Fatigue: An Outcome Measure Following Cardiac Surgery

by

Ruth A. Gregersen

## A Dissertation

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APPROVED:

Advisor

Christine A. Tanner, PhD, RN, FAAN, Professor, Department of Adult Health and Illness, School of Nursing, Research

Barbara J. Stewart, PhD, Professor, Department of Family Nursing, School of Nursing, Committee Member

Marci-lee Catanzaro, RN, PhD, Associate Professor, Department of Physiological Nursing, University of Washington, Committee Member

Carol A. Lindeman, RN, PhD, FAAN, Dean, School of Nursing

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### ABSTRACT

TITLE: Fatigue: An Outcome Measure Following Cardiac Surgery

AUTHOR: Ruth A. Gregersen

APPROVED:

Christine A. Tanner, PhD, RN, FAAN, Professor,

Department of Adult Health and Illness, School of

Nursing, Research Advisor

The purpose of this study was to examine the subjective fatigue following cardiac surgery and to develop and test an outcome measure for fatigue-based intervention studies. A three-phase study was conducted.

The first phase was a qualitative study with 8 Cardiac Surgery subjects experiencing fatigue. Tape-recorded interviews were conducted in subjects' homes 1-6 months following surgery. Interviews were analyzed using constant comparative analysis.

Based on the qualitative data, a 42-item scale was developed during the second phase. Evidence for face validity was sought from 10 lay persons who had suffered fatigue; and content validity from a panel of 10 expert reviewers.

During the third phase, psychometric evaluation of the new Fatigue Outcome Measure (FOM) was performed on responses of 146 persons to a mailed questionnaire. The sample was predominantly male (71%), and Caucasian (91%). Ages ranged from 37 - 86 years (M = 65). Most had a greater than high school education (62%); the length of time since surgery was 2 weeks to 7 months.

Factor analysis was performed as a part of construct validity. Two subscales (Fatigue and Exhaustion) were identified; Chronbach's alpha was .93 and .88 respectively. Further evidence for construct validity was gathered. Using the contrasted groups approach, the instrument was administered to 50 subjects 2-5 weeks following surgery and again 4-5 weeks later. The mean scores from the two groups differed significantly (p = .00), suggesting the instrument is sensitive to change. Cross sectional differences were assess by using one-way analysis of variance (ANOVA) to compare three groups (Early, Middle and Late) based on time since surgery. T-tests were used to test group differences. The Early Group FOM Fatigue mean score was higher ( $\underline{p} < .05$ ) than both the Middle and Late Groups. Early Group FOM Exhaustion mean score was higher than the Late Group but not the Middle Group. To assess convergent validity, the FOM Fatigue and Exhaustion scales were correlated (.62-.85) with four available fatigue instruments. The POMS Anger, Confusion, Tension, and

Depression scales correlated moderately (.35-.50) with the FOM Fatigue and Exhaustion scales based on the discriminant validity principle.

Evidence of construct validity for the FOM Fatigue and Exhaustion scales has been provided. In addition, preliminary evidence suggests that two separate dimensions of fatigue may occur following cardiac surgery.

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#### CHAPTER 1

## Statement of the Problem and Significance to Nursing

The American Heart Association (1991) estimates that over 6 million Americans currently suffer from coronary heart disease (CHD). In 1988 alone, an estimated 353,000 coronary artery bypass operations were performed to reduce the symptoms associated with CHD (American Heart Association, 1991). The problem of fatigue in patients following cardiac surgery is of special interest. Frequently, these patients describe their delight with their decrease or absence of anginal episodes; yet these same patients find themselves discouraged due to postoperative fatigue, sometimes lasting for weeks or months. Gregersen (1988) and Tatum (1985) state that weakness and fatigue are the two most persistent symptoms during the convalescent phase following cardiac surgery. Studies of recovery after cardiac surgery have found fatigue to be present up to 6 months postoperatively (Gortner, Rankin, & Wolfe, 1988; Jenkins, Stanton, Savageau, Denlinger, & Klein, 1983; King & Parrinello, 1988).

In the first of a series of conferences to disseminate nursing research, the School of Nursing, University of North Carolina at Chapel Hill, identified fatigue as an important aspect of comfort. The topic (Key Aspects of Comfort--Management of Pain, Nausea and Fatigue) "...was selected because of its importance to the practice of nursing, its

applicability to a broad range of settings,...the ability of nurses to control interventions, and the perceived gap between knowledge and practice." (Tornquist & Funk, 1987, p. Research is limited both in interventions for fatique and in outcome measurements of these interventions. Although strategies designed to decrease fatigue have been proposed in the nursing literature (Aistars, 1987; Gueldner & Spradley, 1988; Mitchell, 1986; Piper, 1986) only one (Gueldner & Spradley, 1988) of these nursing interventions is research based. The existing instruments designed to measure fatigue are for specific patient populations (Piper, Lindsey, Dodd, Ferketich, Paul, & Weller, 1989; Tack, 1991), are incorporated into tools which measure broader, more diverse sets of constructs in specific patient populations (McCorkle & Young, 1978; McNair, Lorr, & Droppleman, 1971), or were developed for use in healthy populations (Kashiwagi, 1971; Pearson & Byars, 1956; Yoshitake, 1971). these instruments may not be applicable during illness. quantifiable indicators of subjective fatigue were identified for patients suffering from fatigue, clinical decision-making could be facilitated and investigators could test interventions designed to reduce or eliminate fatigue.

Review of the literature has failed to reveal an instrument applicable to the study of fatigue in the postoperative cardiac surgery population. Thus, the purpose of this study was to develop and psychometrically test an

outcome measure for nursing intervention studies designed to lower the perception of fatigue in persons following cardiac surgery.

#### CHAPTER 2

## Review of Literature and Conceptual Framework

To understand the conceptual problems surrounding the study of fatigue, a brief historical perspective will be presented followed by a review of the literature which focuses on postoperative fatigue. Other variables which may be associated with fatigue are identified and described. The conceptualization of fatigue for the purposes of the proposed study is grounded in a preliminary study conducted by this investigator; therefore, a summary of the findings from that study will be included. Finally, the existing fatigue instruments will be evaluated based on the needs identified in this study.

### Historical Perspective

In 1947, Bartley and Chute emphasized the complex nature of fatigue and distinguished three distinct facets of the problem. They proposed that the term <u>fatigue</u> should be used only to describe the subjective feelings of lassitude and disinclination towards activity which characterizes the individual suffering from fatigue, and offered the term <u>impairment</u> to identify the true reduction of physical capacity which results from an accumulated oxygen debt in muscle tissues. Deterioration in quality of work performance for reasons other than sheer physical incapacity was designated as <u>work decrement</u>. They argued that there can be an actual decrease in the physical capacity of the

muscle tissue without a subjective feeling of fatigue and that changes in the quality of performance may relate to causes other than the subjective feeling of weariness.

Bartley and Chute stated that these three aspects of the fatigue state are related in a complex way and the presence of one cannot be reliably inferred from the presence of one or both of the others. Although Bartley and Chute attempted to clarify terminology which could have been adopted, most researchers have continue to use the term fatigue to define an objective reduction in physical capacity as well as subjective feelings.

Until the 1970's subjective fatigue research was conducted primarily by industry (Kashiwagi, 1971; Yoshitake, 1971; Yoshitake, 1978), and aviation (Bartley & Chute, 1956; Hauty & Payne, 1956). In 1973, Cameron synthesized the industrial and aviation fatigue literature to date. Many nurse authors draw on his conceptualization. Cameron suggested "a broad conceptualization of fatigue as a generalized response to stress over a period of time, with effects which may be either acute or chronic or both, confined to the subjective state of the individual or extending into measurable aspects of his performance" (p.640). Even though Cameron's conceptualization was made after an extensive review of the industrial and aviation fatigue literature, many aspects of his conceptualization relate to the fatigue manifested during and after illness.

Illness, whether physiological or psychological, is a stressor which may lead to feelings of fatigue.

Hart (1978), the first nurse to investigate fatigue, compared fatigue patterns in multiple sclerosis (MS) patients to healthy controls. She found that the severity of fatigue in patients with MS was greater than that of healthy subjects. Freel and Hart (1977) studied indicators of fatigue associated with MS while Haylock and Hart (1979) replicated that study in cancer patients receiving localized radiation.

In the 1980's, several nurse authors summarized the fatigue literature and offered various conceptualizations of fatigue (Hart & Freel, 1982; Kellum, 1985; Piper, 1986; Piper, Lindsey, & Dodd, 1987; Potempa, Lopez, Reid, & Lawson, 1986). These publications increased nurses' awareness of the problem and made it easier for nurses to comprehend the complexities of fatigue (Piper, 1989). Hence, nurses have begun to study fatigue in a wide variety of populations and settings.

Fatigue associated with cancer and its subsequent therapy has received particular attention. Most recently, nurse researchers have studied fatigue mechanisms in the patient with cancer (St. Pierre, Kasper, & Lindsey, 1992); attentional fatigue following breast cancer surgery (Cimprich, 1992); and correlates of fatigue in people with cancer (Blesch, Paice, Wickham, Harte, Schnoor, Purl,

Rehwalt, Kopp, Manson, Coveny, McHale, and Cahill, 1992;

Jamar, 1989; Pickard-Holley, 1992). Although only

preliminary reports have been published, the Piper Fatigue

Self-Report Scale (PFS) was developed in 1989 (Piper,

Lindsey, Dodd, Ferketich, Paul, & Weller, 1989). The

instrument was designed to measure subjective fatigue in

patients with cancer and was used to described baseline

patterns of fatigue during radiation therapy in 42 subjects

(Piper et al., 1989).

Tack (1990a & 1990b) interviewed a small group (n=20) of patients with rheumatoid arthritis and described the conditions, strategies, and consequences of the associated fatigue. Using an adaptation of the PFS, Tack (1991) studied 133 older adults with rheumatoid arthritis and described dimensions and correlates of their fatigue. Crosby (1991) also studied factors which contribute to fatigue in patients with rheumatoid arthritis.

Other populations in which fatigue has been studied by nurses includes patients with MS (Freel & Hart, 1977; Hart, 1978), patients with catastrophic illness (Cohen & Hardin, 1989, patients with end-stage renal disease (Srivastava, 1989), and older adults (Gueldner & Spradley, 1988).

Of the fatigue research studies conducted and published by nurses, all but one (Gueldner & Spradley, 1988) have been descriptive in nature. These types of studies are certainly appropriate based on the immaturity of the concept of fatigue in ill populations. However, intervention research could be used to test proposed theories of how to lower fatigue in various patient populations. In order to conduct such research, an instrument sensitive to changes in fatigue must be developed and tested.

### Postoperative Fatique

Postoperative fatigue is well documented in the literature. However, despite the common report of fatigue in the convalescent phase after cardiac surgery, only a few research studies could be found documenting its occurrence. Thus, studies of fatigue in general surgical patients will be reviewed first followed by a review of the studies which include a measure of fatigue in the postoperative cardiac surgical patient.

### General Surgery

The study of postoperative fatigue by physicians has focused on the physiological causative factors of fatigue. The first study conducted by Rose and King (1978) focused on the etiology of postoperative fatigue. In their review of the literature, Rose and King pointed out the vast amount of research directed toward understanding the metabolic changes after surgery while a very small effort has been devoted to the patients' postoperative adaptation to his or her environment, including the demands of every day life. While unable to find published reports concerning intellectual and psychomotor performance in post-surgical patients, they

inferred from studies of chronic starvation, physical immobility, sleep deprivation, and short-term sedation, that intellectual and psychomotor performance is likely to be impaired in post-surgical patients.

Rose and King also reviewed published reports on cardiorespiratory performance. They found only two reports that studied postoperative patients. The surgical procedures were meniscectomy and pyloroplasty with vagotomy. One of these studies found a decrease in maximal oxygen uptake and impairment in the adaptability of heart rate to sub-maximal workload after four days of bed rest (Carswell, 1975). After mobilization there was no change from preoperative values in either study. Rose and King reviewed many studies reporting the effects of semi-starvation and bed rest on cardio-respiratory function in normal healthy males, and concluded that cardio-respiratory performance postoperatively needed further investigation. Lastly, even though maximal muscular force of contraction had not been studied in the post-surgical patient, the authors concluded that since it is impaired by caloric restriction and bed rest, similar effects may be seen in the postoperative The authors suggested that a descriptive analysis of physiological performance after surgery could provide a valuable baseline against which the therapeutic measures aimed at reducing postoperative fatigue could be assessed.

In 1982, Edwards, Rose, and King investigated muscle

strength and endurance in 11 subjects undergoing elective surgery and compared the results to two young, healthy, male volunteers on bed rest for seven days. Muscle endurance was decreased in all subjects. Ten of the 11 surgical patients and both of the volunteers showed significant (p < 0.01) impairment of endurance that reached a maximum on days 8 through 10. Isokinetic strength was substantially reduced in two of the surgical patients. Isometric strength was adversely affected in eight of the post-surgical patients and both of the volunteers. Most of the surgical patients were ambulated on the second postoperative day. investigators proposed that because the pattern of disability in the volunteers on bed rest was almost identical to that noted in the surgical patients, inactivity alone may be a major cause of the postoperative fatigue state. One major limitation of this study, besides the small sample size, is that the investigators did not define fatigue explicitly nor did they measure any subjective reports of fatigue. Another major limitation is that activity levels, pain, nutritional status, and sleep/rest patterns were not reported.

Christensen and co-workers designed a series of studies which attempted to understand further the etiology of postoperative fatigue (Christensen, Bendix, & Kehlet, 1982; Christensen, Hjortso, Mortensen, Riis-Hansen, & Kehlet, 1986; Christensen, Hougard, & Kehlet, 1985; Christensen &

Kehlet, 1984; Christensen, Kehlet, Vesterberg, & Vinnars, 1987; Christensen, Nygaard & Kehlet, 1988; Christensen, Stage, Galbo, Christensen, & Kehlet, 1989; Christensen, Wulff, Fuglsang-Frederiksen & Kehlet, 1985). Small samples (12-52) of patients who had undergone uncomplicated abdominal surgery were studied before operation, and 10, 20, and 30 days following surgery. All of these studies used a linear graded scale to measure subjective fatigue. scale quantified fatigue in arbitrary units from 1 to 10. The words fit, slightly tired, tired, and fatigued were used as anchors at points 1, 4, 7, and 10 respectively. addition, short phrases were used to describe ability to perform activities and/or the need for sleep next to the four anchors on the scale. These phrases included: "Tired only by violent exertion, normal need of sleep"; (4slightly tired) "Can manage daily chores, occasionally more strenuous tasks"; (7-tired) "Particularly doing house work, gardening or walking stairs, increased need of sleep"; (10fatigued) "Cannot cope with daily chores or short walks, pronounced need of sleep". The reliability and validity of the scale was not reported in any of the studies.

Various physiological measures were used in each study to attempt to correlate physiological concepts such as nutritional status, cardiovascular status, and muscle strength to subjective fatigue. In one study, Christensen et al.(1986) attempted to correlate the psychological

concepts of anxiety and concentration to subjective fatigue but when no correlation was found in the 16 subjects studied, the investigators did not include psychological concepts in their continuing investigation. In all of these studies, the investigators found that the median degree of postoperative fatigue increased significantly (p < .01-.001) from preoperative values on all three postoperative days tested.

Christensen and co-workers (Christensen & Kehlet, 1984; Christensen, et al., 1985; Christensen, et al., 1987; Christensen, et al., 1988) investigated nutritional status using the parameters of weight, triceps skin fold, and arm circumference. In each case, all three parameters decreased postoperatively; however, weight loss was the only parameter that had a significant correlation ( $\underline{r} = .56$ ,  $\underline{p} < .05$ ) to increased postoperative fatigue.

The investigators (Christensen, et al., 1982;
Christensen, et al., 1989) used orthostatic stress test and bicycle ergometer exercise to correlate cardiovascular status to subjective fatigue. The only significant findings were a decrease in oxygen consumption postoperatively and a positive correlation between postoperative fatigue and increased pulse rates after surgery during orthostatic stress and bicycle exercise. The authors stated that the findings of impaired cardiovascular adaptability to exercise and orthostatic stress in postoperative patients are similar

to those described after inactivity and detraining and suggested a therapeutic role of exercise in the treatment of postoperative fatigue.

Christensen and colleagues (Christensen et al., 1985; Christensen et al., 1988) also studied muscle function and fiber composition. The decrease in muscle force and endurance found postoperatively was negatively correlated to increases in fatigue; however the decrease in slow twitch fiber diameter was correlated to loss of body weight but not directly to postoperative fatigue. The authors stated that these and previous findings emphasize the importance of the skeletal muscles in the catabolic response during surgical convalescence and suggest a therapeutic role of combined exercise and nutrition in reducing postoperative loss of muscle mass and function.

In one study, Christensen and Kehlet (1984) divided the subjects (n=36) into two groups according to the degree of fatigue 30 days after surgery. Group A (n=12) had a greater degree of fatigue than Group B (n=24). No difference was found in age, gender, duration of surgery, or hospitalization time between the two groups. Group A showed a more pronounced weight loss, decrease in skin fold caliper and arm muscle circumference. Preoperative nutritional status did not predict the level of postoperative fatigue.

In another study, Christensen et al. (1985) compared subjective fatigue and nutritional status in a small group

(n=15) of subjects undergoing minor otological surgery to a larger group (n=52) of subjects undergoing major abdominal surgery. Subjective fatigue increased significantly (p < .001) following major surgery but did not increase after minor surgery. The minor surgical group did not exhibit any postoperative change in nutritional parameters however, body weight, triceps skin fold thickness, arm muscle circumference, and serum transferrin all decreased significantly in the group undergoing major surgery. Postoperative fatigue was not correlated with type and duration of anesthesia. In addition, increased postoperative fatigue was not predictable from preoperative degree of fatigue, age, or gender. The results of this study suggest that postoperative fatigue might depend of the magnitude of the surgical trauma.

Clark and Zeiderman (1988) used the fatigue scale developed by Christensen and colleagues (1982) to study the relationship between fatigue and exercise tolerance in the immediate postoperative period. When compared to preoperative values, muscle function was unchanged three days following surgery. Postoperative heart rate increased when compared to preoperative levels at rest and during exercise (treadmill walking). The respiratory rate increased and the tidal volume decreased during exercise on the third postoperative day.

The series of studies by Christensen and colleagues and

the one by Clark and Zeiderman show an excellent progression of research to determine the causative factors of postoperative fatigue. Based on these studies, it is clear that there is a relationship between postoperative fatigue and the impairment of cardiovascular adaptability to exercise, orthostatic stress and weight loss found following surgery. These finding are important to nursing and may assist in the development of interventions to treat postoperative fatigue.

A qualitative nursing study was conducted by Rhoten (1982) to attempt to define the concept of postoperative fatigue and to identify the manifestations and the characteristics of those at high risk for fatigue. sample consisted of 5 patients, ages 35 to 71, who had undergone major abdominal surgery. Patients were observed simultaneously by two nurses using an observation check list for three 15-minute periods at 24, 48, and 72 hours postoperatively. Interviews of 20 to 30 minutes were conducted after each observation using an open-ended item approach. After the interview, patients were asked to assign their level of fatigue on the Rhoten Fatigue Scale. In addition, information about the patients' illness, treatments, socio-economic levels, and demographic data was obtained. Some of the sample characteristics such as extent of surgery, length of anesthesia, amount of pain medication, and number of abnormal laboratory values seemed to operate

in a synergistic manner (i.e., the greater the number of these variables present, the higher the level of fatigue). Using the observation check list, patients were ranked by the investigators from most fatigued to least fatigued at each observation time. Categories showing the greatest difference between most and least fatigued patients, were general appearance, eyes, facial expression, speech, movement, and attitude. Criterion attributes from interviews showing major differences between most and least fatigued patients were general sensation, pain, frequency of pain medication, concentration, attitude, and motivation. Criterion attributes showing very few differences were localized sensations, movements, sleep, appetite, emotional state, and primary concerns.

Qualitative studies are very useful to describe little understood phenomena such as fatigue. Data emerging from the study described above suggests that pain, concentration, attitude and motivation are related to post-operative fatigue and deserve further investigation. Data also suggest that observation may be an effective measure of post-operative fatigue.

## Cardiac Surgery

In a nursing study, King and Parrinello (1988) used structured interviews to describe patient perceptions of recovery from coronary artery bypass graft (CABG) surgery after discharge from the hospital. Thirty-four subjects

were interviewed in person on the fourth to sixth postoperative day to elicit their preoperative status and by telephone six times over an 8-week period after discharge to report their current status. The interview schedule consisted of four parts. The subjects were asked to rate (1) general feelings of well being, (2) the occurrences of symptoms (fatigue, sleep disturbances, changes in appetite, changes in bowel function, incisional and non-incisional discomforts), (3) activities such as walking, stair climbing, going out of the house, receiving visitors, work around the house and work around the yard with respect to their usual level of activity, and (4) changes in mood.

The only symptom that was reported to be present by the majority of subjects at all times of measurement was fatigue. Although equal numbers of subjects reported fatigue pre-operatively and at 6 weeks after discharge (62%), the severity of fatigue was reported to be less at 6 weeks after surgery than before surgery. The majority of subjects reported that sleeping or resting in the afternoon was helpful in dealing with the fatigue. Correlations between presence of preoperative fatigue and postoperative fatigue in the first four weeks after discharge were not significant; however, the correlation between pre-operative fatigue and postoperative fatigue at 6 and 8 weeks after surgery were  $\underline{r} = 0.38$  and  $\underline{r} = 0.33$  (p < 0.05) respectively. By 6 weeks after surgery, 76% of subjects reported that they

were doing most of their usual activities and by 8 weeks, 59% reported doing more walking than usual as a part of an exercise routine. Mood changes were reported by 38% to 53% of subjects the first three weeks after surgery. By 8 weeks, only 24% of subjects stated that they were experiencing mood changes with "feeling down" as the primary feeling reported. In contrast to general surgery patients, this study suggests that fatigue levels following CABG surgery may be about the same as preoperative levels. This finding is most likely a result pre-existing cardiac disease causing high levels of fatigue prior to the cardiac surgery.

This study is important because the researchers describe symptoms which may influence fatigue such as sleep disturbances, loss of appetite, and pain as well as activity levels and mood changes. However, the focus of the research was on general recovery and a description of the many variables that influence recovery. Information about how these variables may actually influence fatigue was not gathered. Another limitation of this study is the lack of information regarding the reliability and validity of the five-point rating scale used to measure fatigue.

Lanuza and Cisar (1990) examined the relationship between hemoglobin, hematocrit, and red blood cells and subjective fatigue (using the Rhoten Fatigue Scale) in 74 CABG patients. Data were collected preoperatively, on the fourth and sixth postoperative days, and at the 3-4 week

postoperative clinic visit. At all postoperative times, the hemoglobin, hematocrit, and red blood cells were significantly lower (p = .001) than preoperative levels. The postoperative fatigue scores increased markedly (p < .05) from the preoperative scores only on the fourth postoperative day. Although mean fatigue scores were not reported, it is possible that the lack of increase in postoperative fatigue scores on day six and 3-4 weeks after surgery was do to high preoperative levels of fatigue. This was the only study done by nurses to attempt to correlate postoperative fatigue with physiological variables.

The two studies described were the only ones found that specifically described fatigue in patients following cardiac surgery. Two other studies were found that mentioned fatigue in the context of describing the overall outcome of CABG surgery.

To evaluate the benefits of CABG surgery, 318 subjects (all under 70 years of age) were interviewed and tested before and six months after surgery (Jenkins, Stanton, Savageau, Denlinger, & Klein, 1983). Biomedical, psychoneurological, physical function, role function, occupational, social, family, sexual, emotional and attitudinal variables were assessed. Ten scales were used to measure self-perception and emotions to gain a perspective of the general sense of well-being. Among the four scales (depression, fatigue, vigor, and hostility)

administered from the Profile of Mood States (POMS), postoperative fatigue scores declined significantly (p = .001) when compared to preoperative values. Despite the decrease in fatigue scores 6 months after surgery, the authors remarked that fatigue and weakness remained among the most common complaints expressed by participants 6 months following surgery.

In a nursing study, Gortner, Rankin, and Wolfe (1988) described elders recovery from cardiac surgery. A cohort of 11 elders, 70 years of age and older, were contrasted with two other age groups (less than 50 and 51-69 years of age) in the areas of family functioning, self-report of recovery, self-efficacy, realized benefits, mood (using the POMS), and preference for choice of treatment. Although fatigue scores were not reported, the authors stated that both patients and spouses of the elder cohort reported more fatigue after surgery than the other two groups.

Based on the above studies, it is clear that fatigue is one of the most reported symptoms following cardiac surgery. Unlike general surgical patients, it appears that fatigue is also a problem for these patients prior to surgery. Deficiencies in study methodology make it difficult to draw solid conclusions about the influence of various factors on fatigue following cardiac surgery. Each study used a different fatigue measure. Fatigue measures included a 5-point rating scale, the Rhoten fatigue scale, and a fatigue

subscale from a mood state questionnaire. With the exception of the Profile of Mood States (POMS), psychometric properties on the fatigue scales used in these studies were not available; however, as will be discussed later, the POMS fatigue subscale may not be sensitive to the certain aspects of fatigue that are particularly important in this population. Furthermore, fatigue may have several dimensions, yet only the severity of fatigue has been measured.

## Variables Associated with Fatique

Fatigue may be closely related to other variables such as age, gender, pain, and depression. Very little is known about the relationship between fatigue and these other variables in people who have undergone cardiac surgery. Therefore this review will encompass a broader population range.

### Age and Gender

The impact of age and gender on fatigue in the general population is controversial. Chen (1986) reported data from the First National Health and Nutrition Examination Survey which suggests that women are more likely to report feeling fatigued than men. He found no association between fatigue and age. Riddle (1982) states that fatigue ranks as one of the most common complaints of women workers. Family practice physicians have reported that patients, regardless of age or gender, commonly present with symptoms of fatigue

(Allen, 1944; Ffrench, 1960; Jarrett, 1981; Kirk et al., 1990; Morrison, 1980; Sugarman & Berg, 1984; Valdini, Steinhardt, & Jaffe, 1987; Valdini, Steinhardt, Valicenti, and Jaffe, 1988). Morrison (1980) reported that fatigue occurred more commonly in women than in men and in younger people, ages 15 to 34 years. However, the other physicians who reported demographic information found that although women reported fatigue more often than men, there was not a significant association between age or gender and fatigue (Kirk et al., 1990; Valdini et al., 1987; Valdini et al., 1988).

Brody and Kleban (1983) conducted a study which examined day-to-day mental and physical health symptoms in 132 older adults (age 62-98). Three groups were included: those with normal mental function, those with a history of a diagnosed functional mental disturbance, and a group with senile dementia. Approximately 70% of all subjects reported that weakness and fatigue bothered them.

Christensen & Kehlet (1984) and Christensen et al.

(1985) found no correlation between gender or age and
fatigue in postoperative abdominal surgery patients.

Gortner, Rankin, and Wolfe (1988) reported that 11 elders,
70 years of age and older experienced more fatigue after
CABG surgery than two younger age groups (less than 50 and
51-69 years).

The effect of gender and age on postoperative fatigue

in the CABG patient has not been thoroughly investigated. Because these patients tend to be male and in older age categories, it may not be possible to determine the relationship between fatigue, age, and gender in this population.

### Pain

According to Johnson (1977), the typical response to pain is sympathetic stimulation, which causes an increase in heart rate, elevated blood pressure, increased rate and depth of respiration, increased perspiration, and dilated pupils. Because the body cannot maintain continued sympathoadrenal stimulation, the autonomic nervous system becomes depressed and sensations of fatigue occur. Johnson also believes that fatigue can decrease pain tolerance causing a vicious cycle of fatigue and pain.

Dorpat and Holmes (1955) documented the relationship between pain and skeletal muscle fatigue and is frequently cited in the literature when the relationship between pain and subjective fatigue are discussed. The researchers state "the development of muscle fatigue parallels the genesis of pain [and thus] precludes the possibility of a strong contraction, and hence high-intensity pain, continuing over long periods" (p. 637). The relationship here seemed to be protective in that muscle fatigue protects against pain.

Two nursing studies did correlate pain and fatigue.

Rhoten (1982) used an observation checklist to determine

levels of fatigue in 5 postoperative, general surgical patients. She reported that the most fatigued patients experienced the most pain. Tack (1990b) reported that the degree of pain (measured with a visual analog scale) correlated moderately high (<u>r</u> .73) with the degree of fatigue (measured with a visual analog scale) in patients with rheumatoid arthritis

The relationship between pain and fatigue in the postoperative CABG surgical patient has not been systematically studied. It is possible that a relationship exists and warrants future study. However, while pain and fatigue may be correlated, fatigue typically persists longer than pain (King & Parrinello, 1988) suggesting other factors contribute to the experience of fatigue in this population.

#### Depression

Fatigue, as a symptom of depression, has been well documented in the literature. Family practice physicians have diagnosed depression in 2-20% of patients with a primary complaint of fatigue (Allen, 1944; Ffrench, 1960; Jarrett, 1981; Kirk et al., 1990; Morrison, 1980; Sugarman & Berg, 1984). Chen (1986) reports that approximately 50% of patients with chronic depression experience fatigue.

According to DSM-III (American Psychiatric Association, 1980), the diagnosis of major depression requires the patient to demonstrates at least five of the following nine symptoms during the same 2 week period. At least one of the

symptoms is either a persistent dysphoric mood (sad or blue) or pervasive anhedonia (loss of interest or pleasure). The nine symptoms are dysphoric mood, anhedonia, sleep disorder, appetite change, low energy, psychomotor changes, loss of self-esteem, trouble concentrating, and suicidal ideation. Using these criteria, it is apparent that fatigue is only one criterion of several used to diagnose depression.

