134
74	123	122	119	116	115	117	121	127	133
73	122	120	118	115	114	116	120	126	131
72	121	119	117	114	113	115	119	125	130
71	120	118	116	113	112	114	118	124	129
70	118	117	115	112	111	113	117	123	128
69	117	116	114	111	110	112	116	122	127
68	116	115	113	110	109	111	116	121	126
67	115	113	112	109	109	110	115	120	125
66	114	112	110	108	108	109	114	119	124
65	112	111	109	107	107	108	113	118	123
64	111	110	108	106	106	107	112	117	122
63	110	109	107	105	105	106	111	116	120
62	109	107	106	104	104	106	110	115	119
61	107	106	105	103	103	105	109	114	118
60	106	105	104	102	102	104	108	113	117
59	105	104	103	101	101	103	107	112	116
58	104	103	101	100	100	102	106	111	115
57	103	102	100	100	100	101	105	110	114
56	101	100	100	99	99	100	104	108	113
55	100	100	99	98	98	100	103	107	112
54	100	99	98	97	97	99	102	106	111
53	99	98	97	96	96	98	101	105	110
52	97	97	96	95	95	97	100	104	108
51	96	96	95	94	94	96	100	103	107
50	95	94	94	93	93	95	99	102	106
49	94	93	92	92	92	94	98	101	105
48	93	92	91	91	91	93	97	100	104
47	91	91	90	90	90	92	96	100	103
46	90	90	89	89	89	91	95	99	102
45	89	88	88	88	88	90	94	98	101
44	88	87	87	87	87	89	93	97	100
43	86	86	86	85	85	88	92	96	100
42	85	85	85	84	85	88	91	95	99
41	84	84	83	83	84	87	90	94	97
40	83	83	82	82	83	86	89	93	96
39	82	81	81	81	82	85	88	92	95
38	80	80	80	80	82	84	87	91	94
37	79	79	79	79	81	83	86	90	93
36	78	78	78	78	80	82	85	89	92
35	77	77	77	77	79	81	84	88	91
34	75	75	76	76	78	80	83	87	90
33	74	74	74	75	77	79	82	86	89
32	73	73	73	74	76	78	81	85	88
31	72	72	72	73	75	77	80	84	87
30	71	71	71	72	74	76	79	83	85
29	69	70	70	71	73	75	78	82	84

table continued on next page . . .

Table D-2 (Continued)
 Estimated WAIS-R Full Scale IQ from *Shipley* Total Score Stratified by Age

Total	16-17	18-19	20-24	25-34	35-44	45-54	55-64	65-69	70-74
28	68	68	69	70	72	74	77	81	83
27	67	67	68	69	71	73	76	79	82
26	66	66	67	68	70	72	75	78	81
25	64	65	66	67	69	71	74	77	80
24	63	64	65	66	68	70	73	76	79
23	62	63	64	65	67	69	72	75	78
22	61	62	63	64	66	68	71	74	77
21	60	61	62	63	65	67	70	73	76
20	58	59	60	62	64	67	70	72	75
19	57	58	59	61	63	66	69	71	73
18	56	57	58	60	62	65	68	70	72
17	55	55	57	59	61	64	67	69	71
16	54	54	56	58	60	63	66	68	70
15	53	53	55	57	59	62	65	67	69
14	52	52	54	56	58	61	64	66	68
13	51	51	53	55	57	60	63	65	67
12	49	49	51	54	56	59	62	64	66
11	47	48	50	53	56	58	61	63	65
10	46	47	49	52	55	57	60	62	64
9	45	46	48	51	54	56	59	61	63
8	44	44	46	49	52	54	57	59	61
7	42	43	45	48	51	53	56	58	60
6	41	42	44	47	50	52	55	57	59
5	40	41	43	46	49	51	54	56	58
4	39	40	42	45	49	51	54	56	57
3	38	39	41	44	48	50	53	55	56
2	36	38	40	43	47	50	52	54	55
1	35	37	39	42	46	49	51	53	54
0	34	35	38	41	45	48	50	52	53

Appendix C
Karnofsky Performance Status
(Karnofsky & Burchenal, 1948)

NAME _____ DATE _____

TRANSPLANT DATE _____

RATER _____ PROFESSION _____

KARNOFSKY PERFORMANCE STATUS SCALE

Condition	Performance Status, per cent	Comments
A: Able to carry on normal activity and to work. No special care is needed.	100	-Normal. No complaints. No evidence of disease.
	90	-Able to carry on normal activity. Minor signs or symptoms of disease.
	80	-Normal activity with effort. Some signs or symptoms of disease.
B: Unable to work. Able to live at home and care for most personal needs. A varying degree of assistance is needed.	70	-Cares for self. Unable to carry on normal activity or to do active work.
	60	-Requires occasional assistance, but is able to care for most of his needs.
	50	-Requires considerable assistance and frequent medical care.
C: Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	40	-Disabled. Requires special care and assistance.
	30	-Severely disabled. Hospitalization is indicated although death not imminent.
	20	-Hospitalization necessary, very sick, active supportive treatment necessary.
	10	-Moribund. Fatal processes progressing rapidly.
	0	-Dead.

