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Factors Related to Body Image Appraisal Associated With Receiving Treatment for A Malignant Brain Tumor

ву

Ruth Ann Mulnard

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

> Doctor of Nursing Science University of San Diego

> > 1991

Dissertation Committee Mary P. Quayhagen, DNSc RN FAAN, Chairperson Kathleen Heinrich, PhD RN Judith Chodil, PhD RN

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Abstract

Within a stress-coping-adaptation framework, a path analytic model was hypothesized to explain the interrelationships among the variables of gender, age, duration of illness, steroid dosage, social support, perceived health status limitations, and coping skills, and their subsequent effect on body image appraisal in the population of subjects undergoing treatment for a malignant brain tumor. The many potential changes in physical appearance and functional abilities, including the loss of hair, the onset of Cushing's syndrome and varied physical disabilities, may cause devastating alterations in body image, requiring tremendous coping skills for adaptation in these individuals.

One hundred and ten subjects were assisted, during home or clinic visits, to complete a demographic questionnaire, the Sickness Impact Profile Scale (SIPS) to assess perceived health status limitations, the PRQ-85 social support instrument, the Revised Jalowiec Coping Scale, the Body Cathexis/Self-Cathexis Scale to measure body attitude, and the Modified Topographic Device to measure body perception. The data were analyzed using descriptive statistics along with bivariate and multiple regression techniques to explain the greatest amount of variance in the causal model.

The simplified model contained 12 significant

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direct effects and two significant indirect effects for predicting the dependent variables. In the post hoc analysis, differences were found between the low grade tumor group and the high grade tumor group in terms of their impact on causal relationships within the model. The variables with the strongest ability to predict body image appraisal in the high grade tumor group included steroid dosage and physical health status limitations. Conversely, the variables able to explain the greatest amount of variance in body image appraisal for the low grade tumor group included confrontive coping, duration of illness, and social support through confrontive coping. Among both groups, male gender and age negatively influenced body attitude, while male gender was predictive of a positive body perception.

Knowledge about the concept/construct of body image has implications for the practice, research and theoretical realms of nursing. Spanning the scope of all nursing settings and populations, and applicable within nursing conceptual frameworks, body image should impact the arenas of the clinical practitioners, researchers and educators within our profession.

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DEDICATION

Despite the trials of doctoral study over the past five years, the hills and valleys of life have continued to evolve. Therefore, this research has a multifold dedication. First, to my wonderful husband, David, who has given me unending love, support and encouragement throughout the doctoral program. We were married during the course of this doctoral program, on February 14, 1988, a true testament that love can endure all.

Secondly, I dedicate this research to my father, Lonnie Thomas Crabbe, who died on June 1, 1989, during the composition of this research proposal. As I complete this body of work today, I feel certain that he shares my joy and pride.

Thirdly, I dedicate this project to all persons with brain tumors, that they may find the strength to endure, while medicine searches for the cure to their disease, and nursing tries to foster adaptation. Specifically, I recognize my niece, Amy Kathleen Long, now age 17, who was diagnosed with a brain tumor in October 1989. I am so proud of her fight against her disease, and her continued pursuit of college and future dreams.

Finally, I need to acknowledge the true foundation of my life in the Lord, Jesus Christ, who has made all things possible. May He continue to guide my work in this helping profession, and touch the lives of all who need Him.

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I thank my dear friend, Vicky Bowden RN, DNSc, whom I met during the first summer of doctoral study at USD, for her continual support and prayers throughout those long, four years of commuting to San Diego, and through the accomplishment of this research project.

By far, the greatest contribution to my academic development and success at this research endeavor, is attributed to Dr. Mary P. Quayhagen. Mary is a nursing scholar of notorious caliber, who strives to develop the unique potential of each of her students. I feel fortunate, and forever grateful, to have been mentored throughout my doctoral program by this renowned nurse researcher.

Appreciation is also extended to my other two dissertation committee members , Dr. Judith Chodil and Dr. Kathleen Heinrich, for their support and guidance throughout the completion of this project.

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CHAPTER ONE

Background of the Problem

Neuroscience patients often experience changes in physical appearance and functional abilities as a result of their neurological diseases and/or the operative and medical interventions recommended to treat the neurological diseases. Patients diagnosed with malignant brain tumors, as a subgroup of the neuroscience population, may encounter all of these phenomena in the course of receiving treatment for the tumor. For example, initially a biopsy and/or craniotomy with associated shaving of hair may be required to make the diagnosis, with concomitant megadose corticosteroid therapy.

Large doses of the steroids may cause signs of Cushing's syndrome: moon face, buffalo hump, fat deposition in elbows and knees, weight gain, truncal obesity, and proximal muscle wasting (Nelson, 1989). Following the surgical diagnosis, radiation therapy is often delivered to the brain (sometimes both through internal implantation of radioactive seeds, as well as through external beam modalities), causing associated alopecia which usually lasts for a one year period of

time. As well, victims of brain tumors are at risk for problems with functional abilities based upon tumor location and operative morbidity (Moore, 1988). The totality of this illness experience, including the Cushing's syndrome, the loss of hair, and the physical disabilities may cause devastating alterations in body image and self concept, and requires tremendous adaptation tasks and coping skills. Yet, the important factors which influence the body image adaptation in the adult with a brain tumor have not been examined in the nursing research literature.

Purpose of the Study

The purpose of this study is to investigate the interrelationships between gender, age, steroid dosage, duration of illness, perceived health status limitations, social supports and coping skills, and their influence on body image appraisal in persons undergoing treatment for a malignant brain tumor; and to explore the relationship between the identified primary adaptive task of the brain tumor patient and the associated coping skills utilized in conjunction with that adaptive task.

Given adequate sample size, the study will also allow a post-hoc analysis of differences between groups of brain tumor patients, controlling for selection of patients within strategic time points of illness and/or

treatment course.

Theoretical Framework

Influenced by the areas of psychosomatic medicine and crisis theory, Rudolf Moos (1977 & 1984), developed his conceptual framework of coping with physical illness. As it will be utilized in the present study, the framework subsumes that a serious physical illness has occurred, and is understood as a life crisis for the individual. Through the individual's cognitive appraisal of this crisis, basic adaptive tasks are set forth to which various coping skills are applied. The background and personal characteristics, the illnessrelated factors, and the features of the physical and sociocultural environment, influence the individual's cognitive appraisal of the situation, the definition of the adaptive tasks involved, and the choice and effectiveness of coping strategies for dealing with the crisis event. Ultimately the outcome of the crisis is affected jointly by these factors.

Background and personal factors include such variables as age, intelligence, cognitive and emotional development, philosophical or religious beliefs, and previous coping experiences and illnesses. Illnessrelated factors include the type and location of symptoms - whether painful, disfiguring, disabling, or in a body region vested with special importance. The

physical and social environment might include the physical milieu,... the aesthetic quality of one's surroundings, the amount of personal space available, and the usual degree of sensory stimulation... relationships of patients and their families, of staff and patients, the social supports in the wider community, and sociocultural norms and expectations.

Of the seven major adaptive tasks, three are illness-oriented, covering the areas of dealing with the discomfort, incapacitation, and other symptoms of the illness and injury; management of the stresses of special treatment procedures and of the hospital environment; and developing and maintaining adequate relationships with medical and other health care staff. The other four adaptive tasks include preserving a reasonable emotional balance; preserving a satisfactory self-image and maintaining a sense of competence and mastery; sustaining relationships with family and friends; and preparing for an uncertain future. Although all seven of the adaptive tasks are usually encountered with a serious physical illness, the relative importance or emphasis on specific tasks is dependent on the nature of the disease, the personality of the individual and the unique set of circumstances surrounding that crisis of physical illness.

Moos (1984) divides the possible realm of coping

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skills into three domains: the appraisal-focused coping skills which attempt to find a pattern of meaning in the crisis, the problem-focused coping skills which attempt to deal with the tangible aspects of the reality of the crisis, and the emotion-focused coping skills which attempt to manage the emotions provoked by the health crisis.

As illustrated in Figure 1, the study variables referable to Moos' model include: age and gender as background and personal factors, duration of illness and steroid dosage as illness-related factors, social support as a social environmental factor, perceived health status limitations as a cognitive appraisal, coping skills as a manifestation of coping, and the measures of body image appraisal (body perception and body attitude) as the outcome or adaptation to the crisis of physical illness. The adaptive tasks of primary importance to the brain tumor patient will be examined via selection on the demographic data sheet.

Definitions of Concepts

The following concept definitions will be used:

 Body image: the combination of the concepts of body attitude and body perception (Fawcett & Frye, 1980; Fisher & Cleveland, 1968) as measured by body perception and body attitude.

A. Body attitude: the array of feelings,

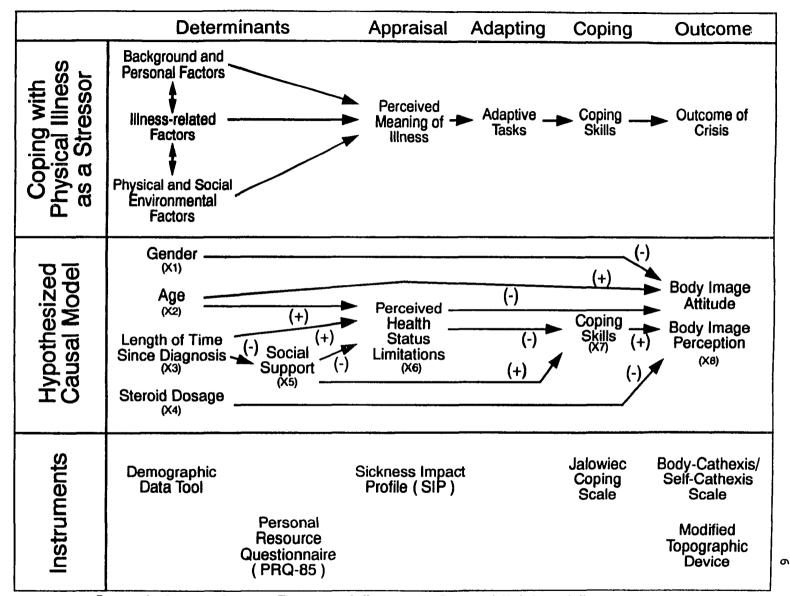


Figure 1. Linkage Between Theoretical Framework, Proposed Model, and Instrumentation

emotional reactions and attitudes toward one's body (Traub & Orbach, 1964) as measured by the Body Cathexis/Self Cathexis Scale (Secord & Jourard, 1953).

- B. Body perception: the mental experience of the physical image of the body, including perceived body space as measured by the Modified Topographic Device (Fawcett, 1976).
- Social support: the presence of and satisfaction with situational support and the perceived level of support from resources as measured by the PRQ-85 (Brandt & Weinert, 1981).
- 3. Perceived health status limitations: the dysfunction reported to be the behavioral concomitant of self-evaluated sickness (Gilson, Gilson, Bergner, Bobbitt, Kressel, Pollard, & Vesselago, 1975). This term reflects an illness orientation as perceived by the respondent.
- 4. Coping skills: the problem-oriented coping strategies which attempt to deal with the stressful situation itself; the affective-oriented strategies which attempt to handle the distressing emotions evoked by the situation (Jalowiec, 1979).

Research Hypotheses

Direct Hypotheses

H1: Gender (females) will have a direct, negative

effect on body image appraisal.

- H2: Age will have a direct, positive effect on body image appraisal and perceived health status limitations.
- H3: Duration of illness will have a direct, positive effect on perceived health status limitations and a direct, negative effect on social support.
- H4: Steroid dosage will have a direct, negative effect on body image appraisal.
- H5: Perceived health status limitations (illnessorientation) will have direct negative effects on body image appraisal and affective-focused coping skills.
- H6: Social support will have a direct, negative effect on perceived health status limitations and a direct, positive effect on affective-focused coping skills.
- H7: Affective-focused coping skills will have a direct, positive effect on body image appraisal.

Indirect Hypotheses

- H8: Body image appraisal will be indirectly affected by age through perceived health status limitations, and through perceived health status limitations and coping skills: (X2-->X6-->X8; X2-->X6-->X7-->X8).
- H9: Body image appraisal will be indirectly affected

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by duration of illness through social support and coping skills; through social support and perceived health status limitations; through the influence of perceived health status limitations alone; and through social support, perceived health status limitations, and coping skills: (X3-->X5-->X7-->X8; X3-->X5-->X6-->X8; X3-->X6--> X8; X3-->X5-->X6-->X7-->X8).

- H10: Body image appraisal will be indirectly affected by social support through perceived health status limitations and coping skills; through coping skills alone; and through perceived health status limitations alone: (X5-->X6-->X7-->X8; X5-->X7--> X8; X5-->X6-->X8).
- H11: Body image appraisal will be indirectly affected by perceived health status limitations through coping skills: (X6-->X7-->X8).
- H12: Coping skills will be indirectly affected by age through perceived health status limitations: (X2-->X6-->X7).
- H13: Coping skills will be indirectly affected by duration of illness through social support alone; through perceived health status limitations alone; and through social support and perceived health status limitations: (X3-->X5-->X7; X3-->X6-->X7; X3-->X5-->X6-->X7).

H14: Perceived health status limitations will be indirectly affected by duration of illness through social support: (X3-->X5-->X6).

Significance of the Problem for Nursing Knowledge about the concept/construct of body image has implications for the practice, research and theoretical realms of nursing. Spanning the scope of all nursing settings and populations, and applicable within nursing conceptual frameworks, body image should impact the arenas of the clinical practitioners, researchers and educators within our profession.

Practitioners in nursing are frequent observers of body image alterations among patients in clinical practice settings. Such situations may occur in any environment in which nursing care is delivered. Nurses may actually observe the physiological, psychological, and/or sociological manifestations and etiologies or body image alterations in the recipients of nursing care. Yet, nurses may lack the knowledge to identify the concept, the ability to qualify and or quantify the patient's expression of the alteration and the skills to implement appropriate interventions for the client.

Physiological manifestations of a body image disturbance might appear in conjunction with disorders that impair non-dominant parietal lobe function in the brain. Anosognosia, denial of the left side of the

body, occurs with cortical interruption of fibers that convey high levels of cortical perception in the nondominant hemisphere. This phenomenon might occur as a result of non-dominant hemisphere cerebrovascular accident or brain tumor formation (Head, 1920; Shontz, 1974). Yet, nurses without the knowledge base to realize the parietal lobe function in perceptual abilities would label the patient as uncooperative, rather than perceptually-impaired. The clinical nurse's knowledge base, in addition, may not support the correlation between this obvious patient deficit and a less evident impairment in body perception. Greater understanding of the concept of body image would further the nurse's actions in dealing with the alteration of perception and minimize the stereotyping of the phenomenon.

Another physiological manifestation of body image impairment might appear in the amputee who develops phantom limb pain, a type of deafferentation pain syndrome (Head, 1920). Again, this phenomenon has been linked to the parietal lobe of the brain that is contralateral to the amputated limb as the source of the phantom limb pain syndrome. This pain syndrome can be obliterated as a subsequent lesion, usually a stroke, occurs in that responsible parietal lobe. Again, clinical nurses rarely have sufficient knowledge

phantom limb pain and body perception alteration.

Body image disturbances, particularly those with body attitude problems, commonly produce psychological or sociological issues in the clinical setting (Henker, 1979). Most nurses have dealt with the patient who refuses to look at his own reflection in a mirror because of a surgical or traumatically-induced scar, a bald head after a craniotomy, or the altered posture and stance after a disabling neurological disease. Despite the nurse's instinctual desire to comfort such patients, the intervention is rarely based upon the understanding that the body image is a dynamic aspect of the personality which does not adjust or accommodate to new body changes immediately after the changes occur. Rather, the patient with new body changes will need to adapt their perception and attitude of their body over time (Henker, 1979; Roberts, 1986). The nurse is not wrong to comfort such a patient, but does a disservice in dismissing the patient's upset and assuming that the patient will have adapted by the following day. Persons with body attitude problems may even develop profound and serious psychological problems such as anorexia nervosa, bulimia, and schizophrenia (Shontz, 1974).

Sociologically, body image alterations may cause

about body image to make the conceptual link between

people to seek an extended, if not perpetual sick role. The person whose body image is not favorable or who has undergone a recent alteration in a previously healthy body image, may label her/himself as deviant in appearance (Goffman, 1963). Societal labelling may occur simultaneously. Compliance or noncompliance to health care regimens may be linked to the individual patient's self-concept, of which body image is a subset (Fisher & Cleveland, 1968), particularly when the body attitude is altered.

The body image alterations experienced by persons with malignant brain tumors can arise from multiple sources: the physical disabilities associated with tumor location and surgical manipulation, the alopecia associated with surgical intervention and postoperative radiation therapy, and the effects of the chronic corticosteroid dependency necessary for comfortable control of brain tumor symptomatology. These alterations may lead to social isolation and depression and eventually to non-compliance as ultimate effects of poor quality of life. Yet, research literature is lacking concerning these frequent attitude and perception problems in the brain tumor population.

As we raise clinical practice questions through observation of practice phenomenon, we invite and demand systematic nursing investigations, not only to

identify and measure the phenomena, but also to design appropriate research-based nursing interventions or protocols. Hence, this research project was designed to measure the factors which were associated with body image alterations in the malignant brain tumor patients, in an attempt to expand our nursing knowledge base, upon which interventions can be designed and tested in the future.

CHAPTER TWO

Literature Review

Cancer as a Stressor: Physical and

Psychological Changes

The diagnosis of cancer has quite a profound impact on patients and their significant others (Stoll, 1986; Sutherland, Orbach, Dyk, & Bard, 1952). The stress invoked by this disease may be influenced by the current societal trends toward total disclosure by the physician concerning diagnosis and prognosis, the increasing distrust of expert opinions, less religious faith activities, less family support and less personal rapport with the family physician (Stoll, 1986). New surgical techniques along with advances in radiation and chemotherapy treatments have impacted the improved survival rates from cancer. The improved cancer survival statistics, however, have created a variable chronic illness, the psychosocial adjustment to which has become of great concern to those affected (Gotay, 1984; Meyerowitz, Sparks, & Spears, 1979).

Yet, transformation of the physical body often occurs as a direct effect of these medical and surgical treatments for different types of cancer. Examples of

physical body changes may include the loss of a breast or testicles, loss of bladder and/or sexual control, addition of a colostomy or ileostomy, loss of scalp and/or body hair, and addition of body fat, as in the patient who is steroid-dependent for cancer control.

In several studies, body image alterations have been measured in breast/gynecological cancer patients who have experienced these bodily changes, in an attempt to measure psychological well-being or adjustment to the disease (Meyerowitz, Watkins, & Sparks, 1983; Sanger & Reznikoff, 1981). This research on psychological adjustment to breast cancer has provided the prototype model for studying body image alterations in the cancer population, and therefore will be elaborated further.

Sanger and Reznikoff (1981) studied body image and psychological adjustment on 20 women who underwent modified radical mastectomy and 20 women who underwent conservative surgical treatment for breast cancer. The two procedures differentially affected the body barrier and body satisfaction of the subjects. Women who had undergone the radical surgery showed significantly greater changes in their body satisfaction scores as compared to the women who had had breast-saving surgeries performed. The finding of a significant difference in the body barrier scores supports Fisher

and Cleveland's (1968) speculation that feelings regarding external body boundary may be influenced by actual physical events impinging on the outer layers of the body.

While stressing the importance of quality of life for the mastectomy patient, researchers found that women with segmentectomies had a statistically more positive sexual and body image than those women with mastectomies (Kemeny, Wellisch & Schain, 1988; Margolis, Goodman & Rubin, 1990). Women undergoing multiple outpatient visits for the purpose of diagnosis and treatment of cervical intraepithelial neoplasia were found to have their most positive evaluations of self esteem and body image at the time of post-surgical follow-up visit (McDonald, Neutens, Fischer, & Jessee, 1989), emphasizing the implications of body image appraisal with minor types of internal operative procedures.

Further, in another study, (Meyerowitz, Watkins & Sparks, 1983) when asked to describe the residual psychosocial effects of adjuvant chemotherapy following surgery for breast cancer, 35 women reported five areas of concern: marital/family relationships, sexual relationships, financial situation, general activity level, and work-related activity level, as well as other remaining physical concerns such as weight

changes, loss of menstruation, loss of hair, and sleep difficulties.

Psychiatric morbidity after cancer surgery has been studied extensively, especially in the breast cancer population, demonstrating the existence of depression, anxiety and mood impairment five and ten years after cancer treatment (Deadman, Dewey, Owens, Leinster & Slade, 1989; Meyer & Aspegren, 1989).

Cancer of the Brain

The diagnosis of cancer of the brain has similar physical and psychological adjustment factors as does cancer of other bodily parts, yet, no published research exists on the psychosocial adjustment of brain tumor patients. The initial surgical procedures, whether biopsy or craniotomy, may require the shaving of the entire head of hair, followed by external beam radiation therapy with a concomitant loss of scalp hair within the field of radiation for approximately a one year period of time. The hair, when it returns, may even be of a different texture or quantity.