The determination of depression in patients with physical illness is difficult because some of the symptoms of major depression (sadness, fatigue, anorexia, sleep impairment and psychomotor retardation) could be due to the primary medical problem rather than to fatigue per se.

Cohen-Cole and Stoudemire (1987) raise the concern that many patients with severe physical illness may be misdiagnosed.

Depression has been reported to be common in patients with coronary heart disease (CHD). Estimates of prevalence range from 18 to 30% (Carney, Rich, Freedland, Saini, teVelde, Simeone, and Clark, 1988; Carney, Rich, teVelde, Saini, Clark, and Jaffe, 1987; Eriksson, 1988). Carney and associates (1987) discuss the concern that the variability of these estimates may be due to the reliance on symptoms of dysphoric mood and fatigue in making the diagnosis of depression. In a study of 50 patients with CHD, Carney et al. found that 18% met criteria (DSM-III) for major depression when tested by two experienced psychologists. The researchers also used the Beck Depression Inventory

(BDI) to assess depression. The sensitivity and specificity of the BDI for detecting depression (using a score of  $\geq$  10) compared to the DSM-III criteria was 78% and 90% respectively.

The prevalence of depression following CABG surgery appears to be quite low. Eriksson (1988) used the BDI to measure depression in 101 CABG patients pre- and postoperatively. Depression was found in 10% of patients postoperatively compared to 29% prior to surgery. was used to assess depression in 318 patients before and 6 months after CABG surgery (Jenkins, Stanton, Savageau, Denlinger, & Klein, 1983). Although specific scores were not reported, the authors state that the depression scores preoperatively were lower than those reported in the population as a whole and that postoperative scores dropped even lower. Rankin (1990) also used the POMS to assess depression pre- and postoperatively in 117 CABG surgery Results indicate a statistically significant decrease in depression 3 months postoperatively when compared to preoperative scores. An especially interesting finding in this study was that females consistently scored lower than men on all the POMS sub-scales, including the depression scale.

The relationship between fatigue and depression has not been investigated in the patient following CABG surgery. It is interesting to note that in studies where the POMS is

used to measure depression and fatigue in the preoperative and postoperative surgical phases, both scores tend to drop in the postoperative phase.

## Conceptualization of Fatique in the Study Population

Specification of the intended use of a measure during the conceptualization and development phase is very important (Kirshner & Guyatt, 1985). The purpose of this study is to develop an outcome measure for nursing intervention studies designed to lower the perception of fatigue in the postoperative cardiac surgery patient. Instruments developed for the purpose of evaluating nursing interventions must include all aspects of the phenomenon of interest which may change as a result of treatment effects (Stewart & Archbold, 1992). To identify those aspects and to understand the fatigue experience and how it is expressed, it is important to go directly to the source. Therefore, the following definition and tentative conceptualization draws heavily on a preliminary study done by this investigator. Based on interviews with 5 people who had recently experienced fatigue following cardiac surgery, three areas of concern were identified: (1) sensations of fatigue, (2) impact on lifestyle, and (3) coping with or reducing sensations of fatigue. From these areas of concern, the following broad definition of fatigue was developed: A perceived feeling of tiredness or low energy which has an adverse effect on a persons' sense of well

being and, when severe, may interfere with daily functions, necessary activities, and relationships. Alterations in lifestyle may be required to cope with and/or reduce sensations of fatigue.

Many of the descriptors used by the subjects in the preliminary study were also found in the literature. The following is a summary of the findings and a comparison of those findings with those found in the literature.

The experience/sensation of fatigue includes two subconcepts. The subconcept of physical signs included descriptors such as "dull eyes", "pale face", "short of breath", and "whole body sags". These descriptors were frequently found in the literature (Aistars, 1987; Hart & Freel, 1982; Rhoten, 1982). Kashiwagi (1971), Rhoten (1982), and Yoshitake (1971) all used these types of descriptors in their fatigue measurement scales under the heading of general appearance. The descriptors of the subconcept subjective feelings were words such as "tired", "worn out", "weak", "run down", and "drowsy". These words were commonly used in the entire fatigue literature and were included in most fatigue measurement scales (Kashiwagi, 1971; McNair et al. 1971; Pearson & Byars, 1956; Rhoten, 1982; Yoshitake, 1971).

The second area of concern, labeled <u>impact of fatigue</u>, contained phrases that trouble subjects such as "going back to alcohol", "can't help yourself", and "cry for no reason

at all". These subjects seemed to be describing an increased vulnerability. Tearful episodes were mentioned by Aistars (1987) but crying as a manifestation of fatigue was not frequently mentioned elsewhere in the literature.

Subjects also described situations which they found adversely affected fatigue or their response to it. Some examples of these situations were: "arguing with my kids", "frustrations", and "things that annoy you". One subject mentioned physical activity but the others identified emotional issues. All of these activities and situations seem to indicate that fatigue interferes with daily functions, activities, and relationships.

Learning to cope with fatigue included activities that subjects used to manage fatigue. Activities such as "sit down", "go to bed", and "do nothing" seemed to be activities people do because they can't do anything else. Both Rhoten (1982) and Aistars (1987) described these behaviors and grouped them in a category labeled attitude. Activity—seeking behaviors ("force myself to get up and go" and "keep doing a little more") and diversion—seeking behaviors ("watch TV" and "have a beer") described by subjects in the study were quite different from anything mentioned in the literature. Both of these behaviors may represent ways of coping with fatigue.

Based on the results of the preliminary study and a review of the literature, a tentative conceptualization is

as follows. The fatigue experience following cardiac surgery has three major aspects: (1) sensations of fatigue include both physical signs and subjective feelings, (2) fatigue impacts day-to-day life by interfering with valued and necessary activities and relationships, and (3) fatigue may require alterations in lifestyle to cope with and/or reduce sensations of fatigue.

Nursing interventions proposed to reduce fatigue may alter one or all of these major aspects of fatigue. It is important that the instrument developed to evaluate these interventions include all aspects of fatigue which may change as a result of the intervention. For this reason, further qualitative work is needed to explore and describe fatigue more fully and to gain a better understanding of the total fatigue experience.

### Existing Fatique Instruments

Nurses often propose interventions such as more rest or increased activity in an attempt to decrease the amount of fatigue experienced by their clients. In order to test the effectiveness of such interventions, an outcome measure must be sensitive to even small changes in the level of fatigue and also must be able to detect clinically important changes (Stewart & Archbold, 1992). For the cardiac patient suffering from postoperative fatigue, these clinically important changes may mean changes in the sensations of fatigue, changes in the ability to perform activities of

daily living (ADLs), changes in relationships with others, and changes in the ability to cope. The following critique will examine the ability of existing fatigue instruments to capture clinically important changes in the sensations of fatigue and its impact on lifestyle in the postoperative cardiac surgical patient.

Examples of tools which measure other concepts in addition to fatigue are the Profile of Mood States (POMS) (McNair et al. 1971) and the Symptom Distress Scale (McCorkle & Young, 1978). The POMS was developed to measure six identifiable mood or affective states: Tension-Anxiety: Depression-Dejection; Anger-Hostility; Vigor-Activity; Fatigue-Inertia; and Confusion-Bewilderment. The Fatigue-Inertia sub-scale has 5 items. Some examples of these items are: "worn out", "weary", "exhausted", and "bushed". POMS Fatigue factor score has proved sensitive to change associated with psychotherapy (McNair et al. 1971). Although this tool has been widely used in many patient populations, it is not specific to fatigue. It measures only one dimension, the level of fatigue, and does not capture how people cope with fatigue nor how fatigue impacts lifestyle .

The Symptom Distress Scale (McCorkle & Young, 1978) was designed for use in patients with cancer. This scale was developed to measure ten symptoms: nausea, mood, appetite, insomnia, pain, mobility, bowel pattern, concentration,

fatigue, and appearance. Each symptom is measured on a 5point rating scale. Like the POMS, this scale measures only
the level of fatigue and does not capture the various
dimensions fatigue nor its impact on lifestyle.

Yoshitake (1971) developed a 30-item symptom check list with three categories designed to be used as a subjective report of fatigue. The three categories of symptoms are: dull, sleepy factor; a decline in motivation to work; and projection of fatigue to some parts of the body. is a simple check list and does not measure the intensity of feelings; however, a greater number of symptoms identified equates with a greater level of fatigue. The dimensions of fatigue which the tool seems to capture are: (1) physical feelings and symptoms such as eye strain, heaviness in the head, drowsiness, the desire to lie down, headache, dizziness, husky voice, and spasms of the eyelid; (2) problems of concentration such as difficulty in thinking, forgetfulness, and a disinterest in thinking; (3) emotional feelings of nervousness, anxiety, and lack of patience. Although the scale attempts to capture various dimensions of fatigue, the wording of many of the items is awkward. "Feel heavy in the head, feel the brain hot or muddled, and feel oppressed in breathing" are examples of phrases which may be difficult to interpret. Other limitations of this scale is that it does not rate the level of fatigue nor does it capture the full impact fatigue has on lifestyle.

Kashiwagi (1971) constructed a 20-item fatigue rating scale which allows a judgment of human fatigue through a person's appearance. Objective manifestations of the first two dimensions of Yoshitake's scale were identified and became the scale items. An obvious limitation of this scale is that it relies on the judgment of another person to rate a subjective feeling. Both of these tools were developed and tested on a population of healthy Japanese workers. It is questionable that these measures are transferable to Americans who are ill.

Pearson and Byars (1956) developed the Feeling-Tone Checklist on a healthy population of male air force trainees. This scale has a 10-item adjective list defining a fatigue level continuum in short phrases: extremely peppy, very lively, very refreshed, slightly pooped, fairly well pooped, petered out, extremely tired, and ready to drop. The subject is to rate whether he or she feels better than, the same as, or worse than the specific feeling. This tool is designed to measure only the level of fatigue and does not capture its effect on lifestyle. I also question how ill patients, 30 years after this scale was developed, will respond to words such as "pooped" and "petered out".

Rhoten (1982) developed an observation checklist with four general categories: general appearance, communication, activity, and attitude. Each category has sub-categories with descriptors. The Rhoten Fatigue Scale is a single

subjective rating, on a scale of 1 to 10, to be used by the patient to quantify fatigue. The observation checklist and the fatigue scale was used on a small sample (n=5) of postoperative patients to correlate the level of fatigue assigned from the objective observation check list and the patient's reported subjective feeling. This scale could easily be used by nurses in the ill population and deserves further testing. The limitation of this tool is that it requires a skilled observer which may not always be possible in nursing research on fatigue.

Piper and colleagues (1989) developed the Piper Fatigue Self-Report Scale (PFS), an instrument to measure seven dimensions of subjective fatigue: temporal, intensity/ severity, affective, sensory, evaluative, associated symptoms, and relief. The PFS is in two forms, a baseline form designed to measure usual patterns of fatigue and any changes during 6 months prior to a medical diagnosis (PFS-B) and a current form which determines fatigue patterns for that day (PFS-C). Each dimension subscale has 5 to 18 items for a total of 76 items. Fatigue symptoms are measured using a visual analogue scale anchored at each end by verbal descriptors "none" and "a great deal". Although this scale includes the three identified dimensions of interest plus others, the length of the instrument severely limits its usefulness in this fatigued population.

Tack (1991) developed a 16-item Multidimensional

Assessment of Fatigue (MAF) scale based on the PFS which measures four dimensions of fatigue: severity, distress, degree of interference in activities of daily living (ADL's), and timing. Fourteen items are visual analog scales and 2 items have multiple choice responses. The MAF was tested using 133 subjects with rheumatoid arthritis. The computed Cronbach's alpha was 0.93. The author reported that subjects had difficulty understanding the concept of and marking the visual analog scales. In addition, since testing the instrument, the author has added a section to ask about the importance of each ADL to the subject. This newly developed measure is short, self-administered, and includes items that capture the important aspects of fatigue. The author has identified an important limitation, but it certainly deserves further testing.

Because the POMS, the Symptom Distress Scale, and the Pearson and Byars Fatigue Feeling Checklist measure only levels of fatigue, they may be insensitive to the certain aspects of fatigue in the postoperative cardiac surgery patient. In addition, these instruments do not capture how fatigue impacts activities and relationships. The symptom check list developed by Yoshitake does include various dimensions of fatigue but it does not rate intensity of symptoms nor does it address ability to perform ADLs. The Piper Fatigue Self-Rating Scale and the Rhoten Fatigue Scale along with the observation checklist, seem to be the most

comprehensive fatigue instruments available. They measure the fatigue level as well as capturing various dimensions of fatigue. However, the limitation of the PFS is the extreme length of the measure. The limitation of the Rhoten tool is that it requires a skilled observer which may not always be possible in nursing research on fatigue. The most promising tool is the new measure developed by Tack (1990); however, it needs revision and further testing, especially regarding its sensitivity to changes in fatigue. Based on the preceding discussion of currently available tools which may be used to measure fatigue, it is apparent that a short, easily understood, self-administered tool, that is sensitive to changes in fatigue and its impact on lifestyle has yet to be developed. Prior to conducting any nursing intervention studies on fatigue in the cardiac surgery population, tool development is essential.

#### Summary

The problem of fatigue following cardiac surgery has been well documented in the literature (Gortner et al., 1988; Jenkins et al., 1983; King & Parrinello, 1988).

However, research is limited both in interventions for fatigue and outcome measurements of these interventions.

The existing instruments designed to measure fatigue are either too long or do not capture the dimensions identified to be important in this population. In addition, they may not be sensitive to changes in fatigue.

### Purpose and Aims

The overall purpose of this study was to describe and understand fatigue in persons who had undergone cardiac surgery. The specific aims of this study were to:

- 1. Identify reliable and valid indicators of subjective fatigue in the postoperative cardiac surgical patient.
- 2. Develop and psychometrically test an outcome measure for nursing intervention studies designed to lower the perception of fatigue in this high risk population.

In order to achieve the specific aims of this study, a multi-phase study was planned. The first phase of this study consisted of a qualitative study of fatigue in postoperative cardiac surgical patients. The information gained from the first phase, along with a review of the literature, was used for the second phase, instrument development. During the third phase, an initial psychometric evaluation of the new measure was conducted.

#### CHAPTER 3

### PHASE I: QUALITATIVE PHASE

The purpose of the qualitative phase was to further conceptualize the fatigue experience following cardiac surgery and to generate items for a new fatigue instrument.

Nurses have studied fatigue following cardiac surgery primarily as part of the recovery process rather than as a single concept (Gortner, Rankin, & Wolf, 1988; Jenkins, Stanton, Savageau, Denlinger, & Klein, 1983; King & Parrinello, 1988). Although this limited previous research provides support for the presence of fatigue following cardiac surgery, it does not describe fatigue or examine the fatigue experience in this population.

#### Method

Semi-structured qualitative interviews were planned as the first phase of the study to further conceptualize the fatigue experience. An interview guide (Appendix A) was developed consisting of two parts. The first question was general, designed to elicit the sensations associated with fatigue such as subjective feelings and physical signs. The second part contained questions designed to assess the impact fatigue may have on the subjects' lifestyle and how the subject has coped with fatigue. Data from the interviews and from the literature were used as a source for a beginning set of items.

### Sample

A preliminary project during the first year of doctoral study demonstrated that it is important to sample subjects who are not as fatigued as well as those who are very fatigued to obtain the full range of the fatigue continuum. In addition, Lincoln and Guba (1985) suggest that sampling of extreme cases assists in obtaining information about unusual cases. Therefore, the sampling plan was to interview subjects who were considered expert informants with a range of fatigue. To capture this range of fatigue, purposive sampling sought subjects at various times during the postoperative period from the first month after discharge from the hospital to 6 months following surgery. The post discharge phase was chosen in order to obtain data regarding the effects fatigue may have on the demands of every day life.

Other considerations for sample selection included the ability to communicate with the investigator and representation of gender and race. In 1988, 23.5% of coronary artery bypass graft (CABG) operations were performed on women (American Heart Association, 1991). Statistics by race were not available. Thus, criteria for selection of the sample included: (1) cardiac surgery in the past 6 months; (2) English speaking; (3) adults (18 years of age or older); (4) currently living at home; and (5) representative of gender and racial groups.

### Sample Recruitment

Subjects were recruited from a large northwest health maintenance organization (HMO). To reflect the national statistics, the sample included 25% women. African-Americans and other ethnic minorities were not available for inclusion in this sample.

### Sample Characteristics

The sample included 8 Caucasian subjects, 6 men and 2 women. Age of the subjects ranged from 45 to 74 years with a mean of 65 years. All of the subjects had undergone CABG surgery in the past 6 months. The length of time since surgery ranged from 2 to 6 months. All subjects had been living at home since surgery.

### Procedure

Potential subjects were identified by an HMO computer specialist, using ICD-9 diagnostic codes. Ten potential subjects were contacted initially by a letter sent by a health care provider (Appendix B) to introduce the investigator and briefly explain the study. The potential subjects were asked to return a postage-paid postcard indicating willingness to speak to the investigator. Nine of the 10 potential subjects returned the postcard. Upon receipt of the postcard, the investigator contacted 8 of the 9 potential subjects by telephone to invite participation, and to schedule the interview. The ninth subject could not be reached by telephone. Prior to the interview, the study

was explained and a consent form signed (Appendix C). Tape recorded interviews were conducted in subjects' home or place of work using the interview guide. Two subjects requested that their spouse be present during the interview; therefore comments made by the spouse were included in the tape recorded interview. An attempt was made to limit the interviews to 30 to 45 minutes to prevent overtaxing the subjects suffering from fatigue; however most subjects wanted to talk longer. A journal of field notes and impressions from each interview was kept by the researcher. Five subjects were re-interviewed to obtain their reaction to the analysis.

## Protection of Human Subjects

Approval for this study was obtained from the Human Subjects Review Committee of the Oregon Health Sciences University, Portland, OR. The study was considered exempt (category 3) by the Department of Health and Human Services regulations on human subjects. In addition, approval was obtained from the HMO Human Subjects Review Committee.

All information obtained from subjects remained strictly confidential. The tapes from the interviews were placed in a locked file. The subjects were assigned a code number and only the code number appeared on the typed transcripts. Transcripts were stored in a computer with a restricted password.

The only risk anticipated during the interviews was

increased fatigue. The subjects were instructed to stop the interview if undue fatigue occurred. In addition, the investigator observed the subjects for undue fatigue and was prepared to terminate the interview if the subject complained of or showed objective signs of fatigue or other distress. Only one subject showed signs of fatigue; however he denied undue fatigue and requested to continue the interview for another 20 minutes.

## Analysis

The purposes of the qualitative data analysis were: (1) to describe dimensions of fatigue and (2) to generate items reflecting these dimensions. The data from the interviews were transcribed and analyzed using the constant comparative method described by Glaser (1978). transcript was read soon after the interview to gain a sense of the whole. Data included both the transcript and the researcher's journal. Potentially important statements, incidents, or descriptions pertaining to the major concepts guiding the study (sensations of fatigue, its impact on lifestyle, and coping with or reducing fatigue) and any other concepts emerging from the data were identified and categorized. As these statements or incidents were coded into categories or domains, they were compared with others from the same respondent or other respondents to clarify relationships between categories. These emerging categories were also clarified by comparing them to categories found in

the literature.

Indicators of these categories or domains (such as sensations of fatigue and the impact of fatigue on lifestyle) were used to generate items for the tool. Items that represented dimensions of each domain or category were included in the instrument.

## Reliability and Validity

Threats to the reliability and validity of the interview data were addressed using the methods identified by LeCompte and Goetz (1982). Methods to enhance external reliability were: the use of the interview guide, the recording of field notes immediately following the interviews, verbatim transcription of the interviews, and verification of the analysis with subjects. Tape recording the interviews and discussion of the analysis with my advisor and colleagues were strategies used to improve internal reliability.

One of the major strategies to improve internal reliability was the use of colleagues to validate data analysis. A list of data excerpts was organized into five major categories. Each category was then divided into two to four sub-categories with a label and definition of that label. Colleagues were asked to read each data excerpt and indicate if it fit the label and definition (Appendix D).

Threats to internal and external validity were minimized by assessing the subjects' reaction to the

analysis, discrepant case analysis, and by a comparison of derived categories to those found in the literature.

#### Results

Of the 8 subjects interviewed, 7 indicated that fatigue had been a major problem following surgery. The one subject who denied fatigue following surgery described herself as having a very positive attitude. As she recounted her recovery process, it was clear that she went to bed earlier and took more frequent rest periods to prevent fatigue.

All but one of the subjects described a recovery pattern that included decreasing frequency and intensity of fatigue. That one subject continued to be plagued by intense episodes of fatigue that occurred daily and affected all aspects of his life.

Three major concepts were verified from the qualitative analysis: Sensations/experience of fatigue; Impact of fatigue on lifestyle; and Coping with fatigue. Two additional concepts were identified in this sample: (1) Things that make fatigue worse and (2) Role of spouse or other caregiver. Situations or problems that adversely affected fatigue or their response to it seemed to fit under the category of impact of fatigue on lifestyle. The role of spouse or other caregiver seemed to be one of helping the subject cope with fatigue. Thus these latter two concepts were incorporated into the original three categories

Many of the descriptors used by the subjects or their spouse were very similar to the descriptors found in the preliminary study and were also found in the literature. The following is a summary of the findings and a comparison of those findings with those found in the preliminary study and in the literature.

The first major concept, experience/sensation of fatigue, included three subconcepts. The subconcept physical signs included data excerpts such as "I notice when he's pale"; "he looked old"; "a little shortness of breath"; and "round shoulders, slump, and a drooping face". preliminary study the descriptors for physical signs were "dull eyes", "pale face", "short of breath", and "whole body sags". These descriptors were also frequently found in the literature (Aistars, 1987; Hart & Freel, 1982; Rhoten, 1982). Kashiwagi (1971), Rhoten (1982), and Yoshitake (1971) used these types of words or phrases in their fatigue measurement scales under the heading of general appearance. "The term I like to use is 'run out of gas'", "I was exhausted", and "I'm real drowsy" were data excerpts subjects used to describe the subconcept subjective feelings. Descriptors from the preliminary study were words such as "tired", "worn out", "weak", "run down", and "drowsy". These words and phrases were commonly used in the entire fatigue literature and were included in most fatigue measurement scales (Kashiwagi, 1971; McNair et al. 1971;

Pearson & Byars, 1956; Rhoten, 1982; Yoshitake, 1971). The subconcept signs of energy included examples of lack of fatigue or increased energy that could be observed. "He has a spring in his step" and "He's doing stuff all the time" were observations made by a subject's son that indicated lack of fatigue. "I enjoy a lively discussion" was an excerpt from a subject in the preliminary study that indicated how she knew she was feeling better.

The second major concept, impact of fatigue on lifestyle, was divided into four areas: (1) activities of daily living; (2) household chores; (3) social activities and hobbies; and (4) work activities. Examples of data excerpts which demonstrated the impact of fatigue on each of the four areas were: "It's very difficult to do some things like take a shower...to get dressed"; "Simple tasks seem to be a chore"; "I wasn't really up to reading anything of significance because I couldn't...comprehend"; "He could barely get up the stairs"; "We're usually very social...but we've had to put a halt to it"; and "There were three (work related) trips I had to cancel". Many data excerpts were long narratives that indicated the need to stop and rest during activities or the need to stop the activity completely.

The category, things that make fatigue worse, also seemed to fit under the impact on lifestyle concept.

Subjects described situations which they found adversely

affected fatigue or their response to it. Two examples of these situations were: "my kids hounding me" and "a verbal fight". Similar situations such as "arguing with my kids", "frustrations", and "things that annoy you" were mentioned in the preliminary study. Subjects described both physical activity and emotional issues. Several phrases that troubled subjects such as "going back to alcohol", "can't help yourself", and "cry for no reason at all" were mentioned in the preliminary study. Similar examples of the impact of fatigue of lifestyle were "Have to be told what to do" and "It's hard to go out in the wider world" were found in this study. Several subjects became tearful during the interview when they described how fatigue affected their life. These subjects seemed to be describing an a decrease in the ability to cope with fatigue or an increased vulnerability. Tearful episodes were mentioned by Aistars (1987) but crying or increased vulnerability as a manifestation of fatigue was not frequently mentioned elsewhere in the literature. All of these activities and situations seem to indicate that fatigue interferes with daily functions, activities, and relationships.

Activities that subjects used to manage fatigue were labeled coping with fatigue. Many of the data excerpts which were identified as coping strategies were related to taking naps, resting, or pacing of activities. Examples are: "The naps have always been good", "I'm going to bed

earlier...", and "I sit down and take five". Both Rhoten (1982) and Aistars (1987) described these behaviors and grouped them in a category labeled attitude. Activity-seeking behaviors ("go ahead and do things", "force myself to get up and go" and "keep doing a little more") and diversion-seeking behaviors ("watch TV" and "played the piano") described by subjects in this study and the preliminary study were quite different from anything mentioned in the literature. Both of these behaviors may represent ways of coping with fatigue.

Almost all of the subjects mentioned the importance of a spouse, adult child, or other caregiver in their ability to cope with fatigue. Phrases such as "I couldn't have gotten by alone", "She did everything for me", and "They watched over the old man pretty well" were common themes in the subjects' narration of how they coped with fatigue. It is interesting to note that the one subject who continued to have severe problems with fatigue 4 months after surgery, did not have someone to help him following surgery.

Based on the results of the this study, the preliminary study, and a review of the literature, items were generated for the Fatigue Outcome Measure. Because the fatigue experience following cardiac surgery has three major aspects (1) sensations of fatigue including both physical signs and subjective feelings, (2) impact of fatigue on day-to-day life, and (3) coping with fatigue, the items represented

each of these aspects of fatigue.

#### CHAPTER 4

### PHASE II: INSTRUMENT DEVELOPMENT PHASE

The purpose of this phase was to develop the instrument and prepare it for testing. Items for a paper and pencil Fatigue Outcome Measure (FOM) were generated from the qualitative data. Because the intended use of this tool is an outcome measure for nursing interventions, the items chosen consisted of aspects of fatigue that have the potential to undergo clinically important change as a result of nursing interventions (Stewart & Archbold, 1992).

#### Methods

#### Item Generation

Items were chosen to represent the three major concepts derived from the qualitative analysis: (1) Sensations/ experience of fatigue; (2) Impact of fatigue on lifestyle; and (3) Coping with fatigue. There were many data excerpts which indicated physical signs and subjective feelings associated with fatigue such as "I was tired" and "He looked old". All of these data excerpts were used that could logically be worded as items on the fatigue scale. Many of these items used the exact words of the subjects.

Data excerpts which described the impact of fatigue on lifestyle were frequently long narratives that indicated the need to stop and rest during activities or the need to stop the activity completely. Most of the excerpts in this category were paraphrased into items for the new measure and

represented the four major areas in which fatigue impacts on lifestyle.

Many of the data excerpts which were identified as coping strategies were related to resting or pacing activities; however a few were diversional activities. Many of these items were direct quotes from the qualitative interviews.

Data excerpts which indicated a lack of fatigue were infrequent. "I have a spring in my step" and "I feel perky" were the only data excerpts which could be used as items. Three more items were chosen based on concepts found in long narratives. These items were: "I can do more this week than last week", I can stay up all day without difficulty" and "I enjoy a lively discussion".

Of the 44 items generated from the data excerpts, 17 related to the category "experience/sensation of fatigue"; 19 related to the category "impact of fatigue on lifestyle"; and 8 related to the category "coping with fatigue". An attempt was made to represent all of the concepts in each of the three categories and to use the exact words of the subjects whenever possible.

### Initial Instrument Development

The first version of the new measure consisted of 44 items. The items were arranged in a random order. The response scale consisted of a horizontal line with 6 vertical markers dividing the scale into 5 steps. Anchors

(Yes, describes me exactly, Somewhat describes me, No, doesn't describe me at all) were placed above the first, third, and fifth steps of the response scale.

## Content Validity

Nunnally (1978) states that "...measures developed specifically for experiments should be constructed to have content validity." (p. 312). Evidence for content validity was drawn from two sources: (1) items grounded in field research and literature (Waltz, Strickland, & Lenz, 1984) and (2) review by two panels of experts for components of content validity, specifically domain representativeness (Messick, 1980) and clinical relevance. One panel consisted of professional experts while the second panel consisted of lay experts.

### Professional Expert Review

Sample. Ten professional experts reviewed the 44 initial items using procedures suggested by Imle and Atwood (1988). The number of experts for content review was selected based on guidelines suggested by Lynn (1986). Two reviewers were research experts experienced in the development and testing of new measures. Eight reviewers were clinical nurse experts experienced either in the care of patients following cardiac surgery or in symptom management.

Procedures. Content validation depends upon how well
and how adequately items represent the meaning of the

conceptual domain and how well they avoid redundancy (Imle and Atwood, 1988). Therefore, each panel member was given a set of items and asked to judge how well the items represented and covered the major concepts identified in Phase I and the relevance of each item to those concepts. The items were separated into 3 lists. Each list contained items that seemed to fit one dimension of fatigue. The three dimensions were labeled and defined. The experts were instructed to read one list of items at a time and indicate whether each item fit the label and definition. In addition, the experts were asked if each item was clearly worded and if there was anything missing from the list.

Results. Of the 44 items included in the newly developed instrument, 29 items were judged to fit the label and definition by 100% of the experts (Table 4-1). Nine items were judged to fit by 90% of the experts; 3 items by 80% of the experts; 2 items by 70% of the experts; and 1 item was judged to fit the label and definition by only 60% of the experts. An item with a content validity index of less than 80% was considered for elimination (Lynn, 1986).

Several experts suggested that some items were related to fatigue but fit another label and definition better than the one assigned. For example, experts suggested that "I cry for no reason", "I have to sit down and rest", and "I don't go out as much as I used to" should be defined as coping strategies rather than an impact of fatigue.

