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The purpose of this 4-year study is to determine the effects of the Comprehensive Coping Strategy Program (CCSP) on clinical outcomes and quality of life in breast cancer patients and their primary caregivers. Specifically, the purpose of this study was to compare descriptions of pain, psychological distress, fatigue, and perceived health status and burden of care in breast cancer patients who received autologous bone marrow transplant (ABMT) and their primary caregivers (PCGs) and participated in a CCSP and ABMT breast cancer patients and their PCGs who did not receive the CCSP. A randomized controlled clinical trial design was used . Thus far, 110 patients and 85 primary caregivers have entered the study. Data are presented on 100 patients and 83 PCGs. Fifty patients were randomly assigned to the CCSP treatment group and 45 to the control group. The ABMT was canceled in 5 patients before baseline data were collected but after the consent from had been signed. Data were collected 20 days before hospitalization (baseline), during hospitalization (7 days after the ABMT), and again during the post hospitalization period which was 6 months to a year following the ABMT. The results showed trends that support the use of the CCSP in the reduction of psychological distress, improving the mental health status of the patient and increasing the number of hours of sleep. The CCSP group was able to avoid catastrophizing to a higher degree than the control group and reported a higher perception of health than the control group. Quality of life was improved in the psychological/spiritual domain within the treatment group. The treatment group showed an overall improvement in QOL of 10 points ($p<0.001$). The control group showed a smaller (6.8 points) improvement in QOL that was also significant (0.05).

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Fannie Easton-Johnson Sept 15, 1997

PI - Signature Date

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Introduction

Autologous bone marrow transplantation (ABMT) consists of the administration of high-dose chemotherapy and in some cases, total body radiation, followed by rescue with autologous, cryopreserved, bone marrow cells. This treatment regimen has become an established alternative treatment in a variety of malignant diseases including breast cancer[1]. While potentially life-saving, ABMT can be a traumatic procedure and can seriously impact the patient's quality of life (QOL). The often severe and unrelenting pain from the treatment regimen, medical procedures and persistent adverse physical side effects such as pain, fatigue and nausea and vomiting result in a critically ill and psychologically distressed patient. These symptoms in turn affect the patient's health status and QOL[2-3]. The patient's primary caregiver may also experience psychological distress, severe fatigue, increased burden of care, and a less than optimum QOL[4-9].

The overall purpose of this four year research project is to measure the effects of a comprehensive coping strategy program (CCSP) on pain, psychological distress, fatigue, perceived health status, burden of care, and QOL for breast cancer ABMT patients and their primary caregivers. The specific purpose of this paper is to present data from the first 32 months of data collection that describe physical symptoms psychological distress, QOL, fatigue, perceived health status and coping in breast cancer patients who receive ABMT and burden of care, fatigue, psychological distress and QOL in primary care givers who participate in the CCSP and those who do not participate in the CCSP.

Literature Review

ABMT Patients

Pain associated with ABMT is well documented and is related to either the conditioning regimen and/or the ABMT procedure itself. Painful side effects of ABMT include the following: gastrointestinal complications- painful effects on the epithelial membranes of the oral cavity (stomatitis and ulcerations); gastritis, diarrhea and nausea and vomiting; genitourinary complications- painful effects on the mucosal epithelial membranes of the bladder wall (chemical cystitis), renal complications; veno-occlusive disease; pancytopenia effects- infection, high fever, sepsis, hemorrhage; neurological complications; cardiac toxicities; alopecia with resultant effects on body image; and fatigue [2, 3, 10]. ABMT treatment causes pain through necessary invasive procedures such as bone marrow aspirations, spinal taps and Hickman Catheter placement. Rappaport[11] reported that anxiety and depression were the most common psychological reactions in patients post-ABMT. The subtle and overt interrelationships among the many potential physical and psychological symptoms related to ABMT make care of this population a very complex process.

As ABMT therapeutic advances for breast cancer have led to improvement in prognosis and overall survival, emphasis on the psychosocial well-being of the patient has become more important [12]. Anxiety regarding painful procedures, strict protective isolation, and depression were universal reactions during and for several months following ABMT[13]. Gaston-Johansson and associates[5] found that ABMT patients had moderate anxiety and

depression during hospitalization and at discharge with anxiety and depression reaching peak intensity 5 days post ABMT. Jenkins and associates[14] found that 40% of ABMT patients, suffered from major depression at some stage during the transplant procedure. Case studies and anecdotal description suggest that strict protective isolation, medical procedures, and pain are frequent contributors to anxiety and depression in ABMT patients, with pain described as the most frequent factor[14]. Research documenting a positive relationship of pain to anxiety and depression in cancer patients is extensive[15, 16].

About 33-76% of patients who undergo ABMT experience a high degree of fatigue[17]. Frequency and severity of pain, psychological distress and fatigue influences a patient's perceived health status, QOL and length of hospital stay[18]. Additional research targeting treatment-related fatigue and patient response to this symptom is needed [19].

Coping strategies of breast cancer patients have been recognized as a critical component of psychosocial well-being. Some of the psychological aspects of the BMT process are well-known: decreased contact with supportive persons because of protective isolation; anxiety related to the unpredictability of the progress through the BMT experience; and side effects [20]. Numerous factors affect psychosocial reactions to the BMT experience: age; social support; personality/intelligence; financial worries; religion; culture; and past experiences [21]. However, few longitudinal studies conducted over time to explore these factors have been completed [22]. Although few studies have been conducted to identify psychosocial aspects of the BMT experience from the patient's perspective, a hermeneutical inquiry was conducted which identified five major themes of coping patterns among BMT patients: physiological functioning; alertness; attitude; social relationships and; spirituality [20].

A patient's beliefs about his/her health status have been shown to be an important determinant of health outcomes[9]. The health status of ABMT patients varies. Some breast cancer ABMT patients leave the hospital within three weeks, while others stay 2 to 3 months. About 35% of patients utilize emergency room services and about 15 to 50% require one or more rehospitalizations[23].

Primary Caregiver (PCG)

It is well recognized that cancer impacts not only the patient, but also persons who comprise the patient's support system [24, 25, 26, 27, 28]. Northouse [28] presented summary empirical evidence from 19 studies that families may experience similar emotions as the breast cancer patient. The PCG is the person identified by the patient as the significant other. The PCG is usually the single greatest support person for the patient during the transplant process and at other difficult times[29]. Not only does the PCG devote energies to the patient during the pretransplant period and peritransplant period, but also because of the decreased length of stay for the ABMT patient additional responsibilities may be added: dispensing oral medications and administering intravenous fluids and medications via an infusion pump; and assessment of the patient in the home for sequel of the ABMT process- fever, nausea and vomiting, diarrhea or other reportable side effects and symptomatology [30]. Few studies to date have documented the PCG's psychological distress or negative outcomes related to care of the breast cancer ABMT patient, or how they cope with problems related to caregiving burden. Pistrang and Barker [26] explored the role of the helping relationship with the partner related to women's psychological response to breast cancer. Their findings suggest that the

partner plays a key role in breast cancer patients' adaptation and also that interventions focusing on couples may be effective in reducing psychological distress [26]. Burdens which can contribute to this distress include the patient's medical regimen, the constant/multiple patient demands prior to, during and months/years after ABMT, possibly traveling long distances and displacement from home, friends and work, possibly living with a very ill person for a long time, and competing family/work responsibilities. There is some evidence that caregivers experience positive reactions [29]. However, most investigators suggest that caregivers responsibilities have negative effects on the caregivers' QOL[6]. Caregivers frequently demonstrate poor health and severe fatigue, in addition to frustration, anxiety and depression. Improving support within this close relationship may lessen PCG burden of care and allow for better adjustment to the cancer experience for both the patient and the PCG.