Chemotherapy may also be a part of the treatment plan, with common side effects of nausea and vomiting, bone marrow suppression, renal toxicity, and pulmonary toxicity. The location of the tumor and/or the surgical manipulation of the brain structures may cause loss of physical function, the specific loss dependent

on anatomical location of the tumor (Mcore, 1988). Common signs and symptoms experienced from brain tumors may include headache, vomiting, drowsiness, visual failure, motor weakness, and seizure activity.

Malignant brain tumors comprise about 2% of annual deaths in the United States (Moore, 1988). Gliomas are the most common type of malignant brain tumor, further classified as oligodendrogliomas, astrocytomas, anaplastic astrocytomas, glioblastoma multiformes, and gliosarcomas. The recommended standard of treatment for these tumors, with the best survival statistics, includes surgical debulking for removal of as much tumor volume as possible, followed by external beam radiation to the tumor bed, and intravenous BCNU (Jelsma & Bucy, 1969; Shapiro, 1986; Walker, Alexander, Hunt, MacCarty, Mahaley, Mealey, Norrell, Owens, Ransohoff, Wilson, Gehan, & Strike, 1978; Walker, Green, Byar, Alexander, Batzdorf, Brooks, Hunt, MacCarty, Mahaley, Mealey, Owens, Ransohoff, Robertson, Shapiro, Smith, Wilson & Strike, 1980; Walker, Strike & Sheline, 1979;). Until recently, these malignant gliomas were characterized by a rapidly progressive course with 50% mortality in six months and 90% mortality in 18 months. New protocols are constantly in process to find modalities of treatment which will prolong quality survival time and/or cure the cancer.

The most recent completed trial included the use of PCNU versus intra-carotid Cisplatin (Green, Shapiro, & Burger, Selker, Mahaley, Mealey, Robertson, Hochberg, vanGilder, Ransohoff & Young, 1989), without significant improvement in survival rates, nor a significant difference in the two chemotherapy agents. Currently, several trials are in process, utilizing modalities such as interstitial brachytherapy to treat high grade gliomas at the time of diagnosis; variable combinations of BCNU, intra-arterial Cisplatin, and 10-EDAM chemotherapy agents to treat high grade gliomas who have failed other treatments or who are not eligible for other treatment options; and radiation therapy in an early versus late format of treatment for low grade glioma patients, with as yet inconclusive results. Therefore, the prognosis for survival from malignant brain tumors remains limited.

Brain edema in the peritumoral region, is a major cause of neurologic deficit, increased intracranial pressure, and subsequent decline in function. Edema is the primary central nervous system response to all types of traumatic events, whether physical, infectious or ischemic. The phenomenon is generally a white matter event, characterized by the accumulation of extracellular fluid (Ransohoff, 1972).

The ability of corticosteroid drugs to alleviate

symptoms, prolong life, and inhibit growth of tumors is well known, especially in the treatment of brain tumors, where steroids assume a major role in the reduction of cerebral edema (Galicich & French, 1961). The untoward side effects of megadose corticosteroids, however, are quite unfavorable to the patient population, and include increased appetite, weight qain, qlycosuria, leukocytosis, abdominal striae, truncal obesity, moon face, a buffalo hump, and proximal muscle wasting (Collu, Brown, & Van Loon, 1988; Geelhoed, & Chernow, 1985; Nelson, 1989). All of these physical bodily changes may produce body image changes, both body attitude and body perception alterations, in the brain tumor patient. It is not uncommon for cancer patients to acknowledge body image changes, such as these, as a significant stressor during the course of their chronic illness (Gotay, 1984). In an attempt to examine the factors associated with body image appraisal in the brain tumor patient, normative empirical support from the research literature will be investigated for the proposed relationships in the path model (Figure 1).

The Relationship Between Gender and Body

Image Appraisal

Attitudes toward the body and it's parts are important variables in personality theory and are

expected to vary between the genders and as a function of time, as reflected in critical human development periods. Hunt and Feldman (1960) studied a sample of 65 college students with respect to their feelings about selected body parts, using the body cathexis scale (Secord & Jourard, 1953) and human figure drawings (Machover, 1948).

Women were found to cathect their body parts more highly than men, as evidenced by the greater variability in the womens' scores (Hunt & Feldman, 1960). This finding suggests that the body is more likely to be a source of satisfaction as well as dissatisfaction to women than to men. The body part values shown to change most from early adolescence to college age were body build and height in men, and body build, breast, and weight in women. The age of these research subjects, generally 19 to 21 years of age, presents a significant limitation to the generalizability of the results to older age groups.

A similar study attempted to investigate the relationship between gender differences and global body attitude (Kurtz, 1969), again sampling the undergraduate college population of men and women, between the ages of 18 and 23. A semantic differential scale was utilized studying the factors of evaluation, potency and activity.

Consistent with the findings of Hunt and Feldman (1960), was the supported hypothesis that women had a more clearly differentiated notion of what they liked or disliked about their bodies (Kurtz, 1969). Females in this sample also had a significantly more positive global body attitude (evaluative factor) than did the These findings may be suggestive of greater men. awareness and concern about bodily appearance among the female subjects. Further analysis revealed that men have significantly larger potency factor mean scores and significantly larger activity factor mean scores than do women. As noted by the author, it is uncertain whether cultural variations or homosexuality would influence these results in different samples.

Further support for female gender being associated with a negative body image appraisal is contained in the recent research study on body consciousness (Ross, Tait, Grossberg, Handal, Brandeberry, & Nakra, 1989), in which women (both old and young together) scored significantly higher than men on private body consciousness (awareness of internal body sensations), public body consciousness (concern with external appearance), and body competence (a subjective evaluation of one's body), equating the variables of health, depression and education for all subjects. These results imply once again that women may be more

aware of bodily processes, and bodily appearance than are the men, and therefore more likely to demonstrate discontent with the body.

Striking body image differences were found among the genders in a study of body attitudes in medically ill individuals (Schwab & Harmeling, 1968). Subjects' medical illnesses covered a wide range of systemspecific problems, including psychiatric illnesses in 27% of participants. In general, medically ill patients expressed more negative feelings about their bodies than did healthy persons, focusing the dissatisfaction on the body part or function involved in the illness.

Unlike the body image variability noted in the studies of college females, medically ill females were significantly more dissatisfied with their bodies than were men. The negative body images of the females were associated with high anxiety, perception of illness as having adverse influences on their life, increasing dependency, and distortions about the severity of their illness and prognosis. Although some males had very negative body image scores, there was no significant correlation with an illness orientation (Schwab & Harmeling, 1968). The consistent direction for the relationship between gender and body image appraisal supported in the research literature just reviewed, is

a negative association between female gender and body image appraisal, as will be tested in this research project.

The Relationship Between Age and Body Image Appraisal

It is well accepted that the process of aging is associated with physical as well as physiological changes. Age as a predictor of body image appraisal has a wealth of historical research literature support, primarily in the psychological literature. Directional inconsistency exists concerning this relationship when one combines institutionalized with noninstitutionalized subjects, and with the addition of persons with psychiatric disorders. Otherwise, age is predominantly positively correlated with body image appraisal.

Human figure drawings have been utilized as projective devices for the study of body image perception (Machover, 1948). Several classic studies have utilized this technique in determining the relationship between age and body image perception (Gilbert & Hall, 1962; Lakin, 1960). In examining differences between the human figure drawings of the institutionalized versus the noninstitutionalized elderly, Lakin (1960) found that the noninstitutionalized aged drew larger, taller and more adequately centered figures than did the group of

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institutionalized elderly. The sample's age range was 67-85 years, and results did not distinguish age categories within this range.

Investigating the changes in the human figure drawing throughout the entire life span, Gilbert and Hall (1962) sampled 400 persons between the ages of 10 and 91 years. The drawings were evaluated both quantitatively and qualitatively. The quantitative scores reached a peak during the third decade of life, and showed continual and significant declines throughout the remainder of the life decades.

Qualitatively, there was a gradual decline in the quality of the drawings from the third decade to the seventh decade; however, the difference is not statistically significant, until after the seventh decade of life, when distorted body images begin to appear (Gilbert & Hall, 1962). It is not known the extent to which perceptual-motor deficits in the elderly may contribute to the deterioration in the quality of the drawings as opposed to an emotional disturbance which may likewise result in a deteriorated self-concept and body image. Caution is urged by the authors with respect to evaluating the body image distortions relevant to aging using the human figure drawings exclusively, since many of the findings from the aged's drawings were found to correlate to younger

psychotic patients.

Bodily part preferences of men and women were studied as a function of age and socioeconomic status among 2000 subjects (Weinstein, Sersen, Fisher, & Vetter, 1964). The only apparent and significant change in preference that occurred with increasing age was the devaluation of the sex-specific parts, namely, the breast for the female, and the penis and testicles for the male. Although the list of bodily parts was quite limited, and included no bodily function categories, the lack of preferential difference among the age groups is an important finding.

Consistent with these findings are the results of research by Plutchik, Conte and Weiner (1973) in which subjects were asked to rank order a specific list of bodily parts and assign a specific dollar value to each of the parts (the monetary value was defined as being equal to that amount of money expected from an insurance company should the body part be lost or hopelessly injured in an accident). The leg, eye and arm were again specified as the top ranking body parts. Despite the variability of the sample with respect to age (mean age groups ranging from 20-83), the value of the body parts was invariant over all age groups.

Body image has been examined as a conceptual subset of self-concept (Champion, Austin, & Tzeng,

1982; Chodil, 1978; Rosen & Ross, 1968). In a group of institutionalized veterans, ranging in age from 50 to greater than 70, age was positively correlated with self-concept (r=.230, p<.02) and life satisfaction (r=.256, p<.01) (Nehrke, Hulicka & Morganti, 1980). The authors hypothesized this finding as evidence that the older residents had resolved Erikson's ego integrity versus despair crisis to a greater degree than had the younger veteran residents.

Extension of the work by Nehrke, Hulicka and Morganti (1980) was done, studying noninstitutionalized individuals spanning the years from fourteen to ninetyfour (Morganti, Nehrke, Hulicka & Cataldo, 1988). Again, age was significantly correlated with selfconcept (r= .44, p<.05), with lower levels of selfconcept characterizing adolescents and young adults, while a more positive self-concept characterized all older age groups.

In evaluating the effect of age on body consciousness, researchers found that elderly persons (62-79 years of age) tended to be more conscious of their external physical appearances, as well as more positive in their self-evaluations of body competence than young persons (17-28 years of age) when health, depression and education were equal among the two groups (Ross, Tait, Grossberg, Handal, Brandeberry &

Nakra, 1989). This research finding may indicate a greater awareness toward the external physical appearance by the older age group (particularly the women), perhaps as a result of the common societal stigmatization that occurs with the aging process.

Somewhat dissimilar results were obtained by Larson, Boyle and Boaz (1984) in studying 255 veteran residents with a mean age of 57.7 years. A curvilinear relationship was found between age and physical selfconcept, as measured by the Tennessee Self-Concept Scale (Fitts, 1965), with the middle-aged group having the least positive scores. All other self-concept subscale scores gradually increased with increasing Unlike the institutionalized subjects in Lakin's age. research (1960), the age range of subjects in this study were considerably younger. The middle-aged subjects yielded lower physical self-concept scores than did the older population, suggesting perhaps that other factors such as disability or financial difficulties precluded independent living by this group. The predominant empirical support for the relationship between age and body image appraisal is a positive one (Gilbert & Hall, 1962; Morganti, Nehrke, Hulicka & Cataldo, 1988; Nehrke, Hulicka & Morganti, 1980; Plutchik, Conte & Weiner, 1973; Weinstein, Sersen, Fisher & Vetter, 1964), as will be tested in

this research project.

The Relationship Between Age and Perceived Health

Status Limitations

Since the normal process of aging is associated with greater health problems than commonly seen in the younger age groups, the elderly persons will be likely to perceive a greater amount of health status limitations. Especially in the elderly population afflicted with cancer, very poor perceptions of health are further associated with high levels of depression as well (Cavanaugh, 1986).

In a sample of 460 middle-aged and aged adults, Levkoff, Cleary and Wetle (1987) examined self-reported health as a dependent variable to determine which age group was more optimistic or pessimistic in their selfratings. Results indicated that older adults, those subjects greater than 65 years of age, are less positive in their self-appraisal of health status. For the middle-aged adults, education and number of medical diagnoses were the most salient factors, with those respondents who were less educated and had more diagnoses reporting poorer perceptions of their health. Within the elderly age group, psychological distress, number of diagnoses and education were all important predictive factors of a poor health perception. In the current research project, a positive relationship

between age and perceived health status limitations in the brain tumor population will be tested, anticipating that the older individual will have a greater illness orientation.

The Relationship Between The Duration of Illness

and the Perceived Health Status Limitations

Duration of illness as an exogenous variable in the hypothesized model, captures the element of the time interval that has elapsed since the diagnosis of brain cancer was made in the proposed study subjects. Because of the cross-sectional nature of the proposed data collection, subjects with brain cancer will represent a variety of time points in the course of treatment for brain cancer. For example, some patients will have been newly diagnosed; others will have undergone surgery, radiation therapy, and/or chemotherapy. In other words, some patients will be in an acute phase of diagnosis and treatment, while others will be in a chronic phase of treatment or convalescence. The chronicity of the illness will be anticipated to positively effect the perceived health status limitations of the subjects in this study, meaning that greater duration of illness will be associated with a greater perception of health status limitations (greater illness orientation).

The Relationship Between The Duration of Illness and Social Support

Both the social networks and the quality of support are affected by chronic illnesses. Individuals with chronic health problems are at high risk for social isolation and impairment. These individuals may suffer from loss of energy, physical disabilities, bodily disfigurements, and the time expense of maintaining their treatment regime. Little time and energy may be left for maintaining social relationships, especially those requiring reciprocal social interactions (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek & Weiner, 1984; Tilden & Weinert, 1983).

Cancer as a diagnosis often provides a stigma which is a salient factor in avoidance behavior of significant others and subsequent withdrawal of or nonmaterialization of social support (Cobb & Erbe, 1978). Two hundred persons, half of which were women diagnosed and treated for breast cancer were sampled by Peters-Golden (1982), in an attempt to evaluate perceived social support in the breast cancer patients as compared to the lay person's evaluation of perceived social support for the cancer patient. Half of the cancer patients judged the social support they received as adequate to meet their needs, with 26% judging the

support to be inadequate. Those with recurrent disease (chronic disease, rather than the acute illness) reported less satisfactory support than did those with no cancer recurrence. Those patients with recurrent disease, currently engaged in ongoing treatment for the disease, reported the least amount of social support.

Of the healthy one hundred other subjects, however, 61% stated they would probably avoid contact with someone who was known to have cancer, and yet 42% would rely on a combination of family, friends and professionals for support should they be found to have cancer. Men in the population tended to view the diagnosis of breast cancer as more devastating to a woman than any other type of cancer diagnosis, emphasizing the sexuality issue and the stigma associated with this diagnosis.

Within the current research framework, the longer duration of illness (chronic illness) is anticipated to correlate with less social support.

The Relationship Between The Steroid Dosage and

Body Image Appraisal

The administration of corticosteroids is most essential to prolongation of life in the malignant glioma population. Without the use of steroids to control cerebral edema, the mass effect of the tumor becomes more readily apparent, both radiographically

and clinically (Galicich & French, 1961; Ransohoff, 1972). Well-known side effects of chronic corticosteroid therapy include ... and the Cushing's syndrome. The major objection voiced by those patients who are dependent upon the therapeutic effect of the corticosteroids is the increased appetite and the subsequent weight gain that occurs. This weight gain may be a major factor in the body image alterations that these patients experience. A synopsis of the psychological research literature concerning obesity and body image appraisal will be reviewed, as analogous to the steroid-dependent brain tumor patient with significant weight gain and Cushingoid appearance.

Research studies have investigated the effect of obesity on body image, discovering that one's perception of body size is an important element of the self-concept, and that body image disturbances are common among the overweight population (Bruch, 1973; Stunkard & Burt, 1967; Stunkard & Mendelson, 1961). Other researchers (Glucksman & Hirsch, 1969) postulated and researched a phenomenon termed 'phantom body size,' in which the obese person tended to overestimate their body size even after weight reduction had occurred. The nonobese in comparison were more likely to underestimate their total body size. In all studies, body image was appraised as negative for obese subjects

regardless of age or gender.

Body image distortion, a related concept to body image disturbance, was investigated in a normal weight population of college students in relation to gender, and self-esteem and several other variables (Mable, Balance, & Galgan, 1986). Women were found to distort their body image significantly more than men, more than 15% above their reported weight deviations from the midpoint of a normal range. Multiple regression analysis demonstrated that gender (sr2=.25, p<.0001) and body dissatisfaction (R2=.03, p<.05) had significant individual relationships to body distortion. Extrapolation of the results to the steroid-dependent brain tumor population causes concern for the distortion that may occur from the steroidassociated weight gain, especially in the female brain tumor patient, since females tend to distort their body image more than men.

Gray (1977) studied the perception of normalcy of body weight and the associated body affect of 179 college undergraduate social science students, as related to the social characteristics of gender, age, race, and normalcy of actual body weight. Age range of the group was 18 to 60, with a mean of 28.52 years.

A non-named paper and pencil test was utilized to measure body affect, resulting in an over-all score.

Actual height, weight, gender and age of the subjects were compared against the desirable norms from standardized insurance company charts for these variables. Respondents were also asked to judge themselves as underweight, average weight or overweight. 49.2% of the respondents misperceived their weight-related appearance (as compared to the established norms). Females were more likely to perceive themselves as appearing heavier than actual weight, while males were more likely to perceive themselves as appearing lighter than actual weight. Body affect scores in this study were unrelated to gender of the respondents (Gray, 1977).

Since the amount of weight gain and Cushingoid appearance changes are dependent upon steroid dosage over time, it is expected that the greater amount of steroids consumed will yield a more negative body image appraisal in the brain tumor patient.

The Relationships Between Social Support, Perceived

Health Status Limitation, Coping Skills,

and Body Image Appraisal

In the brain tumor population, the chronicity of the illness experience considerably taxes the resources of the individuals and significant others. Various coping skills or strategies are employed to deal with the situations that present a threat to the individual.

Coping behavior is deemed effective when the individual is able to resolve the uncomfortable feelings associated with the threat(s), ultimately preserving the integrity of one's life roles, relationships and self-concept (Lazarus & Folkman, 1984).

The meaning of the illness to the individual has a direct effect on coping behavior (Lipowski, 1970). Illness will be perceived differently by each individual, throughout the spectrum of experience as a loss, a gain, or an event of no significance. Miller (1983) studied 56 chronically ill adults to determine the types of coping strategies utilized by ill adults. The coping strategies were characterized as approach strategies or avoidance strategies. The behaviors of seeking information and enhancing one's spiritual life were the two most frequently used approach strategies. Avoidance strategies included denial, minimization of symptoms and withdrawal from others.

One of the antecedents theorized to affect stress and coping is social support (Lazarus & Folkman, 1984). Social support is postulated to enhance the effectiveness of coping with a stressful event (Cobb, 1976). Further, social support has received much attention as a buffer between psychosocial stress and health outcome or well-being (Cohen & McKay, 1984; Cohen & Syme, 1985). Specifically, social support

mediates the negative effect of psychosocial stress on health and well-being, lessening the effect of the stress for those persons with stronger social support systems (Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson, Heyden, Tibblin & Gehlbach, 1983; Cobb, 1976; House, 1981). The rationale for this relationship may include the attenuation of threat and/or the reduction or elimination of reaction to the threat through support system access. Further, there appears to be a strongly supported relationship between social support and mental health and mortality (Caspi, Bolger & Eckenrode, 1987; Cohen & Wills, 1985; Myers, Lindenthal & Pepper, 1975).

McNett (1987) tested a causal model based on Lazarus' theory of stress and coping in a functionally disabled population of 50 wheelchair-bound individuals, studying the effects of social supports, threat appraisal, and coping responses on coping effectiveness. Results concluded that perceived availability of social support, rather than the actual use of social supports, was positively related to coping effectiveness, as mediated through emotionfocused and problem-focused coping strategies.

Again consistent with the theory of the buffering effect of social support and coping strategies in attenuating the effect of negative life events,

Billings and Moos (1981) studied 294 families with respect to these variables. Coping strategies and the qualitative indices of social support were found to moderate the effect of a negative life event on overall functioning. Persons who tended to use avoidance-type of coping responses were more commonly women, who also had fewer social resources, which ultimately affected the functioning in response to the stressor.

