

1999

## The Effect of Social Support on the Psychological Adaptation of an Individual receiving an Alternate Form of Nutrition Therapy

Kristin J. Ladd  
*Grand Valley State University*

Follow this and additional works at: <https://scholarworks.gvsu.edu/theses>



Part of the [Nursing Commons](#)

---

### ScholarWorks Citation

Ladd, Kristin J., "The Effect of Social Support on the Psychological Adaptation of an Individual receiving an Alternate Form of Nutrition Therapy" (1999). *Masters Theses*. 516.  
<https://scholarworks.gvsu.edu/theses/516>

This Thesis is brought to you for free and open access by the Graduate Research and Creative Practice at ScholarWorks@GVSU. It has been accepted for inclusion in Masters Theses by an authorized administrator of ScholarWorks@GVSU. For more information, please contact [scholarworks@gvsu.edu](mailto:scholarworks@gvsu.edu).

THE EFFECT OF SOCIAL SUPPORT ON THE PSYCHOLOGICAL  
ADAPTATION OF AN INDIVIDUAL RECEIVING AN ALTERNATE FORM OF  
NUTRITION THERAPY

By

Kristin J. Ladd

A THESIS

Submitted to

Grand Valley State University

In partial fulfillment of the requirements for

The degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

1999

Thesis Committee Members:

Lori Rodrigues-Fisher, EdD, R.N.

Ruth Ann Brintnall, MSN, OCN, RN, CS

Jaculin DeYoung, PharmD, BCNSP

## ABSTRACT

### THE EFFECT OF SOCIAL SUPPORT ON THE PSYCHOLOGICAL ADAPTATION OF AN INDIVIDUAL RECEIVING AN ALTERNATE FORM OF NUTRITION THERAPY

By

Kristin J. Ladd

The purpose of this study was to examine the effect of social support on an individual's psychological adaptation to an alternate form of nutrition support. Betty Neuman's Systems Model provided the framework for this study. A descriptive correlational design was chosen for this study, and data were collected using a questionnaire methodology. Proposed data analyses measures were Pearson's product moment correlation, *t*- Test, and Mann-Whitney *U*. The targeted sample size for this study was 20 patients with cancer or gastrointestinal disorders, however, termination of the study occurred when only four individuals were recruited after five months of data collection. This study provides impetus for early identification of individuals having altered nutritional status with any type of chronic illness, early intervention for those requiring alternate form of nutrition support, and awareness for nurses to provide and promote social support in individuals' psychological adaptation to alternate nutrition therapy.

## DEDICATION

This thesis is dedicated to those individuals who face an inexorable challenge placed before them when receiving a basic need in life, nourishment, in a way that defies the natural, God given gift of eating.

May we be aware of our God-given gifts, and be supportive, loving, and respectful of those that are not as blessed as we.

## ACKNOWLEDGEMENTS

I extend sincere appreciation to my thesis committee chairperson, Lorraine Rodrigues-Fisher, EdD., RN for her guidance, and support; and to my thesis committee members, Ruth Ann Brintnall, MSN, OCN, R.N., C.S. for her wisdom and mentorship, and Jaculin DeYoung, PharmD, BCNSP for her assistance and expertise.

I extend a sincere thank-you to Linda Scott, PhD., RN for her words of encouragement and unfailing support throughout this endeavor. I extend a deep sense of gratitude to Michelle Telemaque, RD, CNSD for her kind support, clinical expertise, and heartfelt wisdom in the care of individuals receiving an alternate form of nutritional support.

I especially thank my parents, Sylvia and Willet Oeschger; sister, Stephanie, and my brother and sister-in-law, Dean and Joni Easlick; my soul sister, and Colleen Mahon-VanDoren for their confidence, loving support, and perseverance throughout my academic endeavors. And to my friend and confidant, Ted Skantze, I express my love and appreciation for his undaunting support, and hugs when I needed them most.

## Table of Contents

	PAGE
Dedication.....	iii
Acknowledgments.....	iv
List of Figures.....	vii
List of Appendices.....	viii
 CHAPTER	
1 INTRODUCTION.....	1
Statement of Purpose.....	3
Statement of Problem.....	3
2 CONCEPTUAL FRAMEWORK AND LITERATURE.....	6
Conceptual Framework.....	6
Review of Literature.....	12
Summary & Analysis.....	33
Implications for study.....	36
Research Questions.....	37
Definition of Terms & Variables.....	38
3 METHODOLOGY.....	41
Design.....	41
Demographic Variables.....	42
Setting.....	42
Sample.....	43
Informed Consent & Confidentiality.....	43
Instruments.....	45
Data Collection.....	48
Procedure.....	49
Study Termination.....	51
Threats to External Validity.....	43
4 DATA ANALYSIS.....	53

5	DISCUSSION AND IMPLICATIONS.....	55
	Problems with Data Collection.....	55
	Research Implications.....	60
	Clinical Implications.....	61
	Summary.....	64
	APPENDICES.....	66
	REFERENCES.....	95

## List of Figures

1. Figure 1. Relationship of Neuman's Health  
Systems Model to the current research.....11



## List of Appendices

APPENDIX A	Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part 1.....	66
APPENDIX B	Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part .....	67
APPENDIX C	Approval from Grand Valley State University's Human Research Review Committee.....	68
APPENDIX D	Approval from Spectrum Health Research and Human Rights Committee.....	69
APPENDIX E	Informed Consent to Participant in the Nursing Research Study.....	70
APPENDIX F	Psychological Adjustment to Illness Scale- Self Report (PAIS-SR).....	72
APPENDIX G	Personal Resource Questionnaire- (PRQ-85).....	80
APPENDIX H	Follow-up cover letter.....	89
APPENDIX I	Termination letter.....	90
APPENDIX J	Permission to use the Betty Neuman's Health Care Systems Model.....	91
APPENDIX K	Permission to use the Personal Resource Questionnaire-(PRQ-85) Clarann Weinert, SC, PhD, RN, FAAN and Patricia Brandt, ARNP, PhD.....	92
APPENDIX L	Permission to use the Psychological Adjustment to Illness Scale-(PAIS-SR) Leonard R. Derogatis, PhD.....	94

## CHAPTER 1

### INTRODUCTION

The importance of the psychosocial dimensions of chronic illness has been slow to emerge in modern health care, partly because past health care has evolved around a disease-centered medical treatment and cure model (White, Richter, & Fry, 1992). The individual that develops a chronic illness with lifestyle change faces a variety of life interruptions and inexorable psychological changes. Such changes may include loss of social and vocational roles, permanent changes in life-style, threats to self-image and self-esteem, disruption to normal life transitions, uncertain and unpredictable futures, and decreasing resources. The ability to adapt to these changes depends on the guidance and support of significant others.

The experience of a chronic illness often plays an integral role in all aspects of daily living. A person's ability to adapt to a chronic illness over a long period of time has a direct influence on the successful outcome of the situation. Feldman (1974) described adaptation to chronic illness as "coming to terms with the reality of the illness as a state of

being, discarding false hope and destructive hopelessness, and restructuring the environment in which one now functions" (p. 16).

In the statement of Research Priorities for the 1980's, the American Nurses' Association (ANA) commission on Nursing Research included social support networks as an example of personal and environmental determinants of wellness and health functioning in individuals and families (ANA, 1995). Social support has been shown to be related to a wide variety of outcomes including physical health, mental well-being, and successful social functioning. Lazarus (1981) noted "that people have fared better when faced with stressful life events if they have support, and the lack of social support has been found to contribute to psychological deterioration and illness" (White, et al., 1992, p. 213).

Studies investigating social support and psychological adaptation among individuals experiencing Parkinson's disease (MacCarthy & Brown, 1989) and rheumatoid arthritis (Lambert, Lambert, Klipple, & Mewshaw, 1989) have demonstrated significant positive associations between social support and healthy psychological and physical outcomes in patients with chronic illnesses. In a multistage project that

examined the life-stage transitions of diabetic women, White, et al., (1992), supported the above findings that social support was a significant predictor in the process of adjusting to chronic illness. In other words, these authors determined that the greater the social support, the better the psychosocial adjustment to illness.

#### Statement of Purpose

Based on the multistage project conducted by White et al (1992), the purpose of this replication study was to further investigate the impact of social support on the psychological adaptation of individuals with chronic illnesses requiring alternate forms of nutrition therapies.

#### Statement of Problem

Individuals that suffer from a chronic illness, such as cancer or gastrointestinal disorders, undergo a series of lifestyle changes. Lifestyle changes include psychological and physical adaptation to altered nutrition as a result of or side effect of the illness. If unable to consume nutrients or in satisfactory quantities, the individual faces receiving sustenance in an alternate way. Alternate methods of receiving nutrition may include enteral or parenteral nutrition delivered by devices attached to various body sites

that completely bypass the norm of eating a meal. When this happens, the ability to adapt to meeting a basic need in life becomes unfamiliar, feels abnormal, and requires seemingly extraordinary measures to meet this need. The effect of social support on psychological adaptation of individuals to alternate forms of nutrition therapies was the focus of this study.

### Significance

In 1980, the American Nurses' Association (ANA) published Nursing: A Social Policy Statement, which stated that "nursing is the diagnosis and treatment of human responses to actual or potential health problems" (1995, p. 6). Delineated further, the major categories of human responses included "impaired functioning in areas such as nutrition; emotional problems related to illness and treatment or daily life experiences; strains related to life processes; and self image changes required by health status" (ANA, 1995). The presence of social support on the psychological adaptation to alternate nutrition therapy incorporates the basis of the ANA Social Policy Statement.

This study was conducted for contribution to nursing theory, research, and practice. By using Betty Neuman's Health Care Systems Model (Neuman, 1989) as a conceptual framework for this study, a link to nursing

theory was achieved. The outcomes of the study also contributed to the development of the model as a theoretical base for nursing practice. The effect of social support as a primary prevention tool that strengthens the flexible lines of defense against stressor invasions (alternate forms of nutrition therapies) was seen as a positive predictor in the achievement of reconstitution (psychological adaptation) of the client system.

The results of this study promote the understanding of social support on the psychological adaptation of individuals receiving alternate forms of nutrition therapies. In addition, the findings provide the impetus to design and implement nursing interventions that reinforce those aspects of social support that enhance the personal well-being of individuals receiving nutrition support.

## CHAPTER 2

### CONCEPTUAL FRAMEWORK AND LITERATURE

#### Betty Neuman's Health Care Systems Model

The Betty Neuman Health Care Systems Model (1989) was the conceptual framework chosen for this study. This conceptual framework is an open systems model, fitting well within the wholistic concept of optimizing a dynamic yet stable interrelationship of mind, body, and spirit of the client in a constantly changing environment and society (Neuman, 1989, p.10). Wholism, implicit within the Neuman Systems Model, is both a philosophical and a biological concept implying relationships and processes arising from wholeness, dynamic freedom, and creativity in adjusting to stressors in the internal and external environment. These stressors, or tension-producing stimuli, have the potential to cause disequilibrium. A tendency exists within any system to maintain a steady state or balance among the various disruptive forces or stressors.

The Neuman Systems Model identifies the individual as a central core with lines of defense that act as protective mechanisms to prevent or reduce potential stress reactions. When disequilibrium occurs, nursing actions can help to restore homeostasis and promote reconstitution. The four major concepts of this model are: (a) man, (b) environment, (c) health, and (d) nursing.

Man.

Neuman terms man, as "client or a client system" (1989, p. 27). The client is portrayed as a composite of interacting variables--physiological, psychological, developmental, sociocultural, and spiritual--optimally functioning harmoniously in relation to both internal and external environmental stress influences.

The client system is depicted by Neuman (1989) diagrammatically as a central core surrounded by three concentric rings. These circles function as protective mechanisms for the basic structure or client system against invasion by stressors. The basic structure, or central core consists of factors common to all organisms, that is, normal temperature range, genetic structure, response pattern, ego structure, and organ strengths and weaknesses.

The flexible line of defense forms the outer boundary of the client system. This broken line is accordion like in function, dynamically drawing closer to the normal line of defense as less protection is available. Conversely, the flexible line of defense expands when greater protection is provided. Elements related to the five client variables are found within this protective buffer system functioning for the client's normal or stable state. Specific examples of such elements are coping patterns and life-style factors.

The solid normal line of defense positioned between the flexible line of defense and lines of resistance represents



the client's usual wellness level (Neuman, 1989). Dynamic in function, this line has the ability to become and remain stabilized in dealing with life stresses over time, thereby providing additional protection to the basic structure and client system.

The lines of resistance are a series of concentric broken circles encircling the basic structure. These lines are activated when there is an invasion of the normal line of defense by stressors. Effective against stressors, the lines of resistance enable the system to reconstitute, whereas, ineffectiveness leads to energy depletion and system demise.

#### Environment.

Neuman (1989) broadly defines environment as all internal and external factors surrounding the identified client or client system at any given point in time. The relationship between the client and the environment is reciprocal in nature with the end product being corrective or regulative for the system.

#### Health.

Health is viewed as a wellness-illness continuum that occurs between the client system and the environment. Neuman describes optimal system stability in which the variables are in balance or harmony with the whole of the client system. The process of reconstitution occurs as a "return and maintenance of system stability following treatment of stress reaction" (Neuman, 1989, p. 71).