Comprehensive Coping Strategy Program (CCSP)

The Gate-Control Theory of pain by Melzack and Wall [15] and the Stress, Coping and Adaptation Paradigm by Lazarus[16] provide the theoretical framework for this study. Pain is defined as a multi-dimensional sensory and affective experience associated with discomfort[15]. Coping is defined as constantly changing cognitive and behavioral efforts used to manage specific external and /or internal demands that are appraised as taxing or exceeding the resources of a person[16]. Positive coping strategies refer to internal thoughts and behaviors people use to manage their pain, or their emotional reactions to the pain and to reduce emotional distress. Catastrophizing, a negative coping strategy, is defined as a method of cognitive coping characterized by negative self-statements and thoughts about the future[23, 31]. Previous research studies have shown that pain and emotional distress can be reduced in pain patients by providing a comprehensive coping strategy program (CCSP) which includes: preparatory information to increase control[31]; b) cognitive restructuring which includes positive coping statements and avoidance of catastrophizing [31]; and c) relaxation with guided imagery. A combination of these three components has been found to be the best overall coping intervention to reduce pain and stress rather than using each component separately [31]. However, no prospective or retrospective study was found in the scientific literature which included these three components in a unified coping strategy program to reduce pain and emotional distress and fatigue in breast cancer ABMT patients.

The following questions were asked in the three year report of this study :

1. Is there a difference in how breast cancer patients who receive ABMT and participate in a CCSP describe physical symptoms/problems (pain, sleep, fatigue, and nausea); psychological distress (anxiety and depression); perceived health status and QOL compared to breast cancer patients who receive ABMT but not the CCSP?

2. Is there a difference in how primary caregivers, of breast cancer patients who receive ABMT and participate in a CCSP, describe their burden of care, and psychological distress compared to primary caregivers of ABMT patients who do not receive the CCSP?

Methods and Instrumentation

Study Design

The study has a prospective randomized controlled clinical trial design with repeated treatment and measurements. Participants were randomized to one of two comparison groups for the purpose of measuring the effect of the proposed intervention, i.e. participation in the CCSP. Group I was composed of breast cancer patients and their PCGs who received the CCSP intervention. Group II included breast cancer patients and their PCGs who did not receive the CCSP. The initial preliminary effect of the CCSP was assessed by comparing differences in the means between the 2 groups in terms of the outcome measures. Eligibility criteria for participation in the project were as follows: 1) scheduled to receive ABMT for stage III or IV breast cancer; 2) able to speak and read English; 3) age $\geq$ 18; 4) able to give informed consent.

Instruments

Sauce-demographic and Background Variables

The information about demographic and background variables was collected on a standardized form and included the following information: age; gender; race/ethnicity; marital status; educational level; religion; household income; employment status; occupation; and whether the subjects lived alone or with another person.

Pain Intensity and Quality

The Painometer® (POM) is a hard white plastic tool which measures 8 inches long, 2 inches wide and 1 inch thick. It is light weighted and can easily be held by the subject. A list of 15 sensory and 11 affective pain descriptors are located on the front side of the POM and a 100 mm visual analogue scale with a moveable marker is located on the back side of the POM (POM-VAS). An intensity value (from a low of one to a high of five) is pre-determined for each sensory and affective word located on front of the POM. A maximum score can be obtained for the sensory component of pain and for the affective component. A total score can be obtained by adding the sensory and affective scores. Test-retest reliability of the POM has been demonstrated as well as criterion related[34] and construct validity[32-36].

Psychological Distress

Anxiety and depression were assessed as measures of psychological distress. Anxiety was measured using the State-Trait Anxiety Inventory (STAI). The STAI consists of two separate self-report scales for measuring state and trait anxiety[37]. State anxiety is a transitory emotional response to a stressful situation. Trait anxiety reflects a stable predisposition to anxiety as determined by a personality pattern. Respondents rate themselves in relationship to the statement on a Likert scale from 1 to 4. The total score is the sum of all 20 responses and ranges from a minimum score of 20-39 (low anxiety), 40-59 (moderate anxiety), to a

maximum score of 60-80 (high anxiety). Test-retest reliability and validity have been demonstrated for the STAI[37]. Depression was measured using the Beck Depression Inventory (BDI). The BDI consists of 21 items that describe particular symptoms of depression [38]. Subjects respond to a Likert-type scale by rating each item 0 (no symptom) to 3 (severe or persistent presence of the symptom). Scores ranging from 0 to 9 are normal, 10 to 15 mild depression, 16 to 23 moderate depression, and 24 to 63 severe depression. The total score (range 0 to 63) is obtained by summing the 21 responses. Test-retest correlations of the BDI ranged from .60 to .90 in nonpsychiatric patients [38].

Fatigue

The Piper Fatigue Scale (PFS) was used to measure fatigue. This scale was designed to measure fatigue as a multidimensional phenomenon, defined as "a subjective feeling of tiredness, influenced by circadian rhythm, and other factors varying in duration, unpleasantness, and intensity" [39]. The scale consists of 41 horizontal 100 mm VAS items measuring four dimensions of subjective fatigue: 1) temporal dimension; 2) intensity/severity dimension; 3) affective dimension; and 4) sensory dimension. A total fatigue score is calculated by summing the four scores and dividing by four [39] . A 100 mm visual analogue scale was also used to measure overall fatigue.

Perceived Health Status

The Short-Form Health Survey (MOS-FS)[40] was used to measure perceived health status. The 20-item survey assesses physical functioning (6 items), role functioning (2 items), social functioning (1 item), mental health (5 items), health perception (5 items) and pain (1 item)[40]. Reliability[40] and construct validity has been demonstrated for the MOS-SF.

Coping Strategies

The Coping Strategy Questionnaire (CSQ), developed by Keefe[23], will be used to assess a person's use of pain coping strategies. The categories of coping strategies assessed by this measure include:1) diverting attention; 2) reinterpreting pain sensations; 3) ignoring pain sensations; 4) praying and hoping; 5) catastrophizing; and 6) increasing activity level. For each category of coping strategies there are 6 items on the CSQ with scores ranging from 0 to 36. Each item is rated on a 7 point scale to indicate how often that strategy is used to cope with pain (0 = never, 3 = sometimes, and 6 = always). The CSQ also includes 2 items which measure overall effectiveness of those strategies used by asking the subjects to rate on a 7-point scale (with scores ranging from 0 to 6) how much control they have over the pain, and how much they are able to decrease their pain[23]. Reliability and construct validity have been demonstrated for the CSQ[23].

Burden of Care

Burden of care (BOC) was assessed using the Measurement of Objective Burden (MOB) and the Measurement of Subjective Burden (MSB) scales developed by Montgomery, Gonyea and Hooyman[41]. The MOB is a 9-item, 5-point scale ranging from (1), " a lot more or better", to (5), "a lot less or worse", designed to assess the extent to which caregiving behaviors have changed the caregiver's lives in nine areas: time for oneself; privacy; money; personal freedom; energy; recreational/social activities; vocational activities; relationships with other family members; and health. The MSB is a 13-item, 5-point scale from (1) "rarely or never" to (5) "most of the time", designed to assess attitudes toward or emotional reactions to the caregiving experience. Items for the MSB were adapted from the 29-item inventory relating to attitudes and feelings about caregiving developed by Zarit and associates [42]. Reported alpha was .85 for the MOB scale and .86 for the MSB scale[41].

CCSP Intervention

Purposes

The three purposes of the CCSP are to: 1) teach the patient and PCG how to decrease and control pain and discomfort; 2) enhance the coping ability of the patient and PCG by teaching them to recognize distorted thinking, and how to use positive coping self-statements and; 3) teach the patient and PCG how to use relaxation with imagery. The goal of the CCSP is to reduce pain, psychological distress, and reduce fatigue that is known to be intensified by pain and psychological distress. A decrease in these symptoms is expected to positively influence the subjects perceived health status and QOL. A detailed description of the CCSP is presented in the Appendix A.

Data Collection Procedure and Administration of CCSP

This 4 year study has been in effect for 36 months and data have been collected over a period of 32 months. Major points for data collection were: during pre-hospitalization (baseline); during hospitalization (7 days after the ABMT) and during post hospitalization (6 months to 1 year following the ABMT). It takes about one year and 2 months for a complete set of data to be collected for each subject.