Still, the greatest criticism in the area of social support research is the unproven causal direction of the relationship between social support and health due to uncertain identification of the antecedents and consequences of the concepts (Broadhead, et al., 1983). The continued stratification of the variables of physical health and functional ability in relation to social support is encouraged to assist in sorting out the causal direction of the association (Berkman, 1986).

As postulated in this research project, a greater perception of health status limitations will be associated with diminished social supports, a negative body image appraisal and less use of affective-focused coping skills, while a greater amount of social support will be associated with more utilization of affectivefocused coping skills.

Few empirical studies have investigated the

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relationship between health status and body image appraisal. Although common sense suggests that functional disability and changes in physical appearance would yield a less positive self-concept (body image is a subset of self-concept), some contradictory results have been obtained. Meighan (1970) found that visually handicapped adolescents had less positive self-concepts than a group of nondisabled control adolescents, while Williams (1976) found the exact opposite result. Yet, other studies have demonstrated that both the type of disability (Shelsky, 1957) and the severity of disability (Smits, 1964) were related to self-concept.

Through studying the relationship of self-concept to selected demographic variables among veteran residents, Larson, Boyle and Boaz (1984) demonstrated that the more disabled veterans had lower physical self-concept scores and slightly lower personal selfconcept scores as measured by the Tennessee Self-Concept Scale (Fitts, 1965) and the PULSES Index (Moskowitz & McCann, 1957). Regardless of the type of disability, the negative self-concept seemed to be related to the severity of the disability.

Schwab & Harmeling (1968), in investigating the relationship between body image appraisal and inpatient's perception of their medical illness, found

likewise that a more negative body image was associated with a self-rating of increased severity of illness, a negative effect of the illness on one's life, and a poorer outlook on the illness. These results were found for females only, however. With the male subjects, negative body attitude scores were associated with increasing age and higher socioeconomic status. The general belief was verified that medically ill individuals express more negative feelings about their bodies than do healthy persons.

A paucity of research literature support exists for the relationship between coping skills and body image appraisal. Matson and Brooks (1982) longitudinally studied the variables affecting social and psychological adjustment in multiple sclerosis patients, and found a significant relationship between coping strategies and a positive self-esteem (F=3.18; df 7,95; p<0.01).

Although coping has traditionally been viewed as a response to emotion, recent evidence exists to support the reciprocal nature of this relationship, namely, that coping affects emotion or emotional reaction (Folkman & Lazarus, 1988a; Folkman & Lazarus, 1988b). Since body image appraisal conceptually includes body perception as well as the emotional reaction of body attitude (one's feeling about one's body), it is

hypothesized in the current model that the body image appraisal will be influenced by the affective-focused coping skills utilized by the brain tumor population.

Emotion-focused coping skills are more likely to be chosen and utilized by an individual, in response to stress, if the outcome is appraised as unchangeable (Folkman & Lazarus, 1980). Since the body image alterations experienced by this brain tumor population are caused by treatments, medications, and the anatomy of the tumor, the alterations are not changeable by the patient, other than to refuse treatment, which will ultimately shorten their life expectancy.

Summary

Empirical literature support has been reviewed for all proposed relationships within the hypothesized model as displayed in Figure 1. Although research literature is non-existent concerning the brain tumor patient's psychosocial adjustment/adaptation to the illness and treatment regimes, general support from the psychological, sociological and cancer research literature has been reviewed. Analogous to the experiences of other cancer patients, i.e. breast cancer, prostate cancer, etc., the brain tumor patient experiences body image alterations as a result of their medical and surgical treatment regime, as well as imposed physical disabilities from the disease process.

An understanding of these alterations is necessary to build a knowledge base for nursing science, as a prelude to developing interventions for this population.

CHAPTER THREE Research Methodology

<u>Research Design</u>

A correlational design using path analytic technique, as illustrated in Figure 1, was developed to provide the conceptual framework for studying the relationship between the proposed variables. Within this recursive model, the exogenous variables include gender, age, time since diagnosis and steroid dosage, while the endogenous variables include social support, perceived health status limitations, coping skills, and body image appraisal.

The structural equations for the direct relationships in the causal model were as follows: X1= e1 X2= e2 X3= e3 X4= e4 X5= p53 X3 + e5 X6= p62 X2 + p63 X3 + p65 X5 + e6 X7= p75 X5 + p76 X6 + e7 X8= p81 X1 + p82 X2 + p84 X4 + p86 X6 + p87 X7 + e8

Research Subjects

One hundred ten subjects who were undergoing treatment for a malignant brain tumor were recruited for the study to provide sufficient variable to subject ratio and to protect the power of the resulting data. Given 110 subjects with moderate effect size (f2) of .15 (for multiple regression analysis), seven independent variables and 100 error degrees of freedom, a lambda of 18 is attained, resulting in a power of .83 (Cohen, 1988). Subjects were persons being treated for a malignant brain tumor at large university hospitals who were ambulatory, had a minimum Karnofsky score (Karnofsky & Burchenal, 1949) of 50, near-normal visual acuity and visual fields and were English speaking. Community-wide recruitment was also done to meet the sample size requirements.

A cross-sectional sampling method was utilized allowing simultaneous data collection at unique treatment time points for each patient. Demographic data information was gathered about the individual's course of illness and treatment, to allow post-hoc analysis of different groups of brain tumor patients.

The subjects were interviewed either in their home environment or in outpatient clinic settings during their usual interval visits to their physician. Demographic characteristics of the sample are

summarized in Table 1. The sample consisted of 56 females (50.9%) and 54 males (49.1%), ranging in age from 21 to 73 years. Weights of the subjects varied from 109 to 230 pounds. All participants had normal visual acuity (some with lense correction), as was specified in the inclusion criteria.

The sample was predominantly married (61.8%) and of caucasian ethnicity (81.8%). Occupations were widely varied with 26 subjects (23.6%) not employed and 43 subjects (39.1%) permanently disabled from their brain tumor disease at the time of data collection.

Disease-related characteristics of the sample are summarized in Table 2. 84 patients (76.4%) had high grade brain tumor types such as anaplastic astrocytoma, glioblastoma multiforme, lymphoma, ependymoma, medulloblastoma and gliosarcoma. The remaining 26 patients (23.6%) had low grade tumor types such as mixed glioma, oligodendroglioma, and astrocytoma. Subjects ranged from 1 to 92 months since the diagnosis had been confirmed. 14 subjects (12.7%) had undergone only a biopsy of their brain mass for diagnostic purposes, without having undergone subsequent craniotomy. All but 16 of the subjects (14.5%) had completed or at least started a course of external radiation therapy.

No complications were experienced by 70 of the

TABLE 1

n = 110 Males =	54 (49.1%)	Females = 56	(50.9%)	
Age		Occupati	on	
21-30	20 (18.2%)	No Occupation		18 (16.4%)
31-40	34 (30.9%)		nial Service	1 (0.9%)
41-40	26 (23.6%)		killed Worker	8 (7.3%)
51-60	13 (11.8%)	Sem	niskilled Worker	14 (12.7%)
61 -70	15 (13.6%)	Skil	led Manual Worker	12 (10.9%)
71-73	2 (0.02%)	Cler	rical & Sales	6 (5.5%)
		Tec	hnicians/Semiprof	11 (10.0%)
Educational Level			Managers	
< H.S.	9 (8.2%)	Less	Lesser Professionals	
H.S.	36 (32.7%)	Maj	or Professionals	14 (12.7%)
Trade School	8 (7.3%)			
Associate Degree	11 (10.0%)	Employr	nent Status	
Baccalaureate Degr	ree 35 (31.8%)	Not	Not Employed	
Masters Degree	10 (9.1%)	Реп	Permanently Disabled	
Doctoral Degree	1 (0.9%)	Part	-Time	21 (19.1%)
		Full	-Time	20 (18.2%)
Marital Status				
Single	22 (20%)	Karnofsl	ky Score	
Married	68 (61.8%)	50 Requires Considerab		ble
Widowed	5 (4.5%)		Assistance	9 (8.2 %)
Divorced	15 (13.6%)	60	Requires Occasiona	al
			Assistance	27 (24.5%)
Ethnicity		70	Unable to Work	21 (19.1%)
White	90 (81.8%)	80	Normal Activities	
Asian	7 (6.4%)		with Effort	29 (26.4%)
Black	8 (7.3%)	90	Minor Signs or	
Hispanic	5 (4.5%)		Symptoms	22 (20.)%)
•		100	Normal	
Annual Family Income			No Symptoms	2 (1.8%)
\$ 5,000 - \$10,000	7 (6.4%)		• •	
\$11,000 - \$20,000	11(10.0%)	· .		
\$21,000 - \$30,000	18 (16.4%)			
\$31,000 - \$40,000	22 (20.0%)			
\$41,000 - \$50,000	13 (11.8%)			
\$51,000 - \$60,000	16 (14.5%)			
\$61,000 - \$70,000	14 (12.7%)			
Over \$71,000	9 (8.2%)			

Demographic Characteristics of the Sample

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TABLE 2

High Grade Tumors = 84 (76.	.4%) Low Grade Tu) Low Grade Tumors = 26 (23.6%) Monthly Steroid Dosage (milligrams)		
e Diagnosis	Monthly Steroid Dosage			
18 (16.3%)	0	40 (36.4%)		
24 (21.8%)	15-30	2 (1.8%)		
20 (18.2%)	60-120	15 (13.6%)		
16 (14.5%)	180-240	11 (10%)		
16 (14.5%)	300-360	9 (8.2%)		
11 (10%)	480-540	18 (16.3%)		
2 (1.8%)	600-720	14 (12.7%)		
1 (0.9%)	900	1 (0.9%)		
2 (1.8%)				
	Adaptation Task			
Craniotomies	-			
96 (87.3%)	Dealing with pain and			
23 (20.9%)	incapacitation.	30 (27.3%)		
erapy	Dealing with hospital			
16 (14.5%)	environment and treatme	ent		
94 (85.5%)	procedures.	14 (12.7%)		
23 (20.9%)	•	, ,		
	Developing and maintain	ning		
ns	• •	-		
40 (36.4%)	care staff.	0 (0%)		
11 (10%)		· · · ·		
4 (3.6%)	Preserving a reasonable			
1(0.9%)	emotional balance.	14 (12.7%)		
Chemotherapy Treatments	Preserving self-image ar	Preserving self-image and sense		
37 (33.6%)				
3 (2.7%)				
· · ·	Sustaining relationships	with		
• •	. .	7 (6.4%)		
• •		. (
· · ·	Preparing for an			
	• •	10 (9.1%)		
• •		10 (21170)		
•				
3 (2.7%)				
	e Diagnosis 18 (16.3%) 24 (21.8%) 20 (18.2%) 16 (14.5%) 16 (14.5%) 11 (10%) 2 (1.8%) 1 (0.9%) 2 (1.8%) Craniotomies 96 (87.3%) 23 (20.9%) herapy 16 (14.5%) 1 94 (85.5%) 23 (20.9%) herapy 16 (14.5%) 1 (10%) 4 (3.6%) 10 (0.9%) Chemotherapy Treatments 37 (33.6%) 3 (2.7%) 9 (8.2%) 12 (10.9%) 15 (13.6%) 11 (10%) 13 (11.8%) 6 (5.5%) 1 (0.9%)	e Diagnosis Monthly Steroid Dosage 18 (16.3%) 0 24 (21.8%) 15-30 20 (18.2%) 60-120 16 (14.5%) 180-240 16 (14.5%) 300-360 11 (10%) 480-540 2 (1.8%) 600-720 1 (0.9%) 900 2 (1.8%) 600-720 1 (0.9%) 900 2 (1.8%) Dealing with pain and incapacitation. Craniotomies 96 (87.3%) Dealing with hospital environment and treatments 96 (87.3%) Dealing with hospital environment and treatments 96 (87.3%) 1 94 (85.5%) procedures. Developing and maintain relationships with health care staff. 11 (10%) 4 (3.6%) Preserving a reasonable emotional balance. Chemotherapy Treatments Preserving self-image ar of competence/mastery. 3 (2.7%) 9 (8.2%) Sustaining relationships family and friends. 15 (13.6%) 11 (10%) Preparing for an uncertain future. 6 (5.5%) 1 (0.9%) Preparing for an uncertain future.		

Disease - Related Characteristics of the Sample

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patients (63.6%), while 11 patients (10%) experienced 2 complications, 4 patients (3.6%) experienced 3 complications, and 1 unfortunate patient (0.9%) had experienced four significant complications during the course of treatment. The list of complications included meningitis, hydrocephalus, aphasia, hemiparesis/hemiplegia, retinitis, pulmonary fibrosis and postoperative hemorrhage.

No patients with low grade tumor types had received chemotherapy (26/110 or 23.6%), and 11 patients from the high grade tumor group additionally received no chemotherapy, totalling 37 patients (33.6%) who received no chemotherapy. The majority of chemotherapy recipients received between 3 and 6 treatments (46.2%).

Forty of the patients (36.4%) were not taking corticosteroids at the time of data collection, yet dosages for the remaining steroid-dependent patients ranged from 15 to 900 milligrams of steroids ingested for the thirty day period of time just prior to data collection (0.5 to 30 milligrams per day). Of the 70 patients prescribed to take daily steroids, 68 patients (97.1%) described a weight gain related to the steroid ingestion, with 100% of this group expressing distress about the associated weight gain.

When asked to choose the adaptation task of most

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importance to the subject in their daily life of living with a brain tumor and the associated treatments, 30 subjects (27.3%) identified the task of dealing with pain and incapacitation, 14 (12.7%) identified the task of dealing with the hospital environment, 14 (12.7%) identified the task of preserving a reasonable emotional balance, 35 (31.8%) identified the task of preserving a satisfactory self image, 7 (6.4%) identified the task of sustaining relationships with family and friends, and 10 (9.1%) identified the task of preparing for an uncertain future. However, no subjects identified the task of developing and maintaining relationships with health care staff as their primary adaptive concern at that time.

<u>Research Measures</u>

Demographic data was collected to describe the individual illness and treatment course for each subject. From this data, study variables of gender, age (collected both as actual age and birthdate), the time in months since diagnosis, and the steroid dosage in milligrams was extracted. Additional demographic data useful in the subsequent analysis of the social support measure (PRQ-85) to be discussed were marital status, education, occupation, employment status, and race. The respondent was also asked to identify, from

a list of seven choices (Moos, 1976), the adaptive task which was of current primary importance to the individual.

The <u>PRO-85</u> (Personal Resource Questionnaire) (Brandt & Weinert, 1981) is a two-part instrument measuring the number of and satisfaction with interpersonal resources that a person can count on across various life situations in part 1, and the subject's perceived level of social support in part 2. Part 1 contains 30 questions addressing the area of situational support. Part 2, containing 25 questions, and measuring perceived level of social support, is a Likert scale, and has five subscales of intimacy, social integration, nurturance, worth and assistance. The entire questionnaire can be self-administered or interview-administered, and takes about 10 minutes to complete.

A dummy variable format is utilized to code the situational support variable of Part 1, also recording the total number of interpersonal resources available. The likert scaling portion of Part 1 and the totality of Part 2 are scored in a straight forward manner, recording the number corresponding to the level of satisfaction (Part 1) or agreement (Part 2), recoding items 11d, g, j, p, and x to be consistent with the positive direction of the remaining items.

Reliability and validity properties are adequate and are displayed in Table 3. The PRQ-85 has been used predominantly in samples of well individuals in the adult years of 20-80 years of age. Reliability estimates have ranged from 0.85 to 0.93 for Part 2, with basically consistent subscales and 0.87-0.91 for the total scale. The test-retest reliability for a group of 100 adults was 0.72 for Part 2 (perceived social support) and 0.81 for Part 1 (interpersonal resources). Construct, convergent and discriminant validity were demonstrated in a cross-sectional design study of 100 adult men and women, as the PRQ-85 was administered simultaneously with five other social support measures: Interpersonal Support Evaluation List, Social Support Scales, Norbeck Social Support Questionnaire, Cost and Reciprocity Index, and the Inventory of Socially Supportive Behaviors. Intercorrelations between the PRQ-85 and all other scales were significant (0.25, p<.01; 0.40-0.74, p <.001). Discriminant validity was supported through evaluation of the correlation with the Profile of Mood States (-0.29, p<.01).

The <u>Sickness Impact Profile</u> (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981) is an instrument measuring perceived health status limitations as a measure of the outcome of contact with the health care

TABLE 3

Psychometric Properties of Measures

VARIABLES	MEASURES	N OF ITEMS	RELIABILITY	VALIDITY
Social Support	Personal Resource Questionnaire (PQR-85)	55 (Part I: 30 Part II: 25)	.8593 _b (Part II) .8791 _b	Construct Convergent Discriminant
Perceived Health Status Limitations	Sickness Impact Profile (SIP)	136	.8797 .8194 _b	Construct Convergent Descriptive Clinical Discriminant
Coping Skills	Jalowiec Coping Scale	40	.7879 _c .8586 _b .5586 _b	Content Construct
Body Image Apprais	al:			
Body attitude	Body Cathexis/ Self-cathexis (BC/SC)	46 55	.7883 _b .8892 _b	Face Convergent Construct
Body perception	Modified Topographic Device	1	.5697	Face

а

Test-retest reliability coefficient (KR) Internal consistency reliability coefficient alpha (Cr) Test-tetest reliability coefficient (Spearman's Rho) b

С

delivery system. The SIP measures this perception based on sickness-related changes in behavior, or "dysfunctions" perceived by the consumer of health care services. A higher score on the SIP signifies a greater perception of health status limitations by the individual. The SIP is a paper and pencil test, either self-administered or interview-administered, in 20-30 minutes. The 136 statements about health related dysfunction represent the three dimensions of psychosocial, physical and independent categories. Subjects are asked to check all items that apply to them and effect their state of health at the time of the interview.

Included within the psychosocial dimension are the categories of social interaction, alertness behavior, emotional behavior, and communication; within the physical dimension are the categories of ambulation, mobility and body care and movement. Independent categories include sleep and rest, eating, work, home management, and recreation and pastimes.

Scores on the SIP may be obtained for each category of the tool, or the researcher may choose to obtain a percent score for the entire SIP, both of which were derived for the present study. The SIP score is calculated by summing the scale values for each item checked in all categories, dividing by the

maximum possible dysfunction score and then multiplying by 100.

Table 3 displays the adequate reliability and validity properties for this tool. The 1973 pilot phase of the SIP development tested the prototype version of the instrument, containing 312 items, on a sample of 246 subjects, including outpatients, inpatients, home care patients, walk-in clinic patients and nonpatients. General reliability for overall score reproducibility was 0.88, and for category items reproducibility was 0.56. Statistical analysis for the purpose of item reduction resulted in the revised version of the instrument consisting of 189 items.

The 1974 field trial, using the revised form of the tool, utilized four subsamples of rehabilitation medicine outpatients and inpatients, outpatients with chronic health problems, and a group of enrollees in a prepaid health plan who were not ill at the time (Bergner, Bobbitt, Kressel, Pollard, Gilson & Morris, 1976). Test-retest reliabilities of the SIP were calculated using different interviewers, different forms, different administration procedures and a variety of subjects with different types and severities of dysfunction, yielding coefficients of 0.75-0.92 for the scores, and 0.45-0.60 for items checked. Internal consistency was 0.97 in this trial, while general

reliability of overall score reproducibility and category item reproducibility showed strong stability between trials with coefficients of 0.88 and 0.50 respectively.

Discriminant validity was established by examining the relationships between the SIP scores and several other measures: one based on the subject's selfassessment of health status, one on a clinician's assessment of health status, and one on the subject's score on another related instrument.

A 1976 field trial administered the 189-item revised format of the instrument to a large stratified random sample (n=696), who were members of a prepaid health plan, and who represented a broad diversity of illness and sociodemographic levels (Bergner, Bobbitt, Pollard, Martin & Gilson, 1976; Pollard, Bobbitt, Bergner, Martin & Gilson, 1976). Simultaneously, a quota sample of 199 ill subjects were interviewed to assist with final item revision.

Three types of administration of the SIP were compared in this trial: an interviewer administered (I), an interviewer-delivered self-administration (ID), and a mail-delivered self-administration (MD). High levels of test-retest reliability (0.97, 0.87 respectively) were revealed for Is and IDs, and analysis of variance showed no significant difference

between the overall mean scores among the administration methods. Internal consistency was 0.94 for the IS and IDs, and 0.81 for the MDs, while general reliability of overall score reproducibility was 0.92 and for category items was 0.50, again demonstrating the stability of the instrument over subsequent field trials. Mail-delivered SIPs were found to yield less consistent results when compared to the I and the ID methods of administration.

Construct validity was demonstrated in each field trial by recurrent high correlations between level of dysfunction and overall level of sickness, as evaluated by the subject's. Further evidence was provided for construct validity since all SIP items were derived from sickness-related behaviors, yet all preliminary scaling of the individual SIP items employed the concept of dysfunction. This provided a strong relationship between judgments and SIP scores based on items scale values.