#### Table 4-1

# Content Validity Responses from Professional Experts

**Label:** Impact of fatigue (or increased energy).

**Definition:** How fatigue (or increased energy) afficts the ability to carry out day-to-day activities.

Item

I have to be told what to do	90
I frequently run out of gas	100
I can't keep going	100
Do more this week than last	100
I don't want to do anything	100
Climbing the stairs is hard	100
Hurts my pride to tire easily	70
I don't have the zip	100
I cry for no reason	70 <sup>b</sup>
I Have to sit and rest	90b
I don't go out as much	90b
I just can't concentrate	100
I have good days and bad days	80
T amino - 131 1'	

I enjoy a lively discussion 80

It takes longer to do things 100 I don't do things I used to 100 To shower & dress is too much 100

It's a chore to go out Simple tasks are a chore

% Agreementa

**Label:** Sensation/experiennce of fatigue (or increased energy).

**Definition:** Signs of fatigue (or increased energy) that can be observed or ways of describing how fatigue makes one feel.

Item	% Agreement
Others notice I look tir I feel tired Have a spring in my step Body tells me I must lie Body signals I have over. The pillow looks good I feel wiped out My color is pale I feel drowsy I look old I feel perky My shoulders slump	ed 100 100 90 down 100
I just want to lie down I feel very vulnerable I feel exhausted I am irritable	100 90 100 100
I feel worn out	100

Label: Coping with fatigue (or indicators that energy is returning.

**Definition:** Strategies used to manage fatigue (or indicators that strategies are not needed).

Item	% Agreement <sup>a</sup>
I take frequent rest per All I can do is watch TV I have simplified my list I take naps I stay up all day I have to pace myself I don't push myself I go to bed early	V 80

a % of Professional Experts agreeing that the item fits the label and definition

One expert suggested that these items fit better under coping with fatigue

Alternate wording to enhance the clarity of some items was suggested by several experts. For example, "It takes too much effort to shower and dress" was suggested as an alternate to "To shower and dress seems to take almost too much effort". Because many of the items were quite general when taken out of the context of the interviews, a suggestion was made to add a phrase to make them more specific to fatigue. In addition, three experts suggested that items be added related to eating and/or sexual activity.

### Lay Expert Review

Sample. The newly developed instrument was reviewed by 10 lay persons for face validity. Seven reviewers were subjects who had been interviewed during Phase I. Three reviewers were persons who had experienced fatigue following an injury or non-cardiac surgery.

Subjects who had been interviewed during Phase I were contacted by phone and asked if they would be willing to review the instrument. Seven of the 8 subjects agreed to participate. The eighth subject could not be reached by phone or mail. The subjects were given a choice of completing the instrument in their home with the investigator present or by mail. Five of the subjects chose to have the investigator present and two chose to complete the instrument by mail. The three reviewers who did not participate in Phase I of the study were lay co-workers of

the investigator and chose to complete the instrument with the investigator present.

Procedure. The reviewers were asked to complete the newly developed instrument and then answer the following questions: (1) Did you understand all of the items; (2) Did you understand the instructions; and (3) In your experience with fatigue, is there anything that is not mentioned (Imle and Atwood, 1988). If the reviewer answered "no" to any of the questions, an explanation was requested.

Results. All of the reviewers indicated that they understood the items and the instructions. Several subjects told the investigator that their answers to the questions now (about 1 year post-operative) were very different than the answers would have been a few weeks or months after surgery. Three subjects suggested additional items that were not included in the instrument. One subject indicated that fatigue interfered with the ability to engage in sexual activity. Two subjects mentioned that the lack of predictability regarding their level of energy interfered with making plans to participate in activities such as taking trips, taking walks alone, and accepting invitations. A few subjects wrote comments regarding specific items. subjects wrote "I look old because I am old". One subject wrote that she didn't go out much because her husband didn't want to go out. These written comments and some verbal comments made while the reviewers were completing the

instrument led to some changes in the instructions to respondents, changes in the wording of some of the items and the deletion of one item.

Pilot Study. A pilot study of the new measure was conducted as a part of the review process by the lay experts. The <u>purposes</u> of the pilot study were (1) to determine how long it took for subjects to complete the instrument and (2) if they experienced any difficulties in the research procedures such as fatigue which would hinder their ability to complete the instrument. The subjects were instructed to complete the instrument and then answer the review questions. The investigator timed the subjects who completed the instrument in her presence. The subjects who completed the instrument by mail were instructed to time themselves.

The <u>results</u> of the pilot study were as follows: (1) subjects required 4 to 11 minutes to complete the instrument and (2) subjects denied any problems in the research procedures. Because important changes were made in the instrument following the expert review process, the responses from the subjects in the pilot study were not included in the final data analysis.

# Instrument Revision

The new measure was revised based on the content validity index and the suggestions made by the professional and lay expert reviewers discussed above. Of the 44

original items, 4 items were deleted ("It hurts my pride to tire so easily"; "I have good days and bad days"; "The pillow looks so good"; "I look old"). Two items were added, one related to sexual activity and one related to eating. Eight items were reworded so that they were more specific to fatigue. In addition, the example item included in the instructions to respondents was changed from an item not related to fatigue to an item related to fatigue. During the revision, an attempt was made to keep the wording of the items as close to the words of the Phase I subjects as possible. The second version of the new measure consisted of 42 items. The response scale remained the same as described in the first version.

#### CHAPTER 5

#### PHASE III: PSYCHOMETRIC TESTING PHASE

During the third phase, an initial psychometric evaluation of the new Fatigue Outcome Measure (FOM) was performed. The internal consistency reliability and item analysis were computed on the responses to the instrument of 146 subjects who had undergone cardiac surgery. Initial evidence for construct validity was gathered using a variety of methods. Ongoing psychometric evaluation of the measure will occur as a part of future research.

#### Method

# Setting

Potential subjects were recruited from three settings. The first setting was a large northwest health maintenance organization (HMO). The HMO contracts with thoracic surgeons from two medical facilities to perform surgery and provide postoperative care during hospitalization. After hospital discharge, they receive follow-up nursing care in their home by HMO visiting nurses and outpatient medical care by HMO cardiologists. Approximately 250 HMO enrollees undergo cardiac surgery each year. The second setting was a Northwest University Medical Center (UMC). Approximately 100 adults receive cardiac surgery at the UMC every year. The third setting was a large Northwest Private Hospital (NPH). A group of seven surgeons perform over 1,000 cardiac surgeries in this facility each year.

# Sample

### Sample Selection

To capture a broad range of degree of fatigue, sampling sought subjects at various times during the postoperative period, from the first week after discharge from the hospital to 7 months following surgery. The post discharge phase was chosen in order to obtain data regarding the effects that fatigue may have on the demands of every day life.

Other considerations for sample selection included the ability to read and write English and representation of gender and race. In 1988, 23.5% of coronary artery bypass graft (CABG) operations were performed on women (American Heart Association, 1991). Statistics by race were not available. Thus, criteria for selection of the sample included: (1) cardiac surgery in the past 7 months; (2) able to read and write English; (3) adults (18 years of age or older); (4) currently living at home; and (5) representative of gender and racial groups.

The entire population from the HMO and UMC who had surgery between December, 1991 and May, 1992 and who met the above selection criteria was given the opportunity to participate in the study. Recruitment of potential subjects from the NPH differed. Because subjects who had been discharged from the hospital within the past week and female subjects were needed to fulfill the requirements of adequate

representation of female gender and patients from the early postoperative period, only subjects meeting these criteria were recruited from this medical facility.

The number of subjects was determined based on the projected number of items on the final Fatigue Scale.

Nunnally (1978) states that 5 subjects per item is the minimum that can be tolerated for item analysis. Because the final Fatigue Outcome Measure was projected to have approximately 20 items, the desired minimum number of subjects for this phase was at least 100.

# Sample Characteristics

The final sample included 146 subjects. Of the 146 subjects, 104 (71%) were male and 42 (29%) were female. Ages ranged from 37 to 85 years with a mean of 65 years. The ethnic origin of the majority of subjects was Caucasian (91%). The education level of the subjects varied from less than 12th grade education (12%) to completion of an advanced college degree (12%). The majority of subjects completed high school (25%) or had a greater than high school (61%) education. Table 5-1 summarizes the demographic characteristics of the sample.

#### Procedures

### Recruitment Procedures

Access to potential subjects was negotiated with the three medical facilities described above. Procedures for recruiting subjects differed somewhat by setting and sample

Table 5-1
Demographic Characteristics of Sample (N=146)

Variable	Frequency (%)
Gender Male Female	104 (71) 42 (29)
Ethnic Origin Caucasian African-American (Black) Native American Asian/Pacific Islander Other (Jewish) [Missing data]	133(91.1) 5 (3.4) 3 (2.1) 1 (.7) 1 (.7) 3 (2.1)
Education < 12th Grade Completed high school Post high school vocational train Attended college Completed college Completed advanced college degree [Missing data]	18 (12.4) 37 (25.3) 12 (8.2) 36 (24.7) 23 (15.8) 17 (11.6) 3 (2.1)
Time in Surgery  2 to 4 hours 4 to 6 hours 6 to 8 hours > 8 hours Unknown [Missing data]	28 (19.2) 49 (33.6) 18 (12.3) 3 (2.1) 41 (28.1) 7 (4.8)
Age (years): M = 65.47 SD = 10.07 Skewness = -0.69 Kurtos	Range = 37 to 86

group.

HMO. Subjects from the HMO who had undergone cardiac surgery in the past 1 to 7 months (Single-Test Group) were identified by a computer specialist, using ICD-9 diagnostic codes. Subjects who had been discharged from the hospital following cardiac surgery (Retest Group) were identified by a nurse in the Community Health Services division and referred to the investigator on a daily basis. Potential subjects from the Single-Test Group (n=108) and the Retest Group (n=53) were contacted initially by a letter from their health care provider to introduce the investigator and briefly explain the study (Appendix E<sup>a</sup>).

UMC. Single-Test Group subjects who had undergone surgery in the past 1 to 7 months at the UMC were identified by the investigator from the Intensive Care Unit census log book. The investigator called the unit clerk on a weekly basis to identify Retest Group subjects who had been discharged from the hospital that week. Potential subjects from the Single-Test Group (n=26) and the Retest Group (n=15) were contacted initially by a letter from the investigator to introduce the investigator and briefly explain the study (Appendix E<sup>b</sup>).

NPH. A computerized list of subjects who had undergone surgery in the past 1 to 7 months (Single-Test Group) at the NPH was generated by the surgeons' office assistant. In order to increase the percent female subjects, the

investigator chose to contact only the female subjects who had undergone surgery on Wednesdays for the past 1 to 7 months. The investigator called the physicians' assistant on a weekly basis to identify the subjects who had been discharged from the hospital that week (Retest Group). Potential subjects from the Single-Test Group (n=22) and the Retest Group (n=68) were also contacted initially by a letter from the investigator to introduce the investigator and briefly explain the study (Appendix E<sup>b</sup>).

Recruitment Procedures Common To All Settings. The initial recruitment letter from all three settings requested potential subjects to return a postage-paid postcard indicating willingness to receive a copy of the questionnaire. Upon receipt of the postcard, the investigator sent the potential subject a copy of the questionnaire. A cover letter (Appendices F & G) accompanied the instrument. A thank you/reminder postcard was sent to all participants after 7 to 10 days and a replacement copy of the instrument was sent to non-respondents in 3 to 4 weeks. A cover letter (Appendix H) requesting information regarding non-response accompanied the replacement copy.

The Retest Group subjects completed the questionnaire during the first 5 weeks after surgery. The cover letter (Appendix G) requested these subjects to sign a form indicating willingness to complete the instrument again 4 to

5 weeks later. A second copy of the instrument and a thank you cover letter (Appendix I) was sent to willing participants 4 weeks following the return of the initial copy.

# Recruitment Strategies

The questionnaire packet which included the cover letter, the questionnaire, and a postage-paid return envelope was based on the Total Design Method developed by Dillman (1978). Dillman suggests that the use of the Total Design Method (based on the social exchange theory) in the development and administration of a mail survey will increase the response rate to 75%. The social exchange theory advocates the following to maximize the response to mail surveys: 1) maximize the rewards of responding by showing positive regard, giving verbal appreciation, using a consulting approach, and making the questionnaire interesting; 2) minimize the cost of responding to the survey by such things as making the task appear brief, eliminating the chances for embarrassment, and eliminating any direct monetary cost; and 3) establish trust by providing a token of appreciation in advance and identifying with a known organization that has legitimacy.

To maximize the rewards, each cover letter was addressed individually to the potential subject. The cover letter gave verbal appreciation and used a consultive approach; the questionnaire was relatively short and was

designed in an interesting manner. Offering to accept collect telephone calls regarding questions about the study and including a self-addressed, stamped envelope eliminated direct respondent costs. The attempt to establish trust in the potential HMO subjects included: 1) The initial letter of introduction describing the study and inviting participation used the HMO letterhead and was signed by an HMO cardiologist; 2) The cardiologist made reference to the investigator's extensive work as a nurse caring for patients following cardiac surgery in the initial letter; and 3) The cover letter used Oregon Health Sciences University (OHSU), School of Nursing letterhead. A similar initial letter to the potential subjects from the other two medical facilities was sent by the investigator using OHSU School of Nursing The cover letter accompanying the questionnaire letterhead. to these participants also used OHSU letterhead stationery.

The follow-up procedures suggested by Dillman (1978) were used to encourage an adequate response rate: 1) a thank-you/friendly reminder postcard was sent to all subjects 7 to 10 days following the initial mailing of the instrument; and 2) a replacement copy of the instrument was sent 3 to 4 weeks following the initial mailing to non-respondents. Dillman's third follow-up procedure was not used as it was thought to be too coercive: sending a replacement copy by certified mail 7 weeks after the initial mailing.

# Response Rate

From a total of 292 questionnaires mailed, 148 (51%) responded. (See Table 5-2.) Of these 148 respondents, 2 were missing more than 25% of the Fatigue Outcome Measure items and were dropped from analysis. (The decision to eliminate subjects missing more than 25% of the scale items is described later in this chapter.) Therefore, the final sample was 146.

The overall response rate was 51%. The response rate of the HMO sample (61%) was much greater than the response rate of the UMC (37%) and the NPH (38%) samples. greater response rate of the HMO sample may have been related to fact that the recruitment letter was from an HMO cardiologist on HMO letterhead stationery. In addition, the overall low response rate (51%) may be related to the use of the recruitment letter requiring the return of a postcard prior to the actual mailing of the questionnaire. When the overall response rate is divided into components, it is clear that the response rates of the HMO sample is consistently higher than for the other two samples. sample response rate to the initial recruitment letter was 70% compared to the 46% and 42% response rates of the UMC and the NPH samples respectively. Following the return of the postcard, the return rate of completed questionnaires of all three samples was 85% (HMO sample 88%, UMC sample 79%, NPH sample 89%). Thus, 85% of the subjects who agreed to

Table 5-2

# Derivation of the Time 1 Final Sample

Health Maintenance Organization (Total Mailing, n=161)	University Medical Center (Total Mailing, n=41)	Northwest Private Hospital (Total Mailing, n=90)
Recruitment Letter S Group, n=108 R Group, n=53	Recruitment Letter S Group, n=26 R Group, n=15	Recruitment Letter S Group, n=22 R Group, n=68
Sample Questionnaire Mailing S Group, n=75 R Group, n=37	Sample Questionnaire Mailing S Group, n=13 R Group, n=6	Sample Questionnaire Mailing S Group, n=13 R Group, n=25
ion	tíonn	tion
s Group, n=s1 10 Questionnaires Remailed	S Group, n=10 K Group, n=5 4 Questionnaires Remailed	S Group, n=10 R Group, n=23 5 Questionnaires Remailed
1 Returned 2 Returned n=66 n=33	0 Returned 0 Returned $n=10$ $n=5$	0 Returned 1 Returned n=10
Total Time HMO Sample=99 Total Eligible Sample=161 HMO Response Rate=61%	Total Time 1 UMC Sample=15 Total Eligible Sample=41 UMC Response Rate=37%	Total Time 1 NPH Sample=34 Total Eligible Sample=90 NPH Response Rate=38%
HMO Final Time 1 Sample=98 (1 person excluded°)	UMC Final Time 1 Sample=15	NPH Final Time 1 Sample =33 (1 person excluded°)
	Total Time 1 Sample=146	

S Group = Single-Test Group R Group = Retest Group

 $<sup>^{\</sup>rm a}$  4 subjects reported an inability to complete the questionnaire  $^{\rm b}$  2 subjects reported an inability to complete the questionnaire  $^{\rm c}$  subjects excluded due to missing data

participate completed the questionnaire. Several subjects called the investigator to report an inability to complete the survey due to re-hospitalization or continued illness.

The sample of 146 persons was divided into 2 groups, Single-Test Group and Retest Group, to allow for construct validation plans. Of the 146 subjects, 84 completed the instrument only once (Single-Test Group).

Of the 146 subjects, 62 subjects completed the instrument during the first four weeks following discharge from the hospital (Time 1) and again 4 to 5 weeks later (Time 2) to allow a comparison of the responses at Time 1 and Time 2. This group is referred to as the Retest Group. Of the 62 subjects who completed the questionnaire at Time 1, 52 (84%) completed the questionnaire at Time 2. Due to missing data, one of these subjects was excluded at Time 1 and one was excluded at Time 2. Therefore, the final Retest Group sample was composed of 50 subjects.

# Protection of Human Subjects

Final approval for this study was obtained from the Human Subjects Review Committee of the Health Maintenance Organization (HMO) following development of the new measure. Approval was also obtained for this phase of the study from the Human Subjects Review Committee of a northwest university medical center (UMC) and from the Institutional Review Board of a large northwest private hospital (NPH). A letter of introduction which explained the study and invited

participation was sent to all potential subjects. Informed consent was inferred from the return of the enclosed postage-paid postcard.

#### Instruments

The new Fatigue Outcome Measure was combined with demographic questions and four other instruments into a single questionnaire (Appendix J). An open-ended question (Is there any information that you would like to tell me or you think I should know about fatigue following cardiac surgery?) completed the questionnaire.

# Demographic Questions

Date of birth, gender, race, years of education, and length of time in surgery were the demographic questions. A self-report of length of time in surgery served as a measure of the complexity of the surgery.

#### Fatique Outcome Measure

The new measure consisted of 42 items. Of the 42 items, 15 related to the category "experience/sensation of fatigue"; 19 related to the category "impact of fatigue on lifestyle"; and 8 related to the category "coping with fatigue". A 5-point scale with three anchors (5 = Yes, describes me exactly; 3 = Somewhat describes me; and 1 = No, doesn't describe me at all) was used. Subjects were instructed to read each item carefully and place a check in the blank that best described how they had felt in the past two days.

# Profile of Moods State

The Profile of Mood States (POMS) has been widely used to measure several concepts which may be related to fatigue as well as fatigue in psychiatric and non-psychiatric individuals (McNair et al. 1971). The POMS fatigue subscale is a general measure which would be expected to be sensitive to changes in fatigue in this population but would not be expected to be as sensitive to these changes as the new measure. The short version of the POMS was used to prevent overtaxing the subjects. This version consists of 30 single-word items that describe a wide range of feelings that people have. The subject was instructed to use a 5point scale to describe how they had been feeling during the past week: 0 = not at all, 1 = a little, 2 = moderately, 3 = quite a bit, and 4 = extremely. The POMS is divided into 6 subscales that measure anger, vigor, fatigue, confusion, tension, and depression. The reported internal consistency reliabilities of the POMS subscales range from 0.84 for Confusion to 0.95 for Depression (McNair et al. 1971). For the sample (n=146) used in this study, the internal consistency reliabilities were: Anger .85, Vigor .92, Fatigue .93, Confusion .76, Tension .80, and Depression .82.

# Self-Rating Scale

A self-report of fatigue was obtained from all subjects using an 11-point <u>Self-Rating Scale</u> to quantify the subject's perceived fatigue. It consisted of numbers 0 to

10 with anchors labeled <u>not tired at all</u> (0) to <u>extremely</u> tired (10). There are no data on the validity of the scale. However, similar visual analog scales have been used by many researchers who have studied subjective fatigue (Ans, Kobashi-Schoot, Hanewald, van Dam, & Burning, 1985; Christensen, et al. 1982; Rhoten, 1982).

# Multidimensional Assessment of Fatique

The Multidimensional Assessment of Fatigue (MAF) Scale (Tack, 1991) is a new measure of fatigue which was adapted from the Piper Fatigue Scale for use with rheumatoid arthritis patients. The MAF scale contains 16 items and measures four dimensions of fatigue: severity (items 1 and 2), distress (item 3), degree of interference in activities of daily living (ADL) (items 4 through 14) and timing (items 15 and 16). The MAF was modified to eliminate the visual analog scales (VAS) as some people were not able to understand the concept of VAS during the initial testing of the instrument. Instead of the VAS, an 11-point scale consisted of numbers 0 to 10 with anchors labeled not at all (0) to a great deal (10) was used. In addition, 11 items were added to assess the importance of the activities to the subjects. A Global Fatigue Index was calculated using the author's instructions by adding: (1) Items 1 and 2 which assess severity of fatigue; (2) Item 3 which assesses the distress caused by fatigue; (3) the average of items 4 through 14 which assess the degree of interference in ADLs;

and (4) item 15 multiplied by 2.5 to assess and weight the timing of fatigue. Item 16 is not included in the Global Fatigue Index. The MAF was initially tested with 133 subjects suffering from rheumatoid arthritis. The computed value of Cronbach's alpha was .93 for this initial test. For the sample (n=141) used in this study, the Cronbach's alpha for the Global Fatigue Index was .94.

# Pearson Byars Feeling-Tone Checklist

The Pearson Byars (1956) Feeling-Tone Checklist was also used. This 3-point scale consists of 10 items. The subject is instructed to use the scale (1 = better than, 2 = same as, 3 = worse than) to rate how he feels at the moment with regard to each item.

This rating scale was used by Haylock and Hart (1979) to measure subjective fatigue in cancer patients receiving radiation therapy; by Freel and Hart (1978) and Hart (1977) to describe fatigue in patients with multiple sclerosis; by Cohen and Hardin (1989) to describe fatigue associated with catastrophic illness; by Srivastava (1989) to measure levels of fatigue in end-stage renal disease; by Jamar (1989) to assess fatigue during chemotherapy; and by Gueldner and Spradley (1988) to test the benefits of outdoor walking to lower fatigue in nursing home residents. The measure was able to detect a change in the level of fatigue in the Gueldner and Spradley study. Hart (1977) used a modification of the tool in her study (subjects chose the

single phrase that best described their feeling-tone at six different times in the day) and was the only investigator to report how the instrument performed. She reported reproducibility coefficients to range from .21 to .87 at six time periods throughout the day. These results were obtained from the responses of the healthy, control subjects to the instrument which was administered twice at an interval of one week. The Cronbach's alpha was .88 for the sample (n=142) used in this study.

# Reliabilities of the Scales Used for Validation Purposes

The Cronbach's alpha for all but one of the scales met Nunnally's (1978) criterion of .80 or higher for mature scales. The effect of using the group mean to estimate missing values tends to make the reliability somewhat lower (Cohen and Cohen, 1983). This may account for the Cronbach's alpha of .76 for the POMS Confusion subscale.

# Missing Data

Cohen and Cohen (1983) describe and make distinctions about various kinds of missing data. Missing data may be selective or random, may have a pattern, or may be large or few in number. They describe three alternatives for handling missing data in multiple regression analyses and the problems associated with each: (1) Dropping predictor variables may not be a satisfactory solution because potentially important information is lost; (2) Dropping subjects is not a satisfactory solution if the proportion of

missing data is large and the sample size is small because it reduces the statistical power and when missing data are nonrandom, the results may be nonrepresentative of the population sampled; (3) Pairwise deletion also gives nonrepresentative results when missing data are nonrandom.

In this study, subjects were dropped if they were missing more than 25% of the Fatigue Outcome Measure items. Of the 148 subjects who returned the questionnaire at Time 1, two were missing 25% of the items. Of the 52 subjects who returned the questionnaire at Time 2, two subjects were missing 25% of the items. Thus, a total of two subjects (1.4%) were dropped at Time 1 and two subject (4%) at Time 2 because of missing scores. Cohen and Cohen (1983) suggest that no serious objection can be raised for dropping less than 5% of subjects with missing data.

Although there are no absolute guidelines for the proportion of missing data that are practically important, Cohen and Cohen (1983) suggest that the magnitude of the problem is obviously less if 1% versus 40% of the data are missing. Based on experience and Cohen and Cohen's recommendation of keeping as many subjects as possible, an arbitrary cutoff of 25% of missing items for all scales was established. This value was chosen because it seemed a legitimate yet conservative way to derive a score.

For subjects missing less than 25% of the items on a measure, the missing values were replaced with the group

mean for that item. The group mean was used to estimate a missing value because it was viewed as a more conservative strategy than estimating the missing value with the subject's mean on the 75% or more items answered in each scale. If missing values for each scale totaled more than 25%, the subject was dropped from that scale.

Following a careful examination of the missing data from the POMS, an exception was made to the above rule. Of the 11 subjects missing data, only 4 subjects were missing more than 25% (27% and 37%); and these 4 subjects were missing a whole column of items rather than missing or skipping items at random. If the data are not missing randomly, the results will not represent the population sampled and the statistical power and precision will be reduced (Cohen and Cohen, 1983). Therefore the group mean was used to estimate POMS missing values for these 4 subjects as well.

# Item Analysis and Reliability Plans

Frequency distributions were computed for each item along with item means, standard deviations, skewness, and number of missing values. Item-to-item and item-to-total correlations were calculated on the 42-item measure as well as the subscales. The internal consistency reliabilities were calculated using Cronbach's alpha. Because the construct of fatigue is quite focused and the items were expected to have some redundancy, the internal consistency

reliabilities were expected to be high.

The purpose of a test-retest reliability is to provide evidence of the short-term consistency of the measurements yielded by an instrument (Knapp, 1985). In order to examine test-retest reliability for fatigue measures, a very short interval (1 week or less) would need to be used due to natural changes expected in fatigue levels during normal recovery. This type of reliability was not estimated in this study. However, correlational stability over a 1 month interval was computed in the study but was not expected to be high due to the instability of the construct over that time period.

# Construct Validity Plans

Construct validity is especially important whenever no criterion is accepted as entirely adequate to define the quality to be measured as it is in the case of fatigue (Carmines & Zeller, 1979). Evidence for construct validity of the instrument was gathered by the methods described below.

Factor analysis was employed to examine whether one or more factors existed. Data analysis from the preliminary study suggested that the fatigue associated with cardiac surgery could be described along underlying dimensions. The questions and probes in the qualitative interview guide reflected these dimensions.

A second approach to construct validity was to

administer the newly developed instrument along with the others described above to 50 subjects during the first 2 to 5 weeks following surgery and again to the same subjects 4 to 5 weeks later. These two times in the postoperative period were selected based on the difference in the expected level of fatigue. The mean scores from subjects in these two time periods should differ significantly (p < .05) if the instrument is sensitive to changes in fatigue. Sensitivity to change is a requirement for construct validity for measures intended for use in intervention studies (Kirshner & Guyatt, 1985; Stewart & Archbold, 1992).

A third approach to construct validity was to compare three groups of subjects who were categorized based on length of time since surgery: Early Group (2 to 5 weeks), Middle Group (6 weeks to 3 months), and Late Group (4 to 7 months). The contrasted groups approach may be an important method to demonstrate construct validity of this proposed measure in terms of its potential sensitivity to change.

A fourth approach to construct validity was focused on convergent and discriminant validity. Subscales of the Fatigue Outcome Measure were correlated with other measures of fatigue as well as other concepts expected to be related to but not the same as fatigue. Conceptually, fatigue would be expected to be related to, but not the same as, depression, confusion, and tension in postoperative cardiac surgical patients. Based on the discriminant validity

principle, one would expect a mid-level correlation (.30 to .60) between the new measure and the POMS depression, confusion and tension scales, a moderately high negative correlation (-.60 to -.70) between the new measure and the POMS vigor scale, and a high level of correlation (>.80) between the new measure and the POMS fatigue scale.

Three scales specific to fatigue were also used to assess construct validity. A self-report of fatigue was obtained from all subjects using an 11-point <u>Self Rating</u>

<u>Scale</u> to quantify the subject's perceived fatigue. The Pearson Byars (1956) Feeling-Tone Checklist and the Multidimensional Assessment of Fatigue Scale (Tack, 1991) were also administered. A high correlation (>.80) between these three fatigue scales and the new measure would provide further evidence for construct validity (Nunnally, 1978).

#### Results

The 42 items from the newly developed instrument were evaluated by a variety of statistical and psychometric methods to determine which items were best suited for inclusion in the final version of the Fatigue Outcome Measure. The final version was evaluated for internal consistency reliability and initial construct validity.

# Item Descriptive Statistics

Frequency distributions were computed for each of the individual items. The distribution for each item was inspected to identify any items which had a narrow range of

responses at the low end of fatigue or were very positively skewed. Six items, "I have to be told what to do", "It takes too much effort to eat", "Others tell me I look tired", "I cry more easily", "All I can do is watch TV" and "My color is pale", were very positively skewed and had a narrow range of response grouped at the low end of fatigue. More than 60% of the 146 subjects answered each of these items with a response of 1 (doesn't describes me at all).

