Order Number 9020907

Subjective perceptions of the demands of hospitalization and anxiety in bone marrow transplant patients

Coxon, Valerie Jean, Ph.D.

University of Washington, 1989

U·M·I
300 N. Zeeb Rd.
Ann Arbor, MI 48106

SUBJECTIVE PERCEPTIONS OF THE DEMANDS OF HOSPITALIZATION AND ANXIETY IN BONE MARROW TRANSPLANT PATIENTS

by

Valerie Jean Coxon

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington
1989

Approved by Helen Halpern-Logan
(Chairperson of Supervisory Committee)

Program Authorized to Offer Degree

School of Nursing

Date December 8, 1989

In presenting this dissertation in partial fulfillment of the requirements for the Doctoral degree at the University of Washington, I agree that the library shall make its copies freely available for inspection. I further agree that extensive coping of this dissertation is allowable only for scholarly purposes, consistent with "fair use" as prescribed in the U.S. Copyright Law. Requests for copying or reproduction if this dissertation may be referred to University Microfilms, 300 North Zeeb Road, Ann Arbor, Michigan, 48106, to whom the author has granted "the right to reproduce and sell (a) copies of the manuscript in microform and/or (b) printed copies of the manuscript made from microform."

Signature Valeria J Colon

Date December 8, 1989

University of Washington

Abstract

SUBJECTIVE PERCEPTIONS OF THE DEMANDS OF HOSPITALIZATION AND ANXIETY IN BONE MARROW TRANSPLANT PATIENTS

by Valerie Jean Coxon

Chairperson of Supervisory Committee:

Professor Helen Nakagawa Kogan
School of Nursing

The purpose of this study was to explore the relationship of hospital related demands to the presence of anxiety in hospitalized patients, and to detect a relationship between anxiety, uncertainty, and loss of control in hospitalized patients. A third purpose was to examine for partial effects of perceived uncertainty and control in accounting for levels of hospital related demands in these patients.

Anxiety is an emotional response to the perception of threat related to a patient's cognition of uncertainty, loss of control, and resultant perceptions of vulnerability. The self-assessment of uncertainty and loss of control may influence, and be influenced by the frequency and intensity of small demands, or hassles, encountered in the daily hospitalization experience.

Research was completed in two parts. First a pilot study was conducted to develop an instrument which measured hospital related demands as perceived by Bone Marrow Transplant (BMT) patients. For this

study, 153 questionnaire items generated from a literature review were administered to fifty nurses, nurse researchers, and recently hospitalized individuals in the community, U. of W. School of Nursing, Fred Hutchinson Cancer Research Center (FHCRC), and Swedish Hospital Medical Center. Seventy-Five final scale items divided into six subscales (alpha coefficients range from .78 to .91, overall scale alpha: .9635) were retained.

For the main study, thirty-two individuals admitted to the FHCRC for BMT were recruited. Informed consent, demographic data, trait anxiety, and a subjective degree of illness rating were collected prior to hospitalization.

Psychometric data gathered on the third day after the BMT procedure, included the State Anxiety Inventory, the Perceived Social Control subscale of the Coan Personal Opinion survey, the Mishel Uncertainty in Illness Scale, and the Hospital Related Demands Scale (from the pilot study).

Data were analyzed using basic descriptive statistics, correlations and multiple regression procedures. Results indicated that perceptions of anxiety were higher for patients who perceived significantly more hassles ($r=.6705$; $p<.001$). Anxiety was also related to uncertainty ($r=.5904$; $p<.001$), and to control ($r=-.4246$; $p<.01$). Educational level, LAF room assignment, perceived health, marital status, or gender had no effect on anxiety levels, although women had a significantly lower level of perceived control ($p=.004$). These results may help in the understanding and development of nursing interventions to reduce anxiety.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGMENTS

There must be a word beyond mentor to describe Dr. Helen Nakagawa Kogan's support and encouragement during this study and throughout my doctoral education. Her insights, encouragement and support, have been tremendously valuable to me. Dr. Kogan extended to me a steady challenge to fully explore and utilize surrounding resources and possibilities, while offering continual support and confidence in my behalf.

Dr. Mel Haberman is also truly a mentor, and my sincere appreciation goes out to him for his continual support and guidance through the sometimes difficult paths at "the Hutch". Appreciation is also thankfully extended to Dr. Richard Kronmal, for his guidance through the tribulation, and into the fascination of statistics. I thank Dr. Beverly Horn and Dr. Patricia Betrus for their support and encouragement throughout this study.

Special thanks are also given to Dr. Carol Patsdaughter, for her statistical guidance, and Lynne Buchanan for her steadfast assistance and comfort as I endeavored to develop and conduct my dissertation. The dear and special friends of my life - Keith Goodman, Jim Hanke, Diane Gallagher, Bob O'Connor, Dennis, and my parents, Don and Doris Coxon - Thank you so much. Where would I be, without your constant love and care over the past four years?

Finally, sincere appreciation is given to the staff and nurses at Fred Hutchinson Cancer Research Center, to Joleen Kelleher, R.N, M.N, Patricia Buchsel R.N, B.S.N, Laura Ulz, R.N. and Tucker. Most important, a heartfelt thank you is extended to the thirty-two men and women who laughed, and talked, and cared with me, while waiting and walking through the valley of the shadow.

This study was supported, and acknowledgment is gratefully extended to:

National Institute of Mental Health Psychophysiologic Research Training Grant number :T32 NUO 73030-01

Hester McLaws Scholarship Fund, School of Nursing, University of Washington.

Dedication

To My Parents:
Donald and Doris Coxon

"Did you ever know that you're my heroes?
And everything I would like to be?
I can fly higher than an eagle.
Cause you are the wind beneath my wings"

J. Henley

CHAPTER 1

Introduction

STATEMENT OF THE PROBLEM

"Merely looking at the sick is not observing. To look is not always to see. It needs a high degree of training to look, so that looking shall tell the nurse aright... It is most important to observe the symptoms of illness; it is, if possible, more important still to observe the symptoms of nursing: of what is the fault not of the illness, but of nursing."

FLORENCE NIGHTINGALE, AUGUST 25, 1908

For those in the nursing profession to be able to "look" at a patient as Nightingale entreats, they must possess, as nursing knowledge, comprehension of the array of potential needs and problems experienced by patients. One potential problem often passed over is that of hospital generated anxiety in the hospitalized patient. Poor discernment of anxiogenic components of the hospitalization experience is indeed a "symptom of nursing" which may significantly intensify the burden of illness.

Anxiety is commonly identified as a major concern in patients hospitalized for physiological illness and/or medical interventions (Munday, 1973). The presence of excessive anxiety has been implicated in reducing the quality of health and possibly prolonging recovery. Anxiety responses depend on situational factors related to environmental demands, patient coping skills, and individual vulnerabilities. Many day to day situations and practices encountered in the hospital may affect these factors in an anxiogenic direction, particularly if they generate patient perceptions of uncertainty and loss of control.

Growing recognition of the significant effects of anxiety in extending illness requires increasing efforts to identify and remove unnecessary

anxiogenic stressors encountered during hospitalization. This priority is further supported by rising costs of health care, growing consumer involvement in personal and social health care practices (Mechanic, 1986), and increasing demands on nursing to recognize and provide holistic health education and intervention (Gadow, 1977).

Anxiety is an emotional response to the perception of threat. It seems to be especially related to a patient's cognition of uncertainty, loss of control, and resultant perceptions of vulnerability (Kimball, 1979). Uncertainty and loss of control in the hospital derive from many sources, including the novelty of the environment, role changes, loss of common coping strategies while a patient, patient powerlessness, overstimulation, competing demands depleting time and energy, and caregiver neglect of holistic needs in an environment which focuses on physiological priorities. (Imboden,1972; Kiely, 1972; Cohodes, 1985).

Uncertainty results when a stimulus contains one or more of the following eight dimensions: vagueness; lack of clarity; ambiguity; unpredictability; inconsistency; probability; multiple meanings; lack of information. When stimuli are perceived as uncertain, the individual cannot complete a subjective evaluation of the event necessary to determine an appropriate response (Mishel, 1984). Instead the person is forced into either denial or vigilance responses which further delay understanding or resolution of the threat.

Control implies the ability to affect a state of affairs. Normally, if a person notices a discrepancy between perceived and desired reality, he or she will take action to attempt to lessen it (Fisher, 1984). This action can include such common problem focused coping skills as information seeking, seeking social support, changing aspects of the physical environment, or exerting role power to influence a state of events (Seeman and Seeman, 1983; Taylor, 1982). It can also include emotion focused coping skills including reappraisal of perceived or desired reality, refocusing of attention, denial, or thought processes designed to cognitively decrease the perceived

discrepancy (Lazarus and Folkman, 1984).

Partial or total failure in the above attempts can lead to a state of high stress reaction, a reappraisal of personal control, a continuation of the states of anxiety and uncertainty, and ultimately helplessness and vulnerability. Whereas a successful attempt at achieving control assumes there is an available means of avoiding, attenuating, or terminating a condition perceived as undesirable or unpleasant, and that there is competence in this respect. If the person feels a sense of control, then adverse events should be perceived as predictable, not uncertain (Lefcourt, 1973).

Certainty and control relates to anxiety by three ways: One, when an individual knows when and where noxious events are likely to occur, he or she can fit in periods of rest and relaxation, or periods of relief from anxiety. Two, it stops the individual from always looking for cues which *might* signal the noxious stimuli. Three, a predictable event requires less attention, so attention can be turned towards other stimuli (Kandel,1983).

It is important to examine sources of loss of control, uncertainty, and anxiety inherent in the hospitalization experience itself. This requires pinpointing sources of threat generated from hospitalization experiences, as opposed to threat from illness, family, finances, or other concerns. It also requires identification of hospitalization experiences which exacerbate the threat of related concerns.

The awareness of some degree of loss of control in any area derives from interactions between the person and the environment in which the individual perceives a discrepancy exists, takes physical or mental action, and then assesses a lack of control. Objective observation of this process is difficult as loss of control assessment is subjective, and possibly subconscious, and may be very hard to identify (Averill, 1973 and Janis, 1974). Also, since the assessment of loss of control produces fear, the assessment itself becomes a stressor, and cognitive and behavioral coping mechanisms may intervene to distort the relationship between the stressor (Hospital factor) and the stress response (perceptions of anxiety and uncertainty,

and loss of control).

Which situations generate anxiogenic perceptions of uncertainty and loss of control? Major encounters with life, trauma, death, or debilitation may provide some basis. Probably, however perceptions fluctuate in response to the smaller day to day encounters which demand a reaction. When the response is less than satisfactory, or difficult, or ineffectual, the perceptions of certainty and loss of control are altered. The stimuli and encounters behind such responses are often categorized as demands, or hassles.

Demands are relatively minor stressors, including irritating, frustrating and distressing experiences which affect daily life (Kanner, Coyne, Schaefer, and Lazarus, 1981). Demands reflect uncertainty by indicating an event where the individual lacks understanding of either the event, or the available and appropriate coping responses. The event has usually reached the point of being highly unpredictable, and thus, for the individual, highly unpreventable.

A demand may also indicate lack of clarity of the current situation. Demands reflect loss of control in two ways. One, perceived demands may be items which are not usually bothersome, but have been made so by a new lack of control over their presence and/or their repetition. For example, a patient is forced to drink cold coffee every morning, or is unable to retrieve dropped items. Two, demands might be novel stimuli which force an action, and thus bring to attention deficits in controllability. An example of this is the patient helplessly watching the IV run out, or a patient who is unable to understand hospital jargon.

Perception, intensity, and repetition of hospital related demands as reported by the patient may provide a good indicator of the degree and breadth of perceived threat due to uncertainty and loss of control in the hospital. As such, these demands may be correlated with anxiety.

STATEMENT OF THE PURPOSE

The purpose of this research is to explore environmental, intrapersonal and interpersonal hospitalization experiences surrounding demands, uncertainty, and loss of control which might contribute to anxiety, distress, stress, or the exacerbation of illness in Bone Marrow Transplant patients. Understanding of these experiences is requisite to forming appropriate nursing interventions to decrease the negative effects of hospitalization. This will improve the quality of care, and potentially the health of the hospitalized patient.

It is theorized that there will be significant and measurable levels of anxiety, uncertainty, loss of control, and perceived demands in this population. Relationships between these variables will be explored by pursuing the following key objectives.

The first objective of this study is to explore the relationship of hospital related demands to the presence of anxiety in hospitalized patients. The next objective is to detect a relationship between anxiety, uncertainty and loss of control in hospitalized patients. A third objective is to examine for partial effects of perceived uncertainty and control in accounting for levels of hospital related hospital related demands in these patients.

This study includes a related pilot study. The purpose of the pilot study is to develop an instrument which will accurately and reliably measure hospital related demands as perceived by the patient hospitalized for bone marrow transplantation.

CHAPTER 2

Review of the Literature

HEALTH

While the concept of health refers to the wholeness and intactness of a fully vital human being, the precise definition of health is constantly evolving (Salk,1985). Many health beliefs and practices observed in our culture today stem from the emphasis on scientific and technological approaches to illness founded in the early part of the century. This "biomedical" approach, as it came to be known, defined health as the absence of disease, and focused medical care on the definition and eradication of physiological symptoms (Dossey, 1982).

Physicians often insist that illness should be defined in terms of deviations from measurable biological parameters of functioning which have predictable outcomes for capacity and longevity. It should be remembered that the importance attached to different parameters is variable (Twaddle, 1972). One variation is the increasing awareness that health is more than just the absence of physiological dysfunction. Although measuring physiological parameters is basic to health assessment, there are a myriad of other influences - social, cognitive, emotional, spiritual, vocational, recreational, and familial, which profoundly influence an individual's health status (Eberst, 1984).

A literature search by Smith (1981) looking for fundamental concepts of health revealed that current conceptions and ideas of health fall into a hierarchy of four distinctive types: eudaimonistic, adaptive, role-performance, and clinical. The simplest, the clinical type, describes health as removal of pain and symptoms of morbid physical and/or mental conditions. Health as determined by role performance is the ability to adequately perform one's roles in life. Adaptive health describes an organism

which can engage in effective interaction with it's physical and social environment. Finally, eudaimonistic health describes the person who can measure up to wisest and best aspirations in a holistic manner.

Any expanded definition of health then takes into account social and psychological factors in it's definition of how health is demonstrated. Stress is one of these psychological factors. For the purposes of this dissertation, stress is defined generically, as the whole set of physiological and psychological phenomena including the objective event or stressor, the person's perception of the stressor, the conditioning factors or contextual stimuli, the various intervening variables or the residual stimuli, and the manifestations of response to the stressor (Pollock, 1989).

STRESS AND ILLNESS

Psychosocial stressors have demonstrated effects on physiological variables in both humans and animals (Gottschalk, 1983). Diverse forms of psychosocial stressors, whether deprivations or excesses, whether social support, or sensory stimulation, or economic well-being, are widely suspected as causal factors in physical illness (Volicer, 1977). The type and intensity of somatopsychic reactions to stressors depend on factors which can be grouped into three categories: stressors of the illness, characteristics of the host, and situational components (Johnson, Leventhal and Dobbs, 1971).

Stress responses in animals have been well documented. Henry and Meehan (1981) report that animals, including baboons, pigs, monkeys, rabbits and mice, subjected to a stressful, failure prone psychosocial environment where they had to compete for food, water, and mates, demonstrated sustained elevated blood pressure levels. Mice, exposed to the stress of immobilization, showed an inhibited ability to activate macrophages (Gottschalk, 1983).

In humans, psychosocial stress increases blood pressure (Volicer, 1977), a symptom related to arteriosclerosis, heart and kidney failure, and stroke (Henry and Meehan, 1981). Psychosocial stress has also been reported in women who experience labor alone. These women have increased levels of plasma epinephrine as well as increased reports of anxiety. The effects of increased epinephrine includes prolonged labor, a reduction in blood flow to the uterus, and fetal hypoxia (Heater, 1985).

Stressful life events have been associated with developing cancer in children (Gottschalk, 1983). Stress has been implicated in altering immunological pain-related responses (Orshan, 1988). Increased cortisol production which occurs with stress has been shown to inhibit the wound healing process (DeVillier, 1984). In addition, stress has been implicated in increasing exposure to carcinogens such as alcohol and nicotine (Gottschalk, 1983).

STRESS AND CANCER

Psychological or social events have been linked with impacts on the immune system in many different groups, including college students, psychiatric patients, caregivers of Alzheimers disease victims, and divorced individuals (Kiecolt-Glaser and Glaser, 1988). There are two main theories with postulate a link between stress and cancer.

One proposed method is through increased exposure to carcinogens. Distressed individuals are more likely to abuse alcohol and drugs, substance abuse which itself alters immunological function. Smoking, an addiction often used to adapt to stressful environments, causes about 30% of all U.S. deaths from cancer (Cox, 1984). Distressed individuals often have appetite disturbances which can affect nutrition which in turn alters immune function. Finally, smoking and caffeine alter immune function and catecholamine measurements. Sleep disturbances, and altered exercise possibly contribute to altered immune function (Kiecolt-Glaser and Glaser, 1988).

The second theory is that of promotion of malignant transformation through suppression of immune surveillance. B-cells come from bone marrow and are responsible for antibody production. Alterations in B-cell function may result in the production of blocking antibodies which enable tumors to be protected from the host defenses (Cox, 1984).

T-cells are a heterogeneous collection of lymphocytes dependent on humeral factors released by the thymus for their activation. Once activated, usually by being exposed to an antigen on a macrophage, they remember very well, and can be reactivated quickly if the antigen returns. Exposure to stress and glucocorticoids suppress antibody synthesis, and T-cell mediated immune processes. T-cell responsiveness has been shown to be depressed after bereavement (Irwin, Daniels, Bloom, Smith, and Weiner, 1987).

Natural killer (NK) cells are thought to act as an immune surveillance system, reacting to any foreign cell or substance, until the main immune response reacts. NK activity may be boosted by interferon, a substance whose production is suppressed by stress. Alternately, NK activity is suppressed by glucocorticoids, or stress hormones. Depressed NK activity has reported in depressed, anxious, and lonely persons, and those undergoing significant losses and life changes (Irwin et al, 1987).

CANCER AND ANXIETY

In the general public, cancer causes more fear and anxiety than almost any other illness (Silverfarb and Greer, 1982). In the cancer patient, anxiety is a common occurrence. In Benedicts (1988) study of the experiences of suffering of cancer patients, anxiety was the third highest cause of suffering, following both disability and physical pain. Of the range of psychosocial experiences measured, anxiety ranked the highest, along with changes in daily activities. Anxiety outranked fear of death, disability, or recurrence, loss, anger, guilt, worry, or depression. In Pecks

1972 study, cited in Silver and Wortman (1980), 49 of 50 cancer patients responded with feelings of anxiety and this anxiety was rated as severe in almost one-half of those interviewed.

In another study seventy-nine patients were interviewed before and approximately six weeks after a course of radiotherapy. The single variable which predicted functioning following radiotherapy was emotional distress-not concern, social support, symptoms, or unanticipated experiences. When the individual components of emotional distress were examined, the tension/anxiety subscale was the best predictor of functioning (Silverfarb and Greer, 1982).

Lewis notes that increased anxiety levels in cancer patients correlated with the length of time since diagnosis. She postulates that if patients through a history of non-control come to believe that what they do does not matter, and that it will not affect their situation, they see themselves as having no control. They can suffer anxiety, diminished sense of purpose, and lower self esteem (Lewis, 1982).

Early studies of cancer patients, survival, and psychological measures taken soon after diagnoses, suggest that patients who can remain less depressed, who feel angry without losing emotional control, and who can engender some sense of well-being survive longer (Cox, 1984).

BONE MARROW TRANSPLANT

Procedure

Bone marrow transplantation is rapidly becoming a common treatment for many types of hematology disorders and cancers including Acute Lymphocytic Leukemia (ALL), Acute Nonlymphocytic Leukemia (ANL), Chronic Myelogenous Leukemia (CML), Aplastic Anemia (AA), Hodgkins Disease, and various lymphomas, including breast and brain cancers (Fleischer, 1988; McGlave, 1985).

The procedure commences with a seven to 10 day "work-up" at the

Outpatient Clinic. This work-up includes lab and diagnostic tests, a medical record review, teaching and education about the transplantation, family conferences, bone marrow aspiration, pulmonary function studies, chest x-ray, electrocardiograph, and other diagnostic studies (FHCRC Handbook, 1989).

Upon admission to the inpatient facility a Hickman catheter is placed, and the patient undergoes a preparative regimen. This consists of a combination of chemotherapy and/or total body irradiation, fractionated over four to seven days, followed within one or two days by the bone marrow transplant. Marrow engraftment usually occurs between 14-28 days following the transplant, and the patient is discharged to the Outpatient Clinic usually within 30-40 days post-transplant. Patients remain in outpatient care for 100 days post-transplant for observation, medical care of complications, and stabilization (Duffy, Lewis and Tubbs, 1987; Cogliano-Shutta, Broda, and Gress, 1985).

Physiological Complications

The list of side effects, complications, and invasive procedures which accompany the BMT procedure can seem overwhelming. Common symptoms experienced by patients run the gamut from erythematous, pruritic rash of GVHD, and nose bleeds to abdominal cramping from infections. The most uncomfortable side effects of the preparative regimen include nausea, vomiting, diarrhea, and alopecia. Mucositis, where the oropharyngeal mucosa becomes denuded and very painful, is a common problem until the new marrow begins to produce white blood cells (Andrykowski, 1989).

Complications of bone marrow transplant are multiple and serious. Pancytopenia and immunodeficiency creates common risks for bleeding and bacterial, viral, and fungal infections (Fleischer, 1988). Renal disease develops in over half of BMT patients (Ford and Ballard, 1988).

Other common complications in the early weeks following trans-

plant include veno-occlusive disease of the liver, graft versus host disease (GVHD) and Mucositis. Interstitial pneumonia and cytomegalovirus (CMV) infection of the gastrointestional tract or lungs are major causes of death during this time (Fleischer, 1988; Freedman, 1988). Long-term complications include chronic GVHD, leukoencephalopathy, chronic lung complications, mental changes, hypothyroidism, sterility, loss in pulmonary function, eye cataracts, restricted growth, and relapse of the leukemia in the host cells. (Fleischer, 1988; Freedman, 1988; Nims and Strom, 1988).

Psychological Complications

Bone marrow transplant hospitalization is especially difficult psychologically. The protracted length of the hospitalization, the long-term isolation and related isolation procedures, complications from radiation and chemotherapy, and the complications from graft versus host disease, all contribute to emotional distress and difficulty coping (Brack et al, 1988). Approximately six stages of BMT with unique concurrent psychological demands and responses have been delineated, These are: the preadmission period, the conditioning regimen, immunosuppression and germ-free isolation, transplantation and waiting for engraftment, and hospital discharge and outpatient treatment (Haberman, 1989).

Emotional strains related to the BMT hospital experience include anxiety, uncertainty, depression and defenselessness (Hengeveld, Houtman, and Zwaan, 1988). Some of the emotional demands surround issues of waiting for results and treatments, imputing meaning and purpose to the treatments, uncertainties surrounding treatment outcomes, isolation, and loss of control (Haberman, 1987).

Cognitive and emotional responses of significant others to the transplantation experience are perhaps similar to those whose partners are undergoing heart transplantation. In these individuals, responses center around redesigning their dreams of returning to normal lifestyle

after the transplant. Over the course of the transplant, this belief is redefined to fit the reality of the medical/treatment environment. This includes redefinition of patient - partner roles, independence vs. dependence norms, and terms of permanence, vulnerability and stability of in regards to the future (Mishel and Murdaugh, 1987).

Nursing Care

A situation characterized by such intensity and length of sustained care creates a strong emotional relationship between the primary nurse and patient. Yet nurses are also under stress from the uncertainty about the benefits and risks of the technique, as well as the distress of increasing a seriously ill patient's discomfort (Brack et al, 1988).

One issue contributing to psychological distress the the possibility of double bind communications. A recent study by Brack, LaClave, and Blix (1988), while raising several methodological issues, outlines the double bind possibilities. In their study of bone marrow transplant unit staff members, they note the presence of a double bind between wanting to provide accurate information, while always trying to be optimistic and cheerful, and to protect the patient emotionally.

In addition, while the staff overwhelmingly felt that BMT was a good choice for patients, only 29.4% of staff agreed they would choose a BMT for themselves. Finally a double bind exists between expecting patients to be both compliant and adult-independent. This conflict extends through to weaning from the intensely supportive hospital environment to the survival period (Hengeveld et al, 1988).

Isolation

The extreme risk of infection which accompanies immunosuppression has led to the extensive use of patient isolation techniques. Laminar air flow rooms and protective isolation, including handwashing and masks, sterile food and oral nonabsorbable antibiotics are all in use today

(Freedman, 1988). Isolation creates its own psychological problems. Sensory deprivation includes restricted mobility, visual patterns, hearing, and human touch. Patients experience the altered taste of irradiated foods. The isolation tends to create a sense of security, it also creates an almost infantile dependency.

Patients often react to regain autonomy via aggressively controlling and influencing others. Loss of touch especially seems to create a sense of psychological distress (Lesko, Kern, and Hawkins, 1984; Haberman, 1987). Other sensations include a sense of coldness, frustration, and emotional distancing (Holland, Plumb, Yates, Harris Tuttolomondo, Holmes, and Holland, 1976).

The conclusion seems to be that the isolation unit does not itself create severe psychological distress, or sensory delusions. It does accentuate the distress of other concerns and/or cognitive impairments related to the disease and its treatments (Holland et al, 1976). Some studies note that passive-oriented individuals may tolerate the confines of the isolation better than more active individuals (Haberman, 1988).

Post-discharge

Post-discharge psychological complications include difficulty readjusting to the germy outside environment, and re-establishing relationships and roles (Rooymans, Kraal-Dingjan, Pluut and Zwaan, 1979). Fatigue, guilt,anxiety, fear, and relief are all common emotions in both the patient and the family during the recovery phase (Nims and Strom, 1988).

A comparison of mood states in BMT survivors with survivors of testicular cancer, lung cancer, and BMT donors shows greater mood disturbance, especially tension, depression, and anger, among BMT survivors (Andrykowski, Henslee, and Farrall, 1989). In one follow - up study of long term BMT survivors, 14 of 17 patients interviewed felt the BMT had negative social consequences, while 13 felt their personality had changed. All patients retrospectively felt the BMT and its' consequences had cre-

ated severe emotional strains, including anxiety, uncertainty depression and defenselessness (Hengeveld, Houtman, and Zwaan, 1988).

ANXIETY

Anxiety has been a common human experience for many years. The word anxiety comes from the latin root 'angor' which means transitory physical symptoms, and 'anxietas' which means an abiding predisposition to mental disquiet, uncertainty, and fear (Lader, 1984).

Anxiety, is defined for this dissertation as "a subjective experience of apprehension or tension imposed by the expectation of danger or distress or the need for a special effort" (Kelly, 1980). Anxiety is considered a normal response to threat or the absence of safety, but it can become dysfunctional when it is abnormally intense, frequent or becomes chronically associated with neutral events which are not dangerous or signaling danger (Kandel, 1983), yet are perceived as threatening (phobias).

A general approach to the etiology of anxiety begins by assuming all stimuli in the world, including the hospital environment, can be divided into three categories - neutral, conditioned stimuli, and unconditioned stimuli. Unconditioned stimuli are stimuli which engender an automatic response from an individual (such as withdrawal from pain). Unconditioned stimuli need to be paired with a conditioned stimulus (cues) to acquire a non-neutral significance, thereby eliciting a response (Clark and Jackson, 1983).

Stimuli pairing is thought to occur in animals and humans to ensure survival. This cognitive process allows an individual to recognize signals of approaching harm. As Pavlov stated in 1927 - "the sound of the beast signals the approach of its' teeth and claws" (Kandel, 1983). Another survival requisite - being able to recognize cues to harm enables the creature to predict the absence of harm - a factor essential in rest, rebuilding, and relaxation. Learning to link neutral stimuli and unconditioned stim-

uli to conditioned stimuli in order to predict danger is a primary mechanism leading to the development of both anticipatory and chronic anxiety (Kandel, 1983).

In anticipatory anxiety, the perceived conditioned stimulus signals the perceived approach of physical or emotional harm. In contrast, chronic anxiety occurs when the individual has already labeled a wide range of always present environmental cues as signaling threat, or when harm happens in the environment unpredictably and is not signaled by recognizable cues. Always anticipating harm as in chronic anxiety prevents the individual from achieving a calm and relaxed.

Physiological Mechanisms

There are many theories addressing the physiological response to threat known as anxiety. Most researchers agree that anxiety has both a somatic and psychic component.

Somatic Component

The somatic component of anxiety includes physical symptoms such as palpitations, tightness in the chest or throat, dyspnea, epigastric upset, tremor, dizziness, dry mouth, weakness, sweating, vomiting, paranesthesia, faintness, headache, facial pain and cold extremities (Bass, 1984; Lader, 1980). These symptoms occur through the stimulation of the autonomic nervous system with concurrent increase in plasma catecholamine concentrations (Fell, 1985). Catecholamines, especially epinephrine, act on end point target organs to produce a somatic response which in turn produces the symptoms of anxiety.

Many of these responses interact with each other. For example, epinephrine release in response to threat causes hyperventilation which in turn leads to respiratory alkalosis. Respiratory alkalosis causes increased beta - adenoreceptor responsiveness which feeds back to further stimulate hyperventilation (James, 1984). Respiratory alkalosis also

causes increased vasoconstriction and decreased cerebral oxygenation which increases heart rate (Pfeffer, 1984).

Adrenal medullary secretion is controlled by stimulation through the sympathetic nervous system pathway. Among the stimuli known to elicit increased secretion are cold, pain, anoxia, hypoglycemia, hypotension, hemorrhage, burns, physical exercise, psychosocial stimuli, and pharmacological agents, including caffeine, nicotine, and alcohol. Conditions characterized by novelty, anticipation, unpredictability, and change usually produce a rise in epinephrine output (Frankenhauser, 1975).

Psychic Component

For the purposes of this paper, the psychic component of anxiety will be addressed at the neurochemical level of brain functioning. At the neurochemical level, several theories have been proposed in recent literature regarding the etiology and treatment of anxiety. Brain epinephrine, endogenous opiates and benzodiazepines, purines, and gamma-aminobutyric acid (GABA) have all been implicated in pre-clinical trials (Charney, 1983).

One very interesting theory concerning physiologic changes due to anxiety has been formulated by studying the marine snail Aplysia. Eric Kandel (1983) and his associates have been able to demonstrate both anticipatory and chronic anxiety in Aplysia. Using Pavlovian conditioning techniques, Aplysia were exposed to systematic pairing of electric shock with a shrimp smell. After pairing, the researchers found behavior consistent with anticipatory anxiety (defined as increased escape locomotion in conditioned snails) with the presentation of the shrimp smell alone.

They also found evidence of chronic anxiety (defined as a generally heightened responsiveness) which was unaffected by the presence or absence of the shrimp smell cue, when shock was administered randomly. After examination of the neurons of the anxious Aplysia, and reviewing other pharmacological and biochemical studies, these researches proposed

the following biochemical cascade which occurs when the defensive arousal system is activated.

Normally as an action potential moves toward a synaptic terminal of the sensory neurons, it depolarizes the terminal and produces an action potential in the terminal. The depolarizing effect of this action potential allows calcium, and then potassium to enter the cell. The potassium repolarizes the cell and turns off the calcium channels. Calcium is a critical element in cell functioning as it allows transmitter containing vesicles to bind to discharge sites - in preparation for release of neurotransmitter into the synaptic cleft.

In anxiety, the hypothesis suggests, the anxiety producing stimulus causes facilitating neurons to release 5HT (Serotonin). 5HT acts on a 5HT receptor in the presynaptic terminal of the sensory neuron, activating adenylate cyclase which increases cyclic AMP in the terminal. This AMP activates a protein kinase which phosphorylates a certain potassium channel protein. Phosphorylation changes the protein, which closes these specific potassium channels and thus reduces the repolarizing current. Since the cell stays depolarized longer, more calcium flows and more transmitter is released. The behavioral effect of the sequence is a heightened responsiveness which seems to be similar to that seen in anxiety (Kandel, 1983).

Anxiety has been considered to be a state of overarousal of the central nervous system (Greenspan, 1979). Increased arousal is manifested by an increased number of neurons firing per unit of time. This is what happens with alertness, concentration, or flight/fight reactions in response to chronic cues of threat. Another theory in the literature postulates that this over-arousal, anxiety, is mediated through excessive epinephrine output, slow removal of epinephrine from the receptor sites, or excessive receptor sensitivity (Mathew et al, 1982). Norepinephrine is one catecholamine currently linked with anxiety. Early work in the 1940's demonstrated that norepinephrine was an adrenergic neurotransmitter

and adrenomedullary hormone (Frankenhauser, 1975).

Evidence that epinephrine is related to anxiety comes from studies of the alpha-2 adrenergic autoreceptor antagonist drugs Yohimbine, and Piperoxane. Given to human volunteers these drugs, which act to increase adrenergic turnover, induce anxiety states in normal subjects (Heninger, 1983). They also increase plasma MHPG levels, and this significantly correlates with subjective yohimbine produced anxiety states. MHPG (3-methoxy-4hydroxyphenylethyleneglycol) appears to be the major metabolite of brain epinephrine, and plasma MHPG levels have been demonstrated to reflect brain MHPG levels (Charney et al, 1983).

GABA is thought to be the most common inhibitory neurotransmitter in the brain (Nestoros, 1984). Firing of GABAergic neurons, however, above certain frequencies leads to failure or "fading" of these neurons. This in turn causes decreased inhibitory effects of GABA, and hyperexcitability of the cortex (Nestoros, 1984).