Preliminary estimates of convergent validity were demonstrated in the 1974 field trial by examining the relationship between the SIP and self-assessments of sickness and dysfunction (0.54, 0.52), between the SIP and clinician's assessments of subject's sickness and dysfunction (0.30, 0.49), and between the SIP and other measures of dysfunction, namely, the Activities of

Daily Living Index (ADL) (0.46), and the National Health Interview Survey (NHIS) (0.61). Further analysis of the relationships between the SIP and each of the criterion variables utilizing the multitraitmultimethod methodology was crucial in further strengthening the convergent and discriminant validity of the instrument. Low correlations among the category scores (0.32 +/- 0.19; 0.40 +/- 0.21) supported the distinctness of each category, while high correlations of category scores to overall scores (0.60 +/-0.16; 0.66 +/- 0.17) supported the contribution of each category to the SIP. The reproducibility of SIP scores was higher than the reproducibility of other related measures of sickness or dysfunction (0.82 +/- 0.08 > 0.76 +/- 0.12, 0.66 +/- 0.06, 0.41 +/- 0.11). A multiple regression analysis was undertaken to determine the amount of variance explained by the SIP category scores in each of the criterion measures in the field trials, (dysfunction: 0.41-0.59; sickness 0.37-0.48; NHIS: 0.39-0.52; ADL: 0.60), providing confirmation of the multitrait-multimethod analysis.

Clinical validity was established by choosing clinical measures, generally related to patient function in three selected patient populations: total hip replacements (Harris Analysis of Hip Function), hyperthyroidism (Adjusted T4, pulse), and rheumatoid

arthritis (Activity Index). All participants also completed the self-assessment of dysfunction and the self-assessment of sickness measures. Patients were administered the SIP and the clinical measures within a 24 hour period. Correlations between the SIP and the clinical measures were moderate (r=0.41) to high (r=-0.84).

Pattern and profile analysis was applied to the SIP in an effort to demonstrate descriptive validity for the measure of health status. Profiles of category scores for each diagnostic sample, total hip, hyperthyroidism and rheumatoid arthritis were assessed in terms of mean differences (elevations), variability differences (scatter) and pattern differences (shape). The study of these three diagnostic samples with respect to validity and sensitivity supports the value of the SIP as a measure of health status. Final revision of the SIP involved category and item analyses and resulted in the present 136 items contained within 12 categories.

The <u>Revised Jalowiec Coping Scale</u> (Jalowiec, 1987), is a 60 item dual questionnaire, rated by the respondent on a 0- to 3-point Likert-type scale to indicate use and effectiveness of alternative coping behaviors. The tool can be utilized to assess general coping strategies or those strategies that are

situation-specific. The tool can be self-administered or interview-administered in a 10-15 minute period.

In the 1979 version of the scale (Jalowiec, 1979), the multidimensionality of the concept of coping skills was demonstrated through a factor analysis in which four conceptual labels were attached to the skills: 1) problem-resolving, cognitive, autonomy-oriented, goaldirected, purposive, or reality-oriented; 2) tensionmodulating, avoidant/evasive, morale-maintaining, acquiescent, or palliative; 3) powerlessness, pessimistic, impotency-related, nugatory, or regressive; and 4) other-directed, dependency-oriented, support-related, or linkage-directed. While the first conceptual label mentioned above is strongly problemfocused, the remaining three are affective-focused.

Adequate reliability and validity estimates are displayed in Table 3 (Jalowiec, Murphy & Powers, 1984). Content validity is empirically supported because the instrument evolved from an extensive and critical review of classic works in the field of coping and adaptation (Jalowiec & Powers, 1981), along with the systematic method of instrument development. Construct validity was demonstrated by having a panel of 20 volunteer judges independent classify each of the 40 coping methods on the scale as a problem-oriented or an affective-oriented strategy. Overall agreement was 85%

for the 40 items, with an 88% agreement on problemoriented items and 82% agreement on affective-oriented items.

Stability of the scale was supported, using 28 subjects from a general population, with retesting after two weeks, demonstrating Spearman's Rhos of 0.79 for the total scale, 0.85 for problem-oriented scores, and 0.86 for affective-oriented scores. A 30 day retest on a sample of 30 subjects again yielded stable scores as evidenced by rhos of 0.78 for total scores, 0.84 for problem and 0.83 for affective-oriented scores.

The instrument was used to measure coping in a sample of 141 subjects consisting of hypertensive and emergency room patients, a general population, and dialysis patients, yielding a coefficient alpha of 0.86, indicating overall homogeneity of the content of the scale as an initial element of establishing construct validity. The factor analysis, as mentioned above, lends further support to the construct validity of the scale, demonstrating which variables share a common variance and are therefore measuring the same attribute. Four dimensions of coping were substantiated, with alpha coefficients of 0.86, 0.73, 0.75 and 0.55 corresponding to the problem-oriented (Factor 1), affective-oriented: acceptance, resignation

(Factor 2), affective-oriented: tension-releasing mechanisms (Factor 3), and other-directed factors (Factor 4) respectively.

The revised 1987 format of the tool (Jalowiec, 1987) supports sixteen subscales, eight of which measure coping usage and eight of which measure coping strategy effectiveness. The scales are labeled confrontive, evasive, optimistic, fatalistic, emotional, supportive, self-reliant, and palliative. Psychometric properties for the revised scale are presented in Table 4, demonstrating poor alpha reliabilities for the fatalistic and palliative subscales (Jalowiec, 1988).

Body image appraisal, because of the multidimensionality of the construct (Champion, Austin, & Tzeng, 1982; Fawcett and Frye, 1980; McCrea, Summerfield & Rosen, 1982) is measured conceptually through multiple measures, specifically, those of body perception and body attitude. Body perception and body attitude are thought to be conceptually independent dimensions of body image (Fawcett & Frye, 1980), related by Schilder (1950) as body perception depending on the body attitude.

The <u>Body Cathexis Self Cathexis Scale</u> (BC/SC) (Secord & Jourard, 1953) will be utilized to measure body attitude, through the relational concept of body

TABLE 4

Psychometric Properties of Revised Jalowiec Coping Scale

SUBSCALES	N OF ITEM	ALPHA RELIABILITY (CR)	TEST-RETEST RELIABILITY	VALIDITY
USE SUBSCALES				
Confrontive	´10	.5681	.2373	Construct supported for all
Evasive	13	.4980	.7894	subscales and total scales.
Optimistic	9	.7586	.1077	
Fatalistic	4	.2068	.2568	Concurrent not supported.
Emotive	5	.3979	.6685	••
Palliative	7	.2164	.6078	
Supportant	5	.4071	.1868	Predictive supported by
Self-Reliant	7	.5879	.5567	correlations with coping
Total Use	60	.8894	.6182	ability rating, level of stress rating, stressor scale
EFFECTIVENESS SUI	BSCALES			score.
Confrontive	10	.5884	.3771	
Evasive	13	.3678	.4384	
Optimistic	9	.7293	.5482	
Fatalistic	4	.4569	.1649	
Emotive	5	.0679	.2366	
Palliative	7	.2759	.2750	
Supportant	5	.2071	.4070	
Self-Reliant	7	.3989	.2358	
Total Effectiveness	60	.8196	.3659	

, . , and self satisfaction. The body cathexis scale is a 46-item instrument eliciting Likert-type responses addressing both the strength and direction of feelings of satisfaction about the bodily processes or parts. The instrument's method is described by the authors as "direct," assuming that individuals are aware and capable of describing their feeling of satisfaction/dissatisfaction about their bodies. The respondents are asked to rate their feelings of satisfaction for the 46 items as 1 = strong negative feelings, 2 = moderate negative feelings, 3 = no feelings on way or the other, 4 = moderate positive feelings, and 5 = strong positive feelings.

The self-cathexis scale lists 55 items of conceptual aspects of the self, and are rated utilizing the exact scaling instructions as the body scale. Moderate intercorrelations (r= 0.58 for men; r= 0.66for women) were found between the body cathexis and the self-cathexis scores, implying that individuals have a moderate tendency to cathect their body and their self to the same degree and in the same direction (Secord & Jourard, 1953).

Once completed, the scores of the body cathexis scale and the self cathexis scale are simply added, or may be added and divided by the total number of items, 46 and 55 respectively, yielding the body cathexis and

self cathexis scores for each individual.

Additionally, an anxiety-indicator score may be calculated for each subject by summing the ratings of the 11 items most negatively cathected by the male and then the female subjects.

Split-half reliability coefficients were 0.78 and 0.83 for males and females on the body cathexis scale; and 0.88 and 0.92 for males and females on the self cathexis scale (Secord & Jourard, 1953); 0.84 and 0.75 for adult male and female groups on the body cathexis scale (Weinberg, 1960); and 0.81 to 0.86 and 0.78 to 0.87 for college male and female students, respectively, for the body cathexis scale (Franzoi & Shields, 1984).

In another report, while simultaneously examining the test-retest reliability of the body cathexis scale (.87), the internal structure and dimensionality of the scale were examined using a factor analytic technique with varimax rotation (Tucker, 1981). Within a sample of 83 college males, four independent factors emerged: health and physical fitness, face and overall appearance, subordinate and independent body features, and physique and muscular strength, with the first two factors rated as significantly more favorable than the second two dimensions. Further extension of this analysis, using a sample of 316 college males, yielded

slight modification of the factor labels as: health and physical fitness; face, weight, and overall appearance; facial features and body senses; and physique and muscular strength (Tucker, 1983). It was concluded that males tend to perceive their appearance as a function of their face and upper-body build, including his chest, shoulders, and arms.

Similar factor analysis was performed with a sample of 160 female college students (Tucker, 1985), revealing the four independent factors of physical skills and fitness; face and overall appearance; miscellaneous items; and weight and lower body. The greatest satisfaction was reported on the second factor, and the least satisfaction on the fourth factor. Females interpreted their body build as a function of their legs, hips, waist, weight and appetite, as opposed to the upper-body orientation of the males.

Reliability and validity was further studied by Balogun (1986) by simultaneously administering the Body Cathexis Scale and the Tennessee Self-Concept Scale (Fitts, 1965) to a group of 50 college women. Testretest reliability was demonstrated with a correlation coefficient of 0.89 over a two week period of time. Significant correlations were demonstrated between the body cathexis scale and the physical-self score (r=

0.64, p <.01), the personal self (r= 0.60), the family self (r= 0.35), the social self (r= 0.62), and the total positive score (r= 0.62). These moderate intercorrelations with aspects of the Tennessee Self Concept Scale lend some support to construct validity for the Body Cathexis Scale, suggesting that the subjects perceive their body parts much like they perceive other aspects of themselves.

The finding that the Body Cathexis Scale was significantly related to global self-esteem and four of the five subscales of the Tennessee Self-Concept Scale offer some weak support to convergent validity for the Body Cathexis Scale (Balogun, 1986).

Body perception will be estimated using the <u>Topographic Device</u> originally devised by Schlacter (1971) and revised by Fawcett (1976) through the relational concept of perceived body space. This device consists of a clear vinyl mat containing concentric circles of various sizes. The subject is asked to stand in the center circle, and to point to the circle which would best approximate the space their bodies occupy, imagining that they are encased in a cylinder whose base is one of the circles (Fawcett & Chodil, 1980). The data collector records the code number on the designated circle and later converts it to inches. Face validity and test/retest reliabilities

have been reported as displayed in Table 1.

Procedure for Data Collection

Access to study subjects was facilitated through affiliation with several large teaching university hospitals, at which multiple federally-funded protocols are being implemented for treatment of malignant brain tumors. The study population were patients with lowgrade and high-grade gliomas, lymphomas, medulloblastomas, and ependymomas.

Human subjects approval was initially sought at the University of San Diego (see Appendix B), followed by approval at the University of California, Irvine Medical Center (UCI) (see Appendix C), and the University of California, Los Angeles (UCLA) Medical Center (see Appendix D), where data collection proceeded. It was also required that all nursing research activities at UCI be presented and approved by the nursing research committee of that medical center prior to seeking approval from the university's human subjects review committee.

Measures were administered to subjects by making home and/or clinic visits for data collection. It was proposed that the relaxed atmosphere of the subject's home would generate purer data for the study; however, the clinic settings were utilized at the request of the subjects and/or agencies. The body image instruments

were administered prior to other tools, to prevent contamination of the outcome variable. The remainder of the instruments were administered in random order to each patient. Total time for administration of measures was estimated to be one to one and one-half hours, and actually took up to three hours on rare individual subjects, necessitating multiple home visits. The instruments were completed by the subject one time only for the purposes of this study.

Data Analysis Procedures

The causal design was analyzed using regression techniques. Initially, bivariate correlation coefficients (a correlation matrix) were derived between all variables to allow identification of possible multicollinearity, which, if present, might have greatly limited the validity of the regression model. The actual existence of multicollinearity could not be determined until the partial correlation of each independent variable with the remaining independent variables in the model had been estimated (Schroeder, 1990). Then general multiple regression analysis was done with progressive inclusion of variables.

All dependent variables, beginning with the earliest dependent variable, were regressed on all preceding independent variables to arrive at the regression equations. This procedure allowed testing

of the research hypotheses as well as the null hypotheses.

Beta weights were examined along with R2 and the adjusted R2 to determine the amount of influence of the variables, and the amount of variance accounted for by each of the regression equations. The coefficients were then placed appropriately on the path model. The level of significance for this study was .05.

Chapter Four

Results

Data Reduction

Initially, reliability estimations were calculated on all research instruments (see Table 5), including the estimation of subscale reliabilities where appropriate. Acceptable ideal standards for the reliability estimations included the mean inter-item correlations \geq .20, item-total correlations \geq .30 and Cronbach's alpha \geq .70 (Carmines & Zeller, 1979) to establish parsimonious, reliable factors for entry into the regression analyses. Next, a bivariate correlation matrix of all variables in the model was examined for evidence of multicollinearity (Schroeder, Sjoquist & Stephan, 1986).

Body Cathexis/Self Cathexis Scale

Reliability estimation for this instrument was conducted for the total instrument as well as the two subscales of body cathexis and self cathexis. The total scale revealed three items with item-total correlations of less than .30, out of a total of 101 items. When analyzed as two all-inclusive subscales, the body cathexis subscale contained two items out of

TABLE 5

Reliability Estimations For All Scales

INSTRUMENTS		EAN INTER-ITEM	ITEM-TOTAL CORRELATION	STANDARDIZED ALPHA
Body Cathexis/				
Self Cathexis		.29	.2279	.98
	Body Cathexis	.43	.2585	.97
	Self Cathexis	.37	.1686	.97
Revised Jalowiec	Confrontive Coping	g .20	.0269	.81
Coping	Evasive Coping	.14	.0874	.78
	Optimistic Coping	.06	.0135	.48
	Fatalistic Coping	.33	.0376	.79
	Emotional Coping	.17	.0170	.67
	Palliative Coping	.14	.0669	.70
	Supportive Coping		.0952	.57
	Self-Reliant Coping	g .21	.1162	.79
Sickness Impact				
Profile			.0068	.90
	Physical Dimension		.0875	.91
	Psychosocial Dime	nsion .07	.00366	.77
Personal Resource	Received social			
Questionaire	Support	.30	.1573	.91

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forty-six and the self cathexis subscale contained three items out of fifty-five with item-total correlations less than .30. Standardized item alphas were .98 for the total scale, and .97 for each of the two subscales.

Modified Topographic Device

Reliability estimations could not be calculated arithmetically for this instrument as a result of it's complexity and uncharacteristic format. However, content validity was established for this instrument in this malignant brain tumor population through the use of six content experts, identified from among the brain tumor patients (2 experts) as well as health care professionals from a brain tumor clinic (4 experts), as suggested by Lynn (1986). A single page questionnaire was devised (see Appendix F), listing the label and definition of the concept of body perception and giving directions to the selected expert. Each expert was requested to read the label and definition of body perception, keeping these in mind while following the directions for using the topographic device instrument. The expert was asked to record the code number which corresponded to their chosen circle on the topographic device, before answering a series of questions about the device.

Responses among the experts were predominantly

consistent (see Appendix G). The experts agreed (6/6, 100%) conceptually that the device measured body perception as well as perceived body space. All experts also agreed that they experienced feelings about the measurement or their body during the exercise.

Five out of six (83.3%) agreed that the device could not be utilized adequately by persons with visual limitations. Four out of six (66.7%) experts agreed that persons who were unable to stand could not meaningfully complete the exercise. Five out of six (83.3%) agreed that persons with significant self-care limitations (Karnofsky less than 50) could not meaningfully complete the exercise.

When asked to identify conceptual elements of body perception omitted in this research instrument, three experts (50%) felt that positive and negative feelings toward body and/or self were omitted and not measured by this instrument. The other three experts (50%) felt that the instrument had no omissions in measuring the concept of body perception in the malignant brain tumor population.

<u>Revised Jalowiec Coping Scale</u>

Initially, reliability parameters were calculated for the sixteen subscales of this instrument - eight coping usage subscales and eight coping effectiveness

subscales. The alpha reliabilities ranged from .26 to .66 for the coping usage subscales, and from .18 to .69 for the coping effectiveness subscales. Recent alpha reliabilities reported by the author (Jalowiec, 1989) are also predominantly trending toward low values, .20 to .86 for the use subscales, and .06 to .93 for the effectiveness subscales.

Therefore, a decision was made to calculate the multiplicative scores for each of the eight subscales, multiplying the usage score by the effectiveness score. This calculated score is supported by the instrument's author and is termed the combined coping score for each of the eight subscales. Reliability estimations for these multiplicative subscales are displayed in Table 5.

Three of the eight subscales (confrontive coping, fatalistic coping and self-reliant coping) met the \geq .20 criteria for the mean inter-item correlation. For the item-total correlations, none of the subscales met the overall criteria of \geq .30. However, examination of the standardized alphas for the eight multiplicative subscales demonstrates that five of the subscales meet the \geq .70 criteria for alpha reliability. The remaining three subscales - optimistic coping, emotional coping, and supportive coping - had mediocre alpha reliabilities of .48, .67, and .57 respectively.

Due to the newness of the revised version of this coping scale, the lack of utilization of this instrument in the brain tumor population, the strong bivariate correlations between the multiplicative coping scales and other variables in the model, and the author's sole reliance on alpha and test-retest reliabilities in psychometric reporting, the decision was made to retain all of the eight subscales for the regression analysis.

Sickness Impact Profile Scale (SIPS)

Reliability estimations were calculated for the total SIPS scale, as well as the physical dimension subscale and the psychosocial dimension subscale, as shown in Table 4. Of the 136 item scale, 77 items did not meet the item-total correlations; yet, the alpha value was .90 for the overall scale.

Similar findings were found for the two physical and psychosocial subscales; yet, alpha reliabilities were quite acceptable at .91 and .77 respectively. Because the two subscales were not all-inclusive of the total scale, a decision was made to allow the two subscales to remain in the regression analysis, but to drop the overall SIPS scale, in an attempt to isolate the effects of physical and psychosocial health status limitations in the brain tumor population.

Personal Resource Questionnaire (PRO-85)

Part 1 of the PRQ-85 addresses the amount of social support that a person identifies, as well as the satisfaction of the individual with the available support during recent life events. This portion of the instrument typically yields descriptive data only, and therefore was not analyzed for the purpose of this research.

Part 2 of the PRQ-85 measures perceived social support, and demonstrated rather sound reliability in this analysis. The mean inter-item correlation was .30; the item-total correlations ranged from .15 to .73, with only three items failing to meet the \geq .30 criteria; and the alpha reliability was .91, exactly as reported by the authors. Only part 2 of the PRQ-85 was retained for entry into the multiple regression analysis.

Correlation Matrix Analysis

A correlation matrix of all variables to be entered into the regression analysis was inspected for multicollinearity (coefficient $r \ge .60$) (Asher, 1983; Nunnally, 1978; Schroeder, Sjoquist & Stephan, 1986). The matrix is exhibited in Table 6. No evidence of multicollinearity was found among the study variables. It is noted that the body cathexis and self cathexis subscales have high correlations with the Body

TABLE 6

	BC	SC	BCSC	BP	MULCONF	SIPSPHY	SIPSPSY	PERCSS	GENDER	AGE	TIME	STEROIDS
BC		.47	.89	23	.22	31	23	.30	16	36	.28	32
SC			.83	22	.19	02	19	.24	38	21	.23	08
BCSC				26	.24	21	24	.31	30	34	.30	24
BP					21	.08	.04	00	.35	.10	09	.19
MULCONF						18	30	.49	.02	.08	.08	09
SIPSPHY							.52	24	.01	03	.01	.54
SIPSPSY								36	.01	.13	.01	.43
PERCSS									05	04	.12	19
GENDER										03	16	01
AGE											11	.20
TIME												11

Correlation Matrix for all Variables in the Model

Coefficients $\geq \pm$.16 are significant at p \leq .05 level	
BC = Body Cathexis Scale	SIPSPSY = SIPS Psychosocial Dimension Score
SC = Self Cathexis Scale	PERCSS = Perceived Social Support Score
BP = Body Perception	(PRQ-85, Part 2)
BCSC = Body Cathexis/Self Cathexis Scale	TIME = Months Since Diagnosis
MULCONF = Multiplicative Confrontive Coping Score	STEROIDS = Monthly Steroid Dosage
SIPSPHY = SIPS Physical Dimension Score	

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Cathexis/Self Cathexis Scale, as would be expected, since the total scale is all-inclusive of the subscales. However, the researcher assured that the subscales did not enter the multiple regression analysis simultaneously with the total scale, but rather chose to enter these variables as dependent variables in different formats of the proposed model. <u>Results of Data Reduction</u>

As a result of inspecting the reliability estimations and the bivariate correlation matrix, a decision were made to retain the body cathexis/self cathexis subscales and total scale as dependent variables in separate formats of the model. Also the strength of the correlations between the eight multiplicative coping subscales and the other variables further supported the retention of all eight coping subscales for entry into the regression analysis.