Name: _____

Date of Birth: _____ Age: _____

Sex: _____ Transplant Date: _____

Months post transplant: _____ Transplant center _____

Pre-illness status("before you got sick") _____

Employed?: _____

Occupation: _____

% Employment: _____

Not working? _____

Comments? _____

If homemaker/retired, _____

Fully active at home? _____

Not fully active at home? _____

Comments? _____

Pretransplant status ("the week or two before transplant")

Home _____

Hospital _____

ICU _____

Karnofsky Status (see table)

Percentage _____

Comments _____

If more than 100%, reason related to: post-transplant problems? _____

Other problems? _____

If other problem prevents employment, were they present before transplant? _____

If unable to work, what is the problem that prevents work? _____

We would like to understand your situation in more detail. Would you be willing to be interviewed in more detail later? _____

Interviewer: _____ Date: _____

Appendix D

SCL-90-R
Scoring Profile
and
Scoring Guide

(Derogatis, 1983)

SCL-90-R®

SIDE 1

INSTRUCTIONS:

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask about them.

SEX

MALE

FEMALE

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR. ___ SEP. ___ DIV. ___ WID. ___ SING. ___

DATE		
MO	DAY	YEAR

ID. NUMBER

AGE

VISIT NUMBER: _____

EXAMPLE

HOW MUCH WERE YOU DISTRESSED BY:

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	0	1	2	3	4

HOW MUCH WERE YOU DISTRESSED BY:

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1. Headaches	1	0	1	2	3	4
2. Nervousness or shakiness inside	2	0	1	2	3	4
3. Repeated unpleasant thoughts that won't leave your mind	3	0	1	2	3	4
4. Faintness or dizziness	4	0	1	2	3	4
5. Loss of sexual interest or pleasure	5	0	1	2	3	4
6. Feeling critical of others	6	0	1	2	3	4
7. The idea that someone else can control your thoughts	7	0	1	2	3	4
8. Feeling others are to blame for most of your troubles	8	0	1	2	3	4
9. Trouble remembering things	9	0	1	2	3	4
10. Worried about sloppiness or carelessness	10	0	1	2	3	4
11. Feeling easily annoyed or irritated	11	0	1	2	3	4
12. Pains in heart or chest	12	0	1	2	3	4
13. Feeling afraid in open spaces or on the streets	13	0	1	2	3	4
14. Feeling low in energy or slowed down	14	0	1	2	3	4
15. Thoughts of ending your life	15	0	1	2	3	4
16. Hearing voices that other people do not hear	16	0	1	2	3	4
17. Trembling	17	0	1	2	3	4
18. Feeling that most people cannot be trusted	18	0	1	2	3	4
19. Poor appetite	19	0	1	2	3	4
20. Crying easily	20	0	1	2	3	4
21. Feeling shy or uneasy with the opposite sex	21	0	1	2	3	4
22. Feelings of being trapped or caught	22	0	1	2	3	4
23. Suddenly scared for no reason	23	0	1	2	3	4
24. Temper outbursts that you could not control	24	0	1	2	3	4
25. Feeling afraid to go out of your house alone	25	0	1	2	3	4
26. Blaming yourself for things	26	0	1	2	3	4
27. Pains in lower back	27	0	1	2	3	4
28. Feeling blocked in getting things done	28	0	1	2	3	4
29. Feeling lonely	29	0	1	2	3	4
30. Feeling blue	30	0	1	2	3	4
31. Worrying too much about things	31	0	1	2	3	4
32. Feeling no interest in things	32	0	1	2	3	4
33. Feeling fearful	33	0	1	2	3	4
34. Your feelings being easily hurt	34	0	1	2	3	4
35. Other people being aware of your private thoughts	35	0	1	2	3	4