The general alarm system in the brain which alerts the brain to threat is postulated to be noradrenergic neurons whose cell bodies are in the locus coeruleus, and whose axons travel intensively to other brain areas. The counteraction to the alarm system is thought to be the GABA inhibitory neurons throughout the brain. Overactivity of the alarm system "triggers" the rapid firing rate, and eventual fading of potency, of GABAergic neurons which further enhance overactivity of the alarm system (Uhde, 1984; Nestoros, 1984). This is one speculative link among several theories of anxiety.

Anxiety: Psychosocial

The cognitive component of anxiety includes personal beliefs, constructs, assumptions and expectations about how the world works and one's role in the world. How information is acted on is the result of the interaction between the individual's personal characteristics and environmental events. Anxious preoccupation may arouse emotions that interfere

with the perception and appraisal of events and of the reactions of others. This is likely to produce errors and uncertainties in interpersonal behavior. High anxiety is associated with high levels of irrational beliefs (Sarason, and Sarason, 1986)

Threat is the intervening variable, perceived and appraised, underlying all negatively toned affects. (Keily, 1972). High anxiety subjects who experience failure have a greater need to maintain self-esteem (Frey, Stahlbert and Fries, 1986). High anxiety subjects perceive self-relevant situations as more self threatening than do their low anxiety counter parts, also experience failure with greater discomfort. Anxious subjects are generally very self-preoccupied, and tend to devaluate themselves after a failure (Frey et al, 1986).

Psycho-Somatic Relationship

There appears to be feedback loops operating between the mind and the body. The mind is directing a continual loop of perceptual recognition of cues, and rumination of these inputs. The body is operating a system of somatic arousal, sending sensory messages altered by arousal to other organs and back to the brain. As the brain is ruminating on it's arousal messages influenced by memories, cues, emotional responses, cognitive thought processes, etc., it is sending a steady stream of information indicating arousal to the body. The body responds by activating and tensing even more and sending elevated arousal messages back to the brain, to spur on the brains' hyperarousal state (Snyder, 1985).

ANXIETY AND ILLNESS

There are several separate ways in which anxiety can affect illness and hospitalization:

1. Anxiety can generate it's own physiology, there are 21 different symptoms of anxiety from palpitations, to nausea, to fatigue, to respira-

tory distress (Bass, 1985). Any of these symptoms, may increase the discomfort of illness, or be mistaken for illness symptoms.

2. Anxiety alters symptom appraisal. Perception and appraisal processes strongly affect illness phenomenon, and anxious preoccupation with oneself or the world around one, tends to skew that perception (Lazarus and Folkman, 1984). Anxiety can increase the perceived intensity of negative symptoms such as pain or nausea (Leventhal, 1982).

3. Anxiety increases the demand on an individual. It competes for time and attention; it draws on already taxed resources - coping, listening, learning; it demands emotional reserves, confidence, and courage. The individual is left drained and vulnerable as subsequent crises occur (Silver and Wortman, 1980).

4. Anxiety changes priorities away from physical illness. The individual's focus changes from reducing danger, to reducing fear (Imboden. 1972). This is a coping response which may actually increase danger. Anxiety can cause the person to resist the diagnosis, and to devalue the authority of the provider or his/her interventions (Gottschalk, 1983).

5. Anxiety causes secondary, unrelated illnesses. Attempts to cope with anxiety may cause complications related to drugs, alcohol, tranquilizers or smoking. Anxiety has been found to be a major predictor of angina. It has been implicated in ulcers, hypertension, and cardiovascular arrhythmias. It can decrease resistance to infection, suppress the immune system, and cause insomnia.

6. Anxiety interferes with social aspects of illness care (Twaddle, 1972). It is often perceived as voluntary and the failure to control anxiety beyond a certain period may be seen as a weakness, or a sign of lack of motivation to recover (Silver and Wortman, 1980). Being around an anxious person makes caregivers uncomfortable and frustrated, and may compel them to withdraw their support (Kruglanski, 1983). They may even invoke negative sanctions on the patient. In health care personnel, frustration with anxiety or anxiety related behaviors may invoke the

diagnosis of "problem patient" (Lorber, 1981).

7. Finally, if anxiety is manifested as fatigue, weakness, restlessness, anxorexia or insomnia, the patient may be regarded and treated as if the original illness was persisting (Imboden, 1972).

COPING

For the individual attempting to manage the demands of the surrounding environment, coping serves two main functions. These include changing the uncomfortable situation, and regulating the accompanying emotional distress (Wrubel, Benner, and Lazarus, 1981). Coping includes cognitive and behavioral processes, emotional reactions, and physiological responses (Silver and Wortman, 1980).

Cognitive processes are thought to play a major role in an emotional response such as anxiety, as they are used to evaluate and interpret stimuli. A person's cognitive appraisal of the stressful situation includes two categories, threat appraisal and coping appraisal (Rippetoe and Rogers, 1987). These appraisals influence the emotional responses that are elicited, the additional coping strategies that are employed, and the ultimatesuccess of a person's adjustment to the crisis (Silver and Wortman, 1980).

For patients there are four major appraisal-related categories of concerns: disease related concerns, personal related concerns, family related concerns, and social related concerns (Derdiarian, 1986). Coping strategies used in the hospital include information seeking, direct action, turning to others, and intrapsychic coping such as avoidance, imagery, and positive thinking (King and Gregor 1985).

In one study by King and Gregor (1985) of patients undergoing coronary artery bypass grafting, the researcher found that these patients used information seeking the most prior to surgery. Post surgically, information seeking was used to compare the self to others, followed by turning

to family and friends. Other clinical studies examined the effects of enhanced coping in patients. Subjects receiving accurate sensation description preparatory to pain showed less intense emotional response than procedural information (Johnson, 1986). This effect has been demonstrated in gastroendoscopy, cast removal, and health examination (Derdiarian, 1986).

Information seeking is a coping mechanism closely related to the perceptions of uncertainty. Derdiarian (1986) notes that information seeking is the primary mode of coping with threatening events. The nature of seeking varies by two factors: the perceived harms, threats or losses related to the noxious event, and informational needs or deficits perceived as associated with the event.

Other coping includes defenses aimed at conservation of energy, which includes regression, possibly leading to dependency and helplessness. Defenses aimed at excluding the threat from awareness includes denial and rationalization. Finally, defenses aimed at mastery and control include intellectualization and acceptance (Verwoerdt, 1972).

Various investigators have suggested coping factors which lead to disease include: the way the individual copes; the failure of the individual's coping efforts; the emotional state of giving up; having specific psychological conflicts that affect the coping process, and, having maladaptive personality traits (Cohen, 1979). Coping failure occurs when one of two things happen: the person lacks the requisite coping strategies and resources, or uses coping strategies that are inappropriate or ineffective due to the uniqueness of the situation (Wrubel et al, 1981).

Evidence in the literature suggests that emotional distress, a common indication of inadequate coping, increases when the person: is exposed to a source of stress with little or no time for anticipatory preparation, experiences a stressor for a prolonged period of time, experiences multiple stressors concurrently, is exposed to an ambiguous or uncertain event, or is exposed to an event that involves an important aspect of life,

such as health or survival (King and Gregor, 1985).

Finally, an important impact of the emotional process of coping is that individual may seek care in order to control his or her emotions rather than to receive treatment for the underlying physical disorder, or the situational events stimulating either the symptom or the emotion. (Leventhal, Nurenz and Straus, 1982).

UNCERTAINTY

Uncertainty has been described as one of the universal features of anxiety and possibly it's main driving force, yet the source of this uncertainty is often difficult to find (Tyrer, 1982). Uncertainty is defined as a cognitive state created when an event cannot be adequately structured or categorized because sufficient cues are lacking. The decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes in situations characterized as vague, ambiguous, unpredictable, unfamiliar, inconsistent or lacking information. Unable to locate an agent of harm, the individual is compelled to use vigilance and avoidance coping mechanisms (Mishel, 1984).

Uncertainty is frequently further subdivided into risk and ambiguity. Risk occurs when the outcomes are unknown, yet have a specific probability of occurrence, ambiguity ensues when the outcomes are unknown and have unspecified probabilities of occurrence (Curley, Eraker, and Yates, 1984). It is the perception of ambiguity which creates the difficulties in illness and hospitalization.

Elements which affect the development of uncertainty in illness include the event familiarity, congruency of the symptom pattern, as well as the congruence between expectations and the reality of illness related events. Symptom pattern congruency includes consistent symptom display, salience of symptoms, and distinguishability. Event familiarity includes symptom habituality, repetitiveness, or recognizable cues (Mishel

and Brandon, 1988).

These antecedents are influenced also by structure providing elements of education, social support and credible authority, whose function is to assist the patient in determining pattern and familiarity of symptoms (Mishel and Branden, 1988).

Uncertainty and Hospitalization

Predictability in situations allows some confidence that the self can act to create desirable effects, whether it is recognizing a difference, avoiding the onset, or "steeling" the self to "get through it". When aversive events are predictable, the patient can plan coping efforts so the stressor creates mimimal disruption (Wallston, Smith, K. Wallston, King, Rye and Heim, 1987). Other elements include the information processing ability of the patient, and personal resources available to aid in interpreting illness related events (Mishel, 1988).

By itself, a symptom is inherently ambiguous. The process of health status designation can be seen as an attempt to reduce ambiguity, consisting of interaction between an individual and his status definers in which normative standards of adequacy are applied to the individual in the context of a specific situation to assess his capacities for present or future task performance (Twaddle, 1972). Situations of high ambiguity create decision avoidance and deferral (Curley et al, 1984), and promote vigilance and anxiety.

In a high threat situation, such as serious illness, uncertainty can force an individual into the constant arousal of vigilance. The impact of uncertainty can cause neutral incidents to be evaluated as threatening and misinterpreted as potentially ominous signs (Mishel, 1984). Cohen and Martinson (1988), note that parents of children diagnosed with cancer are unable to appraise typical growth and development changes as normal, but instead see all changes in the child or siblings as alarming. They seek medical support and use other 'danger appropriate' coping strategies.

These appraisals imply a strong aversion to being 'caught off guard' again.

In the hospital uncertainty has been linked with low comprehension of treatment regimens, a pessimistic view of the present and future, and a precursor of difficulties in psychosocial adjustment (Mishel, 1983). A 1975 study by Hackett and Cassem of myocardial infarction patients found that patients rated unfamiliarity of surroundings, and lack of information about medical devices as the most stressful events of hospitalization (Hackett and Cassem, 1975).

Other concerns include being unable to understand hospital jargon, or to predict the discomfort, pain, and intensity of anticipated experiences (Mishel, 1984). Finally, in hospitalized patients, uncertainty has been related to more emotion focused coping, and increased emotional distress, which persists after discharge (Christman, McConnell, Pfeiffer, Webster, Schmitt, and Ries, 1988).

Much of the research which has been done on uncertainty in the health care setting surrounds the effects of preparatory information designed to increase treatment related predictability on the reduction of emotional distress. Multiple studies have demonstrated that preparatory information reduces patient distress (Mishel, 1984). In a 1979 study by Johnson et al. of women undergoing cholecystectomy surgeries, women given sensation information and an action plan were discharged a full day earlier than controls, and were on their feet and out of their homes 3 days earlier (Leventhal, Nerenz, and Straus, 1982).

Cancer is also set apart due to the high uncertainty of it's outcome. Both recurrence and prognosis are highly uncertain. Also, while it is in actuality a chronic disease, it is attacked with the vigor of an acute illness, which increases the feelings of helplessness and uncertainty linked to the disease (Silberfarb and Greer, 1982).

Haney (1984) lists some of the uncertainties which require a coping response in the cancer victim. These include threats to life, bodily integrity and comfort, disability, permanent physical changes, incapacitation,

self concept, future plans, loss of control, emotional equilibrium, threats to social roles and activities, needs to adjust to new physical or social environments, and need for decision making in stressful and unfamiliar situations (Haney, 1984).

CONTROL

Control is defined as the ability to regulate or influence one's behavior or environment in a given situation (Wallston et al, 1985). Social situations are often at odds with individual goals, and the task is then to overcome those odds to avoid moving in directions not chosen (Wrubel, Benner, and Lazarus, 1981). Control falls into multiple topologies: Choice is behavioral control; predictability refers to the control gained by knowledge.

The perceptions of freedom and control do have consequences. The effects of random noise, especially of higher intensity, is to reduce attempts at an insoluble problem solving task. When shock is the aversive stimulus, Straub, Tursky and Schwartz (1971) found that subjects who self-selected the intensity, and self-administered the shock endured stronger shocks and reported less discomfort at higher levels of shock than did paired subjects passively receiving shock.

However, when all subjects engaged in a second series of shock trials conducted without subject control, the previously self-controlling subjects lost their tolerance. This group rated lower intensity shock levels as more uncomfortable and endured less shock than the earlier trial. There was no change in the group passively receiving shock (Lefcourt, 1973).

The mere knowledge that one can exert control serves to mitigate the debilitating effects of stressful stimuli. This was demonstrated in one study where subjects, who could flick an "off" switch if aversive noise became too loud, tried almost five times the number of insoluble puzzles

than subjects given no option to control aversive noise (Lefcourt, 1973). In experiments where subjects are exposed to unpredictable and uncontrollable electric shocks. Epinephrine excretion was about three times as high as during a relaxation period. Where subjective arousal remains at a high level, epinephrine output also stays high (Frankenhauser, 1975).

It is the perception of uncontrollability over an important outcome, not the physical stressor itself, that causes stress related reactions (Cohen, 1979). Lack of control and lack of anticipation increase the severity of the event as a stressor and reduce the ability to adjust to it. Normally small hassles may become large stressors in novel environments (Vinokur and Caplan, 1986).

Stress responses arise when one feels compelled to respond to a situation for which one has no adequate response, and the consequences of failure to respond effectively are important to a person (Suls and Mullen, 1981). Seligman (1983) argues that continual exposure to uncontrollable events frequently results in a psychological state of helplessness, including a lower sense of control over outcomes, depression, and decreased motivation to initiate new problem solving approaches.

Laboratory studies of students in various control situations, indicate that when the difficulty of maintaining control becomes sufficiently high, subjects simply "give up", and simply endure the aversive stimulus (Wright, 1984). Loss of control may add to the lack of positive events, and be a substantial source of stress, as well as preventing rest, and rejuvenation from dealing with the presence of negative events (Kanner, Kanfry, and Pines, 1978).

Control and Hospitalization

In hospitalized patients, a low sense of control is significantly associated with less self-initiated preventive care, less optimism concerning the efficacy of early treatment, poorer self-rated health, less patient education, more illness episodes, more bed confinement and greater depend-

ence upon the physician (Speedling and Rosenberg, 1986).

One of the basic requisites for maintaining a sense of control is sufficient power. Patients have no sustaining source of power. The sources of powerlessness and loss of control are multiple, stemming from the patient role, the limitations of the illness and the environment, and interpersonal power issues. Although "experts" in their own body and illness, this expertise is generally not recognized and is ascribed minimum power. Any financial power is minimized by it's cost in inconvenience, effort, and potential reduction in health care. Coercive power is often limited to threats of malpractice. Rewardant power is limited to verbal or written praise (Northouse, 1985).

While patients are powerless, physicians and nurses are powerful. Their familiarity with the environment, technical and medical knowledge, and ascribed role authority give them power which is expert, legitimate, rewarding, coercive, and mystical. Nurses using position-centered strategies naturally assume that the authority of the care giver role provides the implicit right to control patient's behavior.

The comprehensiveness, immediacy, and continuity of nursing care provides opportunity for powerful influence (Gadow, 1980) To this end, nurses use commands, directives and compliance-gaining appeals based on rule and role power in what they see as an efficient, appropriate, and competent way to influence attitudes, beliefs and actions (Kasch and Knutson, 1985). A literature review by Miller (1984) cites multiple studies which find that dependency is verbally and nonverbally reinforced by nursing staff, especially in elderly clients. This reinforcement, combined with social and physical deprivations found in the hospital experience, reinforce the state of loss of control.

A study asking staff what constituted good vs. problem patients in the hospital, supported the contention that problem patients were those who created trouble for the staff. These included patients whom staff felt were uncooperative, constantly complaining, overemotional, and depend-

ent, had deviant attitudes. or required more than the average amount of time. Any patient resistance to the assigned patient role, or to losing personal control runs the risk of being confronted and labeled as troublesome (Lorber, 1981).

In a significant sense, the sick person is defined as helpless and not responsible for his condition. He is supposed to see it as undesirable, and has an obligation, in proportion to the severity of the condition, to seek technically competent help, cooperate completely with the physician, defer to professional authority, and make every effort to get well (Kasch, 1986; Twaddle, 1972).

A large part of this illness role, especially if hospitalized, is to accommodate the self to being in the hands of strangers, accepting a relatively passive-dependent position, cooperating, informing physicians and nurses of needs without overdoing it, and tolerating the peculiar features of hospital life, including the omnipresent background of suspense and uncertainty (Imboden, 1972).

Failure to cooperate may be seen as trying to prolong the illness, and is interpreted as not wanting to get well (Twaddle, 1972). Indeed patients own potential resources are often ignored if those resources conflict or compete with the dependency role. (Northouse, 1985). Patients themselves may hold back attempts at gaining power, perceiving that increasing their participation and demands will erode their image of medical staff as authorities, with the backlash of increasing their own sense of uncertainty (Haney, 1984).

One study conducted in a large urban hospital noted that sixty eight percent of patients interviewed reported that they had refrained from expressing their fears, desires, feelings, or criticisms to the nurse or doctor. Reasons included the understanding that being a good patient included being self controlled and minimally dependent (M. Johnson, 1979).

The outcome of these hospital related losses of control is sick role

behaviors, and staff perceptions of patients which reflect the patient's struggle between autonomy and compliance. Investigators have identified specific behaviors that make up the sick role. These include demands for care and attention, displays of helplessness, excessive compliance, veiled hostility, threats of harm to self, threats to leave treatment if more help is not forthcoming, argumentiveness over details of treatment, dividing professional staff, and silliness. Patients often appear to elicit behaviors from practitioners and other patients that encourage and reinforce the illness role (Leventhal, Nerenz, and Straus, 1982).

Finally, the patient loses control because he is sick. The healthy client can make adjustments in his environment. He can rearrange furniture, move about to avoid unpleasant noises, odors or lights. He can leave. Patients have to simply accept the situation as it is given to them (Kornfeld, 1972).

Cancer is set apart from other illnesses in it's lack of patient control over treatment of the disease. Chemotherapy, surgery or radiation are all medical specialist dependent. All the patient can do is treat the side effects of the disease. Exercise, diet, self-medication are all ineffective (Silberfarb, and Greer, 1982).

Cancer is also set apart due to the high uncertainty of it's outcome. Both recurrence and prognosis are highly uncertain, also, while it is in actuality a chronic disease, it is attacked with the vigor of an acute illness, which increases the feelings of helplessness and uncertainty linked to the disease (Silberfarb and Greer, 1982). Lewis (1982) in her study of fifty-seven adult cancer patients notes that greater experienced personal control over an individual's life was significantly associated with lower self-reported anxiety (-.33 p=.001).

HASSLES

Hassles also known as demands, are defined as the irritating,

frustrating, distressing demands that to some degree characterize everyday transactions with the environment (Kanner, Coyne, Schaefer, and Lazarus, 1981). Hassles, as experiences appraised as salient, and harmful or threatening to the endorser's well-being, can tax or exceed the individual's resources (Lazarus, 1984). Categories of hassles include environmental events, chronic environmental conditions, ongoing worries or concerns, and distressed emotional reactions (Lazarus, 1984).

Interest in the concept of hassles has arisen both from major life events (MLE's) research, and the growing realization that objective life circumstances have repeatedly proved inconsequential predictors of well-being (Zika, and Chamberlain, 1987). MLE's main influence may be to increase daily hassles, and to affect the person's pattern of daily hassles (Kanner, Coyne, Schaefer, and Lazarus, 1981). As such, hassles are thought to be the better predictor of physical and psychological health (Reich, Parrella, and Filstead, 1988).

The impact of hassles on physical and mental health depends on many variables such as a chronically high frequency of hassles, the heightening of hassles during a given period, as in crisis, or the presence of one or a few repeated hassles of compelling psychological importance (Kanner, Coyne, Schaefer, and Lazarus, 1981).

The effect of hassles goes beyond anxiety. One common reaction to chronic daily hassles and stress is the experience of tedium, physical, emotional and attitudinal exhaustion. Contributions to this exhaustion include much negative and few positive life and work aspects, as appraised by the individuals subjective look at relevant features of the environment (Kanner, Kaffrey and Pines, 1978).

Hassles are positively related to more frequent and severe pain, drinking, and smoking (Sternbach, 1986). Volicer found that patients scoring high in hospital stress and demands reported lower physical status, less improvement after discharge, and a lower degree of return to usual activities than patients scoring low in hospital stress (Speedling and

Rosenburg, 1986).

Several etiologies affect the generation of hassles. Change may be a source of hassles. Because individuals tend to be effort minimizers, a large proportion of behavior is habitual, i.e. reflexive or unconscious. People respond to the world about them on the basis of decision rules, habits, and routines of daily living and do not ponder over every decision, although contextual and structural factor do modify the process (Haney, 1984). Change disrupts this everyday routine by multiplying the roles one must play, the choices one must make and the new patterns one must learn in order to survive (Owen, 1983).

The loss of the work role may be a potent source of hassles related to distressed emotional reactions. For many individuals, work is vital to their emotional and economic well-being. The demands related to loss of employment, including reappraisal based on societal values of adequacy, economic loss, self-esteem changes, power and prestige changes, may be overwhelming to the cancer patient (Feldman, 1984).

Hassles may be cumulative, and build in a nonadditive way as the individual becomes taxed and exhausted. If a person is feeling particularly taxed, events typically ignored, or viewed positively, may take on a negative coloration. Hassles, as stressors which require attention and response, may deplete coping reserves and leave one especially vulnerable for adjustment problems at the next crisis (Silver and Wortman, 1980). Some hassles are created when another has more control and is inconsiderate of the patients needs and feelings. The question arises of whether perceived causality of this sort increases the noxiousness of the hassle (Kasch and Knutson, 1985)

Finally, hassles are related to characteristics of the individual. In order to understand the individual's perceptions of the stress of illness, Verwoerdt (1972) lists characteristics of the host which affects his interpretations of events as stressful or non-stressful. These include the amount of intrapsychic conflict pre-existing prior to the illness, the age

and sex of the individual, the body image, and premorbid personality characteristics.

In a study of 45 randomly selected and representative surgical patients 65 years and over, depression of a disabling degree appeared in 22 of them. The principal psychodynamics leading to such severe depression were: the perception of a lack of capacity to resist everyday stress; hostility and guilt; the perception of defects in body image; the loss of self-esteem; the impairments of ability to remain active (Gottshalk, 1983).

Finally, cancer itself causes multiple changes in the individual's lifestyle. It can place tremendous demands on the individual. Family difficulties, including interpersonal relationships, financial difficulties and trouble communicating about important issues all have been reported in multiple studies on cancer patient's (Benedict. 1988).

DEMANDS OF HOSPITALIZATION

Fluctuation in perception of demands in the hospital may be related to events which are significant, imminent and likely to occur, and thus assume more importance, both as a stressor, and as an indication of changes in function, control, certainty,or self image (Derdarian, 1985). Thus awareness of demands may alternate. During tests and procedures, demands are related to direct illness related concerns. In between, at night, while waiting or resting, other concerns surrounding jobs, career, plans, goals, and social relationships gain a momentary foothold.

Reactions to the stressors of hospitalization have been demonstrated by measurable physical changes. Newly admitted patients have exhibited increased urine potassium and corticosteriod levels. Blood pressures were higher shortly before hospitalization than before surgery or discharge (Hart and Kinney, 1981).

Sources of Demands

Hospital related demands may be created or compounded through ignorance and lack of communication between the nurse and patient. Literature shows that many patients are reluctant to reveal significant information about themselves to nurses, and nurses in turn, are reluctant to disclose significant and appropriate information about themselves to patients.

Tagliacozzo as reported in M. Johnson (1989), found patients cited multiple reasons for refraining from expressing their feelings desires, fears, or criticism to either the nurse or the doctor. These included: fear of negative reactions from the nurse, fear of unsatisfactory answers to their questions, and their perception that the nurse was always overworked. In another study, 86% of cancer patients studied wished that they could discuss their situation more fully with someone (Silver and Wortman, 1980).

Nurses, on the other hand, sometimes limit communication to avoid the anxiety producing situation of having the patient question or evaluate their knowledge, performance or authority (Johnson, 1979), or when other nursing priorities take precedence (Roberts, 1982). Nurses are often unaware of the source of the patient's uneasiness, since they generally perceive themselves as always being supportive and helpful to them (Johnson, 1989).

Preconceived threats are often reinforced by the stimuli of fearful sights, smells, and sounds of the hospital environment, proximity to others, lack of privacy, routines which clash with personal autonomy, and medical expectations of staff about patient behavior (Verwoerdt, 1982).

Physical conditions of density and sound are considered environmental stressors when they are defined by the individual as unwanted. (Cohen, 1979). In the hospital, people do not want to hear their neighbors nor vice-versa. This is especially true when the sounds one is exposed to contain meanings that one would rather not hear. Unwanted noise can ac-

tually generate a physiological response in a passive listener. Ones' annoyance increases when one is forced to participate, even passively in an unwanted interaction (Cohen, 1979; Topf, 1985).

Other hospital related demands stem from the following stimuli: Being around serious illness and death 24 hours a day; Anxiety provoking machines, tests, and therapies which staff sees as "routine"; Confusing bedside rounds; feeling separate from normal life and activities; expected to function at a childlike level; loss of dignity; interrupted sleep; and immobility (Kornfeld, 1972). Demand related stimuli in the intensive care environment surround loss of independence, high noise levels, constant flurry of activity, lack of familiar faces, and interruptions of rest (Heater, 1985). Therapeutic measures and devices such as anesthesia, traction, intravenous therapy, catheters and nasogastric tubes provide additional physical stressors (Hart and Kinney, 1981).

Exposure to routines and administrative structures of the hospital which convey to the patients a sense of being seen as an object, number, or diagnoses, long waiting periods which seem like abandonment, and the dehumanizing sense of being "done to" are all stressor and demand related issues (Hart and Kinney, 1981). In the interest of space and safety of people and possessions patients are advised to keep only a minimal number of possessions and clothing with them, and they must live stripped of environmental props that identify their social status. Patients have no control over room choice roommate choice, cleaning, drinking eating and medication schedules. They lose control over the bed night stand, table, care, and call light. Finaly patients things are put away or put out of reach. These loses eliminate control in almost every dimension (Cohodes, 1985).

Attempts to reduce stress responses in the hospital have focused on several interventions: Nursing interventions designed to provide psychological support and /or teaching which are assumed to reduce psychological stress responses have been shown to reduce pain, length of hospitaliza-

tion, postoperative vomiting, narcotic use, and earlier discharge (Volicer, 1977). Preoperative visits by the anesthesiologist have been shown to be a much more powerful tranquilizing agent than pentobarbital, especially when combined with pentobarbital (Egbert, 1986)

In hospitalized psychiatric patients undergoing group therapy, there was a positive relationship between the levels of accurate empathy, nonpossessive warmth, and genuineness elicited by the therapist and the degree of patient improvement. There is no neutrality in human encounters: if helpers do not help, they hurt. (La Monica, 1979).

CHAPTER 3

Pilot Study

STATEMENT OF THE PURPOSE

This pilot study was for questionnaire development utilizing literature review and content area expertise from several subgroups related to the domain of demands. Individual subjects were chosen via purposive and convenience sampling, and categorized into one of four groups. The purpose of this study was to develop an instrument to accurately and reliably measure hospital related demands as perceived by the patient hospitalized for bone marrow transplantation.

METHODOLOGY AND DEVELOPMENT OF THE QUESTIONNAIRE

First, a list of items was gathered from a review of current literature in areas as closely related to hospital generated demands as possible. This included literature on the hospitalization experience, the patient role and illness related needs, anxiety and coping, stress, loss of control, uncertainty, and the nursing care of hospitalized patients.

Related measurement tools examined for demand related content include the original Hassles scale (Kanner, Coyne, Schaefer, & Lazarus, 1981), The Demands of Illness Inventory (Woods, Packard, and Haberman, 1987), The Scale of Humanistic Nursing Behaviors (Fenton, 1987), The Miller Hope Scale (Miller & Powers, 1988), The Mishel Uncertainty in Illness Scale (Mishel, 1981), The Patient Satisfaction Scale (La Monica, 1986) The Hospital Stress Rating Scale (Volicer, 1973), and the Derdiarian Informational Needs Scale (Derdiarian, 1986).

This literature search resulted in a list of 153 possible hospital related demands. These demands were grouped into thirteen content-related subgroups (Table 1). In addition , Space was provided to list up to four additional demands of specific concern to the respondent. Ratings, on a

Table 1: ***Name and size of pilot questionnaire subgroups***

GROUP #	TITLE (DEMANDS RELATED TO)	# ITEMS	GROUP #	TITLE (DEMANDS RELATED TO)	# ITEMS
1	Comfort and Pain	17	8	Mobility	04
2	Day to Day Life	20	9	Personal Care	09
3	Power in Relationships	16	10	Loss of Everyday Routines	08
4	Relationships with Staff	10	11	Situational Worries	10
5	Attitudes toward Staff	07	12	Hospital Environment	14
6	Pers. Family and Friends	08	13	Feelings and Emotions	20
7	Privacy	10	**ITEM TOTAL**		**153**

five-point Likert type scale (from 1 - rarely occurring to 5 - very often) were used as a subjective projective measurement of demand frequency. Subjects were told to mark "not applicable" if they felt unqualified to make a response, or if the item was not applicable to their experiences.

Subjects:

This pilot study questionnaire was then administered in four phases to four separate groups of subjects at the University of Washington, Fred Hutchinson Cancer Research Center (FHCRC), and Swedish Hospital Medical Center (SHMC) (Table 2). All subjects were asked to review the questionnaire, to identify idiosyncratic items and suggest additional demands. They were encouraged to write alternate wordings to

clarify questionnaire items. General criteria for inclusion in the study included the ability to communicate in English, over 18 years of age, a signed consent form, and the ability to understand and respond to the questionnaire.

Table 2: ***Pilot Study Questionnaire - Subgroup Populations***

ORDER	POPULATION	# SUBJECTS
Group 1 :	Community Sample: Previously Hospitalized patients	20
Group 2 :	Community Sample: Health Care Professionals	10
Group 3 :	FHCRC and SHMC: Staff Nurses	10
Group 4 :	FHCRC and SHMC: Recently Discharged BMT patients	10

Group 1:

This group consisted of a convenience sample of 20 individuals who had experienced a minimum of one illness related hospitalization (greater than 24 hours) in the previous five years. Since demands are predominantly subjective, and hospitalization is an unique experience in our society, these individuals were considered substantive system experts, as they had acquired knowledge via experience rather than formal training or education.

Group 2:

This group was a purposive sample of 10 professionals in the field, including staff nurses, stress management clinicians, and nurse researchers and educators in psychosocial nursing. These were considered conceptual system experts (who spend time and effort attempting to generate, develop and clarify knowledge from the conceptual domain). Since hospitalization, anxiety, and health are a concern for many health care professionals, these people had studied related literature and were considered competent to identify potential hospitalization demands. They were asked to draw upon professional opinion, as well as personal experience, to

respond to questionnaire items.

Group 3:

This group consisted of ten staff nurses currently working on inpatient Bone Marrow Transplant wards at Fred Hutchinson Cancer Research Center (FHCRC) and Swedish Hospital Medical Center (SHMC). Information was gathered from these subjects in an attempt to reflect concerns and priorities more approximate to those of the main study sample.

Group 4:

The final group of subjects administered the pilot questionnaire included a purposive sample of ten recent inpatients at Fred Hutchinson Cancer Research Center who had been discharged from their initial impatient treatment within the prior 2 weeks. These subjects were considered the most experienced and familiar with the concerns and priorities of the main study sample. Specific inclusion criteria for this group included willingness to read and sign the consent form, between 18 and 60 years of age, with the following diagnoses: Leukemia (including AML, AMML, AMOL, ALL, CML), Multiple Myeloma, Non Hodgkins Lymphoma, Hodgkins, Solid Tumors, and Aplastic Anemia.

SAMPLING

A total of 23 subjects in group one were approached by phone or in person with a request to participate in the pilot study. After verbal consent was obtained, an informational letter, as well as copies of the questionnaire were mailed or delivered to the person, as per the person's preference. There were no refusal's to participate, however one subject became ill and passed away prior to completion of the questionnaire, and two subjects failed to complete and return the questionnaire within the allotted time.

Thirteen subjects in group two were approached by letter or in person with a request to participate in the pilot study. An informational letter, and copies of the questionnaire were mailed or delivered to the person's office. Ten questionnaires were completed and returned.

Thirteen subjects in Group three were approached by the Chair of the Nursing Research Committee at Fred Hutchinson Cancer Research Center (FHCRC) with a request to participate in the pilot study. An informational letter, and a copy of the questionnaire were sent via interdepartmental mail to the person's workstation. Ten questionnaires were completed and returned.

Subjects in group four were approached according to the human subject protocol at FHCRC. An independent staff person working in the outpatient department made phone contact with the prospective client and read a brief description of the study. If the client consented to participate, an appointment was scheduled with the researcher within the following seven days. Client and researcher met in a private conference room in the outpatient department at FHCRC. Consent was explained and a signature was requested. The questionnaire was explained to the client and the researcher remained in the room to answer questions.