## Nursing.

Neuman (1989) views nursing as a profession that is "concerned with all the variables affecting an individual's response to stressors" (p. 72). This concern acts in keeping the client system stable through accurate assessment and interventions that assist in the client's adjustment. The goal of nursing is reduction of stress factors and adverse conditions that threaten or penetrate the lines of defense through nursing actions that restore and strengthen the protective mechanisms. Neuman's prevention as intervention format identifies three modalities used to achieve this goal. They are primary, secondary, and tertiary interventions.

Neuman states "intervention can begin at any point at which a stress is either suspected or identified" (1989, p. 73). Primary prevention strategies occur when the risk of or threat from a stress is present or imminent, but a reaction has not yet appeared. These strategies function to strengthen the flexible lines of defense. Secondary prevention is used when a stress has already occurred. By using the client's internal and external resources, this secondary prevention as intervention deals with existing client variables and attempts to strengthen the lines of resistance. Tertiary prevention protects client system reconstitution following treatment. Ultimately, "the goal is

to maintain optimal wellness level by supporting existing strengths and conserving client energy" (Neuman, 1989, p. 37).

In this study, the Neuman Systems Model examined social support as primary prevention and as an intervention to strengthen the client's flexible lines of defense when a stressor, in this case, an alternate form of nutrition therapy, was used. This study examined if social support promoted reconstitution or individual psychological adaptation.

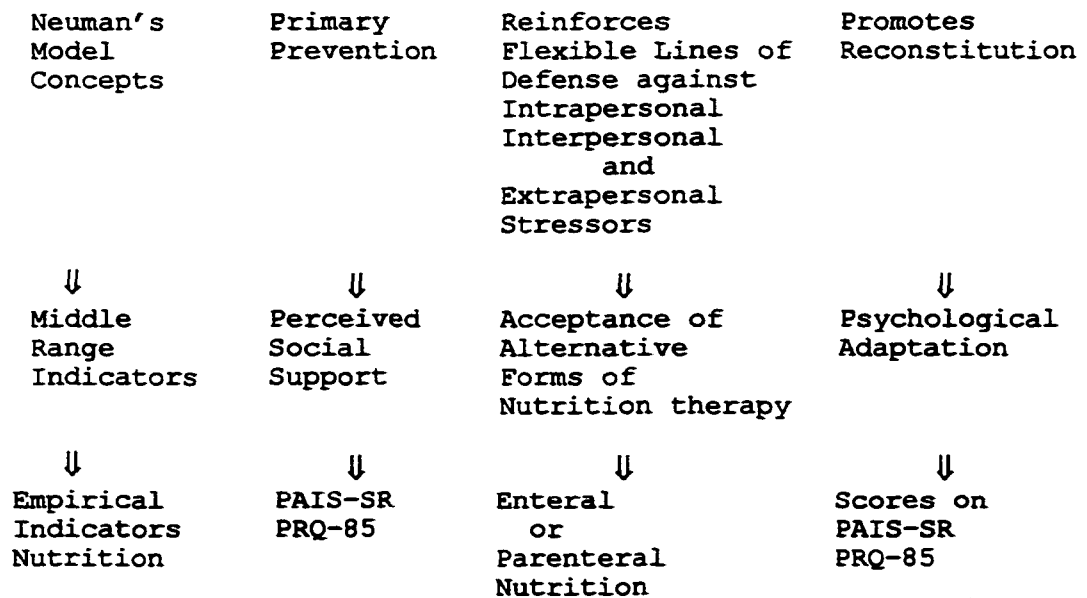
The interactions of intrapersonal, interpersonal, and extrapersonal stressors are paramount in the outcome of psychological adaptation of the individual receiving an alternate form of nutrition therapy. Intrapersonal and interpersonal stressors on an individual's perception of social support and the roles of individuals in the client's environment are complex. As a major environmental variable, social support is a multifaceted and multifunctional concept. Lambert et al. (1989) defined social support as "the availability of individuals on whom one can rely for aid and love" (p.129)

It is believed that the presence of social support is integral for prevention of harmful effects of stressors and promotion of well-being, adjustment, and adaptation to various life circumstances, including chronic illness. Adaptation suggests that reorganization and acceptance of

ones self occurs so that there is a meaning and purpose to living that carries beyond the circumstances commanded by the illness.

"The complexities of who should provide what type of support for what types of adaptive outcomes must be understood" (Primino, Yates, & Woods, 1990, p. 154), in order for successful reconstitution or psychological adaptation of the individual receiving an alternate form of nutrition therapy. The priority for nursing actions in the area of prevention as intervention is to determine the nature of an individual's stressors, the threat of the stressors to the client or client system, and understand the implications of psychological adaptation for the individual.

Figure 1. Relationship of Neuman's Health Care Systems Model to the current research.



## Review of Literature

Psychological well-being, or one's belief that one is doing well, is a desired outcome of effective coping with a stressful event (Lambert, et al., 1989). Individuals with chronic illness face change, such as loss of social and vocational roles, permanent change in life style, threats to self image and self esteem, disruption to normal life transitions, uncertain and unpredictable futures, and decreasing resources. Social support is a significant predictor in adjustment to chronic illness. The greater the social support, the better the psychological adjustment to illness (White, et al., 1992). Nurse scholars have contributed to the vast literature "positing that social support protects people from the harmful effects of stress and improves well being and levels of adjustment to chronic illness" (Bloom & Spiegel, 1984, p. 831).

A greater understanding of how adults with chronic illnesses manage their lives over the course of their disease is required. Illnesses of focus may include irritable bowel disease, Crohn's disease, ulcerative colitis, short-gut syndrome, radiation enteritis, or cancer of the esophagus, trachea, liver, pancreas, bowel, and ovaries and cervix. Individuals with these chronic illnesses in particular, often require alternate forms of

nutrition to provide their nourishment. Alternate forms of nutrition therapies, such as enteral or parenteral nutrition can cause added stress and pose a nursing challenge. The following literature review discusses how various stressors or chronic illnesses and social support relate to an individual's psychological adaptation.

#### Social Support and Psychological Adaptation.

White, Richter, and Fry (1992) examined the impact of potential stressors, coping strategies, and perceived social support on the psychological adaptation of women with diabetes mellitus. In their study, diabetes was selected as the prototype of a chronic illness because of its prevalence as a chronic disease and the necessity for significant life style changes.

This multistage project examined 193 adult women with a diagnosis of diabetes mellitus. Participants were recruited by mail through the state American Diabetes Association. The sample consisted of individuals who were predominantly middle-class Caucasians and who were educated beyond high school. The majority of women were Type 1 diabetics (86%), married (67%), and currently employed (59%).

Coping strategies were measured using the Ways of Coping Questionnaire (Lazarus & Folkman, 1984), which assesses thoughts and actions of individuals as they cope with life stressors. Alpha coefficients ranging from 0.61 to

0.79 were computed for the sample. Social support was measured using the Personal Resource Questionnaire (PRQ-85, Weinert, 1987), Part 2, which examined the dimensions of intimacy, social integration, nurturance, worth, and assistance. The alpha coefficient computed for the sample in this study was 0.93.

Psychological adaptation was measured by the self-report from the Psychological Adjustment of Illness (PAIS-SR, Derogatis, 1986), a multidimensional instrument designed to assess the psychological and social adjustment of medical patients to their illnesses. The scale consists of seven domains measuring: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. Reliability estimates for the subscales ranged from 0.47 to 0.85, however, in the current study, the total scale demonstrated an internal consistency of 0.93.

The findings indicated that stressful life events and health status had a direct impact on the use of palliative coping strategies and accounted for 15% of the variance. Interestingly, stressful life events, health status, palliative coping and perceived social support all had a direct impact on psychosocial adjustment, accounting for 56% of the variance. Better health and more social support were

associated with better adaptation than were stressful life events and the use of palliative coping. However, those individuals experiencing a chronic illness were influenced not only by normative changes and life events, but also by stressors produced from the uncertainties of the illness course and the changing demands required to manage the illness. The authors determined that social support and the use of palliative coping strategies are significant predictors in the process of adjusting to chronic illness.

Primino, Yates, and Woods (1990) explored which individuals in a woman's network provided what form of support in relation to psychosocial adjustment to chronic illnesses. Network was defined as those individuals who were significant and who provided personal support to the woman. The study sample consisted of 125 women with breast cancer (n=58), non-metastatic breast cancer or fibrocystic breast disease (FBD) (n = 36), and diabetes (n = 31). The mean age of the group was 41.3 years. Seventy percent of the women were married, had an average of two years of college education, and approximately 65% were employed. The sample consisted of predominantly Caucasian, middle-class women with an average length of time since diagnosis of five years.

Social support was measured using the Norbeck Social Support Questionnaire (NSSQ) (Norbeck, 1981). The subscales



of support that were measured consisted of affect, affirmation, aid, illness confident, and reciprocity. Individual adaptation to illness was conceptualized as the absence of depressed mood. Depression, a common response to chronic illness was measured using the CES-D (Center for Epidemiological Studies-Depression: Radloff, 1977). This 20-item scale measured the frequency of symptoms of depressed affect, somatic complaints, and interpersonal transactions. In this study, an alpha coefficient of 0.90 was obtained.

"On the average, women reported receiving quite a bit of affective and illness confident support and a moderate amount of affirmation, aid, and reciprocity" (Primino, et al., 1990, p. 156) from their respective networks. Because none of the dimensions of support differed across the three groups of chronic illnesses, the groups were combined. There were statistically significant differences in the amount of support from the various sources of support (spouse, family, friends, and others), however, identical results were obtained in analyses conducted using only the partner, family, and friends ( $n = 85$ ;  $p < .001$ ). "For all types of support, the partner consistently provided the greatest amount of support (significance level of  $p < .001$ ). That is, the partner provided significantly more effective support, affirmation, tangible aid, and was more likely to be confided in about the illness and to reciprocate"

(Primino, et al., p. 157).

The authors noted that various dimensions of support from different sources in the network were related to different types of adjustment to chronic illnesses. In particular, this study found that the greater the woman's perception of receiving affect and affirmation from her partner and family members, the greater her self-reported marital and family quality and functioning. Furthermore, it was found that the level of the woman's illness demands and depression were lower.

Friedman (1993) examined relationships of social support sources to measures of psychological well-being of women with congestive heart failure (CHF). This study investigated whether sources of emotional support (provision or availability of love and concern from others) or tangible support (assistance from others to aid in daily functioning) are related to psychological well-being in women with this chronic illness.

This study sample consisted of 80 women who were 55 years of age or older who had been hospitalized with a diagnosis of CHF one to twelve months before the interview. None of the subjects in the study had undergone surgery in the past two months or had a history of psychosis. All subjects spoke English. Eighty percent of the subjects were Caucasian and 20% were African-American. Fifty-one percent

were widowed, 20% were married, 14% were divorced or separated, and 6% were never married. None of the women were employed at the time of the interview.

Emotional and tangible support were measured using Krause's modified version of the Inventory of Socially Supportive Behavior (1990). Cronbach's alphas for the subscales used in the analyses were 0.76 for the emotional support scale and 0.58 for the tangible support subscales, respectively. The affective component of psychological well-being was measured using the 20-item Positive and Negative Affect Schedule (PANAS) (Watson, 1998). This scale contains ten negative mood adjectives and ten positive adjectives with higher scores on each adjective component reflective of greater negative or positive affect, respectively. Cronbach's alphas were 0.77 for the positive affect items and 0.78 for the negative items. The Satisfaction with Life Scale (SWLS) was used as the evaluative indicator of psychological well being. This scale was developed to assess global life satisfaction and not positive affect or loneliness. Cronbach's alpha was 0.74 for this sample.

The most frequent category of support source identified was for married versus unmarried subjects. Ninety percent of the sample members named their husbands as a source of tangible support with 64% of unmarried women without

children naming other relatives. The two groups of women did not vary on their perceptions of emotional support. Since married and unmarried women did not differ on any of the three measures of psychological well being (positive affect, negative affect, and satisfaction with life), subsequent analyses were not performed by marital status.

Results showed that the relationship of the source of tangible support to satisfaction with life found that tangible support is related to psychological well-being. In addition, the researcher noted that older women may expect and feel more satisfied when tangible support comes from family members, instilling feelings of security and satisfaction with life during illness. The evidence suggested that individuals who lack emotional or tangible support from family members may be vulnerable to experiencing reduced psychological well-being.

As stated, psychological well-being, or one's belief that one is doing well, is a desired outcome of effective coping with stress. Lambert, Lambert, Klipple, and Mewshaw (1989), examined two psychological factors--social support and the personality characteristic, hardiness to determine whether or not they would predict psychological well-being in women with rheumatoid arthritis (RA). Effective coping with a stressful event such as RA cannot be judged completely by how well it removes the problems from the

individual's life, but rather how well it enhanced one's sense of psychological well-being. Lambert, et al, 1989, noted that social support is having individuals close at hand that one may rely on for aid and love. Furthermore, these authors described that as an inherent health-promoting personality factor, hardiness, assists one in coping with a stress-laden human environment.

Subjects for this study were obtained from a large outpatient rheumatology clinic located in a teaching facility. A convenience sample of 122 women was obtained over the course of one year. These women ranged in age from 21 to 80 years, with a mean age of 57. Of the women, 98 (80%) were married, 16 (13%) were divorced, and 1 (1%) had never married. The educational status of the subjects was 8 to 21 years of formal education. The ethnic/racial distribution of the subjects included 82% Caucasians, 12% African-Americans, 1% Chicano, 3% Latinos, 1% Filipino, and 1% Native American. Duration of illness in the subjects ranged from 1 to 65 years.