Table 5-3 lists the 42 items with the percent of subjects giving each response, the mean, standard deviation and skewness for each item, and the number and percent of missing values. The mean scores for the 42 items ranged from 1.38 to 3.61. The standard deviations ranged from .83 to 1.62 with a median value of 1.36. The nine negatively skewed items had skewness values ranging from -.03 to -.69 with a median value of -.28. The 33 positively skewed items ranged from .02 to 2.18 with a median value of .63. number of missing values ranged from 0 to 20 . Fourteen items had no missing values, 12 items had 1 missing value, and 14 items had 2 to 4 missing values. Only 2 items, "Climbing the stairs is hard for me" and "I don't have the energy to participate in sexual activity" had more than 4 missing values (10 and 20 respectively). In the sample of 146, several subjects indicated that they did not climb the stairs for reasons other than fatigue and that they either did not participate in sexual activity or chose not to

Descriptive Statistics for Items on the Fatigue Outcome Measure Table 5-3

	Fatigue Outcome Measure		qns %	Subject Res	Response					N N
#	9 J L	e.	0			o U	200	É		
		4	7	7	ti.		Mean	SD	SKew	(%) #
	Told what to do	79	6	9	9	0	1.38	0.83	2.18	1 (0.7)
2	Run out of gas	20	16	3.0	15	19	2.98	1.37	0.02	0 (0.0)
m	Can't keep going	45	16	18	10	10	2.24	1.39	0.75	3 (2.1)
4	Do more this week	16	7	18	21	39	3.61	1.45	69	1 (0.7)
S	Don't want to do anything	47	19	22	8	S	2.05	1.19	0.87	0 (0.0)
9	Hard to climb stairs	32	12	22	14	13	2.60	1.44	0.30	10(6.8)
7	Too much effort to eat	75	10	8	Ŋ	2	1.49	0.98	2.02	3 (2.1)
œ̂	Don't have the zip	30	12	33	12	12	2.64	1.35	0.22	3 (2.1)
6	Others tell me I look tired	99	12	10	9	m	1.66	1.11	1.63	4 (2.7)
10	I feel tired	20	14	31	14	14	2.76	1.37	0.17	1 (0.7)
11	I cry easily	68	11	7	7	9	1.69	1.21	1.65	3 (2.1)
12	I have to sit down and rest	12	14	33	17	23	3.25	1.30	16	0 (0.0)
13	I have a spring in my step	37	19	23	10	10	2.38	1.35	0,58	2 (1.4)
14	I take freq. rest periods	11	13	30	19	27	3.38	1,31	30	1 (0.7)
15	Body tells me to lie down	29	19	17	16	19	2.77	1.49	0.21	1 (0.7)
16	All I can do is watch TV	64	18	10	9	7	1.64	1.02	1.60	(0.0) 0
17	Don't go out as much	40	13	24	10	12	2.41	1.42	0.53	2 (1.4)
18	I have simplified my life	22	11	29	16	20	3.00	1.42	90	2 (1.4)
19	I just can't concentrate	54	10	23	10	3	1.98	1.22	0.84	1 (0.7)
20	I take naps	19	13	25	12	3.0	3.20	1.49	0.28	2 (1.4)
21	I can stay up all day	26	21	23	9	24	2.82	1.50	0.28	(0.0)

Table 5-3 (cont.)

Descriptive Statistics for Items on the Fatigue Outcome Measure

	Fatigue Outcome Measure		% Subj	ect	Response					Missing
#	Item	13	2	3ъ	4	5°	Mean	SD	Skew	(%) #
22	Body tells I have overdone	18	16	31	16	20	3.04	1.35	03	0 (0.0)
23	Enjoy a lively discussion	15	12	23	12	37	3.44	1.47	38	2 (1.4)
24	I feel wiped out	41	15	23	8	13	2.36	1.41	0.63	0 (0.0)
25	I have to pace myself	10	12	33	20	25	3.36	1.26	28	0 (0.0)
26	It's a chore to go out	47	18	17	8	10	2.17	1.36	0.88	1 (0.7)
27	My color is pale	70	10	8	5	5	1.62	1.14	1.82	3 (2.1)
28	I don't push myself	80	13	31	19	30	3.50	1.25	33	1 (0.7)
29	Simple tasks are a chore	50	16	16	w	11	2.12	1.38	96.0	0 (0.0)
30	I feel drowsy	39	16	27	6	8	2.30	1.30	09.0	1 (0.7)
31	It takes long to do things	31	2.0	26	6	14	2.55	1.37	0.46	1 (0.7)
32	I go to bed early	35	14	19	10	23	2.71	1.57	0.29	0 (0.0)
33	I feel perky	32	12	34	ω	12	2.56	1.35	0.34	2 (1.4)
34	My shoulders slump	47	14	19	ω	11	2.20	1.40	0.82	3 (2.1)
35	I just want to lie down	52	15	17	S	10	2.06	1.35	1.04	1 (0.7)
36	I feel vulnerable	45	17	15	7	13	2.23	1.44	0.83	4 (2.7)
37	I feel exhausted	45	15	21	9	11	2.22	1.38	0.80	4 (2.7)
38	Don't do things I used to	14	8	37	15	25	3.30	1.32	27	1 (0.7)
39	I feel irritable	41	12	30	10	8	2.30	1.30	0.53	0.0)
40	No energy for sex	27	10	15	10	24	2.93	1.62	0.06	20 13.7
41	I feel worn out	38	15	26	σ	12	2.40	1.38	0.54	(0.0)
42	Too much to shower & dress	09	13	15	7	Ø	1.86	1.23	1.24	0 00

\* No, doesn't describe me at all Somewhat describes me 'Yes, describes me exactly

answer the question due to its personal nature.

# Item Correlations and Scale Reliabilities

The negative items were reverse coded so that a rating of 1 indicated things more likely associated with a low level of fatigue and a rating of 5 indicated those associated with a high fatigue level. The internal consistency reliability for the 42-item measure was .97 using Cronbach's alpha. Inspection of the item-to-item correlations revealed 4 items ("I feel tired", "It's a chore to go out", "It takes longer to do things", and "I feel worn out") with very high (r = .80 or greater) inter-item correlations. Table 5-4 lists these items and the other items that approached .80 redundancy.

The 42 individual items exhibited item-total correlations (see Table 5-6) ranging from .02 to .88. Of the 42 items, nine had an item-total correlation of .80 or above.

# A Priori Scale Reliabilities and Item Statistics

Three a priori subscales were identified: 1) Experience of fatigue; 2) Impact of fatigue; and 3) Coping with fatigue. The internal consistency reliabilities for the three scales were .93, .82, and .75 respectively. Compared to the alpha of .97 for the total scale, the lower alpha for the subscales may be due in part to the smaller number of items. The range of the item-total correlations for the three scales were .46 to .83, .04 to .70, and .37 to .54

# Table 5-4

# Items Having High Item-To-Item Correlation with at Least One Correlation of .80 or Greater

Ite	m with .80 Corr.	Ite	ms with r Approaching .80	<u>r</u>
10	I feel tired	31 41 24 37 29 2	It takes longer to do things I feel worn out I feel wiped out I feel exhausted Simple tasks are a chore Run out of gas	.80 .80 .75 .73 .72
26	It's a chore to go out	41 29 17 42 24 31	I feel worn out Simple tasks are a chore Don't go out as much Too much effort to shower/dress I feel wiped out It takes longer to do things	.80 .75 .74 .72 .71
31	It takes longer to do things	41 10 8 24 37 17 26	I feel worn out I feel tired I don't have the zip I feel wiped out I feel exhausted Don't go out as much It's a chore to go out	.81 .80 .75 .75 .74
41	I feel worn out	31 26 10 24 8 5	It takes longer to do things It's a chore to go out I feel tired I feel wiped out Don't have the zip I don't want to do anything	.81 .80 .78 .75

respectively. Four of the 15 items (27%) comprising the Experience scale had a item-total correlation of .80 or above indicating possible redundancy of the items. All of the 19 Impact scale items and all of the 8 Coping scale items had item-total correlations of less than .80. Table 5-5 lists the item-total correlations for the three scales.

The three scales, were highly intercorrelated:

Experience with Impact = .93; Experience with Cope = .81;

and Cope with Impact = .81. One would expect the scale-toscale correlations to be consistently lower than the
internal consistency reliabilities of the scales if they
measured distinctly separate concepts. The high scale-toscale correlations suggested higher than desirable overlap
of content and further consideration of the three a priori
scales was discontinued.

### Elimination and Retention of Items

The three major categories for item elimination were:

1) evidence that the item was not sensitive to change; 2)

statistical and psychometric evidence of a faulty item; and

3) evidence of poor wording or lack of conceptual fit. A

matrix (see Table 5-6), consisting of a list of the 42 items

and the five specific criteria for elimination, was

developed to assist with the item elimination decisions.

Items meeting a single criterion in any category were

considered for elimination.

Because the scale is intended to be used as an outcome

Table 5-5

Item-Total Correlations For Three A Priori Subscales

Experience of Fatigue									
9 Others I look tired	.58	33 I feel perky	.64						
10 I feel tired	.82	34 Shoulders slump	.46						
13 Spring in my step	.59	35 Just want to lie down	.77						
15 Body tells to lie down	.66	36 I feel vulnerable	.57						
22 Body tells meoverdone	.62	37 I feel exhausted	.83						
24 I feel wiped out	.82	39 I feel irritable	.53						
27 My color is pale	.48	41 I feel worn out	.87						
30 I feel drowsy	.66								
	Impact o	f Fatigue							
1 Told what to do	.22	17 Don't go out as much	.70						
2 Run out of gas	.66	19 I just can't concentrate	.33						
3 I can't keep going	.39	23 Enjoy lively discussion	.34						
4 Do more this weeklast	.04	26 It's a chore to go out	.68						
5 Don't want to do anything	.61	29 Simple tasks are a chore	.77						
6 Hard to climb stairs	.24	31 Takes longer to do things	. 67						
7 Too much effort to eat	.51	38 Don't do things I used to	.43						
8 I don't have the zip	.43	40 No energy for sex	.31						
11 I cry more easily	.28	42 Effort to shower/dress	.60						
12 Sit down and rest	.61								
C	oping wi	th Fatigue							
14 Take frequent rests	.50	21 I can stay up all day	.48						
16 All I can do is watch TV	.48	25 I have to pace myself	.55						
18 Have simplified my life	.40	28 I don't push myself	.37						
20 I take frequent maps	.40	32 I go to bed early	.48						

Table 5-6 Criteria for Elimination Matrix

Item	Change	S	Statistics		
	t-value (p)	Mean	I-T	Corr*	Probb
1 I have to be told what to do	3.22 (.002)	*1.38	.55	.40	
2 I frequently "run out of gas"	4.95 (.000)	2.98	.74	.67	
3 I can't keep going	4.57 (.000)	2.24	.72	.57	
4 Do more this week than last week <sup>E</sup>	*-0.38 (.703)	3.61	.02	*09	* *
5 I don't want to do anything	4.43 (.000)	2.05	.74	.66	
6 Climbing the stairs is hard for me	4.07 (.000)	2.60	.51	.43	**
7 It takes too much effort to eat	4.60 (.000)	*1.49	.59	.39	
8 I don't have the zip to do things	4.66 (.000)	2.64	*.81	.61	
9 Others tell me that I look tired	2.45 (.018)	*1.66	.57	.43	
10 I feel tired <sup>E</sup>	6.20 (.000)	2.76	*.83	.69	
11 I cry more easily than I used to <sup>E</sup>	*1.98 (.053)	*1.69	.31	*.27	
12 I have to sit down and rest	5.90 (.000)	3.25	.72	.65	
13 I have a spring in my step	7.08 (.000)	2.38	.58	.60	
14 I take frequent rest periods	7.49 (.000)	3.38	-67	.52	
15 My body tells me I must lie down	6.15 (.000)	2.77	.71	.61	
16 All I can do is watch TV	4.66 (.000)	*1.64	.59	.39	
17 I don't go out as much <sup>s</sup>	5.72 (.000)	2.41	*.83	.66	
18 I have simplified my life <sup>2</sup>	2.34 (.000)	3.00	.57	.46	* *
19 I just can't concentrate	3.55 (.000)	1.98	.62	.56	
20 I take naps	4.54 (.000)	3.20	.58	.43	
21 I can stay up all day	3.48 (.001)	2.82	.56	.49	
22 My body tells me I have overdone	1.98 (.053)	3.04	.63	.55	
23 I enjoy a lively discussion	4.26 (.000)	3.44	.38	.32	* *
24 I feel wiped out <sup>E</sup>	4.64 (.000)	2.36	*.83	.65	
25 I have to pace myself	3.38 (.001)	3.36	.58	.52	
26 It's a chore to go out	4.52 (.000)	2.17	*.81	.59	
27 My color is pale	3.65 (.001)	*1.62	.50	.40	* *
28 I don't push myself like I used to	2.78 (.008)	3.50	.43	.36	* *
29 Simple tasks are a chore <sup>s</sup>	4.02 (.000)	2.12	*.84	.62	
30 I feel drowsy	4.33 (.000)	2.30	.67	.55	
31 It takes longer to do things	5.90 (.000)	2.55	*.86	.68	
32 I go to bed early <sup>E</sup>	*1.70 (.096)	2.71	.49	.37	* *

Table 5-6 (Cont.) Criteria for Elimination Matrix

Item	Change	<u>s</u> 1	tatistic	:8	Concp
	t-value (p)	Mean	I-T	Corr*	Probb
33 I feel perky	5.55 (.000)	2.56	.63	.58	
34 My shoulders slump	4.63 (.000)	2.20	.48	.37	àх
35 I just want to lie down	5.00 (.000)	2.06	.78	.55	
36 I feel vulnerable	5.69 (.000)	2.23	.58	.50	
37 I feel exhausted	5.06 (.000)	2.22	*.84	.64	
38 I don't do the things I used to do	4.98 (.000)	3.30	.53	.42	
39 I feel irritable	4.07 (.000)	2.30	.53	.42	
40 No energy for sexual activity	7.95 (.000)	2.92	.53	.42	
41 I feel worn out <sup>s</sup>	4.24 (.000)	2.40	*.88	.68	
42 Too much effort to shower/dress	5.72 (.000)	1.86	.70	.49	

- Correlation with Self-Report of Fatigue Conceptual Problem Item eliminated

- Consider for elimination
- \*\* See text for explanation

measure for nursing interventions, an important characteristic of the final measure was sensitivity to change. To evaluate the sensitivity of individual items to change, the measure was administered to subjects at 2 to 5 weeks following cardiac surgery and again 4 to 6 weeks later. Paired <u>t</u>-tests were calculated on the subjects' responses to each item to determine the sensitivity of the item to change. Items were considered for elimination if no significant change occurred (i.e., the <u>p</u>-value was > .05).

Statistical and psychometric reasons for consideration of item elimination included the following: (1) items with extremely low means (1.70 or less to identify the items with a restricted range of response); (2) items with very high item-total correlations (.80 or greater to identify redundant items); and (3) items which correlated poorly (<.30) with the subjects' perception of fatigue (measured by the self-report of fatigue).

Conceptual reasons for eliminating items were based on the logical relationship of the item to fatigue in the study population. Some of the items may be indicators of phenomena other than fatigue. For example, several subjects wrote notes in the margin of the instrument indicating that they did not climb stairs because of arthritis rather than fatigue or that they have always gone to bed early. Others indicated that they had simplified their life and stopped pushing themselves due to their underlying heart disease or

because of retirement. Three other items, "I enjoy a lively discussion", "My color is pale", and "My shoulders slump" were also mentioned by subjects as not new nor necessarily related to their fatigue.

None of the scale items met all elimination criteria; however two items ("I can do more this week than last week" and "I cry more easily than I used to") each met three. The item "I can do more this week than last week" did not change significantly (p = .703) between measurement times and was not correlated (r = .09) to the perception of fatigue. Conceptually, the item measures perceived change and may not be a good item to capture changes in the absolute levels of fatigue. The item "I cry more easily than I used to" had only a slight positive correlation (r = .27) with the subjects' perception of fatigue; there was not a significant change (p = .053) between measurement Time 1 and Time 2; and the mean was 1.68, indicating a high proportion of the subjects indicated it did not describe them at all. These two items were eliminated.

Because sensitivity to change and conceptual congruency were high priorities, items that had problems in both of these areas were considered for elimination next.

Conceptually "I go to bed early" may indicate a life-long behavior rather than a strategy to manage fatigue. The response to this item did not change significantly (p =.096) from measurement Time 1 to Time 2. This item was

eliminated.

Several subjects indicated that "I have simplified my life" was much more closely related to retirement or the presence of underlying cardiac disease than to postoperative fatigue. The response to this item did change ( $\underline{p}$  =.000) from Time 1 to Time 2 but the evidence for conceptual incongruence was compelling; therefore this items was also eliminated.

The second priority for item elimination was to reduce the redundancy. "I feel worn out" had the highest corrected item-total correlation (.88) and therefore was eliminated. Three other items with high item-total correlations, "I feel tired" (.83), "I feel wiped out" (.83), and "I feel exhausted" (.84), also had high item-to-item correlations (see Table 5-5). The item "I feel exhausted" was kept because it did not have as many high item-to-item correlations; the other two items were eliminated. Four more items from the impact of fatigue subscale had high item-total correlations. ("I don't go out as much as I used to" .83, "It's a chore to go out" .81, "Simple tasks are a chore" .84, "It takes longer to do things" .86). Two of these four items were eliminated based on conceptual considerations or lack of clarity in the wording of the item. "I don't go out as much as I used to" was eliminated because it seems to denote a lifestyle change that may not be based solely on postoperative fatigue. "Simple tasks are

a chore" was chosen for elimination because the word 'chore' may be confusing in the context of the sentence. The remaining 33 items were used for further analysis.

# Construct Validity

Evidence for initial construct validity of the newly developed Fatigue Outcome Measure was gathered using several methods. Factor analysis was used to further refine the instrument and the resulting subscales were used for subsequent analysis.

# Factor Analysis

Factor analysis was used to organize the remaining 33 items into factors and assist in the decision to retain or eliminate items. Inspection of the loadings based on a 3-factor solution did not substantiate the three hypothesized fatigue factors. However, two factors emerged from the two-factor solution that seemed to make sense conceptually. Table 5-7 displays the items with loadings greater than .40 on Factor 1 and Factor 2 using first the orthogonal and then the oblique factor solution.

Factor 1. Table 5-7 organizes 17 items loading on
Factor 1 from highest to lowest loadings according to the
orthogonal solution. Six additional items that loaded high
on both Factors 1 and 2 are displayed in the Factor 2
section. Of the 23 items loading .40 or greater on Factor
1, 9 were not included in the final Factor 1 scale because
they also had high loadings on Factor 2 and there was no

		Factor 1		Factor 2	
	Factor 1 Items		Obliq	Ortho	Obliq
12	I have to sit and rest	.78	.89	.23	11
31	It takes longer to do things	.77	.77	.44	.15
2	I frequently run out of gas	.70	.74	.33	.05
8	I don't have the zip	.70	.70	.42	.17
22	Body tells me I have overdone	.69	.78	.19	12
14	I take frequent rest periods	.69	.76	.26	03
15	My body tells me to lie down	.66	.68	.35	.09
38	Don't do the things I used to	.62	. 65	.32	.08
13	I have a spring in my step	.60	.66	.23	03
20	I take naps	.59	. 64	.23	01
25	I have to pace myself	.56	.60	.24	.01
33	I feel perky	.56	.56	.34	.13
6	Climbing the stairs is hard	.52	.57	.19	03
30	I feel drowsy	.50	.43	.46	.46
28	I don't push myself	.46	.52	.14	06
21	I can stay up all day	.45	.40	.36	.22
40	No energy for sexual activity	.42	.37	.36	.23
		Factor 1		Factor 2	
	Factor 2 Items	Ortho Obliq		Ortho	Obliq
7	Too much effort to eat	.18	09	.71	.79
1	Have to be told what to do	.14	14	.71	.81
37	I feel exhausted	.55	.40	.67	.55
16	All I can do is watch TV	.23	01	.66	.71
35	I just want to lie down	.49	.33	.64	.54
19	I just can't concentrate	.31	.12	.60	.59
26	It's a chore to go out	.57	.46	.59	.44
5	I don't want to do anything	.48	.35	.58	.48
9	Others tell me I look tired	.27	.09	.57	.57

Table 5-7 (Cont.)
Factor Loadings for Items with Loadings > .40

		Factor 1		Factor 2	
	Factor 2 Items	Ortho	Obliq	Ortho	Obliq
42	Too much to shower & dress	.52	.44	.49	.34
3	I can't keep going	.55	. 47	.49	.33
36	I feel vulnerable	.35	.22	.49	.43
27	My color is pale	.26	.11	.49	.47
23	I enjoy a lively discussion	.11	07	.47	.52
34	My shoulders slump	.26	.14	.44	.41
39	I feel irritable	.33	.23	.42	.36

clear conceptual reason to keep them for the Factor 1 scale. One item, "climbing the stairs is hard for me", was eliminated because several subjects wrote notes to the investigator indicating that reasons other than fatigue (such as arthritis) made it difficult for them to climb stairs. Figure 5-1 presents the loadings of the items on Factors 1 and 2 using the oblique factor solution in the form of a graph. The graph clearly displays that the remaining 13 items demonstrate a high loading on Factor 1 and a low loading on Factor 2.

Conceptually, these 13 items describe a state of fatigue that is frequently observed clinically as a normal part of the recovery process following cardiac surgery. The individual is listening to internal cues and coping with fatigue in a constructive way. The individual is clearly in control of his fatigue. Several names were considered for this scale such as Functional fatigue and Controlled fatigue. Because these names may have a different meanings for health care providers as well as the general population, these names were rejected in favor of simply the <u>FOM Fatigue</u> scale.

Factor 2. Table 5-7 also organizes the 16 items loading on Factor 2 from highest to lowest loadings according to the orthogonal solution. Three additional items that loaded high on both Factors 1 and 2 are displayed in the Factor 1 section. Of the 19 items loading .40 or

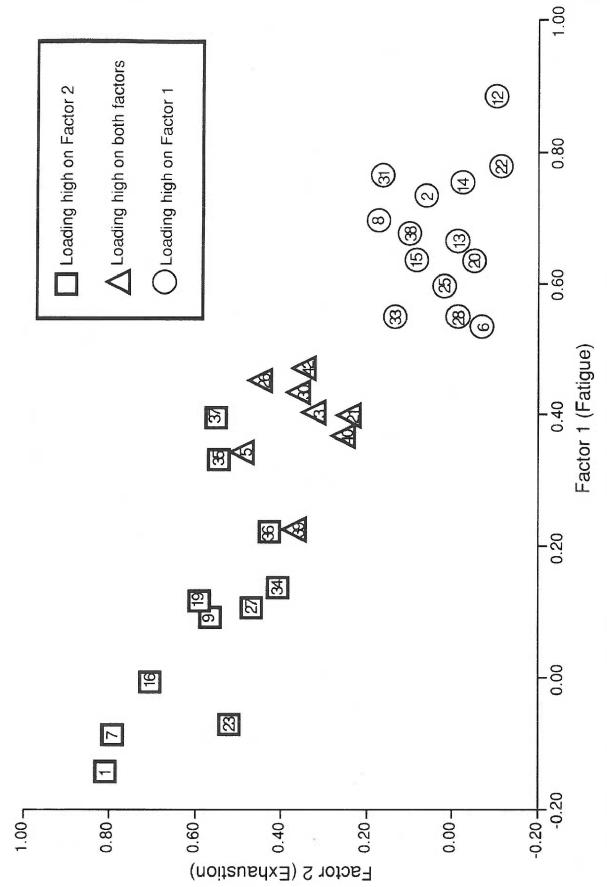


Figure 5-1. Items loading on Factor 1 (Fatigue) and Factor 2 (Exhaustion)

greater on Factor 2, 6 were eliminated from the Factor 2 scale because they also had high loadings on Factor 1 and there was no clear conceptual reason to keep them for the Factor 2 scale. Two items "my color is pale" and "my shoulders slump" were eliminated because subjects wrote notes to the investigator indicating that these characteristics were not new nor necessarily related to their fatigue. The item "others tell me I look tired" was eliminated because it assumes that another person is available and would actually tell the person that he looks The items "I feel vulnerable" and "I feel irritable" tired. were eliminated because the items may represent a concept other than fatigue. Figure 5-1 depicts that the remaining 8 items demonstrate a high loading on Factor 1 and a relatively low loading on Factor 2 using the oblique solution. Two items "I feel exhausted" and "I just want to lie down" loaded relatively high on Factor 1 as well as Factor 2 particularly when using the orthogonal solution. Because these items seemed to fit better conceptually with Factor 2 items, they were included in the Factor 2 scale.

Conceptually, these 8 items describe a state of exhaustion and debilitation. There is a sense of dysfunction and inability to cope with fatigue in a constructive way. After the first or second week, this state is not usually seen clinically as a part of the recovery process following cardiac surgery. The fatigue is

clearly controlling the individual. Names such as Non-Functional fatigue and Uncontrolled fatigue were considered for this scale. The name <u>FOM Exhaustion</u> scale was chosen because it clearly captures the feeling state that this scale measures. It is a term that both health care providers and the general public understands and it does not <u>label</u> the client as dysfunctional.

# Scale Reliabilities, Correlations, and Item Statistics

The internal consistency reliabilities for the two scales, FOM Fatigue and Exhaustion, were .93 and .88 respectively. Cronbach's alpha for both scales meet Nunnally's (1978) criterion of .80 or higher for mature scales. The correlation between the two scales is moderately-high ( $\underline{r}$  =.72) but lower than Cronbach's alpha, suggesting the presence of two separate dimensions.

The ranges of the item-total correlations for the two scales were .47 to .82 and .45 to .81 respectively. All of the items comprising the FOM Fatigue and Exhaustion scales had item-total correlations of .30 or above for their respective scales. Table 5-8 lists the item-total correlations for the scales.

Descriptive statistics for the FOM Fatigue scale were:
mean 3.15, standard deviation .99, and skewness .04.

Descriptive statistics for the FOM Exhaustion scale were:
mean 1.92, standard deviation .88, and skewness 1.08. One
subject was missing more than 25% of the items on the FOM

Table 5-8

Item-Total Correlations for Fatigue and Exhaustion Scales

	Item-Total correlation				
	Fatigue Scale				
1.	I frequently "run out of gas"	.74			
8.	I don't have the zip to do things	.79			
12.	I have to sit down and rest	.77			
13.	I have a spring in my step	. 65			
14.	I take frequent rest periods	.70			
15.	My body frequently tells me to lie down	.72			
20.	I take naps	.60			
22.	My body tells me I have overdone	.65			
25.	I have to pace myself	.59			
28.	I don't push myself like I used to	.47			
31.	It takes me longer to do things	.82			
33.	I feel perky	.64			
38.	I don't do the things I used to do	.68			
	Exhaustion Scale				
1.	I have to be told what to do	.65			
5.	I don't want to do anything	.67			
7.	It's too much effort to eat	.66			
16.	All I can do is watch TV	.64			
19.	I just can't concentrate	.66			
23.	I enjoy a lively discussion	.45			
35.	I just want to lie down	.72			
37.	I feel exhausted	.81			

Exhaustion scale and was excluded from further analysis.

## Evidence for a Two-Dimensional Scale

The relationship between the two postulated dimensions, fatigue and exhaustion, was explored during subsequent analysis. The moderately-high (but lower than Cronbach's alpha) correlation between the FOM Fatigue and Exhaustion scales suggests the presence of two separate dimensions. Fatigue and exhaustion could be on a continuum, with exhaustion being a more intense form of fatigue, or they could be separate but related dimensions. Figure 5-2 presents a scatterplot depicting the relationship between the FOM Fatigue and Exhaustion scores. On the scatterplot, all but one point falls in the lower triangular portion on or below a diagonal equivalent to the equation, Exhaustion score = Fatigue score. Fatigue scores are consistently higher than Exhaustion scores indicating that subjects who score high on the Exhaustion scale also suffer from fatigue. In only one case, is a subject's Exhaustion score higher than her Fatigue score (1.83 and 1.72 respectively). female subject responded to the questionnaire 3 weeks following surgery and declined to participate a second time. She did not provide any information that would explain why her exhaustion score is higher than her fatigue score. left one Exhaustion item blank and responded (1) "No, that doesn't describe me at all" to 6 of the remaining 8 items. "It takes almost too much effort to eat" was the only

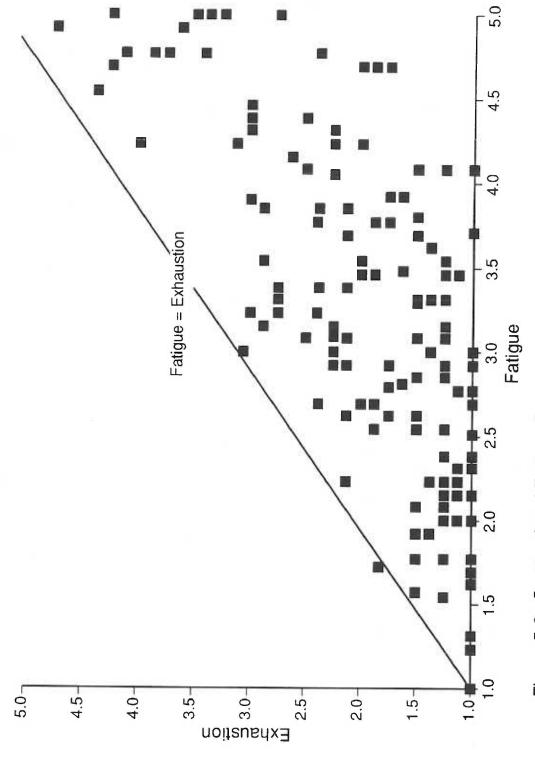


Figure 5-2. Scatterplot of Fatigue Scores with Exhaustion Scores

Exhaustion item that she marked a response slightly higher (2) than the rest.

If fatigue and exhaustion are indeed separate dimensions, one would expect the scales to behave differently in a variety of ways. For example, a different pattern of correlation with other scales may occur. hypothesized that FOM Exhaustion scores would be more highly correlated with POMS depression and confusion scores than FOM Fatigue scores would correlate with depression or confusion. One might also expect exhaustion to be associated with symptoms of physical illnesses such as chronic lung disease or arthritis. Although data were not collected systematically on those latter variables, qualitative data were examined to explore those and other similar associations with exhaustion. Initial evidence suggests two separate dimensions. Further evidence was sought during subsequent analysis.