These recently discharged clients frequently felt quite unwell, and this posed some difficulties with data collection. Three clients initially agreed to participate, but later two telephoned the researcher to cancel, and one failed to meet at the agreed time. Increased feelings of nausea and fatigue were cited as explanations. Two clients opted to finish the questionnaire at home and return it by mail. One client, readmitted to the hospital immediately prior to the appointment, requested an in-hospital visit to sign consent, then returned the questionnaire by mail. Altogether ten questionnaires were completed and returned.

HUMAN SUBJECTS APPROVAL

Approval for both the pilot and the main study were obtained from the University of Washington Human Subjects Committee, and further reviewed and approved by the Institutional Review Board at FHCRC. Three separate informational letters were provided for respective groups one, two, and three (Appendices A,B,C), with the return of a completed questionnaire implied evidence of consent. Each subject in group four signed a consent form prior to beginning the study.

All subjects were allowed to withdraw participation at any time, and to refuse to answer any question with which they felt uncomfortable. All responses remained anonymous as subjects were identified only as a member of the respective group. Subjects in groups three and four were further assured that their responses would be reported in group form and no individual responses would be identifiable in any way by supervisors, peers, or health care providers at FRCRC.

ANALYSIS

All raw data was entered into an IBMpc computer for analysis with the SPSSpc statistical package. Initial analysis included basic descriptive statistics including mean, median, standard deviations, and a histogram of the distribution. Also included were item to total correlations and Cronbach's alpha.

Overall reliability (Alpha) for the scale was .9838. Means and standard deviations for each item are presented in Appendix S. Means and standard deviations were examined for outliers. Standard deviations were found to be within normal ranges. Any item with an overall mean below 2.0 was deleted. Two highly redundant items were also deleted. A total of 5 items were deleted.

The primary concern at this point surrounded the validity of this scale. Determining individual item retention based on the mean item score proved unfeasible as all demands demonstrated a similar moderate to high frequency (Appendix S). Since the target population for the completed scale was bone marrow transplant patients, the information provided by these patients (Group 4), was given priority for determining which items should be retained in the questionnaire. Any demands where five or more of the ten subjects in group 4 answered or responded with a one (this hassle never occurs) was deleted. These manipulations left a total of 73 items out of the original 153 of the questionnaire. Using an integration of empirical and theoretical approach to test construction, remaining items were reassigned to six subscales on the basic of logical and statistical homogeneity.

RELIABILITY AND VALIDITY OF THE FINAL DEMANDS SCALE

Reliability is defined as the stability, consistency, or dependability of a measuring tool (Polit and Hungler, 1978), and the amount of variance in a set of scores that is not the result of errors of measurement (Goodwin and Prescott, 1981). Reliability is generally assessed via stability, internal consistency, and/or equivalence (Polit and Hungler, 1978).

The reliability of this tool was assessed using the internal consistency measure of coefficient (Cronbach's) alpha. Cronbach's alpha gives an estimate of the split-half correlation for all possible ways of dividing the measure into two halves. Reliability coefficient's for each of the six subscales are presented in Table 3. Overall reliability (alpha) of the 73 item scale was .9635.

Table 3: ***Final Subscales for the Demands Questionnaire***

TITLE	# OF ITEMS	ALPHA
Comfort and Pain	17	.8654
Day to Day Life	13	.8664
Personal Care	9	.7864
Mobility and Environment	8	.8116
Changes in Routine	13	.8923
Feelings and Emotions	13	.9110

Two additional items were added to the scale at this point. These items were derived from an analysis of "additional demands and comments" provided by the subjects in group 4. They included:

#18 Supplies and equipment breaks or works poorly

#32 Difficulties communicating about schedules and times

Content validity, the item representativeness of the content (Kerlinger, 1986) was established by asking four groups of experts in the content area to evaluate the representativeness and accuracy of the items. Content validity was also established by gathering items from tools, prior research findings and psychological theory articles as close to the representativeness of the universe of content of hassles as possible.

COMMENTS AND LIMITATIONS OF THE QUESTIONNAIRE.

The possibility of social desirability and reactivity remains a source of bias in this study. Literature reviews and responses from early groups indicated that staff conflicts and concerns were a significant source of hospitalization demands. Group 4 (recently discharged outpatients), declined to endorse staff related items enough to have any item retained in the final questionnaire. Examination of extra comments, however, indicated that slightly less than half of the comments were related to staff demands.

Attempts to minimize this source of bias were implemented from the beginning of the study. These included guaranteeing anonymity, emphasizing group analysis, using independent evaluators, and reassuring clients about the use of the information (Pelletier, 1985). This finding could be related to the passivity and hesitancy to voice complaints and criticisms inherent in the traditional patient role.

A list of the final Demands of Hospitalization Scale items is presented in figure1. A copy of the final Demands of Hospital Scale tool is presented in Appendix L.

Criticisms of demand scale development and limitations of this scale are discussed in Chapter 5. Additional comments and demands identified by subjects in the pilot study are listed in table 4. Note that many of these demands reflected interpersonal issue and communication difficulties. While interpersonal and communication related items did not receive enough endorsement to be retained in the scale, the presence of demands related to these issues is reflected in these additional comments.

Comfort and Pain

1 Being attached to tubes and machines
2 Unusual smells annoying me
3 Having my sleep interrupted
4 Upsetting television (programming, content, commercials)
5 Being woken up early
6 Being too cold
7 Keeping things clean and organized around me
8 Difficulties reaching for things while in bed
9 Not getting enough sleep
10 Being too hot
11 Uncomfortable bed
12 Unable to control room lighting as I want
13 Feeling physically irritated or uncom fortable
14 Trouble relaxing
15 Being in pain
16 Environment preventing me from falling asleep
17 Unexpected/unexplained side effects of treatments
18 Supplies and equipment breaks or works poorly

Day to Day Life

19 Forced to abide by a rule which I feel is unnecessary for me
20 Having to repeat a bad experience
21 Unnecessary Waiting
22 Not being prepared for what to expect
23 Getting the "runaround"
24 Not being able to take care of myself
25 Waiting for treatments/tests
26 Concerns about my safety
27 Side effects of medications or treaments
28 Too many pills
29 Concerned about germs and infections
30 Machines annoying me
31 Difficulty waiting for results of tests
32 Difficulties communicating about schedules and times

Personal Care

33 Unexpected company
34 Too many interruptions
35 Too much noise
36 Unable to have privacy when I want
37 Not being able to shower or take a bath
38 Concerns about bodily functions
39 Not having bathroom facilities
40 Unable to take medications when I want them
41 Trouble controlling what, when and how much to eat

Mobility and Environment

42 Restricted ability to move my body
43 Having to stay in one room all day
44 Unable to go outdoors when I want
45 Not being able to explore or investi gate outside my room when I choose
46 Forced to wait with nothing to do
47 Do not know when I can go home
48 Unnecessary procedures
49 Receiving incomplete explanations

Changes in Routine

50 Unable to enjoy my usual entertain ment or recreation
51 Unable to visit stores or restaurants
52 Not being able to go out and purchase things I want or need
53 Difficulty reading or writing
54 Worried about the future
55 Feeling this experience will never be over
56 Worried about neglecting responsibili-ties
57 Feeling generally insecure about the current situation
58 Can not host family and friends as I would like
59 Unable to be with friends or relatives when I need them
60 Not being touched by others
61 Not being able to touch other
62 Not enough time with people I love

Feelings and Emotions

63 Having no "veto" power over what is done to me
64 Feeling ignored sometimes
65 Feeling I have less power than anyone around me
66 Unable to perform at my usual level
67 Feeling over-regimented
68 Feeling "trapped" in the hospital
69 Feeling over-protected
70 Too many demands on me
71 Feeling I have lost my personal rights
72 Feeling bored
73 Regretting that I can't help or support other people
74 Concerned about my physical appear ance
75 Feeling overwhelmed sometimes

Figure 1: *Demands of Hospitalization Scale Items*

Table 4: *Pilot Study: Hassles and Comments Listed by Subjects*

Group 1: Community Sample of Previously Hospitalized Patients:

1. Hospital admissions needs to keep track of check-outs. I didn't receive lunch or phone calls on last day because they assumed I had already left.
2. Different doctors and nurses every time someone entered the room.
3. Often rude. Talking down to and about the nurses aides
4. Fellow patients being very difficult with staff and other patients.
5. Patients being placed in the wrong ward or part of the hospital.
6. Staff should never forget why they are there, the main reason.
7. Nurses who did not ever take care of an adult
8. Having a nurse who is embarrassed to do her job
9. Having a nurse demand you do something your doctor said you didn't have to do.

Group 2: None

Group 3: Nurses Working with Bone Marrow Transplant Patients

1. Fearful of test results (life threatening as well as prolonging treatment).
2. Feelings of being a "Guinea pig" for research purposes.
3. Feelings of being a burden to donor's family as well as own family.
4. Roommates.
5. Worries about mortality.
6. Feeling angry.
7. Feeling like doing nothing, but made to do things by others.
8. Made to do things I don't want to do.
9. Thinking I may never get well.
10. Feeling very alone.
11. Feeling that I've never been this sick before.
12. Losing sense of time.
13. Repeating same information to multiple staff persons.
14. Decreased ability to choose staff rendering care.
15. Worried about spouse.
16. Not enough teaching about disease.

Group 4: Recently Discharged Bone Marrow Transplant Patients

1. No cable TV.
2. Unable to control temperature in LAF room
3. Unable to turn down fan in LAF (if staff inadvertently left it on High)
4. Not enough room for personal belongings
5. Hospital Isolation gowns all too large.
6. Difficulty getting to the bathroom when plugged into tubes and machines with short cords, short tubes.
7. Lack of choices of foods when on Milk-free diet
8. Seeing others not doing well.
9. Afraid you will get complications seen in others.
10. Strange People coming into the room without knocking or introducing themselves
11. Not having results of tests mentioned or explained.
12. Being told one thing by a staff member and receiving slightly varied information from another.
13. Being told "I'll do that for you" by a staff member and then having to remind them to do it or get it after awhile.
15. Not having any control or ability to regiment or negotiate a daily schedule, not notified of schedule changes, having people not show up for no reason.
16. Difficulty finding out who is in charge, or who to ask questions of.
17. Being told "It can't be done" rather than compromise or fair hearing.
18. Hassles between nursing staff and other departments (nutrition, radiation, etc.), where the patient gets caught in the middle.
19. Not having someone familiar (Such as your nurse) present when procedures are performed. Forced to feel pain, apprehension in a room with total strangers.
20. The intense difficulty and unique negative experiences of LAF room confinement.
21. Equipment which does not work. Sharp lips on drinking glasses.
22. Broken TV speaker at the bedside.
23. Commode bags break or leak when you use them or throw them outside.
24. Lid of commode keeps falling down when you are trying to use it.

CHAPTER 4

Main Study

RESEARCH DESIGN AND SAMPLE

This study was designed using a one-time correlational design and nonprobability, or convenience sampling. This design allows the researcher to compare and summarize linear relationships between pairs of variables (Norusis, 1987). Since the population error variance for the pilot study was .9845, the best method for determining a significant sample is the sample size for a two-tailed test procedures. The sample size for a two-tailed test procedures determines a sample size required to achieve a standard level of significance (Alpha =.05). The formula is based on a standard measure of the power of the test (Beta = .20; power = .80). For a two-tailed test, the required sample size is 61 (Hinkle, 1988). As this sample size was beyond the scope of this dissertation, a convenience sample of 32 consenting subjects were recruited for the study.

Inclusion criteria for subjects are listed as follows: Between eighteen and sixty years of age; admitted to the Fred Hutchinson Cancer Research Center in Seattle for a bone marrow transplant; having one of the diagnoses of Leukemia (including AML, AMML, AMOL, ALL, and CML), Multiple Myeloma, Non Hodgkins Lymphoma, Hodgkins, Solid Tumors, or Aplastic Anemia; able to read and understand the questionnaire; able to speak English; and be willing to sign consent.

Exclusion and withdrawal criteria included rapidly deteriorating physiological status either prior to or after admission to the BMT ward. Transfer to an ICU bed, "breaking" LAF barriers necessitated by medical complications, or a decrease in level of consciousness were also criteria for excluding or withdrawing a patient from the study.

PROCEDURE

Subjects for the main study were identified by reviewing the upcoming patient schedule for the outpatient clinic, and consultation with outpatient scheduling staff members. Patients selected as appropriate for the study were approached by an outpatient scheduler not involved in the study by telephone and/or during an outpatient clinic visit, with a brief description of the study.

With the patient's verbal consent, an interview with the researcher was scheduled. At this interview, the purpose and procedure of the study was explained, and informed consent obtained. Basic demographic data, as well as a measure of trait anxiety were gathered. Data collection during the hospitalization of patients proceeded approximately as follows:

TABLE 5 ***Data Collection Schedule - Main Study***

LOCATION	CONTENT	APPROX. TIME REQUIRED
Outpatient Clinic	CONSENT	15 Minutes
	DEMOGRAPHIC DATA	
	SUBJECTIVE ILLNESS	
	TRAIT ANXIETY (STAI.)	
Inpatient Day + 3 (Window of Day +3 to +7 with option of administering over several days)		
	STATE ANXIETY (STAI.)	15 Minutes
	CONTROL	
	UNCERTAINTY	
	DEMANDS	

Subjects feeling unable to read or respond to questionnaire items in writing could choose to have the researcher read questionnaire items to

them, and then respond verbally. Subjects feeling too ill or tired to complete the questionnaires in one day were allowed to keep the questionnaires overnight, or to have them administered on two or more consecutive days.

Because of the variety and number of medications used during the bone marrow transplant hospitalization, no attempt was made to control for the effect of medications. All data was collected between 6:00 p.m. and 8:30 p.m., and at no time was data collected during a period of acute suffering or emotional distress.

PROTECTION OF HUMAN SUBJECTS

Approval for the first phase of the initial pilot study (groups 1 and 2) was granted by the Human Subjects Review Exemption Committee at the University of Washington School of Nursing on 6/13/88 (See appendix P). Approval for the remainder of the pilot study and the main study was granted by the Human Subjects Review Committee at the University of Washington on 9/15/89 (Appendix Q) and the Institutional Review Office at Fred Hutchinson Cancer Research Clinic on 10/20/88 (Appendix R). Approval for the study was granted by E. Donald Thomas, M.D. Director of Clinical Research at Fred Hutchinson Cancer Research Center on 9/6/89 (Appendix O).

Protection of human subjects included avoidance of coercion by having an independent outpatient staff member approach subjects with a request to participate, as per established protocol at FHCRC. No deception was required, nor adverse effects anticipated nor reported for this activity. All information was coded and kept confidential.

Any subject who expressed hesitation due to fatigue, nausea, or discomfort was reminded that nonparticipation or withdrawal from the study would not affect care at Fred Hutchinson Cancer Research Center in any way.

Subjects feeling unable to read or respond to questionnaire items in writing could choose to have the researcher read questionnaire items to them, and then respond verbally. Subjects feeling too ill or tired to complete the questionnaires in one day were allowed to keep them overnight, and/or have the questionnaires administered on two or more consecutive days.

Risks and benefits to the subject were specifically expressed. The questionnaire format, and the voluntary nature of participation in this study did not indicate significant risk to study participants. Potential concerns included sensitivity to some questionnaire items, as well as time pressure to complete questionnaires when feeling ill. Participants were informed that they did not have to respond to any item they found objectionable, and were encouraged to take extra time as needed to complete questionnaire items. A final potential discomfort included a heightened sensitivity to potential stressors and demands in the hospital environment. While no subject reported any emotional discomfort as the result of the interviews, provision was made for a follow-up debriefing interview with the Director of Clinical Nursing Research, should the need have arisen.

DATA COLLECTION INSTRUMENTS

The data related to the primary purpose of this study includes the State Anxiety (STAI) and the Demands scales. Data on control, and uncertainty are for a secondary purpose to attempt to validate the theory behind the study. Gathering data on institution, LAF, and demographics is an attempt to determine effects (if any) of these variables on anxiety, demands, loss of control, and uncertainty. The qualitative interview was intended to be an attempt to gather subjective perceptions about the hospital experience not accessible via the more restrictive questionnaire format.

Demographic Data Sheet

Demographic data describing the sample population and information which might explain study variance included: Age, Sex, Religion, Marital Status, SES, Race, Education, Occupation, Diagnosis, and Perceived Health Status.

Anxiety: STAI

The State-Trait Anxiety Inventory (STAI) was developed in 1968 by Spielberger, Gorsuch and Lushene. A self-report format, it is designed to measure both the current state of anxiety, as well as the subjects' general tendency towards anxiety. It defines anxiety as current feelings of emotional and physical uneasiness and apprehension associated with perceived stressful events. This test has been used extensively with normal, medical and psychiatric patient populations. A bibliography, compiled in 1983, lists over 2,000 archival publications which have used the STAI.

Reliability of the STAI has been determined. Test-Retest reliability was assessed with both high school and college students. Median reliability coefficients for the Trait Anxiety scale were .695 for high school, and .765 for college students. Internal consistency for samples for working adults, students, and military recruits demonstrated a median coefficient of .92 for the state and .90 for the trait anxiety scales (Spielberger, 1983).

Validity has been determined. Construct validity of the trait scale is evidenced as the scale discriminates between normals and psychiatric patients with anxiety as a major symptom. Construct validity of the state scale was observed in comparing the scores of beginning military recruits in a stressful training program with low stress condition high school and college students. Concurrent validity of the trait scale has been reported with the Taylor Manifest Anxiety Scale, the IPAT Anxiety Scale, and the Zuckerman Affect Adjective Checklist. Correlations of the whole scale had been reported with multiple scales including the Minnesota Multiphasic

Personality Inventory, the Cornell Medical Index, and the US Army Beta intelligence test (no relationship) (Spielberger, 1983).

Control: Personal Opinion Survey – Control in Social Situations

Perceived control was measured using the Control in Immediate Social Interaction Subscale of the Personal Opinion Survey by Richard W. Coan (Used with permission). This subscale is used to measure whether the subject feels able to control social situations and/or secure desired responses from other people. Validity of the subscale is evidenced by low correlations between scales which indicate that the subscales represent separate components of experienced control.

Construct validity is further supported by indications that different subscales can predict differential outcomes as predicted by the interpretations assigned to the factors. Evidence for this has been found in studies on marijuana use, difficulty with dieting, socioeconomic level and dependency (Coan and Fairchild, 1977). The Personal Opinion Survey has test/retest reliabilities which range from .61 to .87 when retested at a three month interval.

Subjects were asked to respond to this questionnaire based on their feelings and experiences during the prior 2 weeks. The questionnaire usually took 5 minutes or less to administer.

Mishel Uncertainty in Illness Scale (MUIS)

This instrument was developed in 1981 by a nurse scientist to investigate the role of uncertainty in illness and recovery. It consists of a 28 item, 5-point Likert-format scale assessing the patient's perception of uncertainty surrounding symptoms, diagnosis, prognosis, treatment, and relationships with caregivers. It has been factor analyzed into two areas: Ambiguity in the state of the illness; Complexity of treatment and the system of care.

Reliability of the original two factor version of the scale was demon-

strated with internal consistencies of .89 for factor 1 and .72 for factor 2 (Mishel and Braden, 1988). Validity of the scale was supported by findings that the scale discriminated among medical, surgical and diagnostic populations in the predicted directions. Validity was also supported by factor clustering into theoretical predicted factors. (Mishel, 1984).

Hospital Related Demands Scale

The demands scale is a 75 item pencil and paper test which lists multiple demands of hospitalization which have been separated into six subscales. Validity and reliability of the scale is discussed in chapter 5.

Subjective Degree of Illness Continuum

Subjects were asked to mark on a visual analog scale of 1 to 100, how sick they felt they were at the time, 1 being perfectly healthy, 100 being the sickest they could imagine.

Qualitative Interview

Subjects were to be asked the following questions: What has this hospitalization experience been like for you; describe the demands you experienced related to your hospitalization which were particularly difficult for you; how did they make you feel; if you could change one thing about the hospital, the staff, or the procedures, what would it be? Information was to be recorded with brief pencil and paper field notes during the interview, augmented with notes and impressions from memory written immediately after the interview.

CHAPTER 5

Results

DESCRIPTION OF THE SAMPLE

Thirty-two adult bone marrow transplant patients ranging in age from 22 to 56 (X=35.9; SD=10.20) participated in the study. Table 6 summarizes basic descriptive data on the subjects.

Table 6: ***Descriptive Demographics for BMT Sample (N=32)***

VARIABLE	MEAN	STD. DIV.	MINIMUM	MAXIMUM
Age	35.91	10.20	22	56
Monthly Family Income	$2,347.84	$2,242.39	0	$10,000
Education	3.56*	1.27	2	6
Health (0-100%)	67.78%	22.78%	5	99

* 3= 4 yr col.,4= Master deg.

Frequency demographics are shown on table 7. The sample was fairly equally divided between male (46.9%) and female (53.1%). The majority of subjects were Caucasian (90.6%), and between Catholic (40.6%), and Christian/Protestant (37.5%). The average bone marrow transplant patient at FHCRC (since 1988; unpublished data) is Caucasian (89.8%), 29.4 years old (range = .09 to 60.9 years) and male (62.9%) vs female (37.1%). This sample had a greater percentage of females, and was older, due to an inclusion criteria of age 18 to 60.

Table 7: ***Frequency Demographics for BMT Sample (N=32)***

VARIABLE	FREQUENCY	VALID%	CUM%
SEX			
Female	17	53.1	53.1
Male	15	46.9	100.0
RELIGION			
Catholic	13	43.3	43.3
Christian/Protestant	12	40.0	83.3
Jewish	1	3.3	86.7
Other	4	13.3	100.0
	2	MISSING	
MARITAL STATUS			
Single	8	25.0	25.0
Married	22	68.8	93.8
Divorced	1	3.1	96.9
Widowed	1	3.1	100.0
ETHNIC IDENTITY			
Afro-American	1	3.1	3.1
Asian-American	1	3.1	6.3
Native American	1	3.1	9.4
Caucasian	29	90.6	100.0
EDUCATIONAL LEVEL			
High school	9	28.1	28.1
Technical or community	5	15.6	43.8
Four-year college	12	37.5	81.3
Master's degree	3	9.4	90.6
Doctorate	3	9.4	100.0
OCCUPATION			
Professional	14	43.8	43.8
Laborer	8	25.0	68.8
Clerical	3	9.4	78.1
Housewife	6	18.8	96.9
Other	1	3.1	100.0
(unemployed/student)			

The sample as a whole was well educated. 71.9% of subjects had attended some college while 56.2% had a four year degree or graduate education. U.S. Census bureau (1989) reports that 37% of the general population over age 25 has had some college, while 19.9 percent have attended four or more years (as of March, 1987). In occupational status, fourteen subjects were professionals (43.8%), followed by laborers (25.0%) and housewives (18.8%).

Monthly family income for subjects ranged from $0 to $10,000 (X= $2,347, SD= $2,242). This is roughly equivalent to the median monthly income (1987) for all household types of $ 2,285 (U.S. Census, 1989). This reported median monthly income is possibly deceiving. In this population one, and frequently both of the wage earners had lost significant income in the past two years due to the illness.

Subjective perceptions of degree of health as measured during the pre-hospitalization admission period on a scale of 1 to 100 (1 was lowest and 100 - highest degree of wellness they had ever felt) ranged from 5% to 99 % (X=67.78, SD=22.78). Many patients stated that they felt perfectly well, and only knew they were ill because they were preparing for a transplant.

Transplant related demographics are presented in Table 8. The majority of subjects were admitted with a diagnoses of Leukemia (71.9%). Laminar airflow rooms were used for 13 subjects (40.6%), while 19 (59.4%) were assigned to private non-sterile hospital rooms. Patients in the study were fairly equally distributed between Swedish hospital (46.9%) and Fred Hutchinson Cancer Research Center (53.1%).

Table 8: ***Transplant Related Frequency Demographics for BMT Sample (N=32)***

VARIABLE	FREQUENCY	VALID%	CUM%
ADMITTING DIAGNOSES			
Leukemias	23	71.9	71.9
Breast cancer	1	3.1	75.0
Hodgkins	3	9.4	84.4
Non-H lymphoma	3	9.4	93.8
Other	2	6.3	100.0
LAMINAR AIRFLOW ROOM			
No	19	59.4	59.4
Yes	13	40.6	100.0
INSTITUTION			
Hutchinson	17	53.1	53.1
Swedish	15	46.9	100.0

Non Participants

Six subjects refused to participate in the study. Four of these subjects reported feeling too overwhelmed by all of the tests, other research studies, and demands of the hospitalization experience. Two of these subjects reported feeling that refusing to participate in "unnecessary" research studies was a way to maintain some control over the demands being placed on them. One subject felt refusing was a way to maintain her privacy. Two subjects reported feeling too ill and fatigued.

In addition four subjects were withdrawn from the study by the researcher prior to completing the questionnaires. One subject decided to postpone the transplant. One subject became comatose and was transferred to an ICU bed and placed on a respirator. Another made several attempts to complete the questionnaire, but was unable to stay awake and/or was extremely nauseated and vomiting.

Finally, one subject was withdrawn from the study by mutual consent. In this case the subjects father, who was constantly at her bedside, became agitated and objected when the researcher approached, stating she was too ill to participate in anything. While the patient herself was awake and consenting, after three brief visits further attempts were abandoned to avoid the potential of creating emotional distress.

Survival Data

Long term survival of the sample was noted at approximately six months post transplant. Of the thirty-two subjects, 16 have died and 16 remain alive.

CONSIDERATIONS / LIMITATIONS OF THE DATA COLLECTION ENVIRONMENT

The intensive care environment necessitated by the BMT procedure, and the effects of the procedure itself often made data collection a challenge. Since this was a study looking at stress and hassles, one determined priority was, as much as possible, not to be a contributing source. Although the access window was selected primarily in consideration of when the patients would be feeling the best, many patients came into this hospitalization period very sick, and participation was an effort. Common complaints included mucositis which made it difficult to speak, medications which induced sedation or drowsiness, persistent nausea, fatigue, and difficulty concentrating for over 1 to 2 minutes at a time.

Other concerns included the difficulty accessing patients. Competing studies, procedures, nursing care, therapies, all took precedence during the patient's day. Evening access, while more available, ran the risk of impinging on visiting by family and friends. Often the nurse would be involved in patient care, or actually in LAF with the patient. Interruption of this nursing care was never considered. The answer was several attempts

at contact over multiple days.

Laminar Airflow rooms necessitated sterilization of the instruments and sterile procedures to introduce the questionnaires to the patient. Having to get up and walk the three steps around the bed to receive the sterilized questionnaire packet was often overwhelming to these patients, and questionnaires were often read to the patient verbally.The constant low noise of the fan, and the thick plastic curtain made hearing and responding difficult from both directions. Hand signals were used, or the patient whispered into the stethescope bell which ran through the curtain.

Finally, family and friends generally stayed very close to help and support the patient. It is unclear how their presence and involvement might have subdued or otherwise influenced patient response to the questionnaires. Also, privacy was elusive. The speech volume required to speak through the curtain carried into the hall, and perhaps had a inhibitory effect on communications.

RELIABILITY OF THE TOOLS

Prior to utilizing the result of any of these tools, the psychometric properties of the scales were measured. Completion of the scales was greater than 95 percent for all scales. Internal consistency of the scales was assessed with standardized alpha coefficients. All of the major scales demonstrated an alpha reliability coefficient greater than .78. One subscale, the Complexity subscale of the Mishel Uncertainty Scale, demonstrated a low standardized alpha, which will be discussed later. A summary of reliability findings for the major scales is reported in table 9.

Table 9: ***Alpha Reliability Scores of the Major Scales (N=32)***

SCALE	# ITEMS	MEAN	VAR.	STAND. ALPHA	ITEM TOTAL	MEAN INTER-ITEM CORR.
STATE ANX	20	2.131	.0557	.9155	.09-.74	.3514
TRAIT ANX	20	1.92	.054	.9465	.32-.79	.4696
DEMANDS	75	2.469	.1195	.9682	.10-.79	.2889
UNCERT.	28	2.381	.3230	.8572	.05-.75	.1766
CONTROL	14	.6563	.0211	.7886	.16-.59	.2372

Spielberger State/Trait Anxiety Scale

The reliability of this 40 item tool was evidenced with a standardized alpha coefficient of .9155 for state and .9465 for trait anxiety subscales. This compared favorably with established reliabilities in working adults, students and military recruits (median coefficient state =.93, trait = .90) as reported in Spielberger (1983).

Correlations among the two scales were .5275 (p=.001). While this correlation is significant, it is much lower than those reported for normative adults, students and military recruits (.65). Two explanations may be plausible. State/Trait correlations tend to be higher when the two subscales are given in the same testing session. In this sample, the two subscales were administered up two three weeks apart. Also correlations tend to be lower when the individual is exposed to or threatened with some form of physical danger, a highly probable interpretation for this study sample.

Demands of Hospitalization

This 75 item tool designed to measures a patient's perceptions of hospital related demands (hassles) showed a total scale standardized item alpha of .9682. This compares favorably to the pilot study reliability standardized item alpha of .9682. Reliabilities of the six individual subscales are compared to pilot study reliability figures in table 10.

Table 10: ***Reliabilities of the Demands Subscales (N=32)***

TITLE	# OF ITEMS	ALPHA (PILOT)	ALPHA (MAIN)
Comfort and Pain	17(18)[1]	.8654	.8811
Day to Day Life	13(14)[1]	.8664	.9007
Personal Care	9	.7864	.7993
Mobility and Environment	8	.8116	.8504
Changes in Routine	13	.8923	.9039
Feelings and Emotions	13	.9110	.9222
Total Scale	**75**	**.9635**	**.9682**

[1]Main study scale contains one additional item

Mishel Uncertainty in Illness Scale

This 28 item scale designed to measure subjective perceptions of uncertainty in patients contains two subscales designed to measure the ambiguity and complexity dimensions of uncertainty. Standardized alpha coefficient for the whole scale was .8572. Alpha for the ambiguity subscale was .8492, and for the complexity subscale was .5829. Mean alpha levels reported by Mishel for all cancer patients (N = 729) was .89 for the whole scale, .86 for ambiguity and .80 for complexity subscales (Mishel, 1987).

The low reliability coefficient for the complexity subscale has several possible explanations. Low reliability as evidenced by the standardized alpha is when individual items do not correlated well with other items in the scale when the variance of each item is standardized to 1. Questions which comprised the complexity subscale were located at the end of the scale, and seemed to be much harder to understand and answer as the patients were tired by that time. One wonders if the nature of the dimension being measured (complexity) of illness actually reduced the reliability due to the complexity of the construct in the case of BMT patients.

Personal Opinion Survey

The control in social situations subscales of the Coan Personal Opinion Survey is a 14 item questionnaire designed to measure a sense of being able to control the immediate social environment. Standardized alpha coefficients for the subscale was .7886. This is almost equivalent to the Kuder-Richardson reliability coefficient of .76 reported by Coan (1977), and can be considered moderately high for a relatively short factor scale.

DESCRIPTIVE RESULTS OF THE STUDY SCALES

Results of the Anxiety Scale

Anxiety levels as measured by Spielbergers State/Trait Anxiety Scale are reported. The Trait subscale was given during the prehospitalization outpatient visit, the State Scale was administered during the in-hospital visit, approximately day +3 post-transplant. Highest possible total anxiety score for each subscale was 80, and the lowest (low anxiety) was 20.

Results are as follows. Mean State Anxiety level was 42.78 (SD=11.34) (Table 11). While this anxiety level is high compared with a normative group of working adults (males X = 35.72, SD=10.40, N=1,387, females X= 35.20, SD=10.61, N=451), it approximates norms reported for general medical and surgical patients at Veterans Administration Hospitals (X=42.68, SD=13.76) (Spielberger, 1983).

Mean Trait anxiety levels were 38.59 (SD=11.80). Once again this is high compared to a normative group of working adults (males X=34.89, SD=9.19, N=1,387, females X=34.79, SD=9.22, N=451). It was slightly lower than trait anxiety levels for general medical and surgical patients at Veterans Administration Hospitals (X=41.33, SD=12.55).

One significant finding in both general medical/surgical patients and prisoners, is that there is a significant negative correlation between

educational levels and trait anxiety scores. As the mean educational level of this sample (college) is significantly higher than the general population (tenth grade), this might explain the lower trait anxiety scores (Spielberger, 1983).

Table 11: ***State/Trait Anxiety Levels for BMT Patients (N=32)***

	STATE ANXIETY	TRAIT ANXIETY
Mean	42.78	38.59
Standard Deviation	11.34	11.80
Maximum	70.00	68.00
Minimum	23.00	24.00
Range	47.00	44.00

Means and standard deviations for individual state and trait subscale items are presented in tables 12 and 13. The highest possible mean score for each item is a 4, the lowest is a 1. In this scale, approximately half of the items are worded positively, thus, scoring weights are reversed in the following items:

State anxiety: 1,2,5,8,10,11,15,19,20

Trait anxiety: 21,23,26,27,30,33,34,36,39

High means in these reversed scored items actually indicate low agreement with the item.

The items most bothersome, in the state anxiety scales, as determined by individual item means, included S08 'I feel (REVERSE) satisfied' (X=2.56), S20 'I feel (REVERSE) pleasant (X=2.53), and S16 'I feel (REVERSE) content'. The least bothersome item was S13 'I feel jittery' (X=1.81).