SCL-90-R®

SIDE 2

HOW MUCH WERE YOU DISTRESSED BY:		HOW MUCH WERE YOU DISTRESSED BY:				
		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Feeling others do not understand you or are unsympathetic	36	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	37	0	1	2	3	4
38. Having to do things very slowly to insure correctness	38	0	1	2	3	4
39. Heart pounding or racing	39	0	1	2	3	4
40. Nausea or upset stomach	40	0	1	2	3	4
41. Feeling inferior to others	41	0	1	2	3	4
42. Soreness of your muscles	42	0	1	2	3	4
43. Feeling that you are watched or talked about by others	43	0	1	2	3	4
44. Trouble falling asleep	44	0	1	2	3	4
45. Having to check and double-check what you do	45	0	1	2	3	4
46. Difficulty making decisions	46	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	47	0	1	2	3	4
48. Trouble getting your breath	48	0	1	2	3	4
49. Hot or cold spells	49	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	50	0	1	2	3	4
51. Your mind going blank	51	0	1	2	3	4
52. Numbness or tingling in parts of your body	52	0	1	2	3	4
53. A lump in your throat	53	0	1	2	3	4
54. Feeling hopeless about the future	54	0	1	2	3	4
55. Trouble concentrating	55	0	1	2	3	4
56. Feeling weak in parts of your body	56	0	1	2	3	4
57. Feeling tense or keyed up	57	0	1	2	3	4
58. Heavy feelings in your arms or legs	58	0	1	2	3	4
59. Thoughts of death or dying	59	0	1	2	3	4
60. Overeating	60	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	61	0	1	2	3	4
62. Having thoughts that are not your own	62	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	63	0	1	2	3	4
64. Awakening in the early morning	64	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	65	0	1	2	3	4
66. Sleep that is restless or disturbed	66	0	1	2	3	4
67. Having urges to break or smash things	67	0	1	2	3	4
68. Having ideas or beliefs that others do not share	68	0	1	2	3	4
69. Feeling very self-conscious with others	69	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	70	0	1	2	3	4
71. Feeling everything is an effort	71	0	1	2	3	4
72. Spells of terror or panic	72	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	73	0	1	2	3	4
74. Getting into frequent arguments	74	0	1	2	3	4
75. Feeling nervous when you are left alone	75	0	1	2	3	4
76. Others not giving you proper credit for your achievements	76	0	1	2	3	4
77. Feeling lonely even when you are with people	77	0	1	2	3	4
78. Feeling so restless you couldn't sit still	78	0	1	2	3	4
79. Feelings of worthlessness	79	0	1	2	3	4
80. The feeling that something bad is going to happen to you	80	0	1	2	3	4
81. Shouting or throwing things	81	0	1	2	3	4
82. Feeling afraid you will faint in public	82	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	83	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	84	0	1	2	3	4
85. The idea that you should be punished for your sins	85	0	1	2	3	4
86. Thoughts and images of a frightening nature	86	0	1	2	3	4
87. The idea that something serious is wrong with your body	87	0	1	2	3	4
88. Never feeling close to another person	88	0	1	2	3	4
89. Feelings of guilt	89	0	1	2	3	4
90. The idea that something is wrong with your mind	90	0	1	2	3	4