Psychological well-being was measured examining anxiety, depression, positive well-being and self-control. Social support was measured examining the number of supports available as well as satisfaction with the support received. Severity of illness was measured by the amount of morning stiffness, sedimentation rate, and joint function. Hardiness

was measured by examining commitment, control, and challenge.

Results of the study showed that the length of morning stiffness correlated negatively with psychological well-being ( $-0.17, p < .05$ ). This finding suggested that as women with RA become increasingly stiff on rising, they were more likely to manifest a decrease in psychological well-being. Step-wise multiple regression analysis, with severity of illness controlled statistically, was carried out to determine whether or not social support (satisfaction with support and number of supports available) and hardiness were predictors of psychological well-being. Satisfaction with received social support increased the explained variance in the psychological well-being to 38.4% ( $p < .0001$ ). However, when hardiness was entered in the regression analysis, an increase in the explained variance to 43.7% ( $p < .0001$ ) resulted. Interestingly, satisfaction with social support was almost twice as large as that for hardiness, suggesting that satisfaction with social support was more important than hardiness in influencing psychological well-being. The findings of this study demonstrated that both satisfaction with social support and the presence of hardiness were significant predictors of psychological well-being in women with RA, and are integral in the facilitation of coping effectively with the rheumatoid arthritic disease process.

regardless of the severity of the disease.

In contrast, using Lazarus and Folkman's theory of psychological stress and coping, Lee, Graydon, and Ross (1991) examined the relationship between the oxygen-dependent chronic obstructive pulmonary disease (COPD) patient's psychological well-being, physical status, social support, and level of functioning. Lazarus and Folkman (1984) defined psychological stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19).

A non-probability convenience sample of 30 COPD patients (chronic bronchitis and/or emphysema), who had a predicted forced expiratory volume in one second (FEV 1) less than 40% and were on oxygen therapy for at least eight hours a day, were interviewed once in their homes. The names of potential patients were identified from the pulmonary function test records of patients attending two metropolitan hospitals. The sample consisted of 16 men and 14 women, having the mean age of 68.53 years, 70% were married, more than 90% were retired, and all received oxygen per nasal prongs. None of the individuals were smokers at the time of the interview, however, all except one reported a long smoking history.

Variables examined were psychological well-being, physical status, social support, and functioning. Psychological well-being was measured examining moods of tension, anger, vigor, fatigue, depression, and confusion. Somatic symptoms of the subjects' physical status were examined, including fatigue, dyspnea, congestion, and peripheral sensory complaints. The level of functioning was examined based on outcome measures that assessed the changes in usual activities and relationships individuals experienced related to their health.

Social support was measured by using the Personal Resource Questionnaire (PRQ) (Brandt & Weinert, 1981). Variables measured were intimacy, social integration, nurturance, worth, and assistance. Cronbach's alpha obtained in this study was 0.92. Furthermore, statistically significant relationships were found between the measures of physical status ( $r = -.07$ ), psychological well-being (0.58,  $p < .001$ ), and level of functioning ( $p < .05$ ). Patients who experienced more physical symptoms, lower FEV 1 scores, or poorer psychological well-being had more disruption in their level of functioning than did patients with fewer physical symptoms, higher FEV 1 scores, or better psychological well-being. However, the individuals with higher levels of social support had significantly less disruption in their functioning than those with lower



levels.

Multiple regression was used to identify the variables that had the most predictive power in relation to the level of functioning. Measures of physical status accounted for 57% of the variance in the level of functioning scores. Psychological well-being and social support did not enter the equation, probably due to the strong correlation between the physical symptoms and mood states ( $r = 0.58$ ,  $p < .001$ ).

The results of this study suggested that the only coping resource that influenced the level of functioning of oxygen-dependent COPD patients was physical status. Social support did not account for a significant amount of variance in the functioning scores, suggesting that symptom management, particularly better control of dyspnea, was probably the most pressing need of these patients.

#### Nutrition Therapy.

In Home Total Parenteral Nutrition: A Psycho-Social Viewpoint, Robinovitch (1981) noted that "home total parenteral nutrition (TPN) usually necessitates major and probably permanent changes in the patient's lifestyle" (p. 522). Issues that individuals encountered consisted of adhering to prescribed regimens to avoid crises, altering self-perceptions, modifying accustomed roles, and reprioritizing and re-thinking of values. Furthermore,

dealing with machine and medical-centered dependency and assigning a monetary value to life became burdensome.

In addition, interpersonal issues of depression, anger, anxiety, relief, body image, and self-esteem were tantamount. Within the psychological realm, TPN patients approach home therapy in a state of stress. Not only are these patients dealing with the stress of their underlying disease, its pain, debilitating effects, repeated hospitalizations, and surgeries, but the crux of the patient's psychological being is the "stress of promising relief *if* the patient can learn the system in the hospital and *then implement* the learning and maintain the system at home" (Robinovitch, 1981, p. 522).

Robinovitch noted that incorporating TPN therapy into the patient's mental, physical, and emotional capacity to learn and translate it into the home setting is challenging and takes courage. Consideration of how the house is arranged to accommodate supplies, adjusting family eating patterns and habits, and creating meal times as special and not haphazard may be problematic. Another concern involved the availability of a family member who can assist with the management of the system. These individuals undergo financial stress as they face whether or not they will be able to support the TPN therapy and their families. Third party payments, private insurance, and public assistance

programs often cover only a fraction of the financial burden, *if* patients are eligible for coverage. Robinovitch commented that it appears that individuals are robbed of personal independence and dignity in the presence of a health care system that champions to save lives.

Furthermore, these patients may encounter loss of the ability to eat and/or drink, independence, status and position in the realm of work, family and other social arenas, and control of bodily function. The onset of these feelings of loss may vary according to the patient's personal health and illness history. One such patient was depressed and viewed TPN as a limiting, frightening intrusion that was part of her disease process. TPN reminded her of the precipitous loss of her health and all that it entailed, and she responded with anger. As she gained control of her life, there was a concomitant elevation in her feelings of self-esteem, power, and independence so that her anxiety, anger and depression disappeared. This loss, whether gradual or sudden carries with it the threat of future loss. Major psychological spheres of human functioning are affected by the loss and influence the adaptation process. However, for successful adaptation, intervening and interacting variables superimposed on the process are key in influencing the interaction of the time and domain dimensions in the

adaptation to the loss. Robinovitch promoted the need for comprehensive interdisciplinary care for these TPN patients for successful adaptation. Comprehensive in nature, this interdisciplinary care includes medical, professional, and technical support, as well as social support in assisting patients and families in dealing with feelings, relationships, and environmental pressures.

Smith (1993) defined quality of life as a "person's satisfaction with his or her health and function, socioeconomic status, psychological/spiritual life, and family life, which have become a major concern in planning and implementing therapeutic programs for chronic illness"(p. 501). Methodologically, it is often difficult to separate the effects of nutrition therapy from the effects of the underlying pathology on experiential responses, including quality of life.

Using a cross-sectional design, Smith (1993) studied individuals receiving long-term TPN and family variables associated with patient and caregiver quality of life. Study variables examined were psychologic, social, and fiscal aspects of long-term total parenteral nutrition. In this study, 116 adult patients and their family caregivers were examined. The illnesses these patients had were Crohn's disease, ischemic bowel or radiation enteritis, motility disorder, bowel infarction, and trauma. The patients had

been receiving TPN at home for an average of 4.6 years and required daily TPN infusions. The average age of the patients was 52 years, and the gender of the patients and caregivers was nearly equal.

The Quality of Life Index instrument was selected to measure perceptions about the importance and satisfaction of health and function, socioeconomic status, psychological/spiritual life, and family life. This 70-item index has been associated with health status measures in patients requiring hemodialysis or peritoneal dialysis, liver transplant, and therapy for cancer. In this study, multiple regression was used to identify the associations of individual and family variables with Quality of Life Index scores.

The Quality of Life Index mean score for these patients (18.9) was similar to that reported for groups of chronically ill patients' health status measures (16.7 - 21.79) in which the Quality of Life Index was originally developed. A Caregiver Quality of Life Index mean score of 22 was found and similar to that reported for healthy individuals.

Multiple regression analysis of patient questionnaire results indicated that individual variables of self-esteem ( $R^2 = .399$ ), ability to get along on income ( $R^2 = .561$ ), family variables of quality of caregiver-patient

relationship ( $R^2 = .583$ ), and family coping skills ( $R^2 = .499$ ) were associated with quality of life ( $p < .05$ ). Patients and caregivers reported their quality of life, self-esteem, life satisfaction, family cohesion, and quality of the patient-caregiver relationship as similar to the norms that were published for other healthy populations. Overall, both patients and caregivers low quality of life was associated with increasing length of time on TPN, fewer coping skills, and inability to comfortably survive on income.

Two symptoms that were reported from the interview data as most problematic for both patients and caregivers were physical fatigue and depression. Fatigue was mentioned by both groups as an issue that interfered with daily activities. Depression, a psychological problem, was associated with fatigue. Paired *t* test analyses comparing each patient with his or her caregiver on all variables of depression, self-esteem, and change in life satisfaction indicated that there was one significant difference at the .01 level. "That difference occurred between the caregiver and patient on mean depression scores (a mean score of 15.9 indicated patients had mild depression, whereas the caregivers' mean score of 12.7 did not indicate depression)" (Smith, 1993, p. 503).

Self-esteem of both patient and caregiver groups was comparable to that of healthy individuals ( $p < .01$ ). However, "change in life satisfaction after TPN (means 1.4 and 1.0) revealed minimal change on the 10-point scale. The standard deviations (4.3 and 3.5) indicated that there was a wide range of change reported within both the patient and caregiver groups" (Smith, p. 503). The change in life satisfaction after initiation of home TPN was in the positive direction for both patients and caregivers.

The general feeling conveyed by the majority of the subjects was that "strength is gained by the family despite the individual physiologic (fatigue), psychologic (mild depression), fiscal, and social problems encountered" (Smith, 1993, p. 505). This author concluded that even with these problems encountered by the patient and caregiver, "TPN therapy was highly valued as life sustaining and therapeutic" (Smith, 1993, p. 505).

Ladefoged (1980), conducted a psychosocial survey of patients on permanent home TPN to assess the quality of life in these patients. The sample consisted of 7 women and 6 men, who had Crohn's disease, mesenteric infarction, Gardner's syndrome, and exudative jejuno-ileitis combined with chronic pancreatitis and hepatic cirrhosis. The age range of the sample was 24-72 (median 53) years. The length of time of TPN ranged from 2-43 (median 24) months and the

need for parenteral nutrition differed considerably. Consequently, the infusion time of TPN ranged from 4-5 hours three times a week to 12 hours daily. The individuals were asked specific questions about physical symptoms, social and leisure activities, interpersonal relationships, sexuality, psychological problems, and feelings about TPN.

The patients were aware that treatment with TPN would most likely be for life. Only those who had been on TPN for at least two months were interviewed to allow them time to get through the initial problems of adaptation and to gain some sort of perspective on their condition. In order to determine if quality of life systematically improved or deteriorated during treatment with TPN, 9 patients were interviewed twice, at intervals of 6-10 months.

All of the patients received a disability pension or had sick leave while an application for disability pension was pending. None of the patients felt capable of managing a full-time job. Reasons given were complex: rapid fatigue, pain, diarrhea, frequent hospitalization, and the time-consuming therapy of TPN. One patient missed the satisfaction of a self-generated income and togetherness with friends, and felt that being forced to quit work was the most frustrating consequence of the disease. Leisure activities were characterized by low physical efforts in most patients, due to restrictions, such as tiredness and



pain, not TPN.

Of the sample, twelve patients were married or cohabitating. Interestingly, marital tension was reported by three spouses, and was attributed to depressive, apathetic, or irritable behavior of the patients, and/or addiction to narcotics. Sexual activity had ceased completely in five patients above 55 years of age with the cessation occurring in most of them at the same time as the onset of the disease. However, patients younger than 55 years displayed normal and unchanged sexual activity. Ladefoged noted that the reliability of statements relating to sex life can be questioned because it is an embarrassing subject for some individuals. Participation in social activities varied with five individuals indicating that TPN restricted their participation, however, four individuals made journeys locally and abroad without feeling restricted. Acceptance of TPN treatment was fully received as a part of life by six patients. Five individuals sometimes were accepting of treatment, however, two individuals were annoyed with it. None of the patients felt that TPN influenced togetherness with friends or relatives. Interestingly, two individuals noted friends felt pity for them, and two other individuals noted that friends stayed away from them after TPN therapy had commenced.

Psychological symptoms, such as irritability, restlessness, and depression were displayed by four patients on a daily basis. Two related these symptoms to TPN. Other individuals reported that psychological symptoms were due to physical distress, such as fatigue and pain.

Due to the fact that estimation of quality of life may be subject to severe biases, Ladefoged (1981) used the following criteria for an acceptable quality of life:

(a) no major physical complaints, (b) no major psychological symptoms, (c) no substantial restriction of social and leisure activities, (d) ability to accept TPN, and (e) overall satisfaction with conditions of life. Nine individuals who fulfilled at least three of the five criteria were estimated to have a fair quality of life, however, the remaining four individuals who complied with less than three of the criteria were estimated to have a poor quality of life. The quality of life was not related to age, sex, primary disease, presence of a stoma, or duration of TPN. It was concluded that two-thirds of the sample were consistent with an acceptable quality of life.