Baseline data were collected by the clinical nurse specialist about 20 days before the ABMT. Two weeks prior to the ABMT (ABMT day -14), the CCSP intervention was taught to group I (treatment group) by a social worker experienced in teaching patients to use coping strategies and relaxation techniques. Group I (treatment group) patients and PCGs were instructed to practice the CCSP daily. The patients were also told to practice the CCSP when they felt that they needed it. The treatment group was also instructed to document their use of the CCSP in a diary. The CCSP was reinforced in the patient's room by the research nurse participating in the project on three different occasions during the patience's hospitalization. Data were collected by a research assistant who administered the Painometer® and standardized questionnaires to all subjects (patients and their PCG) in groups I (treatment) and II (control) during the patient's hospitalization. Data were collected following the ABMT in the patient's room.

Statistical Analysis

Descriptive statistics (correlations, percentages and chi squares) were used to assess data quality (outpatient, missing data, inconsistant distribution) and analyze the data. Analysis of variance (ANOVA) was used to compare group differences at baseline for demographic, physical, psychological, coping, health and QOL measures in order to examine the successful implementation of the process of randomization. Paired tests were used to compare written group differences between 2 time periods. ANOVA procedures were also used to assess group differences between baseline and hospitalization, hospitalization and post-hospitalization, baseline and post-hospitalization. Multivanzte analysis using MANOVA and repeated measures ANOVA were not performed during this phase of the study because we did not find strong correlations between measures time & groups. These are possible due to small sample size and large standard deviations among the measures conceptually expected to be highly correlated. If adequate sample size is achieved during the last phase of the study, these test and proportional hazards for mortality will be used between groups to assess overall impact of the CCSP. Data entry and validation was performed using EPI Info. (CDC/WHO, 1994) (45) software. All data management, construct development and subsequent analysis were performed using SPSS (SPSS Inc., 1996) (46) software.

RESULTS

Recruitment and Retention of Subjects

Pre-Hospitalization

One hundred and ten subjects have been recruited to the CCSP project at the time of submission of the annual report for 1997. one hundred of these subjects were included in the analysis of data for this report. Data from the remaining subjects and PCGs will be analyzed in the fourth year of the project. Several factors have influenced the recruitment and retention of subjects to the project. A complete analysis of reasons for attrition is presented in table 1.

The ABMT was canceled for 5 subjects after they had signed consent forms and prior to collection of baseline data. The ABMT was canceled in another 5 patients after consent forms had been signed and baseline data were collected. Reasons given for cancellation were that the disease had become more aggressive and the patients had extensive metastatic disease. Although these patients technically entered the study according to IRB criteria at Johns Hopkins University (informed consent forms were signed), they were later eliminated from the study because they did not receive the ABMT.

Three patients withdrew from the study after informed consents were signed and baseline data were collected because they were randomly assigned to the control group. In one of the cases, the patient and her family became so upset that we felt obligated to give them the intervention. We continue to follow this patient. She is still alive and doing well but she has been eliminated from the study. Following this episode, all patients in the

control group were promised the CCSP relaxation tapes once they had completed the study. This procedure has helped to retain patients in the control group.

Although data collection has improved, another problem facing the research team is that the procedure for ABMT has changed with approximately one third (20 - 25 of 60 to 65 ABMTs performed annually) of all breast cancer patients receiving their ABMT in an outpatient setting. The remaining 40-45 ABMT patients will continue on the ABMT protocol that was in place at the start of the project. This new protocol for outpatient ABMT will, however; further complicate recruitment and retention of subjects, although there are now 3 physicians admitting patients to the study.

Hospitalization

During hospitalization the patient is available to the project director for data collection. However, early in the study, our research team understood that during the course of hospitalization many patients were too sick to complete all of the questionnaires, and some patients were too sick and/or psychologically distressed to complete any of the questionnaires even though we followed protocol and rest periods were provided between completion of the questionnaires. Fourteen subjects thus far have been unable to complete any of the questionnaires during hospitalization because of the severity of their illness. The severity of illness was so great in 3 patients that they wished the ABMT had never been performed. To resolve this problem, and prevent ethical issues associated with data collection during hospitalization, our team decided to stream line the questionnaires during hospitalization and only collect data on pain, anxiety, depression, one measure of fatigue (the visual analogue scale), the two most important subcategories of coping (catastrophizing, and coping self statements) and; health status. The longest questionnaires (Piper Fatigue Questionnaire and QOL questionnaire) were eliminated during hospitalization. These adjustments to the protocol decreased the time for completion of questionnaires by a minimum of 25 minutes for the patients. The QOL questionnaire was reinstated in the post hospitalization period which permitted us to compare the quality of life at this point in time with baseline data. Three cases were lost to follow-up during hospitalization because of scheduling and coordination problems. Thirteen subjects participating in the study have died. Two died during hospitalization and 11 died prior to collection to post-hospitalization data.

Data were also collected on the following variables for all patients participating in the study at each data point during hospitalization: analgesic intake; infection (WBC and Differential., culture, temperature); length of stay; rehospitalizations; and survival. There are no data missing for these variables. Collection of these data were not contingent upon the patients condition since they could be extracted from the patient's records. Only about 30% of these data have been entered into the computer at the time of this report. The remaining data are presently being entered into the computer. Therefore, analysis of this data is not presented in this third year report.

The loss of primary caregivers (PCGs)to the study during hospitalization mirrors the attrition rate of patients, i.e., the PCG did not complete questionnaires if the patient died or was too sick to complete the questionnaire. Twenty three patients who under went ABMT

had no PCG. When the study started, almost 100% of the patients had PCGs, but this has gradually changed over the last two years. In addition, PCG attrition was also caused by loss to follow-up during the study. (PCG not returning questionnaires, change of address that differed from the patient's). A few PCGs have also withdrawn from the study due to family or work related issues. The same approach of collecting data over the telephone that was used to increase patient participation in the study at post-hospitalization is presently in process to increase PCGs participation. Calling patients on week-ends to collect post hospitalization data has produced a 99% participation in the study.

Demographic Characteristics of the Sample

The number of subjects entering the study during the third year has increased substantially. In reporting the preliminary results from this study, however, consideration must still be given to the fact that the results are influenced by the sample size. There were a total of 172 subjects recruited to the study by year 3 (100 patients and 72 PCG). Twenty three of the patients had no PCG. Fifty patients and 39 PCGs were randomized to the treatment group. Forty-five patients and 33 PCGs were randomized to the control group.

The demographic characteristics of the sample are presented in Table 2.1 for the patients and Table 5 for the PCGs. The majority of the subjects were Caucasian with incomes of greater than $50,000. They were married, with a college degree or some college, living with their spouses, and actively employed. The mean age of the patients was 44, and 46 for the primary caregivers. Twenty three patients did not have a PCG. There were no significant differences between the treatment and control group with regard to the major demographic variables except for living arrangement. and marital status. There was a difference between the PCGs in the groups with regard to occupation with the treatment group being more highly educated. More people in the control group were single and lived alone (Table 2.1). There were no significant differences between the groups for outcome measures (physical symptoms, psychological distress, coping , health status and QOL) at baseline (Tables 2.2.1 and 2.2.2).

Patients in Treatment and Control Groups

Pain

Fifty four percent of the patients reported no pain at baseline. The affective component of pain was more intense than the sensory component for both treatment and control groups throughout the study. The pain scores increased from pre-hospitalization to reaching the highest peak during hospitalization. There were statistically significant differences between overall pain scores for pre and post-hospitalization for both the control group and the treatment group. Pain scores in both group of subjects had practically disappeared during the post - hospitalization period. Over 50% of the subjects reported no pain at post-hospitalization. There were statistically significant differences among most pain scores for both groups of subjects when pre-hospitalization scores were compared to post-hospitalization scores ($p< 0.05$ to $p< 0.001$) (Tables 3.1, 4a.1, 4b.1).

Sleep

The subjects in both groups slept approximately six hours prior to hospitalization. The treatment group slept an average of three hours longer than the control group during hospitalization. The number of hours of sleep in the post-hospitalization period decreased to just over 3 hours for both groups (Table 4a.1, Fig. 1). This difference was statistically significant within both the treatment and control groups at post-hospitalization when compared to pre-hospitalization ($p<0,001$) (table 4b.1).