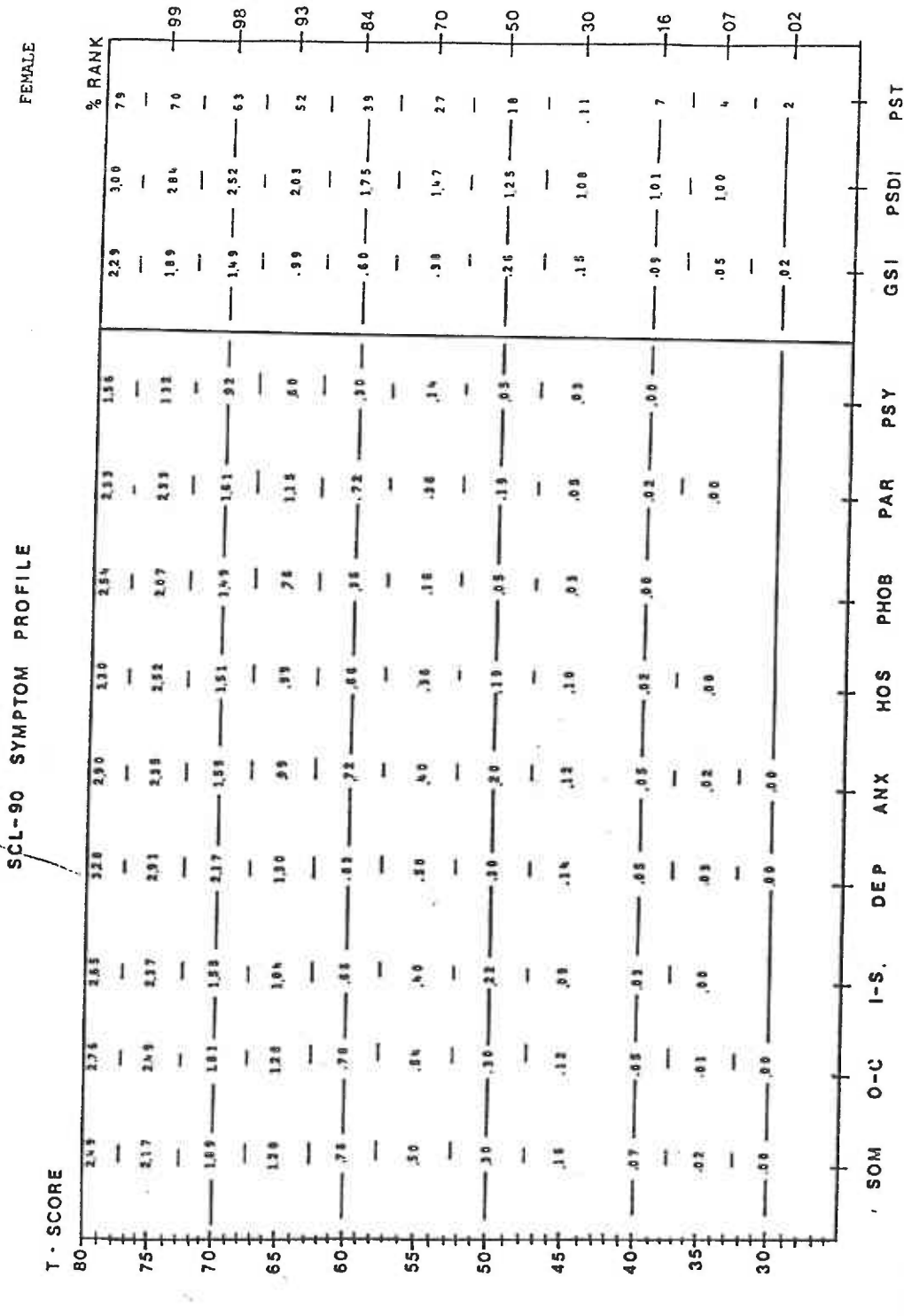
MALE

SCL-90 SYMPTOM PROFILE

T - SCORE	SOM	O-C	I-S	DEP	ANX	HOS	PHOB	PAR	PSY	GSI	PSDI	PST
80	2.04	1.97	1.65	1.74	1.56	2.19	1.69	2.49	1.43	1.30	3.46	75
75	1.55	1.75	1.43	1.69	1.24	1.91	1.26	1.75	1.00	1.24	2.91	60
70	1.31	1.43	1.23	1.07	1.04	1.40	.64	1.43	.84	.80	2.33	52
65	.84	1.05	.80	.87	.70	.99	.36	1.00	.52	.70	1.99	42
60	.56	.70	.50	.54	.40	.50	.15	.74	.30	.46	1.59	31
55	.34	.44	.32	.32	.24	.34	.05	.40	.19	.30	1.39	21
50	.19	.30	.12	.16	.14	.10	.03	.20	.05	.18	1.19	14
45	.10	.09	.06	.06	.06	.05	.01	.05	.03	.10	1.03	8
40	.05	.02	.01	.03	.02	.02	.00	.02	.00	.05	1.00	4
35	.01	.01	.00	.01	.00	.00	.00	.00	.00	.03	.00	2
30	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	1

T SCORE

RAW SCORE



T SCORE
RAW SCORE

SCL-90-R

SCORE PROFILE A

PATIENT'S NAME: _____	SEX: M <input type="checkbox"/> F <input type="checkbox"/>	
PATIENT ID NO.: _____	LOCATION: _____	AGE: _____
DATE: _____	VISIT NO.: _____	RACE: B <input type="checkbox"/> W <input type="checkbox"/> O <input type="checkbox"/>
PSYCHOMETRICIAN: _____	ADMINISTRATIVE MODE: SELF <input type="checkbox"/> NAR <input type="checkbox"/>	

ACTUARIAL DATA:		
<u>GLOBAL PERCENTILES</u>	<u>PEAK SYMPTOM DIMENSIONS</u>	<u>SYMPTOMS OF NOTE</u>
GENERAL SEVERITY INDEX <input type="checkbox"/>	1.	1.
POSITIVE SYMP DIST INDEX <input type="checkbox"/>	2.	2.
POSITIVE SYMPTOM TOTAL <input type="checkbox"/>	3.	3.
	4.	4.
	5.	5.
		6.