#### Summary and Analysis

Review of the literature showed how the presence of a stressor, such as an individual's chronic illness, may be influenced by the presence of social support. The studies reviewed also demonstrated how social support affected an

individual's psychological adaptation to the stressor.

Psychological well-being, or one's belief that one is doing well is a desired outcome of effective coping with stress. The findings of a rheumatoid arthritis (RA) study conducted by Lambert, et al., (1989) suggested that the severity of RA often influences the psychological well-being of women who are forced to contend with the chronicity of this disease process and social support is a valuable factor that facilitates the individual in coping effectively. Smith noted that patients on TPN were found to be mildly depressed and experienced fatigue, fiscal, and social problems. Strength was gained by the family despite encountering these issues. The Friedman study found that individuals who lack emotional or tangible support from family members were vulnerable to experiencing reduced psychological well being. In contrast, Lee, Graydon, and Ross (1991) found that the relationship between oxygen-dependent COPD patients' psychological well-being was dependent on their physical status, and not their social support or level of functioning.

In studying psychosocial adjustment and health outcomes of individuals with chronic illnesses, it may well be more beneficial if these variables were examined over time in order to more fully understand adaptive processes during the course of the disease. Furthermore, in the White, et al.,

(1992) study, the relatively healthy role adjustment of this sample across all subscales may represent an inherent bias in the sampling structure. Consequently, it cannot be assumed that a survey of non members of support groups, such as these women associated with a national diabetic support group, would result in similar findings.

The sample sizes of Friedman, Lee, and Ladefoged studies may be a limitation in generalizing the results to larger populations. In addition, most of the studies presented were conducted on women and cannot be generalized across gender. In both the Friedman and Smith studies, the marital status of the participants was of a small proportion or not indicated. This leads one to conclude that support may have been more available to married individuals versus unmarried. The types of support, who provides the support, and numbers of support can create a vast variance in the outcomes of a study.

In their multistage project of diabetic women, White, et al., (1992), noted that the length of time that the women had lived with diabetes had not influenced either psychosocial adjustment or health outcomes. In addition, Ladefoged concluded that home TPN in 66% of individuals receiving therapy 3-49 months was consistent with an acceptable quality of life. In the study conducted by Smith (1992), overall participants indicated that low quality of

life was associated with increasing length of time on TPN and fewer coping skills. Health professionals cannot assure that adaptation is a normal and expected outcome for everyone experiencing chronic illness nor should they predict a negative trajectory in health or more difficult adjustment for those individuals.

A limitation of this study was due in part to the lack of literature regarding patients receiving home enteral and parenteral nutrition and psychological adaptation to such therapies. The nutrition support studies presented involve parenteral nutrition. There may be a bias on patients' adaptation to parenteral therapy versus individuals receiving enteral therapy in the home setting.

#### Implications for Study

Based on the literature discussed, social support does predict psychological well-being in individuals who have chronic illnesses, such as diabetes, RA, breast disease, COPD, and gastrointestinal disorders. The studies consistently indicated that when the demands of chronic illness exceeding resources (stressors), disturbance in the psychosocial adjustment to illness (disruption in the flexible lines of defense) occurs.

Because of the limited research in the area of social support on psychological adaptation to patients receiving home nutrition therapy, this study was

conducted to foster knowledge and to facilitate the identification of effective nursing interventions that promote positive health outcomes in these individuals.

#### Research Questions

The intent of this study was to investigate the effect that social support had on the psychological adaptation of individuals with cancer and gastrointestinal disorders receiving alternate forms of nutrition therapy. The following were the study hypotheses:

1. There will be a positive relationship between the level of psychological adjustment of the individual receiving enteral or parenteral therapy and the amount of perceived social support.
2. Patients receiving enteral or parenteral therapy who score low on the PRQ will have a decreased psychological adaptation to nutritional therapy when compared to patients receiving enteral or parenteral therapy who score high on the PRQ.
3. Patients receiving enteral or parenteral therapy who scored high on the PRQ will gain more weight on alternate nutritional therapy when compared to patients receiving enteral or parenteral therapy who scored low on the PRQ.

### Definition of Terms and Variables

Various terms were used consistently throughout the course of this research study. Selected terms were defined conceptually, and the independent and dependent variables were defined both conceptually and operationally.

#### Nutrition Support.

The term nutrition support was defined as an alternate form of nutrition that consists of enteral or parenteral nutrition. The enteral form is a commercially prepared formula comprised of carbohydrates, proteins, fats, free water, electrolytes, vitamins, and minerals that is delivered to the gastrointestinal tract via a nasoenteric or percutaneous feeding tube. Parenteral nutrition is a commercially prepared intravenous solution, that essentially contains the same admixtures only in a parenteral form and is intended for delivery via an intravenous access device.

#### Gastrointestinal Disorders and Cancer.

Disorders of that the subjects had in this study included cancers of the following: abdomen, esophagus, trachea, lung, and pancreas.

#### Independent variable.

The independent variable, social support, was conceptually defined as "the availability of individuals

on whom one can rely for aid and love" (Lambert, et al., 1992, p. 129). This involved satisfaction with support and amount of support available. Social support was defined operationally by the Personal Resource Questionnaire (PRQ) developed by Weinert and Brandt (1981) and was to provide information about an individual's resources and satisfaction with help received from these resources. Also, social support consisted of provision for attachment/intimacy, social integration, opportunity for nurturant behavior, reassurance of worth, and the availability of informational, emotional, and material assistance.

#### Dependent Variable.

The dependent variable, psychological adaptation, was conceptually defined as "one's belief that one is doing well" (Lambert, et al., 1992, p. 156). The Psychosocial Adjustment to Illness Scale (PAIS) was to be used to operationally assess and quantify the psychological as well as social adjustment of patients suffering from medical illnesses and the effects of the illnesses.

#### Demographic Variables.

The following demographic data were collected for this study: gender, age, ethnic group, years of education, religion, marital status, employment status, type of feeding tube or catheter for nutrition, length of hospital stay after placement of a feeding device, reason



for nutrition support, and amount of weight that was gained or lost while on nutrition support.

## CHAPTER 3

### METHODOLOGY

This chapter describes the methodology that was to be used to study the effect of social support on the psychological adaptation of individuals receiving alternate nutrition therapies. The study design, demographic variables, setting, sample, informed consent and confidentiality, instruments, and data collection are discussed.

#### Design

A descriptive correlational design was to be used in conducting this study. A convenience sample of twenty individuals receiving an alternate form of nutrition therapy, such as parenteral or enteral nutrition due to cancer or gastrointestinal disorders, was to be studied. However, after five months of data collection with only four subjects recruited, the thesis committee agreed to termination of the study. The purpose of this study was to determine the effect that social support has on the psychological adaptation of these individuals to their alternate nutrition regimen.

### Demographic Variables

Demographic data was collected using the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire - Part I and Part II (Appendices A and B). Demographic data included: gender, age, ethnic group, years of education, religion, marital status, and employment status. Additionally, demographic data in respect to an individual's type of feeding tube or intravenous (IV) catheter, period of time with the alternate nutrition, length of hospital stay after receiving the alternate nutrition, reason for the alternate nutrition weight, and amount of weight gained/lost while on alternate nutrition was collected. This information was collected for sample description.

### Setting

A convenience sample of twenty subjects was to be selected from a population of an acute care non-profit teaching hospital located in the Midwest. However, after lack of subjects, research was extended to another acute care facility in close proximity to the targeted data collection site. Both hospitals service a population of 500,000 and receive referrals from outlying hospitals located in the western and northwestern areas adjacent to this site. The

population served consists of trauma, cardiopulmonary, neurological, cancer, and gastrointestinal disorders.

### Sample

Participants were to be recruited from individuals served by the Nutrition Support Services. Criteria for inclusion in the sample were: (a) age 40 years or greater; (b) malignancy or disorder of the gastrointestinal tract requiring either enteral or parenteral nutrition; (c) 1-30 days in-patient hospitalization; (d) read, write, and speak English; (e) no known mental or physical disabilities preventing them from participation in the study; (f) will not be discharged permanently to an extended care facility; and (g) life expectancy equal to or greater than six months.

### Informed Consent and Confidentiality

Approval to conduct this study was obtained from Grand Valley State University Institutional Review Board (IRB) Committee (Appendix C) and of the participating institutions (Appendix D). At the time of in-patient admission, each potential participant was visited by the nurse researcher who explained and discussed the purpose and nature of the study, anticipated time commitment, and expectations of the participant. Possible detrimental and beneficial

effects of study participation were included on the informed consent form (Appendix E) and discussed with each participant.

A written consent form was given to each candidate to read. Signature of the participant indicated agreement to participate in the study. Two copies of the signed informed consent were made and distributed as follows: (a) one was given to the participant, (b) one kept in the participant's chart, and (c) the original placed in a locked file in the researcher's possession. The option to withdraw from the study at any time was explained to the participant. Individuals were assured that no change in planned care would result from refusal to participate in the study.

Confidentiality of all findings was assured and was to be reported as group data only. No names were associated with the data. Each participant was assigned a ten-digit code which in no way reflected an individual's identity. The code indicated the participant's gender, age, year of study participation, and hospital setting. For example, the assigned code, 01024599SE, reflected the following: first subject in the study, 01; gender: male, 02 (01 indicates female); two digits for age, 45; two digits for year of study, 99; and participating hospital. The participant's name

and identification was destroyed by shredding on completion of the study.

### Instruments

#### Home Nutrition Support Services Demographic and Quality Assurance Questionnaire.

Demographic data were collected using the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire Part I and II. The demographic data included (a) background information: gender, age, ethnic group, weight, diagnosis, education level, religion, marital status, and employment status; (b) type of nutrition (that is, parenteral (IV) or enteral (feeding tube); (c) length of time the individual had the nutrition therapy; and (d) length of hospital stay; (e) reason for alternate nutrition therapy; and (f) weight gained/lost while receiving nutrition therapy. Descriptive statistics were to be drawn from the demographic information about the participants.

#### Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR).

The Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) (Appendix F) developed by Leonard Derogatis is comprised of 46-items organized along a four-point Likert scale. Norms of the scale were established using 170 cardiac bypass patients and 114

heterogeneous cancer patients. The principal domains are: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. Questions in each of the domains assess that aspect of the patient's adjustment; for example, does work have the same importance or are social activities the same as before the illness? Response choices vary from question to question. The questionnaire is a reflection on the most recent 30 days in the respondent's life. The items are rated on a 4-point (0-3) Likert scale with scores summed for each of the principal domains and an overall adjustment score. High scores indicate poorer adjustment. Alpha coefficients for the various domains or subscales were generally high in the cancer patients (.93). Interrater reliability was established in two cancer groups ( $r = .86$  and  $r = .83$ , respectively).

Personal Resource Questionnaire (PRQ-85).

Participants were given the Personal Resource Questionnaire (PRQ-85) (Appendix G) form for completion during hospital admission upon receipt of informed consent to participate in the research study. The Personal Resource Questionnaire (PRQ-85) is a two-part measure of the multidimensional characteristics of

social support.

Part one provided descriptive information about the individual's resources, the satisfaction with these resources, and whether or not there was a confidant. This section consists of ten life situations in which one might need assistance. For each of the ten situations, the respondent indicated the sources of support. Any or all of the following responses were to be chosen: no one, spouse, child, relative, friend, spiritual advisor, professional person, agency, books, or prayer. The respondent next indicated if the situation had been experienced in the past three to four months and to what extent satisfaction was felt with the assistance that was received. There were five categories with regard to the satisfaction measure. These were included to clarify the differences between the availability of responses and the actual efficacy of the resources when the respondent was in need. The time frame indicated was to allow adequate time for specific situations to have occurred and for minimizing recall distortion. Finally, the following question was asked of each respondent, "is there anyone in particular you confide in or talk to about yourself or your problem?" (Brandt & Weinert, 1981, p. 278). This question was included to provide a concurrent validity



measure for the PRQ.

Part two contained a "seven-point Likert scale, composed of 25 items, rated from 'strongly agree' (7) to 'strongly disagree' (1) "(Brandt, & Weinert, 1981, p. 278). In each of the five relational dimensions five items were addressed: intimacy, social integration, nurturance, worth, and assistance.

Predictive validity coefficients for Part 1 ranged from 0.21 to 0.23 ( $p < .004$ ), whereas the range for Part 2 coefficients was 0.30 to 0.44 ( $p < .001$ ). Using Cronbach's alpha, an internal consistency reliability coefficient of  $\alpha = .89$  was to be used. The reliability for the dimensional subscales ranged from 0.61 to 0.77, indicating there was a good level of internal consistency in the total PRQ-Part 2 and average internal consistency for the individual dimensional subscales. Reliability of PRQ-Part 1 was not addressed. Reliability of the instruments was to be examined further using the data from the current study.

#### Data Collection

Instruments used to collect data from subjects are the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part I and II, the Personal Resource Questionnaire (PRQ-85), and the Psychosocial Adjustment to Illness Scale (PAIS-SR). The

Home Nutrition Support Services Demographic and Quality Assurance Questionnaires were developed by the participating institution's nutrition support registered nurse. The PRQ-85 was developed by Clarann Weinert and Patricia Brandt in 1981 to measure the concept of social support and to assess the social network. The PAIS-SR was developed by Leonard DeRogatis in 1975 to assess and quantify the psychological as well as social adjustment of patients suffering from medical illness.