# Convergent and Discriminant Validity

The FOM Fatigue and Exhaustion scales were correlated with three scales specific to fatigue and the six POMS scales. These correlations confirmed the hypothesis that the FOM Fatigue scale would correlate highly (.80 or greater) with the other measures of fatigue, and moderately-high and negative with vigor (-.70 or less), and moderately (.30 to .60) with anger, tension and depression. Table 5-9 lists the correlations.

Table 5-9
Convergent and Discriminant Validity

	Fatigue	Exhaustion
Convergent Validity	r	r
Self-Report of Fatigue	.77	.67
Global Fatigue Index (MAF)	.85	.76
Pearson-Byars Fatigue Scale	.69	.62
POMS Fatigue Scale	.83	.80
POMS Vigor Scale	74	66
	Fatigue	Exhaustion
Discriminant Validity	r	r
POMS Anger Scale	.35	.36
POMS Confusion Scale	.35	.43
POMS Tension Scale	.50	.53
POMS Depression Scale	.47	.53

Convergent Validity. The FOM Fatigue Scale correlated highly with the MAF Global Fatigue Index ( $\underline{r}$  =.85) and the POMS Fatigue scale ( $\underline{r}$  =.83). Moderately-high correlations were found between the FOM Fatigue scale and the Self-Report of Fatigue ( $\underline{r}$  =.77) and the Pearson Byars Feeling-Tone Checklist ( $\underline{r}$  =.69). [NOTE: The Pearson Byars Feeling-Tone Checklist did not correlate highly with any of the other scales specific to fatigue ( $\underline{r}$  =.66 with Self-Report of Fatigue;  $\underline{r}$  = .69 with POMS Fatigue scale;  $\underline{r}$  = .75 with MAF Global Fatigue Index.)] A moderately-high negative correlation ( $\underline{r}$  =-.74) with the POMS Vigor subscale was found as expected.

The correlations between the <u>FOM Exhaustion Scale</u> and the scales specific to fatigue were all moderately-high but .03 to .10 lower than the correlations of the FOM Fatigue scale with the other scales specific to fatigue. These results suggest that the FOM Exhaustion scale may measure a different dimension of fatigue. However, these correlations may also be a result of the smaller number of items on the FOM Exhaustion scale or its smaller standard deviation, both of which tend to lower correlations with other variables.

Discriminant Validity. The FOM Fatigue Scale correlated moderately (.30 to .60) with the POMS Anger, Confusion, Tension and Depression scale. The Anger and Confusion scales had low-moderate ( $\underline{r}$  = .35) correlations with the FOM Fatigue scale; while Tension and Depression

correlated somewhat higher at  $\underline{r}$  =.50 and .47 respectively. Based on the discriminant validity principle, the FOM Fatigue scale should be correlated with anger, confusion and depression at lower levels than with other fatigue measures indicating that these differing constructs are related to but not the same as fatigue.

The <u>FOM Exhaustion Scale</u> also correlated moderately with the POMS Anger, Confusion, Tension, and Depression scales, but in a slightly different way. The Anger scale had the same low-moderate ( $\underline{r}$  = .36) correlation with the FOM Exhaustion scale as it did with the FOM Fatigue scale. The correlations with the Confusion, Tension, and Depression scales ( $\underline{r}$  = .43, .53, and .53 respectively) were higher than the correlations with the FOM Fatigue scale ( $\underline{r}$  = .35, .50, and .47 respectively). Although not statistically significant, the difference in the magnitude of the  $\underline{r}$ 's provide further evidence that the FOM Fatigue and Exhaustion scales may measure a different dimension of fatigue.

#### Sensitivity to Change

The most definitive evidence of construct validity for an outcome measure is documentation of longitudinal within-subject change in the expected direction (Kirshner and Guyatt, 1985; Stewart and Archbold, 1993). Therefore the new measure was assessed for sensitivity to change using a longitudinal and cross sectional approach.

Longitudinal Sensitivity to Change. The longitudinal

sensitivity to change of the two scales was assessed by comparing the mean scores of each scale at two time periods 4 to 5 weeks apart (Table 5-10). The instrument was administered to 50 subjects during the first 2 to 5 weeks following surgery (Time 1) and again 4 to 6 weeks later (Time 2). These two time periods were selected based on the difference in the expected level of fatigue (King and Parrinello, 1988). Using paired  $\underline{t}$ -tests, the mean scores on the FOM Fatigue scale at Time 1 were significantly ( $\underline{p}$  =.000) higher than at Time 2. The moderate correlation ( $\underline{r}$  =.44) between Time 1 and Time 2 indicates that the relative position of subjects on the FOM Fatigue scale varies from Time 1 to Time 2 suggesting that fatigue is more of a state than a trait in this population.

Using paired  $\underline{t}$ -test, the mean scores on the FOM Exhaustion scale at Time 1 were also significantly ( $\underline{p}$  =.000) higher than at Time 2; however, the magnitude of change was less. The moderate correlation ( $\underline{r}$  =.48) between Time 1 and Time 2 suggests that, like fatigue, exhaustion is more of a state than a trait in this population.

Table 5-10

Longitudinal Sensitivity to Change

Scale	Time 1 Mean(SD)	Time 2 Mean(SD)	Corr.	t-value (p-value)
Fatigue	3.56 (.96)	2.55(.81)	.44	7.50(.00)
Exhaustion	2.21(1.10)	1.43(.47)	.48	5.71(.00)

Scatterplots of the individual scores at Time 1 and Time 2 for the FOM Fatigue and Exhaustion scales are displayed in Figures 5-3 and 5-4. Examination of these scatterplots provides further evidence of the difference between these two scales. Fatigue scores were relatively high (> 3.0) at Time 1 and lower at Time 2 (<3.0). For some subjects, the FOM Fatigue score decreased over time suggesting that fatique resolves gradually; however. approximately 24% of subjects continued to experience a high (> 3.5) level of fatigue 4 to 7 months after surgery. Conversely, for most subjects (70%), FOM Exhaustion scores were fairly low (2.5 or less) at both Time 1 and Time 2. the 50 subjects, 6 (12%) had exhaustion scores of 1 (no exhaustion) at Time 1 and by Time 2 16 (32%) had exhaustion scores of 1. These results suggests that exhaustion is not necessarily a part of the usual post operative experience.

Cross Sectional Sensitivity to Change. To further describe the sensitivity of the Fatigue Outcome Measure to change, the entire sample (n=146) was divided into three groups based on the length of time since surgery: Early Group (2 through 5 weeks), Middle Group (6 weeks through 3 months), and Late Group (4 through 7 months). It was hypothesized that fatigue would be lower in groups further from surgery. The FOM Fatigue and Exhaustion mean scores are presented in Table 5-11 and were compared using a one-way analysis of variance (ANOVA). Following the significant

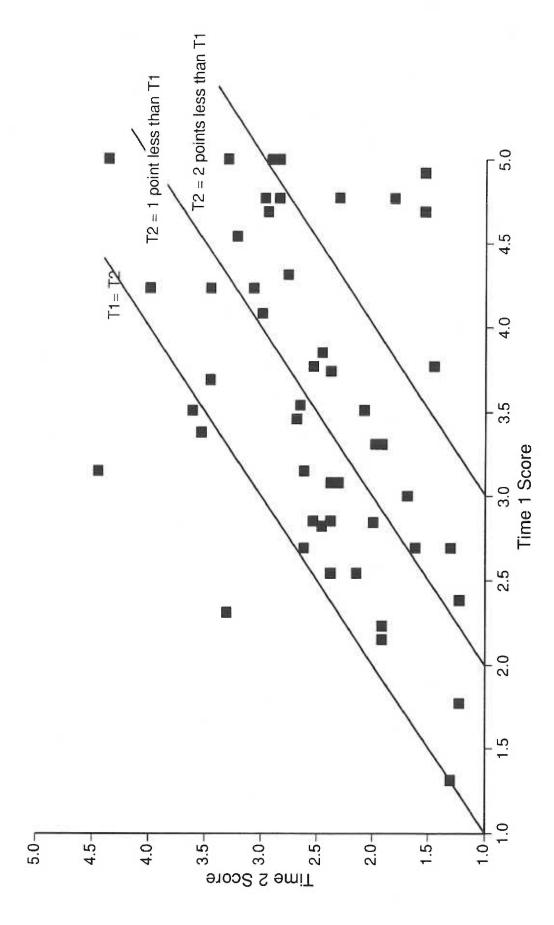


Figure 5-3. Individual Fatigue Scores at Time 1 and Time 2

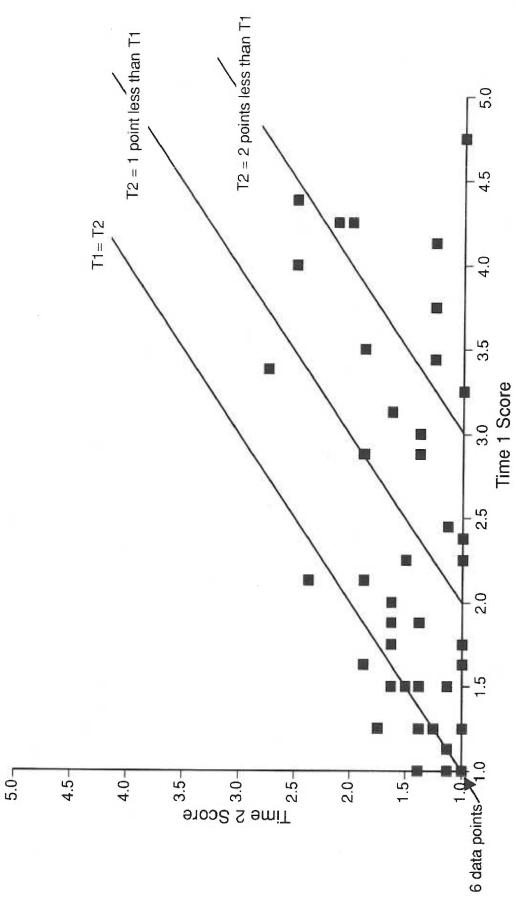


Figure 5-4. Individual Exhaustion Scores at Time 1 and Time 2

F in the ANOVA,  $\underline{t}$ -tests (using the least-significant-difference method) were used to test the hypothesized group differences. As expected, the Early Group mean FOM Fatigue score was significantly ( $\underline{p} = <.05$ ) higher than both the Middle and Late Groups; however, the Middle Group mean FOM Fatigue score was not higher than the Late Group mean score. The Early Group mean FOM Exhaustion score was significantly ( $\underline{p} = <.05$ ) higher than the Late Group but not higher than the Middle Group as hypothesized. The Middle and Late Groups were not significantly different on the FOM Exhaustion scale.

Planned comparisons of the 3 groups were made first using Scheffe's method because the sample size of the three groups was not equal. After obtaining the results, it was felt that the more conservative Scheffe's method may not have been able to detect the hypothesized differences among groups. Although the chance of a Type 1 error was increased, <u>t</u>-tests were used as a less conservative test. Both tests produced the same results.

Table 5-11 Cross-Sectional Differences

Scale	Weeks Post Surgery			Groups Sig	
	Gp 1 <sup>a</sup> n=59	Gp 2 <sup>b</sup> n=32	Gp 3 <sup>C</sup> n=56	Different <sup>d</sup>	
Fatigue	Mean (SD) 3.51 (.99)	Mean (SD) 3.00 (.91)	Mean (SD) 2.87 (.92)	Group 1 > 2 Group 1 > 3	
Exhaustion	Mean (SD) 2.15 (1.07)	Mean (SD) 1.91 (.82)	Mean (SD) 1.67 (.56)	Group 1 > 3	

- a Group 1 = Early Group (2 weeks to 5 weeks post surgery)
- b Group 2 = Middle Group (6 weeks to 3 months post surgery)
  c Group 3 = Late Group (4 to 7 months post surgery)

d p < .05 significance level

The distributions of FOM Fatigue and Exhaustion scores from these three groups are displayed in Figures 5-5 and 5-These graphs illustrate both the differences and the overlap in the distributions of scores for the three groups. The distribution of FOM Fatigue scores (Figure 5-5) for the Early Group had two main peaks, one in the middle at 3.3 (Somewhat describes me) and the highest at 4.8 (Yes, describes me exactly). The distribution of scores for the Middle Group had small peaks at each end and a major peak in the center at 3.3. As expected, the scores for the Late Group were spread over the low end (No, doesn't describe me at all) of the distribution curve and tapered off at the high end; however 24% of this group continued to report high (>3.5) levels of fatigue.

The distribution of the scores on the FOM Exhaustion scale (Figure 5-6) was positively skewed for each of the three groups and very different from the corresponding

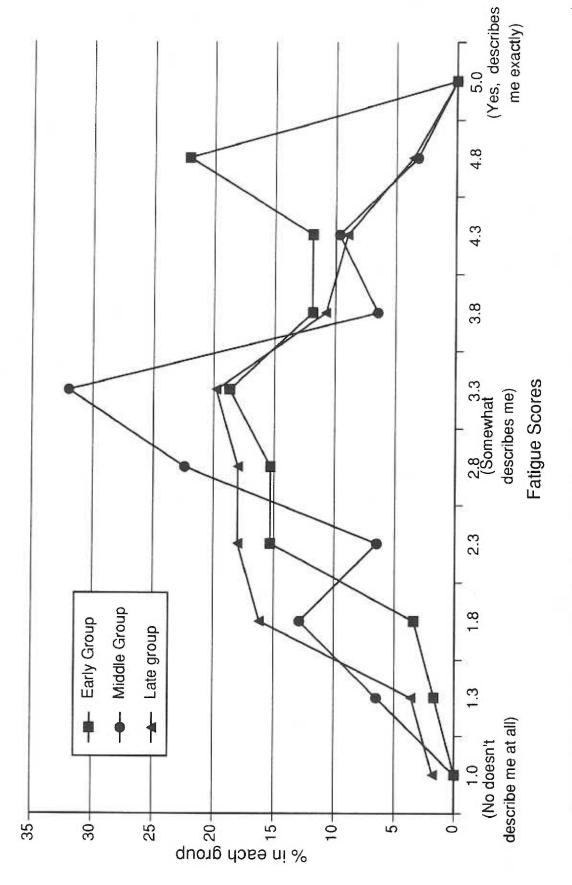


Figure 5-5. Frequency Distributons of Fatigue Scores of 3 groups based on time since surgery.

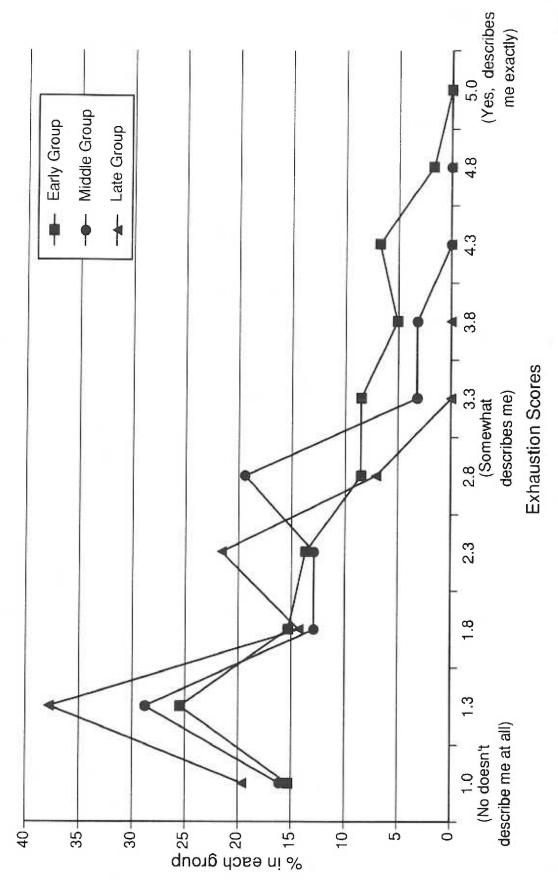


Figure 5-6. Frequncy Distribution of Exhaustion Scores of 3 groups based on time since surgery.

distribution on the FOM Fatigue scale. The scores for all three groups were clustered around the low end (No, doesn't describe me at all) of the distribution curve. About 20% of the Early and Middle Group scores were clustered in the center (Somewhat describes me). About 10% of the Early Group scores were at the high end (Yes, describes me exactly) while none of the Middle Group scores were above 3.8. The scores of the Late Group had a bimodal distribution with a major peak at 1.3, a smaller peak at 2.3, and then a dramatic drop. None of the Late Group FOM Exhaustion scores was above the middle response category (3.0).

The results of the contrasted groups approach, provide evidence that the new measure has potential to be sensitive to changes in fatigue over time. Whether it is able to detect a change as a result of a nursing intervention is yet to be determined.

#### Summary

Evidence of construct validity for the Fatigue and Exhaustion scales from the Fatigue Outcome Measure has been provided. In addition, preliminary evidence for two separate dimensions has been gathered. The purpose of the new instrument is an outcome measure for nursing interventions designed to lower the perception of fatigue following cardiac surgery. Therefore, the most convincing evidence of construct validity is the sensitivity of the new

measure to change.

#### CHAPTER 6

#### Discussion and Conclusions

A discussion of the study results, including comparisons between findings from this study and other studies, are presented in this section. Strengths and limitations of the study are discussed. Implications for nursing practice and research conclude this section.

#### Discussion of Results

# Phase I: Qualitative Phase

Previous nursing research has provided support for the presence of fatigue following cardiac surgery (Gortner, Rankin, & Wolf, 1988; Jenkins, Stanton, Savageau, Denlinger, & Klein, 1983; King & Parrinello, 1988); however, there has been no previous research which describes the nature of fatigue associated with cardiac surgery or examines the fatigue experience in this population. Thus, studies describing fatigue in other illnesses, such as rheumatoid arthritis (Tack, 1990) and chemotherapy for ovarian cancer (Jamar, 1989), were used to compare the experience of fatigue among these three populations.

Three major concepts emerged from pilot work and were supported by the qualitative data analysis in this study:

(1) Sensations/experience of fatigue; (2) Impact of fatigue on lifestyle; and (3) Coping with fatigue. The sensations/experience of fatigue included the subconcepts of physical signs and subjective feelings. Most of these

physical signs such as pale color, rounded shoulders, and drooping face, were described by the subjects' spouse rather than the subject in this study. Tack (1990) used the question "How do other people know you are fatigued?" to elicit physical signs. Respondents in her study stated that their eyes were different or not as bright. One woman said that her whole countenance was different: facial expression, eyes, the way she carried herself, and her posture. Rhoten (1982) used many of these physical signs in her observation checklist designed for general postoperative patients. It is possible that subjects themselves do not necessarily notice their own physical signs unless related to how someone else sees them.

The subconcept <u>subjective feelings</u> included descriptors such as tired, worn out, weak, exhausted, and run down. In a study of women receiving chemotherapy for ovarian cancer, Jamar (1989) found that subjects used these words and phrases frequently and labeled them "descriptors related to changes in energy level". These words and phrases are commonly used in the entire fatigue literature and are included in most fatigue measurement scales that assess severity of fatigue.

In this study, the descriptions surrounding impact of fatigue on lifestyle told of how fatigue interfered with daily activities such as bathing, dressing, reading, concentrating, and other physical and mental activities.

Subjects also described situations, both physical and emotional, which adversely affected fatigue or their response to it. Tack (1990) used the category "consequences" to group similar descriptions of the impact of fatigue in subjects with rheumatoid arthritis.

Respondents in her study indicated that the consequences of fatigue included irritability with self and others, frustration due to an inability to complete a task, and overwhelming sense of helplessness and hopelessness, strained relationships, and lack of control.

Many activities that subjects used to manage fatigue in this study were related to taking naps, resting, or pacing activities and were labeled coping with fatigue. subjects used strategies such as maintaining a positive attitude and making themselves do just a little more or used diversional activities such as watching TV or listening to music to cope with fatigue. Tack (1990) and Jamar (1989) reported similar coping strategies in their study populations. Almost all of the subjects in this study mentioned the importance of a spouse, adult child or other caregiver in their ability to cope with fatigue. Tack used the term "energy enhancers" to describe strategies used to manage fatigue and the term "social resources" to describe the assistance family and friends provided that enhanced energy.

Many of the descriptions of fatigue related to physical

and mental illness found in the literature are very similar. Studies which examine the pattern of fatigue in various illnesses indicate differences. Tack (1990) found that the pattern of fatigue associated with rheumatoid arthritis varied based on factors such as disease activity, emotional stress, and treatment (dose of steroids). The pattern of fatigue described by 16 women treated for ovarian cancer was portrayed as worse fatigue at the beginning of the chemotherapy cycle and less fatigue in the later weeks (Jamar, 1989). The pattern of fatigue described by the 8 subjects in the current qualitative study was one of decreasing intensity over time. Factors that temporarily increased fatigue were factors that slowed the overall recovery process. Complications such as an irregular heart rhythm, a wound infection, and reactions to medications were identified by the respondents in this study.

# Phase III: Psychometric Evaluation the New Fatique Outcome Measure

During psychometric evaluation of the Fatigue Outcome Measure (FOM), factor analysis was employed to determine the presence of any dimensions. The two factor solution suggested the presence of two scales, <a href="Fatigue">Fatigue</a> and <a href="Exhaustion">Exhaustion</a>, that make sense clinically and conceptually.

## FOM Fatique Scale

The FOM Fatigue scale consists of items that portray feelings such as "I don't have the zip" and "My body

frequently tells me that I have overdone" that many subjects used to describe the fatigue that is commonly associated with cardiac surgery. Items such as "I frequently 'run out of gas'" and "It takes longer to do things" describe the impact of fatigue on day-to-day activities. Items that describe constructive coping strategies commonly used during the recovery process (I take naps, I take frequent rest periods, and I have to pace myself) are also included in the Fatigue scale. The items capture the general quality of fatigue that many patients describe during uncomplicated postoperative recovery periods.

Relationship To Other Measures. As hypothesized, the FOM Fatigue scale correlated highly to moderately-high with other measures of fatigue (MAF Global Fatigue Index  $\underline{r}$  =.85; POMS Fatigue scale  $\underline{r}$  =.83; Self-Report of Fatigue  $\underline{r}$  =.77; Pearson Byars Feeling-Tone Checklist  $\underline{r}$  =.69) and moderately high and negative ( $\underline{r}$  =-.74) with vigor. Because the Self-Report of Fatigue is a one-item scale, a slightly lower correlation was anticipated. Although the Pearson Byars Feeling-Tone Checklist has been frequently used by nurses in other fatigue research, its correlation with other measures of fatigue has not been reported. In the current study, the Pearson Byars tool did not correlate highly with any of the other measures of fatigue ( $\underline{r}$  =.66 with Self-Report of Fatigue;  $\underline{r}$  = .69 with POMS Fatigue scale;  $\underline{r}$  = .75 with MAF Global Fatigue Index). The POMS Anger, Confusion, Tension

and Depression scales all correlated moderately (Anger and Confusion scales  $\underline{r}$  =.35; Tension  $\underline{r}$  =.50; Depression  $\underline{r}$  =.47) with the FOM Fatigue scale as expected.

FOM Fatique Scores Over Time. The FOM Fatique scale was administered to a subset of subjects (n=50) during the first 2 to 5 weeks following surgery (Time 1) and again to the same subjects 4 to 5 weeks later (Time 2). The mean scores on the FOM Fatigue scale were examined at Time 1 and Time 2 to gather information about the sensitivity of the measure to change. Using paired t-tests, the Time 1 mean scores were significantly (p = .000) higher than at Time 2. Information from these two times in the postoperative period were also examined to gather information about the normal course of fatigue in the recovery process. Using the scatter plot of the individual FOM Fatigue scores at Time 1 and Time 2 (Figure 5-3), it is clear that in this sample, fatigue scores are relatively high (> 3.0) at Time 1 and lower at Time 2. However, the Fatigue scores of 4 subjects increased at Time 2. These 4 subjects did not make any comments on the questionnaire that would explain this increase in Fatigue scores. One could speculate that an emotional or physical complication may have occurred. longitudinal data points would expand information about the usual pattern of fatigue as patients move towards complete recovery.

From these data, one might also extrapolate how much

FOM Fatigue score would be expected to change over a 4 to 5 week uncomplicated recovery period. When the Time 1 FOM Fatigue scores are greater than 4, most subjects improve by 2 points or more by Time 2. When the FOM Fatigue score is between 3 and 4 at Time 1, most subjects improve by .5 to 1.5 points in the 4 to 5 week period. For subjects with lower Time 1 FOM Fatigue scores, there is less room for improvement therefore the improvement is about .5. These data are only begin to examine the expected rate of recovery from fatigue following surgery. If more normative data were known, nurses could diagnose fatigue levels which were not improving at the normal rate and suggest interventions to hasten the recovery rate.

A second method was used to examine the fatigue experience over time. Three cross sectional groups of subjects (n=146) were categorized based on length of time since surgery: Early Group (2 to 5 weeks), Middle Group (6 weeks to 3 months), Late Group (4 to 7 months). Using the distribution of the FOM Fatigue scores from these three groups (Figure 5-5), cross sectional patterns of fatigue for this sample can be described. Based on the FOM Fatigue scores in this study, 33% of the Early Group experienced moderate levels of fatigue (scores of 2.5 to 3.5) while 44% experienced high (scores > 3.5) levels of fatigue 2 to 5 weeks following surgery. From 6 weeks to 3 months, the Middle Group FOM Fatigue scores reflected a gradual decrease

in levels of fatigue: 54% reported moderate and 18% reported high levels of fatigue. By 4 to 7 months post surgery, 38% of the Late Group reported moderate levels of fatigue while 24% continued to report high levels of fatigue. That is, more than half (62%) of the Late Group continue to experience moderate to high levels of fatigue.

The cross sectional description adds to the normative information gained from the scatterplots. Written narratives from subjects about their postoperative experience also provides some insight into individual patterns of fatigue. The following excerpt is from a subject with a FOM Fatigue score of 2.31, 12 weeks after surgery:

Just after my surgery was completed,...I felt as weak and lazy as anyone could feel and a feeling of doom or 'what's the use'. I took naps and felt pooped all the time. Now, I walk between one and four miles a day. I force myself to do it even though I may not feel like doing it.

On the other hand, another subject described a very different experience and his fatigue score reflects this difference. Five months after surgery, a subject with a fatigue score of 1.31 wrote:

I truly feel fine and am not having <u>any</u> problems as far as fatigue is concerned. I

continue to work 8 hours a day and continue my side work off the job (roofing, plumbing, and the like). I go boating and have since about the middle of May! (One month after surgery.) Also, my sex life has increased.

Comparing the narratives from subjects with their fatigue scores suggests that the FOM Fatigue scale is able to provide a measure of the subjects' perceived level of fatigue. With more normative testing, it is possible that the FOM could assist in the diagnosis of fatigue that falls outside the usual post cardiac surgery pattern.

### FOM Exhaustion Scale

The FOM Exhaustion scale items portray a very different quality of fatigue. The item "I feel exhausted" describes the underlying feeling. Items such as "It takes almost too much effort to eat" and "I feel so tired that I have to be told what to do" describe a state that interferes with the most basic day-to-day functions and activities. "All I can do is watch TV" and "I feel so tired that I don't want to do anything" are items that portray a sense of dysfunction and inability to cope with fatigue in a constructive way. In the qualitative study, some subjects used these statements to describe their experience during the first 1 or 2 weeks following surgery; however, one subject,

4 months following surgery, continued to use these type of statements to describe his current state.

Based on clinical experience, persons who describe this type of exhaustion after the first or second postoperative week are frequently experiencing added effects of other physical or emotional problems.

Relationship To Other Measures. Like the FOM Fatigue scale, the FOM Exhaustion scale correlated moderately with the POMS Anger, Confusion, Tension, and Depression scales, but in a slightly different way. The Anger scale had the same low-moderate ( $\underline{r}$  = .36) correlation with the FOM Exhaustion scale as it did with the FOM Fatigue scale. The correlations with the Confusion, Tension, and Depression scales ( $\underline{r}$  = .43, .53, and .53 respectively) were higher than the correlations with the FOM Fatigue scale ( $\underline{r}$  = .35, .50, and .47 respectively). Although not statistically significant, the difference in the magnitude of the  $\underline{r}$ 's provide some evidence that exhaustion may have a stronger component of confusion, tension, and/or depression than fatigue.

To further explore this difference, partial correlations were calculated for the FOM Exhaustion and Fatigue scales with three POMS scales: Confusion, Depression and Tension. The correlation between exhaustion and confusion partialling out fatigue was .27 (p < .01) while the correlation between fatigue and confusion partialling out exhaustion was only .06 (p NS). Similarly, the correlation between exhaustion and depression

partialling out fatigue was .31 (p < .01) while the correlation between fatigue and depression partialling out exhaustion was only .16 (p NS). The partial correlations between tension and exhaustion partialling out fatigue was .28 (p < .01) and between fatigue and tension partialling out exhaustion was .20 (p < .05). These partial correlations add to the evidence that fatigue and exhaustion are two separate dimensions. Exhaustion seems to have more added components of other problems such as depression and confusion than does fatigue.

FOM Exhaustion Scores Over Time. Comparing the scatter plots of FOM Fatigue and Exhaustion scores at Time 1 and Time 2 (Figures 5-3 and 5-4), very different patterns are depicted. Unlike the Fatigue scores, Exhaustion scores are relatively low at both Time 1 and Time 2. In addition, most Exhaustion scores that are relatively high (> 3.0) at Time 1 decrease by at least one or two points by Time 2. This pattern suggests that exhaustion is not a usual part of the recovery process beyond two or three weeks.

Using the distribution of the FOM Exhaustion scores from the three groups (Figure 5-5), cross sectional patterns of fatigue for this sample can be described. The distribution of the FOM Exhaustion scores from this sample looks much different than the pattern of the FOM Fatigue scores. Less than half (29%) of the Early Group (2 to 5 weeks post surgery) subjects report moderate or high levels

of exhaustion. These numbers drop further and by 6 weeks to 3 months after surgery, 22% of the Middle Group report moderate exhaustion and only 3% report Exhaustion scores of greater than 3.5. By 4 to 7 months, there are no Exhaustion scores greater than 2.8. These data provide more evidence that exhaustion is not a usual part of the recovery process beyond the first few weeks following surgery.