The overall SIPS scale was eliminated from the model, since it represented many extraneous variables outside of the interest of this study (other than the physical and psychosocial dimensions), and failed to meet the item-total correlation criteria for 50% of the items. Therefore, the SIPS physical and psychosocial dimension subscales were retained in the analysis. There was no further support for deletion of other variables prior to commencing the regression analysis.

Statistical Assumptions

Linear regression assumes that the sample is representative of the population to which the research applies, and that all variables are normally distributed. Like correlation analyses, the assumption of homoscedasticity applies, and the relationship between all variables is linear (Munro, Visintainer & Page, 1986). Linear regression further assumes that the effects of the error terms or residuals are normally distributed about a zero mean, have equality of variance, independence, fixed distribution and are linear (Verran & Ferketich, 1987).

In this research study, the relationship between all variables was linear, the sample was representative of the national brain tumor population, and all variables are normally distributed. The histogram and scatterplots of the residuals were normally distributed about the mean. The zresidual mean value for all regression analyses was .00.

ANOVA assumptions include mutually exclusive groups, nominal level independent variables, interval level dependent variables, normal distribution of the dependent variable, and homogeneity of variances (Munro, Visintainer & Page, 1986). The first assumption was partially met since the two groups (low grade and high grade tumors) were independent groups.

The sample was one of convenience, however, not of random selection. All dependent variables were measured at the interval level in this study. All independent variables entered into the ANOVA analyses were measured at the nominal level.

Regression Analysis of Path Model

Multiple regression analysis was performed on the path model, progressively eliminating those variables from previous time orderings that did not predict the subsequent dependent variable. Body perception and body attitude were treated as dependent variables in separate trials of the proposed path model, in an attempt to explain the greatest variance among the variables within the model.

Neither body perception nor body cathexis and self cathexis had any ability to predict the other, when each was utilized as an independent variable for the other. Therefore, no relationship was established between these two dependent variables, supporting the idea that these two variables are conceptually quite distinct, despite the low but significant bivariate correlations that exist between these variables (-.26, p <.003; -.23, p <.009; -.22, p <.01).

Established parameters for inclusion of each variable in the final path model included a minimum beta weight of .10, with a significance level of .05

(Asher, 1983). Other values of interest included the amount of variability (R^2) accounted for by the variables in each equation, and the adjusted R^2 (corrected for sample size), as shown in Table 7. A simplified path model (see Figure 2) demonstrates the significant direct effects of each variable in the model. The simplified model contains 12 direct effects. Table 8 depicts the direct effects between all variables, denoting those that are of statistical significance. Table 9 depicts a decomposition table, in which the indirect and total effects of all independent variables on all dependent variables are displayed.

Two significant indirect effects occurred among the variables in this model. One occurred between steroid dosage and body cathexis (indirect beta = -.136) and the other was demonstrated between social support and body perception (indirect beta = -.150). Specifically, these indirect paths imply that steroid dosage indirectly effects body cathexis through it's direct effect on physical health status limitations; and that social support indirectly effects body perception through it's direct effect on confrontive coping. Both indirect effects had beta weights greater than .10 and were trending in the direction of significance.

TABLE 7

Beta Weights and	Regression Coefficients for Simplified Model

<u> </u>			Criterion (Dependent) Va	ariable		
Predictor (Independent)	Body	Body	Self	·•			·····
Variable	Perception	Cathexis	Cathexis	MULCONF	SIPSPHY	SIPSPSY	PERCSS
Confrontive Coping (MULCONF)	347**						
SIPS Physical Dimension (SIPSPHY)		250*					
SIPS Psychosocial Dimension (SIPSPSY)							
PRQ-85 Perceived Social Support (PERCSS)				.433***	154+	299***	
Gender	.369***	144+	361***				
Age		348***	204*		137+		
Time Since Diagnosis		.178*					
Monthly Steroids	.239*				.544***	.368***	179+
	.29	.37	.28	.27	.34	.27	.05
Adjusted R ²	.16	.31	.22	.22	.30	.24	.01
F	2.23**	7.18***	4.79***	5.42***	10.48***	7.76***	1.27
* p <u>≤</u> .05	** p≤.01	4	*** p <u>≤</u> .001	+ = Tre	end of signifi	cance	

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TABLE 8

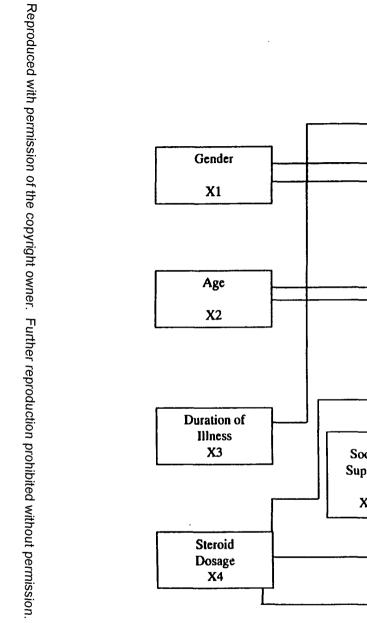
Matrix of Direct Effects

Varia	ble	X5	X6a	X6b	X7a	X8a	X8b	X8c
X1	Gender	040	.015	.008	.062	144	361***	.369***
X2	Age	.001	137	.052	.114	348***	204*	.097
Х3	Duration of Illness	.091	.072	.089	.061	.178•	.140	022
X4	Steroid Dosage	179	.544***	.368***	.061	074	.012	.239*
X5	Perceived Social Sup	port	154	299***	.433***	.148	.095	.142
X6a	Physical Health Statu Limitations	S			012	250*	.073	042
X6b	Psychosocial Health Status Limitations				176	.058	122	047
X7a	Confrontive Coping					.141	.127	347**
X8a	Body Cathexis							134
X8b	Self Cathexis							019
X8c	Body Perception							
* p≤.	05	** p≤.01	***	• p≤.001				

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Self -.204* Cathexis Physical X8b Health Status Limitations .544*** X6a .369*** Confronting Body Coping .433*** Perception Social -.347** X7a Support X8c .299*** .239* X5 Psychosocial Health Status Limitations .368*** * $p \le .05$ ** $p \le .01$ *** $p \le .001$ X6b

.178*

-.250*

-.361***

-.348***

Body

Cathexis

X8a

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Figure 2. Simplified Path Model Relating Body Image Appraisal to Predictor Variables

TABLE 9

Decomposition Table of Effects of Variables

			Causal Effects			
	Total	Direct	Indirect	Total	Non-Causal	
	Covariance	Effects	Effects	Effects (B+C)	Effects (A-D)	
	(A)	(B)	(C)	(D)	(E)	
Body Perception			······································			
X8cX7a	209*	347***	None	347	.138	
X8cX6b	.037	047	.061	.014	.023	
X8cX6a	.083	042	.004	038	.121	
X8cX5	002	.142	130	.012	014	
X8cX4	.194*	.239*	087	.152	.042	
X8cX3	093	022	016	038	055	
X8cX2	.102	.097	.036	.133	031	
X8cX1	.345***	.369***	027	.342	.003	
Self Cathexis						
X8bX7a	.192*	.127	None	.127	.065	
X8bX6b	186*	122	022	144	042	
X8bX6a	023	.073	002	.071	094	
X8bX5	.239**	.095	.080	.175	.064	
X8bX4	076	.012	.020	.032	108	
X8bX3	.234**	.140	.011	.151	.083	
X8bX2	213*	203*	.002	201	012	
X8bX1	383***	361***	.006	355	028	

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TABLE 9 (Continued)

Decomposition Table of Effects of Variables

			Causal Effects		
	Total	Direct	Indirect	Total	Non-Causal
	Covariance	Effects	Effects	Effects (B+C)	Effects (A-D)
	(A)	(B)	(C)	(D)	(E)
Body Cathexis			·······		
X8aX7a	.219**	.141	None	.141	.078
X8aX6b	228**	.058	025	.033	261
X8aX6a	313***	250*	002	252	061
X8aX5	.295	.148	.082	.230	.065
X8aX4	317***	074	132	206	111
X8aX3	.282***	.178*	.009	.187	.095
X8aX2	361***	348***	.053	295	066
X8aX1	157*	144	001	145	012
Confrontive Copi	ng				
X7aX6b	299***	176	None	176	123
X7aX6a	177*	012	None	012	165
X7aX5	.494***	.433***	.054	.487	.007
X7aX4	085	.061	149	088	.003
X7aX3	.082	.061	.023	.084	002
X7aX2	.076	.114	.008	.122	046
X7aX1	.023	.062	016	.046	023

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Continued...

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TABLE 9 (Continued)

Decomposition Table of Effects of Variables

			Causal Effects		
	Total	Direct	Indirect	Total	Non-Causal
	Covariance	Effects	Effects	Effects (B+C)	Effects (A-D)
	(A)	(B)	(C)	(D)	(E)
Psychosocial Hea	Ith Status Limitations		·		
X6bX5	361***	299***	None	299	062
X6bX4	.425***	.368***	.053	.421	.004
X6bX3	.008	.089	027	.062	054
X6bX2	.127	.052	.0003	.052	.075
X6bX1	.005	.008	.012	.020	015
Physical Health S	Status Limitations				
X6aX5	243**	154	None	154	089
X6aX4	.538***	.544***	.028	.572	034
X6aX3	.009	.072	014	.058	049
X6aX2	033	137	.0002	.137	.104
X6aX1	.012	.015	.006	.021	009
Perceived Social	Support				
X5X4	188*	179	None	179	009
X5X3	.116	.091	None	.091	.025
X5X2	043	.001	None	.001	044
X5X1	053	040	None	040	013

Testing of the Hypotheses

Comparison of the simplified model with the original research hypotheses indicates that seven of the 11 hypotheses were supported by direct effects among the variables. All but two of these were in the direction of prediction. In addition, two new significant direct effects were revealed in the analysis concerning the influence of illness duration on body image appraisal and the influence of steroid dosage on both physical and psychosocial health status limitations.

Of the fifteen predicted indirect hypotheses, the only hypothesis supported was the influence that social support had on body image appraisal through coping skills alone. An additional indirect pathway was created in the simplified model, revealing the indirect influence that steroid dosage had on body image appraisal through physical health status limitations. Each hypothesis will be discussed with respect to data support or lack of support.

<u>Gender as an exogenous variable in the first time</u> <u>ordering</u>: The first direct hypothesis predicted that female gender would have a direct, negative effect on body image appraisal, which was not supported in the negative direction of prediction. Instead, females showed a more positive self cathexis than did males,

and a more negative body perception. In other words, females perceived themselves to be more satisfied with self while also perceiving their body to be smaller than those of men. Both perceptions are positive in nature, rather than negative as predicted. In addition, there was a trend toward prediction of a negative body cathexis in males, further supporting that females had a more positive body cathexis (body image appraisal) than did males.

Age as an exogenous variable in the first time ordering: The second direct hypothesis predicted that age would have a direct, positive effect on body image appraisal and perceived health status limitations. The direct effect of age on body image appraisal (body and self cathexis) was supported, but in the negative direction, while the direct effect of age on perceived health status was not supported in the model.

The indirect hypotheses predicted for the influence of age on body image appraisal through perceived health status limitations, and through perceived health status limitations and coping skills were not supported in the simplified model. There was a trend of prediction in which age affected a negative perception of physical health status limitations, implying that greater age would be associated with less physical health status limitations.

Duration of illness as an exogenous variable in the first time ordering: The third direct hypothesis predicted that the duration of illness would have a direct, positive effect on perceived health status limitations and a direct, negative effect on social support. Neither direct relationship was supported.

Also, none of the indirect hypotheses originally predicted were supported by the data. These included the effect of duration of illness on body image appraisal through social support and coping skills; through social support and perceived health status limitations; through the influence of perceived health status limitations alone; and through social support, perceived health status limitations, and coping skills. However, an unpredicted effect emerged from the simplified model, concerning the direct, positive effect that duration of illness had on body image appraisal, as measured by body cathexis. The longer the illness, the greater satisfaction with the body in this brain tumor population.

Steroid dosage as an exogenous variable in the first time ordering: The fourth direct hypothesis was well supported concerning the negative effect that steroid dosage had on body image appraisal, as measured by body perception. A greater steroid dosage was predictive of a larger body perception in the study

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population. Two unpredicted direct, positive effects were evident in the simplified path model, in which a greater steroid dosage predicted greater physical and psychosocial health status limitations. A trend toward prediction existed between steroid dosage and perceived social support, in which a greater amount of steroids was predicted to effect the perception of less social support).

Although no indirect hypotheses, involving the influence of steroid dosage on body image appraisal, were predicted in the original path model, an indirect negative effect emerged through perceived physical health status limitations, in the simplified model.

In summary, the exogenous variables in the first time ordering had three direct effects as predicted, all of which were on the final outcome variable of body image appraisal. In addition, two other direct effects emerged, relating steroid dosage to physical and psychosocial health status limitations, in the third time ordering. The single direct effect between the first and second time ordered variables in the original model was not supported; hence, there was no direct nor indirect linkages between the first and second time ordered variables in the simplified model.

Social support hypotheses in the second time ordering: Social support was supported as predicted to

have a direct, negative effect on perceived health status limitations (as measured by the psychosocial dimension), and a direct, positive effect on coping skills (as measured by confrontive coping strategies). Social support would then be associated with less psychosocial health status limitations, and greater use of confrontive coping skills.

A trend toward prediction was also established, in which social support was predicting a negative perception of health status limitations. In other words, the model predicted the trend of greater perceived social support to cause a perception of fewer physical health status limitations.

Although two of the indirect hypotheses concerning the effect of social support on body image appraisal through perceived health status limitations and coping skills, and through perceived health status limitations alone, were not supported by the data, the indirect effect was supported through coping skills alone. Therefore, social support has an indirect effect on body perception through confrontive coping strategies.

Physical and psychosocial health status limitations in the second time ordering: All hypotheses concerning these variables in the original path model utilized the total scale as the predictor or criterion variable. However, the total scale was not

retained in the simplified model. All discussion of hypotheses will thus include discussion of the physical and/or psychosocial subscales of the total scale.

The direct effect hypothesis predicting a negative effect on body image appraisal was supported. Specifically, greater physical health status limitations predicted lesser satisfaction with one's body. The other direct hypothesis predicting a negative effect on coping skills was not supported.

The indirect effect of perceived health status limitations through coping skills was not supported, nor was the indirect effect of duration of illness on perceived health status limitation through social support.

Confrontive coping in the fourth time ordering: The final direct hypothesis concerning the positive effect that coping skills had on body image appraisal was supported by the data. Specifically, confrontive coping predicted a smaller body perception, which is equated with smaller perceived body space. However, no association was evident between confrontive coping and the measures of body cathexis and self cathexis.

All indirect hypotheses concerning the effect of age on coping skills through perceived health status limitations; the effect of duration of illness on coping skills through social support alone, through

perceived health status limitations alone, and through social support and perceived health status limitations, were unsupported by the data.

In summary, there are 12 direct effects predicted by the simplified model, including the deletion of four direct effects from the original model and the addition of three new pathways for direct effects. Two indirect effects, from among the proposed fifteen in the original model, were supported in the simplified model. None of the exogenous variables in the first time ordering were predictive of social support in the second time ordering. All first time ordered variables had direct effects on aspects of body image appraisal.

Adaptive Task and Coping Skills

Other then investigating the interrelationships between the predictor and criterion variables, a second purpose of this research was to explore the relationship between the identified primary adaptive task of the brain tumor patient and the associated coping skills utilized in conjunction with that adaptive task. Seven adaptive tasks, as proposed in Moos' (1984) theoretical model, included dealing with pain, incapacitation, and other symptoms; dealing with the hospital environment and special treatment procedures; developing and maintaining adequate relationships with health care staff; preserving a

reasonable emotional balance; preserving a satisfactory self-image and maintaining a sense of competence and mastery; sustaining relationships with family and friends; and preparing for an uncertain future. No hypotheses were proposed for this relationship since the purpose was simply exploratory in nature.

Table 12 demonstrates the stratification of coping styles by gender in relation to the adaptive task chosen. In the overall sample, evasive and supportive coping strageties were the predominant coping styles. Men and women utilized evasive and supportive styles of coping, yet men also showed some tendency to utilize confrontive coping strategies, which were not reported by the women.

Post-Hoc Analysis

A post-hoc analysis was performed to examine the differences among the predictor and criterion variables between the persons with high grade (rapidly growing) and low grade (slow growing) malignant brain tumors, while simultaneously examining the effect of gender on the same variables. A two by two ANOVA statistical analysis was utilized. No interactive effects between the two variables were discovered (see Tables 10 & 11).

<u>Gender effects on selected variables</u>: Gender differences were evaluated for all dependent variables in the simplified model. Four variables, body/self

<u>TABLE 10</u>

Relationship Between Adaptive Task and Coping Style

Adaptive Task	Overall Sample	<u>Coping</u>	<u>style Subscales: Com</u> Females	lse X Effectiveness Males		
Dealing with pain, incapacitation and other symptoms (n=30)	Evasive Coping Supportive Coping	14/30 12/30	Evasive Coping Optimistic Coping Supportive Coping	5/16 4/16 7/16	Evasive Coping Supportive	8/14 6/14
Dealing with the hospital environment and special treatment procedures (n=14)	Evasive Coping Supportive Coping	6/14 4/14	Evasive Coping Supportive	4/8 2/8	Evasive Coping Supportive Confrontive	2/6 2/6 2/6
Preserving a reasonable emotional balance (n=4)	Optimistic Coping Supportive Coping	5/14 5/14	Optimistic Evasive Coping Supportive	4/12 3/12 3/12	Supportive	2/2
Preserving a satisfactory self-image and maintaining a sense of competence and mastery (n=35)	Evasive Coping Optimistic Coping Supportive Coping	17/35 10/35 7/35	Evasive Coping Optimistic Supportive	4/16 4/16 4/16	Evasive Coping Optimistic Supportive	10/19 6/19 5/19

TABLE 10 (Continued)

Relationship Between Adaptive Task and Coping Style

A de statue Theolo	Coping Style Subscales: Combined Use X Effectiveness					
Adaptive Task	Overall Sample		Females		Males	
Sustaining relationships	Optimistic Coping	4/7	Optimistic	4/6	Confrontive	1/1
with family and friends (n=7)	Evasive Coping	2/7	Evasive	2/6		
Preparing for an	Evasive Coping	5/10	Evasive Coping	2/3	Evasive Coping	3/7
uncertain future	Optimistic Coping	3/10			Optimistic	2/7
(n=10)					Confrontive	2/7

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<u>TABLE 11</u>

Gender Differences Among Selected Variables

Variable	Female (n=56)		Males		
	Mean	S.D.	Mean	S.D.	F
Body/Self Cathexis	6.83	.31	6.42	.32	13.23***
Body Cathexis	3.20	.12	3.05	.12	4.67*
Self Cathexis	3.64	.19	3.37	.20	18.12***
Body Perception	24.88	1.38	26.79	1.42	15.29***
Perceived Social Support	129.95	.92	129.08	.94	.33
SIPS Physical	11.34	.66	11.70	.68	.12
SIPS Psychosocial	12.11	.29	12.19	.30	.07
Confrontive Coping	62.98	.70	65.15	.72	.01
* p≤.05	** p<.01	*** p≤.001			

TABLE 12

Effect of Tumor Type on Selected Variables

Variable	High Grade (n=84)		Low Gra		
	Mean	Ś.D.	Mean	Ś.D.	F
Body/Self Cathexis	6.52	.24	6.98	.42	11.73**
Body Cathexis	3.03	.19	3.42	.35	18.67***
Self Cathexis	3.49	.05	3.56	.08	1.57
Body Perception	25.98	.41	25.27	.75	2.05
Perceived Social Support	127.46	4.27	136.12	7.77	10.77***
SIPS Physical	14.56	6.32	1.68	11.52	16.03***
SIPS Psychosocial	13.86	3.56	6.61	6.48	15.93***
Daily Steroids	309.82	151.62	0.00	276.26	37.14***
Confrontive Coping	57.85	12.78	84.08	23.29	6.21*
Duration of Illness	16.38	4.17	24.65	7.60	9.94**
* p≤.05	** p <u><</u> .01	*** p≤.001	<u> </u>		

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cathexis, body cathexis, self cathexis, and body perception demonstrated significant differences when analyzed by gender. Specifically, the women had significantly higher body/self cathexis, body cathexis and self cathexis, while men attained significantly higher scores on body perception.