Fatigue

Fatigue increased during hospitalization by 21 points in the control group compared to 17 points in the treatment group. There was a statistically significant higher level of fatigue during hospitalization compared to pre-hospitalization for both groups ($p<0.001$) (Table 4a.1). There were no significant differences within the groups when comparing pre and post-hospitalization fatigue scores (Table 4b.1). Fatigue was higher in the control group in the post-hospitalization period compared to pre-hospitalization (means = 29.5 to 30.3) and the treatment group (22.6 to 22.8) (Table 4a.1).

Nausea

Nausea increased significantly within both the treatment and control groups from pre-hospitalization to hospitalization by 24.5 points in the control group and 23.1 points in the treatment group ($p<0.001$). There were no significant difference between the groups with regard to nausea (Tables 4a.1 & 4b.1). Nausea returned to similar levels as were seen in the pre-hospitalization period during post-hospitalization.

Psychological Distress

The treatment group reported less psychological distress than the control group. Anxiety was reduced by almost 4 points during hospitalization in the treatment group which was statistically significant ($p<0.05$). Anxiety gradually decreased in the treatment group over time. In the control group, anxiety reached its peak level during hospitalization and reached its lowest level at post - hospitalization. There was no significant difference in the level of anxiety at the different measurement points in the control group (Table 4a.1). Although there were no statistically significant differences between the control and treatment groups the level of anxiety increased in the control group from pre-hospitalization to hospitalization (39.4 to 40.4) and decreased from 39.9 to 35.9 in the treatment group. The mean difference between the groups was -3.4 with the treatment group reporting lower anxiety ($p<0.06$) (Table 4a.1, Fig.2).

Depression rose slightly in the treatment group during the hospitalization period. In the control group, depression also rose during the hospitalization. There was no significant differences between or within the two groups with regard to depression (table 4a.1, Fig. 3).

The mental health status of the patients in the treatment group gradually increased over time with the highest scores being reached in the post hospitalization period. There was an increase in mental health scores for the treatment group. This finding indicated an improvement in the mental health status of the treatment group over time. The same pattern

of improvement was also seen in the control group with the patient's mental health status gradually increasing over time (Fig. 12). There was however, no significant differences found between the mental health scores of the groups (tables 4a.1 & 4b.1, Fig. 4).

Coping

The treatment group, to a greater extent than the control group, increased their ability to avoid catastrpohizing. The mean difference for the treatment group was -.02 compared to a difference of 1.7 for the control group (Fig. 11). Except for coping self statements and ignoring pain, all of the other coping strategies increased during hospitalization compared to pre-hospitalization, Coping self statements were significantly lower within both groups ($p<0.001$)(Table 4a.1). Diverting attention was significantly higher in the control group ($p<0.001$)(Table 4a.1). There were statistically significant difference between the treatment and the control group with regard to diverting attention and reinterpretation ($p<0.05$). The control group had higher coping scores during hospitalization. There were no other statistically significant difference within or between the groups regarding coping during hospitalization.

Health Status

The health status of the patients in both the treatment and the control groups decreased between pre-hospitalization and hospitalization with regard to between group differences, social health status decreased more in the control group than the treatment group ($p<0.09$) (Table 4a.2). With regard to within group differences for pre-and post-hospitalization there were statistically significant higher scores for the treatment group in all health status categories except for social whereas the control group only showed improvements in role (Table 4b.2). There were statistically significant higher scores within the treatment and control groups with regard to all of the health status variables between hospitalization and post-hospitalization(Table 4c.2) The treatment group showed a lower overall health score compared to the control group between pre-hospitalization and hospitalization ($p<0.05$) (table 4a.2, Fig. 5-10). Overall health status improved in the post-hospitalization period for both groups with greater improvements seen in the treatment group (mean =52.9 for pre-hospitalization and 60.5 during post-hospitalization ($p<0.001$) (Fig. 13-18). The control group means were 51.7 at pre-hospitalization and 56.5 at post-hospitalization. There were no statistically significant differences between the group for health status (Table 4b.2).

Quality of Life (QOL)

Quality of life improved in the treatment group in the following areas: health ($p<0,001$); psychological/spiritual ($p<0,01$); family ($p<0.05$); and overall quality of life ($p<0.001$). The control group did not show statistically significant improvements in the QOL in the area of psychological/spiritual but did show improvements in the socioeconomic ($p<0.05$) from pre-hospitalization to post-hospitalization (Table 4b.2, Fig. 19-23).

With regard to statistically significant differences between the groups there were none, but the treatment group showed improvements in QOL related to health of 4.6 points

compared to 2.6 for the control group ($p<0.08$). The psychological/spiritual domain of QOL improved in the treatment group by 2.8 points compared to 0.3 points in the control group ($p<0,06$). The treatment group showed an overall improvement in QOL of 10 points compared to 6.8 points in the control group (Table 4b.2).

Benefits of the CCSP Intervention: CCSP Patients

The CCSP intervention (handouts and audiotapes) was reinforced according to protocol in all subjects who remained in the study. In addition, patients were instructed to use the CCSP at least once a day during hospitalization on a routine basis. The patients in the treatment group were also instructed to identify other situations in which they felt that the CCSP intervention was helpful and to record in the diary the situation in which the CCSP handouts and audiotapes were used. The patients were also instructed to document whether or not the CCSP intervention was beneficial in relieving their symptoms.

It was interesting to note the time of day and the situations in which the patient chose to use the CCSP handouts and audiotapes (Table 2.2.3). The most frequent use of the CCSP intervention was during the evenings around bedtime. The most frequent symptoms\problems for which the patients used the CCSP intervention were psychological problems(51%) and sleep problems (60%). Twenty one percent of the patients used the CCSP to deal with chemotherapy side effects (Table 2.2.3). The CCSP handouts and audiotapes were used 385 times by the patients. Both the handouts and the audiotapes were beneficial based on the patients reports. However, the patients documented the CCSP audiotapes as more beneficial. The audiotapes were used over 50% more often than the handouts. Twenty one (78%) of the patients reported that the audiotapes were effective 90-100% of the time compared to 19 (70%) of the patients reporting that the handouts were beneficial 90 to 100% of the time. Four (15%) of the subjects found the handouts to be beneficial 50 - 89 % of the time compared to 6 (22%) of the subjects reporting the audiotape to be beneficial 50 - 89 % of the time. Four patients reported that the handouts were beneficial less than 50% of the time (Table 2.2.4). The remaining subjects in the treatment group only indicated that they had used the CCSP according to protocol and did not record additional situations in which they had used the handouts and audiotapes.

Primary Caregivers

Primary caregivers in the CCSP treated group reported lower anxiety scores over time with the highest mean score at baseline and the lowest score during hospitalization. The PCGs in the control group reported a similar pattern of anxiety. With regard to depression, the PCGs in both group reported lower scores during the patients' hospitalization, however, the control group had a significantly lower mean score during hospitalization compared to pre-hospitalization (Tables 6 & 7). There were no statistical significant differences between the groups with regard to anxiety or depression.

The objective and subjective burden of care remained stable over time with similar scores at baseline with a slightly increased score for subjective burden and a decreased score for objective burden. (Tables 6 & 7). There were no significant differences between the groups with regard to burden of care.

DISCUSSION

The focus of the study during year 3 was recruiting, retaining and analyzing the data of breast cancer patients who underwent ABMT and received a coping strategy program to help them deal with adverse symptoms associated with treatment. The focus of this third year was also on recruiting and retaining PCGs in the study. During the last 2 years more and more women with breast cancer who do not have a PCG are receiving ABMT. Thus far, approximately one third of the breast cancer patients do not have a primary caregiver. An intensive process has been put in place to call each PCG over the weekend to maintain a high level of PCGs participation in the study. We have been very successful in retaining patients in the study by calling them over a weekend. We believe that the procedure used with the patients will be as effective with the PCGs. The data collected from the PCGs will be analyzed during the fourth year after completion of the weekend collection of post-hospitalization data. We have reported on an accrual of 100 patients and 72 PCG's. The reason for the discrepancy in the dyad for patients and PCG's is that 23 of the patients had no PCG.