CLINICAL NARRATIVE:

SCL-90-R: COMPUTATION OF FACTOR SCORES

SOMATIZATION		OBSS-IMPULSIVE		INTERPERSONAL SENSITIVITY	
ITEM	SCORE	ITEM	SCORE	ITEM	SCORE
1. HEADACHES	1	2. REPETITIVE UNPLEASANT THOUGHTS THAT WON'T LEAVE YOUR MIND	1	4. FEELING CRITICAL OF OTHERS	1
4. FAINTNESS OR DIZZINESS	1	9. TROUBLE REMEMBERING THINGS	1	21. FEELING SHY OR UNFAST WITH THE OPPOSITE SEX	11
12. PAINS IN HEART OR CHEST	12	10. WORRIED ABOUT SLOTTINESS OR CARELESSNESS	12	24. YOUR FEELINGS BEING EASILY HURT	11
27. PAINS IN LOWER BACK	13	28. FEELING FLOCKED IN GETTING THINGS DONE	13	26. FEELING OTHERS DO NOT UNDERSTAND YOU OR ARE UNEMPATHETIC	11
40. NAUSEA OR UPSET STOMACH	14	30. HAVING TO DO THINGS VERY SLOWLY TO INSURE CORRECTNESS	14	27. FEELING THAT PEOPLE ARE UNFRIENDLY OR DISLIKE YOU	11
42. SOMETIMES OF YOUR MUSCLES	14	45. HAVING TO CHECK AND DOUBLE CHECK WHAT YOU DO	14	43. FEELING SUPERIOR TO OTHERS	11
48. TROUBLE GETTING YOUR BREATH	14	46. DIFFICULTY MAKING DECISIONS	14	61. FEELING UNEASY WHEN PEOPLE ARE WATCHING OR TALKING ABOUT YOU	11
49. HOT OR COLD SPELLS	14	51. YOUR MIND GOING BLANK	14	69. FEELING VERY SELF-CONSCIOUS WITH OTHERS	11
52. NUMBNESS OR TINGLING IN PARTS OF YOUR BODY	14	55. TROUBLE CONCENTRATING	14	73. FEELING UNCOMFORTABLE ABOUT EATING OR DRINKING IN PUBLIC	11
53. A LUMP IN YOUR THROAT	14	65. HAVING TO REPEAT THE SAME ACTIONS SUCH AS TOUCHING, COUNTING, WASHING	14		
54. FEELING WEAK IN PARTS OF YOUR BODY	14				
58. HEAVY FEELINGS IN YOUR ARMS OR LEGS	14				
TOTAL ITEM SCORE / 12		TOTAL ITEM SCORE / 10		TOTAL ITEM SCORE / 9	
DEPRESSION		ANXIETY		HOSTILITY	
5. LOSS OF SEXUAL INTEREST OR PLEASURE	1	2. NERVOUSNESS OR SHAKINESS INSIDE	1	11. FEELING EASILY ANNOYED OR IRRITATED	11
14. FEELING LOW IN ENERGY OR SLOWED DOWN	14	17. TREMBLING	17	24. TEMPER OUTBURSTS THAT YOU COULD NOT CONTROL	11
15. THOUGHTS OF ENDING YOUR LIFE	15	23. SUDDENLY SCARED FOR NO REASON	15	63. HAVING URGES TO BEAT, INJURE, OR BASH SOMEONE	11
20. CRYING EASILY	20	33. FEELING FEARFUL	20	67. HAVING URGES TO BREAK OR SMASH THINGS	11
22. FEELING OF BEING CAUGHT OR TRAPPED	22	39. HEART POUNDING OR RACING	22	74. GETTING INTO FREQUENT ARGUMENTS	11
26. BLAMING YOURSELF FOR THINGS	26	57. FEELING TENSE OR KETED UP	26	81. SHOUTING OR THROWING THINGS	11
29. FEELING LONELY	29	72. SPELLS OF TERROR OR PANIC	29		
30. FEELING BLUE	30	78. FEELING SO RESTLESS YOU COULDN'T SIT STILL	30		
31. WORRYING TOO MUCH ABOUT THINGS	31	80. THE FEELING THAT SOMETHING BAD IS GOING TO HAPPEN TO YOU	30		
32. FEELING NO INTEREST IN THINGS	32	86. THOUGHTS AND IMAGES OF A FRIGHTENING NATURE	32		
34. FEELING HOPELESS ABOUT THE FUTURE	34				
71. FEELING EVERYTHING IS AN EFFORT	71				
79. FEELINGS OF WORTHLESSNESS	79				
TOTAL ITEM SCORE / 13		TOTAL ITEM SCORE / 10		TOTAL ITEM SCORE / 6	
PHOBIC ANXIETY		PARANOID IDEATION		PSYCHOTICISM	
13. FEELING AFRAID IN OPEN SPACES OR IN THE STREETS	13	8. FEELING OTHERS ARE TO BLAME FOR MOST OF YOUR TROUBLES	8	7. THE IDEA THAT SOMEONE ELSE CAN CONTROL YOUR THOUGHTS	7
25. FEELING AFRAID TO GO OUT OF YOUR HOUSE ALONE	25	10. FEELING THAT MOST PEOPLE CAN NOT BE TRUSTED	10	16. HEARING VOICES THAT OTHER PEOPLE DO NOT HEAR	16
47. FEELING AFRAID TO TRAVEL ON BUSES, SUBWAYS, OR TRAINS	47	43. FEELING THAT YOU ARE WATCHED OR TALKED ABOUT BY OTHERS	43	35. OTHER PEOPLE BEING AWARE OF YOUR PRIVATE THOUGHTS	35
50. HAVING TO AVOID CERTAIN THINGS PLACES, OR ACTIVITIES BECAUSE THEY FRIGHTEN YOU	50	64. HAVING IDEAS OR BELIEFS THAT OTHERS DO NOT SHARE	64	62. HAVING THOUGHTS THAT ARE NOT YOUR OWN	62
70. FEELING UNEASY IN CROWDS, SUCH AS SHOPPING OR AT A MOVIE	70	76. OTHERS NOT GIVING YOU PROPER CREDIT FOR YOUR ACHIEVEMENTS	76	77. FEELING LONELY EVEN WHEN YOU ARE WITH PEOPLE	77
75. FEELING NERVOUS WHEN YOU ARE LEFT ALONE	75	83. FEELING THAT PEOPLE WILL TAKE ADVANTAGE OF YOU IF YOU LET THEM	83	84. HAVING THOUGHTS ABOUT SEX THAT BOTHER YOU A LOT	84
82. FEELING AFRAID YOU WILL FAINT IN PUBLIC	82			85. THE IDEA THAT YOU SHOULD BE PUNISHED FOR YOUR SINS	85
TOTAL ITEM SCORE / 7		TOTAL ITEM SCORE / 6		TOTAL ITEM SCORE / 10	
ADDITIONAL ITEMS		SYMPTOM		GLOBAL SCORES	
19. POOR APPETITE	19	TOTAL	N	RAW SCORES	
60. OVEREATING	60	SOMATIZATION			
44. TROUBLE FALLING ASLEEP	44	OBSS-IMPULSIVE			
64. AWAKENING IN THE EARLY MORNING	64	INTER SENSITIVITY			
66. SLEEP THAT IS RESTLESS OR DISTURBED	66	DEPRESSION			
59. THOUGHTS OF DEATH OR DYING	59	ANXIETY			
89. FEELINGS OF GUILT	89	HOSTILITY			
		PHOBIC ANXIETY			
		PARANOID IDEATION			
		PSYCHOTICISM			
		ADDITIONAL			
				GRAND TOTAL <input type="text"/>	
				1 GSI (GRAND TOTAL/90) <input type="text"/>	
				2 PST <input type="text"/>	
				3 PSDI (G7/PST) <input type="text"/>	