Table 12: ***Item Means for the State Subscale of the STAI (N=32)***

ITEM	STATEMENT	MEAN	REVERSE	SD
SO1	I FEEL CALM	2.13	R	.83
S02	I FELL SECURE	2.13	R	.83
S03	I AM TENSE	2.22		.87
S04	I FEEL STRAINED	1.91		.86
S05	I FEEL AT EASE	2.34	R	.87
S06	I FEEL UPSET	2.00		.92
S07	I AM PRESENTLY WORRYING OVER POSSIBLE MISFORTUNES			
		1.88		1.18
S08	I FEEL SATISFIED	2.56	R	1.01
S09	I FEEL FRIGHTENED	2.03		.90
S10	I FEEL COMFORTABLE	2.34	R	.94
S11	I FEEL SELF-CONFIDENT	1.97	R	.90
S12	I FEEL NERVOUS	1.81		.90
S13	I AM JITTERY	1.94		.98
S14	I FEEL INDECISIVE	1.97		.86
S15	I AM RELAXED	2.34	R	.90
S16	I FEEL CONTENT	2.50	R	.84
S17	I AM WORRIED	2.03		.93
S18	I FEEL CONFUSED	1.88		.94
S19	I FEEL STEADY	2.28	R	1.02
S20	I FEEL PLEASANT	2.53	R	.88

Trait anxiety items with the highest means included T22 'I feel nervous and restless', (X=2.31), T26 ' I feel (REVERSE) rested' (X=2.25), and T29 'I worry too much over something that doesn't really matter' (X=2.19). The item with the lowest mean was T35 'I feel inadequate' (X=1.56).

Table 13: ***Means for Each Item in the Trait Subscale of the STAI***

ITEM	STATEMENT	MEAN	REVERSE	SD
T21	I FEEL PLEASANT	1.72	R	.85
T22	I FEEL NERVOUS AND RESTLESS	2.31		.69
T23	I FEEL SATISFIED WITH MYSELF	1.81	R	.82
T24	I WISH I COULD BE AS HAPPY AS OTHERS SEEM TO BE	1.94		1.01
T25	I FEEL LIKE A FAILURE	1.44		.72
T26	I FEEL RESTED	2.25	R	.88
T27	I AM "CALM, COOL, AND COLLECTED"	2.13	R	.83
T28	I FEEL THAT DIFFICULTIES ARE PILING UP SO I CANNOT OVERCOME THEM	1.81		.86
T29	I WORRY TOO MUCH OVER SOMETHING THAT REALLY DOESN'T MATTER	2.13		.83
T30	I AM HAPPY	1.69	R	.74
T31	I HAVE DISTURBING THOUGHTS	1.94		.98
T32	I LACK SELF-CONFIDENCE	1.97		.78
T33	I FEEL SECURE	1.84	R	.92
T34	I MAKE DECISIONS EASILY	2.09	R	.86
T35	I FEEL INADEQUATE	1.56		.67
T36	I AM CONTENT	1.88	R	.91
T37	SOME UNIMPORTANT THOUGHT RUNS THROUGH MY MIND AND BOTHERS ME	2.16		.88
T38	I TAKE DISAPPOINTMENTS SO KEENLY THAT I CAN'T PUT THEM OUT OF MY MIND	1.94		.91
T39	I AM A STEADY PERSON	1.78	R	.75
T40	I GET IN A STATE OF TENSION OR TURMOIL AS I THINK OVER MY RECENT CONCERNS AND INTERESTS	2.16		.88

Total scale descriptive data for the State Trait Anxiety Scale is presented in Appendix T.

Results of the Demands Scale

The Demands scales was administered during a 5 day window surrounding day +3 post-transplant. Range of responses was on a 5 point Likert scale ranging from 1 - this demand never bothers me to 5 - this demand very frequently bothers me.

In analysis of the Demands scale two separate scores were calculated. Response frequency was calculated as the number of responses in the scale/subscale greater than one (one = this demands never bothers me) (Table 14). Response intensity was calculated as the sum of the responses in the scale/subscale divided by the number of items in the scale (Table 15).

Table 14: ***Mean Freq. of Demands Scale and Subscales***

SUBSCALE (# ITEMS)	RANGE	MEAN (SD)	MIN/MAX
Comfort & Pain (18)	0-18	13.25 (4.52)	0-18
Day to Day Life (14)	0-14	9.97 (4.40)	0-14
Personal Care (9)	0-9	5.34 (2.89)	0-9
Mobility & Environ.(8)	0-8	5.56 (2.60)	0-8
Changes in Routine (13)	0-13	9.38 (3.75)	0-13
Feelings & Emot. (13)	0-13	9.37 (4.20)	0-13
TOTAL SCALE (75)	**0-75**	**52.02(18.92)**	**0-75**

Table 15: ***Mean Intensities of Demand Scales and Subscales***

SUBSCALE (# ITEMS)	RANGE	MEAN (SD)	MIN/MAX
Comfort & Pain (18)	18-90	44.62 (12.46)	18-70
Day to Day Life (14)	14-70	33.19 (11.31)	14-53
Personal Care (9)	09-45	20.66 (7.23)	9-35
Mobility & Environ.(8)	08-40	20.16 (7.22)	8-32
Changes in Routine (13)	13-65	34.31 (12.10)	13-59
Feelings & Emot. (13)	13-65	32.25 (11.12)	13-58
TOTAL SCALE (75)	**75-375**	**185.19 (51.11)**	**75-284**

Correlations between the demands scale and subscale intensity and frequency scores are given in table 16. Since most of the correlations were significant. Only demands intensity scores will be used for further data analysis.

Table 16: ***Correlations Between Demands Freq. and Int. Subscales (N=32)***

CORRELATIONS:	COMPFREQ	DAYLFREQ	PRIVFREQ	MOBLFREQ
COMPINT	.8170**	.6083**	.3018	.3818
DAYLINT	.6737**	.9060**	.6891**	.6274**
PRIVINT	.5359**	.7681**	.8501**	.4824*
MOBLINT	.6242**	.7287**	.6370**	.8468**
ROUTINT	.3646	.5925**	.5252*	.4267*
FEEMINT	.5315**	.7428**	.5551**	.5904**
DEMDINT	.7142**	.8622**	.6813**	.6492**

CORRELATIONS:	ROUTFREQ	FEEMFREQ	DEMDFREQ
COMPINT	.2932	.4506*	.5874**
DAYLINT	.5535**	.6728**	.8139**
PRIVINT	.5384**	.5577**	.7300**
MOBLINT	.7105**	.7283**	.8300**
ROUTINT	.8702**	.6638**	.6815**
FEEMINT	.7950**	.8381**	.8018**
DEMDINT	.7494**	.7799**	.8795**

N of cases: 32 1-tailed Signif: * - .01 ** - .001

Specific demands intensities were examined, to see which items were endorsed as being the most, and the least bothersome to Bone Marrow Transplant patients in this sample. A list of the ten highest and ten lowest "bothersome" individual items is presented in tables 17 and 18.

Table 17: ***Items Endorsed as MOST Bothersome in the Demands Scale (N=32)***

QUESTION #	LABEL	MEAN	STD DEV
03	Having my sleep interrupted	3.19	1.26
44	Unable to go outdoors when I want	3.19	1.35
66	Unable to perform at my usual level	3.19	1.09
72	Feeling bored	3.00	1.19
15	Being in pain	3.00	1.14
62	Not enough time with people I love	2.94	1.39
13	Feeling phys. irritated or uncomfortable	2.94	1.32
27	Side effects of meds/RX	2.84	1.17
50	Unable to enjoy usual entertainment or rec.	2.81	1.38
54	Worried about the future	2.81	1.47
43	Having to stay in one room all day	2.81	1.42
75	Feeling overwhelmed sometimes	2.78	1.31
55	Feeling this experience will never be over	2.78	1.56
28	Too many pills	2.78	1.29
01	Being attached to tubes and machines	2.78	1.10

Table 18 ***Items Endorsed as LEAST Bothersome in the Demands Scale (N=32)***

QUESTION #	LABEL	MEAN	STD DEV
40	Unable to take meds. when I want them	1.81	1.12
26	Concerns about my safety	1.84	1.05
33	Unexpected company	1.94	1.11
70	Too many demands on me	1.97	1.03
07	Keeping things clean and org. around me	2.00	1.19
23	Getting the "run-around"	2.06	1.39
10	Being too hot	2.16	1.14
06	Being too cold	2.19	.97
12	Unable to control room lighting as I want	2.19	1.40
41	Trouble controlling what, when, how to eat	2.19	1.35
48	Unnecessary procedures	2.19	1.26
08	Difficulty reaching things while in bed	2.22	1.21
45	Unable to explore or invest. outside my room	2.31	1.33

Total scale data for the Demands of Hospitalization tool are presented in Appendix T.

Results of the Mishel Uncertainty in Illness Scale

This 28 item scale was designed to measure patients subjective sense of uncertainty in illness. Item responses are on a 5 point scale (1 - Strongly Disagree, 5 - Strongly Agree). Uncertainty scores are determined by adding the 28 items (items 6,7,9,17,20,22,23,25,26,27, and 28 are reverse scored), to obtain a total score. The subscale Ambiguity (16 items) is obtained by adding the scores to items 1, 2, 3, 4, 8, 9, 12, 13, 14, 15, 16, 17, 19, 22, 23, 25. The subscale Complexity (12 items) is obtained by adding the scores to items 5, 6, 7, 10, 11, 18, 20, 21, 24, 26, 27, and 28.

The mean uncertainty level of this BMT population is 66.69 (Table 19). Individual questions with the highest and lowest mean scores are reported in table 20. Total mean scores for all illness types (N=729) reported by Mishel is 64.4 (SD=15.6). For all Cancer cases (N=330) reported by Mishel the mean is 65.3 (SD=14.5). Normative data for the subscales as reported by Mishel shows a mean for Ambiguity of 38.7 (SD 11.0) for all cases, a mean for Complexity of 25.6 (SD= 6.6) for all cases. These means are very close to the means obtained for the subscales in this BMT population.

Table 19: ***Descriptive Data on Uncertainty Levels in BMT Patients (N=32)***

VARIABLE	(#ITEMS)	MEAN	STD DEV	MINIMUM	MAXIMUM
TOTAL SCALE	(28)	66.69	14.47	37.00	99.00
AMBIGUITY	(16)	39.03	10.29	19.00	60.00
COMPLEXITY	(12)	27.66	5.71	18.00	40.00

Table 20: ***Mishel Questions with Highest and Lowest Mean Scores***

	QUESTIONS REFLECTING HIGH UNCERTAINTY	MEAN	STD DEV
14	The course of my condition keeps changing. I have good and bad days.	3.47	1.16
17	I usually know (reverse) if I am going to have a good or bad day.	3.38	1.01
20	I can generally (reverse) predict the course of my condition.	3.34	1.04
25	My physical distress is (reverse) predictable. I know when it is going to get better or worse.	3.31	1.06
26	My diagnosis is definite and will not change.	2.97	1.51
	QUESTIONS REFLECTING LOW UNCERTAINTY:		
01	I don't know what is wrong with me.	1.53	1.08
06	The purpose of my care is (reverse) clear to me.	1.84	1.25
15	I have been given many differing opinions about what is wrong with me.	1.47	.67
18	The results of my tests are inconsistent.	1.81	.78
24	They have not given me a specific diagnosis.	1.34	.55

Results of the Coan Control Scale

The results of the Perceived Control in Social Situations subscale of the Coan Locus of Control scale are presented in Table 21. This 14 item True/False subscale is designed to measure an individuals subjective sense of being able to control social situations and/or secure desired responses from other people (Coan, 1977). Scoring is accomplished by summing the items to arrive at a raw score (range is 0 to 14, 14 being the highest level of control). Overall mean for this sample was 9.87 (SD=3.03). Means for individual questions are given in table 21. A distribution of sample means is given in table 22.

Means for this scale as reported by Coan for normal college students (N=235) are : 7.34, (SD = 3.29). Means for psychiatric inpatients are 7.13 (SD=3.50) (Werner, Becker, Yesavage, and Isaacs, 1982). there is very little other normative data available for this subscale. Two of the 14 items in the scale had no variability.

Table 21: ***Coan Control Scale Frequency of Items (N=32)***

ITEM	MEAN	STD DEV	MINIMUM	MAXIMUM
C01	.31	.47	.00	1.00
C02	.59	.50	.00	1.00
C03	.72	.46	.00	1.00
C04	.75	.44	.00	1.00
C05	.81	.40	.00	1.00
C06	1.00	.00	1.00	1.00
C07	.69	.47	.00	1.00
C08	.47	.51	.00	1.00
C09	.81	.40	.00	1.00
C10	.72	.46	.00	1.00
C11	1.00	.00	1.00	1.00
C12	.69	.47	.00	1.00
C13	.59	.50	.00	1.00
C14	.72	.46	.00	1.00
COANTOT	**9.87**	**3.03**	**3.00**	**14.00**

Table 22: ***Mean Control Scores (0=Low – 14=High Control) N=32***

```
         3.00 \\\\\\\\\\ 1
         4.00 \\\\\\\\\\\\\\\\\\\\ 2
         5.00 \\\\\\\\\\ 1
         7.00 \\\\\\\\\\\\\\\\\\\\ 2
         8.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 3
         9.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 5
        10.00 \\\\\\\\\\\\\\\\\\\\ 2
        11.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 5
        12.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 4
        13.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 4
        14.00 \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ 3
MEAN          I.........I.........I.........I.........I.........I
              0         1         2         3         4         5
              NUMBER OF SUBJECTS
```

RELATIONSHIPS BETWEEN SCALES AND HYPOTHESIS TESTING

The primary objective of this study was to explore the relationship of hospital related demands to the presence of anxiety in hospitalized patients. Correlations were run between the hospital demand scale and subscales and state and trait anxiety levels in all 32 BMT patients. Results of this correlation procedure are presented in table 23.

Table 23: ***Correlations between Anxiety (STAI) and Demands Scale/Subscales***

	STATE ANXIETY	TRAIT ANXIETY
TOTAL DEMAND SCALE	.6705**	.3563
SUBSCALES:		
1. COMFORT AND PAIN	.4184*	.2658
2. DAY TO DAY LIFE	.5558**	.2104
3. PERSONAL CARE	.5159*	.0823
4. MOBILITY AND ENVIRONMENT	.4985*	.1996
5. CHANGES IN ROUTINE	.6479**	.3856
6. FEELINGS AND EMOTIONS	.6842**	.5232*
N of cases: 32	1-tailed Signif.: * - .01	** - .001

As predicted in the conceptual framework, total demands were significantly correlated (.6705, $p < .001$) with state anxiety. All of the demands subscales were also significantly correlated with state anxiety, with the highest correlations between the subscales 4, (Mobility and Environment) and 6 (Feelings and Emotions) and state anxiety.

None of the correlations between the demands scale and subscales and trait anxiety reached significance, with the exception of subscale 6 (Feelings and Emotions). This lack of correlations is also supported by the conceptual framework, as trait anxiety scale is designed to measure more stable personality characteristics indicating an anxiotypic personality.

Subjects with higher anxiotypic personality responses may have been more sensitive to demands which fell under the feelings and emotions subscale of the Demands questionnaire.

A further issue, that people who are anxiotypic may perceive and label neutral environmental factors as demands, where others wouldn't, was not supported, as indicated by the lack of correlation between trait anxiety and demands.

Another objective is to detect a relationship between perceived uncertainty and/or control, and hospital related demands in hospitalized patients. Perceived Uncertainty as measured with the Mishel Uncertainty in Illness scale, is significantly correlated with the total Demands scale (.5491 $p<.001$) and five of the six Demands subscales (Table 24). Subscales of the Mishel Uncertainty in Illness scale are also significantly correlated with several of the Demands of Hospitalization subscales (Table 24). The Complexity subscale of the MUIS shows consistently lower correlations, and once again brings up concerns regarding the low reliability score of the subscale in this population (see page 63).

The subscale not correlated with the Mishel Uncertainty in Illness scores was the Day-to-Day Life Subscale of the Demands questionnaire. Demands listed in this subscale are those which reflect the annoyances of day-to-day life in the hospital. As such, these hassles may be perceived as demanding not because they create a sense of uncertainty, but rather of annoyance and bother.

Table 24: ***Correlations Between Uncertainty and Demands Scales/ Subscales***

	UNCERTAINTY	AMBIGUITY	COMPLEXITY
TOTAL DEMAND SCALE	.5491**	.6112**	.2896
SUBSCALES:			
1. COMFORT AND PAIN	.5010*	.5408**	.2945
2. DAY TO DAY LIFE	.3349	.3145	.2815
3. PERSONAL CARE	.5031*	.4695*	.4284*
4. MOBILITY AND ENVIRONMENT	.4323*	.3382	.4858*
5. CHANGES IN ROUTINE	.4996*	.4904*	.3819
6. FEELINGS AND EMOTIONS	.5742**	.5662**	.4342*

N of cases: 32 1-tailed Signif.: * - .01 ** - .001

The expected relationship between Perceived Control and Perceived Demands in this population was not supported (Table 25). There were consistent trends in the expected direction. Perceived control was negatively correlated with demands in the total scale and five of the six subscales. Several of the correlations approached significance. Limitations and considerations of the control scale are discussed on page 105.

Table 25: ***Correlations Between Control and Demands Scales/Subscales***

	CONTROL	
TOTAL DEMAND SCALE	-.2456	(p=.088)
SUBSCALES:		
1. COMFORT AND PAIN	-.3544	(p=.023)
2. DAY TO DAY LIFE	-.1900	(p=.149)
3. PERSONAL CARE	.0009	(p=.498)
4. MOBILITY AND ENVIRONMENT	-.2449	(p=.088)
5. CHANGES IN ROUTINE	-.2115	(p=.123)
6. FEELINGS AND EMOTIONS	-.1501	(p=.206)

N of cases: 32 1-tailed Signif.: * - .01 ** - .001

Finally, another hypothesis tested was is there a relationship between anxiety, uncertainty, and loss of control. This was also tested by determining correlation coefficients for the scales. Both control and uncertainty were significantly correlated with each other (-.4564 p<.01) and with state anxiety (control -.4246 p<.01, Uncertainty .5904 p<.001).

Table 26: ***Correlations Between Anxiety, Uncertainty and Control***

CORRELATIONS:	CONTROL	STATE ANXIETY
CONTROL	1.000	-.4246*
UNCERTAINTY	-.4564*	.5904**
N of cases: 32	1-tailed Signif: * - .01 ** - .001	

RELATIONSHIPS BETWEEN DEMOGRAPHIC VARIABLES AND MAJOR SCALES

Re-Coding of Demographic Variables

Four demographic groups, marital status, education level, diagnosis, and occupation, had several subgroups with few cases in them. These subgroups were collapsed into larger groups, (Appendix U) which were then compared using T-tests to look for differences between the two means.

There were no significant differences in mean scores on the major study scales between married and single/divorced/or widowed patients in the study (see Table 27). While most of the patients in the study had at least one family or friend in close contact daily, the presence of an established significant and /or stable other in the patients personal life did not seem to affect the perception of uncertainty, loss of control, or hospital related demands in this sample. The closest scale approaching significance was the Demands of Hospitalization scale (p=.157), where the single/ divorced/widowed subgroup had a higher demand intensity score.

Table 27: ***T-Test Marital Status by Major Scale Scores***

						(Pooled Var. Est.)		
		Mean	**SD**	**f Value**	**2/Tail Prob.**	**t Value**	**deg. Freedom**	**2/Tail Prob.**
DEMAND INTENSITY SCORES								
S/D/W	10	204.3	49.0					
MARRIED	22	176.5	50.7	1.07	.966	1.45	30	.157
STATE ANXIETY SCORES								
S/D/W	10	44.1	11.5					
MARRIED	22	42.1	11.4	1.02	.912	.44	30	.665
CONTROL SCALE								
S/D/W	10	10.1	2.96					
MARRIED	22	19.7	3.13	.12	.907	.28	30	.783
UNCERTAINTY SCALE								
S/D/W	10	69.1	14.9					
MARRIED	22	65.5	14.4	1.07	.851	.63	30	.534

The sex of the patient did not significantly affect mean scores of the major study scales (Table 28) with the notable exception of the Control in Social Situations Scale. In this scale, females reported a significantly lower sense of control (p=.004). Females also reported a higher sense of anxiety which approached significance (p=.130).

Table 28: ***T-Test Sex by Major Scale Scores***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
DEMAND INTENSITY SCORES								
FEMALE	17	190.52	48.2					
MALE	15	179.13	55.2	1.31	.602	.62	30	.538
STATE ANXIETY SCORES								
FEMALE	17	45.64	11.6					
MALE	15	39.53	10.3	1.28	.649	1.56	30	.130
CONTROL SCALE SCORES								
FEMALE	17	8.47	2.9					
MALE	15	11.46	2.3	1.53	.427	-3.17	30	.004
UNCERTAINTY SCORES								
FEMALE	17	68.5	16.5					
MALE	15	64.5	11.8	1.96	.214	.79	30	.438

Educational level of the subjects did not significantly affect the mean for the major scales in the study. Differences for uncertainty approached significance (p=.138) with college educated subjects reporting a higher level of uncertainty than their less educated counterparts (Table 29).

Table 29: ***T-Test Educational Level by Major Scale Scores***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
DEMAND INTENSITY SCORES								
H.S.OR C.C.	14	170.92	49.4					
COLLEGE	18	196.27	50.9	1.06	.929	-1.41	30	.168
STATE ANXIETY SCORES								
H.S.OR C.C.	14	41.64	11.2					
COLLEGE	18	43.66	11.6	1.08	.907	-.49	30	.624
CONTROL SCORES								
H.S.OR C.C.	14	9.4	3.0					
COLLEGE	18	10.2	3.0	1.00	1.000	-.73	30	.472
MISHEL UNCERTAINTY SCORES								
H.S.OR C.C.	14	62.35	12.5					
COLLEGE	18	70.05	15.2	1.47	.488	-1.52	30	.138

Admitting diagnosis did not significantly alter the means of major scale scores (Table 30).

Table 30: ***T-Test Diagnosis by Major Scale Scores***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
DEMAND INTENSITY SCORES								
LEUKEMIAS	23	182.8	51.5					
CANCERS	9	191.2	52.4	1.03	.883	-.41	30	.683
STATE ANXIETY SCORES								
LEUKEMIAS	23	43.00	11.0					
CANCERS	9	42.22	12.7	1.32	.570	.17	30	.865

Table 30: ***(Cont.)***

CONTROL SCALE SCORES								
LEUKEMIAS	23	10.1	2.8					
CANCERS	9	9.2	3.6	1.66	.329	.76	30	.456
UNCERTAINTY SCORES								
LEUKEMIAS	23	68.3	15.3					
CANCERS	9	62.5	11.6	1.75	.422	1.101	30	.320

Subjects occupation did not significantly affect mean scores on the major study scales (Table 31). Differences between the means on the control subscale approached significance (p=.107). with professionals reporting a greater sense of control than non-professionals.

Table 31: ***T-Test Occupation by Major Scale Scores***

						(Pooled Var. Est.)		
				f	2/Tail	t	deg.	2/Tail
		Mean	SD	Value	Prob.	Value	Freedom	Prob.
DEMAND INTENSITY SCORES								
PROF.	23	194.5	55.9					
NONPROF.	9	191.2	47.3	1.399	.883	.91	30	.372
STATE ANXIETY SCORES								
PROF.	23	43.00	12.8					
NONPROF.	9	42.61	10.3	1.54	.400	.09	30	.925
CONTROL SCALE SCORES								
PROF.	23	10.8	2.7					
NONPROF.	9	9.1	3.1	1.32	.615	1.66	30	.107
UNCERTAINTY SCORES								
PROF.	23	70.7	15.9					
NONPROF.	9	63.5	12.7	1.57	.378	1.441	30	.161

Other demographic variables, including perceived degree of health prior to the transplant, age, and income, were not significantly correlated to any of the major study scales (see tables 32, 33 and 34).

Table 32: ***Correlations Between Health and Major Scales***

Correlations:	STATE ANX.	TRAIT ANX.	DEMANDS	UNCERT.	CONTROL
HEALTH	-.1812	-.3778	-.1321	-.4498	.1158
N of cases: 32	1-tailed Signif: * - .01 ** - .001				

Table 33: ***Correlations Between Age and Major Scales***

Correlations:	STATE ANX.	TRAIT ANX.	DEMANDS	UNCERT.	CONTROL
AGE	-.3365	-.1858	-.3572	-.2965	.0132
N of cases: 32	1-tailed Signif: * - .01 ** - .001				

Table 34: ***Correlations Between Income and Major Scales***

Correlations:	STATE ANX.	TRAIT ANX.	DEMANDS	UNCERT.	CONTROL
INCOME	-.1146	-.1532	-.0453	-.1577	.2734
N of cases: 32	1-tailed Signif: * - .01 ** - .001				

HOSPITALIZATION RELATED VARIABLES

Hospitalization related variables, including LAF room assignment and institution, were analyzed to see if they made a significant difference in the means of the major study scales. As reported in tables 35 and 36, there were no significant differences in major scale scores due to LAF / non LAF room assignment, or to institution. One major concern was that the restrictions of the LAF environment would increase the perceptions of demands, and loss of control. This was not reflected in this sample.

Table 35: ***T-Test Institution by Major Scale Scores***

					(Pooled Var. Est.)		
			f	2/Tail	t	deg.	2/Tail
	Mean	SD	Value	Prob.	Value	Freedom	Prob.
DEMAND INTENSITY SCORES							
HUTCHINSON	17	182.6	56.6				
SWEDISH 15	188.0	45.8	1.53	.430	- .29	30	.770
STATE ANXIETY SCORES							
HUTCHINSON	17	40.52	11.9				
SWEDISH 15	45.33	10.3	1.34	.585	-1.20	30	.238
CONTROL SCORES							
HUTCHINSON	17	9.6	3.1				
SWEDISH 15	10.1	3.0	1.04	.953	-.45	30	.658
MISHEL UNCERTAINTY SCORES							
HUTCHINSON	17	66.82	16.1				
SWEDISH 15	66.53	12.8	1.59	.388	.06	30	.956

SURVIVAL

Six month survival data was analyzed to see if any of the major scales or demographics were related to survival scores. None of the major scale score means were significantly different for subjects who survived (Table 36).

Table 36: ***T-Test Six Month Survival by Major Scores***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
DEMAND INTENSITY SCORES								
ALIVE	16	180.2	47.4					
DEAD	16	190.1	55.6	1.38	.544	-.54	30	.593
STATE ANXIETY SCORES								
ALIVE	16	42.37	8.9					
DEAD	16	43.18	13.5	2.28	.122	-.26	30	.843
CONTROL SCALE SCORES								
ALIVE	16	9.50	2.7					
DEAD	16	10.25	3.3	1.51	.435	- .69	30	.494
UNCERTAINTY SCORES								
ALIVE	16	64.0	12.4					
DEAD	16	69.3	16.2	1.70	.316	-1.05	30	.302

For the demographic data, perceived degree of health prior to the transplant was significantly higher in those who survived (Table 37). Age approached significance, with survivors being older than those who died (Table 37).

Table 37: ***T-Test Six Month Survival by Demographics***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
AGE								
ALIVE	16	38.3	10.2					
DEAD	16	33.4	9.8	1.09	.876	1.39	30	.175
PERCEIVED DEGREE OF HEALTH								
ALIVE	16	76.81	16.2					
DEAD	16	58.70	25.1	2.41	.099	2.41	30	.022

Several major scale subscale means also approached significant differences between survivors and those who died (Table 38). No interpretations can be made with this sample size due and the lack of significance, however the trends were all in the same direction. Those who died had higher mean levels of day to day life demands, personal care demands, and uncertainty.

Table 38: ***T-Test Six Month Survival by Subscales***

						(Pooled Var. Est.)		
		Mean	SD	f Value	2/Tail Prob.	t Value	deg. Freedom	2/Tail Prob.
MISHEL AMBIGUITY SUBSCALE								
ALIVE	16	36.2	8.0					
DEAD	16	41.8	11.7	2.15	.149	-1.56	30	.128
DAY TO DAY LIFE INTENSITY DEMAND SUBSCALE								
ALIVE	16	30.12	10.5					
DEAD	16	36.25	11.5	1.19	.738	-1.57	30	.128
PERSONAL CARE INTENSITY DEMAND SUBSCALE								
ALIVE	16	18.9	6.3					
DEAD	16	22.3	7.8	1.50	.439	-1.36	.183	

Additional crosstabulation charts of survival data with demographic variables are presented in Figure 2.

SURVIVAL by SEX

SEX		FEMALE	MALE	ROW TOTAL
SURVIVE	YES	10	6	16
	NO	7	9	16
	Column	17	15	32
	Total	**53.1**	**46.9**	**100.0**

SURVIVE by MARITAL STATUS

MARITAL		SINGLE	MARRIED	DIVORCED	WIDOWED	ROW TOTAL
SURVIVE						
	YES	3	12	1		16
	NO	5	10		1	16
	Column	8	22	1	1	32
	Total	**25.0**	**68.8**	**3.1**	**3.1**	**100.0**

Figure 2: ***Crosstabulations of Survival by Demographic Data***

SURVIVE by ETHNIC IDENTITY

ETHNIC	AFRO-AMERICAN	ASIAN AMERICAN	NATIVE AMERICAN	CAUCASIAN	ROW TOTAL
SURVIVE					
YES	1			15	16
NO		1	1	14	16
Column	1	1	1	29	32
Total	**3.1**	**3.1**	**3.1**	**90.6**	**100.0**

SURVIVE by ADMITTING DIAGNOSIS

DIAGNOSIS	LEUKEMIA	BREAST CANCER	HODGKINS	NON-H LMPHOMA	OTHER	ROW TOTAL
SURVIVE						
YES	13		1	2		16
NO	10	1	2	1	2	16
Column	23	1	3	3	2	32
Total	**71.9**	**3.1**	**9.4**	**9.4**	**6.3**	**100.0**

Figure 2: ***(Cont.)***

SURVIVE By EDUCATION

	H.S.	C.C.	4YR. COLL.	MASTERS	PHD	ROW TOTAL
SURVIVE						
YES	4	3	8		1	16
NO	5	2	4	3	2	16
Column	9	5	12	3	3	23
Total	**28.1**	**15.6**	**37.5**	**9.4**	**9.4**	**100.0**

SURVIVE By OCCUPATION

	PROF.	LABORER	CLERICAL	HOUSEWIFE	OTHER	ROW TOTAL
SURVIVE						
YES	6	5	2	3		16
NO	8	3	1	3	1	16
Column	14	8	3	6	1	32
Total	**43.8**	**25.0**	**9.4**	**18.8**	**3.1**	**100.0**

SURVIVE by LAF

LAF	NO	YES	ROW TOTAL
SURVIVE			
YES	8	8	16
NO	11	5	16
Column	19	13	32
Total	**59.4**	**40.6**	**100.0**

Figure 2: ***(Cont.)***

SURVIVE by INSTITUTION

INSTIT.	HUTCH.	SWEDISH	ROW TOTAL
SURVIVE			
YES	7	9	16
NO	10	6	16
Column	17	15	32
Total	**53.1**	**46.9**	**100.0**

Figure 2: ***(Cont.)***

MULTIPLE REGRESSION

Further testing of the relationship between the dependent variable, anxiety, and the independent variables of demands, uncertainty and loss of control were obtained using the multiple regression analysis. The two main question addressed were: How important was demands, uncertainty, and control when they are used together to predict anxiety levels; How important were control and uncertainty when used together to predict level of demands?

First, relationships between the major scales were plotted to check for outliers (Figures 3, 4, 5).