#### Procedure

Upon admission to the participating institutions, the admitting registered nurse assessed a patient's physical condition, including nutritional status. Based on select assessment criteria for nutritional risk factors and upon completion of a nutrition consult from the nutrition support services and medical nutrition therapy departments, the nutrition support registered nurse/study researcher was contacted.

The researcher reviewed the patient's chart to determine if the potential participant met the sample selection criteria. Only individuals meeting inclusion criteria were asked to participate in the study. Potential participants who met sample selection criteria were approached by the researcher. At that

time, the research nurse explained the purpose of the study, anticipated time commitment, and expectations of the subject. The possible detrimental and beneficial effects of study participation were discussed with the individual. A written consent form was given to each participant to read, discuss, and sign if the individual agreed to participate in the study.

Upon receipt of written consent, the participant was given the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part I and Personal Resource Questionnaire (PRQ-85) forms for completion during hospital admission. The participants were instructed to not write their names on the forms; however, an identification number was written on the top right corner of the forms for coding purposes. The participant's confidentiality was maintained. The participant was instructed to place the completed forms in the provided envelope, and the nurse researcher personally retrieved these from the participant during the in-patient hospitalization.

Within thirty days of discharge, study participants were mailed a follow-up letter (Appendix H) regarding the study, the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part II, and the Psychosocial Adjustment

to Illness Scale-Self Report (PAIS-SR) for completion. The participants were instructed to not write their names on the forms. However, the forms had an identification number at the top right hand corner for coding purposes. An enclosed, self-addressed, stamped envelope was provided for convenience of returning the forms to the nurse researcher.

#### Study Termination

After five months of data collection and with only four subjects successfully recruited, it was the recommendation of the thesis committee to terminate this study. Letters were sent to the four participants explaining the nature of the study results, impact of the study on nursing research, and future implications for nursing practice (Appendix I). In addition, appreciation for support and participation in this research study was extended to each participant.

#### Threats to External Validity

A problem anticipated in research studies may be the low return rate of the data collection questionnaires. In this particular study, this occurred in two of the four subjects due to death. To avoid this problem, data collection was intentionally conducted on recruits within one month's period of time of the individual's discharge from the acute care setting to

home.

The participants' involvement required in this study consisted of answering questions at their leisure. In retrospect, the number of questionnaires and the length of each questionnaire could have been a limiting factor that potentially may have affected successful data collection with the study recruits or potential candidates for the study.

The small sample size was viewed as a weakness of the study, therefore, led to the early termination of this study.

## CHAPTER 4

### DATA ANALYSIS

Due to insufficient sample size, this study was terminated after five months of data collection at the recommendation of the thesis committee. Data analysis was to be conducted using Statistical Packages for the Social Sciences (SPSS) for Windows. An alpha level of  $p < .05$  was established to determine significance for analysis for all data.

Descriptive statistics was to be used to describe and summarize the following: (a) demographic data (gender, age, ethnic group, years of education, religion, marital status, employment status, type of feeding tube or intravenous (IV) catheter for nutrition, number of months since having the feeding tube or IV catheter for nutrition, number of hospital days spent after receiving the feeding tube or IV catheter for nutrition, and reason (disease) for receiving nutrition support; (b) the independent variable (social support); and (c) the dependent variables, psychological adaptation and weight gain or loss.

Three hypotheses were to be tested in this study. The prediction of a positive relation between the level

of psychological adaptation and amount of social support were to be examined using a Pearson's product moment correlation. In order to test the remaining hypotheses, the participants were to be divided into two groups using the median scores of the PRQ to represent low and high levels of social support. An independent t-test was to be used to examine the level of psychological adaptation between the two groups. To assess the difference in weight gain and loss by the level of social support, the Mann-Whitney *U* test was to be performed.

## CHAPTER 5

### DISCUSSION

The purpose of this study was to investigate the effect of social support on the psychological adaptation of individuals with chronic illnesses requiring an alternate form of nutrition therapy. In spite of the fact that limited accrual of subjects forced early termination of this study, indications for examining the issues that lead to problems with data collection, future research, and clinical implications for health care practitioners need to be discussed.

#### Problems with Data Collection

In the five months of data collection, four subjects with cancer receiving enteral nutrition were successfully recruited for the study. However, of the four subjects, only two completed all of the questionnaires required for the data collection process. Two subjects did not complete the second set of questionnaires in the home setting before expiring. At this writing, three of the four individuals recruited have died, with death occurring one to three weeks after recruitment into the study.

The criteria for sample selected for the study were: a) participant's age >40 years; b) disease processes: cancer of the head, neck, or abdomen, or



gastrointestinal disorders, such as ulcerative colitis, Crohn's disease, radiation enteritis, or short gut syndrome; c) inpatient hospitalization length of stay of one to thirty days at a specified acute care facility; d) discharge from the inpatient setting to home; e) ability to read, write, and speak English; and f) life expectancy of  $\geq 6$  months. The criteria age, inpatient length of stay, and the ability to read, write, or speak English had no negative bearing in recruiting potential subjects. However, the criteria of the diseases selected, targeted data collection site, life expectancy, and discharge from the inpatient setting to home may have resulted in limited recruitment of subjects for this study.

Several existing studies in the literature have investigated individuals' social support and psychological adaptation to chronic illnesses such as Parkinson's disease (MacCarthy & Brown, 1989) and rheumatoid arthritis (Lambert, Lambert, Klipple, & Mewshaw, 1989). In this study, sample size could have been increased if the sample criteria included individuals that required alternate forms of nutrition therapy for health problems caused by dysphagia (such as cerebrovascular insults, amyotrophic lateral sclerosis (ALS), or laryngeal edema status post anterior cervical fusion repair). Social support and psychological adaptation issues that plague individuals

with these conditions may parallel individuals who have cancer or a gastrointestinal disorder.

After three months of data collection, only two individuals were successfully recruited for the study. In an effort to try to increase patient population for this study, an attempt was made to recruit subjects from another acute care 500-bed facility, which had merged with the original acute care facility selected as the sample site. Despite expanding the data collection sites, only one subject was successfully recruited to participate in the study. One reason for the lack of available subjects at the second site may be the result of the merger in which there was a reallocation of patient care services. The number of potential study subjects may have become diluted in the process of reallocation of patient services between the facilities.

Furthermore, the researcher believes that a problem in recruitment may have been due to inadequate communication between the researcher and contact individuals at the second acute care facility. It may be postulated that the researcher did not advertise the study adequately, did not effectively communicate the study inclusion criteria through written and verbal instructions to appropriate contact individuals, and did not effectively communicate the essential implications of this study for research and health care

interventions.

Another possible explanation for poor recruitment of subjects may be due to the lack of personal investment in the study by the contact individuals at the second acute care facility. In this particular study, notice of potential recruits was received by the researcher typically several hours prior to the subjects' discharge from the inpatient setting. This created a challenge logistically for the researcher to successfully recruit subjects.

Lack of study recruits may be further attributed to the number of potential subjects transferred to extended care, hospice, or subacute care facilities. According to Nutrition Support Services and Nutrition Medical Therapy archived data for the first six months of 1997-1999, the trend of individuals discharged to home on an alternate form of nutrition therapy had decreased with more individuals discharged to extended care, hospice, or subacute care facilities. It may be postulated that many individuals are more debilitated at the time of discharge and require more supportive care than can be delivered in the home care setting. Because the goal of this study was to specifically examine an individual's demographics, social support, and psychological adaptation to an alternate nutritional therapy in the home setting, individuals not meeting this criteria were excluded.

Individuals with life expectancy  $\geq 6$  months was a determinant in the inclusion criteria established for this study. Subjects that were recruited into this study did not have cancer staging information available and this information was not sought by the researcher when assessing subject's life expectancy criteria. In retrospect, the lack of this information may have been a potential barrier to recruiting appropriate subjects for completing the study questionnaires.

Another limitation in recruitment occurred because candidates were too physically or mentally debilitated from the illness or lack of nutrition. In particular, a husband and wife, both receiving an alternate form of nutrition therapy due to cancer-induced weight loss were not approached for the study due to physical and mental limitations placed on them from their illnesses. Individuals with limitations, such as this couple, perhaps are the most *appropriate* for examining the impact of social support and psychological adaptation when receiving an alternate form of nutrition therapy.

Recruiting participants from a retrospective point of view by could have increased the sample size for this study. However, the goal of the study was to recruit subjects that were initially new to the alternate form of therapy and follow them prospectively through the study process. Including both prospective

and retrospective subjects concurrently would have increased sample size. However, this may have made the study statistically and logistically cumbersome with a potentially insignificant statistical data outcome and would not have answered the research questions.

#### Research Implications

The findings of this study suggest that individuals with disease processes requiring an alternate form of nutrition therapy may expand to conditions other than those targeted for this study. As discussed, the inclusion criteria may be expanded to those individuals suffering the consequences of neurological conditions or requiring nutritional support for any indication.

Lubkin (1986) defines chronic illness as the "irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6). Research findings studying the impact of social support in conjunction with individuals' psychological adaptation to chronic illness are limited. To this author's knowledge, this is the first study that attempted to examine the impact of social support on an individual's psychological adaptation to an alternate form of nutrition therapy. The impact of social support on the psychological adaptation of individuals with any chronic illness must

be considered in further research endeavors for development of nursing interventions to better meet these individuals' needs.

This study design has limitations with regard to the number of instruments and the length of the questionnaires required for completion by the subjects. Because of the importance of this study for nursing research, it is recommended for utility of future study design to use condensed tools that measure both the independent and dependent variables respectively.

#### Clinical Implications

Findings from this research have implications for health care practitioners who serve individuals requiring an alternate form of nutrition therapy as the result of cancer, gastrointestinal disorders, or any chronic illness requiring this therapy. Progressive weight loss and nutritional depletion are common among cancer patients and many individuals with chronic disease.

"The importance of malnutrition as a major source of morbidity and mortality in cancer patients is widely appreciated. Malnourished cancer patients should be identified prior to initiation of antineoplastic treatment and efforts should be made to improve their nutritional status." (Daly & Shinkin, 1995, p. 580). Malnourished patients with chronic disease states tend to respond poorly to chemotherapeutic, radiation, and surgical interventions with poor wound healing,

increased susceptibility to infection, and increased length of hospital stay. Furthermore, the impact on financial, psychological, and social well-being of the patient often is as much a sobering reality.

In an age of managed care and diagnostic related groups (DRGs), maximizing health care interventions is key to providing cost-effective, quality-based health care. Clinical pathways for various cancer, gastrointestinal and/or neurological disease states have been developed along with case management teams to off set lengthy, costly hospital stays and provide appropriate utilization of quality, cost-effective diagnostic and therapeutic interventions. Nutrition is one of many variables of focus in clinical pathway and case management structures. Despite literature that supports the significance of poor nutrition in relation to morbidity and mortality, it seems that it has less priority in disease management until it becomes an acute issue.

Three of the four recruits for this study expired one to three weeks after being recruited for the study. Each individuals' alternate form of nutrition therapy was initiated one to three days prior to study recruitment. This raises several questions: a) would the patient's survival time been longer if alternate nutrition therapy had been initiated sooner? b) should treatment modalities been delayed until the patient's

nutritional condition was stabilized? and c) did the patient have a comprehensive nutritional assessment done early in the course of the disease?

Betty Neuman views nursing as an act that keeps the client system stable through accurate assessment and interventions. Nursing, as well other members of the health care team would benefit by using Neuman's prevention as intervention modalities when approaching individuals with disease processes that may adversely affect nutrition. Neuman's framework includes primary prevention, secondary intervention, and tertiary intervention in promoting wellness.

By using a standardized nutrition assessment tool, such as the Patient-Generated Subjective Global Assessment (PG-SGA) (Ottery, 1999), primary prevention might possibly be accomplished by early identification, assessment, and evaluation of individuals that are potential candidates for malnutrition. This tool may be used by the nurse, health care provider, or case management team in the inpatient or outpatient setting.

Once malnutrition is identified, it is important for the health care provider to consider the disease trajectory and treatment modalities. At this time, it becomes important for the health care provider to discuss the risks and benefits of the disease treatment modalities with the patient with regard to the patient's poor nutrition status. If secondary intervention is necessary, the patient may be educated



on the alternate forms of nutrition therapy by the health care provider or nutrition experts on the health care team. The goal in mind is to educate the patient on various alternate nutrition therapy options in order to empower the patient in having a sense of choice and control in disease management. The earlier that malnutrition is identified, the more likely for successful intervention and making a difference in the nutritional status and disease process. This may place the burden on the health care provider, however, the benefits of early intervention outweigh the risks of malnutrition.

Tertiary prevention may be provided for individuals with established alternate nutrition therapy through the support of individuals that have already undergone the therapy. Individuals may receive support from others who are receiving an alternate form of nutrition therapy by using national nutrition support groups, such as the Oley Foundation, or by establishing hospital or community-based support groups. Through this mechanism, support provided for the patient in dealing with the multiple facets of the disease course and nutrition therapy, will hopefully assist the individual in psychologically adapting to the illness as a whole.