When the project started in 1994, only one physician was responsible for recruitment of ABMT patients. Since September 1996 there are 3 physicians participating in the ABMT program and recruiting subjects to the project. Since this change, an improvement in accrual has taken place. Retention to the study has posed some difficulties mainly due to death of the patients, the psychological and physical seriousness of the patients' condition, and loss-to-follow-up. We are addressing the loss-to-follow-up problem by contacting the patients between 6 months to 2 years from baseline to collect data . This effort has been very Successful with 99% of the patients who were called agreeing to complete questionnaires over the phone.

Several cautions need to be kept in mind with the interpretation of these preliminary findings. Although the demographic characteristics of the sample appear to be comparable at this point in time, we have not as yet controlled for intervening factors such as severity of illness, medications, trait anxiety, and health locus of control. Thus far, however, most of the preliminary data seem to be promising and in line with expectations.

Benefits of The CCSP

The patients overwhelmingly reported that they found the CCSP intervention helpful. They used the CCSP intervention during critical points in their treatment and on days when they experienced most side effects from the ABMT and found the CCSP intervention to be helpful 90 to 100% of the time. The subjects used the CCSP in situations that are supported theoretically in the scientific literature for use of behavioral treatment strategies such as to decrease their psychological distress, to decrease side effects of chemotherapy, and to induce sleep. Although the CCSP was mainly used during the evenings, it was also frequently used during the afternoons.

The patients used the CCSP audio-tapes more frequently and found them to be more helpful than the CCSP handouts. The increased use of the audio-tapes may be explained by the fact that it is a procedure that has to be followed whereas the handouts support cognitive restructuring. Hopefully, the information in the handouts gradually becomes an automatic part of the subjects' thinking processes and therefore do not need to be read so frequently.

The audio-tapes make relaxation possible through the participation of subjects in a carefully outlined progressive relaxation procedure combined with imagery. The audio-tapes are also designed to help the subjects become relaxed more quickly as they become more comfortable with the information and instructions on the tape.

The benefits derived from the CCSP, as experienced by the patients, have important implications for clinical practice. The effects of the CCSP may be helpful to a broader group of cancer patients who are treated with chemothearpy for breast cancer but do not receive the ABMT. The audiotape is inexpensive and can easily be used in a variety of situations to help cancer patients cope with psychological distress, and sleeplessness. Clearly, the breast cancer patients in the treatment group in this study have overwhelmingly acknowledged the benefits of the CCSP.

Patients in The Treatment and Control Groups

Physical Symptoms

The breast cancer patients participating in this study experienced pain, sleeplessness, fatigue and nausea prior to, during and post hospitalization for ABMT. The symptoms were more severe about 7 days after the ABMT. Although fifty four percent of the patients had no pain when baseline data were collected, a sizable number of patients reported pain prior to any procedure connected with the ABMT was performed. The emotional component of pain was more intense than the sensory component of pain at all measurements in both the CCSP treated group and the control group. Pain reached its lowest levels at post-hospitalization with 50% of the patients reporting that they were pain free. However, 50% of the subjects were still experiencing pain one year after the ABMT.

These preliminary findings are supported by other studies[5]. Except for the pain scores, the mean scores for the other symptoms/problems (sleep, fatigue, nausea), were more severe during hospitalization in the control group than in the treatment group. It was also interesting that the patients reported using the CCSP in situations where they experienced problems with nausea, sleep and psychological distress and reported that the CCSP was beneficial in combating theses problems.

Psychological Distress

The reduction of anxiety during hospitalization in the treatment group may be one of the most important findings coming out of this study. Previous research has shown that anxiety reached its peak during hospitalization and especially 5 to 7 days post ABMT. Our study has verified this finding. Anxiety in the present study reached peak levels in the control group 7 days after the ABMT. When comparing differences between groups we found that anxiety was more severe in the control group than the treatment group at an almost statistically significant level ($p<0.06$). An increased sample size might be needed in order to achieve a higher level of significance.

The above finding associated with anxiety suggests that the CCSP is effective in relieving anxiety at a time when the patient is suffering from intense physical symptoms. Earlier studies have shown that decreased anxiety is associated with decreased pain, fatigue, and depression. This means that there could be other indirect benefits derived from the effects of the CCSP on anxiety. Most importantly, it t could be that the CCSP intervention is

effective in reducing anxiety and the pattern of change that we are seeing in the anxiety scores are a results of the effects of the CCSP intervention in the treatment group. Patients in the treatment group reported that they used the CCSP to reduce psychological distress. The fact that the CCSP appeared to be more effective during hospitalization when the physical symptoms were most severe and anxiety was at its highest level in the control group, may provides some insight into answering the questions: "Under what condition is the CCSP most effective?" and ; " When should the CCSP intervention be used?"

Coping, Perceived Health Status, and QOL

The patients in both groups had a similar coping pattern throughout the study except for the avoidance of catastrophizing. Since the treatment group had received instruction and handouts about how to avoid catastrophizing as part of the CCSP, it was expected that the treatment group would perform better in this area. This finding is an indication that the CCSP was being practiced.

The preliminary results showed that the CCSP treated patients avoided the use of catastrophizing to a greater extent than the control group during hospitalization. This finding offers support that the patients were using the CCSP intervention 7 days after the ABMT, when patients are sickest. Previous findings from the project have shown that there are significant correlations between decreased catastrophizing and decreased pain, anxiety and depression, and fatigue. The above findings support the theoretical bases for using the CCSP intervention. The avoidance of catastrophizing is a central theme of the CCSP intervention and effective coping.

The most notable difference between the CCSP and the control groups was related to health perception and overall health status. How a person perceives his/her own health status is extremely important with regard to well being and recovery. Earlier findings from this study have shown that perceived health status was related to pain, anxiety, depression and fatigue. The preliminary findings are in line with the results of other studies. Previous studies have shown that patients who perceive themselves as doing well do better than those who do not feel positive about their health status. The treatment group also showed more improvement in social, role, and physical functioning than the control group over the course of the study.

Quality of life improved to a greater extent in the treatment group than in the control group. This was especially true with regard to psychological/spiritual, health related quality of life and overall QOL. Although differences between the treatment and control groups did not reach a statistically significant level of $p<0.05$ with regard to psychological/spiritual, the difference between the groups is of clinical significance and supported by findings related to anxiety. The greatest effect of the CCSP may be associated with reducing psychological distress, improving the patients health status, and improving the quality of life. Finally, the patients in the treatment group who underwent ABMT and received a CCSP compared to patients who did not receive the CCSP reported less anxiety ($p<0.06$) greater social health status ($p<0.09$), and a higher quality of life with regards to health related QOL ($p<0.08$) and psychological/spiritual ($p<0.06$).

CONCLUSIONS

Some exciting preliminary data are surfacing in this study. Thus far, the majority of the findings are in the expected direction, and in line with the findings from previous studies. New information may be produced about the effects of the CCSP on anxiety, and when it is appropriate to use the CCSP. It appears that the CCSP might be most effective in controlling psychological distress 7 days after the ABMT when the patients are experiencing their most severe symptoms. Differences between the treatment group and the control group were found with regard to anxiety, social health status, physical functioning QOL, and psychological/ spiritual QOL which are of clinical significance. The large mean differences between groups indicate a possibility of achieving significance in the difference between groups when adequate statistical power is obtained through the increase in sample size and adjustment for covariates.

The patients found the CCSP overwhelmingly helpful; used the intervention at different time points during the ABMT, and in different situations independent of project personnel or hospital staff, and selected appropriately situations to use the CCSP.

FUTURE DIRECTIONS

We are proposing the following:

1. Continue to collect the remaining data of the 110 patients already admitted to the project for the fourth year of the project. Analyze all data collected and submit findings in annual report to U S Army in August of 1998. Submit at least 5 manuscripts for publication based on findings from the study.

2. Expand the present project for one year and 3 months. In addition to meeting the requirements listed in the above (# 1) the project team would continue to increase the number of subjects (approximately 40) to the project. The findings from the present study with regard to major variables being studied are promising. The patients perceive the CCSP intervention as being overwhelmingly beneficial to them with regard to controlling and coping with pain, sleep problems, nausea, psychological distress, and feeling lonely/homesick. Although we are unable at this time to show statistically significant differences between the control and the treatment group, we are able to show clinically significant differences between measurements of psychological distress and mental health in the CCSP treated group that do not appear in the control group. An increased sample size might be helpful in clearly delineating whether there are statistical differences between the CCSP treated group and the control group.