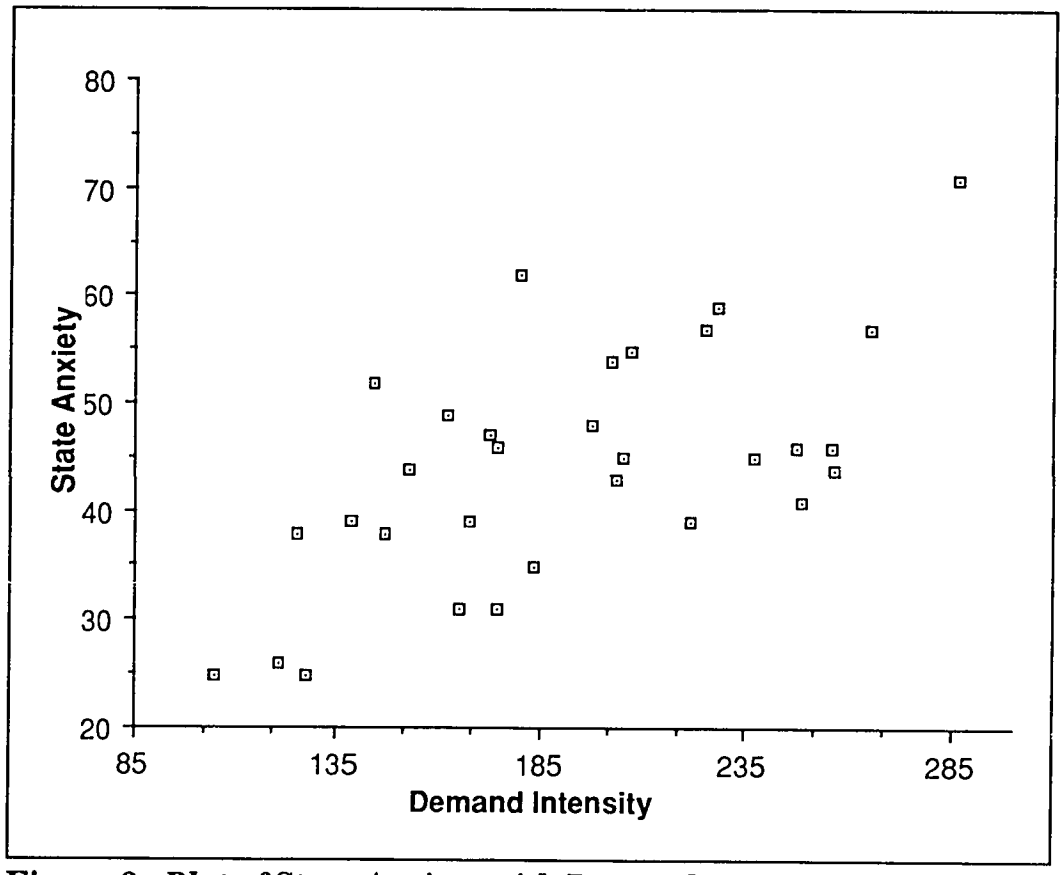


Figure 3: ***Plot of State Anxiety with Demand Intensity***

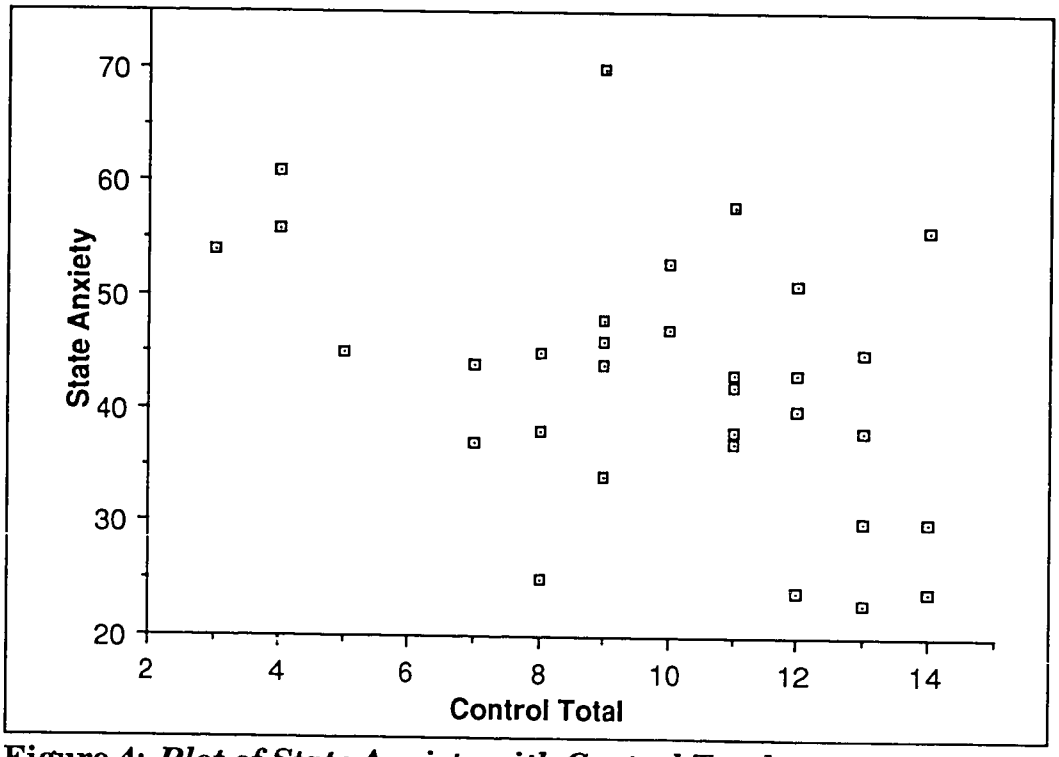


Figure 4: ***Plot of State Anxiety with Control Totals***

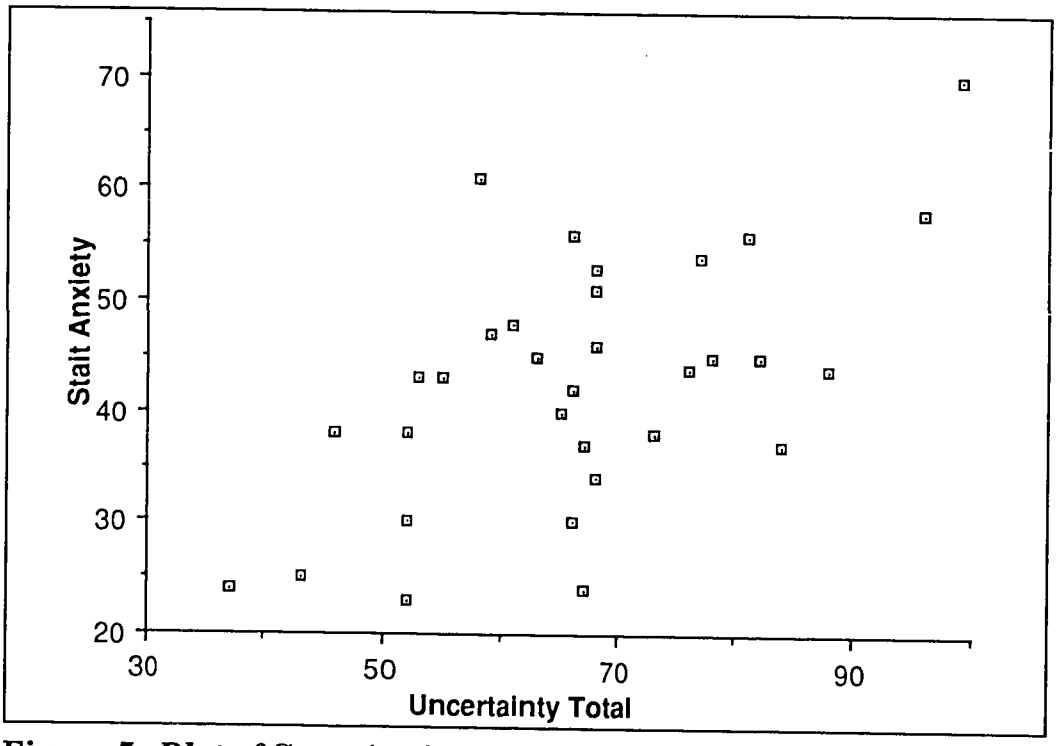


Figure 5: ***Plot of State Anxiety with Uncertainty Totals***

Stepwise regression analysis was used to determine the impact of the demands of hospitalization, uncertainty, and loss of control on state anxiety (Table 39). Demands explained 44 percent of the variance in anxiety (sign. F =.0001). Control was selected next, as the variable with the highest partial correlation. It added .07 to raise the R Square to .52. The variable of Uncertainty did not meet entry criteria in the Stepwise regression equation.

Table 39: ***Regression of Demands, Uncertainty and Control with State Anxiety***

Equation # 1 Dependent Variable **STATE ANXIETY**
Beginning Block # 1. Method: Stepwise
Variable(s) Entered on Step Number

1. DEMAND SCALE INTENSITY

Multiple R	.67054
R Square	.44963
Adjusted R Square	.43128
Standard Error	8.55080

Analysis of Variance

	DF	SUM OF SQUARES	MEAN SQUARE
Regression	1	1791.98156	1791.98156
Residual	30	2193.48719	73.11624

F = 24.50867 Signif F = .0000

Variables in the Equation

VARIABLE	B	SE B	BETA	T	SIG T
DEMAND INT	.14875	.03005	.67054	4.951	.0001
(Constant)	15.23547	5.76577		2.642	.0130

Table 39: ***(Cont.)***

Variables not in the Equation ————————

VARIABLE	B	SE B	BETA	T	SIG T
CONTROL	-.27652	-.36132	.93966	-2.087	.0458
UNCERTAINTY	.30639	.33813	.67033	1.935	.0628

Variable(s) Entered on Step Number

2. CONTROL

Multiple R	.72214
R Square	.52148
Adjusted R Square	.48848
Standard Error	8.10943

Analysis of Variance

	DF	SUM OF SQUARES	MEAN SQUARE
Regression	2	2078.34388	1039.17194
Residual	29	1907.12487	65.76293

F = 15.80179 Signif F = .0001

Variables in the Equation ————————

VARIABLE	B	SE B	BETA	T	SIG T
DEMAND INT.	.13368	.02940	.60262	4.548	.0001
CONTROL	-1.03317	.49511	-.27652	-2.087	.0458
(Constant)	28.22846	8.28671		3.406	.0019

Variables not in the Equation ————————

VARIABLE	BETA IN	PARTIAL	MIN TOLR	T	SIG T
UNCERTAINTY	.20936	.22739	.56452	1.236	.2269

End Block Number 1 PIN = .050 Limits reached.

The next question to be examined was: how important were control and uncertainty when used together to predict level of demands? Once again, relationships between the major scales were plotted with scatter-plots to check for outliers, and to examine the data for linearity (Figure 6, 7).

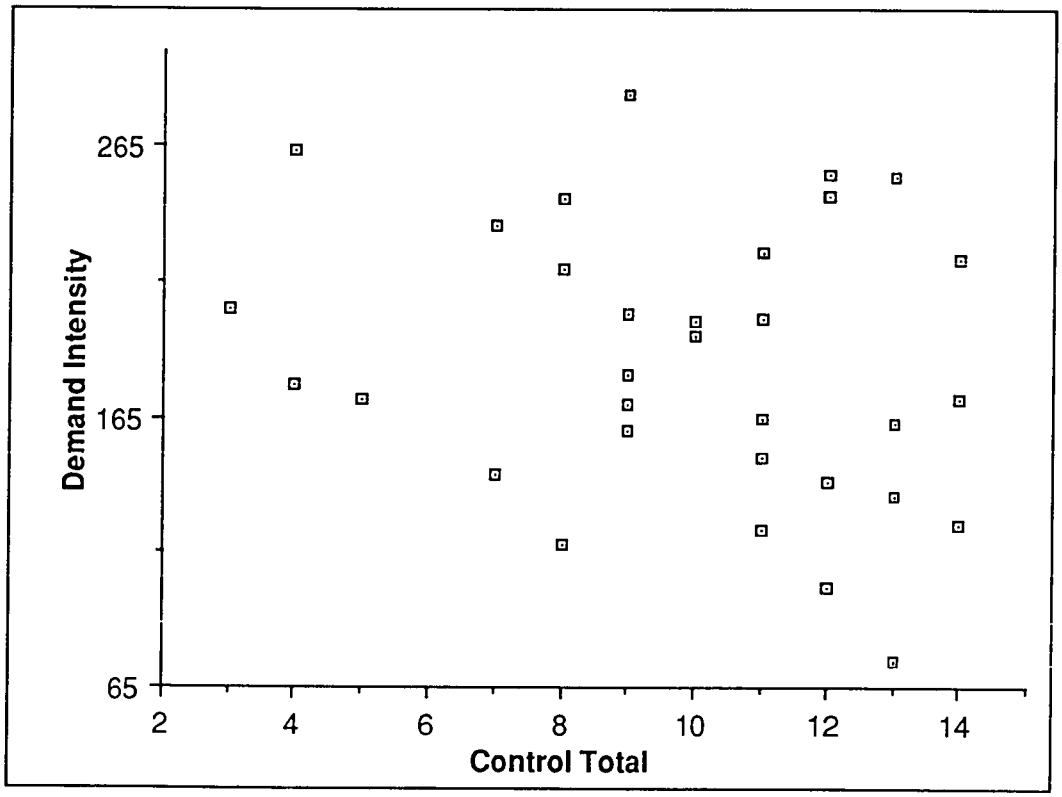


Figure 6: ***Plot of Demand Intensity with Control Total***

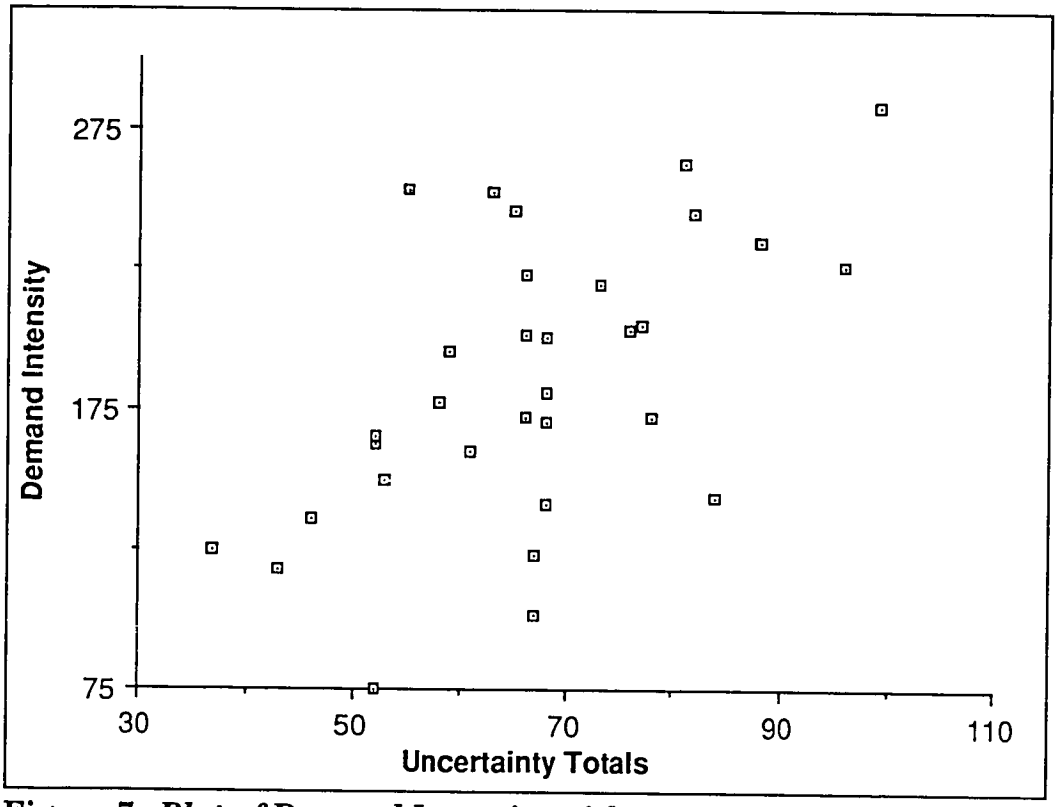


Figure 7: ***Plot of Demand Intensity with Uncertainty Totals***

Stepwise regression analysis was used to determine the impact of uncertainty, and loss of control on demand intensity levels. Uncertainty explained 32 percent of the variance in anxiety (sign. = .0006). Control did not enter the equation (Table 40).

Table 40: ***Regression of Uncertainty and Control with Demand Scale Intensity Scores***

Equation # 1 Dependent Variable.. DEMAND INTENSITY

Variable(s) Entered on Step Number

1. UNCERTAINTY

Multiple R .57417
R Square .32967
Adjusted R Square .30733
Standard Error 42.54085

Analysis of Variance

	DF	SUM OF SQUARES	MEAN SQUARE
Regression	1	26701.16645	26701.16645
Residual	30	54291.70855	1809.72362

F = 14.75428 Signif F = .0006

Variables in the Equation

VARIABLE	B	SE B	BETA	T	SIG T
UNCERTAINTY	2.02821	.52803	.57417	3.841	.0006
(Constant)	49.93107	36.00675		1.387	.1757

Variables not in the Equation

VARIABLE	BETA IN	PARTIAL	MIN TOLR	T	SIG T
CONTROL	.02069	.02249	.79173	.121	.9044

End Block Number 1 PIN = .050 Limits reached.

CHAPTER 6

Discussion

This chapter contains a discussion of the results of the study. It is divided into several parts. Part one is the direct results of the study, part two are issues related to the design, methodology, and procedure. Part three discusses nursing implications, and part four is a summary of the study and guide for future recommendations.

DIRECT RESULTS OF THE STUDY

The basic purpose of this dissertation was to look at the experience of anxiety in patients hospitalized for bone marrow transplantation. Specifically the primary question was whether anxiety was related to demands of hospitalization, and whether or not anxiety, and demands were related to perceptions of uncertainty and loss of control in these patients. In addition, was this relationship, if any, affected by patient characteristics, such as trait anxiety, perceptions of health, or demographics such as age and educational level? Finally, were these relationships, if any, affected by environmental considerations including LAF room assignment, or institutional assignment?

Demands (Hassles)

The presence of multiple demands of significant frequency and intensity as perceived by the patient was supported. The average frequency of reported demands was 69% of all demands listed on the Demands of Hospitalization scale. In all probability there are additional demands which did not appear on this list.

The average frequency of hospitalization demands was 52 out of a possible 75 demands. While there are no established normative data to

compare to, the mean intensity score for this population is a 2.46, of a possible 5 point intensity scale. If we examine only those demands which were endorsed as being present (i.e. higher than 1 - never occurs), the mean intensity score is 3.69 on the 5 point intensity scale, which is between "sometimes" and "frequently" bothers me.

This significant frequency is in support of the work of many researchers, who note that hospitalization is generally a stressful experience. Hospitalization contains many stressor producing events, with stressor related stimuli arising from many directions, including unfamiliarities, fears, changes in roles and communications, and loss of control.(Dossey, 1982; Ahmadi, 1985; Volicer, 1977; Volicer, 1975).

The most bothersome demands included: having my sleep interrupted; unable to go outdoors when I want to; unable to perform at my usual level; feeling bored; and being in pain. These are all cognitive/behavioral demands which may be especially salient as they interfere with the mechanisms of coping. In particular, they may alter, or reflect the alteration of the individual's coping competence (Wrubel, Benner, and Lazarus, 1981). The constant mental drain of being unable to sleep, being in pain, unable to distract or escape or replenish the psyche may truly deplete coping reserves.

The least bothersome demands tended to be issues of day-to-day 'housekeeping' which could have reflected powerlessness, but which were not identified by the subjects as problematic. Control over medication schedules, safety, unexpected company, external demands, keeping things clean and organized were not problems. Lazarus (1984) notes that occurrences which are seen has demands by some, are experienced as neutral incidents, or as uplifts by others. If these low - endorsed events occurred, they may not have been seen as threatening, but merely as stimuli, or even adjuncts to coping.

Anxiety

The hypothesis that there would be a significant level of anxiety in this population was supported in this sample. This is also well-documented in the literature (Roberts, 1984; Kornfeld, 1972). State anxiety levels were approximate for norms of medical and surgical patients as reported by Spielberger (1983). Trait anxiety levels were lower, possibly due to the higher education level of this population (Spielberger, 1983).

There is some concern (Fadden, 1986) that STAI may not be a good indicator of anxiety in hospital patients. Some research studies using the STAI report they were unable to find high anxiety levels in patients who theoretically should be high, such as myocardial infarction patients.

The hypothesis that there would be a relationship between state anxiety levels and perceived demands in this population was strongly supported with a correlation coefficient for the total scale of .6705 ($p=.0001$). Correlations between state anxiety and all subscales of the demands questionnaire were also significant to $p=.01$ or better. This is reminiscent of findings of Kanner, Coyne, Shaeffer, and Lazarus (1981) who found strong correlations ($r=.60$, $p<.001$) between psychological symptoms (measured by the Hopkins Symptom Checklist) and hassles (measured by the Hassles and Uplifts scale) in a community sample of 100 middle-aged adults.

The absence of significant correlations between trait anxiety and demands is also informative. Many individuals come into the hospital with an anxiogenic personality, enhanced by several months of dealing with a life threatening illness. This would be reflected in elevated trait anxiety levels. It could be argued that these individuals would be inclined to take any stimuli and call it a demand, as a function of their trait anxiety and related coping skills.

This contention was not supported in this sample, with the possible exception of demands in the feelings and emotions subscale. Feelings and emotions had the highest correlation of any subscale for both state and

trait anxiety. Since anxiety is both a long-standing, and a day-to-day emotion, specific "feeling and emotion" demands may directly spur day to day feelings of anxiety. Endorsing these demands may also be a reflection of trait anxiety which has affected the translation and expression of emotion related stimuli in the hospital situation.

The next highest correlations with state anxiety were demands related to changes in routine, and day to day life. These correlations with anxiety may reflect, as the hypothesis predicts, a sense of uncertainty, threat to coping, and loss of control. Finally, they may indicate the individual's awareness of the changes and limitations which create a sense of vulnerability and threat.

Surprisingly, the lowest correlations with state anxiety were with comfort and pain demands. This is interesting as this demand subscale demonstrated one of the proportionally highest frequencies, and means. Comfort and pain nursing interventions are also among the most common responses to hospital distress (Roberts, 1982). So although comfort and pain demands occur frequently with significant intensity, they are less correlated with state anxiety than other demand areas in this sample.

As an aside, during data collection, many nurses were asked what interventions they used for patient anxiety. The answer most frequently given was the naming of a specific anti-anxiety medication. In addition, several nurses described the closeness of the nurse-patient relationship, and expressed confidence that patients perceived that their nurse was accessible as a supportive listener and educator.

Multiple regression

The hypothesized model stated that uncertainty and control would have the primary effects on demands, and demands in turn would have a primary effect on anxiety. The question remained whether or not this relationship would hold up when demands, uncertainty and control were analyzed as a group to determine their relative influence on anxiety.

Results of a stepwise multiple regression procedure, with anxiety as the dependent variable, and demands, uncertainty and control as the independent variables, continued to support the hypothesized model. Demands explained 44 percent of the variance of anxiety (R Square = .44963). Control contributed only another 7 percent (R Square = .52148). When forced entry hierarchical regression was used, either control or uncertainty could be entered into the equation, but not both, probably due to the redundancy of these independent variables.

Demands and Uncertainty

The hypothesis that there would be elevated levels of uncertainty in this population was supported. Total mean uncertainty levels were slightly higher than those reported by Mishel (1988) for both cancer patients and all illness types.

The two individual questions with the highest uncertainty scores reflected issues surrounding the ability to predict the coming day: "The course of my condition keeps changing, I have good and bad days"; "I usually know [reverse] if I am going to have a good or bad day". Low uncertainty questions for this population surrounded knowing what is wrong, and knowing the purpose of care. The adequacy of provision of this type of information to the patient is a recognized priority at FHCRC. The fact that high uncertainty items related to day to day life lent support to the hypothesis that demands and anxiety may be due to uncertainty surrounding the little demands of day to day life.

Mishel (1984) notes that it is the vagueness, lack of clarity and lack of information about events that accounts for their evaluation as stressful, rather than the events themselves. Support for this was seen in the positive relationship between uncertainty and demands. The correlation between uncertainty and the total demands was .5491 (p=.001). Five of the six subscales, with the exception of day to day life, were correlated to the uncertainty scale to p=.01 or better.

Once again, day to day life demands (waiting for tests and medications, taking too many pills, worrying about germs and infections etc.) may not be perceived as uncertainty related, but are demanding in some other way.

Demands and Control

Relationships between control and demands approached, but did not reach significance with a correlation of -.2456 (p=.088). This is contrary to much of the research on hospitalization and illness in individuals (Dennis, 1987; Hart & Kinney, 1981). There are three possible reasons why no significant relationship was detected. One, the Control scale is accurate, and no loss of control exists in this population. Two, the Control scale is inaccurate. Three, the Control scale is accurate, but inappropriate for this population. Limitation of the scale are discussed in the next section. It would be premature to rule out a relationship between control and demands in this population.

Demographics and Major Scale Scores

Effect of demographic variables on the major study scales of demands and anxiety, uncertainty and loss of control were nonsignificant for most of the demographic variables. Marital status, educational level, diagnosis, occupation, perceived health prior to hospitalization, age, and income all did not significantly affect the mean of any major scale scores.

The one exception was the variable of sex, where females reported a lower sense of control t=-3.17 (2-Tail p=.004). In the literature, age, education and severity of illness have been shown to be related to uncertainty, however with no consistent pattern of effects (Christman, McConnell, Pfeiffer, Webster, Schmitt, and Ries, 1988).

Mishel (1984) notes that limited prior hospital experience may accentuate uncertainty, as younger people lack a frame of reference by which to reduce uncertainty. This effect was not demonstrated in this

sample, maybe because many of these people had been repeatedly hospitalized.

The ability and experience of learning (a basic way to reduce uncertainty), as reflected in educational level, may not be of help in an acute illness setting. The novelty of the situation, the cognitive and behavioral limitations of the illness and hospital setting, hinders this coping skill. In fact, more educated people may have had a better grasp of the limitations of the science in curing their illness, an understanding which would increase their uncertainty.

Subjective perceptions of health were high, averaging 67 percent on a scale of 100. This subjective perception of health was significantly associated with survival. Explanations for this could include a greater awareness of health status, better coping reserves, or general resiliency.

Institutional variables of LAF room assignment and Institution also did not significantly affect the mean. This is interesting in light of concerns surrounding the additional stressors and restrictions of the LAF environment. It has been noted that patients often feel more secure in protective isolation (Haberman, 1987).

COMMENTS AND LIMITATIONS OF THE STUDY

Demands Questionnaire

There are two main considerations for further use of the demands questionnaire. These include validity of the questionnaire for use in a non-transplant population, and conceptual difficulties in measuring "hassles".

Priority for determining individual item retention for the final scale was based on a small sample size of the target population — recently discharged bone marrow transplant patients. This decision was actuated by the fact that all 153 original demand items demonstrated a similar moderate to high frequency (Appendix S), yet the scale had to be shortened to a workable length. This does create validity limitations, as the

scale has been developed and tested in a very narrow population.

Nevertheless, it is postulated that many of the demands, and demand intensities are functions of the traditions, restrictions and environments common to hospitals. The high overall frequencies of the demand items from the pilot study, and the lack of difference between institution and environments in the main study population lend additional support to this hypotheses.

One of the major criticisms of the Hassles and Uplifts Scale developed by Lazarus (1980), is the confounding of occurrence and severity indication, since the minimum endorsement of a hassle was "somewhat" severe. Any hassle which was recognized, but not seen as bothersome, could not be endorsed by a subject. Lazarus contended that the appraisal process could not be so divided. He argued that objective occurrence and subjective severity were inseparable in the measurement of psychological stress (Reich, Parrella, and Filstead, 1988).

This Demands Scale also supported the inseparability of the concepts, yet it differed from the Hassles and Uplifts Scale by expanding the choices on the less severe side of the scale. Subjects could respond that an item never, rarely, sometimes, often, or very frequently "bothers me". This opened up the possibility of capturing demands which were infrequent, but met some internal criteria for being labeled a demand. It also delineated demands which were recognized as such, but never bothered the individual in the hospital. It did not provide opportunity to express recognition of the item, but disaffirmation of it as a possible hassle.

Finally, three sources of bias which have been identified in connection with the Hassles and Uplifts Scale, need to be noted here as well. First, there is the possibility of overlapping items between the Demands Scale, and psychological measures. The possibility of overlapping concepts does exist, as anxiety, as measured in the STAI, may also be reflected in the demand subscale - Feelings and Emotions. Close examination of the individual items of the STAI and the Demands Scale finds no similarity in

content or wording between the two. The bias of overlapping items is not a significant limitation in this Demand tool.

Next, the presence of psychological distress may increase the perception of hassles. The limitation of this scale, according to the arguments of Dohrenwend and Shrout (1985), is that endorsement of any choice indicates difficulty in coping, which is by default a psychological disturbance, and thus the scale is a measure, not a predictor, of psychological disturbance. Finally, individuals experiencing distress may report elevated levels of hassles, as a self-explanation of their difficulties (Monroe, 1983). Although hassles have been shown to significantly predict future psychological symptoms (Monroe, 1988), these considerations are still valid.

Recommendations for further study of the demands subscale are similar to those of other client satisfaction scales. The primary focus is to continue to investigate what types of individuals indicate problems in what demand areas (Pelletier, 1985). Additional study should address what types of demands occur at what stages of hospitalization, and what demands are common to all patients, as opposed to those that vary with individual perceptions.

Control

The focus of the Personal Opinion Survey is to delineate the various ways in which people actually experience control (Coan, Fairchild and Dobyns, 1973). There is much validational evidence supporting the utility of the differential subscales, rather than the whole scale, in measuring different aspects of control (Hyams, Domino and Spencer, 1980). Yet there is little normative data available for this subscale, and it is difficult to interpret results from this group of subjects.

The moderately high control scores apparent in this sample (when compared to college students and inpatient psychiatric subjects) could have several sources. The one main concern is the loss of validity of these control subscale questions in the BMT environment.

The Coan scale was chosen over the more popular Rotter Internal/ External locus of control scale as the intent was not to assess a general internal expectancy of control. Coan et al. (1973) notes that people can experience different levels of control in different aspects of their lives, the targeted construct for this study was the reality of day-to-day perceived achievement of control.

The inaccuracy of this scale occurs with the individual questions. These questions are designed to measure control in immediate social interactions, yet the immediate social interactions typified by the subscale questions are "worlds away" from the immediate environment where data was collected. In fact, presenting questions that were not directly relevant to the moment, seemed almost antagonistic to such an intensely ill and focused population.

While probably losing much of its environmentally-specific sensitivity, the scale did seem to tap into the concept of control. The scale may have actually measured general memories of control in immediate social interactions prior to the illness experience. If this is so, it is reasonable to assume that, given the age, income, education, and professional levels of the subjects, this remembered control would be high.

Uncertainty

The Mishel Uncertainty in Illness questionnaire is based on four categories of events each with a specific illness focus: discomfort, incapacitation, and other symptoms of illness; management of special treatment procedures and their side effects; technical environments including relating with medical and other health care providers; and assessment of the future and reassessing independence (Mishel, 1984). While this specific illness focus was a good base, it left out many categories of significant sources of uncertainty surrounding hospitalization.

Other Concerns and Limitations of Data Collection

The demographic question of monthly family income was most likely a misleading indicator of socioeconomic status. Subjects in this study were experiencing very unstable financial situations. In most cases, one or both wage earners (and many partners) had quit or temporarily left employment to seek care and treatment for the illness. An alternative question would query income prior to diagnoses, and change in income over the prior year.

Originally a qualitative interview had been planned to assess for demands not covered on the questionnaire, to ask about coping skills, and to elicit any comments or concerns about the questionnaires. Although many patients wanted to talk, structured interviews were not pursued. The degree of sedation and nausea, the concentration needed for the questionnaires, the presence of visitors and interruptions by staff, and the inability to talk without mouth pain, discouraged these interactions.

Selective denial of certain aspects of illness in cancer patients is well documented in the literature, and may be what allows the patient to face each coming day (Quigley, Bielecki and O'Rourke, 1989). Denial of psychological distress was a real possibility in this patient population. Inclusion of a denial scale would have been advisable. Finally, no effort was made to control for any medications, including those with sedative or anti-anxiety effects. It can be presumed that these medications were moderately to extensively used, and perhaps had an effect on the study results.

NURSING IMPLICATIONS

The underlying direction of this research was toward a greater understanding of practical interventions to reduce anxiety in hospitalized patients. One of the basic implications for nursing in this study is the evidence that subjective perceptions of frequency and intensity of demands are related to anxiety. Evidence also indicates that demands are

markers of uncertainty. Demands may reflect loss of control, although the latter was not demonstrated in this study.

The benefit of assessing perceived demands as opposed to anxiety, uncertainty and loss of control, is that demands offer a more focused direction for nursing interventions aimed at reducing anxiety. Focusing on a specific demand allows one to target coping and stressor-related interventions for maximum effect. This differs from providing anxiety symptom control through medication, or offering more vague supportive counseling based on the nurses presumption of the patients concerns.

Secondly, with further study, clustering and patterns of demands may indicate types of stressors which are particularly noxious to the individual. Clusters of demands may also indicate areas of deficits in personal coping abilities. Lazarus (1984) notes that hassles tend to group into the following recurrent themes: vulnerability to criticism, need to be approved or loved, failure to communicate what is wanted or felt, need to always be in control, resentment about another person's insistence on autonomy, tendency to put others down, self-depreciation, and inability to criticize or complain.

Stressors and Coping — Adjusting the Match

A basic explanation for the presence of hassles in the hospital is the existence of a mismatch between coping skills and situations which demand coping responses. First, the person may not possess, or know to choose, the specific coping skills needed. Second, environmental barriers and restrictions may prevent the individual from using coping skills.

Finally, changes in the individual due to the altered physiology of the illness, or other competing priorities, may make it impossible to use anxiety reducing coping skills which may have been previously available. For example, the experiences of illness creates feelings of loss (Kiely, 1972). Perhaps the confrontation with the hassle is a culminating moment where the person experiences a sense of loss - loss of power, autonomy,

self-esteem, normalcy, and the sense of being lovable - the very life and breath behind adequate coping responses.

Demands and the Theory of Human Care

An approach to determining nursing interventions using identified demands may follow Jean Watson's (1979) nursing theory of human care. Watson rejects the purely biomedical approach to illness, and teaches that nurses need to develop new and unique ideas of what it means to be human, to nurse, to be ill and be cared for. Basic to this process are her "caretive factors":

1. Formulation of a humanistic-altruistic system of values.
2. Instillation of faith-hope.
3. Cultivation of sensitivity to self and others.
4. Development of a helping trust relationship (including congruence, empathy, non-possessive warmth, and effective communication).
5. Promotion and acceptance of the expression of positive and negative feelings.
6. Systematic use of the scientific problem-solving method for decision making.
7. Promotion of interpersonal teaching-learning.
8. Provision for a supportive, protective or corrective mental,physical, sociocultural, and spiritual environment.
9. Assistance with the gratification of human needs.
10. Allowance for existential-phenomenological forces.

Three basic assumptions of Watson's theory provide particular direction in the understanding of the relationship between demands and anxiety in the hospital setting. They are: Patient self-awareness; barriers in nursing and health care; and the unrecognized complexity of the human.

Patient Self - Awareness

Watson believes that many times it is the client, not the nurse, who knows best what is wrong, what is needed, and how best to approach the therapeutic process. Supporting this belief in relationship to removing demand-related anxiety, uncertainty, and loss of control includes removing barriers identified in relationship to demands, which interfere with patients attempts to self-assess and cope. It also includes allowing patient input, self assessment and self- adjustment, and helping the patient focus on priorities and integrate the new demands and environment with coping abilities.