## Summary

The impact of social support on an individual's psychological adaptation to an alternate form of nutrition is important for identifying nursing interventions that best maximize outcomes for the individuals involved. "Nursing interventions are intended to produce beneficial effects for the patient, family, or community" (ANA, 1995, p.10). To add to future nursing research, this study may be extended to include individuals with alternate nutritional therapy who are discharged to long term or subacute care facilities and hospice environments. This would expand the opportunity to use nursing interventions that are supportive to the health and well being of not only the patient, but also the family and community alike.

## **APPENDICES**

APPENDIX A

HOME NUTRITION SUPPORT SERVICES DEMOGRAPHIC AND QUALITY  
ASSURANCE QUESTIONNAIRE

Date \_\_\_\_\_  
Identification # \_\_\_\_\_

In order to evaluate the quality of service provided to individuals receiving nutrition support, we would like you to complete the following questionnaire to provide us with basic demographic information of the individuals that have received this service. Upon completion of the questionnaire, place the form in the provided envelope, and the nutrition support nurse will retrieve the envelope from you during your stay in the hospital. Please do not write your name on the form. Thank you for your time.

PART I

Please circle the item that best applies to you:

1. Gender: 1) M 2) F
  
2. Age (years): \_\_\_\_\_
  
3. Ethnic Group: 1) African-American 2) Native American 3) Asian  
4) Hispanic 5) Caucasian 6) Pacific Islander 7) Other
  
4. Years of education: 1) 9-12 2) 13-16 3) >16
  
5. Religion: 1) Catholic 2) Jewish 3) Protestant 4) Other 5) None
  
6. Marital Status: 1) Single 2) Married 3) Separated/divorced 4) Never married 5) Widowed
  
7. Employment status: 1) Full time 2) Part time 3) Retired 4) Unemployed

APPENDIX B

HOME NUTRITION SUPPORT SERVICES DEMOGRAPHIC AND QUALITY ASSURANCE QUESTIONNAIRE

Date \_\_\_\_\_
Identification # \_\_\_\_\_

During your recent hospitalization, you received instructions regarding home nutrition therapy. Please evaluate the effectiveness of this service by taking a moment to complete the questionnaire and return it in the enclosed envelope. Your comments are welcome and will help us continue to provide quality care in the future. Please do not write your name on this form to help us maintain confidentiality. Thank you for your time.

PART II

Please circle the item that best applies to you:

- 1. Type of feeding tube or intravenous (IV)catheter for nutrition: 1) Gastric (stomach) 2) Jejunal (bowel) 3) IV 4) Don't know
2. Please indicate the number of months since you have had your feeding tube or IV for nutrition: 1) 1-4 months 2) 5-8 months 3) 9-12 months 4) 13-16 months 5) 17-20 months
3. Please indicate number of days you stayed in the hospital after receiving your feeding tube or IV for nutrition: 1) 0-2 days 2) 3-5 days 3) 6-8 days 4) 9-11 days 5) 12+days
4. Reasons for nutrition support : 1) Cancer 2) Gastrointestinal problem 3) Surgery 4) Stroke 5) Unable to take in adequate amount of food 6) Other 7) Don't know
5. Please indicate the amount of weight that you gained while you were on nutrition support therapy: 1) 1- 5 pounds 2) 6 - 10 pounds 3) >10 pounds 4) None 5) Lost weight

Please mark the appropriate answer for the following questions:

- 6. Did you receive instruction in: 1)The care of the IV site/Feeding tube site? 2) Signs and symptoms of infection to watch for when caring for your IV site/feeding tube? 3) The name of the tube feeding formula that you were receiving? 4) Where to obtain supplies? 5) Signs and symptoms of high/low blood sugars? 6) Signs and symptoms of too much or too little fluid intake?
7. Did you experience any problems with: 1) Infection with your IV catheter or feeding tube site? 2) Bowel or bladder habits after you were discharged?
8. Did the staff nurse reinforce what you learned from the Nutrition Support Nurse?
9. Were you able to practice your new skills while in the hospital?
10. Were your family/friends involved in your teaching?
11. Did you have a Home Care Nurse when you went home? 1) Was this helpful to you? 2) Did the nurse continue your TPN/feeding tube teaching?
12. Did you feel that you received the right amount of education to feel comfortable and in control of your particular nutritional need?
14. Is there anything else that you wish we had taught you?
15. Did you feel that you received enough physical, emotional, & spiritual support during your hospital stay?
15. Were you able to take care of yourself at home?
16. Who provided your care if you were unable to take care of yourself?

Comments: \_\_\_\_\_



**GRAND VALLEY  
STATE UNIVERSITY**

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

June 1, 1999

Kristin J. Ladd  
639 Hoyt SE  
Grand Rapids, MI 49507

Dear Kristin:

Your proposed project entitled *The Effect of Social Support on the Psychological Adaptation of an Individual Receiving an Alternative Form of Nutrition* has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

  
Paul Huizenga, Chair  
Human Research Review Committee



# Spectrum Health

*Downtown Campus*

100 MICHIGAN STREET NE GRAND RAPIDS MI 49503-2560  
616 391 1774 FAX 391 2745 [www.spectrum-health.org](http://www.spectrum-health.org)

July 1, 1999

Kristin Ladd, RN, BSN  
639 Hoyt, SE  
Grand Rapids, MI 49507

Dear Ms. Ladd:

By means of the expedited review process your project, "The Effect of Social Support on the Psychological Adaptation of an Individual Receiving Alternate Form of Nutrition Therapy", was given approval by the Spectrum Health Research and Human Rights Committee, on June 29, 1999.

This approval does not include the awardence of any monies for your study. The Spectrum Health number assigned to your study is #99-118.

Please be advised that any unexpected serious, adverse reactions must be promptly reported to the Research and Human Rights Committee within five days; and all changes made to the study after initiation require prior approval of the Research and Human Rights Committee before changes are implemented.

The Research and Human Rights Committee and the F.D.A. requires you submit in writing, a progress report to the committee by **May 1, 2000**, and you will need reapproval should your study be ongoing at that time. Enclosed are some guidelines, entitled "Protocol Points", for your convenience in working with your study.

If you have any questions please phone me or Linda Pool at 391-1291\1299.

Sincerely,

Jeffrey S. Jones, M.D.  
Chairman, Spectrum Health Research and Human Rights Committee

JSJ/jfn

c: Jan Hodges, MSN, RN  
Beverly Deliyianides, MSN, RN  
File

**INFORMED CONSENT FOR PARTICIPATION IN  
THE NURSING RESEARCH STUDY ENTITLED:  
*"The Effect of Social Support on the Psychological Adaptation of an Individual  
Receiving an Alternate Form of Nutrition Therapy"***

**INTRODUCTION**

This research study is being conducted to discover how well people have adjusted to their alternate form of feeding therapy. People experiencing nutrition therapy for an illness differ in their acceptance of and adaptation to the therapy. To benefit nursing research, we ask that you take about twenty minutes to read over and complete the Home Nutrition Support Services Demographic and Quality Assurance Questionnaire-Part I and Personal Resource Questionnaire that accompanies the written consent form.

**PROCEDURE**

You can help by completing the enclosed questionnaires. Please do not write your name on the questionnaires. We ask you to sign the two consents and keep one for your records. Once completed, please return the questionnaires and one of the signed consent forms in the envelope provided by the nurse researcher. The minimum of twenty participants will be obtained for use in this study.

Approximately thirty days after your discharge from the hospital, you will receive the Home Nutrition Therapy Quality Assurance Questionnaire- Part II and the Psychological Adjustment to Illness Scale Questionnaire to complete. It will take about twenty minutes to complete these forms. The information you provide in these questionnaires is valuable in determining the adjustment to alternate forms of feeding therapy. Please return the questionnaires in the enclosed, self-addressed, stamped envelope.

**BENEFIT**

Tabulated information about personal experiences with feeding therapy may help nurses and physicians to better prepare other patients and their families for the changes they may experience in receiving an alternate form of nutrition therapy.

**RISK**

There are no risks to your participating in this study. It will only take about twenty minutes to complete each questionnaire.

**VOLUNTARY PARTICIPATION**

Your participation in this project is entirely voluntary. If you choose not to participate or if you do not complete this study, your current or future care will not be affected in any way by your decision.

**COMPENSATION**

You will receive no financial compensation of any kind for participation in this project.

**CONFIDENTIALITY**

All data collected will be processed and reported in a group. No individual data will be released. Data may be provided/reviewed by Spectrum Health's Human Rights Committee, the Federal Drug Administration, or the researcher's designee.



**INFORMED CONSENT FOR PARTICIPATION IN  
A NURSING RESEARCH STUDY ENTITLED:  
*"The Effect of Social Support on the Psychological Adaptation of an Individual  
Receiving an Alternate Form of Nutrition Therapy"***

If you have any questions about this research study, please contact Kristin Ladd, RN, BSN, Nutrition Support Nurse at (616) 774-5268, Paul Huizenga, GVSU Institutional Review Board at (616) 895-2472, or Linda Pool of Spectrum Health Research and Human Rights Committee at (616) 391- 1291.

Thank you for your time.

I have read and understand the information above and voluntarily agree to participate in this study.

Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Witness \_\_\_\_\_

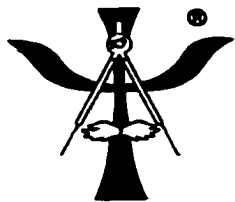
Participant's Initials: \_\_\_\_\_

APPENDIX F

# PAIS

S • R

• SELF REPORT •



CLINICAL PSYCHOMETRIC RESEARCH

Copyright © 1978, 1983 by Leonard R. Derogatis, Ph.D.

## SECTION I

(1) Which of the following statements best describes your usual attitude about taking care of your health?

- a) I am very concerned and pay close attention to my personal health.
- b) Most of the time I pay attention to my health care needs.
- c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
- d) Health care is something that I just don't worry too much about.

(2) Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.

- a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.
- b) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
- c) I do a pretty good job taking care of my present illness.
- d) I pay close attention to all the needs of my present illness and do everything I can to take care of myself.

(3) In general, how do you feel about the quality of medical care available today and the doctors who provide it?

- a) Medical care has never been better, and the doctors who give it are doing an excellent job.
- b) The quality of medical care available is very good, but there are some areas that could stand improvement.
- c) Medical care and doctors are just not of the same quality they once were.
- d) I don't have much faith in doctors and medical care today.

(4) During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?

- a) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
- b) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.
- c) The treatment has been pretty good on the whole, although there have been a few problems.
- d) The treatment and the treatment staff have been excellent.

(5) When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.

- a) I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
- b) My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
- c) My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
- d) I feel worn out and very weak from my illness, and there are times when I don't know if I am really ever going to be able to overcome it.

(6) Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.

- a) My doctor and the medical staff have told me very little about my illness even though I have asked more than once.
- b) I do have some information about my illness but I feel I would like to know more.
- c) I have a pretty fair understanding about my illness and feel that if I want to know more I can always get the information.
- d) I have been given a very complete picture of my illness, and my doctor and the medical staff have given me all the details I wish to have.

DO NOT WRITE IN THIS BLOCK

RESPONDENT'S NAME: _____	1. PT. ID. NO. _____	2. STD. NO. _____
MEDICAL INSTITUTION: _____	3. Dx _____	4. Dx Cd. _____
TREATING DOCTOR'S NAME: _____	5. Rx _____	6. Rx Cd. _____
DATE FORM WAS COMPLETED: _____	7. Med. Dept. _____	
AGE: _____ SEX: _____ EDUCATION: _____	8. Visit Cd. _____	9. Soc. Stat. _____
OCCUPATION: _____	10. Tech. _____	
MARITAL STATUS: _____		

**INSTRUCTIONS**

The present form contains a set of questions concerning the effects that your recent illness has had on you. We are interested in knowing what effects it has had on your relationships and performance at home and on your job, as well as on family and personal relationships. Other questions deal with its effects on your social and leisure time activities, and how you have felt emotionally.

In answering each question, please put a check mark (✓) in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 30 days, including today. Answer each question in terms of what your experience has been like during this time. In the event you are presently a patient in the hospital, please report your experiences for the 30 days before entering the hospital.

Some questions on the form assume that you are married or have a steady partner you are close to. Other questions ask about family relationships. If these questions do not apply to you because you are unmarried, or you have no family or partner, please leave them blank. Try to answer all the questions that do apply to you, however.

Section II asks questions about your job performance. If you have either full-time or substantial part-time employment, please answer in terms of your job. If you are primarily a student, answer in terms of your school work. If you are a housewife, answer as though housework, neighbors, etc. are your work environment.

-----

We appreciate the time you have taken to do this form. Please check again to make sure you have completed all the items. If you have any questions about the form, please ask. If you are responding by mail, please write them in the space provided below. Please return the form as soon as you have completed it.

Thank You.

---

(7) In an illness such as yours, people have different ideas about their treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.

- a) I believe my doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.
- b) I have trust in my doctor's direction of my treatment; however, sometimes I have doubts about it.
- c) I don't like certain parts of my treatment which are very unpleasant, but my doctors tell me I should go through it anyway.
- d) In many ways I think my treatment is worse than the illness, and I am not sure it is worth going through it.

(8) In an illness such as yours, patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.

- a) I have been told almost nothing about my treatment and feel left out about it.
- b) I have some information about my treatment, but not as much as I would like to have.
- c) My information concerning treatment is pretty complete, but there are one or two things I still want to know.
- d) I feel my information concerning treatment is very complete and up-to-date.

**SECTION II**

(1) Has your illness interfered with your ability to do your job (schoolwork)?