Tumor type effect on selected variables: The data was next analyzed by high grade and low grade tumors among the group. Statistically significant differences occurred among eight of the ten variables based upon the two tumor types. Persons with low grade tumors had higher levels of body/self cathexis, body cathexis, and self cathexis, whereas body perception was greater in the high grade tumor group. The duration of illness was greater in the low grade group, who also showed a propensity toward confrontive coping strategies, and greater perceived social support. Persons with high grade tumors had greater physical and psychosocial health status limitations, and consumed steroids, in comparison to the low grade group, none of whom were prescribed to take steroids.

Summary of the Results

In the original model, variables were hypothesized to explain body image appraisal in the malignant brain tumor population. For purposes of the simplified model, the total body/self cathexis score, all coping

scales other than confrontive, the overall SIPS, and Part 1 of the PRQ-85 were dropped from the original model. Seven of the 11 direct hypotheses were supported by the data, although two were in the opposite direction of prediction. Two additional direct paths surfaced in the simplified model. One of the originally-proposed indirect hypotheses was supported in the simplified model, and yet another indirect pathway was revealed in the analysis. A considerable amount of body image appraisal in the malignant brain tumor population can be explained through an understanding of the simplified model, as will be discussed in the final chapter.

Chapter Five

Discussion - General Overview

This research aimed to investigate the influence of selected variables on body image appraisal in the malignant brain tumor population, utilizing a stressadaptation framework, in which the physical illness is viewed as the primary stressor. The simplified model, (Figure 2) as extracted from the data results and reduction procedures, indicates that body image appraisal is strongly predicted by gender, age, duration of illness, steroid dosage, physical health status limitations, and confrontive coping strategies. Also, physical health status limitations and confrontive coping strategies became mediating variables involved in indirect effects of steroid dosage and social support, respectively, on body image appraisal.

This correlational design using path analysis fits well with the conceptualization of Moos' (1984) theoretical framework of coping with a physical illness (Figure 1). Crisis theory, the underpinning of this conceptual model, would seem logically to coincide with the experience of persons dealing with the diagnosis of

terminal brain cancer. Further, although the data analysis supported the removal of certain subscales, due to lack of contribution to prediction of the dependent variables, no single time ordering was eliminated in the simplified model, lending support to the logical construction and interpretation of the model.

In the final simplified model, the total BCSC (body cathexis/self cathexis) scale (Secord & Jourard, 1953) was not retained for several reasons. First, conceptually, the outcome variable of interest was <u>body</u> image, not necessarily self image, lending strong support to the separate analysis of the two subscales, but not necessarily supporting the analysis of the combined scale as a distinct outcome variable. Additionally, upon inspection of the direct effects predictive of the BCSC, no new knowledge was gained that was not duplicated through analysis of the direct effects upon the two subscales.

Seven of the eight subscales of the Revised Jalowiec Coping Scale (Jalowiec, 1987) were also not retained in the final model, due to lack of statistical support for prediction of body image appraisal. Rather than explaining this phenomenon as simply unique to the malignant brain tumor population, further inspection of the psychometric data reported by the author is

indicated. Particularly, it is important to note that only alpha and test-retest reliabilities are reported for the original sixteen subscales of the instrument.

If one were to limit reliability testing in this manner, the standardized alpha coefficients reported in Table 5 for the eight combined coping subscales would meet acceptable levels in six of the eight scales, which is consistent with the author's report. However, Table 5 indicates poor overall mean inter-item correlations for five of the eight combined subscales, and poor overall item-total correlations for all eight combined subscales. Confrontive coping, fatalistic coping, and self-reliant combined coping subscales demonstrated the best estimates of reliability; however, only confrontive coping had any significant ability to predict the outcome variable in the initial regression equation, and was therefore retained in the simplified model.

The Sickness Impact Profile Scale (SIPS) overall score was also discarded from the final analysis due to the targeted interest of the study on physical and psychosocial variables of import, rather than many of the other subscales contained in the 136 item scale. Conceptually, then, removing the overall SIPS scale from the analysis, removed the potential effects of health status limitations related to work behavior,

eating behavior, recreation and pastime behavior, home management behavior, and sleep and rest behavior, from the model. The removal of this total scale score assisted with emphasis on the physical and psychosocial dimensions, while preventing potential overlap of information between the overall score and the subscale scores.

Finally, Part 1 of the PRQ-85 (Brandt & Weinert, 1981) social support instrument was also not retained in the data analysis. The authors qualify the purpose of Part 1 as simply descriptive of the situational support that a person has available and has utilized recently; whereas, Part 2 measures perceived social support, and lends itself to more rigorous data analysis techniques. Part 2 was therefore retained in the simplified model.

The Influence of Gender on Body Image Appraisal

The data did not confirm the hypothetical prediction that female gender would negatively influence body image appraisal. In fact, in this study, female gender predicted significantly greater self cathexis than did male gender, and a trend toward greater body cathexis as well. In other words, females were more satisfied with their selves and their bodies, as was supported previously in young adult samples (Hunt and Feldman, 1960; Kurtz, 1969).

Consistent with this measurement of body attitude (body cathexis) is a similar finding that female gender was predictive of a smaller body perception. While understanding that the body perception measurement equates to perceived body diameter, the female perception of a smaller size is consistent with a traditional positive appraisal of body image. Unlike the studies of medically ill individuals, (Schwab & Harmeling, 1968), women with brain tumors in this study, did not demonstrate a greater dissatisfaction with their bodies than did men.

A potential explanation for this unexpected direction of prediction lies in the group differences between low grade tumor patients and high grade tumor patients in their attitude and perception of body image. Although the group sizes are nearly equal, the large amount of variance between the two groups may have skewed the results.

The Influence of Age on Body Image Appraisal

Although the data supported the direct effect of age on body cathexis and on self cathexis, the hypothesized positive direction of the influence, was not supported. In this sample of brain tumor patients, greater age caused low values of body and self satisfaction.

Although the age of the sample ranged from 21 to

73 years, the mean age was 43 with a standard deviation of 13.6 years. When the range was examined more closely, it was noted that 58 of the subjects were between the ages of 35 and 58 years, clearly a predominantly middle-aged sample. Only 17 subjects were over the age of 58 years.

These results are similar to those of Larson, Boyle and Boaz (1984) in which a curvilinear relationship was found between age and physical selfconcept. These authors found that middle-aged adults had the least positive scores of physical self-concept. One might postulate that other factors such as disability, loss of income, functional loss of productivity, and perhaps, a generally poor prognosis, during the prime of life, may have contributed to similar results in the brain tumor population.

Various other reports in the literature review, supporting the positive correlation of age with body image appraisal, studied healthy subjects. How one views one's body and self when undergoing normal aging processes may indeed be quite different from that experienced by the malignant brain tumor population.

Also hypothesized in the original path model was the positive association between age and perceived health status limitations, in an attempt to validate the research of Levkoff, Cleary and Wetle (1987), in which persons over 65 years of age were less positive in their self-appraisal of health status. Although the relationship was partially supported by a trend toward significance, the direction of the trended prediction was negative, meaning that greater age was associated with fewer health status limitations, in this study sample.

The substantially greater life expectancy for the low grade tumor group, in comparison to the high grade tumor type, may have contributed to these results, since the low grade tumor patients usually live much longer lives without progressive physical disabilities. Therefore, the less aggressive cancer would foster older age with less physical and psychosocial health status limitations.

The Influence of Illness Duration on Body Image Appraisal

In the original path model, duration of illness was predicted to positively influence perceived health status limitations, and to negatively influence social support. Neither relationship was substantiated by this research. This is the result of a misconception on the part of the author in the original model design. In the construction of the relationships in the model, a longer duration of illness was equated with the brain cancer as a chronic illness. Chronic illness was

equated with poor health; therefore, the patient was expected to have greater health status limitations with the more chronic form of the cancer.

However, in this research sample, the longer duration of illness associated with the low grade tumor types, was not equated with greater health status limitations, when compared to the acute, complicationprone, short-term (18 month) course of devastating illness experienced by the patients with high grade brain tumors. Therefore, within the limits of the sample selection criteria (Karnofsky \geq 50), the longer illness was associated strongly with fewer health problems and complications. Selection of this sample based upon a Karnofsky score greater than or equal to 50 did preselect a certain state of 'health' in the study population, and thereby eliminated an element of extreme effect of the disease on health status.

From the same pattern of logic, the lack of support for the negative effect of duration of illness on perceived social support (beta weight = 0.091, n.s.), can also be explained. Again, the longer duration of illness implies a fortunate, rather than unfortunate, chronicity to the disease. These persons live longer, healthier lives, and would most likely perceive greater social support from their social environment.

An unanticipated pathway in the model was supported between duration of illness and body cathexis, in which the longer duration of illness affected a higher body cathexis score (beta weight = .178, $p \le .05$). This unexpected relationship can be explained, again, on the basis of the group differences related to tumor type. The low grade tumor group, who lived significantly longer, healthier lives, had fewer disabilities (fewer perceived health status limitations) and, subsequently had a better attitude toward their body.

The Influence of Steroids on Body Image Appraisal

As is conventional neurosurgical treatment (Galicich & French, 1961; Ransohoff, 1972), most of the patients with high grade tumors were taking daily corticosteroids, while none of the low grade tumor patients were taking steroids to control their disease. Of the patients taking steroid dosages from 15 to 900 milligrams per month, most of whom were experiencing associated weight gain (98%), all verbalized their distress concerning the effect of the steroids on their appetite and body weight.

Steroids were found to have a strong direct, predictive ability on body perception (beta = .239, $p \le$.05), and a strong indirect predictive effect on body cathexis through physical health status limitations.

This relationship is supported arithmetically, meaning that a greater steroid dosage, associated with greater body weight and onset of Cushing's syndrome, would yield larger scores of body diameter on the topographic device. A larger body perception would equate with a negative perception of one's body.

Unexpectedly, however, was the emergence of steroid dosage as predictive of health status limitations, both the physical and psychosocial subscales. Remembering that corticosteroids were only taken by patients with high grade tumors, the larger steroid dosages predicted greater health status limitations, which was consistent with the poorer health and increased incidence of complications and rapid neurological compromise. Those patients with greater steroid dosages also had greater health status limitations in the psychosocial realm, perhaps due to progressive disease limiting socialization. The Influence of Social Support on Body Image Appraisal

Although no direct effect of social support on body image appraisal was supported by this research data, social support did indirectly affect body perception through the confrontive coping strategy. Greater perceived social support was predictive of greater use of confrontive coping strategies and a smaller body perception. The brain tumor patient with

the greater amount of perceived social support, namely the low grade tumor group, used more confrontive coping strategies to deal with their illness, and therefore had a satisfactory body perception.

However, it is difficult, from this research data, to support the postulate that social support acts as a buffer between psychosocial stress and health outcome or well-being (Cohen & McKay, 1984; Cohen & Syme, Social support, while indirectly affecting body 1985). image appraisal through confrontive coping, does not link to the exogenous variables in the first time ordering. The question arises as to the correct placement of the social support variable within the model. Reflection back to Moos' theoretical framework places social support in the first time ordering as a determinant variable of the social environment. Other predictors of the social support variable should be identified, (Broadhead, et al., 1983) since the chronicity factor did not predict the level of social support in this population.

The Influence of Perceived Health Status on Body Image Appraisal

Of the two SIPS subscales, only the physical scale was predictive of a body image appraisal outcome variable, which was limited to body cathexis. This predicted relationship was negative in the simplified

model, meaning that greater perception of physical health status limitations predicted less satisfaction with one's body (Larson, Boyle & Boaz, 1984; Schwab & Harmeling, 1968). This finding again related to the intra-group differences found between the two types of malignant brain tumors. Body cathexis was significantly lower in the high grade tumor group, and perceived physical health status limitations were significantly higher in the same group.

The Influence of Coping on Body Image Appraisal

Consistent with the findings of Miller (1983) that chronically ill individuals utilize approach or avoidance coping strategies, the coping strategy of most significance in this path model was confrontive coping, which one could classify as an approach-type of strategy. Confrontive coping utilization in this study group was predicted by high levels of perceived social support, in accordance with Cobb (1976), who postulated that social support enhances the effectiveness of coping with a stressful event. The low grade tumor patients, with higher levels of perceived social support, utilized significantly more confrontive coping. This coping style was predictive of a diminished body perception, or a more positive body image appraisal, which again well fits the low grade tumor population, because of lack of gross disability

and lack of steroid dependency.

The terms affective (emotion) - focused and problem focused types of coping strategies, although utilized in the research hypotheses of this study, were. not utilized in the final analysis, in light of the revised edition of the Jalowiec Coping Scale that was utilized and the lack of similar terminology in Dr. Jalowiec's coping language.

Summary

The simplified path model (Figure 2) relating body image appraisal to predictor variables in the malignant brain tumor population explained an appreciable amount of variance within the model. All time-orderings were retained from the theoretical model and the causal model, despite the reduction of several subscales. When the regression analysis is interpreted simultaneously with the intra-group differences of the post-hoc analysis, it becomes evident that group membership influences the predictive effects of the variables within the path model.

Significant differences for the patients with low grade malignant brain tumors included greater body cathexis, greater perceived social support, less physical and psychosocial health status limitations, no steroid therapy, greater use of confrontive coping strategies and a longer duration of illness. Patients

with high grade malignant brain tumors, on the other hand, had lower body cathexis, less perceived social support, greater physical and psychosocial health status limitations, steroid dependency, less use of confrontive coping, and shorter duration of illness. There were no significant differences between the groups with respect to self cathexis and body perception.

The direct pathways within the simplified model attributed to membership in the high grade tumor group include all three paths affected by steroid dosage, since only the high grade tumor patients received steroid therapy. The direct physical health status limitations effect on body cathexis as well as the indirect effect of steroid therapy on body cathexis are reflective of the impact of the high grade tumor group. The duration of illness effect on body cathexis, the direct social support effect on confrontive coping as well as the indirect social support effect on body perception and the confrontive effect on body perception are all likely the result of the low grade tumor group, since significant group differences exist among these variables.

From the largest amount of variance explained to the least, the variables effecting body image appraisal in the malignant brain tumor population, are gender,

age, confrontive coping, perceived physical health status limitations, steroid dosage, duration of illness, social support through confrontive coping, and steroid dosage through perceived physical health status limitations.

Strengths and Limitations

Internal Validity

The internal validity, or linking power in a study, refers to the logical relationship or linkage between variables in a study (Krathwohl, 1985). The proposed relationships in this study are explained in the literature review. The literature, therefore, supported the credibility of the hypotheses. All hypotheses were written as directional statements, based upon the acceptable knowledge base obtained from the literature review.

Translation fidelity presented a partial threat to the study design. Although the construct of body image had been extensively studied for many years, few researchers had achieved an operational definition of universal acceptance. In this study, body image was measured as a combination of body attitude and body perception. Body attitude, a form of body image conception, was measured with paper and pencil testing methodology, while body perception was measured with a projective technique. The dissimilar methods of

measurement made it impossible to calculate an overall score for the construct of body image; hence, multiple outcome variables with varied path models were tested.

Rival explanations must be eliminated to achieve internal validity for the study. Maturation, the biological or psychological changes in the subjects during the course of the study, would definitely be a factor responsible for a rival explanation. Selection bias may have also effected validity, since all participants were volunteers from brain tumor centers, who were pre-screened for inclusion criteria by the investigator. The threat of the research expectancy effect was reduced since the investigator performed all data collection. Diffusion did not pose a threat since no difference in care occurred in study patients versus non-study patients. It was difficult to envision an adverse, or reactive effect occurring, from simply administration of tools to measure body image. No treatment was administered in this study.

External Validity

External validity, or generalizing power (Krathwohl, 1985) were not threatened by explanation generality or translation generality since the study sample was truly representative of the population of brain tumor patients as reported by the National Cancer Institute. Certain restrictive or rival explanations

may have limited the external validity of the study results. The testing/treatment interaction factor may initially have been a threat at the time of participant consent. Simply knowing that your body image is being measured may have effected the responses to the instruments. Also, the subjects may have responded to the instruments based on an interpretation of the experimenter's expectancies, causing another rival explanation for the results.

It is possible that replication of the study utilizing different instrumentation would yield very different results. This problem is partially related to the difficulty in measuring body perception in the brain tumor population.

Nursing Implications

Nursing Practice Implications

Body image is a concept of broad application within many nursing practice settings and populations. Practitioners of nursing are frequent unknowing observers of body image alterations among recipients of care. The actual physiological, psychological, and sociological manifestations of body image alterations may occur in our patients; yet, without knowledge of the concept, the identification, qualification and determination of interventions, in response to the patient's expression of the disturbance, may not occur.

It is hoped that this research may raise the consciousness of nurses who care for patients with potential body image disturbances. Awareness and assessment of the problem is the initial step.

This study of the malignant brain tumor population may help us to identify themes of care that are common to other patient populations. In this way, application of knowledge gained from this research project may eventually serve other patient groups. For example, steroid therapy administered to transplant (renal, liver, cardiac) populations, and chronic disease (multiple sclerosis, arthritis, asthmatics) populations may have the same clinical implications, in terms of body image disturbances, that occur during brain tumor treatment.

To other neuroscience patient populations with varying forms of the same disease, like multiple sclerosis or myasthenia gravis, it may be possible to apply knowledge from the brain tumor population. For example, the slow and chronic form versus the rapidly progressive form of M.S. may be similar enough to the low grade and high grade brain tumor types, that knowledge could eventually be transferred from one disease state to another.

Physical disabilities represent another frequent, common experience of the neuroscience patient

population. Just as the significance of these physical disabilities (health status limitations) to poor body image appraisals was statistically supported in the malignant brain tumor population, it may be possible to apply this knowledge to other disabled neuroscience patients.

Nursing Research Implications

Continued research on body image concerns is necessary, since it is an issue of more frequent occurrence that we realize. As scientific advances in the laboratory and technological surges contribute to the prolongation of life, many more persons are surviving their illness, but living with residual effects of their treatment. Although grateful for continued life, the psychological outcomes, such as body image alterations, are difficult challenges to face.

Body image theory building, then, is a crucial area of nursing science needing further development through nursing research. To date, nursing's involvement to explore the concept/construct of body image in various nursing care settings and populations has been quite limited. Testing conceptual models, from nursing or other disciplines, in various populations, is one way of supporting or refuting the proposed relationships or causal pathways, for that

patient population.

Despite the young age of nursing science, and the need to research at the exploratory and descriptive levels to study the phenomena of nursing, interdisciplinary bodies of research can lend strong support to nursing research of nursing phenomena. In this research project, little contribution came from the nursing research literature. The majority of support for the conceptual model, as well as relationships within the model arose from the medical, psychological, or sociological literature sources. Without this link to related disciplines, there would have been inadequate support for the causal relationships between the variables. The research would then have been conducted at a lower level, either correlational or exploratory/descriptive. Yet, nursing can borrow from and contribute to the behavioral research library, through our collaborative work.

It is planned that the findings from this research project will be shared in multiple formats and arenas to facilitate wide dissemination of knowledge. It is further planned that more nursing research continue on the concept of body image appraisal in various patient populations, with the ultimate goal of designing nursing interventions to assist with these outcomes of medical therapy.

Nursing Education Implications

Nursing education can play a significant role in the transmission of this information to the student nursing population. All too often, nurses concentrate on the physiological issues of apparent concern, and omit the psychologically-based issues of patient care. Through emphasis of the link between psychosocial and physiological issues that patients experience, nursing faculty contribute to the foundation upon which patient care is conceptualized by the nurse for the remainder of their career. Since nursing schools provide the students with their first exposure to nursing diagnoses, as a means to qualify patient problems, it is essential that equal emphasis be given to the psychosocial diagnoses as well as the physiologicallyoriented diagnoses. As the body of nursing knowledge on body image expands, it will be crucial for nursing education to provide the transfer of this new knowledge to the students of nursing science.