Appendix E
Quality of Life Scale (QOLS)
(Burckhardt, 1985)

INSTRUCTIONS FOR SCORING THE QUALITY OF LIFE SCALE

This form has 16 items rather than the 15 originally in the Flanagan references. Item #16 "Independence, doing for yourself" was added after a qualitative study indicated that the instrument had content validity in chronic illness groups but that it needed an item that reflected the importance to these people of remaining independent and able to care for themselves.

The instrument is scored by summing the items to make a total score. Subjects should be encouraged to fill out every item even if they are not currently engaged in it. (e.g. they can be satisfied even if they do not currently participate in organizations. Or they can be satisfied about not having children.) Missing data can be treated by entering the mean score for the item.

If you wish to compare scores in your groups with any scores that we have published, please be aware that the Burckhardt references cited below used the 15 item scale and did not include the independence item. Any subsequent work that uses the scale will include item #16.

If you have further questions, please write to me or call.

Carol S. Burckhardt, RN, PhD (503) 494-7827
Associate Professor
Department of Mental Health Nursing
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201-3098

References

Burckhardt, C.S. (1985). The impact of arthritis on quality of life. Nursing Research, 34, 11-16.

Burckhardt, C.S. (1988). Quality of life for women with arthritis. Health Care for Women International, 9, 229-238.

Burckhardt, C.S., Woods, S.L., Schultz, A.A. & Ziebarth, D.M. (1989). Quality of life of adults with chronic illness: A psychometric study. Research in Nursing and Health, 12:3437-354.

Flanagan, J.C. (1978). A research approach to improving our quality of life. American Psychologist, 33, 38-147.

Flanagan, J.C. (1982). Measurement of the quality of life: Current state of the art. Archives of Physical Medicine and Rehabilitation, 63:56-59.

A0226M.01C

Name _____
Date _____

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

Appendix F
Tables Reporting Correlation Coefficients
Among the Elements of the Measures

Table F1

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Somatization.