3. The sample size was originally calculated on expected pain scores based on preliminary data. We are finding that approximately 30% of the patients who remain in the study following ABMT do not report pain. We are seeing that 10% of the ABMT are being canceled after consent forms are signed by patients and primary caregivers. Because of these issues, we will test the process of randomization into CCSP treated or control group

during the final phase of our project. During the final analysis we will attempt to re-calculate our statistical power based on the patients health status which has been consistently answered by the respondent throughout the study. The health status instrument includes measures of pain, functional status and psychological distress. Sample size was originally calculated on expected pain scores based on preliminary data. We are finding that approximately 30% of the patients who remain in the study following ABMT do not report pain. We are seeing that 10% of the ABMT are being canceled after consent forms are signed by patients and primary caregivers. Because of these issues, we will test the process of randomization into CCSP treated or control group during the final phase of our project. During the final analysis we will attempt to re-calculate our statistical power based on the patients health status which has been consistently answered by the respondent throughout the study.

The research team has enclosed one manuscript with this report " Pain, Psychological Distress, Health Status, and Coping in Breast Cancer Patients scheduled for Autologous Bone Marrow Transplantation". This manuscript presents a descriptive, correlational analysis of baseline data and has been submitted for publication to Oncology Nursing Forum. The second manuscript "Fatigue and Health Status in Breast Cancer Patients scheduled for ABMT also presents a descriptive analysis of baseline data. Review of the literature has been completed and data have been analyzed. The manuscript is in its final stage of preparation. The third manuscript "Benefits of a Coping Strategy Program as Perceived by Breast Cancer Patients is in the same stage of completion as the second manuscript. After these 2 manuscripts have been completed, and submitted for publication, additional data will be analyzed followed by a series of manuscripts submitted for publication.

The first national presentation of an abstract based on findings from this project will take place at the annual conference of the America Academy of Pain Management in September, 1997. Abstracts have also been submitted for presentation of findings from this study at a symposium at the 1998 conference of the Oncology Nursing Society. A poster will also be presented at the U.S. Army sponsored Conference in Washington D.C, 1997

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APPENDIX

A Comprehensive Coping Strategy Program

Presentation: A variety of teaching strategies are used to present the Comprehensive Coping Strategy Program (CCSP) to help promote and maintain breast cancer ABMT patient and PCG interest. Patients, particularly in clinical settings, are likely to experience a range of physical and psychological factors, such as pain, fatigue and anxiety resulting from high psychological stress, which compete with the educator for their interest levels [43]. Consideration was also given to providing the best match between specific content areas and the most appropriate teaching. Oral communication (lecture) has been found most effective in establishing rapport and in teaching new knowledge such as preparatory information, while slide tapes are especially beneficial for abstract concepts. Videotapes are most effective in situations when learning step-by-step procedures with movement is required, such as relaxation techniques with guided imagery [43-44]. A conference/treatment room is used to present the CCSP. This setting has comfortable chairs and adequate space to practice relaxation. The setting is also appropriate for presenting educational materials.

Preparatory Information: The purposes of the CCSP are presented by the instructor using an overhead. A schematic drawing of the symptoms (pain, psychological distress, and fatigue) that patients are known to experience is presented. The instructor reviews the overhead pointing out the relationship among the different symptoms and how they can influence each other. The instructor summarizes the information by stressing that adequate control of pain can lead to decreased psychological distress and a decrease in physical symptoms other than fatigue. The subjects are told that the information presented is based on the experiences of patients who have successfully undergone ABMT. Handouts that cover appropriate information are reviewed and given to the participants: 1) "Ways in Which You Can Participate in Reducing Pain and Psychological Distress, and; 2) "Some General Ways To Increase Control". The above information is presented by the instructor using simple terminology and principles of learning. In order to make sure that the content is presented in a standardized manner, a detailed script and specific overheads are used by the instructor to present this material.

Treatment of Pain: Theoretical Considerations: This part of the CCSP is a slide presentation with an accompanying tape. Interaction between the instructor and the participants is also encouraged. Information covered include the following topics: definition of pain; the three components of pain; a brief explanation of the Gate Control Theory and; theoretical reasons why increasing control through use of coping self-statements and relaxation with imagery can relieve pain and emotional distress. A handout, titled "Ways in Which You Can Participate In Reducing Pain" is reviewed by the instructor and given to the participants at the end of the session. Colorful slides of simple pictures, that symbolize neuro-physiological structures are used when the Gate Control Theory is presented.

Cognitive Restructuring: This segment of the CCSP is also a slide presentation with accompanying tape. This information focuses on the avoidance of catastrophizing, distorted thinking and the use of positive coping self-statements. Cognitive restructuring is directed at modifying thought processes in order to lessen negative sensations and psychological distress. The subjects are taught to conduct an internal dialogue with themselves which directs and refocuses their attention and thinking. This includes descriptions of unproductive catastrophizing statements made by people experiencing discomfort and distress, and then alternatives that may prove more useful in coping. This includes statements such as "I feel relaxed", "I am in control and can handle this situation" and "I know any discomfort I may feel won't last forever". Two handouts, titled "15 Styles of Distorted Thinking to Avoid", and "15 Positive Coping Self-Statements," will be reviewed by the instructor and given to the participants.

Relaxation With Imagery: This part of the CCSP is presented on video-tape in a participant modeling format in which each component of relaxation will be briefly presented, described and demonstrated. The treatment includes a brief progressive muscle relaxation procedure with tense-release cycles being used with specific muscle groups (face, neck and shoulders, stomach and chest, arms and legs). Following these cycles, cue-controlled relaxation will be used involving deep breathing and saying the word "relax" to begin to develop an association between a state of relaxation and these cues. With practice, the cues can then be used to achieve a state of relaxation in a much shorter period of time. Imagery is introduced into the relaxation exercise and participants are permitted to choose the imaginary scene. At the end of the session, the instructor reviews two handouts and gives them to the participants. The handouts are: "Learning and Using Relaxation Therapy" and "Benefits of Relaxation Therapy". The instructor will also give the patient and PCG a small hand-held audiotape recorder (Walkman) with two sets of ear phones and an audiotape. The purpose of the tape is to guide the participants in active participation in the relaxation exercise. The participants are instructed to review all handouts and to practice the relaxation exercise, using the 15 minute audiotape at least every day and prior to stressful events. The subjects are instructed how to review the handouts and record their use of the audiotape in a diary.

Reinforcement of CCSP: The reinforcement of the CCSP includes: review of the patients and PCGs diaries, responding to any questions that the subjects have concerning the CCSP; measuring relaxation prior to and post reinforcement of the CCSP; reviewing all handouts with the subjects; and having the subjects listen to the 15 minute audiotape with the relaxation exercise with imagery. Reinforcement of the CCSP takes about 30 minutes.