The cross sectional description adds to the information gained from the scatterplots. Written narratives from subjects about their postoperative experience also provides some insight into individual exhaustion experiences.

Several subjects who had relatively high exhaustion scores wrote notes indicating that another illness or problem complicated their recovery and added to their exhaustion.

The following is a excerpt of a letter from a subject 9 weeks following surgery with an FOM Exhaustion score of 2.75:

My heart surgery consisted of the replacement of my aortic valve with bypass and the replacement of my aorta into the heart. The surgeon said it was the toughest heart operation he had ever done - they nearly lost me one or two times due to excessive bleeding. I am exhausted! I also had a set back this last week. My husband was diagnosed with cancer. Who says we get

better with age!

Another subject who had a heart attack in 1983 and 1989, prostate cancer in 1990, and was primary caregiver for his debilitated wife could not complete the last scale on the questionnaire because it was after 2 P.M. and "...I am extremely tired".

A third subject with an FOM Exhaustion score of 2.75 states that his level of exhaustion varies over the course of the day. Twelve weeks following surgery he wrote:

I'd like to explain my fatigue more fully because answers on a day-to-day basis seems contradictory. Yet, in fact, I do feel energetic and exhausted in the same day.

I'll start off with a bounce in my step and then at 1 or 3 P.M. I'll just have to sit down and stare. After a while, I'll have some renewed vigor but the time for critical thought has passed for the day.

The very different patterns of the FOM Fatigue and Exhaustion scores and the narratives from subjects provide more evidence that fatigue and exhaustion are two separate dimensions.

To explore the dimension of exhaustion further, responses to individual FOM Exhaustion scale items were examined. Of the 146 subjects, 32 scored moderate to high (2.5 or greater) on the FOM Exhaustion scale. Of these 32

subjects, 14 responded "Yes, describes me exactly" to items 35 and 37 (I just want to lie down and I feel exhausted). None of the 32 subjects answered "No, doesn't describe me at all" to these 2 items. Twelve subjects responded "No, doesn't describe me at all" to the reverse-coded-item 23 (I enjoy a lively discussion). None of the 32 subjects answered "Yes, describes me exactly" to this item. items "I just can't concentrate" and "I feel so tired that I don't want to do anything" were answered "Somewhat describes me" to "Describes me exactly" by 29 and 24 subjects respectively. Only a few subjects (0 to 3) responded "Describes me exactly" to items 1, 7, and 16 (I feel so tired that I have to be told what to do, It takes almost too much effort to eat, All I can do is watch TV). However, 13 to 15 subjects answered "Somewhat describes me" to these three items. Based on the responses of these subjects to individual items, one could describe them as follows: They are feeling exhausted and wanting to lie down. Most of them are having some problems with concentration and would not feel up to engaging in a lively discussion. A few even need someone to tell them what to do. Some feel that all they can do is watch TV; however, most would rather do nothing. Some of these subjects are so tired that they would rather not eat.

Strategies to Reduce Fatigue and Exhaustion

Both FOM Fatigue and Exhaustion scores typically

decrease over time. One subject with high Time 1 FOM Fatigue (4.77) and Exhaustion (3.44) scores wrote: "Contrary to my expectations, my fatigue is not improving; although significantly weaker, I felt nearly as energetic on my first days home as I do now in Week 3." Four weeks later, his FOM Fatigue and Exhaustion scores had dropped to 2.85 and 1.25 respectively. His comment at Time 2 was: improvement has been dramatic. It is incredible that one's body and spirit can be so quickly renewed after suffering the affront and trauma of heart surgery. Thank-you for your interest in the phenomenon of post-surgery fatigue". The subject did not indicate if exercise or other specific interventions were employed to improve the levels of fatigue and exhaustion. However, another subject whose scores were high (Fatigue 5, Exhaustion 4.25) at Time 1 (4 weeks post surgery) and dropped to moderate levels (Fatigue 2.92, Exhaustion 2) 4 weeks later at Time 2 reports that he is using a variety of exercises to improve his fatigue level. On Week 8 he wrote:

I have been active all my life and hate to slow down. I had a heart attack in April and a bypass in June. I began gently riding a stationery bicycle 20 minutes a day 4 weeks ago. I have gone on walks of 1 1/2 miles, but not during hot weather. Today I went to a driving range and began hitting golf balls

gently. I will do this three days a week and begin playing in September. I have ordered a Nordic rowing machine which I shall begin using this week for 20 minutes, twice a day, to build up my upper and lower body. I find the more I exercise I am becoming more alert and feel less fatigue. I find that inactivity causes sleepless nights and more fatigue.

This anecdote and the series of studies by Christensen and colleagues (Christensen, et al., 1982; Christensen, et al., 1989) suggest that regular exercise hastens recovery and lowers fatigue. It is possible that this newly developed measure could assist in the diagnosis of abnormal fatigue and exhaustion following cardiac surgery and also assist in monitoring the results of prescribed exercise and other nursing interventions designed to lower fatigue.

#### Fatique Patterns in Other Illnesses

Belza and colleagues used the Multidimensional
Assessment of Fatigue (MAF) and other measures to assess the pattern of fatigue in older adults (> 55 years) suffering from rheumatoid arthritis (RA) (Belza, Henke, Yelin, Epstein, & Gilliss, 1993). They found that subjects with relatively long duration (mean of 18 years) of RA report a high degree of fatigue that causes moderate distress, occurs every day, and remains constant during the course of a week.

Activity level was negatively related to and explained a significant amount of fatigue in this study. Furthermore, the sample reported very little regular participation in activities and exercise which the authors suggest may have had a negative impact on fatigue levels.

Although the pattern of fatigue is somewhat different in these two populations, it is likely that there may be similarities in nursing interventions for the two groups. The FOM scale could be used to assess the efficacy of those interventions.

## FOM Fatique and Exhaustion Scale Reliabilities

Using Cronbach's alpha, the internal consistency reliabilities of the FOM Fatigue and Exhaustion scales were .93 and .88 respectively. Although this is a new measure, the internal consistency reliabilities of the two scales are well within the .80 criterion suggested by Nunnally (1978) for mature scales.

# Validity of Findings Internal Validity

Self selection into the study was the major threat to the internal validity of Phase III. It is not possible to know if those persons who chose to respond to the questionnaire were different than those who did not respond. Persons not responding may have been too fatigued or frail to complete the questionnaire. Six potential subjects or their spouses did call or write the investigator

stating that poor health prohibited completion of the questionnaire. Other persons not responding may have been doing well and denied that they had experienced fatigue. For them, the study would have had little relevance.

# External Validity

If the purpose of Phase III of the study was to generalize findings to all persons undergoing cardiac surgery, external validity would be threatened because random sampling was not done, not all subjects queried responded to the questionnaire, and not all persons completed all questions. However, the purpose of this phase of the study was to begin to gather evidence for reliability and validity of the new measure. According to Cook and Campbell (1979), external validity is more enhanced by smaller studies with haphazard samples (i.e., samples of convenience) than by large studies with initial representative samples that become haphazard over time (i.e., as a result of attrition). Because this is the first step in a research plan to test the new measure with persons following cardiac surgery as well as with other illnesses, it seems that external validity is adequate.

#### Limitations of the Study

Limitation of this study include the threats to design validity noted above, the lack of important demographics such as marital status and living situation, the lack of information about variables related to fatigue such as

activity level, sleep pattern, and pain level, and the sample itself. Each is discussed below.

# Variables Associated with Fatique

Although the primary purpose of this project was to develop and psychometrically test an outcome measure of fatigue, the inclusion of other variables associated with fatigue would have strengthened the study. The presence of a spouse or other caregiver was identified by subjects in Phase I as important in coping with fatigue in the early days at home following cardiac surgery. Belza and colleagues (1993) found that social support, along with depression and learned helplessness accounted for 4% of the variance in fatigue associated with RA.

Activity level, sleep pattern, and overall level of pain are variables that logically relate to fatigue.

Several subjects reported that pain disturbed their sleep and therefore, contributed to their fatigue. However, while pain and sleep disturbance may be correlated with fatigue, King & Parrinello (1988) found that fatigue typically persists longer than pain and sleep disturbances in this population.

Belza and associates (1993) found that overall pain rating was positively associated with fatigue in subjects with RA and contributed 19% of the variance in fatigue.

They also reported that quality of sleep and activity level contributed an additional 14% (8% and 6% respectively) of

the variance in fatigue in their sample.

Additional information regarding these variables in this study sample would have been desirable. However, the information was not essential in the development and testing of the new Fatigue Outcome Measure.

#### The Sample

Although the letter accompanying the questionnaire encouraged the respondents to take a break should they become fatigued, no other attempts were made to control fatigue associated with completion of the questionnaire. It is possible that undue fatigue may have contributed to missing values or the inability to complete the questionnaire

This predominantly Caucasian sample was not reflective of society at large, nor of the racial distribution of heart disease. In this study women represented 29% of the sample. Historically, women have been underrepresented in studies of persons with cardiovascular disease. However, women are reported to undergo cardiac surgery less often than men. In 1988, only 23.5% of coronary artery graft bypass (CABG) surgeries were performed on women (American Heart Association, 1991).

# Implications for Nursing Theory and Practice Fatigue and Exhaustion Theory

Fatigue has been identified and studied by many disciplines. Psychiatry and medicine view fatigue as a

symptom of a disease process rather than a problem in and of itself. Nurses have viewed fatigue in a broader sense than other disciplines. For example, Piper, Lindsey, and Dodd (1987) developed a fatigue framework for the conceptualization of fatigue in healthy and in clinical populations. It synthesizes literature from five disciplines (psychology, physiology, ergonomics, medicine, and nursing) that have studied fatigue and represents a holistic, multidimensional approach to fatigue that is unique.

Some of the concepts found in the literature that are closest to exhaustion are labeled with different terms. The most common include learned helplessness (Seligman, 1975), giving-up-given-up syndrome (Engel, 1968), and exhaustion (Selye, 1956). In nursing the concept appears as powerlessness (Miller, 1983) and impoverishment (Erickson & Swain, 1982). Basic commonalities include a serious decline in spirit and absence of physical motivation. Many of the FOM Exhaustion scale items describe the serious decline in spirit and absence of physical motivation described in the theories of learned helplessness, giving-up-given-up syndrome, powerlessness, and impoverishment. On going research is needed to explore the relationships among these concepts and the capability of the FOM Exhaustion Scale to accurately measure the concepts.

Both health care professionals and the lay public use

the terms fatigue an exhaustion interchangeably, one presumed to be a more extreme meaning of the other. Rhoten (1982), proposed an intensity progression of fatigue which was superimposed on a health-illness continuum. On this continuum, health is depicted on the energy side while tiredness, fatigue, and exhaustion represent illness. This proposal of a fatigue-exhaustion continuum is the only way fatigue and exhaustion have been depicted together in the literature.

Evidence has been gathered in this study that suggests that fatigue and exhaustion are two related but separate dimensions.

Close examination of the FOM Fatigue and Exhaustion scores reveal a very different pattern. The partial correlation of exhaustion with the variables tension and depression partialling out fatigue suggests that exhaustion is more closely related to tension and depression than fatigue is related to these variables. The narratives from subjects whose exhaustion scores were high suggest that other emotional and/or physical problems may be present. Ongoing research is needed to further delineate these two dimensions.

#### Nursing Practice

Because the Fatigue Outcome Measure is short and easy to complete, it could be used in a variety of clinical settings as well as for nursing research. The FOM Fatigue

and Exhaustion scales are unique in attempting to measure two types of fatigue. The evidence gathered in the current study suggests that the FOM Fatigue scale measures the usual fatigue associated with cardiac surgery. The evidence also suggests that the FOM Exhaustion scale measures a different dimension of fatigue that may be associated with the inability to cope with the day-to-day consequences of fatigue; thus requiring immediate intervention. An anecdote from a visiting nurse's practice illustrates how the new measure may be used:

An 85-year-old man had been in good health prior to a myocardial infarction (MI). Two weeks following the MI, CABG surgery was performed. Four weeks following surgery, he and his wife were living with his son. was not performing any usual activities of daily living for himself and was not walking or doing any other form of exercise secondary to fatigue. He described himself as "weak as a kitten". His score on the FOM Fatigue and Exhaustion scales were 5 and 4.38 respectively. Because of the high score on the FOM Fatigue and Exhaustion scales, and the report of lack of any exercise, the nurse assessed activity tolerance by comparing the client's heart rate before and after walking

around the house for a 2-minute period.

Walking was terminated at that point due to a perception of high exertion by the client.

The nurse prescribed two minutes of indoor walking four times per day for two days. If tolerated, the client was to increase the walking time by one minute every other day.

After one week of this very minimal exercise program, the client reported decreased fatigue and a more positive outlook because "I feel like I'm doing something for my recovery". His FOM Fatigue and Exhaustion were 4.25 and 2.75 respectively.

This clinical vignette is an example of how these scales may be used as a diagnostic tool as well as a measure of the success of a nursing intervention.

Because the new measure was developed specifically for use in persons following cardiac surgery, it could be used to further describe and document the pattern of fatigue in this population.

It would be especially useful to describe the variables associated with fatigue such as pain, sleep, and activity level in this population. This information could be used as a basis for teaching patients and their families about fatigue following cardiac surgery.

The FOM was developed specifically for use in nursing

intervention studies designed to ameliorate fatigue following cardiac surgery. Strategies to reduce fatigue may include a program of physical activity and exercise designed specifically for each person depending on their level of fatigue and their exercise tolerance.

#### Recommendations for Future Research

Recommendations for future research fall into three major categories: (1) Continued psychometric evaluation of the new measure including its use as an outcome measure for nursing interventions; (2) Gathering more normative information about the two proposed dimensions, fatigue and exhaustion, and their usual pattern following cardiac surgery to assist in diagnosis of fatigue; and (3) The possible predictive utility of the new measure.

## Future Psychometric Evaluation

Evidence for initial construct validity of the Fatigue Outcome Measure was obtained from this study. Ongoing psychometric evaluation of the measure needs to continue. First, the instrument needs refinement. Specifically, some items from the 13-item FOM Fatigue scale should be eliminated so that the number of items in each scale are more comparable.

Second, the sample needs to be expanded to include more women and minorities. In addition, the sample size needs to be increased to provide an opportunity for a more equal sample size in groups categorized based on length of time

since surgery.

Third, the measure must be used in intervention studies designed to reduce the perception of fatigue. These studies are necessary to determine the ability of the measure to detect clinically meaningful changes as a result of nursing interventions.

# Use of the Measure as a Diagnostic Tool

More information about the variables associated with fatigue needs to be obtained as a part of future research for two reasons. First, this information could be used to further describe and document the pattern of fatigue in this population.

It would be especially useful to describe the variables associated with fatigue such as pain, sleep, and activity level. In addition, information about the presence of a spouse or other caregiver should be gathered to determine if there if a association between the presence of a caregiver and the level of fatigue. Second, the information may provide further evidence for two separate dimensions, fatigue and exhaustion. Information obtained in this study suggests that other physical or emotional problems may contribute to high exhaustion scores. Future studies should explore this relationship further.

Information about the usual pattern of fatigue over the course of the day needs to be gathered. This information could assist the nurse in helping clients plan activities

based on their energy level.

Longitudinal data which includes collection of multiple data points following surgery would serve two purposes: (1) Provide more information regarding the sensitivity of the measure to change and (2) Accumulate more normative data about the usual pattern of fatigue and exhaustion following cardiac surgery. This information could assist in the diagnosis of fatigue that falls outside the normal pattern and allow for early nursing intervention.

#### Predictive Utility of the Measure

The FOM was designed specifically as an outcome measure for nursing interventions. However, with more normative data, it may have predictive utility. The measure may be able to detect patterns of fatigue and exhaustion that predict long-term prognosis based on fatigue and exhaustion levels.

Finally, using the measure to study persons suffering from fatigue as a result of other surgery, trauma and chronic illnesses is recommended. These are some of the strategies that will assist in the refinement of the newly developed instrument.

#### Summary

This study focused on understanding the fatigue associated with recovery following cardiac surgery. Specifically, it identified indicators of fatigue in this population and from those indicators, a measurement tool was

developed that can be used to assess the efficacy of nursing interventions designed to lower the perception on fatigue.

In order to achieve the specific aims of this study, a multi-phase study was planned. The first phase of this study consisted of a qualitative study of fatigue in postoperative cardiac surgical patients. The information gained from the first phase, along with a review of the literature, was used for the second phase, instrument development. During the third phase, an initial psychometric evaluation of the new measure was conducted.

During Phase I and following approval of the study by the Human Subjects Committee of a large northwest health maintenance organization, 8 subjects who had undergone surgery in the past 6 months were interviewed. recorded interviews were conducted in subjects' home or place of work using an interview guide. The data from the interviews were transcribed and analyzed using the constant comparative method described by Glaser (1978). Potentially important statements, incidents, or descriptions pertaining to the major concepts guiding the study (sensations of fatigue, its impact on lifestyle, and coping with or reducing fatigue) and any other concepts emerging from the data were identified and categorized. The purpose of the qualitative data analysis was item generation. analysis validated that the fatigue experience following cardiac surgery has three major aspects (1) sensations of

fatigue including both physical signs and subjective feelings, (2) <u>impact</u> of fatigue on day-to-day life, and (3) <u>coping</u> with fatigue. The items represented each of these aspects of fatigue.

The purpose of Phase II was to develop the instrument and prepare it for testing. The first version of the new measure consisted of 44 items. The items were arranged in a random order. The response scale consisted of a horizontal line with 6 vertical markers dividing the scale into 5 steps. Anchors (Yes, describes me exactly, Somewhat describes me, No, doesn't describe me at all) were placed in the first, middle, and last steps. Evidence for content validity of the new measure were drawn from two sources: (1) items grounded in field research and literature and (2) review by two panels of experts for components of content validity, specifically domain representativeness (Messick, 1980) and clinical relevance. One panel consisted of professional experts while the second panel consisted of lay experts.

The new measure was revised based on the content validity index and the suggestions made by the professional and lay expert reviewers discussed above. Of the 44 original items, four items were deleted, two items were added, and eight items were reworded so that they were more specific to fatigue. In addition, the example item included in the instructions to respondents was changed from an item

not related to fatigue to an item related to fatigue.

During the revision, an attempt was made to keep the wording of the items as close to the words of the Phase I subjects as possible. The second version of the new measure consisted of 42 items.

During the Phase III, an initial psychometric evaluation of the new Fatigue Outcome Measure was performed. The internal consistency reliability and item analysis were computed on the responses to the instrument of 146 subjects who had undergone cardiac surgery. Evidence for initial construct validity was gathered using a variety of methods.

Approval was for this phase of the study was obtained from the Human Subjects Review Committee of a northwest health maintenance organization (HMO), a northwest university medical center (UMC) and from the Institutional Review Board of a large northwest private hospital (NPH). Criteria for selection of the sample included: (1) cardiac surgery in the past 7 months; (2) English speaking; (3) adults (18 years of age or older); (4) currently living at home; and (5) representative of gender and racial groups. The entire population from the HMO and UMC who met the above selection criteria was given the opportunity to participate in the study. Recruitment of potential subjects from the NPH differed. Because subjects who had been discharged from the hospital within the past week and female subjects were needed to fulfill the requirements of adequate

representation of female gender and patients from the early postoperative period, only subjects with these criteria were recruited from this medical facility. A letter of introduction which explained the study and invited participation was sent to all potential subjects. Informed consent was inferred from the return of the enclosed postage-paid postcard.

Following the return of the postcard, a questionnaire packet which included a cover letter, the questionnaire, and postage-paid return envelope was mailed. A total of 292 questionnaires mailed, 148 responded. Of these 148 respondents, 2 were missing more than 25% of the Fatigue Outcome Measure items and were dropped from analysis. Therefore, the final sample was 146. The design of the questionnaire was based on the Total Design Method developed by Dillman (1978) to increase mail survey response rates. The overall response rate was 51%. As illustrated in Table 5-1, the response rate of the HMO sample (61%) was much greater than the response rate of the UMC (37%) and the NPH (38%) samples. This self selection into the sample was viewed as the major threat to internal validity.

The sample of 146 was predominantly male (71%) and Caucasian (91%). Ages ranged from 37 to 85 years with a mean of 65 years. The majority of subjects completed high school (25%) or had a greater than high school (61%) education. Table 5-3 summarizes the demographic

characteristics of the sample.

The new Fatigue Outcome Measure was combined with demographic questions and four other instruments (three scales specific to fatigue and the Profile of Mood States) into a single questionnaire (Appendix E). An open-ended question (Is there any information that you would like to tell me or you think I should know about fatigue following cardiac surgery?) completed the questionnaire. The Cronbach's alpha was calculated for all scales used in the study. All but one of the scales met Nunnally's (1978) criterion of .80 or higher for mature scales. The effect of using the group mean to estimate missing values tends to make the reliability somewhat lower (Cohen and Cohen, 1983). This may account for the Cronbach's alpha of .76 for the POMS Confusion subscale.

Frequency distributions were computed for each item along with item means, standard deviations, skewness, and number of missing values. Item-to-item and item-to-total correlations were calculated on the 42-item measure as well as the subscales. The item analyses, evidence of item sensitivity to change, and evidence of conceptual fit were strategies used to determine which items were best suited for inclusion in the factor analysis.

Factor analysis was the first construct validity strategy employed. It was used to examine the remaining 33 items and determine whether one or more factors existed.

The two factor solution suggested the presence of two factors that make sense conceptually. Factor analysis also assisted in further scale refinement by facilitating the decision regarding retention and elimination of the remaining items. Thus, a 13-item FOM Fatigue scale and an 8-items FOM Exhaustion scale were used for subsequent analysis and construct validity. Using Cronbach's alpha, the internal consistency reliabilities of the FOM Fatigue and Exhaustion scales were .93 and .88 respectively.

Conceptually, the 13-item FOM Fatigue scale describes a state of fatigue that is a normal part of the recovery process following cardiac surgery. The individual is listening to internal cues and coping with fatigue in a constructive way. The individual is clearly in control of his fatigue. However, the 8-item FOM Exhaustion scale describes a state of exhaustion and debilitation. There is a sense of disfunction and inability to cope with fatigue in a constructive way. After the first or second week, this state is not a usual part of the recovery process following cardiac surgery. The fatigue is clearly controlling the individual. Subsequent analysis focused on construct validation of these two scales.

The FOM Fatigue and Exhaustion scales were correlated with three scales specific to fatigue and the six POMS scales. These correlations confirmed the hypothesis that the FOM Fatigue scale would correlate highly (.80 or

greater) with most other measures of fatigue, and moderately high and negative with vigor (-.70 or less), and moderately (.30 to .60) with anger, tension and depression. Table 5-10 lists the correlations.

The new measure was assessed for sensitivity to change using a longitudinal and cross sectional approach. The longitudinal sensitivity to change of the two scales was assessed by comparing the mean scores of each scale at two time periods 4 to 5 weeks apart. The instrument was administered to 50 subjects during the first 2 to 5 weeks following surgery (Time 1) and again 4 to 6 weeks later (Time 2). These two time periods were selected based on the difference in the expected level of fatigue (King and Parrinello, 1988). The mean scores on the FOM Fatigue scale at Time 1 were significantly (p = .000) higher than at Time 2. The mean scores on the FOM Exhaustion scale at Time 1 were also significantly (p = .000) higher than at Time 2; however, the magnitude of change was less. These results are displayed in Table 5-11.

To further describe the sensitivity of the Fatigue

Outcome Measure to change, the entire sample (n=146) was

divided into three groups based on the length of time since

surgery: Early Group (2 through 5 weeks), Middle Group (6

weeks through 3 months), and Late Group (4 through 7

months). It was hypothesized that fatigue would be lower in

groups further from surgery. The FOM Fatigue and Exhaustion

mean scores from these groups are presented in Table 5-12 and were compared using a one-way analysis of variance (ANOVA). Following the significant F in the ANOVA, t-tests were used to test the hypothesized group differences. As expected, the Early Group mean FOM Fatigue score was significantly (p = <.05) higher than both the Middle and Late Groups; however, the Middle Group mean FOM Fatigue score was not higher than the Late Group mean score. The Early Group mean FOM Exhaustion score was significantly (p = <.05) higher than the Late Group but not higher than the Middle Group as hypothesized. The Middle and Late Groups were not significantly different on the FOM Exhaustion scale.

Because the Fatigue Outcome Measure is short and easy to complete, it could be used in a variety of clinical settings as well as for nursing research. The FOM Fatigue and Exhaustion scales are unique in attempting to measure two types of fatigue. The FOM Fatigue scale measures the usual fatigue associated with cardiac surgery. The FOM Exhaustion scale measures a different dimension of fatigue that may be associated with the inability to cope with the day-to-day consequences of fatigue. Because the new measure was developed specifically for use in persons following cardiac surgery, it could be used to further describe and document the pattern of fatigue in this population. It would be especially useful to describe the variables

associated with fatigue such as pain, sleep, and activity level in this population. This information could be used as a basis for teaching patients and their families about fatigue following cardiac surgery.

The FOM was developed specifically for use in nursing intervention studies designed to ameliorate fatigue following cardiac surgery. Strategies to reduce fatigue may include a program of physical activity and exercise designed specifically for each person depending on their level of fatigue and their exercise tolerance.

Evidence for initial construct validity of the Fatigue Outcome Measure was obtained in this study. Ongoing psychometric evaluation of the measure needs to continue as a part of future research. The measure must be used in intervention studies designed to reduce the perception of fatigue. These studies are necessary to determine the ability of the measure to detect clinically meaningful changes as a result of the intervention. Using the measure to study persons suffering from fatigue as a result of other surgery, trauma and chronic illnesses is recommended. These are some of the strategies that will assist in the refinement of the newly developed instrument.

Fatigue is becoming a symptom of interest to nurses in practice and research as well as others in health related fields. The process of research application and theory building, as well as the psychometric testing of new

instruments are components in the development of nursing knowledge. The implementation of clinical trials to evaluate the FOM will contribute to this knowledge development.

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## Appendix A

## Fatigue Interview Guide

## General Questions:

- 1. Have you experienced fatigue since surgery?
- 2. (If yes) Tell me about that experience.
  - What does it feel like?
  - How do you know you are tired?
- 3. (If no) Many people have experienced fatigue. What have you done to prevent it?

## Specific Questions:

- 1. How has fatigue affected your lifestyle since surgery?
  - How has it affected the things you need to do everyday?
  - Has it affected your relationships with others?
  - Has it affected your work?
  - Has it affected your leisure activities?
- 2. What advice regarding fatigue would you give others who are about to have surgery?
  - What do you do to cope with or minimize these effects?
  - What do you do to reduce fatigue?

Date: August 21, 1991

# Appendix B

Date

Name Address

Dear Patient

Many people experience fatigue following surgery -especially cardiac surgery. Very little is known about this
experience, the cause of it, or what to do about it. Ruth
Gregersen is a nurse who has cared for cardiac surgery
patients for over 15 years. She has worked in the intensive
care unit and as a visiting nurse in patients' homes. She
is currently a doctoral student and is conducting a study to
learn more about the fatigue associated with cardiac
surgery.

Since you have had cardiac surgery recently, you may have first-hand experience with postoperative fatigue. If you have, you are considered an expert in how that experience feels and how it affects your life. If you have not experienced fatigue since surgery, it is important to know what you may have done to prevent it.

Ruth Gregersen would like to interview you, as a part of her research, to gain a better understanding of postoperative fatigue and how it affects a person's life. The interview would be conducted in your home or other convenient place of your choosing. The interview would last about 30-45 minutes. If you would be willing to have Ruth call you to explain more about her study, please return the enclosed postcard. Returning the post- card does not obligate you in any way. Participation in the study is completely voluntary and your care by Group Health Cooperative providers will not be affected by your decision.

As a cardiologist, I would encourage your participation in this study. Fatigue is a problem for many people and sharing your experience with Ruth now, may help other patients in the future. If you have any questions, please feel free to call Ruth at (206) 523-6698.

Sincerely,

Lee C. Amsler, M.D. Cardiologist, Group Health Cooperative

enclosure

## Appendix C

#### GROUP HEALTH COOPERATIVE OF PUGET SOUND

### OREGON HEALTH SCIENCES UNIVERSITY

#### Consent Form

### TITLE:

The Development of a Tool to Measure Fatigue in the Patient Following Cardiac Surgery

PRINCIPAL INVESTIGATOR: Ruth A. Gregersen, R.N. (206) 523-6698

<u>PURPOSE</u>: Many people experience fatigue following cardiac surgery. Very little is known about this experience or how to treat fatigue. In order to develop treatments which may reduce fatigue, it is important to be able to measure it. The purpose of this research study is to develop a way to measure fatigue in people who have undergone cardiac surgery. In order to develop this tool, it is important to learn more about fatigue by talking to people who have experienced it.

<u>PROCEDURES</u>: If you agree to participate in this study, you will be asked questions about your experiences regarding fatigue following your recent surgery. The interview will be tape-recorded and is expected to last 30-40 minutes.

RISKS AND DISCOMFORTS: The only risks associated with this study are the inconvenience of the time it takes to complete the interview and the possibility of you becoming over-tired during the interview. You may choose to end the interview at any time.

<u>BENEFITS</u>: You may not personally benefit from participating in this study - but, by serving as a subject, you may contribute new information which may benefit patients in the future.

CONFIDENTIALITY: All information obtained from you will remain confidential as provided by law. The tape-recorded interviews will be transcribed and the tapes will be erased. A code number will be assigned to your transcription and

only the investigator and her advisory committee will have access to the data which will be retained indefinitely. Neither your name nor your identity will be used for publication or publicity purposes. Study records may be reviewed by funding or regulating federal agencies.