- a) No problems with my job
- b) Some problems, but only minor ones
- c) Some serious problems
- d) Illness has totally prevented me from doing my job

(2) How well do you physically perform your job (studies) now?

- a) Poorly
- b) Not too well
- c) Adequately
- d) Very well

(3) During the past 30 days, have you lost any time at work (school) due to your illness?

- a) 3 days or less
- b) 1 week
- c) 2 weeks
- d) More than 2 weeks

(4) Is your job (school) as important to you now as it was before your illness?

- a) Little or no importance to me now
- b) A lot less important
- c) Slightly less important
- d) Equal or greater importance than before

(5) Have you had to change you goals concerning your job (education) as a result of your illness?

- a) My goals are unchanged
- b) There has been a slight change in my goals
- c) My goals have changed quite a bit
- d) I have changed my goals completely

APPENDIX F

(6) Have you noticed any increase in problems with your co-workers (students, neighbors) since your illness?

- a) A great increase in problems
- b) A moderate increase in problems
- c) A slight increase in problems
- d) None

**SECTION III**

(1) How would you describe your relationship with your husband or wife (partner, if not married) since your illness?

- a) Good
- b) Fair
- c) Poor
- d) Very Poor

(2) How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?

- a) Very Poor
- b) Poor
- c) Fair
- d) Good

(3) How much has your illness interfered with your work and duties around the house?

- a) Not at all
- b) Slight problems, easily overcome
- c) Moderate problems, not all of which can be overcome
- d) Severe difficulties with household duties

(4) In those areas where your illness has caused problems with your household work, how has the family shifted duties to help you out?

- a) The family has not been able to help out at all
- b) The family has tried to help but many things are left undone
- c) The family has done well except for a few minor things
- d) No problem

(5) Has your illness resulted in a decrease in communication between you and members of your family?

- a) No decrease in communication
- b) A slight decrease in communication
- c) Communication has decreased, and I feel somewhat withdrawn from them
- d) Communication has decreased a lot, and I feel very alone

(6) Some people with an illness like yours feel they need help from other people (friends, neighbors, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?

- a) I really need help but seldom is anyone around to help
- b) I get some help, but I can't count on it all the time
- c) I don't get all the help I need all of the time, but most of the time help is there when I need it
- d) I don't feel I need such help, or the help I need is available from my family or friends

(7) Have you experienced any physical disability with your illness?

- a) No physical disability
- b) A slight physical disability
- c) A moderate physical disability
- d) A severe physical disability

**(8) An illness such as yours can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your illness?**

- a) Severe financial hardship
- b) Moderate financial problems
- c) A slight financial drain
- d) No money problems

#### SECTION IV

**(1) Sometimes having an illness can cause problems in a relationship. Has your illness led to any problems with your husband or wife (partner, if not married)?**

- a) There has been no change in our relationship
- b) We are a little less close since my illness
- c) We are definitely less close since my illness
- d) We have had serious problems or a break in our relationship since my illness

**(2) Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?**

- a) Absolutely no sexual interest since illness
- b) A marked loss of sexual interest
- c) A slight loss of sexual interest
- d) No loss of sexual interest

**(3) Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?**

- a) No decrease in sexual activities
- b) Slight decrease in sexual activities
- c) Marked decrease in sexual activities
- d) Sexual activities have stopped

**(4) Has there been any change in the pleasure or satisfaction you normally experience from sex?**

- a) Sexual pleasure and satisfaction have stopped
- b) A marked loss of sexual pleasure or satisfaction
- c) A slight loss of sexual pleasure or satisfaction
- d) No change in sexual satisfaction

**(5) Sometimes an illness will cause interference in a person's ability to perform sexual activities even though the person is still interested in sex. Has this happened to you, and if so, to what degree?**

- a) No change in my ability to have sex
- b) Slight problems with my sexual performance
- c) Constant sexual performance problems
- d) Totally unable to perform sexually

**(6) Sometimes an illness will interfere with a couple's normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?**

- a) Constant arguments
- b) Frequent arguments
- c) Some arguments
- d) No arguments

SECTION V

- (1) Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?
- [ ] a) Contact is the same or greater since illness  
 [ ] b) Contact is slightly less  
 [ ] c) Contact is markedly less  
 [ ] d) No contact since illness
- (2) Have you remained as interested in getting together with these members of your family since your illness?
- [ ] a) Little or no interest in getting together with them  
 [ ] b) Interest is a lot less than before  
 [ ] c) Interest is slightly less  
 [ ] d) Interest is the same or greater since illness
- (3) Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
- [ ] a) I need no help, or they give me all the help I need  
 [ ] b) Their help is enough, except for some minor things  
 [ ] c) They give me some help but not enough  
 [ ] d) They give me little or no help even though I need a great deal
- (4) Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?
- [ ] a) Socializing with them has been pretty much eliminated  
 [ ] b) Socializing with them has been reduced significantly  
 [ ] c) Socializing with them has been reduced somewhat  
 [ ] d) Socializing with them has been pretty much unaffected, or (I have never done much socializing of this kind)
- (5) In general, how have you been getting along with these members of your family recently?
- [ ] a) Good  
 [ ] b) Fair  
 [ ] c) Poor  
 [ ] d) Very poor

SECTION VI

- (1) Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?
- [ ] a) Same level of interest as previously  
 [ ] b) Slightly less interest than before  
 [ ] c) Significantly less interest than before  
 [ ] d) Little or no interest remaining
- (2) How about actual participation? Are you still actively involved in doing those activities?
- [ ] a) Little or no participation at present  
 [ ] b) Participation reduced significantly  
 [ ] c) Participation reduced slightly  
 [ ] d) Participation remains unchanged

Please continue on the following page ►



APPENDIX F

(3) Are you as interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your illness?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(4) Do you still participate in those activities to the same degree you once did?

- a) Little or no participation at present
- b) Participation reduced significantly
- c) Participation reduced slightly
- d) Participation remains unchanged

(5) Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(6) How about participation? Do you still go out with your friends and do those things?

- a) Little or no participation at present
- b) Participation reduced significantly
- c) Participation reduced slightly
- d) Participation remains unchanged

SECTION VII

(1) Recently, have you felt afraid, tense, nervous, or anxious?

- a) Not at all       b) A little bit       c) Quite a bit       d) Extremely

(2) Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?

- a) Extremely       b) Quite a bit       c) A little bit       d) Not at all

(3) Recently, have you felt angry, irritable, or had difficulty controlling your temper?

- a) Not at all       b) A little bit       c) Quite a bit       d) Extremely

(4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?

- a) Extremely       b) Quite a bit       c) A little bit       d) Not at all

(5) Recently, have you worried much about your illness or other matters?

- a) Not at all       b) A little bit       c) Quite a bit       d) Extremely

(6) Recently, have you been feeling down on yourself or less valuable as a person?

- a) Extremely       b) Quite a bit       c) A little bit       d) Not at all

(7) Recently, have you been concerned that your illness has caused changes in the way you look that make you less attractive?

- a) Not at all       b) A little bit       c) Quite a bit       d) Extremely

PERSONAL RESOURCE QUESTIONNAIRE (PRO-85)

• Brandt and Weinert

In our everyday lives there are personal and family situations or problems that we must deal with. Some of these are listed below. Please consider each statement in light of your own situation. **CIRCLE** the number before the person(s) that you could count on in each situation that is described. You may circle more than one number if there is more than one source of help that you count on. In addition, we would like to know if you have had this situation or a similar one in the past **SIX MONTHS**, and how satisfied you are with the help you received.

=====

Q-1a. If you were to experience urgent needs (crisis), who would you turn to for help?  
(Please **CIRCLE** all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you had urgent needs (crisis) in the past **SIX MONTHS**?

- 1 YES
- 2 NO (If NO, skip to Q-2a.)

c. If you have experienced urgent needs (crisis) in the past **SIX MONTHS**, to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

APPENDIX G

Q-2a. If you needed help for an extended period of time in caring for a family member who is sick or handicapped, who would you turn to for help? (Please **CIRCLE** all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you needed help in caring for a sick or handicapped family member in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-3a.)

c. If you have needed help in caring for a sick or handicapped family member in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-3a. If you were concerned about your relationship with your spouse, partner, or intimate other, who would you turn to for help? (Please **CIRCLE** all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

- b. Have you had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-4a.)

- c. If you have had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

- Q-4a. If you needed help or advice for a problem with a family member or friend who would you turn to for help? (Please ~~CIRCLE~~ all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

- b. Have you needed help or advice regarding a problem with a family member or friend in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-5a.)

- c. If you have needed help or advice in the past SIX MONTHS regarding a problem with a member or friend, to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED

Q-5a. If you were having financial problems, who would you turn to for help? (Please **CIRCLE** all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you had financial problems in the past **SIX MONTHS**?

- 1 YES
- 2 NO (If NO, skip to Q-6a.)

c. If you have had financial problems in the past **SIX MONTHS** to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-6a. If you felt lonely, who would you turn to? (Please **CIRCLE** all that apply.)

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you felt lonely in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-7a.)

c. If you have felt lonely, in the past SIX MONTHS, to what extent do you feel satisfied with the help you have received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-7a. If you were sick and not able to carry out your usual activities for a week or so, who would you turn to for help?

- 
- 1 ~~PARENT~~
  - 2 CHILD OR CHILDREN
  - 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
  - 4 A RELATIVE OR FAMILY MEMBER
  - 5 FRIEND
  - 6 NEIGHBOR OR CO-WORKER
  - 7 SPIRITUAL ADVISOR (minister, priest, etc.)
  - 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
  - 9 AGENCY
  - 10 SELF-HELP GROUP
  - 11 NO ONE (No one available)
  - 12 NO ONE (Prefer to handle it alone)
  - 13 OTHER (Please explain) \_\_\_\_\_

b. During the past SIX MONTHS, have you been sick for a week and not able to carry out your usual activities?

- 1 YES
- 2 NO (If NO, skip to Q-8a.)

c. If you have been sick for a week during the past SIX MONTHS to what extent do you feel satisfied with the help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-8a. If you were upset and frustrated with the conditions of your life, who would you turn to for help?

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you been upset and frustrated with the conditions of your life in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-9a.)

c. If you have been upset and frustrated with the conditions of your life in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-9a. If you were having problems with your work at home or at your place of employment, who would you turn to for help?

- 1 PARENT
- 2 CHILD OR CHILDREN
- 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
- 4 A RELATIVE OR FAMILY MEMBER
- 5 FRIEND
- 6 NEIGHBOR OR CO-WORKER
- 7 SPIRITUAL ADVISOR (minister, priest, etc.)
- 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
- 9 AGENCY
- 10 SELF-HELP GROUP
- 11 NO ONE (No one available)
- 12 NO ONE (Prefer to handle it alone)
- 13 OTHER (Please explain) \_\_\_\_\_

b. Have you had problems related to your work in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-10a.)

c. If you have had problems with your work situation in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED

Q-10a. If you needed someone to talk to about your day-to-day personal concerns, who would you turn to for help?

- 
- 1 PARENT
  - 2 CHILD OR CHILDREN
  - 3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
  - 4 A RELATIVE OR FAMILY MEMBER
  - 5 FRIEND
  - 6 NEIGHBOR OR CO-WORKER
  - 7 SPIRITUAL ADVISOR (minister, priest, etc.)
  - 8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
  - 9 AGENCY
  - 10 SELF-HELP GROUP
  - 11 NO ONE (No one available)
  - 12 NO ONE (Prefer to handle it alone)
  - 13 OTHER (Please explain) \_\_\_\_\_
- 

b. Have you needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS?

- 1 YES
- 2 NO (If NO, skip to Q-11)

c. If you have needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

- 1 VERY DISSATISFIED
- 2 FAIRLY DISSATISFIED
- 3 A LITTLE DISSATISFIED
- 4 A LITTLE SATISFIED
- 5 FAIRLY SATISFIED
- 6 VERY SATISFIED



Q-11. Below are some statements with which some people agree and others disagree. Please read each statement and **CIRCLE** the response most appropriate for you. There is no right or wrong answer.