Based on the demographics of this study sample, these subjects were healthy, working, educated and successful individuals prior to their hospitalization. They surely have established multiple effective, individualized, and refined coping skills. To utilize these coping skills patients need an environment which preserves personal dignity, which comforts and is responsive to stress and suffering. The environment also needs to support patients' legitimate concerns regarding information and participation in matters of their care. (Speedling and Rosenberg, 1986)

Providing Patient Support

Lewis (1982) notes that a key component of support-oriented care is affirmation of the individual's worth by fostering a sense of control over his current life situation. While the attributions of freedom and control are illusions largely independent of actual behavioral actions, the mere knowledge that one can exert control, even if it is not done, can mitigate the negative effects of aversive stimuli (Lefcourt, 1973). Also, the greater initial expectation of control, the more controlling behavior an individual will show before giving up, and the more depressed that person will be after giving up (Silver and Wortman, 1982).

The following control enhancement strategies for nurses have been

proposed by Ruth Lindquist (1986): Assist in redefinition of the situation to perspectives which may be more personally manageable; offer guidance for focusing and/or re-attribution of the source of the stress; Provide role models and/or verbal examples, stories or images as sources of information on positive coping strategies; emphasize positive appraisal of the persons own resources; provide and promote distraction and relaxation activities; focus on obtainable goals, and provide choices whenever possible; affirm the cause and effect between patients positive coping behavior and progress toward desired outcomes.

Haberman (1988) notes that nurses can be essential in helping the patient manage uncertainty and loss of control. Nurse counseling to help the patient explore issues surrounding the transplant, even in the absence of the possibility of resolution is beneficial. Basic information about day to day events and choices, along with help identifying strategies (such as realization, visualization, distraction) to cope with demands, will help.

In this study, the two individual questions with the highest uncertainty scores reflected issues surrounding the ability to predict the coming day (The course of my condition keeps changing, I have good and bad days; I usually know [reverse] if I am going to have a good or bad day). Perhaps nursing interventions to reduce these sources of uncertainty would surround communicating parameters and expert assessment to provide information to help the patient predict the course of his or her day. Exposure to reminders of normal life (such as radio, TV., personal items), liberal visiting privileges, reducing external noise and unnecessary machinery, and psychological counseling sessions also affect control related appraisals (Lesko, et al, 1984).

Nursing and Hospital Barriers

"Moral vision" in nursing refers to what one actually comprehends as befitting, good and normative for persons (McInerny, 1987). But how does one know what this is ? When the concluding determination of what

is good for the patient physiologically, opposes what is deemed the necessities of the institution, as well as what best befits the patient holistically, conflict is inevitable.

Watson believes that some of this conflict arises from traditional nursing practices which may interfere with patient health. She notes that many traditions, behaviors and attitudes towards patients reflect the priorities and history of nursing. This includes the adoption of rigid, reductionistic views of health and science, rigid views of women in society, and power and role-related functions within the male-dominated medical care system.

There is evidence that both traditional and modern health care provider values may be inconsistent with the priorities and needs of the patient. For example, Dimatteo and colleagues (1982), found that hospitalized patients were more strongly influenced by the way their psychosocial needs were met than by their perceptions of the competence of their physicians. Larson as cited in Fleming (1987), notes that listening and talking, psychosocial skills highly valued by nurses, and probably the first used when dealing with anxiety, are important to cancer patients only after their basic needs were met.

Refusing to adopt the traditional sick role, or stepping outside established and acceptable patient parameters, can cause turmoil. The view of the nurse as one who helps the client achieve independent self-management of care has not found it's way into the general cultural picture of the nurse role (Gadow, 1977). Hart and Kinney (1981) found that nurses scolded, reprimanded, and then avoided those patients who asked a lot of questions, created emotional scenes, or refused to cooperate with hospital routines. The most common nursing intention to deal with any complaint was with medication (Lorber, 1981).

The hospitalized patient is the lowest member of the power hierarchy (Burt, 1979). If patients through repeated episodes of non-control come to believe that what they do does not matter and that it will not

affect their situation, they see themselves as having no control. They can suffer anxiety, diminished sense of purpose, and lower self esteem (Lewis, 1982).

Another effect of attitude and traditions on nursing care related to stressors and demands involves the subtle influences of expectations and behaviors. "We ourselves, no matter how careful and discreet we believe ourselves to be, are constantly influencing others in ways of which we may be only dimly aware and which, if we knew, we might find totally unacceptable." (Watzlawick, 1976). An example of this subtlety is presented in Barton et al. (1980), who documented that dependent behavior in elderly nursing home residents was directly maintained by staff reinforcement whereas independent personal maintenance behaviors were mostly ignored.

Human Complexity

Finally, Watson assumes that a great deal of the processes inherent in being human are not recognized or measured in nursing research or practice. Aspects of being human include cognitive emotional, spiritual, mental, social, vocational, and recreational elements. These elements interact in a complex way only beginning to be recognized. Nursing recognizes its legacy of caring for the whole human, but needs to re-examine its understanding of the scope of that care.

Fleming, Scanlon, and D'Agostino (1987) note that few studies exist which address the relationship between nurses' beliefs about caring and their actual delivery of care, and that less than 3% of a survey of 302 doctoral nursing dissertations focused on 'care'. The conclude that theoretical insufficiency, definitional ambiguity, measurement insensitivity, and lack of population norms and fluctuations for target ill populations such as cancer patients all create difficulties in pursuing research of this kind.

While posing difficulties in assessment and intervention by nurses,

the complexity of the human holds out promise to ameliorate the psychological traumas of hospitalization. For example, complex self-representation, in terms of possessing multiple self aspects, may buffer the effects of stress and depression, as tragedy or setback in one area represents a smaller proportion of the individuals self-representation (Linville, 1987).

SUMMARY

"The belief that one's own view of reality is the only reality is the most dangerous of all delusions." WATZLAWICK

To it's employees, the hospital environment may seem as familiar and routine as going to the grocery store. Yet to most patients, there are no other experiences or situations which adequately prepare them for the ordeals of hospitalization. Entering the hospital means entering and remaining in a new and unfamiliar world, surrounded by strangers, and requested, compelled really, to voluntarily submit to physical and mental discomfort, almost total lack of privacy, repeated invasion of personal body space, and powerlessness and dependency.

In addition, they must face this experience while feeling sick, uncertain about their future, perhaps having an altered state of consciousness due to drugs, or illness, and quite doubtful of how they are supposed to act, or what to expect, or which way to turn for help in this new place.

Finally, many of the coping skills normally used in dealing with these kinds of threat are hindered or removed while the person is in the hospital, while they have assumed the patient role, or while they are very sick. Information seeking, denial, leaving the situation, regression, turning to others for support, emphasizing an alternate role, are all either impossible, or discouraged while in the hospital.

It is no wonder the common response is the stress response, and no wonder anxiety has been called the one universal response to hospitaliza-

tion (Hallam, 1985). While a certain amount of anxiety can facilitate adjustment to cognitive and emotional demands (Frankenhaeuser, 1975), anxiety has a powerful potential to interfere with an individual's return to health.

One of the main hypotheses of this study was that anxiety is related to the perceptions of threat. Not the overwhelming threat of the illness, but the day to day encounters with demands which remind one of, or reflect uncertainty, loss of control, and/or changes in coping abilities. This hypothesis is supported in this dissertation. The perceptions of uncertainty and control as relating to anxiety were supported. The perceptions of uncertainty as relating to demands was supported. The perceptions of control as relating to demands was not, although reservations must be made due to the psychometric instrument chosen. The moment by moment interaction between stimuli and perceptions seems to not be affected by demographic variables, including age, sex, marital status, income, etc.

When the emotion of anxiety outranks fear of death, disability, recurrence, loss, anger, guilt, worry, or depression (Benedict's 1988), learning about, and intervening to reduce anxiety is a priority for nursing care. Any components of hospital related anxiety which may be iatrogenic, should receive special scrutiny.

To end, Ashley Montagu (1986) states that above all else, our "role as human beings" is to join learning to caring and kindness. "Learning to learn, learning to love and to be kind are so closely interconnected and so profoundly interwoven..., it would greatly help toward our rehumanization...."

BIBLIOGRAPHY

Ahmadi, K. The experience of being hospitalized: stress, social support, and satisfaction. *Int. J. of Nursing Studies*, 1985, *22*:2, 137-148.

Allen, V. Arousal, affect and self-perception: The role of the physical environment. in Spielberger, C. and Sarason, I. and Dafares, P. (eds) *Stress and Anxiety*, *9*. New York: Hemisphere, 1985.

Anastasui, A. Evolving concepts of test validation. *Ann. Rev. Psychol,* 1986, *37*:1-15.

Andrykowski, M.A., Henslee, P.J., and Farrall, M.G. Physical and psychosocial functioning of adult survivors of allogeneic bone marow transplantation. *Bone Marrow Transplantation,* 1989, *4*, 75-81.

Averill, J. Personal control over aversive stimuli and it's relationship to stress *Psychological Bulletin,* 1973, *80*:4, 286 - 303.

Bass, C. Physical symptoms of anxiety. *British Journal of Clinical Practice*, 1985, *39*; 5, (Suppl 38), 834-38.

Benedict, S. The suffering associated with lung cancer. *Cancer Nursing*, 1988, *12*:1, 34-40.

Berdie, D., Anderson, J., and Niebuhr, M. *Questionnaires: design and use.* New Jersey: Scarecrow Press, 1986.

Brack, G., LaClave, L., and Blix, S. The psychological aspects of bone marrow transplant: a staff's perspective. *Cancer Nursing*, 1988, *:*4, 221-229.

Brinberg, D., and McGrath, J. *Validity and the Research Process*. California: Sage, 1985.

Burks, N., and Barclay, M. Everyday problems and life problems and life change events: ongoing vs acute sources of stress. *Journal of Human Stress*. 1985, *11*:1, 27-35.

Burt, R. *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations*. New York: Free Press, 1979.

Charney, D. et al. Neurobiological mechanisms in human anxiety: recent clinical studies. *Psychopharmacology Bulletin*, 1983, *19*:3, 470-5.

Christman, N., Mc Connell, E., Pfeiffer, C., Webster, K., Schmitt, M., and Ries, J. Uncertainty, coping and distress following myocardial infarction: transition from hospital to home. *Research in Nursing and Health*, 1988, *11*, 71-82.

Clark, C., and Jackson, A. *Hypnosis and Behavior Therapy - The Treatment of Anxiety and Phobias*. New York: Springer Publishing, 1983.

Coan, R., and Fairchild, M. *Handbook for the Personal Opinion Survey*. Unpublished manuscript, University of Arizona, 1977.

Coan, R.. Fairchild, M., and Dobyns, D. Dimensions of experienced control. *The Journal of Social Psychology*, 1973, *91*, 53-60.

Cogliano-Shutta, N.. Broda, E., and Gress, J. Bone marrow transplantation: an overview and compairson of autologous, syngeneic, and allogeneic treatment modalities. *Nursing Clinics of North America* , 1985, *20*:1, 49-65.

Cohen, F. Personality, stress, and the development of physical illness. in Stone, G., Cohen, F., and Adler, N., (eds) *Health Psychology*. San Francisco: Jossey-Bass, 1979.

Cohen, M., and Martinson, I. Chronic uncertainty: it's effect on parental appraisal of a child's health. *Journal of Pediatric Nursing*, 1988, *3*:2, 89-96.

Cohodes, D.R. From person to patient. *Health Affairs*, 1985, *4*:3, 95-99.

Cox, T. Stress: a psychophysiological apprach to cancer, in Cooper, C.L *Psychosocial Stress and Cancer* London: Wiley and Sons, 1984.

Curley, S., Eraker, S. Yates, F. An investigation of patients' reactions to therapeutic uncertainty. *Medical Decision Making*, 1984, *4*:4.

Dennis, K.E. Dimensions of client control. *Nursing Research*, 1987, *36*:3, 151-156.

Derdiarian, A. Informational needs of recently diagnosed cancer patients. *Nursing Research,* 1986,*35*:5, 276-281.

DeVillier, B. Physiology of stress: cellular healing. *Critical Care Quarterly,* 1984, *March*, 15-20.

DiMatteo, M., and DiNicola, D. Social science and the art of medicine: from hippocrates to holism. in DiMatteo and Friedman (eds.), *Interpersonal Issues in Health Care.* New York: Academic Press, 1982.

Dohrenwend, B.P., & Shrout, P.E. "Hassles" in the conceptualization and measurement of life stress variables. *American Psychologist*, 1985, *40*, 780-785.

Dossey, L. Consciousness and caring: retrospective 2000. *Topics in Clinical Nursing,* 1982, *3*:4, 75-82.

Duffy, G., Lewis, P., Tubbs, L. Bone marrow transplantation. *Today's O.R. Nurse*, 1987, *9*:7, 11-20.

Eberst, R. Defining health: a multidimensional model. *Journal of School Health,* 1984, *54*:3, 99-104.

Egbert, L. Preoperative anxiety: the adult patient. *International Anesthesiology Clinics*, 1986, *24*:4, 17-37.

Enna, S. The role of neurotransmitters in the pharmacologic actions of benzodiazepines, in Mathew, R., *The Biology of Anxiety.* New York: Brunner/Mazel, 1982.

Enos, D. and Sultan, P. *The sociology of health care.* New York: Praeger, 1977.

Erickson, H. and Swain, M. A model for assessing potential adaptation to stress. *Research in Nursing and Health,* 1982, *5*, 93-101.

Feldman, F. Wellness and work. in Cooper, C.(eds.). *Psychosocial Stress and Cancer.* 1984, Wiley and Sons.

Fell, D. et al. Measurement of plasma catacholamine concentrations. *British Journal of Anesthesia*, 1985, *57*, 770-4.

Fenton, M.V. Development of the scale of humanistic nursing behaviors. *Nursing Research*, 1987, *36*:2, 82-87.

Fisher, S. *Stress and the perception of control.* London: Laurence Erlbaum, 1984.

Fleischer, R. Witherspoon, R., and Sanders J. Bone marrow transplantation: and overview for the primary care PA., *Physician Assistant,* 1988, *12*:7.

Fleming, C. Scanlon., C, and D'Agostino, N. A study of the comfort needs of patients whith advanced cancer. *Cancer Nursing,* 1987, *10*:5 237-243.

Ford, R. and Ballard, B. Acute complications after bone marrow transplantation. *Seminars in Oncology Nursing*, 1988, *4*:1, 15-24.

Frankenhaeuser, M. Experimental approaches to the study of catecholamines & emotion. In L. Levi (ed), *Emotions, Their Parameters & Measurement*. New York: Raven Press, 1975, 209-234.

Freedman, S. An overview of bone marrow transplantation. *Seminars in Oncology Nursing,* 1988, *4*;1, 3-8.

Frey, D., Stahlberg, D., & Fries, A. Information seeking of high & low anxiety subjects after receiving positive and negative self-relevant feedback. *J. of Personality*, 1986, *54*:4, 694-703.

Gadow, S. Existential advocacy: philosophical foundation of nursing. In Specker, S., and Gadow, S. (eds.), *Nursing: Images and Ideals,* New York: Springer, 1980.

Gadow, S. Humanistic issues at the interface of nursing and the community. *Connecticut Medicine*, 1977, 41:6.

Goodwin, L., and Prescott, P. Issues and approaches to estimating interrater reliability in nursing research. *Research in Nursing and Health*, 19 81, *4*, 323-337.

Gottschalk, L. Vulnerability to "stress." *American Journal of Psychotherapy,* 1983, *37*:1, 5-22.

Granville - Grossman, K. Anxiety: presentation of the anxious patient, *Postgraduate Medical Journal*, 1984, *60*, (Suppl 2), 7-11.

Graydon, J. Factors that predict patients functioning following treatment for cancer. *International Journal of Nursing Studies*, 1988, *25*:2, 117-124.

Greenspan, K. Psychophysiological approaches in the treatment of anxiety and tension. *Clinical Anxiety / Tension In Primary Medicine*, New Jersey:Excerpta Medica, 1979, 41-51.

Haberman, M., Woods, N., and Packard, N. The demands of illness inventory: reliability and validity assessment. Manuscript submitted for publication, 1989.

Haberman, M. *Living with Leukemia: The Personal Meaning Attributed to Illness and Treatment by Adults Undergoing a Bone Marrow Transplantation.* Unpublished doctoral dissertation, University of Washington, 1987.

Haberman, M. Psychosocial aspects of bone marrow transplantation. *Seminars In Oncology Nursing*, 1988, *4*:1, 55-59.

Hallam, R. *Anxiety-Psychological Perspectives on Panic and Agoraphobia.* New York: Academic Press, 1985.

Haney, C. A. Psychosocial factors in the management of patients with cancer. In C.L. Cooper. *Psychosocial Stress and Cancer.* London: John Wiley & Sons, 1984.

Hart, L., and Kinney, C. Loss of identity control in Hart, L., Reese,J., and Fearing, M., *Concepts Common to Acute Illness.* Missouri: C.V. Mosby, 1981.

Heater, B. Nursing responsibilities & changing visiting restrictions in the ICU. *Heart and Lung*, 1985, *4*:2, 181-186.

Hengeveld, M.W., Houtman, R.B., & Zwaan, F.E. Psychological aspects of bone marrow transplantaton: a retrospective study of 17 long-term survivors. *Bone Marrow Transplantation*, 1988, *3*, 69-75.

Heninger, G. Introduction to the issues: applying advances in neurobiology to clinical anxiety syndromes. *Psychopharmacology Bulletin,* 1983, *19*, 3.

Henry, J., and Meehan, J. Psychosocial stimuli, physiological specificity and cardiovascular disease. In Weiner, Hofer and Stunkard, (eds) *Brain, Behavior, and Bodily Disease.* New York: Raven, 1981.

Hinkle, D.E. Wiersma, W. and Jurs, S. *Applied statistics for the behavioral sciences,* Boston: Houghton Mifflin Co., 1988.

Holland, J., Plumb, M., Yates, J , Harris S., Tuttolomondo A., Holmes, J. Holland, J. Psychological responses of patients with acute leukemia to germ free environments. *Cancer,* 1977, *40*, 871 - 879.

Hyams, N., Domino, G ., and Spencer, R. Differential aspects of locus of control and attitudes towards death. *Social Behavior and Personality*, 1980, *10*:2, 183-88.

Imboden, J. B. Psychosocial determinants of recovery. *Advances in Psychosomatic Medicine,* 1972, *8*, 142-155.

Irwin, M. Daniels, M., Bloom, E., Smith, T., and Weiner, H. Life events, depressive symptoms and immune function. *American Journal of Psychiatry*, 1987, 144:4.

James, I. Practical aspects of the use of beta-blockers in anxiety states: situational anxiety. *Postgraduate Medical Journal*, 1984, *60*, (Suppl 2), 19-25.

Janis, I.L. Vigilance and decision making in personal crises. In G.B. Coelho, U.A. Hamburg, and J.E. Adams (Eds.), *Coping and Adaptation,* New York: Basic Books, 1974, 139-175.

Johnson, J. and Lauver, V. Alternative explanations of coping with stressful experiences associated with physical illness. *Advances in Nursing Science,* 1989, 11:2, 39-52.

Johnson, J. Leventhal, H. and Dabbs, J. Contribution of emotional and instrumental response processes in adaptation to surgery. *Journal of Personality and Social Psychology,* 1971, *20*:1, 55-64.

Johnson, M. N. Self-disclosure and anxiety in nurses and patients. *Issues in Mental Health Nursing*, 1979, *2*:1.

Johnston, M. Pre-operative emotional states & post-operative recovery. *Adv.Psychosom.Med.*,1986, *15*, 1-22.

Kalisch, P. and Kalisch, B. *The Advance of American Nursing*. Boston: Little, Brown and Co., 1986.

Kandel, E. From metapsychology to molecular biology: explorations into the nature of anxiety. *American Journal of Psychiatry*, 1983, *140*, 10.

Kanfer, F. H. and Goldstein. *Helping People Change*. New York: Plenum Press, 1977.

Kanner, A. Coyne J. Schaefer, C. and Lazarus, R. Comparison of two modes of stress measurment: Daily hassles and uplifts versus major life events. *Journal of Behavioral Medicine,* 1981, *4*:1, 1-39.

Kanner, A. Kaffry, D. and Pines, A. Conspicuous in its absence: the lack of positive conditions as a source of stress, *Journal of Human Stress* 1978, *4*:4, 33-39.

Kasch, C.R., & Knutson, K. Patient compliance & interpersonal style: implications for practice & research. *Nurse Pract.*, 1985, *10*:3.

Kelly, D. *Anxiety and Emotions*, Illinois: Charles C. Thomas, 1980.

Kerlinger, F. *Foundations of behavioral research.* New York: Holt, 1986.

Kiecolt-Glaser, J. & Glaser, R. Methodological issues in behavioral immunology research with humans. *Brain, Behavior, and Immunity*. 1988, *2*, 67-7.

Kiely, W.F. Coping with severe illness. *Advances in Psychosomatic Medicine*, 1972, 8, 105-118.

Kimball, C. Psychotherapeutic interventions in acute medical situations. *General Hospital Psychiatry*, 1979, *1*:2, 150-5.

King, S. and Gregor, F. Stress and coping in families of the critically ill. *Critical Care Nurse*, 1985, *5*:4, 48-51.

Kornfeld, D. S. The hospital environment: it's impact on the patient. *Advances in Psychosomatic Medicine*, 1972, *8*, 252-270.

Kruglanski, A. The lay- model in cognitive therapy. In Rosenbaum et al (eds), *Perspectives on Behavior in the Eighties*, Springer Series on Behavior Therapy & Behavior Medicine, 1983, *9*.

La Monica, E., Oberst, M., Modea, A., and Wolf, R. Development of a patient satisfaction scale. *Research in Nursing and Health*, 1986, *9*, 43-50.

Lader, M. Psychophysiological studies in anxiety. in Burrows and Davies (eds.) *Handbook of Studies on Anxiety*. New York: Elsevier Press, 1980.

LaMonica, E. Empathy in nursing practice. *Issues in Mental Health Nursing*, 1979, *21*. 1-13.

Langer, E. *The Psychology of Control*. California: Sage, 1983.

Lazarus, R. and Folkman, S. *Stress, Appraisal, and Coping*. New York: Springer, 1984.

Lazarus, R. Puzzles in the study of daily hassles. *Journal of Behavioral Medicine*, 1984, *7*(4).

Lefcourt, H. The function of the illusions of control and freedom. *American Psychologist*, 1973, *28*, 417-425.

Lesko, L., Kern, J., Hawkins, D. Psychological aspects of patients in germ free isolation: a review of child, adult, and patient management literature. *Medical and Pediatric Oncology*, 1984, *12*, 43-49.

Leventhal,H., Nerenz, D., Straus, A. Self-regulation and the mechanisms for symptom appraisal, In D. Northouse (ed.) *Symptoms, Illness Behavior, and Health Seeking*. 1982, 55-83.

Lewis, F. Experienced personal control and quality of life in late-stage cancer patients. *Nursing Research*. 1982. *3*:2. 113-119.

Liebman, J. Anxiety anxiolytics and brain stimulation reinforcement. *Neuroscience and Biobehavioral Reviews*, 1985, *9*,75-86.

Lindquist, R. Providing patient opportunities to increase control. *DCCN*, 1986, *5*:5, 304-309.

Linville, P.W. Self-complexity as a cognitive buffer against stress-related illness and depression. *Journal of Personality and Social Psychology*, 1987, *52*(4), 663-76.

Lorber, J. Good patients & problem patients:conformity & deviance in a general hospital. In P.Conrad & R. Kern (eds.) *The Sociology of Health & Illness*. New York:St.Martin's Press, 1981, *26*, 395-404.

Mathew, R. et al. Catecholamines and anxiety. *Acta Psychiat. Scand.*, 1982, *65*, 142-7.

Mattila, V. Salokangas, R. Stress caused by life changes and their role as factors predisposing to illness. *Psychiatrica Fennica,* 1981, *12*, 177 - 182.

McGlave, P. The status of bone marrow transplantation for leukemia. *Hospital Practice,* 1985, *11*, 97-110.

McInerny, W. Understanding moral issues in health care. *Journal of Professional Nursing,* 1987, *3*, 268-277.

Mechanic, D. Stress, illness and illness behavior. *Journal of Human Stress* 1976, *2*:2, 2-6.

Miller, A. Nurse/patient dependency - a review of different approaches with particular reference to studies of the dependency of elderly patients. *Journal of Advanced Nursing*, 1984, *9*, 479-186.

Miller, J., and Powers, M. Development of an instrument to measure hope. *Nursing Research*, 1988, *37*:1, 6-10.

Mishel, M. Adjusting the fit: development of uncertainty scales for specific clinical populations. *Western Journal of Nursing Research,* 1983, *5*:4.

Mishel, M. and Branden, C. Finding meaning: antecedents of uncertainty in illness. *Nursing Research*, 1988, *37*:2, 98-127.

Mishel, M. and Murdaugh, C. Family adjustment to heart transplantation: redesigning the dream. *Nursing Research*, 1987, *36*:6, 332 - 337.

Mishel, M. Parents perception of uncertainty concerning their hospitalized child. *Nursing Research* ,1983, *32*:6, 324-330.

Mishel, M. Perceived uncertainty and stress in illness. *Research in Nursing and Health,* 1984, *7*, 163-171.

Mishel, M. The measurment of uncertainty in illness. *Nursing Research,* 1981, *30*:5, 258-263.

Mishel, M. *Uncertainty in Illness scale: Reliability, Means, Standard Deviation for Total Scale Factors.*Unpublished Manuscript, 1987.

Mishel, M. Uncertainty in Illness. *Image: Journal of Nursing Scholarship,* 1988, *20*:4, 225-232.

Monroe, S. Major and minor life events as predictors of psychological distress: further issues and findings. *Journal of Behavioral Medicine*,1983, *6*, 189-205.

Montagu, A. *Touching: The Human Significance of the Skin.* New York: Harper and Row, 1986.

Munday, A. Physiological measures of anxiety in hospital patients. *Study of Nursing Care Project Reports,* Series #2 and #3, 1973.

Nestoros, J. Gabaergic mechanisms and anxiety: an overview and a new neurophysiological model. *Canadian Journal of Psychiatry*, 1984, *29*.

Nims, J. and Strom, S. Late complications of bone marrow transplant recipients: nursing care issues. *Seminars in Oncology Nursing*, 1988, *4*:1, 47-54.

Northouse, P., & Northouse, L. Professional-patient relationships. *Health Communication.* Englewood Clifts, NJ:Prentice Hall, 1985, 82-95.

Oppenheim, A. *Questionnaire design and attitude measurement.* New York: Basic Books, 1966.

Orshan, S. Pain and stress management in nursing: controversy and theory. *Holistic Nursing Practice,* 1988, *2*:3, 9-16.

Owen, G. The stress of change. *Nursing Times,* 1983, *79*:4, 44-46.

Pasnau, Robert O. *Diagnosis and Treatment of Anxiety Disorders.* Washington D.C.: American Psychiatric Press, 1984.

Patient Bone Marrow Transplantation Handbook. Seattle, WA: Department of Social Work, Fred Hutchinson Cancer Research Center, 1989.

Peet, M. Beta-blockade in anxiety. *Postgraduate Medical Journal,* 1984, *60* (Suppl 2), 16-8.

Pelletier, M. Client satisfaction surveys: variables to watch out for. *Dimensions,* 1985, *6*:2, 37-39.

Pfeffer, J. Hyperventilation and the hyperventilation syndrome. in *Postgraduate Medical Journal,* 1984, *60,* (Suppl 2), 12-5.

Plaut, S. Friedman, S. Stress, coping behavior and resistance to disease. *Psychotherapy and Psychosomatics,* 1982, *38,* 274-283.

Polit, D. and Hungler, B. *Nursing Research: Principles and Methods,* New York: Lippincott, 1978.

Pollock, S. The heartiness characteristics: A motivating factor in adaptation. *Advances in Nursing Science,* 1989, *11*:2, 53-62.

Popkin, M. Foldow, C., Hall, R., Branda, R. and Yarchoan, R. Psychiatric aspects of allogeneic bone marrow transplantation for asplastic anemia. *Diseases of the Nervous System,* 1977, *38,* 925-927.

Press, O., Schaller, J., and Thomas E.D. Bone marrow transplant complications. in Toledo - Pereyra, L. (ed.) *Complications of Organ Transplantation.* New York: Dekker, 1987.

Quigley, K. Bielecki, C. and O'Rourke, A. The critically ill oncology patient. in Riegel, B. and Ehrenreich, D. *Psychological Aspects of Critical Care Nursing*. Maryland: Aspen, 1989.

Rakoff, A. The manifestations of anxiety and tension in gynecologic practice. in *Clinical anxiety/tension in primary medicine*. New Jersey: Excerpta Medica, 1979, 114-127.

Reich, W. Parrella D. Filstead W. Uncounfounding the hassles scale: external sources versus internal responses to stress. *Journal of Behavioral Medicine,* 1988, *11*:3, 239-249.

Rippetoe, P.A., and Rogers, R. W. Effects of components of protection-motivation theory on adaptive and maladaptive coping with a health threat. *J. of Personality & Social Psychology*, 1983, *52*:3, 596-604.

Roberts, C.S. Identifying the real patient problems. *Nursing Clinics of North America*, 1982, *17*:3, 481-9.

Rooymans, H., Kraal - Dingjan, C., Pluut, R., and Zwaan, F. Psychological aspects of the treatment of patients with bone marrow insufficiency. *Netherlands Journal of Medicine*, 1979, *22*, 138-142.

Salk, J. Health and lifestyle . *Health Matrix*, 1985, *3*:3, 3-7.

Sandin, B., and Chorot, P. Changes in skin, salivary, and urinary ph as indicators of anxiety levels in humans. *Psychophysiology*, 1985, *22*, 2.

Sarason, I. G. and Sarason, R. R. Anxiety and interfering thoughts: their effect on social interaction. *Shyness: Perspectives on Research and Treatment*. New York: Plenum Press, 1986, 253-64.

Seeman, M. and Seeman, T. Health behavior and personal autonomy: a longitudinal study of the sense of control in illness. *Journal of Health and Social Behavior,* 1983, *24*, 144-160.

Seligman, M.E. *Helplessness*. San Francisco: Freeman,1975.

Shimko, C. The effect of preoperative instruction on state anxiety. *Journal of Neurosurgical Nursing*, 1981, *13*:6, 318-322.

Silberfarb, P. Greer, S. Psychological concomitants of cancer: clinical aspects *American Journal of Psychotherapy,* 1982, *36*:4, 470-479.

Silver, R.L., and Wortman, C.B. Coping with undesirable life events. in J. Garber and M. Seligman (eds.), *Human Helplessness*. NY: Academic Press, 1980.

Smith, J. A. The idea of health: a philosophical inquiry. *Advances in Nursing Science,* 1981, *3*:3, 43-50.

Snyder, M. *Independent Nursing Interventions.* New York: Wiley and Sons, 1985.

Speedling,E., and Rosenberg, G. Patient well-being: a responsibility for hospital managers. *Health Care Management Review, 11*:3, 1986.

Spielberger, C. *Manual for the State-Trait Anxiety Inventory.* Palo Alto: Consulting Psychologists Press, 1983.

Staub, E. Tursky, B. and Schwartz, G. Self control and predictability: their effects on reactions to aversive stimulation. *Journal of Personality and Social Psychology*, 1971, *18*, 157-162.

Sternbach, R. Pain and "hassles" in the United States: findings of the Nuprin Pain Report. *Pain,* 1986, *27*, 69-80.

Suls , J. and Mullen, B. Life events, perceived control and illness: the role of uncertainty. *Journal of Human Stress,* 1981, 30-34.

Sutherland, J. Walker, P., and Till, J. The development of a method for determining oncology patient's emotional distress using linear analogue scales. *Cancer Nursing,* 1988, *11*:5, 303-308.

Taylor, S. Hospital patient behavior: reactance, helplessness or control. in DiMatteo and Friedman (eds.) *Interpersonal Issues in Health Care,* New York: Academic Press, 1982.

Tetrick, L. and LaRocco, J. Understanding, prediction, and control as moderators of the relationships between perceived stress, satisfaction, and psychological well-being. *Journal of Applied Psychology,* 1987, 72:4, 538-543.

Thorne, S. Helpful and unhelpful communications in cancer care: the patient perspective. *Oncology Nursing Forum,* 1988, 15:2, 167-172.

Topf, M. Noise induced stress in hospital patients: coping and nonauditory health outcomes. *Journal of Human Stress,* 1985, *11*:3, 125-134.

Twaddle, A. The concepts of the sick role and illness behavior. *Adv. in Psychosomatic Medicine*, 1972, *8.*

Tyrer, P. J., Anxiety states. in Paykel, *Handbook of Affective Disorders,* New York: Guilford Press, 1982, 5-69.

Uhde, T. Fear and anxiety: relationship to noradrenergic function. *Psychopathology*, 1984, *17*, (Suppl 3), 8-23.

Verwoerdt, A. Psychopathological responses to the stress of physical illness. *Advances in Psychosymatic Medicine,* 1972, *8*, 119-141.

Vinokur, A. and Caplan, R. D. Cognitive and affective components of life events: their relations and effects on well-being. *American Journal of Community Psychology*, 1986, *14*:4, 351-70.

Vogele, C. Steptoe, A. Physiological and subjective stress responses in surgical patients. *Journalof Psychosymatic Research,* 1986, *30*:2. 205-215.

Volcier, B. Patient's perceptions of stressful events associated with hospitalized adolescents. Unpublished master's thesis. University of Washington, 1978.

Volicer, B. A hospital stress rating scale. *Nursing Research*, 1975, *24*:5, 252-359.

Wallston, B. Smith, R., Wallston, K., King, J., Rye, P., and Heim, C. Choice and predictability in the preparation for barium enemas: a person - by - situation approach. *Research in Nursing and Health*, 1987, *10*, 12-22.

Watson, J. *Nursing: The Philosophical Science of Caring.* Boston: Little, Brown and Co., 1979.