COSTS: There are no costs associated with your
participation in this study.

<u>LIABILITY</u>: Medical treatment is provided as part of this protocol and not as a covered service by GHC. Treatment for any physical injury or other adverse effects will be paid for by GHC to the extent of your GHC coverage as long as you remain an enrollee of GHC. If you are no longer enrolled at GHC, the cost of this care will not be covered by GHC.

OTHER INFORMATION: Participation in this study is voluntary. You may refuse to participate, or may withdraw from this study at any time without affecting your relationship with or treatment at GHC. Upon signing this consent form, you will receive a copy of it. Any questions about the study you may have now or in the future will be answered by the investigator, Ruth Gregersen (206) 523-6698. If you have any questions about your rights as a subject or as a GHC patient, please call (206) 287-2919.

Your signature below indicates that you have read the foregoing and agree to participate in the study.

Name	Date
Principal Investigator	Date

# Appendix D

# SENSATIONS/EXPERIENCE OF FATIGUE

Label: Physical Signs

<u>Definition:</u> Signs of fatigue that can be measured or <u>observed.</u>

Does the definition fit the whole set in general?

Does the label fit the whole set in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

Data bits:

My memory isn't that good (1096).

He got really tired, other people were noticing it (1184).

He could barely get up the stairs and move around, he could barely talk (1266).

His face looked tired, his color wasn't as good, he was slumped sort of, and his general appearance looked old! He was old looking! (1282-85).

Yeah, that out of breath thing still goes on (3556).

I can notice when he's pale, occasionally that'll tip me off (3626).

He isn't as perky as he was (3686). Rounds shoulders, slumps, and makes a drooping face (3690-92).

"Dad's moping around, Mom" (3734).

He was bothered with arrhythmias...when he has over done it, that comes brief, just very brief and then it will go away. But that's a good signal that he's over done. So it's either a little shortness of breath or arrhythmias. (3761-69)

But, at night, my eyes get swollen at night. But I don't pay any attention any longer. (5083-86)

Sometimes in the afternoon when I'm coming home, my speech gets real slurred and simple words become hard to pronounce (6510-14).

I yawn a lot, my speech gets worse, sometimes I have a dry mouth (6653-55).

\_\_\_\_\_

## Label: Subjective Symptoms and Feelings

<u>Definition: Ways of describing how fatigue makes one feel.</u>

Does the label fit the whole set in general?

Does the definition fit the whole set in general?\_\_\_\_

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

Data bits:

It felt good to be in bed (1026).

I just wanted to be in bed (1048).

I guess I was up a few minutes then got tired and exhausted (1055).

I was exhausted last night (1243).

Sleepy, yes, extremely tired (2008).

I was really tired like you get at night when you feel like you want to go to bed(2233-35).

There was something telling me that I must lay down (2236).

Something just let me know that my body needed to rest (2240-41).

Well, I think just a normal feeling, a normal being...out of gas (3555).

I can get up in the morning and I'll feel good or puney ...I'll have a puney day and they know it and they can look at me and tell it (3614-19).

The term I like to use is 'run out of gas'...I mean I just am tired (4206).

I don't have any staying power (4581).

I get achy all over and simple tasks seem to be a chore (6011).

I'm real drowsy (6015).

It's like being real tired, real, real, tired (6035).

It feels like I've worked 40 hours in one day (6065).

I don't want to do anything (6108).

I don't have the will to do it (keep going) (6133).

I'm controlled by fatigue (6148).

I just felt like I was dying, I just couldn't get my breath...it was a very scary feeling, very scary (6173-81).

It feels like a double or triple case of the flu (6238-39).

I'm more irritable (6337).

I was tired (7021).

What really surprised me was the emotion - emotionally it was a downer (7047).

I wasn't physically tired, probably worn out (7096-95).

(After a stress test) I sat down after doing that, I felt like a fish out of water. I was just gulping for air (7149-51).

# Label: Signs of Energy

<u>Definition:</u> Signs of increased energy or lack of fatigue that can be observed.

Does the label fit the whole set in general?\_\_\_\_\_

Does the definition fit the whole set in general?\_\_\_\_\_

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label. Data bits:

He has a spring in his step (3710).

He's doin' stuff all the time, his yard work, he's playing golf (3701-02).

### COPING WITH FATIGUE

\_\_\_\_\_\_

# Label: Managing Fatigue

<u>Definition:</u> Using activities such as rest and exercise to cope with fatique.

Does the label fit the whole set in general?\_\_\_\_\_

Does the definition fit the whole set in general?

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

I spent an awful lot of time in bed, I wanted to be in bed like I had been for 3 or 4 weeks. (1023-25).

He was more down than up as far as I know, in bed or out here in that chair which is a recliner. (1103-06).

This thing (recliner chair) goes way out and it's bed like, and I used this quite a bit. (1108-1111).

One night's sleep brought me back! (1191).

They gave us a set of 10 exercises that I can show you, that was given to people who have had open-heart surgery. This thing (hands behind head, elbows out) and you probably the whole sequence, I can show it to you if you're interested, I unfortunately did not do those for about 10 days. If I had done them faithfully, I may have relieved the back pain some and helped this (fatigue). (1316-26).

I would also recommend after they get home, to do like I did, to spend a good share of the time in bed I think that's part of the recuperation. I would also say to start exercising. (1331-35).

But it's just driving the car and if I get tired, I can lay down someplace and lay across the seat. I did that a couple of times on both days. (1483-87).

I don't think I went to sleep, but I rested...relaxed on my side. (1489-90).

Roughly three weeks after surgery, I knew I had to walk, M encouraged me and the doctors encouraged me, I went on my own, down or around a big block. It's down hill and up hill, a good mile...I took the dog with me. (Which means the dog took him for a drag)...Yeah, and I had to rest several times. (1608-25)

I'm going to bed earlier than I ever did before. I can lay down in the afternoon and take a nap, which is something that I never have done. Um, I perhaps could stay up but I feel tired so I lay down, which is what the doctor told me to do, if I'm tired, rest. (2009-16).

I told my husband, 'I'm going to go in and lay down, I just am real tired'. Well, I fell asleep and he came in and covered me because I had just taken a baby blanket I have and put it over my shoulders. Um, I don't know that I was really tried like you get at night when you feel like you want to go to bed, but I knew that there was something telling me that must lay down. (2227-37)

I do know that I...even when I first came home from the hospital, I could lay down, even if it was just, even in the hospital, just look at that pillow and I could lay down and with 10 minutes, I could take 10 minutes to sleep and it just seemed good, why, I don't know why. (2308-14).

I still say that that pillow looks good and just that few minutes of, it just seems like you're sleepin' and I don't know if you actually really do sleep or if it's just in your

mind that you've closed your eyes and that you're resting. I don't know what it is. (2322-29).

Yeah, R (son) said that even now, as a matter of fact it was just not too long ago, and it's been, what, 8 months for him, February 'till now, he said even now, he's said sometime it will be 7:30, 8 o'clock, he said he's ready for bed. (2332-38).

Uh, the naps have always been good. (3025-26).

And he takes several walks a day. (3039).

I've always, when I played golf, I always carried my own bag and walked. Of course it can't be that way now. Uh, the first time I played, it was, of course, only nine holes so it was an easy little gallop, and I rode a cart, and of course, my bag was on the cart. I was tired but not overly so. (What did you do when you got home?) Just like anybody, I laid down! (laughter) (3097-105).

(Are you still using a cart for your clubs?) Well, for my own self too. I play Nile and it's pretty hilly. (3138-41).

Well, you learn to say no more. Invitations and that sort of thing are politely declined and you don't uh, go to as many shows or many, what ever it is that your doing. (Wife) I think it's just a matter of pacing yourself, honey, when you felt like it, we did things when you, it didn't sound good, we didn't. But every day, he either walked or worked in the yard or something. Always intense and active and remains active. (3174-85).

He can take a cat nap, or he can just get off his feet or he can have something to eat or something and his energy does return. So it's not a, you know, anything dire, it's just a matter of pacing himself and he's not real good at that. He sorta needs a nudge to stop. (3600-07).

Well, I, when I first got home, I was on the couch most of the day. And after about a week, I was up walking from that door to that door (points to the front and back doors), doing the stairs, and...(5101-06)

I spent a lot of time in bed. (4026)

I spend a lot of time, if I'm outside working in the yard, I'll sit down and take five. And the same way here at the house. (4084-88)

I was a little weary so I sat down and actually took a very short nap. (4097-98)

I have to stop and rest for a few minutes and then I can do it again. But in the end, I get what I started out to do, I get it done, it just takes me longer. (4110-4114).

And so I'll stop what I'm doing and perhaps maybe go do something else. Um, maybe not using the same stance or the same leg or arm muscles but I'll do something else. If I'm, for instance I've been doing some pruning, maybe I'll prune for 15 or 20 minutes or a half an hour and I get, my arms will get tired from doing that, well then I'll go do something else and give them a rest. (4208-18)

I'll work at that for maybe a half hour or an hour and my back will get tired and I'll quit that and go do something else. Just a change of pace more that anything else. (4238-42)

What I usually do is to take two days to mow it, I'll mow this part here and half way down on the neighbor's side then I'll do the back part the nest day, weather permitting. Um, because usually by the time I get over on that side I'm pretty well wiped out, I mean I don't think I should continue so I'll just stop. (4246-54)

I just sat down and looked at a magazine or read the paper or something like that. And in a half hour or an hour, I was back on my feet again. (4379-83)

I could go in the chair and sit down and read the paper or a magazine and in five or ten minutes be asleep. (4538-40)

If I'm outside, usually I'll just sit down and pet the dog or whatever. (4594-95)

I just sit down and take 5 or 10 and smoke my pipe and just take a little rest and then I'm ready to go again. The same way when I was cutting up that brush out there, get a little tired and go do something else or do nothing. (4603-10)

I've noticed now that it doesn't take long for me to drop off and maybe just 10 or 15 minutes and everything is fine again. (4613-18)

We do go to bed a lot earlier. (5456)

And if I'm going to write myself notes, I have to do it in the morning (6666-6668)

Just physically relaxing, which is as good as taking a nap, or reading or watching a little television. Actually, what I did a lot of was - we have a computer and computer games - and I played computer games. (7096-102)

I take a long lunch hour (7254)

I probably was back (to work) in three weeks, but not on a steady basis. I'm not back on a steady basis now. I came in yesterday for 10 minutes and today going to be here this morning and gone all afternoon. Tomorrow I don't plan on coming in, so it doesn't interfere because my lifestyle is such. (7283-45)

Our porch faces west and it's kind of semi-enclosed so it's 10 to 15 degrees warmer than what it is normally is, so even though it was May, so the minute we had a little sun I'd go out on the porch were we had a chaise there, and I have a portable compact disc player and I'd listen to good music and that was very relaxing. (7264-73)

If I'm tired, I can lay on the chaise if the sun's nice, or just sit in a chair. Our home is very comfortable - we've been there for 27 years, so it's a safe harbor. There's no one specific thing, but if I do feel tired i will force myself now to rest, which I didn't do before. I always felt I could push myself further. If I were tired but had something to do, I would just go and do it. Now if I'm tired, I'll go and relax. (7281-92)

I had driven down to Oregon to a \_\_\_\_\_ trip. I had broke the trip up, you know, staying over night, didn't drive too far. (8040-42)

I'm back on an exercise program where I try to walk every day a half hour to 45 minutes. (8079).

(I: Were you able to cook your own meals?) Sort of. I had some friends and one of them brought over several dishes that I could stick in the, I had my son get a microwave...Then I went to Meals on Wheels. (8128-36)

I would say that I slept 10 hours or so, uncomfortably but I slept. Then I would get up and have something - not much - maybe a piece of toast, glass of juice, you know keep a moderately well balanced intake. Then, I just spent a lot of time sitting in the old lounge chair. I was very unfortunate because all there was on TV was the damned war - it just drove me crazy. The only thing I could stand was Sesame Street. (Laughter). (8144-52)

Actually, during that first week or week and a half I was probably walking 40 minutes a day in 8 or 10 minute shots. (4170-72).

Then I would probably take a nap. Oh, I was tired - I've got to lie down. I would sleep for an hour. It was a

restless kind of tossing for an hour, would get up, look at television, read the paper. (81772-79).

# Label: Use of diversionary activities

Definition: This category may include things that are done because lack of energy precludes anything else.

Does gener		fit	the v	whole —	e set i	ln	
Does gener	defini	tion	fit _	the	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

I did some reading, maybe I played the piano a little bit...(1097-98).

I've got a lot of projects I'm still on...a lot of the things that needed repair I did and I practiced the piano a little bit so...(1168-70).

He looked exhausted. He could barely get up the stairs and move around...he could barely talk, he was that tired. And I said go in and lie down, well he went and laid down for a bit and he got back up again and I said take a shower 'cuz that usually relaxes him when he's tired. I don't think he did either, really he came in and watched TV. (1266-75).

B (wife) always said that when you feel the worst, that's when you've got to be the busiest. I've painted more rooms when I couldn't stand up. (3920-23).

Well, I wasn't tired to the point where I go lay down but I might sit in the other room there in the chair and read a magazine and unwind a little bit and then if it was time to eat, I'd get something to eat or if one of the kids were here, they'd have it for me. And uh, that's basically all I did. Sometimes I'd have a beer, sometimes I'd have a coke it just depends on what I yearn for that particular time. And uh, but no, I wouldn't have a snack or anything like that. (4367-79)

So he would be walk from the bedroom to the kitchen to out here. He would make those rounds several times a day but that was really about all. (1112-15).

## Label: Using denial

<u>Definition:</u> Coping with fatigue by denying that it occurs.

Does the label fit the whole set in general?

Does the definition fit the whole set in general?

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

B forgets how tired he got. And he totally forgets that first two weeks how much time he spent in bed and how tired he got after being up an hour. (1212-16).

I hope you're beginning to perceive that B has a strong sense of denial and has had for a long time. (1298-1300).

I hate to use the word fatigue because it's not that, it's just tiredness. (3083).

I really don't have much of a problem with it. It took me a little longer to bounce back because I developed an aneurysm and had to go back. And after the aneurysm was fixed, and then I had five mini strokes and had to back to the hospital. So my recovery has been quite slow. (5016-19).

Label: Other ways of coping

<u>Definition: Other ways of coping such as use of medications and a positive outlook.</u>

Does the label fit the whole set in general?

Does the definition fit the whole set in general?\_\_\_\_\_

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

I'm also taking a Robaxin, a half of one of those and a Tylenol #3 when I go to bed to insure sleep. (1410-11)

And uh, I think a lot of it is attitude. I mean, you have to kinda maintain a positive attitude and go ahead and do these things even though you know that you're going to get tired in the process. And you know that you're going to have to stop and take a few minutes to rest and kinda collect yourself. (4109-4122)

You have to be in control and you have to know your body. (7362-63).

Other than that, as far as fatigue, tiredness, overexertion, anything like that, I think we just live with it. (3861-63)

I know that...actually my doctors tell me that I've got an attitude, a great attitude. I had cancer seven years ago and the doctors said I cured myself of cancer by having that great attitude. And, it's just that I don't let things get me down, you know, I'm a Pollyanna. I figure that's gone down and I can't do anything about it, tomorrow's gonna be here whether I like it or not so let's love it today (coughing spell).(I: So the advice you'd give is to have a positive attitude?) A positive attitude, I think, is the best thing. (55206-21)

No, I don't think anything gets me down. I'm kind of mad because I missed the Reno trip this summer, no, I shouldn't, no really nothing gets me down. I've got a fine family and children, grandchildren and great grandchildren and they are my pride and joy and I don't get down. I very seldom, I, like, I'm not like other people, I'm a Pollyanna. Always looking on the rosy side, I've been that way all my life,

and I think it makes, I'm very lucky to be that way. Sometimes you may look so positive that you...maybe I don't worry when I should, but I don't worry. No I've been a Pollyanna all my life, I never worried about anything, that cancer gave me a little, a few sad times, but no, I'm fine I really am fine. (5324-43)

The basic thing is to realize that a lot of people go through it and they have a very small percentage that they have problems with - 3% - before and after and during and what ever, and it's almost a guarantee that you'll be stronger and better when you fully recover, and it takes six months to a year in some cases to get back to where you were and be better. It's nothing really to fear. (7337-47)

## IMPACT OF FATIGUE ON LIFESTYLE

# Label: Activities of Daily Living

<u>Definition:</u> How fatigue affects day-to-day activities such as bathing, eating, dressing, and sleep.

Does the general?			whole	set	in	
Does the general?	definiti	ion fit	the v	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

#### Data bits:

He could barely get up the stairs and move around...he could barely talk, he was that tired. (1266-69)

I'm going to bed earlier than I ever did before. (2009-10)

I was home here and I was really fatigued, or tired, I mean. I spent a lot of time in bed. (4024-27).

I can't go as steady as I did before. I have to stop and rest for a few minutes and then I can do it again. But in the end, I get what I started out to do, I get it done, it just takes me longer. (4109-12)

Simple tasks seem to be a chore, Sometimes writing my name is a chore (6011-13)

So, you know, just to get up into my back door, and I think it was probably a month or five weeks really, before I could stay up, just stay up for twelve hours without going to bed. (8023-27)

Well, you know, I've had coughs you know bronchitis, bronchial pneumonia, - I didn't go in - I was too tired to go in (doctor's office). (8057-60)

I was afraid to go out because I was afraid a large dog would jump on me and I would be in bad trouble and I would never make it home. (8156-59)

I wasn't really up to reading anything of any significance because I couldn't focus very well or comprehend. (8161-63)

The evening would probably tend to be sort of lost - time just passes. I would think, "Oh, maybe I ought to go to bed" (8177-79).

Very difficult to do some things - like to take a shower! Oh God! I think to take a shower, to get ready, to get dressed, to get everything ready seemed to be just an insurmountable effort! (8180-82)

I have friends from the University taking me out of the hospital and driving me home and I have five steps up to my back porch and I was going "uno, dos, tres", it was stressful getting up there. I didn't have a clue as to where to go, what to do now. He looked at me and said, "Maybe you ought to go right to bed." (8224-32).

Like when the visiting nurse comes around. She said "You should get dressed tomorrow." (8244-46)

In one case, I took a shower and fell. That was the only time I thought I was going to faint. I was all wet - got over by the toilet and put my head down. (8259-63)

Life becomes very simplified. It's hard to go out into the wider world. You almost have to have some necessity to do that. (8325-28).

## Label: Household Chores and Activities

<u>Definition: How fatigue affects the ability to do chores</u> and participate in activities.

genei	ral?_			_			
Does		definition	fit	the	whole	set	in

Does the label fit the whole set in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

#### Data bits:

Yeah, what I was describing to you...the work, I'm behind around the house. (1152-54).

I prepared a few meals, very little, but I did prepare meals and I did some dishes, um, really there was not an awful lot left for me to do. I folded clothes. Um, basically took care of my own needs. (So you did your own personal care?) Yeah, but they were in there to, if I wanted my hair put up, or something, she was there to do that or someone was there to wipe my back and make sure that I wasn't overdoing something. (2062-73)

I think that I probably...we started out with just down to the corner from here to 85th, which actually is not very long, then back. (2110-14).

When he doesn't feel good he doesn't make any he doesn't make any tee times, he doesn't go play golf, he doesn't do the yard. (3703-06)

I'll start on a chore outside and or I might be inside doing something and something comes up...the term I like to use is 'run out of gas' I mean I just am tired. And so I'll stop what I'm doing and perhaps maybe go do something else. (4204-10)

Yes, uh, it used to be before that I could do the whole yard in, clip the trees, mowing around the trees, and taking core of the grass and everything, oh it's about a three hour job. And I used to do the whole thing all in one day. But now I just do half and do the other half the next day. Uh, it bothers me that I can't do it all because, of course nobody sees that side yard except my next door neighbor, and I've told B, I've said, 'Don't look over here for a day or two.

I'll mow it eventually.' But there I thing pride enters into the picture a little bit, you like to have your yard and your house looking nice from the outside. And right now outside the yard needs to be mowed to knock down the dandelions, it looks horrible. But by the time I finish my psudomaker business in the house today, I just didn't have the zip to do it. So I just didn't, I'll do it some other day, you know. It's not that important to me but it bothers me pride wise, you know? (4257-83)

I got some garden planted but it's a sorry one compared to what we used to have. (4446-48)

Now mowing the lawn, we have a difficult lawn to mow here because there's so many trees in the side yard that it takes a long time. What I usually do is to take two days to mow it, I'll mow this part here and half way down on the neighbor's side then I'll do the back part the nest day, weather permitting. Um, because usually by the time I get over on that side I'm pretty well wiped out, I mean I don't think I should continue so I'll just stop. (4242-54).

It was for a while - just walking, when I started out, and that did fatigue me, and I was tired. (7019-21)

Yes, first off, the first time I got in the pool - I've only been in three times - the first time I got in the water seemed very cold, when it didn't before, and I just found it hard to put my head under the water. I don't know why psychological - the fear of not being able to breathe. first time I didn't do the crawl at all. I started a little bit but had to take my head out of the water, so I did the side stroke, where your head's out of the water, and a little bit of frog-type of swimming. I did a couple laps that way and then I rested and did a couple more. Then I did do four lengths - not laps - lengths are one way and laps are both - four lengths of the crawl, and I was fairly tired - more tired than I was doing 40 before. The other two times that I've done it - one times I was only able to do three and the other time I did four, and the lengths of the pool doing some other strokes. The maximum I did was 10 strokes - 10 lengths doing different strokes and resting. kind of pride myself in being in pretty good shape - even though I knew and they told me - it did bother me. when I took the stress test exam I only went seven minutes and 13 seconds and the average, I quess, for men over 60 is eight. Of course, I forgot to ask if that's the average for after you've had open heart surgery. (7110-145)

# Label: Social Activities and Hobbies

<u>Definition:</u> How fatigue affects activities that subjects do for pleasure or diversion.

	label		the	whole	e set	in	
Does gener	defini	tion	fit	the	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

#### Data bits:

We had a wedding come up that was concurrent with this operation... so that was in the middle of the recuperation period.(1154-60)... He did get very tired. In fact, he was up longer than he should have been both the night before the wedding, at the rehearsal supper and again he got really tired. Other people were noticing it.

I've always, when I played golf, I always carried my own bag and walked. Of course it can't be that way now. Uh, the first time I played, it was, of course, only nine holes so it was an easy little gallop, and I rode a cart, and of course, my bag was on the cart. (3097-104).

But that was self proclaimed, we did it uh, we're usually very social, very active, go a lot of places, do a lot of traveling, and stuff like that but we've just had to put a halt to it. (3155-60).

Invitations and that sort of thing are politely declined and you don't uh, go to as many shows or many, what ever it is that your doing. (3174-78).

No, we've had visitors, they come and they think it's a social gathering, and you can't get rid of them. And I love 'em but a hospital or a home when you're recuperating, it isn't a place for visitors, socially. And I remember one night we had people in, and of course we served them drinks, and you know, cocktails, um and it's probably our fault but I finally just went in and went to bed. (3637-47)

I can't walk, I decided to give up backpacking, that's out, I don't think my legs can do it. (8210-12)

Another time it was about 9:00 o'clock and if a television

program would be scheduled for 10:00, my friend would say that maybe we should look at that. I'd say that I didn't want to stay up that long. This must have been within the first three days that I was home, and I had a friend there. (8233-41)

## Label: Work Activities

<u>Definition: How fatigue affects activities surrounding work outside the home.</u>

gene	ral?						
	_	definition	fit	the	whole	set	in
Does genei	_	definition	fit	the	whole	set	1

Does the label fit the whole set in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

#### Data bits:

So, I drove a few times our own personal cars then I started back my regular work, now that is cab driving, and I worked Sunday about 10 or 11 hours. I was very tired and told my owner that I wouldn't work the next day 'cuz I needed to recuperate. Then I worked again Tuesday and again, I was very tired. (W: In fact, he was exhausted last night.) Yeah, so I took another day off and tomorrow, I'm going to work again and probably come home quite tired. (1234-47)

I volunteer three days a week in other activities...But anyway, I help the van driver bring these people out to the van and help them in, buckle them in and all this sort of thing. And when I first started out, I was physically exhausted at the end of the day, now it's getting better. (4322-54).

There were three trips I had to cancel because of the recuperation. (7196-98)

I probably still have notes that I kept in preparation for writing. All that is wasted - didn't have any quality whatever. (8354-57). (Retired professor that continues to publish)

### THINGS THAT MAKE FATIGUE WORSE

Label: Aggravating factors

<u>Definition: Physical activities, stressful situations, and other things that cause the subject to feel more tired.</u>

Does gener	label	fit	the	whole —	e set i	in	
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Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

#### Data bits:

Uh, even to hounding me about getting my walk in. I think that was the most stressful thing for me, was to walk, walk, walk. (2037-38)

Well now let me say it this way. I have a son that had bypass surgery in February, a 45 year old. And he was here
one night, he's a school teacher, and I said...I lost it...I
don't usually do that. 'I can't stand it you guys, leave my
alone!' It was just, 'Mom you've gotta walk, walk, you
gotta walk'. (voice cracks) I just had had it! And they
bought me that thing (points to sun visor) so the sun
wouldn't hit my eyes. And I told them, 'Leave me alone, God
damn it, (arms up shielding her eyes, much distress in
voice) I can't stand it!' (2122-35).

One thing of course, this perhaps makes my case a little different than most of yours, (wife died) is the fact that at the present time and in the past, I know I've lost my incentive. (4122-27)

Although I must say they called back to the University one week after for the surgical checkup. My friend drove me down - his wife had an appointment - it was very critical and he couldn't drive me back. And to go out of the house into that huge University lobby which is just pandemonium anyway, oh god! And I got into a fight - a verbal argument - with some aggressive woman while waiting in line when you feel like you're going to fall over, you know. There were two windows and I was sort of standing in the middle of the two windows, I wanted the next open window. And some woman said "Are you in this line, or this line?" and I said that I

would take the next open window. She said, "You can't do that," and I said "You just watch me!" And then I had to catch a cab home. God, I didn't think I could make it. (8346-68)

## Label: Complications of Surgery

<u>Definition: Major problems such as arrhythmias,</u> <u>infections, or medication problems that may have had an</u> adverse impact on fatigue.

	label	fit	the	whole	e set	in	
Does genei	defini	tion	n fit	the	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

I had little problems with an A flutter, here after I went back in the second time. (2318-19)

The Procaine was one of the ones, and I finally have gone off that. That was one of the ones that was really giving me a bad time. (2262-65)

My pulse, we couldn't get it because it went so extremely high. Uh, I had one little bought in the hospital...but I had another little episode with my pulse, where my arrhythmia or my heart just went kafluey. (2413-27)

Well, being that I'm a low grade diabetic, on top of it all, every thing has healed beautifully except the one incision on my leg. I have a little spot there which I'd gone back to see Dr S about this morning. (2487-89)

He had a reaction to Procaine and we thought it was the flu so it was really hard on him that first week, he was very ill, high temperatures and ah we went into emergency three times with the temperature being up there. And finally our, at GH, the cardiologist took a look at his thing when, we asked him, and he said take him off Procaine. (3060-68)

But he was bothered with arrhythmias, in the hospital, and a couple of times when he has over done it, that comes, brief, just very brief and then it will go away. (3761-65)

It took me a little longer to bounce back because I developed an aneurysm and had to go back. And after the aneurysm was fixed, and then I had five mini strokes and had to back to the hospital. So my recovery has been quite slow. (5017-23)

But, then I was in awful pain. Some how they clipped a hole in an artery when they did the angiogram, in the groin here, and they knocked a hole in the artery, I don't know how, with the knife or scissors or something. But it dripped for about a week before anybody knew anything about it, and there was a big knot here (points to groin). And that was the most excruciating pain I've ever felt in my life. I am, I have a very high tolerance to pain, I don't feel pain like other people do. But that hurt! And that's the first pain I've had in my whole life that I couldn't handle. Oh, it was, it just made me want to scream, so finally L took me to emergency and they did something about it. They removed it. (5113-32)

Label: Physical Signs and Symptoms

<u>Definition: Signs and symptoms of physical problems</u> which may contribute to fatigue

Does	the	label	fit	the	whole	set	in
genei	ral?_						

Does the definition fit the whole set in general?\_\_\_\_\_

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

Data bits:

I did have a very, very stiff ankle that came from not using it, I believe, achilles tendon wouldn't go up at all, I had to walk on my tip-toes. (1019-22)

I had a stinging sensation here and that kinda cut me out on that...(1072-73)

The first time I did any kind of driving I noticed a little here (points to chest) there's none of that sharp pain now. (He was getting pain in his shoulder and down his arm from his activity.)
(1079-84)

But some person, when I complained about that back pain that I told you about over the phone, they encouraged me to use hot showers. So I showered right from the start. (1120-25)

I lost a little weight on this operation. My appetite, after the operation went way down. (1136-38)

The other uncomfortable part, because you don't eat much, and because of some of the drugs, you tend towards constipation and that's a little bit of discomfort. (1396-400)

You heard my playing the piano, I lost, I still have tingling in these three fingers particularly the little one. I can move the fingers but they don't have the right feel yet but they say I'm going to get over that. That's supposed to be from that cut too. (1531-38)

My legs bothered me so much I could have cried. And like I said, 'my God, it was in my chest before, the angina was so bad and now it's my legs, it's not my chest'. (2117-21)

I know that it's time to take medication, when you're taking 30 pills a day, my stomach was going...I was so nauseous that, it's a wonder, and I know that I wasn't even, it was on a 2 hour basis, even in the hospital. I couldn't keep my stomach without it being upset. (2253-60)

I sat up in the hospital a lot because my back killed me and I think it was just laying there. (2315-17)

And I take that psyllium powder and I'm still constipated. So she gives me something else and I quit taking the Procaine, which I was taking 1500 milligrams of, which is an awful lot, quit taking that, everything works fine now. So I still think that my medication had some bearing on my bowels. And, it almost made me sick that I couldn't go. I knew I had to go, I knew it was there, but I just couldn't go. I felt like I was blocked. (2539-51).