- 1 = STRONGLY DISAGREE
- 2 = DISAGREE
- 3 = SOMEWHAT DISAGREE
- 4 = NEUTRAL
- 5 = SOMEWHAT AGREE
- 6 = AGREE
- 7 = STRONGLY AGREE

**STATEMENTS**

- 
- a. There is someone I feel close to who makes me feel secure ..... 1 2 3 4 5 6 7

---

  - b. I belong to a group in which I feel important ..... 1 2 3 4 5 6 7
  - c. People let me know that I do well at my work (job, homemaking) ..... 1 2 3 4 5 6 7
  - d. I can't count on my relatives and friends to help me with problems ..... 1 2 3 4 5 6 7
  - e. I have enough contact with the person who makes me feel special ..... 1 2 3 4 5 6 7
  - f. I spend time with others who have the same interests that I do ..... 1 2 3 4 5 6 7
  - g. There is little opportunity in my life to be giving and caring to another person ..... 1 2 3 4 5 6 7
  - h. Others let me know that they enjoy working with me (job, committees, projects) ..... 1 2 3 4 5 6 7
  - i. There are people who are available if I needed help over an extended period of time ..... 1 2 3 4 5 6 7
  - j. There is no one to talk to about how I am feeling ..... 1 2 3 4 5 6 7
  - k. Among my group of friends we do favors for each other ..... 1 2 3 4 5 6 7

- 1 = STRONGLY DISAGREE
- 2 = DISAGREE
- 3 = SOMEWHAT DISAGREE
- 4 = NEUTRAL
- 5 = SOMEWHAT AGREE
- 6 = AGREE
- 7 = STRONGLY AGREE

**STATEMENTS**

- 
- i. I have the opportunity to encourage others to develop their interests and skills ..... 1 2 3 4 5 6 7
  
  - m. My family lets me know that I am important for keeping the family running ..... 1 2 3 4 5 6 7
  
  - n. I have relatives or friends that will help me out even if I can't pay them back ..... 1 2 3 4 5 6 7
- 
- o. When I am upset there is someone I can be with who lets me be myself ..... 1 2 3 4 5 6 7
  
  - p. I feel no one has the same problems as I ..... 1 2 3 4 5 6 7
  
  - q. I enjoy doing little "extra" things that make another person's life more pleasant ..... 1 2 3 4 5 6 7
  
  - r. I know that others appreciate me as a person ..... 1 2 3 4 5 6 7
  
  - s. There is someone who loves and cares about me ..... 1 2 3 4 5 6 7
  
  - t. I have people to share social events and fun activities with ..... 1 2 3 4 5 6 7
  
  - u. I am responsible for helping provide for another person's needs ..... 1 2 3 4 5 6 7
  
  - v. If I need advice there is someone who would assist me to work out a plan for dealing with the situation ..... 1 2 3 4 5 6 7
  
  - w. I have a sense of being needed by another person ..... 1 2 3 4 5 6 7
  
  - x. People think that I'm not as good a friend as I should be ..... 1 2 3 4 5 6 7
  
  - y. If I got sick, there is someone to give me advice about caring for myself ..... 1 2 3 4 5 6 7

## APPENDIX H

Month, day, 1999

Participant  
Street Address  
City, State

Dear Participant,

I would like to thank you for your participation in the Nutrition Support Quality Assessment and Research Study. While you were an inpatient at Spectrum Health, you completed Part 1 of the Demographic and Quality Assurance Questionnaire and the Psychological Adaptation to Illness Scale. As discussed, Part 2 of the Demographic and Quality Assurance Questionnaire and the Personal Resource Questionnaire-SR are to be completed after your discharge from the hospital.

Your answers are important for supporting this research endeavor which examines the home enteral and/or parenteral nutrition patient's social support system and adaptation to this therapy. In addition, your answers will be vital for developing nursing interventions that support patients such as yourself, in adapting successfully to nutrition therapy.

I have enclosed the Nutrition Support Quality Assurance Questionnaire- Part 2 and the Personal Resource Questionnaire-SR for your completion. These forms will take you approximately 20 minutes to complete during your leisure time. Please do not write your name on the forms, and return the forms in the provided addressed envelope. Your participation in this study will remain confidential.

Upon completion of this study, I will notify you of the results. Please feel free to contact me if you have any questions, concerns, or comments about the study at 616-774-5268.

Sincerely,



Kristin J. Ladd, RN, BSN  
Graduate Nursing Student  
Grand Valley State University  
Grand Rapids, MI 49401

APPENDIX I

Month, day, 1999

Name  
Street Address  
City, State

Dear Participant,

At the end of November, the study examining the effect of social support on an individual's psychological adaptation to an alternate form of nutrition therapy was completed. As you recall, you had graciously consented to completing several questionnaires about various personal indicators, such as demographics, social support and psychological adaptation.

At this time I would like to inform you that after five months of data collection, the study was concluded after recruiting four individuals. Despite the small number of individuals recruited, the information that was gleaned has provided the basis for future nursing research, patient care delivery, and nursing interventions that will maximize patient outcomes with regard to individuals that have undergone a form of nutrition therapy.

I would like to thank you for your participation in this study at a time in your life when you were faced with majors challenges.

Thank you for your support of this study. If you have any questions, concerns, or comments about the study, please contact me at 616-774-5268.

Sincerely,



Kristin J. Ladd, RN, BSN  
Graduate Nursing Student  
Grand Valley State University  
Grand Rapids, MI 49401

APPENDIX J

January 7, 1998

Betty Neuman, R.N., Ph.D.  
P. O. Box 488  
Beverly, OH 45715

Dear Doctor Neuman,


I am currently enrolled in Masters of Nursing Graduate program at Grand Valley State University in Allendale, MI. I am undertaking a study that involves examining the impact of social support on the psychological adjustment of patients that undergo alternative forms of nutritional therapies, such a enteral and parenteral nutrition.

I would appreciate using the Neuman Systems Model as the theoretical nursing basis to this study, and would appreciate your permission undergo this endeavor.

I appreciate your assistance in enabling the progression of this study. If there is any remuneration that is required, please feel free to notify me at the address provided.

Again, thank you for your attention in this matter.

Sincerely,

  
Kristin J. Ladd, RN/BSN  
639 Hoyt, SE  
Grand Rapids, MI 49507  
Email: KLadd97444@aol.com  
(616) 452-8372

*The Above permission is granted. 1/8/98.*





UNIVERSITY OF WASHINGTON  
**SCHOOL OF NURSING**

APPENDIX K

January 13, 1998

Kristin J. Ladd, RN, BSN  
 639 Hoyt, SE  
 Grand Rapids, MI 49507

Dear Kristin:

Office of the Dean  
 Box 357260  
 Seattle, WA 98195-7260  
 206/543-8732  
 FAX 206/543-3624

Office of Academic Programs  
 Box 357260  
 Seattle, WA 98195-7260  
 206/543-8736  
 FAX 206/685-1613

Office of Nursing Research and Practice  
 Box 357265  
 Seattle, WA 98195-7265  
 206/685-1525  
 FAX 206/685-9264

Biobehavioral Nursing and Health Systems  
 Box 357266  
 Seattle, WA 98195-7266  
 206/616-1406  
 FAX 206/543-4771

Family and Child Nursing  
 Box 357262  
 Seattle, WA 98195-7262  
 206/543-8775  
 FAX 206/543-6656

Psychosocial and Community Health  
 Box 357263  
 Seattle, WA 98195-7263  
 206/543-6960  
 FAX 206/685-9551

Thank you for your request. You have my permission to use the PRQ and reproduce as many copies as you will require. In this packet you will find a copy of the PRQ85, the directions for scoring, the suggested demographic information, and some additional results from the continued psychometric evaluation of the PRQ. Our latest article entitled "Social Support: Assessment of Validity," is in the July/August 1990 issue of *Nursing Research*.

As we continue with the refinement of the PRQ, we collate data sets provided by the researchers who have used the PRQ. One specific aim is to have a systematized data base that would provide a source of comparison across studies, populations, situations, etc. If you are willing to share your data set we would be most happy to include it in this growing data base. I have included the list of demographic variables that should be sent with the data.

The PRQ has been designed with two distinct parts. Part 1 can address some aspects of the network structure and provides descriptive data regarding situational support. Part 2 is a scale developed to measure the level of perceived social support based on the work of Robert Weiss. While Part 1 can be used without Part 2 or Part 2 without Part 1, we ask that no items or questions be changed/deleted, or the item sequence altered in any way. If you feel you need to change specific items to meet the aims of your research, I would ask that you submit them to me for review. I would be happy to discuss any questions or concerns you have in relation to your specific research.

If you decide to use the PRQ85 in your research please send us a letter with a brief description of your study. Students are to include the name of their research advisor. The tool must be identified, in you questionnaire, as the Personal Resource Questionnaire and authorship of the tool acknowledged in any publication or communication regarding the tool. Thank you for your interest in the PRQ.

Sincerely,

Patricia Brandt, ARNP, Ph.D.  
 Professor, Family & Child Nursing

C:\brandt\PRQ85\letter.doc



**College of Nursing**

**Main Campus**  
Sherrick Hall  
P.O. Box 173560  
Bozeman, MT 59717-3560  
Phone (406) 994-3783  
Fax (406) 994-6020

**Billings Campus**  
Campus Box 574  
MSU • Billings  
Billings, MT 59101  
Phone (406) 657-2912  
Fax (406) 657-1715

**Great Falls Campus**  
2800 11th Ave. South  
Suite 4  
Great Falls, MT 59405  
Phone (406) 455-5610  
Fax (406) 455-2526

**Missoula Campus**  
32 Campus Drive  
Missoula, MT 59812-8238  
Phone (406) 243-6515  
Fax (406) 243-5745

***PERMISSION TO USE THE PERSONAL RESOURCE QUESTIONNAIRE***

**PERMISSION TO USE THE PRQ85**

**IS GRANTED TO: Kristin J. Ladd, RN,BSN**

**THE PRQ85 IS A TWO PART INSTRUMENT . EITHER PART -1 OR PART -2 OR BOTH PARTS MAY BE ADMINISTERED. HOWEVER, THE TOOL MAY NOT BE MODIFIED WITHOUT CONSULTATION WITH THE AUTHORS.**

**\_\_\_\_\_**  
**Clarann Weinert, SC,PhD,RN,FAAN**

**DATE: January 20 1998**

**CLINICAL PSYCHOMETRIC RESEARCH, INC.**  
**100 W. Pennsylvania Avenue, Suite 302**  
**Towson, MD 21204**  
**USA**

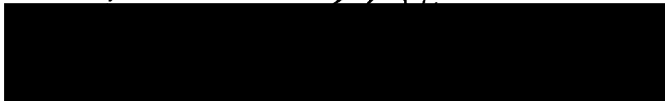
March 17, 1999

Kristin J. Ladd  
639 Hoyt, SE  
Grand Rapids, MI 49507

Dear Ms. Ladd:

This letter is intended to grant permission for you to use the PAIS-SR materials which you have purchased from Clinical Psychometric Research, Inc. in your research.

Sincerely,

A large black rectangular redaction box covers the signature area of the letter.

Leonard R. Derogatis, Ph.D.



## **LIST OF REFERENCES**

## LIST OF REFERENCES

- American Nurses Association. (1995). Nursing's Social Policy Statement. Washington: American Nurses Publishing.
- Brandt, P., & Weinert, C. (1981). The PRQ-A Social support measure. Nursing Research, 30(5), 277-280.
- Bloom, J. R., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Social Science Medicine, 19(8), 831-837.
- Daly, J. M., & Shinkin, (1995). Nutrition and the cancer patient. In G. P. Murphy, W. Lawrence, & R. E. Lenhard (Eds.). American Cancer Society Textbook of Clinical Oncology (pp. 580-596). Atlanta, Georgia: American Cancer Society.
- Derogatis, L. R. (1986). The Psychological adjustment to illness scale (PAIS). Journal of Psychometric Research, 30, 77-91.
- Feldman, D. (1974). Chronic disabling illness: A bibliography. Journal of Chronic Disease, 27, 16-24
- Friedman, M. M. (1993). Social support sources and psychological well-being in older women with heart disease. Research in Nursing & Health, 16, 405-413.

Krause, N. (1990). Measuring social support among older adults. International Journal of Aging & Human Development, 30, 37-53.

Ladefoged, K. (1981). Quality of life in patients on permanent home parenteral nutrition. Journal of Parenteral and Enteral Nutrition, 5(2), 132-137.

Lambert, V. A., Lambert, C. E., Klipple, G. L., & Mewshaw, E. A. (1989). Social support, hardiness, and psychological well-being in women with arthritis. Image: Journal of Nursing Scholarship, 21, 128-131.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Lubkin, I. M. (1986). Chronic Illness-Impact and Interventions. Boston: Jones & Bartlett.

Lee, R., Graydon, J., & Ross, E. (1991). Effects of psychological well-being, physical status, and social support on oxygen-dependent COPD patients' level of functioning. Research in Nursing & Health, 14, 323-328.

MacCarthy, B., & Brown, R. (1989). Psychosocial factors in Parkinson's disease. British Journal of Clinical Psychology, 28, 41-52.

Neuman, B. M. (1989). The Neuman Systems Model. Connecticut: Appleton & Lange.

Norbeck, J. S. (1981). Social support: a model for clinical research and application. Advances in Nursing Science, 20, 43-58.

Ottery, F. (1999, February). Integrating physical examination and laboratory assessment. Nutrition Oncology. Symposium conducted by Kirkhof School of Nursing, Grand Valley State University and Greater Grand Rapids Oncology Nursing Society, Grand Rapids, Michigan.

Primomo, J, Yates, B. C., & Woods, N. F. (1990). Social support for women during chronic illness: The Relationship among sources and types to adjustment. Research in Nursing & Health, 13, 153-161.

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.

Robinovitch, A. E. (1981). Home total parenteral nutrition:: A psycho-social viewpoint. Journal of Parenteral and Enteral Nutrition, 5(6), 523-525.

Smith, C. E. (1993). Quality of life in long-term total parenteral nutrition patients and their family caregivers. Journal of Parenteral and Enteral Nutrition, 17(6), 501-506.

Watson, D. (1988). Intraindividual and interindividual analyses of positive and negative affect: Their relation to health complaint, perceived stress, and daily activities. Journal of Personality and Social Psychology, 54, 1020-1030.

Weinert, C. & Tilden, V. P. (1990). Measures of social support: Assessment of validity. Nursing Research, 39(4), 212-215.

White, N. E., Richter, J. M., & Fry, C. (1992). Coping, social support, and adaptation in chronic illness. Western Journal of Nursing Research, 14(2), 211-224.