Input Variables	Pearson's r with SCL-90-R Somatization
<u>CIPI</u>	
Sleep	.53**
Eating	.37*
Finances	.50**
Employment	.48**
Medications	.50**
Cognitive	.63**
Physical appearance	.40**
Body deterioration	.50**
Sex	.34
Activities of daily living	.59**
Inactivity	.41**
Social activity	.48**
Family/friends contact	.47**
Assertion	.44**
Medical interaction	.40*
Marital difficulty	.44**
Marital overprotection	.47**
Nonmarried relationships	.32
KPS	-.49**
SILS AQ	-.20
SILS estimated IQ	-.32
Age	-.08
Gender	.04
Marital status	.17
Years of education	-.13
Time Since Transplant	-.15

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table F2

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Obsessive-Compulsive.

Input Variables	Pearson's r with SCL-90-R Obsessive-Compulsive
CIPI	
Sleep	.53**
Eating	.41**
Finances	.47**
Employment	.45*
Medications	.44**
Cognitive	.84**
Physical appearance	.36*
Body deterioration	.53**
Sex	.26
Activities of daily living	.58**
Inactivity	.38*
Social activity	.47**
Family/friends contact	.50**
Assertion	.59**
Medical interaction	.52*
Marital difficulty	.48**
Marital overprotection	.53**
Nonmarried relationships	.37
KPS	-.45**
SILS AQ	-.17
SILS estimated IQ	-.43**
Age	-.22
Gender	.06
Marital status	.22
Years of education	-.15
Time Since Transplant	-.06

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table F3

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Interpersonal Sensitivity.

Input Variables	Pearson's r with SCL-90-R Interpersonal Sensitivity
CIPI	
Sleep	.43**
Eating	.23
Finances	.40*
Employment	.27
Medications	.45**
Cognitive	.52**
Physical appearance	.43**
Body deterioration	.45**
Sex	.42*
Activities of daily living	.37*
Inactivity	.55**
Social activity	.53**
Family/friends contact	.56**
Assertion	.62**
Medical interaction	.36*
Marital difficulty	.63**
Marital overprotection	.54**
Nonmarried relationships	.72*
KPS	-.22
SILS AQ	-.14
SILS estimated IQ	-.13
Age	-.26
Gender	.17
Marital status	.46**
Years of education	-.03
Time Since Transplant	-.21

* p significant at ≤ 0.01

** p significant at ≤ 0.001

Table F4

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Depression.

Input Variables	Pearson's r with SCL-90-R Depression
<u>CIPI</u>	
Sleep	.55**
Eating	.49**
Finances	.44**
Employment	.48**
Medications	.63**
Cognitive	.66**
Physical appearance	.45**
Body deterioration	.75**
Sex	.50**
Activities of daily living	.61**
Inactivity	.58**
Social activity	.71**
Family/friends contact	.66**
Assertion	.63**
Medical interaction	.49**
Marital difficulty	.59**
Marital overprotection	.51**
Nonmarried relationships	.49
 KPS	 -.45**
 SILS AQ	 -.09
SILS estimated IQ	-.21
 Age	 -.09
Gender	.14
Marital status	.25
Years of education	-.11
Time Since Transplant	-.21

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table F5

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Anxiety.

Input Variables	Pearson's r with SCL-90-R Anxiety
<u>CIPI</u>	
Sleep	.61**
Eating	.47**
Finances	.55**
Employment	.44*
Medications	.54**
Cognitive	.74**
Physical appearance	.35*
Body deterioration	.58**
Sex	.34
Activities of daily living	.59**
Inactivity	.50**
Social activity	.42**
Family/friends contact	.45**
Assertion	.64**
Medical interaction	.46*
Marital difficulty	.43*
Marital overprotection	.46**
Nonmarried relationships	.42
 KPS	 -.29
 SILS AQ	 -.07
SILS estimated IQ	-.28
 Age	 -.09
Gender	.01
Marital status	.25
Years of education	-.11
Time Since Transplant	-.12

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table F6

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Hostility.

Input Variables	Pearson's r with SCL-90-R Hostility
<u>CIPI</u>	
Sleep	.22
Eating	.43**
Finances	.26
Employment	.52**
Medications	.38*
Cognitive	.55**
Physical appearance	.43**
Body deterioration	.43**
Sex	.40*
Activities of daily living	.46**
Inactivity	.41**
Social activity	.62**
Family/friends contact	.46**
Assertion	.37*
Medical interaction	.35*
Marital difficulty	.52**
Marital overprotection	.47**
Nonmarried relationships	.17
 KPS	 -.56**
 SILS AQ	 -.22
SILS estimated IQ	-.47**
 Age	 -.14
Gender	.15
Marital status	.02
Years of education	-.17
Time Since Transplant	-.07

* p significant at ≤ 0.01
** p significant at ≤ 0.001

Table F7

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Phobic Anxiety.