Watzlawick, P. *How Real Is Real.* New York: Vintage, 1977.

Woods, N. Catanzaro, M. *Nursing Research : Theory and Practice.* St.Louis: C.V. Mosby, 1988.

Wright, R. Motivation, anxiety, and the difficulty of avoidant control. *Journal of Personality and Social Psychology*, 1984, *46*:6, 1376-1388.

Wrubel, J. Benner, P. Lazarus, R. Social competence from the perspective of stress and coping. in Wine, J. and Smye, M. (eds.) *Social Competence*. New York: Guifford Press, 1981.

Zautra, A., Guarnaccia C., Dohrenwend B. Measuring small life events. *American Journal of Community Psychology,* 1986, *14*:6, 629-655.

Zika, S. Chamberlain K. Relation of hassles and personality to subjective well-being. *Journal of Personality and Social Psychology*, 1987, *53*:1, 155-162.

Appendix A: *Informational Letter – Community Sample*

Demands of Hospitalization:
Development of a Questionnaire

Because you have recently been a patient in the hospital for 24 hours or longer, you have a unique understanding of the causes and incidences of stressors faced by hospitalized patients. I would appreciate your sharing this understanding with me by participating in a study looking at hospital related demands. Demands, often referred to as hassles, are the small irritating, frustrating, or otherwise annoying experiences which occur day to day in the hospital. Understanding what these small demands are, and how frequently they occur, will help nurses and other health care professionals understand the source of stressors affecting the physical and emotional health of patients under their care.

Your participation in this study will involve evaluating the content of a questionnaire which lists demands which potentially occur with hospitalized patients. Drawing from your expertise, you will be asked to indicate how frequently you feel each demand might be experienced by someone in the hospital. You will also be invited to list additional demands which you feel might belong on the questionnaire, and point out items which seem unclear or "not applicable" to hospitalized patients.

There are no foreseeable costs to you for your participation in this study except for your time and effort to read and evaluate the questionnaire. There are no foreseeable risks to you by participation in this study. If any question seems too personal or sensitive to you, you are free not to answer it. You are also free to withdraw your participation at any time without reprisal.

All information which you provide will be kept confidential and will be recorded and stored under an code number. When the data for this study is analyzed, any findings will be reported only in group form. A summary of major findings for this study will be sent to you upon it's completion.

If you have any questions about this study, please feel free to contact:
Val Coxon, Ph.C.
School of Nursing
Mail Stop SC-72
University of Washington
Seattle, Wa. 98105
(206) 782-5334

Thank you for your participation in this study. Completion and return of the enclosed questionnaire will be considered your willingness to voluntarily participate in this study.

Appendix B: *Informational Letter – Nurse Educators & Researchers*

Demands of Hospitalization:
Development of a Questionnaire

Because your expertise and research interests include the emotional and physical effects of illness and hospitalization, you have a unique understanding of the causes and incidences of stressors faced by hospitalized patients. I would appreciate your sharing this understanding with me by participating in a study looking at hospital related demands. Demands, often referred to as hassles, are the small irritating, frustrating, or otherwise annoying experiences which occur day to day in the hospital. Understanding what these small demands are, and how frequently they occur, will help nurses and other health care professionals understand the source of stressors affecting the physical and emotional health of patients under their care.

Your participation in this study will involve evaluating the content of a questionnaire which lists demands which potentially occur with hospitalized patients. Drawing from your expertise, you will be asked to indicate how frequently you feel each demand might be experienced by someone in the hospital. You will also be invited to list additional demands which you feel might belong on the questionnaire, and point out items which seem unclear or "not applicable" to hospitalized patients.

There are no foreseeable costs to you for your participation in this study except for your time and effort to read and evaluate the questionnaire. There are no foreseeable risks to you by participation in this study. If any question seems too personal or sensitive to you, you are free not to answer it. You are also free to withdraw your participation at any time without reprisal.

All information which you provide will be kept confidential and will be recorded and stored under an code number. When the data for this study is analyzed, any findings will be reported only in group form. A summary of major findings for this study will be sent to you upon it's completion.

If you have any questions about this study, please feel free to contact:
Val Coxon, Ph.C.
School of Nursing
Mail Stop SC-72
University of Washington
Seattle, Wa. 98105
(206) 782-5334

Thank you for your participation in this study. Completion and return of the enclosed questionnaire will be considered your willingness to voluntarily participate in this study.

Appendix C: *Informational Letter – Staff Nurses*

University of WashingtonSchool of Nursing
Department of Psychosocial Nursing, and the
Fred Hutchinson Cancer Research Center

INFORMATION LETTER

Pilot Study Using Panel of Experts:
Staff Members

The Demands of Hospitalization:
Development of a Questionnaire

Investigators:
Valerie J. Coxon R.N., Ph.C (206-782-5334), Doctoral Candidate, School of Nursing; Mel R. Haberman, R.N., Ph.D, (206-467-5226); and Patricia A. Betrus, R.N., Ph.D. (206-545-6069).

_____ _____

Attending Physician Phone

Because you work closely and on a regular basis with hospitalized patients, you have a unique perspective on some of their hospitalization experiences. I would appreciate your sharing this perspective with me by participating in a study looking at hospital related demands. Demands, often referred to as hassles, are the small irritating, frustrating, or otherwise annoying experiences which occur day to day in the hospital. Understanding what these small demands are, and how frequently they occur, will help nurses and other health care professionals understand the source of stressors affecting the physical and emotional health of patients under their care.

Your participation in this study will involve evaluating the content of a questionnaire which lists demands which potentially occur with hospitalized patients. Drawing from your experiences you will be asked to indicate how frequently you feel each demand might be experienced by someone in the hospital. You will also be invited to list additional demands which you feel might belong on the questionnaire, and point out items which seem unclear or "not applicable" to the patients you work with. The entire questionnaire should take less than one half hour to complete.

There are no foreseeable adverse effects or risks to you for your participation in this study except for your time and effort to read and evaluate the questionnaire. If any question seems too personal or sensitive to you, you are free not to answer it. You are also free to withdraw your participation at any time without penalty or loss of benefits to which you are otherwise entitled.

Appendix C: *(Cont.)*

All information which you provide will be kept anonymous and will be recorded and stored under an code number. When the data for this study is analyzed, any findings will be reported only in group form. A summary of major findings for this study will be sent to you upon request. If you have any questions about your rights as a research participant, please contact Karen Hansen in the Institutional Review Office at Fred Hutchinson Cancer Research Center (206) 467-4867.

If you have any questions about this study, please feel free to contact:

Val Coxon, Ph.C.
School of Nursing
Mail Stop SC-72
University of Washington
Seattle, Wa. 98105
(206) 782-5334

Thank you for your participation in this study. Completion and return of the enclosed questionnaire will be considered your willingness to voluntarily participate in this study.

Appendix D: *Consent Form – Recently Discharged BMT Patients*

University of WashingtonSchool of Nursing
Department of Psychosocial Nursing, and the
Fred Hutchinson Cancer Research Center

CONSENT FORM

Pilot Study Using a Panel of Experts:
Former Hospitalized Patients

The Demands of Hospitalization -
Development of a Questionnaire

Investigators:
Valerie J. Coxon R.N., Ph.C (206-782-5334), Doctoral Candidate School of Nursing; Mel R. Haberman, R.N. Ph.D., (206-467-5226); and Patricia A. Betrus, R.N., Ph.D. (206-545-6069).

_____ _____

Attending Physician Phone

Because you have recently been in the hospital for longer than 24 hours, you have a unique understanding of what happens to a hospitalized patient. You are invited to share some of your experiences by participating in a study looking at hospital related demands. Demands, often referred to as hassles, are the small irritating, frustrating, or otherwise annoying experiences which occur day to day in the hospital. Understanding what these small demands are, and how frequently they occur, will help nurses improve the quality of care they provide to patients.

Your participation in this study will involve evaluating a proposed questionnaire which lists approximately one hundred and fifty demands which might happen to a patient in the hospital. Drawing on your recent hospitalization experiences, you will be asked to indicate how frequently you feel each demand might be experienced by someone in the hospital. You will also be invited to list additional demands which you feel might belong on the questionnaire, and point out items which seem unclear or "not applicable" to your experiences. The entire questionnaire should take less than one half hour to complete.

There are no foreseeable adverse effects or risks to you for your participation in this study except for your time and effort to read and answer the questionnaire. If any question seems too personal or sensitive to you, you are free not to answer it. No staff member, other than the investigators will know whether or not you chose to participate in the study. You are also free to withdraw your participation, all or in part, at any time without

Appendix D: *(Cont.)*

any penalty or loss of benefits to which you are otherwise entitled, and without affecting your care at Fred Hutchinson Cancer Research Center in any way.

All information you provide will be kept confidential and will be recorded and stored under a code number. When the data for this study is analyzed, any findings will be reported only in group form. A summary of major findings for this study will be sent to you upon request. The completed study will constitute a dissertation and will be available from the Health Sciences Library at the University of Washington. Data, identified by code number only, will be retained for approximately 10 years.

There is no monetary compensation for participating in this study. If you have any questions, please feel free to contact the researchers listed at the beginning of this form. If you have any questions about your rights as a research participant, please contact Karen Hansen in the Institutional Review Office at Fred Hutchinson Cancer Research Center - (206) 467-4867. Thank you in advance for your time and effort to respond to this questionnaire. Completion and return of this consent form will be considered your willingness to voluntarily participate in this study.

__ _____

Signature of Investigator/Date

Subjects Statement

The study described above has been explained to me and I voluntarily consent to participate in it. I have had an opportunity to ask questions, and understand that any future questions I may have will be answered by Val Coxon. I understand that my responses will be kept separate from my identity and will be kept confidential. I understand that although the consent form itself will be part of the medical record, the questionnaire itself will not. I understand no staff members or person's other than the key investigators will have access to my responses, and any data resulting from this study will be reported in group form only. I am receiving a signed copy of this consent form.

_____

Signature of Subject/Date

copies to: Subject
Investigator's File
Medical Records

Appendix E: *Consent Form Main Study – BMT Patients*

University of WashingtonSchool of Nursing
Department of Psychosocial Nursing, and the
Fred Hutchinson Cancer Research Center

Consent Form

Anxiety and the
Perceived Demands of Hospitalization

Investigators:
Valerie J. Coxon R.N., Ph.C (206-782-5334), Doctoral Candidate, School of Nursing;
Mel R. Haberman, R.N., Ph.D. (206-467-5226); and Patricia A. Betrus, R.N. Ph.D. (206-545-6069).

Attending Physician _____ Phone _____

Purpose and Benefits

Because your illness requires you to be in the hospital for care and treatment, you will gain a unique understanding of what hospitalized patients experience. You are invited to share some of your insights by participating in a study looking at levels of anxiety and hospital related demands. Demands, sometimes referred to as hassles, are the small irritating, frustrating, or otherwise annoying experiences which occur day to day in the hospital. Understanding how often these demands occur, how intense they become, and how they affect emotions, will help nurses and other health care professionals understand some of the stressors of hospitalization, and help improve the quality of care provided to patients.

Your participation in this study will involve responding to pencil and paper questionnaires at two separate interviews. The first interview, during the outpatient evaluation period, will consist of a short questionnaire which asks you basic information such as your age, sex, and how you feel your health has been.

The second interview will be on the fifth day after your bone marrow transplant procedure. It will involve responding to a questionnaire which asks you to identify the demands you have been experiencing, and several brief questionnaires which ask you about the emotions you might have been feeling. One typical example of a demand questionnaire item is: "Feeling uncomfortable in bed". You will be asked how intensely this item

Appendix E: *(Cont.)*

has affected you. You will also be invited to list additional demands and to point out items which seem unclear or "not applicable" to your experiences.

It should take you less than twenty minutes to answer the questionnaires during this second occasion. If you are feeling ill or tired, the researcher will read the questionnaire items to you, and you may answer verbally. If you prefer, you may keep the questionnaires overnight, or choose to answer them during brief interviews over two or more days. After completing the questionnaires, you will be invited to complete a five to ten minute verbal interview with the researcher about some of the demanding, as well as the uplifting, experiences you have encountered while in the hospital. For example, you might be invited to describe an experience which you found particularly troublesome, or a coping response which worked well for you.

There are no foreseeable adverse effects or risks to you for your participation in this study except for your time and effort to read and answer the questionnaires. If any question seems too personal or sensitive to you, you are free not to answer it. If you do experience any emotional discomfort as a result of completing the questionnaires, you will be given an opportunity to discuss your reaction with the investigator or Dr. Haberman. No staff member, other than the investigators, will know whether or not you chose to participate in the study. You are free to withdraw your participation, all or in part, at any time without penalty or loss of benefits to which you are otherwise entitled, and without affecting your care at Fred Hutchinson Cancer Research Center in any way.

All information you provide will be kept confidential and will be recorded and stored under a code number. When the data for this study is analyzed, any findings will be reported only in group form. A summary of major findings for this study will be sent to you upon it's completion. The completed study will constitute a dissertation and will be available from the Health Sciences Library at the University of Washington. Data, identified by code number only, will be retained for approximately 10 years.

There is no monetary compensation for participating in this study. If you have any questions, please feel free to contact the researchers listed at the beginning of this form. If you have any questions about your rights as a research participant, please contact Karen Hansen in the Institutional Review Office at Fred Hutchinson Cancer Research Center - (206) 467-4867. Thank you in advance for your time and effort to respond to these questionnaires. Completion and return of this consent form will be considered your willingness to voluntarily participate in this study.

_____

Signature of Investigator/Date

Appendix E: *(Cont.)*

Subjects Statement

The study described above has been explained to me and I voluntarily consent to participate in it. I have had an opportunity to ask questions, and understand that any future questions I may have will be answered by Val Coxon. I understand that my responses will be kept separate from my identity and will be kept confidential. I understand that although the consent form itself will be part of the medical record, the questionnaires themselves will not. I understand no staff members or persons other than the key investigators will have access to my responses, and any data resulting from this study will be reported in group form only. I am receiving a signed copy of this consent form.

_____

Signature of Subject/Date

copies to: Subject
Investigator's File
Medical Records

Appendix F: *Demands Scale – Pilot Study*

The Demands Of Hospitalization

Below is a list of demands that people sometimes experience while in the hospital. Read each demand, and based on your personal knowledge and experiences, decide how frequently you think each demand might occur to you, if you were a patient in the hospital.

Please select one of the following discriptors that best describes how frequently you think each demand might occur. Place that number in the space to the left of each demand.

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

Regarding day-to-day comfort while in the hospital, how frequently would the following demands affect you:

1. ——— Being attached to tubes and machines
2. ——— Unusual smells annoying me
3. ——— Having my sleep interrupted
4. ——— Upsetting television (programming, content, commercials)
5. ——— Being woken up early

6. ——— Being too cold
7. ——— Keeping things clean and organized around me
8. ——— Difficulties reaching for things while in bed
9. ——— Not getting enough sleep
10. ——— Being too hot

11. ——— Uncomfortable bed
12. ——— Unable to control room lighting as I want
13. ——— Feeling physically irritated or uncomfortable
14. ——— Trouble relaxing
15 ——— Being in pain

16. ——— Environment preventing me from falling asleep
17. ——— Unexpected/unexplained side effects of treatments

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

How frequently did the following demands related to your day to day life in the hospital affect you:

18. ____ Forced to abide by a rule which I felt wag unnecessary for me
19. ____ Having to remain in a cold impersonal waiting area
20. ____ Having to repeat a bad experience

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

21. ____ Unnecessary waiting
22. ____ Not being prepared for what to expect
23. ____ Getting the "runaround"
24. ____ Not being able to take care of myself
25. ____ Others not letting me make decisions

26. ____ Waiting for treatments/tests
27. ____ Concerns about my safety
28. ____ Side effects of medications or treatments
29. ____ Too many pills
30. ____ Forced to endure pain while waiting

31. ____ Fear of not being treated correctly
32. ____ Concerned about germs and infections
33. ____ People rushing around me
34. ____ Not being able to get pain relief
35. ____ Machines annoying me

36. ____ Difficulty waiting for appointments
37. ____ Difficulty waiting for results of tests

As a patient in the hospital, how often would you experience the following:

38. ____ Feeling reluctant to complain about something
39. ____ Having no "veto" power over what is done to me
40. ____ Feeling ignored sometimes

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

41. ——— Being more assertive than I want to be
42. ——— Not knowing who is truly sympathetic towards me
43. ——— People talk down to me
44. ——— Not knowing who to trust
45. ——— Feeling unsupported and alone
46. ——— Someone seems impatient with me

47. ——— Feeling someone has been rude to me
48. ——— Worrying about confrontations with staff
49. ——— Having to argue with someone to get my way
50. ——— Having my emotional feelings disregarded
51. ——— Feeling reluctant to ask questions
52. ——— Unable to express myself adequately sometimes
53. ——— Feeling anxious with no one to talk to

In your relationships with staff members, how frequently would these demands happen:

54. ——— Experiencing hassles from my doctors
55. ——— Feeling uncomfortable communicating with my doctor
56. ——— Staff member acting insensitive to my preferences
57. ——— Receiving an annoyed response from a staff member
58. ——— Simply feeling uncomfortable with certain staff members

59. ——— Feeling reluctant to assert myself with a staff member
60. ——— A staff member promised to return, doesn't, or is late
61. ——— Staff member was not skillful when caring for me
62. ——— Staff seems to be judging me
63. ——— Staff was unavailable when I needed them

In your attitudes and thoughts towards staff members, how frequently would you experience the following demands:

64. ——— Feeling the staff was overworked

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

65. ____ Not knowing what staff expected from my family/guests
66. ____ Thinking staff feels I am troublesome
67. ____ Thinking staff may gossip about me

68. ____ Feeling hesitant to ask for assistance from staff
69. ____ Staff seem more preoccupied with tasks than with my concerns
70. ____ Feeling like I'm asking too much from staff

In your experiences with family and friends, how frequently would you experience the following demands:

71. ____ Forced to have visitors leave
72. ____ Spouse or friends having hassles due to my hospitalization
73. ____ Visitors making me uncomfortable
74. ____ Could not host family and friends as I would like
75. ____ Unable to be with friends or relatives when I need them

76. ____ Not being touched by others
77. ____ Not being able to touch others
78. ____ Not enough time with people I love

Regarding privacy related demands, how frequently would you experience:

79. ____ Unexpected company
80. ____ Too many interruptions
81. ____ Too much noise
82. ____ To many strangers in the room
83. ____ Unable to use the bathroom in private

84. ____ Other people watching television
85. ____ Unable to keep people out of my room
86. ____ Unable to have privacy when I want
87. ____ Unable to bathe in private

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

88. ____ Disturbed by other patients

Concerning your experiences with mobility, how frequently. did the following affect you:

89. ____ Restricted ability to move my body
90. ____ Having to stay in one room all day
91. ____ Unable to go outside when you want
92. ____ Not being able to explore or investigate outside my room when I choose

Concerning demands related to your personal care, how frequently did the following affect you:

93. ____ Not being able to shower or take a bath
94. ____ Poor personal hygiene
95. ____ Concerns about bodily functions
96. ____ Unable to use the bathroom when I want to
97. ____ Being bathed at times I did not choose
98. ____ Not having bathroom facilities
99. ____ Having to wear a hospital gown
100. ____ Unable to take medications when I want them
101. ____ Trouble controlling what, when and how much to eat

Concerning the loss of everyday routines associated with wellness:

102. ____ Unable to use alcohol when I choose
103. ____ Not being able to wear my own clothes
104. ____ Unable to enjoy my usual entertainment or recreation
105. ____ Unable to visit stores or restaurants

106. ____ Not being able to go out and purchase things I want or need
107. ____ Difficulty reading or writing
108. ____ Unable to see/ care for pet
109. ____ Feeling like I can't express my sexuality

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

Did the following worries about your situation concern you often:

110. ——— Worried about the future
111. ——— Feeling this experience will never be over
112. ——— Worried about neglecting responsibilities
113. ——— Afraid of losing valuables
114. ——— Worried about losing my job

115. ——— Afraid people will lose interest in me
116. ——— Worried about costs of hospitalization
117. ——— Worried about returning to my job
118. ——— Feeling generally insecure about the current situation
119. ——— Worried about losing my ability to do my job

Did these demands related to being in an institutional environment concern you often:

120. ——— Having to lay in a strange bed
121. ——— Forced to wait with nothing to do
122. ——— Having to live among strangers
123. ——— Taken somewhere at a different time than I was initially told
124. ——— Being "taken somewhere" in a passive manner

125. ——— Being treated like I can not understand
126. ——— Not being able to see my medical records
127. ——— Did not know when I could go home
128. ——— Unnecessary procedures
129. ——— Receiving incomplete explanations

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

130. ——— Not being told where I am to be taken
131. ——— Unexplainable delays in care

Appendix F: *(Cont.)*

The frequency of this demand is:

1 - Never occurs
2 - Rarely occurs
3 - Sometimes occurs
4 - Often occurs
5 - Very frequently occurs

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

132. ____ Not being able to read enough about my condition
133. ____ Could not get accurate information when I wanted it

How frequently did the following demands related to your feelings and emotions while in the hospital occur:

134. ____ Losing my sense of "who I am"
135. ____ Feeling I have less power than anyone around me
136. ____ Unable to perform at my usual level
137. ____ Feeling over-regimented

138. ____ Feeling "trapped" in the hospital
139. ____ Feeling over-protected
140. ____ Too many demands on me
141. ____ Feeling I have lost my personal right~
142. ____ Feeling like I am wasting time

143. ____ Unable to make decisions
144. ____ Feeling bored
145. ____ Regretting that I can't help or support other people
146. ____ Feeling self conscious about my weight
147. ____ Feeling ashamed

148. ____ Feeling regrets while remembering past events
149. ____ Feeling I was in the way
150. ____ Losing my dignity
151. ____ Concerned about my physical appearance
152. ____ Doing stupid things
153. ____ Feeling overwhelmed sometimes

Appendix F: *(Cont.)*

Please list any additional demands which you feel might frequently occur to a patient in the hospital which you did not find in this questionnaire:

154. _____

155. _____

156. _____

157. _____

Comments:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix G: *Spielberger State – Trait Inventory*

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STAI Form Y-1

Name _____ Date _____ S ____

Age _____ Sex: M ____ F ____ T ____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

Consulting Psychologists Press
577 College Avenue, Palo Alto, California 94306

Appendix G: *(Cont.)*

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
	1	2	3	4
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

Appendix J: *Demographic Data Sheet*

Code # _____

Demographic Data Sheet

1. Age _____
2. Sex ☐ Male ☐ Female
3. Religious Preference _____
4. Maritial Status
   a. ☐ Single
   b. ☐ Married
   c. ☐ Divorced
   d. ☐ Widowed
5. Approximate *Yearly* Family Income $ _____(gross)
6. Ethnic Identity
   a. ☐ Afro-American
   b. ☐ Asian-American
   c. ☐ Native American
   d. ☐ Hispanic American
   e. ☐ Caucasian
   f. ☐ Other _____ (specify)
7. Admitting Illness

   _____ _____
   diagnosis onset
8. Highest Educational Degree Attained
   a. ☐ Grade school (grades 1 - 8)
   b. ☐ High School
   c. ☐ Technical or Community College
   d. ☐ Four Year College
   e. ☐ Master's Degree
   f. ☐ Doctorate
9. Perceived Current Health Status
   (the degree of health you feel you are in now, with 100% being the best health you have ever been in)
   Very Poor Health Very Good Health
   0% _____ 100%
10. Occupation _____

Appendix K: *Chart Review Sheet*

Chart Review

Patient ID# _____

Date _____

Date of Admission _____

Date of Discharge _____

LAF Yes _____

No _____

Moved _____ Date_____

Broke LAF_____ Date_____

Institution Swedish 10SW _____

Swedish 11SW _____

FHCRC _____

COMMENTS: _____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix L: *Demands Scale – Main Study*

The Demands Of Hospitalization

Below is a list of demands that people sometimes experience while in the hospital. Read each demand, and decide how much the demand has bothered you this hospital stay.

Select one of the following descriptors that best indicates how much the demand has bothered you. Place that number in the space to the left of each demand.

This demand:

1 - Never bothers me
2 - Rarely bothers me
3 - Sometimes bothers me
4 - Often bothers me
5 - Very frequently bothers me

If you do not know, or do not wish to respond to any item, place an "X" in the space to the left of the demand.

Regarding day-to-day comfort while in the hospital, how much do the following demands bother you?

1 ___ Being attached to tubes and machines
2 ___ Unusual smells annoying me
3 ___ Having my sleep interrupted
4 ___ Upsetting television (programming, content, commercials)
5 ___ Being woken up early
6 ___ Being too cold
7 ___ Keeping things clean and organized around me
8 ___ Difficulties reaching for things while in bed
9 ___ Not getting enough sleep
10 ___ Being too hot
11 ___ Uncomfortable bed
12 ___ Unable to control room lighting as I want
13 ___ Feeling physically irritated or uncomfortable
14 ___ Trouble relaxing
15 ___ Being in pain
16 ___ Environment preventing me from falling asleep
17 ___ Unexpected/unexplained side effects of treatments
18 ___ Supplies and equipment breaks or works poorly

How frequently do the following demands related to your day-to-day life in the hospital bother you?

19 ___ Forced to abide by a rule which I feel is unnecessary for me
20 ___ Having to repeat a bad experience
21 ___ Unnecessary Waiting
22 ___ Not being prepared for what to expect
23 ___ Getting the "runaround"
24 ___ Not being able to take care of myself
25 ___ Waiting for treatments/tests
26 ___ Concerns about my safety
27 ___ Side effects of medications or treatments
28 ___ Too many pills
29 ___ Concerned about germs and infections
30 ___ Machines annoying me
31 ___ Difficulty waiting for results of tests
32 ___ Difficulties communicating about schedules and times

Regarding privacy and personal care, how much do the following demands bother you?

33 ___ Unexpected company
34 ___ Too many interruptions
35 ___ Too much noise
36 ___ Unable to have privacy when I want
37 ___ Not being able to shower or take a bath
38 ___ Concerns about bodily functions
39 ___ Not having bathroom facilities
40 ___ Unable to take medications when I want them
41 ___ Trouble controlling what, when and how much to eat

Please turn page

Appendix L: *(Cont.)*

This demand:
1 - Never bothers me
2 - Rarely bothers me
3 - Sometimes bothers me
4 - Often bothers me
5 - Very frequently bothers me

Concerning your mobility, and the environment you are in, how much do the following demands bother you?

42 —— Restricted ability to move my body
43 —— Having to stay in one room all day
44 —— Unable to go outdoors when I want
45 —— Not being able to explore or investigate outside my room when I choose
46 —— Forced to wait with nothing to do
47 —— Do not know when I can go home
48 —— Unnecessary procedures
49 —— Receiving incomplete explanations

How much do these changes in your normal routines bother you?

50 —— Unable to enjoy my usual entertainment or recreation
51 —— Unable to visit stores or restaurants
52 —— Not being able to go out and purchase things I want or need
53 —— Difficulty reading or writing
54 —— Worried about the future
55 —— Feeling this experience will never be over
56 —— Worried about neglecting responsibilities
57 —— Feeling generally insecure about the current situation
58 —— Can not host family and friends as I would like
59 —— Unable to be with friends or relatives when I need them
60 —— Not being touched by others
61 —— Not being able to touch other
62 —— Not enough time with people I love

How much do the following demands on your feelings and emotions bother you?

63 —— Having no "veto" power over what is done to me
64 —— Feeling ignored sometimes
65 —— Feeling I have less power than anyone around me
66 —— Unable to perform at my usual level
67 —— Feeling over-regimented
68 —— Feeling "trapped" in the hospital
69 —— Feeling over-protected
70 —— Too many demands on me
71 —— Feeling I have lost my personal rights
72 —— Feeling bored
73 —— Regretting that I can't help or support other people
74 —— Concerned about my physical appear ance
75 —— Feeling overwhelmed sometimes

Please list any additional demands and comments you may have:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Thank you for taking the time to answer this questionnaire completely and accurately.

Subject _____ Date: _____

Appendix M: *Permission Letter from Dr. Coan*

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721
COLLEGE OF ARTS AND SCIENCES
FACULTY OF SOCIAL AND BEHAVIORAL SCIENCES
DEPARTMENT OF PSYCHOLOGY

November 11, 1983

Val Coxon
219 NW 40th
Seattle, WA 98107

Dear Ms. Coxon:

By all means feel free to reproduce the POS and use it in your research. I shall be interested in knowing what you find out.

The enclosed Handbook contains the items and information on such matters as scoring. I wish I could provide a more up-to-date list of research utilizing this instrument.

Sincerely,

RWCoan
Professor

Appendix N: *Permission Letter from Dr. Mishel*

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721

COLLEGE OF NURSING

August 15, 1988

Valerie Coxon, R.N., Ph.C.
219 N.W. 60th
Seattle, WA 98107

Dear Ms. Coxon:

Thank you for your interest in the Uncertainty Scale.

Enclosed you will find instructions on the use of the Uncertainty Scale, a scoring sheet, reliability scores, and a consent for use form. Wording of items can be modified to address symptoms and treatment for BMT patients.

Please sign and return two copies of the consent for use form. I will sign them and return one to you along with a copy of the scale.

If I can be of any further assistance, please feel free to contact me.

Sincerely,

Merle Mishel

Merle H. Mishel, Ph.D., R.N.
Professor of Nursing

MHM:dm
Enclosures

Appendix O: *Documentation of Permission From Dr. Thomas*

FRED
HUTCHINSON
CANCER
RESEARCH
CENTER

Clinical Research Division
1124 Columbia Street
Seattle, WA 98104

MEMORANDUM

DATE: June 9, 1988

TO: University of Washington
Human Subjects Review Committee

FROM: Mel R. Haberman, RN, PhD *M.R.H*
Director of Clinical Nursing Research

RE: Doctoral Dissertation by Ms. Val Coxon

Ms. Coxon has the approval of E. Donnall Thomas, M.D., Director of Clinical Research and myself to conduct her research project at the Fred Hutchinson Cancer Research Center.

If there are any questions regarding this activity, you may contact me at 467-5226.

MRH:m

Appendix P: *Human Subjects Approval – Expedited Review*

Form HS EX-1 (9/87) * PLEASE TYPE * Part B, Appendix I.

UNIVERSITY OF WASHINGTON

Grant and Contract Services, Human Subjects Division

CERTIFICATION OF EXEMPTION

University procedures provide for departmental review of research involving human subjects if that research is exempt from Federal regulations. The exempt categories are described on the back of this form. Exempt research may be approved by the Department Chair, Director, or Dean provided it is in accord with the general principles stated in the UW Handbook, Vol. IV, Part II, Ch. 2, Sect. 1. (see back of form). This form, properly endorsed, certifies that the research described here qualifies for exemption.

PRINCIPAL INVESTIGATOR Valerie J. Coxon ACADEMIC TITLE Doctoral Candidate

FACULTY SPONSOR (IF PRINCIPAL INVESTIGATOR IS A STUDENT) Dr. Helen Nakagawa Kogan

DEPARTMENT Psychosocial Nursing MAIL STOP SC-72 TELEPHONE 543-6960

PROJECT TITLE Hospital Related Demands: Development of a research tool

STARTING DATE May 20, 1986 ANTICIPATED TERMINATION DATE October 1, 1988

GRANT TITLE (IF DIFFERENT FROM PROJECT TITLE) Psychophysiologic Research Training (T32 NUO 73030-01

PRINCIPAL INVESTIGATOR ON GRANT (IF DIFFERENT FROM PI LISTED ABOVE) Same as Above

FUNDING AGENCY AND APPLICATION DUE DATE (IF APPLICABLE)

I. Under which category does this research qualify for exemption? See the back for a description of exempt categories. Check one. ___1 ___2 X 3 ___4 ___5 ___6

II. ABSTRACT: State briefly (limit 500 words), a) the purpose(s) of the research, b) what subjects will do (if applicable), and c) the nature of the data to be obtained.
See attached abstract

	Yes	No
III. HUMAN SUBJECTS: Are any subjects under 18 years of age?		X
Are any subjects confined in a correctional or detention facility?		X
Is pregnancy a prerequisite for serving as a subject?		X
Are fetuses in utero subjects in this research?		X
Are all subjects presumed to be legally competent?	X	

IV. PRINCIPAL INVESTIGATOR: I certify that the information provided above is correct and that, to the best of my ability to judge, this research qualifies for exemption and will be conducted in accord with the general principles stated in the UW Handbook, Vol. IV, Part II, Ch. 2, Sect. 1.

PRINCIPAL INVESTIGATOR'S SIGNATURE Valerie Coxon RN DATE 5-4-88

V. CHAIR, DIRECTOR, OR DEAN: I certify that this research is exempt from Federal regulations and that it is in accord with the general principles stated in the UW handbook, Vol. IV, Part II, Ch. 2, Sect. 1.

X SIGNATURE Sheila A. Murphy TITLE Acting Chair, PSN DATE 6/13/88

Send completed form to: Grant and Contract Services, Human Subjects Division AD-22

Appendix Q: *Human Subjects Approval – Univ. of Washington*

Form UW 13-11 (Rev. 9/87) UNIVERSITY OF WASHINGTON
Human Subjects Review Committee Application

Investigator's Copy

This box for Human Subjects Review Committee use only

APPROVED

[illegible] 15-336-C

Approval Date | Application No

HUMAN SUBJECTS OFFICE
JUL 26 1988

CONFIDENTIAL

Date July 5, 1988

Please type. Submit 9 copies, (including the signature copy), and all relevant materials, e.g., consent form(s), questionnaire(s), debriefing statement, advertisement(s) to Grant and Contract Services, Human Subjects Division, AD-22. Submit one copy of grant or contract proposals. Students should submit one copy of proposals. Submit one copy of investigator's notebook for clinical drug trials. For information and assistance, call 543-0098.