Summary

This correlational study has addressed the relationships between gender, age, duration of illness, monthly steroid dosage, perceived social support, perceived physical and psychosocial health status limitations, and confrontive coping on the outcome variable of body image appraisal, measured both as body

perception and body attitude. Age, physical health status limitations, and duration of illness have the predictive ability on body cathexis; gender and age have the greatest predictive ability on self cathexis; and gender, confrontive coping and steroid dosage have the greatest predictive ability on body perception. Significant differences in some predictor variables were revealed for the low grade tumor patients and the high grade tumor patients. The relationships within the path model are moderately strong, yet, additional research is implicated to further refine the concepts, relationships and instrumentation.

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Appendix A Research Questionnaires

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DEMOGRAPHIC DATA #1

Gend	ler:	(1) Female	2	(2)	Male	
Age :	years		Date	of	birth:	
Heig	ht: in	ches	Weigh	it:	pounds	5
Visu	al status:	Normal	Abr	orm	al	
	est Level o					
10.	Less than h	Ign school	-	15:	Dipiona	
	High school			10:	Baccalaure	eate degree
13:	Trade schoo Associate d	1			Masters de	
14:	Associate d	egree		20:	Doctoral d	legree
(1) (2) (3) (4)	tal Status: Single, nev Married Widowed Divorced		l		(1) (2) (3) (4)	hicity: White Asian Black Hispanic Other
	al Family I				.	.
	Less than \$				\$41,000 -	
(2)	\$5000 - \$10	,000		(7)	\$51,000 -	\$60,000
	\$11,000 - \$					
	\$21,000 - \$			(9)	Over \$100,	, 000
(5)	\$31,000 - \$	40,000				
Occu	pation:					

Employment Status:

- (1) Not employed
- (2) Permanently disabled
- (3) Employed part-time
- (4) Employed full-time

Self-Care Ability: (Karnofsky Score, 1949)

<u>100</u> Normal, no complaints, no evidence of disease

- <u>090</u> Able to carry on normal activity, minor signs or symptoms or disease.
- <u>080</u> Normal activity with effort, some signs or symptoms of disease.
- <u>070</u> Cares for self. Unable to carry on normal activity or to do active work.
- <u>060</u> Requires occasional assistance, but is able to care for most of own needs.
- <u>050</u> Requires considerable assistance and frequent medical care.

DEMOGRAPHIC DATA #2

Facts About Disease and Treatment: Type of tumor: Location of tumor: Date of onset of symptoms: _____ Months duration: _____ Date of biopsy:_____ Months since:_____ Date of craniotomy #1:_____ Months since_____ Date of craniotomy #2:_____ Months since_____ Date of shunt placement/reservoir:_____ Mo since____ Date of other surgical interventions: _____ Mo since____ Date of external radiation therapy: _____ Mo since_____ Date of I125 seed implantations:_____ Mo since:_____ Dates/types of complications:#1: ____/ Mo since___ Dates and types of chemotherapy sessions: In treatment: Y/N If yes, # of treatments completed: Date of last treatment: ____ Months since____ Current daily steroid dosage:_____ times 30 days = ____ Do you notice any weight gain while on the steroids? Does the weight gain bother/upset you?

DEMOGRAPHIC DATA #3

- Task Adaptation: Choose the task which is of most importance to you currently in your daily life of living with a brain tumor and the associated treatments:
- ____ Dealing with pain, incapacitation, and other symptoms.
- _____ Dealing with the hospital environment and special treatment procedures.
- _____ Developing and maintaining adequate relationships with health care staff.
- _____ Preserving a reasonable emotional balance.
- _____ Preserving a satisfactory self-image and maintaining a sense of competence and mastery.
- _____ Sustaining relationships with family and friends.
- _____ Preparing for an uncertain future.
 - ____ Other____

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> Jalowiec Coping Scale pg.147-151 and Personal Resource Questionaire pg.152-160

University Microfilms International

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SICKNESS IMPACT PROFILE SCALE (SIPS)

(Gilson, Gilson, et al, 1975)

Instructions to the respondent:

Before beginning the questionnaire, I am going to read you the instructions.

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to your state of health.

I will be reading statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As I read the questionnaire, think of yourself today. I will pause briefly after each statement. When you hear one that does describe you and is related to your health please tell me and I will check it.

Let me give you an example. I might read the statement "I am not driving my car." If this statement is related to your health and describes you today, you should tell me. Also, if you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

If you are in the hospital today, you are here because of your state of health, and you are not doing a number of things you usually do. For instance, if driving is usual for you, then you re not driving today because you are in the hospital, and you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement "I am not driving my car" is not related to your health and you should not respond to it. If you simply are driving less, o rare driving shorter distances, and feel that the statement only partially describes you, please do not respond to it.

I am now going to begin the questionnaire. Please tell me if you want me to slow down, repeat a statement, or stop so that you can think about one. Also let me know any times you would like to review the instructions. Remember we are interested in the recent or longstanding changes in your activities that are related to your health.

Numb	er <u>SICKNESS IMPACT PROFILE SCALE (SIPS)</u> (Gilson, Gilson, et al, 1975)
SURE HEAL	SE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF TH. ep and Rest Dimension) SR 0499
1.	I spend much of the day lying down 070-083 in order to rest.
2.	I sit during much of the day 062-049
3.	I am sleeping or dozing most of the time 063-104 day and night.
4.	I lie down more often during the day 066-058 in order to rest.
5.	I sit around half-asleep 065-084
6.	I sleep less at night, for example, 069-061 wake up too early, don't fall asleep for a long time, awaken frequently.
7.	I sleep or map more during the day 071-060
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

(Emotional Behavior Dimension) EB-0705

1.	I say how bad or useless I am, for example, that I am a burden on others 274-087
2.	I laugh or cry suddenly 272-068
3.	I often moan and groan in pain or discomfort 269-069
4.	I have attempted suicide 281-132
5.	I act nervous or restless 284-046
6.	I keep rubbing or holding areas of my body that hurt or are uncomfortable 262-062
7.	I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen 273-078
8.	I talk about the future in a hopeless way 283-089
9.	I get sudden frights 278-074
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

(Body Care and Movement) BCM-2003

1.	I make difficult moves with help, for exam	nple,	,
	getting into or out of cars, bathtubs.		L68-084
2.	I do not move into or out of bed or chair	by	
	myself but am moved by a person or	-	
	mechanical aid.		170-121
3.	I stand only for short periods of time.		155-072
4.	I do not maintain balance.		146-098
5.	I move my hands or fingers with some		
	limitation or difficulty.		152-064
6.	I stand up only with someone's help.		165-100
7.	I kneel, stoop, or bend down only by		
	holding on to something.		171-064
8.	I am in a restricted position all the		
	time.		158-125
9.	I am very clumsy in body movements.		148-058
10.	I get in and out of bed or chairs by		
	grasping something for support or		
	using a cane or walker.		169-082
11.	I stay lying down most of the time.		162-113
12.	I change position frequently.		147-030
13.	I hold on to something to move myself		
	around in bed.		143-086
14.	I do not bathe myself completely, for		
	example, require assistance with bathing.		310-089
15.	I do not bathe myself at all, but am bathe	≥d	
	by someone else.		312-115
16.	I use a bedpan with assistance.		292-114
17.	I have trouble getting shoes, socks,		
	stockings on.		305-057
18.	I do not have control of my bladder.		290-124
19.	I do not fasten my clothing, for		
	example, require assistance with buttons,		
	zippers, shoelaces.		298-074
20.	I spend most of the time partly undressed		
	or in pajamas.		302-074
21.	I do not have control of my bowels.		295-128
22.	I dress myself, but do so very slowly.		300-043
23.	I get dressed only with someone's help.		297-088
	CHECK HERE WHEN YOU HAVE READ ALL STATEMEN	NTS	
	ON THIS PAGE		

THIS GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO IN CARING FOR YOUR HOME OR YARD. CONSIDERING JUST THOSE THINGS THAT YOU DO, PLEASE RESPOND TO ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Home Management Dimension) HM-0668

1.	I do work around the house only for short periods of time or rest often 117-054
2.	I am doing less of the regular daily work around the house than I would usually do 119-044
3.	I am not doing any of the regular daily work around the house that I would usually do 120-086
4.	I am not doing any of the maintenance or repair work that I would usually do in my home or yard 001-062
5.	I am not doing any of the shopping that I 106-071
6.	I am not doing any of the house cleaning that I would usually do 116-077
7.	I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry 107-069
8.	I am not doing any of the clothes washing that I would usually do 111-077
9.	I am not doing heavy work around the 115-044
10.	I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget 105-084
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS

Number _____ SIPS, PAGE 5

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Mobility Dimension) M-0719

1.	I am getting around only within one
	building 134-086
2.	I stay within one room 123-106
3.	I am staying in bed more 130-081
4.	I am staying in bed most of the time 131-109
5.	I am not now using public transportation 140-041
6.	I stay home most of the time 133-066
7.	I am only going to places with restrooms
	nearby 125-056
8.	I am not going into town 124-048
9.	I stay away from home only for brief periods
	of time 139-054
10.	I do not get around in the dark or in
	unit places without someone's help 121-072
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS
	ON THIS PAGE.

SIPS, PAGE 6

Number

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Social Interaction Dimension) SI-1450 I am going out less to visit people. 1. ____ 028-044 2. I am not going out to visit people at all. ____029-101 I show less interest in other people's 3. problems, for example, don't listen when they tell me about their problems, don't _ 003-067 offer to help. I often act irritable toward those around 4. me, for example, snap at people, give sharp answers, criticize easily. 015-084 5. I show less affection. ____ 007-052 6. I am doing fewer social activities with groups of people. _ 012-036 7. I am cutting down the length of visits with ____ 027-043 friends. ____ 034-080 I am avoiding social visits with others. 8. 9. My sexual activity is decreased. ____ 039-051 10. I often express concern over what might _ 018-052 be happening to my health. ____002-056 11. I talk less with those around me. I make many demands, for example, insist 12. that people do things for me, tell them ____ 038-088 how to do things. 13. I stay alone much of the time. ____ 023-086 14.I act disagreeable to family members, for example, I act spiteful, I am stubborn ____ 249-088 15.I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them. ___ 240-119 16.I isolate myself as much as I can from the rest of the family. _ 237-102 17.I am paying less attention to the children. 238-064 18.I refuse contact with family members, for example, turn away from them. ____ 256-115 19.I am not doing the things I usually do to take care of my children or family. ____ 242-079 20.I am not joking with family members as I usually do. 255-043 CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE.

167

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Ambulation Dimension) A-0842

1.	I walk shorter distances or stop to rest
+ •	often 050-048
2.	I do not walk up or down hills 046-056
3.	I use stairs only with mechanical support, for example, handrail, cane, crutches 042-067
4.	I walk up or down stairs only with assistance from someone else 044-076
5.	I get around in a wheelchair 057-096
6.	I do not walk at all 052-105
7.	I walk by myself but with some difficulty, for example, limp, wobble, stumble, have
	stiff leg 049-055
8.	I walk only with help from someone 053-088
9.	I go up and down stairs more slowly, for example, one step at a time, stop often 040-054
10.	I do not use stairs at all 041-083
11.	I get around only by using a walker, crutches, cane, walls, or furniture 047-079
12.	I walk more slowly 051-035
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS

168

Number ____ SIPS, PAGE 8

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Alertness Behavior Dimension) AB-0777

1.	I am confused and start several actions at a time.		223-090
2.	I have more minor accidents, for example, drop things, trip and fall, bump into things.		234-075
3.	I react slowly to thins that are said or done.	<u>_</u>	228-059
4.	I do not finish things I start.		227-067
5.	I have difficulty reasoning and solving problems, for example, making plans, maki decisions, learning new things.	ng	224-084
6.	I sometimes behave as if I were confused disoriented in place or time, for example where I am, who is around, directions, wh day it is.	,	231-113
7.	I forget a lot, for example, things that happened recently, where I put things, appointments.		222-078
8.	I do not keep my attention on any activit for long.	У	220-067
9.	I make more mistakes than usual.	<u> </u>	225-064
10.	I have difficulty doing activities involv concentration and thinking.	ing	217-080
	CHECK HERE WHEN YOU HAVE READ ALL STATEME ON THIS PAGE.	NTS	

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Communication Dimension) C-0725

1.	I am having trouble writing or typing.		191-070
2.	I communicate mostly by gestures, for example	ample	≥,
	moving head, pointing, sign language.		
з.	My speech is understood only by a few people		
	who know me well.		179-093
4.	I often lose control of my voice when I	talk	
	for example, my voice gets louder or soft		
			197-083
5.	I don't write except to sign my name.		188-083
6.	I carry on a conversation only when very		100 005
0.			
	close to the other person or looking		
	at him.		178-067
7.	I have difficulty speaking, for example,	get	
	stuck, stutter, slur my words.	-	176-076
8.	I am understood with difficulty.		200-087
			200-087
9.	I do not speak clearly when I am under		
	stress.		201-064
	CHECK HERE WHEN YOU HAVE READ ALL STATEM	ENTS	
	ON THIS PAGE.		

THE NEXT GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO OTHER THAN MANAGING YOUR HOME. BY THIS WE MEAN ANYTHING THAT YOU REGARD AS WORK THAT YOU DO ON A REGULAR BASIS.

DO	YOU	USUALLY	DO	WORK	OTHER	THAN	MANAGING	YOUR	HOME?
		YES _		_	NO	-			

IF YOU ANSWERED YES, GO ON TO THE	NEXT PAGE.	
IF YOU ANSWERED NO: ARE YOU RETIRED?	YES	NO
IF YOU ARE RETIRED, WAS YOUR RETIREMENT RELATED TO YOUR HEALTH?	YES	NO
IF YOU ARE NOT RETIRED, BUT ARE NOT WORKING, IS THIS RELATED TO YOUR HEALTH?	YES	NO

NOW SKIP THE NEXT PAGE.

IF YOU ARE NOT WORKING, AND IT IS NOT BECAUSE OF YOUR HEALTH, PLEASE SKIP THIS PAGE

NOW CONSIDER THE WORK YOU DO AND RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (IF TODAY IS A SATURDAY OR SUNDAY OR SOME OTHER DAY THAT YOU WOULD USUALLY HAVE OFF, PLEASE RESPOND AS IF TODAY WERE A WORKING DAY) (Work Dimension) W-0515

1. I am not working at all. 100-361 (If you checked this statement, skip on to the next page) I am doing part of my job at home. 2. ____ 094-037 3. I am not accomplishing as much as usual at work. ____ 096-055 4. I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily. 088-080 ___ 095-043 5. I am working shorter hours. I am doing only light work. 6. 086-050 7. I work only for short periods of time or take frequent rests. ____ 090-061 I am working at my usual job but with some 8. changes, for example, using different tools or special aids, trading some tasks with other workers. 092-034 9. I do not do my job as carefully and accurately as usual. 097-062 CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE.

THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Recreation and Pastime Dimension) RP-0422

1. I do my hobbies and recreation for shorter periods of time. ____ 215-039 I am going out for entertainment less 2. 214-036 often. з. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. 207-059 4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. ____ 208-084 5. I am doing more inactive pastimes in place of my other usual activities. ____ 211-051 6. I am doing fewer community activities. ____ 216-033 7. I am cutting down on some of my usual physical recreation or activities. ____ 210-043 8. I am not doing any of my usual physical recreation or activities. ____ 209-077 CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE.

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (Eating Dimension) E-0705

1.	I am eating much less than usual 085-037
2.	I feed myself but only by using specially prepared food or utensils 073-077
3.	I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar 081-043
4.	I eat no food at all by am taking liquids 077-104
5.	I just pick or nibble at my food 083-059
6.	I am drinking less fluids 080-036
7.	I feed myself with help from someone 074-099
8.	I do not feed myself at all, but must be 075-117
9.	I am eating no food at all, nutrition is taken through tubes or intravenous fluids 076-133
	CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE

BODY CATHEXIS SCALE (Secord & Jourard, 1953)

Instructions: On the following pages are listed a number of things characteristic of yourself or related to you. You are asked to indicate which things you are satisfied with exactly as they are, which things you worry about and would like to change if it were possible, and which things you have no feelings about one way or the other.

Consider each item and encircle the number which best represents your feelings according to the following scale:

1.	Have strong	feelings	and wish	change	could
	somehow be	made.			

- 2. Don't like, but can put up with.
- 3. Have no particular feelings one way or the other.
- 4. Am satisfied.
- 5. Consider myself fortunate.

Hair	1	2	3	4	5
Facial complexion	1	2	3	4	5
Appetite	1	2	3	4	5
Hands	1	2	3	4	5
Distribution of hair over body	1	2	3	4	5
Nose	1	2	3	4	5
Fingers	1	2	3	4	5
Elimination	1	2	3	4	5
Wrists	1	2	3	4	5
Breathing	1	2	3	4	5
Waist	1	2	3	4	5
Energy level	1	2	3	4	5
Back	1	2	3	4	5
Ears	1	2	3	4	5
Chin	1	2	3	4	5

Number BODY CATHEXIS SCALE, PAGE 2						
1. 2. 3. 4. 5.	Have strong feelings and wish change could somehow be made. Don't like, but can put up with. Have no particular feelings one way or the other. Am satisfied. Consider myself fortunate.					
Exercise	1	2	3	4	5	
Ankles	1	2	3	4	5	
Neck	1	2	3	4	5	
Shape of head	1	2	3	4	5	
Body build	1	2	3	4	5	
Profile	1	2	3	4	5	
Height	1	2	3	4	5	
Age	1	2	3	4	5	
Width of shoulders	1	2	3	4	5	
Arms	1	2	3	4	5	
Chest	1	2	3	4	5	
Eyes	1	2	3	4	5	
Digestion	1	2	3	4	5	
Hips	1	2	3	4	5	
Skin texture	1	2	3	4	5	
Lips	1	2	3	4	5	
Legs	1	2	3	4	5	
Teeth	1	2	3	4	5	
Forehead	1	2	3	4	5	
Feet	1	2	3	4	5	

- Have strong feelings and wish change could somehow be made. 1.
- 2.
- Don't like, but can put up with. Have no particular feelings one way or the 3. other.
- 4. Am satisfied.
- Consider myself fortunate. 5.

Sleep	1	2	3	4	5
Voice	1	2	3	4	5
Health	1	2	3	4	5
Sex activities	1	2	3	4	5
Knees	1	2	3	4	5
Posture	1	2	3	4	5
Face	1	2	3	4	5
Weight	1	2	3	4	5
Sex (male or female)	1	2	3	4	5
Back view of head	1	2	3	4	5
Trunk	1	2	3	4	5

SELF CATHEXIS SCALE (Secord & Jourard, 1953)

Instructions: You are asked to indicate which things you are satisfied with exactly as they are, which things you worry about and would like to change it if were possible, and which things you have no feelings about one way or the other.

Consider each item and encircle the number which best represents your feelings according to the following scale:

- 1. Have strong feelings and wish change could somehow be made.
- 2. Don't like, but can put up with.
- 3. Have no particular feelings one way or the other.
- 4. Am satisfied.
- 5. Consider myself fortunate.

First name	1	2	3	4	5
Morals	1	2	3	4	5
Ability to express myself	1	2	3	4	5
Taste in clothes	1	2	3	4	5
Sense of duty	1	2	3	4	5
Sophistication	1	2	3	4	5
Self- understanding	1	2	3	4	5
Life goals	1	2	3	4	5
Artistic talent	t1	2	3	4	5
Tolerance	1	2	3	4	5
Moods	1	2	3	4	5
General knowledge	1	2	3	4	5
Imagination	1	2	3	4	5
Popularity	1	2	3	4	5
Self- confidence	1	2	3	4	5

Number	SELF-CA	THEXIS SC	ALE, PAGE	E 2			
1. 2. 3.	somehow b Don't lib Have no p other.	Have strong feelings and wish change could somehow be made. Don't like, but can put up with. Have no particular feelings one way or the other.					
4. 5.	Am satisi Consider	fied. myself fo	ortunate.				
Ability to express sympathy	1	2	3	4	5		
Emotional control	1	2	3	4	5		
Self- consciousness	1	2	3	4	5		
Generosity	1	2	3	4	5		
Ability to accept criticism	1	2	3	4	5		
Thoughts	1	2	3	4	5		
Artistic and literary taste	2 1	2	3	4	5		
Memory	1	2	3	4	5		
Thriftiness	1	2	3	4	5		
Personality	1	2	3	4	5		
Self-respect	1	2	3	4	5		
Ability to concentrate	1	2	3	4	5		
Ability to take orders	1	2	3	4	5		
Sensitivity to opinions of others	1	2	3	4	5		
Ability to lea	d1	2	3	4	5		
Last name	1	2	3	4	5		

Number1. 2. 3. 4. 5.	Have strop somehow be Don't like Have no pe other. Am satisf	e made. e, but can articular	s and wish put up wi feelings o	change co th. ne way or	
Impulses	1	2	3	4	5
Manners	1	2	3	4	5
Handwriting	1	2	3	4	5
Athletic skill	1	2	3	4	5
Intelligence level	1	2	3	4	5
Fears	1	2	3	4	5
Happiness	1	2	3	4	5
Creativeness	1	2	3	4	5
Love life	1	2	3	4	5
Strength of conviction	1	2	3	4	5
Conscience	1	2	3	4	5
Skill with hands	1	2	3	4	5
Capacity for work	1	2	3	4	5
Conscientious- ness	1	2	3	4	5
Ability to meet people	1	2	3	4	5
Self-disciplin	e1	2	3	4	5
Suggestibility	1	2	3	4	5
Neatness	1	2	3	4	5
Vocabulary	1	2	3	4	5

Number	SELF-CATHEXIS	SCALE,	PAGE 4	
--------	---------------	--------	--------	--

- 1. Have strong feelings and wish change could somehow be made.
- 2.
- Don't like, but can put up with. Have no particular feelings one way or the з. other.
- Am satisfied. 4.
- Consider myself fortunate. 5.