Input Variables	Pearson's r with SCL-90-R Phobic Anxiety
CIPI	
Sleep	.37*
Eating	.42**
Finances	.35*
Employment	.53**
Medications	.37*
Cognitive	.52**
Physical appearance	.45**
Body deterioration	.41**
Sex	.28
Activities of daily living	.53**
Inactivity	.51**
Social activity	.50**
Family/friends contact	.49**
Assertion	.47**
Medical interaction	.32
Marital difficulty	.52**
Marital overprotection	.26
Nonmarried relationships	.63
KPS	-.39**
SILS AQ	-.06
SILS estimated IQ	-.29
Age	-.03
Gender	.04
Marital status	.14
Years of education	-.18
Time Since Transplant	-.10

* p significant at < 0.01

** p significant at < 0.001

Table F8

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Paranoid Ideation.

Input Variables	Pearson's r with SCL-90-R Paranoid Ideation
CIPI	
Sleep	.31
Eating	.48**
Finances	.44**
Employment	.45**
Medications	.48**
Cognitive	.54**
Physical appearance	.34*
Body deterioration	.41**
Sex	.33
Activities of daily living	.25
Inactivity	.25
Social activity	.31
Family/friends contact	.44**
Assertion	.53**
Medical interaction	.18
Marital difficulty	.25
Marital overprotection	.48**
Nonmarried relationships	.66
KPS	-.20
SILS AQ	-.01
SILS estimated IQ	-.23
Age	-.32
Gender	.16
Marital status	.29
Years of education	-.17
Time Since Transplant	-.01

* p significant at ≤ 0.01

** p significant at ≤ 0.001

Table F9

Correlations of Scores of Liver Transplant
Recipients on "Input" Variables (Demographic
Characteristics, CIPI, KPS, SILS) and the
"Psychological Mediator", Psychoticism.

Input Variables	Pearson's <i>r</i> with SCL-90-R Psychoticism
CIPI	
Sleep	.52**
Eating	.43**
Finances	.47**
Employment	.51**
Medications	.56**
Cognitive	.67**
Physical appearance	.38**
Body deterioration	.68**
Sex	.41*
Activities of daily living	.58**
Inactivity	.46**
Social activity	.53**
Family/friends contact	.59**
Assertion	.56**
Medical interaction	.45**
Marital difficulty	.56**
Marital overprotection	.58**
Nonmarried relationships	.60
KPS	-.34*
SILS AQ	-.08
SILS estimated IQ	-.23
Age	-.02
Gender	.01
Marital status	.23
Years of education	-.17
Time Since Transplant	-.09

* *p* significant at ≤ 0.01
** *p* significant at ≤ 0.001

AN ABSTRACT OF THE THESIS OF
JOAN A. MESCH
FOR THE MASTER OF SCIENCE

Date of receiving this degree: June, 1992

Title: QUALITY OF LIFE FOLLOWING LIVER TRANSPLANT

Approved: _____

Caroline M. White, DrPH, Thesis Advisor

Standardized cognitive, psychological and social measures developed with normal subjects and various patient populations, but not with liver transplant recipients were used to describe quality of life of liver transplant recipients after liver transplant. The standardized measures included: Shipley Institute of Living Scale (SILS), SCL-90-R, Chronic Illness Problem Inventory (CIPI), Quality of Life Scale (QOLS), and a Karnofsky Performance Status (KPS). The sample included 48 men (n=30) and women (n=18), age 22 to 64, 2 to 67 months post-transplant. These transplant recipients were being treated for routine follow-up in an out-patient clinic.

The design of this study is cross-sectional and correlational and is based on self-reports of quality of life of the sample. The measures were clustered

based on a conceptual framework previously employed to test the relationships among multiple variables and the global measure of quality of life used in this study. Research questions were asked about differences in quality of life because of gender, marital status, age, education and time since transplant. Additionally, the relationships among the variables were explored using correlational analysis.

Quality of life within this population of liver transplant recipients did not systematically vary in relationship to gender, marital status, age, education, time since transplant, or verbal and abstract reasoning skills. Quality of life was related to physical, social, psychological, and global performance measures.

The findings from this research provide some basis for clinical decision making and intervention with regard to health care of liver transplant recipients. Because no differences were observed in quality of life based on gender, marital status, age, education, and time since transplant, it may not be necessary, or even beneficial to provide separate clinical interventions to improve quality of life based on these characteristics alone. These liver transplant recipients reported they had a generally good quality of life, yet problems were

identified. Health care practitioners and researchers should cautiously interpret how problems after transplant affect the transplant recipient's perception of quality of life. Finally, verbal and abstract reasoning skills were mostly normal for this population, indicating usual verbal and written teaching methods can be used.