I. Investigators and associates (application will be filed under name of first person listed)

NAME	POSITION	DEPARTMENT/DIVISION	MAIL STOP	TELEPHONE
Coxon, Valerie J.	Doctoral Candidate	School of Nursing	SC-72	782-5334

II. TITLE OF ACTIVITY: Anxiety and the Perceived Demands of Hospitalization

III. BEGINNING DATE FOR USE OF HUMAN SUBJECTS August 1, 1988

IV. IF SUBMITTED FOR EXPEDITED REVIEW, CHECK HERE ☒ (SEE MANUAL FOR DEFINITION OF EXPEDITED REVIEW.)

V. LIST ALL RELEVANT GRANTS OR CONTRACTS. USE SEPARATE SHEET IF MORE THAN ONE. IF NONE, CHECK HERE ☐.

A. TYPE: ____ RESEARCH GRANT, ____ CONTRACT, X FELLOWSHIP, ____ TRAINING GRANT, ____ OTHER (SPECIFY ____________

B. NAME OF PRINCIPAL INVESTIGATOR: Helen Nakagawa-Kogan, Ph.D., Prof. PSN dept.

C. NAME OF FUNDING AGENCY: National Institute of Mental Health

D. AGENCY'S NUMBER (IF ASSIGNED): T32 NUO 73030-01

E. TITLE OF PROPOSAL: Clinical Research Training: Psychophysiologic Interface

F. INCLUSIVE DATES: FROM August, 1985 THROUGH Present

G. STATUS: ____ NEW ____ COMPETING RENEWAL X NONCOMPETING RENEWAL

H. SUBMITTED THROUGH UNIVERSITY OF WASHINGTON GRANT AND CONTRACT SERVICES? ☐ YES ☒ NO

VI. SIGNATURES

A. Submitted by Investigator: Valerie J. Coxon 7-5-88
TYPED NAME PLUS SIGNATURE DATE

B. Faculty sponsor (for student): Dr. Patricia A. Betrus 7-22-88
TYPED NAME PLUS SIGNATURE DATE OF APPROVAL

C. Department Chairman: Dr. David Allen 7/22/88
TYPED NAME PLUS SIGNATURE DATE OF APPROVAL

DO NOT WRITE IN THIS BOX

D. HUMAN SUBJECTS REVIEW COMMITTEE [illegible] SEP 15 1988 ✓
COMMITTEE CHAIRMAN'S SIGNATURE DATE APPROVE DISAPPROVE

Subject to the following conditions: ____________________

Period of approval is one year, from SEP 15 1988 through SEP 14 1989

Valid only as long as approved procedures are followed.

Appendix R: Human Subjects Review – FHCRC

INSTITUTIONAL REVIEW OFFICE
FRED HUTCHINSON CANCER RESEARCH CENTER
SWEDISH HOSPITAL MEDICAL CENTER
Protocol Disposition Form

Type, complete all sections. Submit to Review Office, FHCRC, 1124 Columbia St., I721, Seattle, WA 98104; 467-4941 (FHCRC), 467-4457 (SHMC), 467-4867 (IACUC).

Date 09/28/88 Protocol # 440
Investigator Valerie Coxon
Phone X 782-5334 Mailstop UW, SC-72
Div/Dept: ☐ BSci ☐ Clin ☐ PubHS ☐ LCSG
☐ SWOG ☐ PSOC ☐ IOL/YAG ☐ PNRF ☐ PSBC
☐ SHMC - Staff ☐ SHMC - Private Physcn ☐ Other, Identify:
Department or Address: University of Washington, School of Nursing

[Shaded Area for Review Office Only]
IR # 3001 Received 10/02/88
Comm: ☐ ACC ☒ IRBA ☐ IRBB ☐ RSC
Review: ☐ Ful ☐ Exe ☐ Exp ☒ Cop
Type: ☒ New ☐ Contng [Exptn:]
Agenda Date: 10/11/88

Affiliations:
Associates:
Protocol coordinator/contact person: Jill Brown Phone X 4222
Title of Protocol/Activity: ANXIETY AND THE PERCEIVED DEMANDS OF HOSPITALIZATION

Protocol will use:
☐ Animals (live, vertebrate) ☒ Human Subjects

☐ Category 1 ☐ Category 2A ☐ Category 4 ☐ Category 2 ☐ Category 3	☐ Full ☐ Minimal Risk [paragraph] ☐ Exempt from IRB Review [paragraph]

Cooperative arrangements:
The protocol will be reviewed at: ☒ UW; ☐ SHMC; ☐ CHMC; ☐ FHCRC
[Contact the Review Office for information on cooperative review arrangements.]

Funding Information: Use supplemental sheets if funding, including staff salary, from more than one agency supports this activity.

Type of support: ☒ Grant ☐ Center Funds ☐ Contract ☐ None [Graduate Study] ☐ Subcontract ☐ Fellowship ☐ Other, identify:	Subcontract information: ☒ FHCRC ☐ SHMC is/will be ☐ recipient ☐ awardee of a subcontract to/from: ☒ UW ☐ CHMC ☐ GHC ☐ Other, identify:

Agency: National Institute of Mental Health Identification number* T32 NU0 73030
Address:
Dates of funding support are/will be from 09/01/1985 to Present
*[*Note: If grant application is new and approval pending, indicate "pending" in Identification Number space above.]*

Dates of Activity:
This activity [☐ has been ongoing since ; ☐ will begin upon approval].
The proposed dates of this activity are from to

FDA Information: Use supplemental sheets if more than one investigational drug or device is used in this protocol.

Investigational Drugs: Drug Name N/A IND # Holder of IND FDA Status: ☐ I ☐ II ☐ III Dosage	Investigational Devices: Device Name N/A IDE # Holder of IDE Risk: ☐ Significant ☐ Nonsignificant

Approvals:

For efficacy/clinical trials [FHCRC]: *Biostatistician [Typed Name]* *Signature* *Date*	*Associate Director or Department Head [Typed name]* *Signature* *Date*
FINAL APPROVAL: *See attached materials* Karen Hansen *Typed Name* Institutional Review Administrator *Title* Dates of approval: 09/15/88 to	Karen Hansen *Signature* 10/20/88 *Date* 09/14/89

••• VALID ONLY AS LONG AS APPROVED PROCEDURES ARE FOLLOWED •••

Orig! - IR File Yellow - Investigator Pink - Coordinator Green - AHR

May 1988

Appendix S: *Pilot Study Frequency Data*

Demands of Hospitalization Questionnaire

Question #	Mean	Std Dev	N	Label
COMP01	3.74	1.08	50	tubes and machines
COMP02	2.68	1.13	50	unusual smells
COMP03	4.00	1.09	50	sleep interrupted
COMP04	2.33	1.23	49	upsetting television
COMP05	3.56	1.18	50	woken up early
COMP06	2.78	1.00	50	too cold
COMP07	2.71	1.12	49	clean and organized
COMP08	3.20	.99	50	difficulties reachin
COMP09	3.42	1.21	50	not enough sleep
COMP10	2.72	.90	50	too hot
COMP11	2.88	1.14	50	uncomfortable bed
COMP12	2.84	1.17	50	room lighting
COMP13	3.44	1.05	50	physically irritated
COMP14	3.20	1.07	50	trouble relaxing
COMP15	3.50	1.05	50	in pain
COMP16	3.22	1.12	49	environment/asleep
COMP17	3.08	1.26	50	side effects of rx
DAYL 18	2.70	1.25	50	rule unnecessary
DAYL 19	2.58	1.20	50	cold impersonal area
DAYL 20	3.12	1.08	50	repeat bad exp.
DAYL 21	3.57	1.19	49	unnecessary waiting
DAYL22	3.12	1.29	50	not being prepared
DAYL23	2.98	1.35	50	"runaround"
DAYL24	3.08	1.07	50	care of myself
DAYL25	2.88	1.15	50	make decisions
DAYL26	3.36	1.22	50	waiting for rx/tests
DAYL27	2.80	1.22	49	safety concerns
DAYL28	3.30	1.27	50	side effects meds/rx
DAYL29	3.06	1.44	48	too many pills
DAYL30	2.86	1.26	50	endure pain waiting
DAYL31	2.70	1.22	50	treated correctly
DAYL32	2.94	1.35	50	germs/infections
DAYL33	2.56	1.16	50	rushing around
DAYL34	2.56	1.18	50	pain relief
DAYL35	2.96	1.26	49	machines annoying
DAYL36	2.59	1.14	49	waiting for appts.
DAYL37	3.26	1.19	50	waiting for results
POWR38	2.90	1.28	50	reluctant complain
POWR39	2.68	1.25	50	no "veto"
POWR40	2.86	1.07	50	feelings ignored
POWR41	2.32	1.02	50	more assertive
POWR42	2.39	1.17	49	who is sympathetic
POWR43	2.63	1.20	49	people talk down
POWR44	2.40	1.09	50	who to trust

Appendix S: ***(Cont.)***

Question #	Mean	Std Dev	N	Label
POWR45	2.26	1.03	50	feeling unsupported
P0WR46	2.37	.83	49	someone impatient
POWR47	2.28	.90	50	someone rude
P0WR48	2.06	1.02	50	confrontations staff
POWR49	2.26	1.08	50	argue with someone
POWR5O	2.39	1.17	49	feelings disregarded
POWR5l	2.32	1.24	50	reluctant questions
POWR52	2.46	1.16	50	unable to express
POWR53	2.48	1.09	50	feeling anxious
RELS54	2.24	.97	49	hassles from MDs
RELS55	2.28	1.25	50	communicating MD
RELS56	2.56	1.01	50	insensitive pref.
RELS57	2.74	1.12	50	annoyed response
RELS58	2.80	1.01	50	uncomfortable
RELS59	2.32	1.24	50	reluctant assert
RELS60	2.88	1.15	50	return: doesn't/late
RELS61	2.52	1.09	50	not skillful
RELS62	2.27	1.04	49	judging me
RELS63	2.60	1.14	50	unavailable
ATTS64	3.36	1.10	50	staff overworked
ATTS65	2.30	1.18	47	family/guests
ATTS66	2.26	.99	50	troublesome
ATTS67	1.96	1.18	50	gossip
ATTS68	2.38	1.16	50	hesitant to ask
ATTS69	2.62	1.24	50	preoccupied with task
ATTS70	2.26	1.23	50	asking too much
PFFR71	1.88	1.03	49	visitors leave
PFFR72	2.56	1.30	50	having hassles
PFFR73	2.06	.79	50	making uncomfortable
PFFR74	2.18	1.20	49	could not host
PFFR75	2.44	1.18	50	unable to be with
PFFR76	2.45	1.21	49	not being touched
PFFR77	2.42	1.25	50	not able to touch
PFFR78	2.80	1.31	50	not enough time
PRIV79	2.56	.97	50	unexpected company
PRIV80	2.92	1.03	50	interruptions
PRIV81	3.12	1.14	50	too much noise
PRIV82	2.36	1.16	50	too many strangers
PRIV83	2.76	1.32	50	use bathroom
PRIV84	2.29	1.20	48	others with t.v.
PRIV85	2.41	1.24	49	out of my room
PRIV86	2.72	1.20	50	privacy when I want
PRIV87	2.23	1.21	48	bathe in private
PRIV88	2.34	1.21	50	disturbed by pts.
MOBL89	2.86	1.15	49	restricted ability
MOBL90	3.37	1.39	49	stay in one room
MOBL91	3.39	1.43	49	go outside

Appendix S: ***(Cont.)***

Question #	Mean	Std Dev	N	Label
MOBL92	3.20	1.35	49	explore/investigate
SCPC93	3.14	1.32	49	shower/bath
SCPC94	2.52	1.23	50	personal hygiene
SCPC95	2.98	1.13	49	bodily functions
SCPC96	2.38	1.19	50	use bathroom
SCPC97	2.36	1.27	50	bathed at times
SCPC98	2.52	1.49	50	bathroom facilities
SCPC99	2.68	1.38	50	hospital gown
SCPC100	2.27	1.06	49	take medications
SCPC101	2.78	1.28	50	when/how to eat
EDRT102	1.74	.99	50	use alcohol
EDRT103	2.38	1.18	50	wear own clothes
EDRT104	3.30	1.31	50	entertainment
EDRT105	3.22	1.42	50	stores/restaurants
EDRT106	2.92	1.40	49	purchase things
EDRT107	2.88	1.22	49	reading/writing
EDRT108	2.58	1.56	48	see/care for pet
EDRT109	2.37	1.47	48	express sexuality
WORY110	3.54	1.20	50	worried about future
WORY111	3.42	1.21	50	experience over
WORY112	3.10	1.22	50	responsibilities
WORY113	1.94	1.09	49	losing valuables
WORY114	2.20	1.55	50	losing job
WORY115	2.12	1.35	49	people lose interest
WORY116	2.90	1.54	50	hospitalization $$$
WORY117	2.60	1.50	50	returning to job
WORY118	3.10	1.23	50	generally insecure
WORY119	2.68	1.54	50	ability to do job
HOSP120	2.12	1.19	50	strange bed
HOSP121	2.96	1.18	50	forced to wait
HOSP122	2.40	1.28	50	live among strangers
HOSP123	2.29	1.12	49	taken somewhere:time
HOSP124	2.13	1.10	45	"taken somewhere"
HOSP125	2.60	1.40	50	can not understand
HOSP126	2.60	1.44	48	see medical records
HOSP127	3.04	1.29	50	when could go home
HOSP128	2.41	1.22	49	unneces. procedures
HOSP129	2.96	1.29	50	incompl. explanation
HOSP130	2.00	1.19	49	told where taken
HOSP131	2.42	1.09	50	unexplainable delays
HOSP132	2.54	1.27	50	read about condition
HOSP133	2.48	1.33	50	accurate information
FEEM134	2.22	1.33	50	sense of "who I am"
FEEM135	2.66	1.42	50	less power
FEEM136	3.74	1.14	50	perform usual level
FEEM137	3.02	1.30	49	over-regimented
FEEM138	3.34	1.51	50	feeling "trapped"

Appendix S: ***(Cont.)***

Question #	Mean	Std Dev	N	Label
FEEM139	2.68	1.38	50	over-protected
FEEM140	2.66	1.30	50	too many demands
FEEM141	2.80	1.36	50	lost personal rights
FEEM142	2.28	1.36	50	wasting time
FEEM143	2.48	1.25	50	make decisions
FEEM144	3.40	1.26	50	feeling bored
FEEM145	2.70	1.22	50	help/support others
FEEM146	2.32	1.33	50	weight
FEEM147	1.88	1.10	50	feeling ashamed
FEEM148	2.38	1.28	50	past events
FEEM149	2.19	1.32	48	in the way
FEEM150	2.52	1.40	50	losing dignity
FEEM151	3.04	1.37	50	physical appearance
FEEM152	1.94	1.07	49	stupid things
FEEM153	3.04	1.29	50	feeling overwhelmed

Appendix T: *Major Scales – Frequency Data*

Coan Locus of Control: Perceived Control in Social Interactions Scale

VARIABLE	MEAN	STD DEV	MIN.	MAX.	N
C01	.31	.47	.00	1.00	32
C02	.59	.50	.00	1.00	32
C03	.72	.46	.00	1.00	32
C04	.75	.44	.00	1.00	32
C05	.81	.40	.00	1.00	32
C06	1.00	.00	1.00	1.00	32
C07	.69	.47	.00	1.00	32
C08	.47	.51	.00	1.00	32
C09	.81	.40	.00	1.00	32
C10	.72	.46	.00	1.00	32
C11	1.00	.00	1.00	1.00	32
C12	.69	.47	.00	1.00	32
C13	.59	.50	.00	1.00	32
C14	.72	.46	.00	1.00	32
COANTOT	9.87	3.03	3.00	14.00	32

Mishel Uncertainty in Illness Scale

VARIABLE	MEAN	STD DEV	MIN.	MAX.	N
Q01	1.53	1.08	1.00	5.00	32
Q02	2.03	1.23	1.00	5.00	32
Q03	2.16	1.25	1.00	5.00	32
Q04	2.75	1.24	1.00	5.00	32
Q05	2.09	1.28	1.00	5.00	32
Q06	1.84	1.25	1.00	5.00	32
Q07	2.47	.98	1.00	4.00	32
Q08	2.56	1.19	1.00	5.00	32
Q09	2.44	1.29	1.00	5.00	32
Q10	2.59	1.16	1.00	5.00	32
Q11	2.16	1.11	1.00	5.00	32
Q12	2.50	1.27	1.00	5.00	32
Q13	2.34	1.29	1.00	5.00	32
Q14	3.47	1.16	1.00	5.00	32

Appendix T: ***(Cont.)***

Q15	1.47	.67	1.00	3.00	32
Q16	2.47	1.19	1.00	5.00	32
Q17	3.38	1.01	1.00	5.00	32
Q18	1.81	.78	1.00	4.00	32
Q19	2.25	1.16	1.00	4.00	32
Q20	3.34	1.04	2.00	5.00	32
Q21	2.87	1.04	1.00	4.00	32
Q22	2.38	.98	1.00	5.00	32
Q23	2.00	1.08	1.00	5.00	32
Q24	1.34	.55	1.00	3.00	32
Q25	3.31	1.06	1.00	5.00	32
Q26	2.97	1.51	1.00	5.00	32
Q27	1.97	1.33	1.00	5.00	32
Q28	2.19	1.23	1.00	5.00	32
TOTAL	66.69	14.47	37.00	99.00	32
AMB.	39.03	10.29	19.00	60.00	32
COMP.	27.66	5.71	18.00	40.00	32

Appendix T: ***(Cont.)***

Spielberger State Trait Anxiety Scale

VARIABLE	MEAN	STD DEV	MIN.	MAX.	N
Q01	2.13	.83	1.00	3.00	32
Q02	2.12	.83	1.00	3.00	32
Q03	2.22	.87	1.00	4.00	32
Q04	1.91	.86	1.00	4.00	32
Q05	2.34	.87	1.00	4.00	32
Q06	2.00	.92	1.00	4.00	32
Q07	1.88	1.18	1.00	4.00	32
Q08	2.56	1.01	1.00	4.00	32
Q09	2.03	.90	1.00	4.00	32
Q10	2.34	.94	1.00	4.00	32
Q11	1.97	.90	1.00	4.00	32
Q12	1.97	.86	1.00	4.00	32
Q13	1.81	.90	1.00	4.00	32
Q14	1.94	.98	1.00	4.00	32
Q15	2.34	.90	1.00	4.00	32
Q16	2.50	.84	1.00	4.00	32
Q17	2.03	.93	1.00	4.00	32
Q18	1.88	.94	1.00	4.00	32
Q19	2.28	1.02	1.00	4.00	32
Q20	2.53	.88	1.00	4.00	32
Q21	1.72	.85	1.00	3.00	32
Q22	2.31	.69	1.00	4.00	32
Q23	1.81	.82	1.00	4.00	32
Q24	1.94	1.01	1.00	4.00	32
Q25	1.44	.72	1.00	4.00	32
Q26	2.25	.88	1.00	4.00	32
Q27	2.13	.83	1.00	4.00	32
Q28	1.81	.86	1.00	4.00	32
Q29	2.19	.97	1.00	4.00	32
Q30	1.69	.74	1.00	3.00	32
Q31	1.94	.98	1.00	4.00	32
Q32	1.97	.78	1.00	4.00	32
Q33	1.84	.92	1.00	4.00	32
Q34	2.09	.86	1.00	4.00	32
Q35	1.56	.67	1.00	3.00	32
Q36	1.88	.91	1.00	4.00	32
Q37	2.16	.88	1.00	4.00	32
Q38	1.94	.91	1.00	4.00	32
Q39	1.78	.75	1.00	4.00	32
Q40	2.16	.88	1.00	4.00	32
STATETOT	**42.78**	**11.34**	**23.00**	**70.00**	**32**
TRAITTOT	**38.59**	**11.80**	**24.00**	**68.00**	**32**

Appendix T: ***(Cont.)***

Demands of Hospitalization Scale

VARIABLE	MEAN	STD DEV	N	LABEL
COMP01	2.78	1.10	32	tubes and machines
COMP02	2.50	1.05	32	unusual smells
COMP03	3.19	1.26	32	sleep interrupted
COMP04	2.25	1.14	32	upsetting t.v.
COMP05	2.50	1.22	32	woken up early
COMP06	2.19	.97	32	being too cold
COMP07	2.00	1.19	32	keeping things clean
COMP08	2.22	1.21	32	difficulties reachin
COMP09	2.69	1.26	32	not enough sleep
COMP10	2.16	1.14	32	being too hot
COMP11	2.31	1.35	32	uncomfortable bed
COMP12	2.19	1.40	32	room lighting
COMP13	2.94	1.32	32	physically irritated
COMP14	2.72	.99	32	trouble relaxing
COMP15	3.00	1.14	32	being in pain
COMP16	2.63	1.36	32	falling asleep
COMP17	2.50	.98	32	side effects of RX
COMP18	1.88	1.21	32	supplies/equipment
DAYL19	1.47	.84	32	unnecessary rule
DAYL20	2.59	1.32	32	repeat bad experienc
DAYL21	2.75	1.27	32	unnecessary waiting
DAYL22	2.34	1.29	32	not prepared
DAYL23	2.06	1.39	32	"runaround"
DAYL24	2.75	1.27	32	care of myself
DAYL25	2.41	1.24	32	waiting for RX/tests
DAYL26	1.84	1.05	32	concerns about safet
DAYL27	2.84	1.17	32	side effects of meds
DAYL28	2.78	1.29	32	too many pills
DAYL29	2.63	1.41	32	germs and infections
DAYL30	2.41	1.29	32	machines annoying
DAYL31	2.34	1.23	32	waiting for results
DAYL32	1.97	.97	32	schedules and times
PRIV33	1.94	1.11	32	unexpected company
PRIV34	2.31	1.12	32	too many interruptio
PRIV35	2.59	1.36	32	too much noise
PRIV36	2.28	1.35	32	privacy
PRIV37	2.50	1.61	32	shower or bath
PRIV38	2.56	1.22	32	bodily functions
PRIV39	2.47	1.52	32	bathroom facilities
PRIV40	1.81	1.12	32	meds when wanted
PRIV41	2.19	1.35	32	what, when, how to e
MOBL42	2.50	1.08	32	restricted ability
MOBL43	2.81	1.42	32	stay in one room
MOBL44	3.19	1.35	32	go outdoors
MOBL45	2.31	1.33	32	explore or investiga

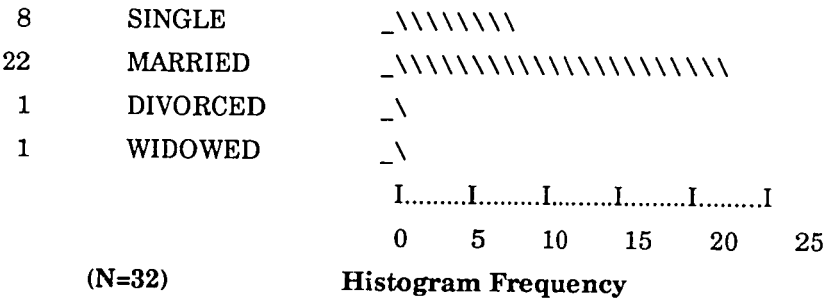
Appendix T: ***(Cont.)***

VARIABLE	MEAN	STD DEV	N	LABEL
MOBL46	2.34	1.15	32	forced to wait
MOBL47	2.75	1.46	32	go home
MOBL48	2.19	1.26	32	unnecessary procedur
MOBL49	2.06	1.27	32	incomplete explanati
ROUT50	2.81	1.38	32	usual environment
ROUT51	2.72	1.25	32	visit stores/restaur
ROUT52	2.41	1.19	32	purchace things
ROUT53	2.53	1.29	32	reading or writing
ROUT54	2.81	1.47	32	worried about future
ROUT55	2.78	1.56	32	never be over
ROUT56	2.47	1.27	32	neglecting responsib
ROUT57	2.31	1.26	32	generally insecure
ROUT58	2.38	1.18	32	host family and frie
ROUT59	2.75	1.50	32	friends or relatives
ROUT60	2.66	1.49	32	not being touched
ROUT61	2.75	1.46	32	not able to touch
ROUT62	2.94	1.39	32	not enough time
FEEM63	2.59	1.46	32	not "veto" power
FEEM64	2.16	1.08	32	feeling ignored
FEEM65	2.41	1.24	32	less power
FEEM66	3.19	1.09	32	unable to perform
FEEM67	2.31	1.00	32	over-regimented
FEEM68	2.59	1.29	32	feeling "trapped"
FEEM69	2.06	1.13	32	feeling over-protect
FEEM70	1.97	1.03	32	too many demands
FEEM71	2.19	1.20	32	lost personal rights
FEEM72	3.00	1.19	32	feeling bored
FEEM73	2.69	1.03	32	can't help or suppor
FEEM74	2.31	1.31	32	physical appearance
FEEM75	2.78	1.31	32	feeling overwhelmed
COMPFREQ	12.38	4.32	32	
DAYLFREQ	9.97	4.40	32	
PRIVFREQ	5.34	2.89	32	
MOBLFREQ	5.56	2.60	32	
ROUTFREQ	9.38	3.75	32	
FEEMFREQ	9.37	4.20	32	
DEMDFREQ	52.09	18.92	32	
COMPINT	44.62	12.46	32	
DAYLINT	33.19	11.31	32	
PRIVINT	20.66	7.23	32	
MOBLINT	20.16	7.22	32	
ROUTINT	34.31	12.10	32	
FEEMINT	32.25	11.12	32	
DEMDINT	185.19	51.11	32	

Appendix U: *Coded and Re-coded Frequencies for Variables: Marital Status, Education, Diagnosis, Occupation*

ORIGINAL CODING

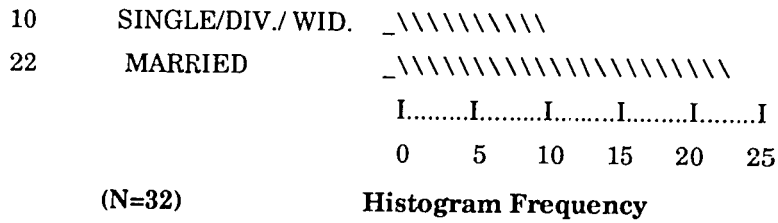
	FREQ.	PERCENT	CUMPERCENT
SINGLE	8	25.0	25.0
MARRIED	22	68.8	93.8
DIVORCED	1	3.1	96.9
WIDOWED	1	3.1	100.0
TOTAL	**32**	**100.0**	



(N=32) **Histogram Frequency**

RE-CODED MARITAL STATUS

	FREQ.	PERCENT	CUM PERCENT
SINGLE/DIV./WID.	10	31.3	31.3
MARRIED	22	68.8	100.0
TOTAL	**32**	**100.0**	

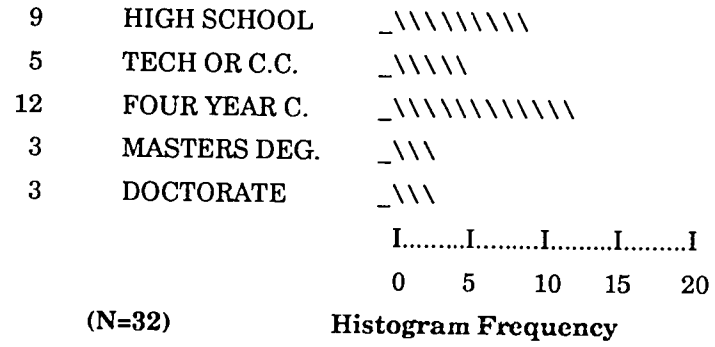


(N=32) **Histogram Frequency**

Appendix U: ***(Cont.)***

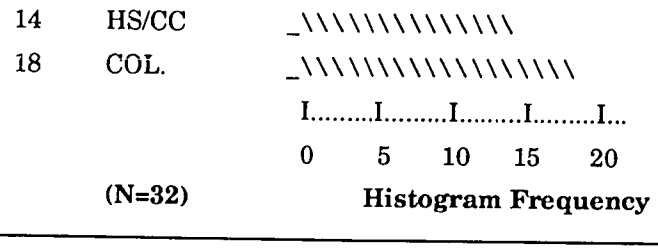
ORIGINAL CODING

	FREQ.	PERCENT	CUMPERCENT
HIGH SCHOOL	9	28.1	28.1
TECHNICAL OR COMMUNITY	5	15.6	43.8
FOUR-YEAR COLLEGE	12	37.5	81.3
MASTER'S DEGREE	3	9.4	90.6
DOCTORATE	3	9.4	100.0
TOTAL	32	100.0	



RE-CODE EDUCATION LEVEL

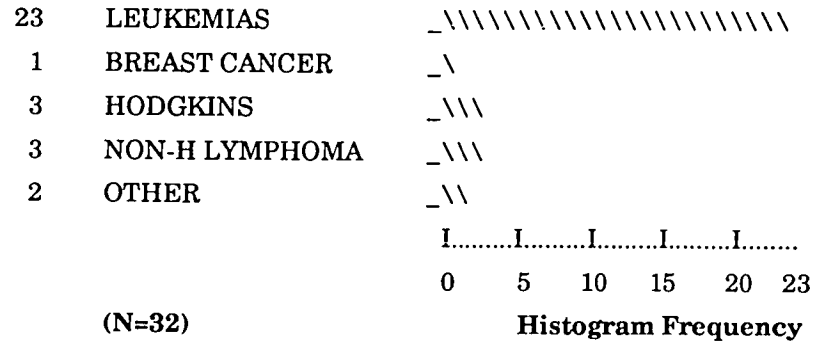
	FREQ.	PERCENT	CUM PERCENT
HIGH SCHOOL OR C.C	14	43.8	43.8
FOUR OR MORE YEARS COLL.	18	56.3	100.0
TOTAL	**32**	**100.0**	



Appendix U: ***(Cont.)***

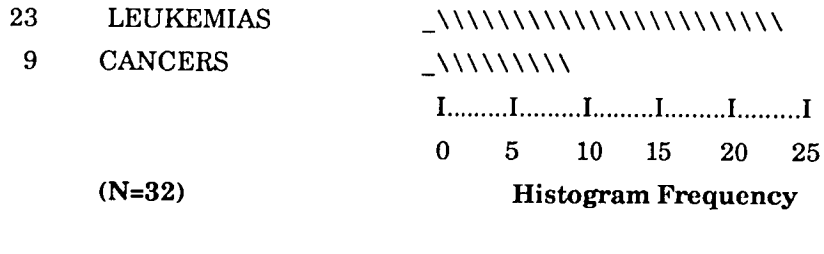
ORIGINAL CODING

	FREQ.	PERCENT	CUMPERCENT
LEUKEMIAS	23	71.9	71.9
BREAST CANCER	1	3.1	75.0
HODGKINS	3	9.4	84.4
NON-H LYMPHOMA	3	9.4	93.8
OTHER	2	6.3	100.0
TOTAL	**32**	**100.0**	



RE-CODED ADMITTING DIAGNOSIS

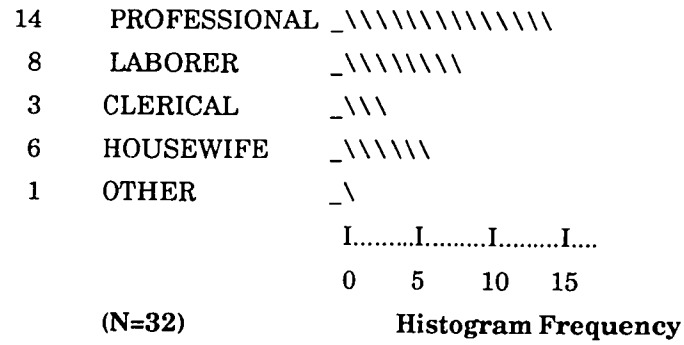
	FREQ.	PERCENT	CUM PERCENT
LEUKEMIAS	23	71.9	71.9
CANCERS	9	28.1	100.0
TOTAL	**32**	**100.0**	



Appendix U: ***(Cont.)***

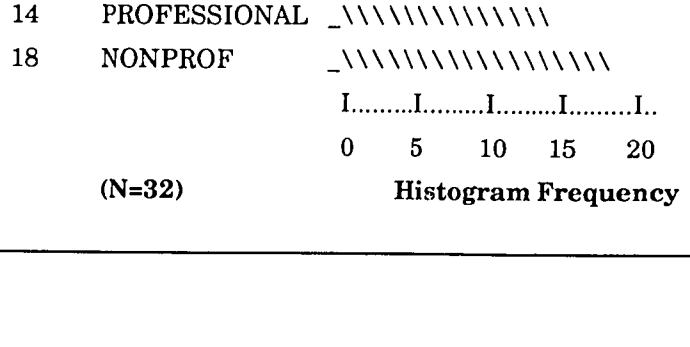
ORIGINAL CODING

	FREQ.	PERCENT	CUM PERCENT
PROFESSIONAL	14	43.8	43.8
LABORER	8	25.0	68.8
CLERICAL	3	9.4	78.1
HOUSEWIFE	6	18.8	96.9
OTHER	1	3.1	100.0
TOTAL	**32**	**100.0**	



RE-CODED OCCUPATION

	FREQ.	PERCENT	CUM PERCENT
PROFESSIONAL	14	43.8	43.8
NONPROF	18	56.3	100.0
TOTAL	**32**	**100.0**	



Biographical Note

Name: Valerie Jean Coxon
Birth: August 6, 1989
Yakima, Washington

Education:

Bellevue Senior High School
Bellevue, Washington, 1976

University of Washington
Seattle, Washington

Degrees:

Bachelor of Science in Nursing
University of Washington, 1980

Master of Nursing
University of Washington, 1985

Doctor of Philosophy
Nursing Science
University of Washington, 1989