I told them that I'm so nauseous that I just...It has to be all these pills in my stomach, I said, 'Food, just even looking at it, it just gags me to think that I gotta eat too.' So L said, 'I don't care if you go out and eat a Burger King and have a malt, I'm not worried about you loosing or gaining weight, I want you putting food in there. You can't starve yourself.' I said, 'Well even that don't sound good right now.' (2555-66)

But I had no appetite and I still have no appetite. I've lost a lot of weight. I weighed about 196 when I went into

the hospital and now, today, I weighed 170. So you can see I've lost some weight. And it hasn't come back yet, it really hasn't come back. (4073-79)

I slept relatively well during that time except at night when I'd roll over, I apparently would pinch the incision and pain would wake me up. (4050-4051)

And so, but my legs, as far as hurting goes, they ache once in awhile and I do get twinges of pain down there now and then but I'm sure that's probably nerve damage that hasn't healed yet. (4157-62)

I had a problem with my leg - a staph infection which went away. I told the two doctors and asked about stitches in there. They didn't pay much attention to me. It came back when I was in New York after taking antibiotics for 10 days. I came back to Seattle at Group Health and they gave me antibiotics again. This time when I was in the hospital a different doctor, a cardiologist, looked at it and said he could take care of that right away and he took the stitches out and the thing has healed up just like that. (7402-16)

Then on the 5th of April I started to get a pulmonary infection and it really knocked me back about a month, about a month, bad. And it really interrupted the whole exercise program and I got over that and about the end of May, I guess, another one even worse -and that was about five or six weeks of bad bronchial coughing, fatigue,...bad. (8044-53)

Label: Emotional Impact of Fatique/Surgery

<u>Definition: Psychological reaction to surgery and emotional vulnerability which may contribute to fatigue.</u>

Does gener	label	fit	the '	whole —	set .	in	
Does gener	defini	tion	fit	the	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

Data bits:

He still comes up with thoughts that shock him...the other

night he was talking... "what happened to my heart while they were working on it. They must have stopped its beating" (1539-43)

Well, I think it was a good idea that nobody ever told me that my chest would be opened up and spread apart and the rib could have been broken, they weren't in my case but don't ever tell any perspective person about what's gonna happen because I don't think I would have gone through with it if I had have realized how serious...(1523-31)

I lost it...I don't usually do that. 'I can't stand it you guys, leave my alone!' It was just, 'Mom you've gotta walk, walk, you gotta walk'. (voice cracks) I just had had it!... It was just, I was just...I think that it had gotten to me that everyone couldn't leave me alone, that they couldn't realize that I know that I had to do it...But I could only take the fact that somebody else really doesn't need to tell me that I have to do it for my own health. But anyway, uh, down in my heart, I know that they were only doing it for my own good. (2126-91)

I know that was in the back of my mind always prior to that was, 'Am I going to live through it?' I'm glad it's over. (2302-04)

For no reason at all, I could start crying. And I don't know why. I could be walking down the hall, and walking by the desk and I started to say something to one of the nurses and all of a sudden, I stated to cry. And I had no reason to, I was delighted, and I was happy, but I just started to cry for no reason at all. And I did that several times. (2656-67)

Could it be that it's the heart itself, and it's the operation, the type of operation it is? (Sigh) It's a life and death thing. And we don't even talk about it because we know that it could have gone either way. We also know that it doesn't take an awful lot that it could have been the other way. And I know that my kids said, 'When we left you that night, you seemed to be really high.' But I know that when I said good-bye to them, I said to myself, 'Am I going to see them again?' And I felt this with all of them, for some reason. I don't know, but that was a big thing with me, that emotional...(2671-87)

As a matter of fact, I, to let you're religion come out and show you something. I had said a Novena prior to having surgery. And after it was all over with, I said to my daughter, I said, 'Well, I'd better send a check, I'd better write it into the times, thanking St Jude.' She said, 'Why?' I said, 'Well, I just made a promise to St. Jude if

everything went well that I would do this.' So there were a lot of things in the back of my mind that I really hadn't said that it was there. But emotionally, I think that it was more...even perhaps being tired. But I think that that could be a lot of the tiredness. (2690-709)

I could swim sprint but I couldn't do the long stuff and that explains it to me. (Voice breaks) Why is this emotional to me? (3389-92)

I'll never forget the feeling going back into emergency (voice very shaky)...(3412-14)

Um, but this sort of thing really brings it out, really brings it out. And sometimes it's well positioned. This is a theory, psychologically speaking but S and S, brother, sister (voice cracks), competition and they were growing apart until daddy had his problem. (Crying openly) And now they're together. (3812-20)

It's not that important to me but it bothers me pride wise, you know? (4281-82)

I kind of pride myself in being in pretty good shape - even though I knew and they told me - it did bother me. Then when I took the stress test exam I only went seven minutes and 13 seconds and the average, I guess, for men over 60 is eight. Of course, I forgot to ask if that's the average for after you've had open heart surgery. That's just the average. (7136-45)

Sometimes there are some psychological problems that are involved. You wake up and feel like you're choking. There's tremendous pain - you think that maybe whatever they've done inside has opened up and hasn't taken - whatever it is - but everybody has experienced these, so just knowing others have gone through it, and if it's properly explained to you at the hospital by the doctors, they shouldn't have too many problems. The fear of the unknown, of course, is the worst. (7349-60)

Especially after, you feel, you're very vulnerable when you're stitched up, wired up, and scar tissue and everything. You think, "Boy, if somebody accidentally bumped into me, it would knock me right down." That's vulnerable, you bet! You think, "Oh god, I need a taxi. I certainly hope he doesn't have an accident." Yeah, you're very vulnerable it doesn't - I've had lots of injuries in my time and every time, whether it's a knee, and elbow, it's like a hermit crab out of the shell. I was glad to get home, in fact that's always the problem. I had a bad auto accident and the same thing, not so much this time but it's

very difficult once you've been really traumatized and shut in. Life becomes very simplified. It's hard to go out into the wider world. You almost have to have some necessity to do that. (8461-82)

\_\_\_\_\_\_

### ROLE OF SPOUSE OR OTHER CAREGIVER

Label: Importance of caregiver

<u>Definition:</u> Words or phrases that indicate the presence or lack of a CG makes a difference in the recovery process.

Does gener	label	fit	the '	whole —	e set i	n		
Does gener	defini	tion	fit -	the	whole	set	in	

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

Data bits:

The other thing is to have a good, competent, medical assistant for a wife. She helped me an awful lot (chuckle). I imagine I couldn't have got by alone. I would have had to stay in the hospital for two or three weeks later. (1368-74)

Let me put it this way, I had it much better than most. My daughter came from California. My husband is very supportive and had had surgery just a month before mine. So she was here for 5 weeks. She did the washing, made sure that I got in my shower and did everything for me...I really can't complain, if I wanted to lay down, I laid down. I really can't say that everyone has the advantage of having someone to care for them. However, the doctors did ask me, 'did I have someone at home'. Perhaps, had it been just my husband...I'm not saying that all men are not as caring, but I don't think men understand, perhaps as much as women do. I don't know. (2030-2051)

Good nurse (nods towards wife) good bed mate, everything. (3324)

I sure had a good team, our son and daughter and (nods head to wife as he again can't talk)...Yeah, my best friend, what's her name (chuckle). (3431-36)

Yeah, we saw a couple of gentleman in the hospital, didn't we honey, that didn't have anyone and your heart goes out to them, you know, you really need someone that cares and you just felt sorry for them. Even thought there are wonderful visiting nurses like you, we really appreciated our visiting nurse too because we had to call about his temperature, you know, and they were the ones we were in contact with most of the time and we're grateful for that...(3571-83)

The kids were here, we have 6 children, and they were all in and out because R (wife) was in the hospital. And so they watched over the old man pretty well. I mean, they made sure I got my bed rest and so on and, of course, I had a nurse that came in two or three times to check on how things were going. (4027-35)

But anyway, uh the kids, they have really rallied around, you know it's been great. And then the church, the parishioners, they've been great too. I don't know what I would have done without either one of them, I'd have probably gone crazy. But anyway it, yeah, they check in on me. (4395-402)

(Did you have any help at home while you were recovering?) Yes, my husband is very, very good about that. (Did he help fix meals and that kind of thing?) Oh, yeah. He is so precious. He really took good care of me, he cooks for me and he's very sweet. (Was that a real important thing, to have someone here to..?) Oh, I don't know what I would have done without him...I, no, I don't know what I would have done...Yeah, there were a few days there when I shouldn't have, I couldn't have taken care of myself. I suppose if you have to, you can but I'm glad I didn't have to. (5150-70)

(What kind of advise would you give regarding recovery?)
Marry a nice man! (Laughter) No, I don't know, with most people, I don't think it would be possible to be home alone. (5203-06)

Yes - somebody to talk to , somebody to care for you, somebody to bring you meals, massage your feet. There's a lot of different things. I would have recovered without it, but it made it much easier and I would recover faster. (7378-84)

Having someone there for the first three days was a good thing - a necessity perhaps. (8280)

I had some friends and one of them brought over several dishes that I could stick in the, I had my son get a microwave... She brought over some marvelous chicken and

salmon. It looked wonderful. (8130-35)

# Label: Protection effect

Definition: Ways in which the spouse or other caregivers protect the subject from fatique or its effects.

Does gener	label	fit	the	whole	set	in	
Does gener	defini	tion	fit	the	whole	set	in

Does each data excerpt fit the definition and label?

Please write Y (yes) or N (no) beside each data excerpt to indicate if it fits the definition and label.

### Data bits:

M (wife) caught me hoeing one day (chuckle) and I had a stinging sensation here and that kinda cut me out on that...(W: And another time earlier, in fact, he was downstairs pounding in the basement... hammering.) And she stopped me and that caused a little bit...(1071-79)

I had to force him to eat. I would leave food there and he would barely eat it. He just would not... well he was taking Lanoxin, he wasn't hungry and I had to make him eat. I offered it to him often and I'd come in...in my work, I'm traveling around, and I would come home and make sure that he ate. But he would eat a few bites and quit. (1139-47)

He could barely get up the stairs and move around...he could barely talk...And I said go in and lie down...(1266-70) Yeah, but they were in there to, if I wanted my hair put up, or something, she was there to do that or someone was there to wipe my back and make sure that I wasn't overdoing something. (2069-73)

Yeah, he felt so badly, he felt so badly for R because it put him through an extra hassle and he came in to apologize to him. But it's nobody's fault and that's the way you learn, that's why we want to do this, and anytime you can help someone, you know, I think R would tell anybody that had to have this sort of thing that it's worth it, I really do. (Wife talking to allow subject to gain composure)...I guess I take the view of my nurse (nods head towards wife) (3255-68)

But B keeps real close tabs on me and makes me come and sit down or she'll bring me a drink of coke or she'll say it lunch time, or whatever. But I think that the best part of recuperating is to have somebody helping you do it (voice get shaky). (3558-70)

I just kinds keep tabs on the time, the amount of time and how heavy a job he's doing and he won't quit (chuckle) and that's why I have to, he just keeps going until he's overly tired so...(3589-94)

So it's not a, you know, anything dire, it's just a matter of pacing himself and he's not real good at that. He sorta needs a nudge to stop. (3603-07)

Well, it's good honey, that's a safety valve, there's nothing wrong with that, it's a lot better than keeping it inside for, heaven sake. (Wife's response when subject cried) (3836-39)

And my wife sat on me - and made sure I didn't exert myself, because she knows me. That's exactly what happened last Thursday when I had to go back to the hospital - it was because I jogged, not thinking. She is very good for me, keeping me under control. (7215-22)

Our home is very comfortable - we've been there for 27 years, so it's a safe harbor. There's no one specific thing, but if I do feel tired I will force myself now to rest, which I didn't do before. I always felt I could push myself further. If I were tired but had something to do, I would just go and do it. Now if I'm tired, I'll go and relax, and if my wife knows if I'm tired, I'll do it more. (7283-94)

You sure do need somebody around in case you hit the deck. (8257)

# Appendix E<sup>a</sup>

Date

Name Address

Dear Patient,

Many people experience fatigue following surgery -especially cardiac surgery. Very little is known about this
experience, the cause of it, or what to do about it. Ruth
Gregersen is a nurse who has cared for cardiac surgery
patients for over 15 years. She has worked in the intensive
care unit and as a visiting nurse in the patient's home.
She is currently a doctoral student and is conducting a
study to learn more about the fatigue associated with
cardiac surgery.

Since you have had cardiac surgery recently, you may have first-hand experience with postoperative fatigue. If you have, you are considered an expert in how that experience feels and how it affects your life. If you have not experienced fatigue since surgery, it is important to know that also.

Ruth Gregersen would like you to participate in her research by completing a questionnaire designed to measure your level of fatigue. A few questions about your surgery and your age and gender will also be asked. Your participation will help her gain a better understanding of postoperative fatigue and how it affects a person's life. The fatigue questionnaire and will take about 15-20 minutes to complete. If you would be willing to participate in Ruth's study, please return the enclosed post-card. Returning the postcard does not obligate you in any way. You may still choose not to participate once you receive the questionnaire. Participation in the study is completely voluntary and your care by Group Health Cooperative providers will not be affected by your decision.

As a cardiologist, I would encourage your participation in this study. Fatigue is a problem for many people and sharing your experience with Ruth now, may help other patients in the future. If you have any questions, please feel free to call Ruth at home (206) 523-6698 or work (206) 654-4273.

Sincerely,

Lee C. Amsler, M.D. Cardiologist, Group Health Cooperative enclosure

# Appendix Eb

Date

Name Address

Dear Patient,

Many people experience fatigue (tiredness) following surgery — especially cardiac surgery. Very little is known about this experience, the cause of it, or what to do about it. I am a nurse who has cared for cardiac surgery patients for over 15 years. I have worked in the intensive care unit and as a visiting nurse in the patient's home. I am currently a doctoral student and am conducting a study to learn more about the fatigue associated with cardiac surgery.

Since you have had cardiac surgery recently, you may have first-hand experience with postoperative fatigue. If you have, you are considered an expert in how that experience feels and how it affects your life. If you have not experienced fatigue since surgery, it is important to know that also.

I would like you to participate in my research by completing a questionnaire designed to measure your level of fatigue. A few questions about your surgery and your age and gender will also be asked. Your participation will help me gain a better understanding of postoperative fatigue and how it affects a person's life. The questionnaire and will take about 15-20 minutes to complete. If you would be willing to participate in my study, please return the enclosed post card. Returning the post card does not obligate you in any way. You may still choose not to participate once you receive the questionnaire.

As a cardiac nurse, I would encourage your participation in this study. Fatigue is a problem for many people and sharing your experience with me now, may help other patients in the future.

Sincerely,

Ruth A. Gregersen, R.N., Ph.C., CCRN Doctoral Student Oregon Health Sciences University

enclosure

## Appendix F

Date

Name Address

Dear Subject,

First, I would like to thank you for volunteering to complete the enclosed survey. I know that your responses will help me begin to understand the fatigue associated with cardiac surgery.

The enclosed questionnaire should take about 15 to 20 minutes to complete. Feel free to take a break if you need to. If there is any question you prefer not to answer, just skip that question.

Participation in the study is completely voluntary and your care by health care providers will not be affected by your decision. If you have any questions or concerns about the survey, please call me (Ruth Gregersen) at (206) 523-6698. If I am not available when you call, just leave your name and number and I will get back to you as soon as possible.

I have enclosed a postage-paid envelope in which you may return the survey. Thank you again for sharing your experience with me.

Sincerely,

### Appendix G

Date

Name Address

Dear Subject,

First, I would like to thank you for volunteering to complete the enclosed survey. I know that your responses will help me begin to understand the fatigue associated with cardiac surgery.

The enclosed questionnaire should take about 15 to 20 minutes to complete. Feel free to take a break if you need to. If there is any question you prefer not to answer, just skip that question.

Because you had your surgery very recently, I expect that you may be quite tired at this time. Your level of fatigue will probably change over the next few weeks as you body begins to heal. I am interested in learning about the change in your fatigue level. If you would be willing to complete the survey again in a few weeks, please fill in your name and address on the attached blue sheet and enclose it with your survey which you will be returning to me by mail. You will then receive another survey in the mail a few weeks later.

Participation in the study is completely voluntary and your care by health care providers will not be affected by your decision. If you have any questions or concerns about the survey, please call me (Ruth Gregersen) at (206) 523-6698. If I am not available when you call, just leave your name and number and I will get back to you as soon as possible.

I have enclosed a postage-paid envelope in which you may return the survey. Thank you again for sharing your experience with me.

Sincerely,

### Appendix H

Date

Name Address

Dear Subject,

Several weeks ago a questionnaire designed to measure your level of fatigue following cardiac surgery was mailed to you. I have not received your response. Because each person's, experience is unique, it is important that your responses be included in the study.

If you are willing to share your experience with me, please complete the questionnaire and return it to me within the next few days. (I have included another copy of the questionnaire in case you did not receive it or it has been misplaced.) The questionnaire should take about 15 to 20 minutes to complete.

Your participation in the study is completely voluntary and care by your health care providers will not be affected by your decision. However, if you decide not to participate, it would help me to know why. Please check one of the reasons listed below and return this letter along with the blank questionnaire.

 I am too ill or tired to complete the survey
 The survey is too long
 I am too busy to complete the survey
Other (please explain)

If you have any questions or concerns about the survey, please call me (Ruth Gregersen) at (206) 523-6698. If I am not available when you call, just leave your name and number and I will get back to you as soon as possible.

I have enclosed a postage-paid envelope for you to use when returning the survey. Thank you again for sharing your experience with me.

Sincerely,

### Appendix I

Date

Name Address

Dear Subject,

Several weeks ago you completed a questionnaire about fatigue following cardiac surgery. At that time, you indicated that you were willing to complete the questionnaire one more time to determine if your level of fatigue has changed.

I would like to thank you for completing the both of the questionnaires. Your responses will help me begin to understand the changes in fatigue following cardiac surgery.

The enclosed questionnaire should take about 15 to 20 minutes to complete. Feel free to take a break if you need to. If there is any question you prefer not to answer, just skip that question.

Your continued participation in the study is completely voluntary and care by your health care providers will not be affected by your decision. If you have any questions or concerns about the survey, please call me (Ruth Gregersen) at (206) 523-6698. If I am not available when you call, just leave your name and number and I will get back to you as soon as possible.

I have enclosed a postage-paid envelope in which you may return the survey. Thank you again for sharing your experience with me.

Sincerely,

Appendix J

# Fatigue Following Cardiac Surgery

# **Fatigue Following Cardiac Surgery**

Purpose: Fatigue is a common experience following cardiac surgery. Very little is known about this experience. The purpose of this survey is to test how well a newly developed questionnaire measures your level of fatigue after cardiac surgery. To achieve this purpose, your responses to four different questionnaires will be compared. Your answers are important because nurses and doctors do not know how postoperative fatigue feels or how it affects your life.

Questionnaire: The questionnaire will take you about 15-20 minutes to complete. You may use either a pen or pencil. If you wish, someone else can mark the answers for you. Directions are given just before each new set of questions. There are no right or wrong answers to any of the questions. When you've finished, please mail the completed questionnaire to me in the self-addressed and stamped envelope.

Thank you for sharing your experience with fatigue.

Ruth A. Gregersen, R.N., Ph.C., CCRN Doctoral Student, Oregon Health Sciences University School of Nursing, Portland, Oregon

# Tell Me About You

IRCLE the r	3	4 5			6 7	8	9	10	
zero to ten,	with 0 rep	resenting "no t represents l	ot tii	red yo	at all" and i	l 0 represent n the past <b>T</b>	ting "c <b>WO D</b>	ould not be	
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				6		-			
	rgery?					_		raining	
						•	1		
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				6	Other (plea	ase specify)	,		
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gender?				4	Hispanic				
, ou.				3					
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No, doesn't

# **FATIGUE SCALE**

Here are some statements that could describe how you feel about yourself. Please read each statement carefully and place a check  $(\lor)$  in the blank that best fits how the statement describes how you have felt in the past **TWO DAYS**.

Yes, describes

Somewhat

Here is an example:	me exactly	(	describes	describe me		
I feel sleepy	1	1 1	1	Ī	at a	ali 
(If you had placed a check as shown in the describes you more than "somewhat" but r	e above example, yo not "exactly".)					
Answer each item as best as you can BASI answers.	ED ON THE PAST T	WO DA	AYS. The	re are NO	right or wrong	g
	Yes, describes me exactly	ć	Somewh describes		No, do describ at	e m
1. I feel so tired that I have to be told wha						_1
2. I frequently "run out of gas"		1				$\perp$
3. I can't keep going						_
4. I can do more this week than last week	<l< td=""><td>1</td><td></td><td></td><td></td><td></td></l<>	1				
5. I feel so tired that I don't want to do ar	ything					
6. Climbing the stairs is hard for me					1	
7. It takes almost too much effort to eat		<b>L</b>				
8. I don't have the zip to do things						
9. Others tell me that I look tired	1					
10.1 feel tired		1				
11.1 cry more easily than I used to				==   0		
12.1 have to sit down and rest		1			<u> </u>	1 8
13.I have a spring in my step	L			1		
14.1 take frequent rest periods	<u>L</u>			1		
15. My body frequently tells me that I must I	ie down	1		1		
16. All I can do is watch TV	<u>L</u>					1
17.1 don't go out as much as I used to bed		1	1	ī	ſ.	1
18 I have simplified my life		<u> </u>				

# Answer each item BASED ON THE PAST TWO DAYS.

	Yes, describes me exactly	Somewha describes t		No, doesn't describe me at all	
19. I just can't concentrate					
20. I take naps					
21.1 can stay up all day without difficulty				1	
22. My body frequently tells me that I have ov	ver done				
23.1 enjoy a lively discussion					
24. I feel wiped out					
25.1 have to pace myself					
26. It's a chore to go out because I feel so t	ired		1		
27. My color is pale			1		
28. I don't push myself like I used to	<u>_</u>		1		
29. I feel so tired that even simple tasks are		1			
30.1 feel drowsy					
31. It takes me longer to do things because I feel	so tired			11	
32.1 go to bed early			1	1 1	
33. I feel perky	L	1			
34. My shoulders slump					
35.1 just want to lie down	<u>L</u>				
36.1 feel very vulnerable	<u> </u>	L			
37.1 feel exhausted					
38.1 don't do the things I used to do			1		
39.1 feel irritable			1	1	
40.1 don't have the energy to participate in					
sexual activity	Let the second second		1		
41.I feel worn out		L			
42. It takes almost too much effort to shower	and dress				

Name			Date /	_ / (month/day/year)
SEX: MALE	M	FEMALE (F)		

Below is a list of words that describe feelings people have Please read each one carefully. Then CIRCLE one number under the answer to the right which best describes **HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY**. The numbers refer to these phrases.

0 = Not at all; 1 = A little; 2 = Moderately; 3 = Quite a bit; 4 = Extremely

Not at all	A little	Moder- ately	Quite a bit	Extremely	Not at all	A little	Moder- ately	Quite a bit	Extremely
1. Tense 0	1	2	3	4	16. Nervous <b>0</b>	1	2	3	4
2. Angry 0	1	2	3	4	17. Lonely 0	1	2	3	4
3. Worn out 0	1	2	3	4	18. Muddled <b>0</b>	1	2	3	4
4. Lively 0	1	2	3	4	19. Exhausted <b>0</b>	1	2	3	4
5. Confused 0	1	2	3	4	20. Anxious0	1	2	3	4
6. Shaky 0	1	2	3	4	21. Gloomy0	1	2	3	4
7. Sad <b>0</b>	1	2	3	4	22.Sluggish0	1	2	3	4
8. Active 0	1	2	3	4	23. Weary 0	1	2	3	4
9. Grouchy <b>0</b>	1	2	3	4	24. Bewildered0	1	2	3	4
10. Energetic <b>0</b>	1	2	3	4	25. Furious 0	1	2	3	4
11. Unworthy <b>0</b>	1	2	3	4	26. Efficient0	1	2	3	4
12. Uneasy <b>0</b>	1	2	3	4	27. Full of pep 0	1	2	3	4
13. Fatigued <b>0</b>	1	2	3	4	28. Bad-tempered <b>0</b>	1	2	3	4
14. Annoyed <b>0</b>	1	2	3	4	29. Forgetful0	1	2	3	4
15. Discouraged 0	1	2	3	4	30. Vigorous <b>0</b>	1	2	3	4
							YOU HA		

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# MULTIDIMENSIONAL ASSESSMENT OF FATIGUE (MAF) SCALE FATIGUE

These questions are about fatigue and the effect of fatigue on your activities. For each of the following questions, CIRCLE the number indicating how you have been feeling DURING THE PAST WEEK.

For example, suppose you really liked to sleep late in the mornings. You would probably circle a number closer to the "10" end of the line. This is where I put it:

	To what de	egree do	o you usua	ally like to	steep late	e in the m	torningss				
	0 Not at all	1	2	3	4	5	6	7	(8)	9	10 A great deal
No	ow please com	plete tl	he follow	ring items	s based o	n the <b>pa</b> .	st week.				
1.	To what degre	e have	you exper	ienced fa	tigue?						
_	0 Not at all	1	2	3	4	5	6	7	8	9	10 A great deal
	IF NO FATIGU	JE, PLE	ASE GO C	ON TO Q	UESTION	17					
2.	How severe is	the fati	gue which	n you hav	e been ex	periencin	g?				
	0 Not at all	1	2	3	4	5	6	7	8	9	10 A great deal
3.	To what degre	e has fa	itigue cau	sed you d	istress?						
	0 Not at all	1	2	3	4	5	6	7	8	9	10 A great deal

CIRCLE the number that indicates to what degree fatigue has interfered with your ability to do the following activities in the past week. For those activities you don't do, for reasons other than fatigue (e.g. you don't work because you are retired), check ( $\sqrt{}$ ) the box to the left.

In the past week, to what degree has fatigue interfered with your ability to: Don't do

4. Do hou	sehold c	chores								
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
5. Cook									91 102	
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
6. Bathe o	r wash									
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
7. Dress										
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
8. Work										
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
9. Visit or socialize with friends and family										
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
	•	-1:-:-:-								
10. Engage			3	4	5	6	7	8	9 10	
0 Not at all	1	2	3	*	3	U	,	Ū	A great deal	
11. Engage	in leisu	re and red	creationa	l activities	5					
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
12. Shop a	nd do er	rands								
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
13. Walk										
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	
14. Exercis	se, other	than wall	king							
0 Not at all	1	2	3	4	5	6	7	8	9 10 A great deal	

activity

CIRCLE) the number next to the statement that describes your fatigue.

- 15. Over the past week, how often have you been fatigued?
  - 4 Every day

1 Hardly any days

3 Most, but not all days

- 0 No days
- 2 Occasionally, but not most days
- 16. To what degree has your fatigue changed during the past week?
  - 4 Increased

- 1 Decreased
- 3 Fatigue has gone up and down
- 0 I didn't have fatigue this past week

2 Stayed the same

CIRCLE one number on each line that best describes how important it is that you are able to do each of the following activities.

How important is it to you to:	Very important					Not at all important
17. Do household chores	1	2	3	4	5	6
18. Cook	1	2	3	4	5	6
19. Bathe or wash	1	2	3	4	5	6
20. Dress	1	2	3	4	5	6
21. Work	1	2	3	4	5	6
22. Visit or socialize with friends and family		2	3	4	5	6
23. Engage in sexual activity	1	2	3	4	5	6
24. Engage in leisure and recreational activities		2	3	4	5	6
25. Shop and do errands		2	3	4	5	6
26. Walk	1	2	3	4	5	6
27. Exercise, other than walking		2	3	4	5	6

# Pearson-Byars Feeling Tone Checklist

**Instructions:** The statements to follow are to help you decide how you feel at this time—not yesterday, not an hour ago—but *right* now. For each statement, you must determine whether you feel (1) "Better than," (2) "Same as," or (3) "Worse than" the feeling described by that statement.

As an example, take a person who feels a little tired. He might respond to the following items as follows:

	Better than	Same as	Worse than			
a)	( )	( )	( V)	extremely fresh		
b)	( )	( <b>V</b> )	( )	slightly tired		
c)	(√)	( )	( )	completely exhausted		

In other words, this person feels worse than "extremely fresh," about the same as "slightly tired," but better than "completely exhausted."

Now, answer each of the following statements as follows:

- If you feel **better than** the statement, place a " $\sqrt{}$ " in the "better than" column.
- If you feel about the *same as* the statement, place a " $\sqrt{}$ " in the "same as" column.
- If you feel worse than the statement, place a " $\sqrt{"}$ " in the "worse than" column.

Remember, answer each question with regard to how you feel at this instant.

Better than		er than Same as				Worse	e than			
1)	(	)		(	)	(	)	very lively		
2)	(	)		(	)	(	)	extremely tired		
3)	(	)		(	)	(	)	quite fresh		
4)	(	)		(	)	(	)	slightly pooped		
5)	(	)		(	)	(	)	extremely peppy		
6)	(	)		(	)	(	)	somewhat fresh		
7)	(	)		(	)	(	)	petered out		
8)	(	)		(	)	(	)	very refreshed		
9)	(	)		(	)	(	)	fairly well pooped		
10)	(	)		(	)	(	)	ready to drop		

Thank you very much for completing this survey! Please use the space below if there is any information that you would like to tell me or you think I should know about fatigue following cardiac surgery.

If you have misplaced the return envelope or have questions regarding this survey, my address and telephone number follow. If you do not live in the Seattle area and you have questions, please do not hesitate to call me collect. Again, your participation in this research study is greatly appreciated!

Ruth A. Gregersen, R.N., Ph.C., CCRN 9043 51st N.E. Seattle, WA 98115 (206) 523-6698