Table 1. Comprehensive Coping Strategy Program
Patient Sample Retention at Follow-Ups
Year 3 Cumulative Participation Rate and Reasons for Attrition

	Pre-Hospital	During Hospital	Post-Hospital
Expected Number	**100**	**95**	**86**
Reasons for Attrition:			
BMT Canceled Prior to Baseline/After Consent	5	-	-
BMT Canceled After Baseline	-	5	-
Patient/PCG refused	0	2	6
Patient too ill to complete questionnaire	0	14*	0
Patient expired	0	2	11
Schedule conflict	0	3*	0
Scheduled time for data collection not reached	0	0	24
Final Participation (Rate)	**95(95%)**	**69(68.4%)**	**45(52.3%)**

* Subsequent contacts made during post-hospital follow-up data collection

Table 2.1 Assessing the Process of Randomization into CCSP Treatment and Comparison Groups at Baseline Among Breast Cancer Patients Receiving ABMT

Factor	Tx N(%)	Ctrl N(%)	X^2	P
Marital Status				
Married	44 (88.0)	25(56.8)		
Single	2 (4.0)	10 (22.7)	12.15	0.00
Divorced	4 (8.0)	9 (20.5)		
Education				
HS/Some College	21 (42.0)	23(52.3)	0.99	0.32
College/Graduate	29(58.0)	21(47.7)		
Degree				
Living Arrangement				
With spouse	44(89.8)	23(52.3)		
With other	2 (4.1)	8(18.2)	16.21	0.00
Alone	3 (6.1)	13(29.5)		
Occupation				
Professional	30(65.2)	22(59.5)		
Non Professional	16(34.8)	15(40.5)	0.29	0.59
Employment				
Employed	38(77.6)	29(67.4)		
Unemployed	11(22.4)	14(32.6)	1.18	0.28
Income				
<50k	12(26.1)	17(42.5)		
≥50k	34(73.9)	24(57.5)	2.59	0.11
Age				
22-30	1(2.0)	4(9.1)		
31-40	12(24.0)	8(18.2)	3.05	0.38
41-50	22(50.0)	24(54.5)		
≥51	12(24.0)	8(18.2)		

Table 2.2.1 Differences in Pain, Nausea, Anxiety, Depression, Fatigue and Coping Among Patients Receiving ABMT

Baseline Differences For Assessing Randomization into CCSP and Comparison Groups

Variable	CCSP			Comparison			Diff:Between Group*	
	N	X	SD	N	X	SD	X	P
Pain Sensory	50	1.4	3.7	45	2.0	4.6	-0.6	.50
Affective	50	1.8	3.3	45	2.9	3.6	-1.1	.12
Total Intensity	50	3.2	6.6	45	4.9	7.3	-1.7	.25
Overall Pain	50	4.2	1.3	45	4.1	1.3	0.1	.67
Sleep	46	6.3	1.6	43	6.5	1.4	-0.2	.56
Nausea	48	3.0	8.3	45	5.8	17.7	-2.8	.33
Fatigue	48	26.7	23.4	45	32.8	27.9	-6.1	.26
Psychological Anxiety	50	40.8	13.5	45	40.4	11.7	-0.4	.86
Depression	50	10.4	6.9	45	12.2	8.1	-1.8	.24
Mental Health	50	22.8	4.7	45	21.6	4.1	1.2	.17
Coping Ignoring Pain	50	14.8	7.5	44	14.0	7.3	0.8	.62
Diverting Attention	50	18.7	7.6	44	15.7	7.6	3.0	.06
Coping statement	50	21.6	5.8	44	22.4	6.6	-0.8	.53
Reinterpretation	50	6.5	6.6	45	7.2	7.0	-0.7	.62
Praying	50	19.6	8.3	44	18.6	7.9	1.0	.52
Behavior	50	17.7	5.4	44	17.5	6.1	0.2	.85
Avoidance of Catastrophizing	50	30.1	5.8	44	29.5	5.9	0.6	.63

* One way analysis of variance.

Table 2.2.2 Differences in Health Status and Quality of Life Domains Among Patients Receiving ABMT

Baseline Differences For Assessing Randomization into CCSP and Comparison Groups

Variable	CCSP			Comparison			Diff:Between Group	
	N	X	SD	N	X	SD	X	P
Health Status								
Physical Functioning	50	3.7	1.7	45	4.0	1.6	-0.3	.38
Role	49	0.8	0.9	45	0.8	0.8	0.0	.98
Social	50	4.5	1.6	45	5.0	1.1	-0.5	.09
Perception	50	15.5	5.5	45	14.3	4.2	1.2	.23
Overall Health	49	51.8	12.4	45	49.7	8.3	1.1	.36
Quality of Life (QOL)								
Health	50	11.0	6.1	45	11.8	5.3	-0.8	.48
Socioeconomic	50	4.9	3.6	45	6.5	4.9	-1.6	.08
Psychological/ Spiritual	50	7.4	6.0	44	8.6	5.4	-1.2	.34
Family	50	2.6	4.8	45	3.5	5.4	-0.9	.38
Overall QOL	50	25.9	16.6	44	30.0	15.5	-4.1	.21

Table 2.2.3 Time of day and situations of use of CCSP Handouts and Audiotapes by Breast Cancer Receiving Patients

Time of day and Situation*	N	%
Time of day		
Morning	14	19
Afternoon	32	37
Evenings/Bedtime	36	44
Physical Problems		
Nausea/Vomiting	8	16
Pain	12	24
Sleep	10	60
Psychological Problems		
Loneliness/Homesick	9	9.6
Coping	17	18.1
Psychological Distress	48	51.1
Side effects from Chemotherapy	20	21.2

* Situation listed if used $\geq$5 times

Table 2.2.4 Evaluation of the benefits of the CCSP Handouts and Audiotapes by Breast Cancer Receiving Patients

CCSP Tool	N	# of Times Used	Found CCSP Tool Beneficial		
			<50% of Time	50-89% of Time	90-100% of Time
Handouts	27	112	4(15%)	4(15%)	19(70%)
Audiotapes	**27**	273	0	6(22%)	21(78%)

Table 3.1 Univariate Measures of Pain, Anxiety, Depression, Fatigue and Coping at Pre-, During and Post- Hospitalization Among Breast Cancer Patients Receiving ABMT

Variable		Pre-Hospitalization			During Hospitalization			Post- Hospitalization		
		N	X	SD	N	X	SD	N	X	SD
Physical										
Pain										
Sensory	C	45	2.0	4.6	37	2.7	4.8	24	0.20	0.50
	Tx	50	1.4	3.7	32	2.9	4.4	21	0.10	0.4
Affective	C	45	2.9	3.6	37	3.8	5.5	24	0.2	0.8
	Tx	50	1.8	3.3	32	5.2	8.0	21	0.2	0.5
Total Intensity	C	45	4.9	7.3	37	6.5	9.9	24	0.4	1.3
	Tx	50	3.2	6.6	32	8.1	11.7	21	0.4	0.9
Overall Pain	C	45	4.1	1.3	37	3.3	1.1	24	4.5	1.4
	Tx	50	4.2	1.3	31	3.4	1.1	21	4.8	1.2
Sleep	C	43	6.5	1.4	37	6.2	2.8	23	4.5	1.4
	Tx	46	6.3	1.6	32	8.9	16.8	21	4.8	1.2
Psychological										
Mental Health	C	45	21.6	4.1	37	22.1	5.0	24	24.1	5.0
	Tx	50	22.8	4.7	31	23.5	3.2	21	25.6	3.9

Table 3.2 Univariate Measures of Health Status and Quality of Life Domains at Pre-, During and Post- Hospitalization Among Breast Cancer Patients Receiving ABMT

Variable		Pre-Hospitalization			During Hospitalization			Post Hospitalization		
		N	X	SD	N	X	SD	N	X	SD
Health Status										
Physical Functioning	**C**	45	4.0	1.6	37	4.4	7.6	24	4.7	1.5
	Tx	50	3.7	1.7	31	3.4	1.9	21	4.4	1.7
Role	**C**	45	0.8	0.8	37	0.7	2.7	24	1.8	1.7
	Tx	49	0.8	0.9	31	0.5	0.8	21	1.3	0.9
Social	**C**	45	5.0	1.1	37	3.6	1.7	24	5.5	0.9
	Tx	50	4.5	1.6	31	4.0	1.7	21	5.4	1.2
Perception	**C**	45	14.3	4.2	37	12.9	4.4	26	15.1	6.4
	Tx	49	15.5	5.5	27	15.4	4.4	23	19.2	5.7
Overall Health	**C**	45	49.7	8.3	37	47.0	14.0	24	56.5	10.8
	Tx	49	51.8	12.4	31	49.8	9.6	21	60.5	11.9
Quality of Life										
Health	**C**	45	11.8	5.3	-	-	-	24	8.6	5.5
	Tx	50	11.0	6.1				21	6.4	6.4
Socioeconomic	**C**	45	6.5	4.9	-	-	-	24	4.7	5.2
	Tx	50	4.9	3.6				21	3.4	4.0
Psychological/ Spiritual	**C**	44	8.6	5.4	-	-	-	24	7,6	6.4
	Tx	50	7.4	6.0				21	4.3	5.2
Family	**C**	45	3.5	5.4	-	-	-	24	0.8	5.0
	Tx	50	2.6	4.8				20	0.6	2.1
Overall QOL	**C**	44	30.0	15.5	-	-	-	24	21.7	17.7
	Tx	50	25.9	16.6				20	14.9	16.1