Procrastinatio	on1	2	3	4	5
Will power	1	2	3	4	5
Self- assertiveness	1	2	3	4	5
Ability to mak decisions	.e 1	2	3	4	5
Dreams	1	2	3	4	5

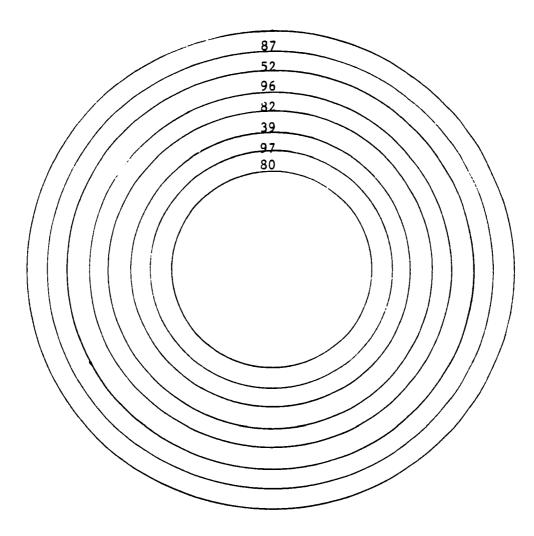
Number ____ MODIFIED TOPOGRAPHIC DEVICE (Fawcett & Chodil, 1980)

The following directions are given to the research subject: Stand inside the center circle and indicate which circle represents the amount of space you think your body occupies. As you are doing this, imagine that you are encased in a cylinder whose base is the circle which approximates your body size.

The code number of the circle identified by the subject is recorded by the investigator, and later converted to inches.

Code number of identified circle____

Inches represented by the identified circle_____



Schematic Representation of the Topographic Device

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Appendix C UCI Human Subjects Review Committee

UNIVERSITY OF CALIFORNIA IRVINE

FACTORS RELATED TO BODY IMAGE APPRAISAL ASSOCIATED WITH RECEIVING TREATMENT FOR A MALIGNANT BRAIN TUMOR

SUBJECT INFORMATION SHEET

Ruth A. Mulnard, R.N., Doctoral Candidate University of San Diego, School of Nursing (714) 634-6112

1. <u>Purpose of Study</u>: You have been asked to participate in a research study using questionnaires to determine factors related to the body image of persons with malignant brain tumors. You have been selected to participate in this study because of your malignant brain tumor. In this study, you will be answering questions about your disease process, your ways of coping with your brain tumor problem, the support people that you lean on during the course of your illness, how you perceive your health, and your feelings toward your self and your body.

2. Procedures

-The investigator will obtain your permission to visit you in your home at your convenience. -This visit to your home will take about 1 to 1 and 1/2 hours. -The investigator is willing to return to your home a second time if you become fatigued or unable to complete the questionnaires during the first visit. -At any time during the visit to your home, you may talk to the investigator about any concerns that you may be having at the present time. Upon completion of the questionnaires, you will also have another chance to talk about your concerns to the investigator. -The day following the visit(s) to your home, the investigator will contact you by telephone to give you another chance to speak about any concerns that you may be experiencing.

3. Risks

Answering these questionnaires should not involve any added risks or discomforts to you except for possible minor fatigue while completing the questions, or a feeling of anxiety from answering some of the questions, since it is possible that the questions may cause you to think about concerns that are not usually on your mind.

4. Benefits

The results of this type of study will help to provide valuable information to nurses and other health care workers, to improve the understanding of the problems associated with being treated for a brain tumor. There are no costs involved in being a part of this study.

UNIVERSITY OF CALIFORNIA INVERSE

CONSENT TO ACT AS A HUMAN RESEARCE SUBJECT

FACTORS RELATED TO BODY IMAGE APPRAISAL ASSCOLATED WITH RECEIVING TREATMENT FOR A

MALIGNANT BRAIN TUMOR TITLE OF STUDY

Ruth A. Mulnard, R.N., Doctoral Candidate: Nursing Department: 634-6112 NAME, DEPARTMENT AND TELEFRONE NUMBER OF INVESTIGATOR

You have been asked to participate in a research study which is exempt from review by a Human Subjects Review Counittee. The purpose of this study, the terms of your participation, as well as any expected risks and/or benefits must be fully explained to you before you sign this form and give your consent to participate.

You should also know that:

1. Participation in research is entirely voluntary. You may refuse to participate or withdraw from participation at any time without jeoparty to future medical care. educational or employment status or other entitlement. The investigator may withdraw you from participation at his/her professional discretion.

2. If, during the course of this study, significant new information which has been developed during the course of the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you by the investigator.

3. Confidentiality will be protected to the extent provided by law.

4. If at any time you have questions regarding the research or your participation, you should contact the investigator or his/her assistants who sust answer the questions.

5. If, at any time, you have comments or complaints relating to the conduct of this research, you may contact the Human Subjects Committees Office. 145 Administration Building, University of California Levine, Levine, CA. 92717.

6. If this study is a modical investigation/experiment, you must also read and be given a copy of the Experimental Subjects Sill of Rights as well as a copy of this consent form to keep.

I consent to participate in this study.

SIGNATURE OF SUBJECT (Age 7 and alder)

SIGNATURE OF FARENT/GUARDIAN (For Minor Subject-All persons under age 18)

SIGNATURE OF WITHESS (OPTIONAL)

Lev. 8/82

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DATE

DATE

DATE

Appendix D UCLA Human Subjects Protection Committee

12/90 Page 1 of 3

UNIVERSITY OF CALIFORNIA LOS ANGELES CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT

FACTORS RELATED TO BODY IMAGE APPRAISAL ASSOCIATED WITH RECEIVING TREATMENT FOR A MALIGNANT BRAIN TUMOR

Ruth A. Mulnard, R.N. Doctoral Candidate in Nursing / University of San Diego (714) 634-6112

Purpose of Study

I have been asked to participate in a research study using questionnaires to determine factors related to the body image of persons with malignant brain tumors. I understand that I have been selected to participate in this study because I have been told that I have a malignant brain tumor. I understand that I will be answering questions about my disease process, my ways of coping with my brain tumor problem, the support people that I have leaned on during the course of my illness, how I perceive my health, and my feelings toward my self and my body.

Procedures

Since I have been asked to be a part of this study, I understand that the investigator will contact me either by telephone or during a routine clinic visit to obtain my permission to visit me in my home for the purpose of answering several questionnaires. This visit to my home will take about 1 to 1 and 1/2 hours, and will be scheduled when convenient for me and my family. I further understand that the investigator is willing to return to my home a second time if I become fatigued or unable to complete the questionnaires during the first visit to my home. I understand that at any time during the visit to my home, I may talk to the investigator about any concerns that I may be having at the present time. Upon completion of the questionnaires, I will also have another chance to talk about my present concerns to the investigator. The day following the visit(s) to my home, I understand that the investigator will contact me by telephone to give me another chance to speak about any concerns that I may be experiencing.

<u>Risks</u>

Answering these questionnaires should not involve any added risks or discomforts to me except for possible minor fatigue while completing the questions, or a feeling of anxiety from answering some of the questions, since it is possible that the questions may cause me to think about concerns that are not usually on my mind.

HSPC #90-09-518

Date of Expiration: December 17, 1991

ALE LOVED DEC 1 8 1990

Page 2 of 3

UNIVERSITY OF CALIFORNIA LOS ANGELES CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT

FACTORS RELATED TO BODY IMAGE APPRAISAL ASSOCIATED WITH RECEIVING TREATMENT FOR A MALIGNANT BRAIN TUMOR

Ruth A. Mulnard, R.N. Doctoral Candidate in Nursing / University of San Diego (714) 634-6112

<u>Benefits</u>

I understand that I will receive no direct benefits from participation in this study. However, the results of this type of study may help to provide information to nurses and other health care workers, to improve the understanding of the problems associated with being treated for a brain tumor.

Costs/Compensations

I understand that there are no costs involved in being a part of this study. I also understand that no money or other rewards will be given to me as a result of answering the questionnaires.

Other Considerations

I understand that I may refuse to answer more questions, or withdraw at any time without any effect on my further medical and/or nursing care that I will receive. I understand that I have the right to refuse to participate in, or to withdraw from this research at any time without prejudice. I understand that circumstances may arise which might cause the investigator to terminate my participation before the completion of the study. I understand that my research records will be kept private from others. My identify will not be revealed to others in the reporting of this research, because only group results will be will be released without my separate consent except as specifically required by law. If the study design or the use of the information is to be changed, I will be so informed and my consent reobtained.

Ruth Mulnard has explained this study to me and answered my questions. If I have other questions or research-related problems, I can reach Ruth Mulnard at any time at (714) 634-6112 through the paging operator, UCI Medical Center, 101 City Drive South, Orange, California 92668. I also am aware that Dr. Keith Black, the faculty sponsor for this research, is available to listen or answer questions at (213) 206-5687, at UCLA Medical Center, Division of Neurosurgery, Room 74-140 CHS, 10833 Le Conte Avenue, Los Angeles, California 90024.

HSPC #90-09-518

Page 3 of 3

UNIVERSITY OF CALIFORNIA LOS ANGELES CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT

FACTORS RELATED TO BODY IMAGE APPRAISAL ASSOCIATED WITH RECEIVING TREATMENT FOR A MALIGNANT BRAIN TUNOR

Ruth A. Mulnard, R.N. Doctoral Candidate in Nursing / University of San Diego (714) 634-6112

I understand that if I have further questions, comments, or concerns about the study or the informed consent process, I may write to call the Office of the Vice Chancellor-Research Programs, 3134 Murphy Hall, UCLA, Los Angeles, CA 90024-1405, (213) 825-8714.

In signing this consent form, I acknowledge receipt of a copy of the form, as well as a copy of the Subjects's Bill of Rights. I consent to be a part of this study.

Signature of Subject

Date

DEC 1 8 HOMAN

HSPC #90-09-518

Date of Expiration: December 17, 1991

Appendix E Consent Letters From Research Instrument Authors



THE JOHNS HOPKINS UNIVERSITY School of Hygiene and Public Health

Health Services Research and Development Center

May 22, 1990

624 North Broadway Baltimore, Maryland 21205 Tel. (301) 955-6546

Ruth A. Mulnard, R.N. University of San Diego School of Nursing 2443 Paseo Circulo Tustin, California 92680

Dear Ms. Mulnard:

This letter grants you permission to use the Sickness Impact Profile (SIP) in your research project entitled Factors Related to Body Image Alterations Associated With Receiving Treatment For A Malignant Brain Tumor. In return, I would appreciate receiving a detailed description of the research you will be doing and a final report of the results when it is completed.

Sincerely yours,

Marilyn Bergner, Ph. (1924) Professor

MB:mej

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Montana State University Sherrick Hall Bozeman, Montana 59717-0005

College of Nursing

May 21, 1990

Ruth Mulnard, R.N., D.N.Sc. 2443 Paseo Circulo Tustin, California 92680

Dear Dr. Mulnard:

Thank you for your recent letter. I am pleased that you are interested in the PRQ85 for inclusion in your research project. If you find it meets your needs, you have my permission to use it and reproduce as many copies as you will require. In this packet you will find a copy of the PRQ85, the directions for scoring, the suggested demographic information, and some additional results from the continued psychometric evaluation of the PRQ. Much of our work is published, but if you have specific questions please do contact me. Our latest article entitled "Social support: Assessment of validity", will be in the July/August issue of <u>Nursing Research</u>.

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

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

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

Sincerely,

Clarann Weinert, S.C., Ph.D.,R.N. Associate Professor

Bozeman (406) 994-3783

PERMISSION FOR USE OF HEART TRANSPLANT STRESSOR SCALE

PERMISSION IS HEREBY GRANTED TO

Ruth A. Mulnard

TO USE THE HEART TRANSPLANT STRESSOR SCALE IN A RESEARCH STUDY

9/29/90

ANNE JALOWIEC, RN, PHD LOYOLA UNIVERSITY OF CHICAGO 199

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Appendix F Topographic Device Content Validity Tool

Appendix F TOPOGRAPHIC DEVICE

ESTABLISHMENT OF CONTENT VALIDITY

Instructions:

This exercise is being done to assist with establishment of content validity for a research instrument called the "Topographic Device." After reading the label, and the definition of the concept below, keep these items in mind as you follow the directions for using the device and answer the questions accordingly.

Label: Body Perception

Definition of Concept: Body perception is defined as the mental experience of the physical image of the body, including perceived body space.

<u>Directions</u>: Stand inside the center circle of the Topographic Device, and indicate which circle represents the amount of space you think your body occupies. As you are doing this, imagine that you are encased in a cylinder whose base is the circle which approximates your body size.

Record the code number which corresponds to the circle you have chosen: _____

<u>Questions:</u>

- Do you think this device measures your body perception? YES_____ NO_____
- 2. Do you think this device measures your perceived body space? YES_____ NO_____
- As you have completed this exercise to measure your body perception, did you simultaneously experience feelings about the measurement or your body? YES_____ NO____
- 4. Do you think that persons with visual limitations could adequately complete this exercise? YES_____ NO_____
- 5. Do you think that persons who are unable to stand could meaningfully complete this exercise? YES_____ NO_____
- 6. Do you think that persons with significant self-care limitations (Karnofsky less than 50) could meaningfully complete this exercise? YES_____ NO____
- 7. Are there any elements of body perception which you think are omitted by this research instrument? YES_____ NO____ If YES, please specify_____

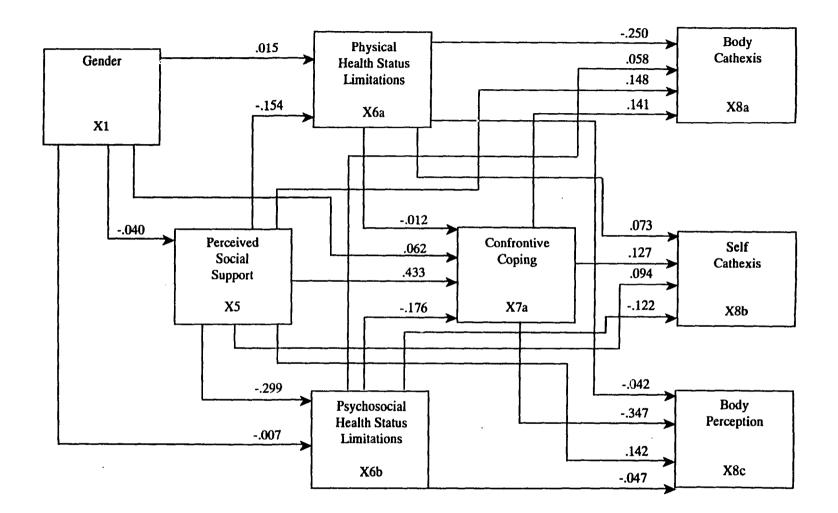
Appendix G Topographic Device Content Validity Results

APPENDIX G

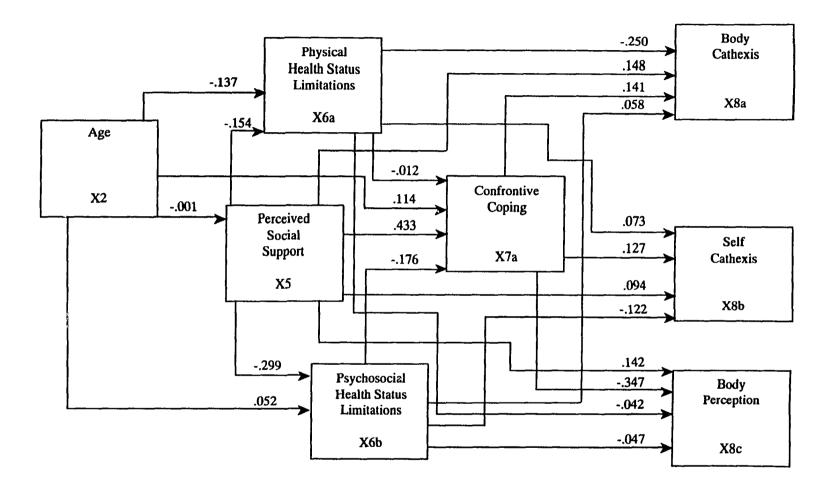
Topographic Device Content Validity Results

		RESPO	RESPONSE		
ITEM	N of SUBJECTS	YES	NO		
Do you think this device measures your body perception?	6	C (100%)	0 (0 %)		
your body perception?	0	6 (100%)	0 (0%)		
Do you think this device measures your perceived body space?	6	6 (100%)	0 (0%)		
During this exercise, did you experience feelings about the measurement of your body?	б	6 (100%)	0 (0%)		
Can persons with visual limitations complete this exercise?	6	1 (17%)	5 (83%)		
Can persons who are unable to stand complete this exercise?	6	2 (33%)	4 (67%)		
Can persons with significant self-care limitations complete this exercise?	б	1 (17%)	5 (83%)		
Are any elements of body perception omitted by this research instrument?	6	3 (50%)	3 (50%)		

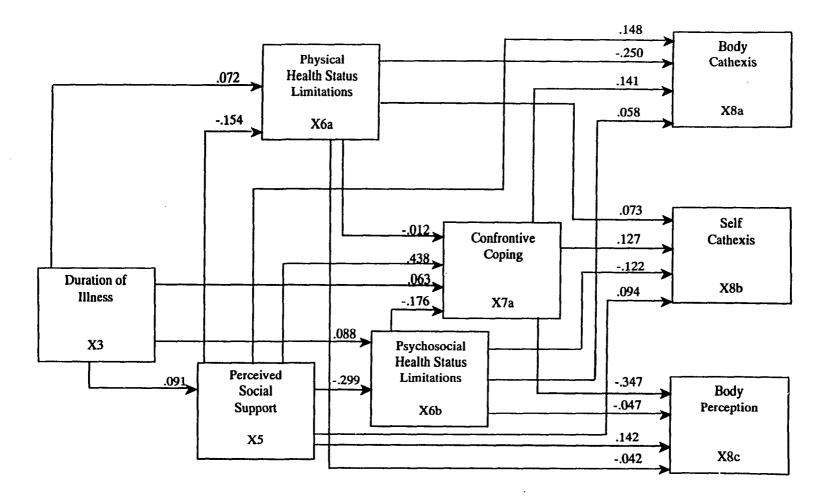
Appendix H



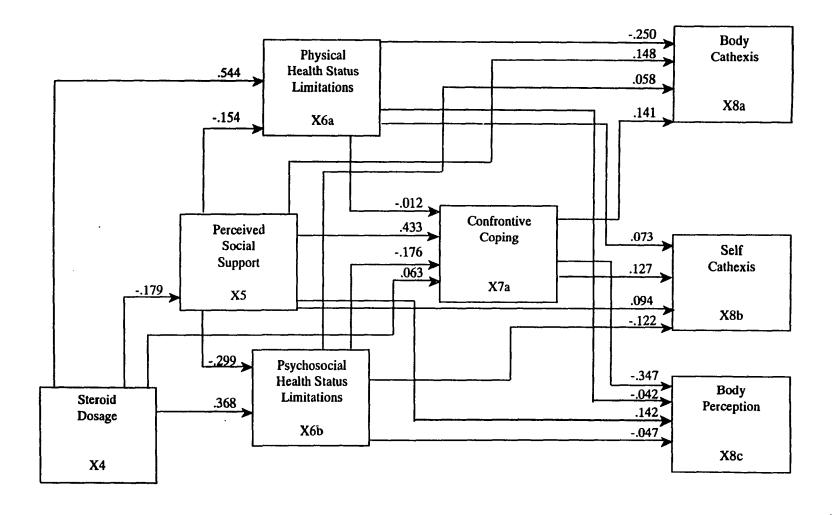
Indirect Effects of Gender and all other Predictor Variables on Body Image Appraisal



Indirect Effects of Age and all other Predictor Variables on Body Image Appraisal



Indirect Effects of Duration of Illness and all other Predictor Variables on Body Image Appraisal



Indirect Effects of Steroid Dosage and all other Predictor Variables on Body Image Appraisal.

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