Table 4a.1 Differences in Pain, Nausea, Anxiety, Depression, Fatigue and Coping Among Patients Receiving ABMT
Group Differences Between Pre- and During Hospitalization

Variable		Pre-Hospitalization			During Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Physical											
Pain											
	C	37	1.8	4.7	37	2.7	4.8	-0.9	0.5	-0.3	.78
Sensory	Tx	32	1.7	4.5	32	2.9	4.4	-1.2	0.3		
Affective	C	37	2.2	2.9	37	3.8	5.4	-1.6	0.14	-1.4	.44
	Tx	32	2.2	3.9	32	5.2	8.0	-3.0			
Total Intensity	C	37	4.1	7.0	37	6.5	9.9	-2.4	.24	-1.9	.57
	Tx	32	3.8	8.0	32	8.1	11.7	-4.3	.1		
Overall Pain	C	37	4.2	1.3	37	3.3	1.1	0.9	.00	0.0	
	Tx	31	4.3	1.3	31	3.4	1.1	0.9	.00		0.97
Sleep	C	36	6.4	1.4	36	6.2	2.8	0.2	.63	-3.0	
	Tx	28	6.3	1.7	28	9.5	17.8	-3.2	.34		.25
Nausea	C	37	4.5	17.1	37	29.0	30.7	-24.5	.00	4.2	
	Tx	31	2.8	9.4	31	23.1	27.,8	-20.3	.00		.56
Fatigue	C	37	28.1	27.2	37	49.7	28.6	-21.6	.00	4.5	.54
	Tx	31	24.8	22.5	31	41.9	24.9	-17.1	.00		
Psychological											
Anxiety	C	37	39.4	11.9	37	40.0	11.3	-0.6	.71	-34	.06
	Tx	32	39.9	13.3	32	35.9	10.5	4.0	.03		
Depression	C	37	11.8	8.7	37	13.0	8.4	-1.2	.39	0.3	.89
	Tx	32	9.9	6.4	31	10.8	6.2	-0.9	.29		
Mental Health	C	37	22.0	4.1	87	22.1	5.0	-0.1	.81	-0.2	.78
	Tx	31	23.6	4.4	31	23.5	3.2	0.1	.88		
Coping		22	14.0	7.4	22	13.0	6.2	1.0	.56	-1.0	.65
Ignoring Pain	C	22	14.5	6.7	22	12.5	6.8	2.0	.13		
	Tx										
Diverting Attention	C	32	15.2	7.8	32	20.3	5.8	-5.1	.00	4.2	.03
	Tx	31	18.8	7.1	31	19.7	7.2	-0.9	.48		
Coping Statement	C	35	22.0	6.2	35	18.1	6.1	3.9	.00	0.6	.52
	Tx	32	21.5	5.5	32	18.2	6.6	3.3	.00		
Reinterpretation	C	33	6.7	6.5	33	11.0	6.6	-4.3	.00	4.0	.04
	Tx	30	6.5	6.4	30	6.8	6.8	-0.3	.83		
Praying	C	22	18.8	8.4	22	21.6	7.2	-2.8	0.08	0.3	.86
	Tx	22	20.4	8.3	22	22.9	8.1	-2.5	.16		
Behavior	C	35	17.5	6.2	32	19.5	5.8	-2.0	.11	1.4	.41
	Tx	30	18.5	5.0	30	19.1	7.5	-0.6	.56		
Avoidance of	C	35	29.6	5.8	35	27.9	6.4	1.7	.09	1.9	.14
Catastrophizing	Tx	32	30.0	5.7	32	30.2	6.1	-0.2	.78		

Table 4a.2 Differences in Health Status Domains
Among Patients Receiving ABMT

Group Differences Between Pre- and During Hospitalization

Variable		Pre-Hospitalization			During Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Health Status											
Physical Functioning	**C**	37	4.0	1.6	37	4.4	7.6	-0.4	.78	-0.5	
	Tx	31	3.5	1.8	31	3.4	1.9	0.1	.55		.70
Role	**C**	37	0.9	0.9	37	0.7	2.7	0.2	.77	0	.91
	Tx	31	0.7	0.9	31	0.5	0.8	0.2	.28		
Social	**C**	37	5.1	1.0	37	3.6	1.7	1.5	.00	0.8	
	Tx	31	4.7	1.6	31	4.0	1.7	0.7	.04		.09
Perception	**C**	37	14.9	4.2	37	12.9	4.4	2.0	.03	0.9	
	Tx	31	16.2	5.7	31	15.1	4.7	1.1	.13		.48
Overall Health	**C**	37	51.0	8.3	37	47.0	14.0	4.0	.09	0.8	
	Tx	31	53.0	12.2	31	49.8	9.6	3.2	.04		.78

Table 4b.1 Differences in Pain, Nausea, Anxiety, Depression, Fatigue and Coping Among Patients Receiving ABMT
Group Differences Between Pre- and Post- Hospitalization

Variable		Pre-Hospitalization			Post- Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Physical											
Pain											
Sensory	C	24	1.2	1.9	24	0.2	0.5	1.0	0.02	-0.9	0.50
	Tx	21	2.0	5.4	21	0.1	0.4	1.9	0.14		
Affective	C	24	1.7	2.2	24	0.2	0.8	1.5	0.00	-0.6	0.54
	Tx	21	2.3	4.7	21	0.2	0.5	2.1	0.06		
Total Intensity	C	24	2.9	3.7	24	0.4	1.3	2.5	0.00	-1.4	0.50
	Tx	21	4.3	9.7	21	0.4	0.9	3.9	0.08		
Overall Pain	C	24	4.2	1.3	24	4.5	1.4	-0.3	0.34	-0.2	0.43
	Tx	21	4.3	1.2	21	4.8	1.2	-0.5	0.02		
Sleep	C	23	6.1	1.4	23	3.3	3.6	2.8	0.00	0.2	0.91
	Tx	19	6.3	1.8	19	3.7	4.0	2.6	0.00		
Psychological											
Mental Health	C	24	22.8	3.7	24	24.1	5.0	-1.7	0.14	-0.4	0.56
	Tx	21	23.5	4.1	21	25.6	3.9	-2.1	0.3		

Table 4b.2 Differences in Health Status and QOL Domains Among Patients Receiving ABMT

Group Differences Between Pre- and Post- Hospitalization

Variable		Pre-Hospitalization			Post- Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Health Status											
Physical Functioning	C	24	4.2	1.8	24	4.7	1.5	-0.5	0.17	0.4	0.46
	Tx	21	3.5	1.8	21	4.4	1.7	-0.9	0.01		
Role	C	24	0.9	0.9	24	1.8	1.7	-0.9	0.04	0.16	0.82
	Tx	21	0.6	0.9	21	1.3	0.9	-0.7	0.00		
Social	C	24	5.3	1.0	24	5.5	0.9	-0.2	0.52	0.8	0.30
	Tx	21	4.8	1.5	21	5.4	1.2	-0.6	0.06		
Perception	C	24	14.3	4.1	24	16.0	5.5	-1.7	0.18	4.6	0.48
	Tx	21	16.1	6.2	21	19.0	5.8	-2.9	0.01		
Overall Health	C	24	51.7	9.0	24	56.5	10.8	-4.8	0.04	12.4	0.36
	Tx	21	52.9	12.5	21	60.5	11.9	-7.6	0.00		
Quality of Life											
		24	8.6	5.5	24	10.6	5.3	-2.0	0.05	6.6	0.08
Health	C	21	6.4	6.4	21	11.0	6.4	-4.6	0.00		
	Tx										
Socioeconomic	C	24	4.7	5.2	24	6.3	5.3	-1.6	0.05	2.5	0.69
	Tx	21	3.4	4.0	21	4.5	3.3	-0.9	0.23		
Psychological/ Spiritual	C	23	7.5	6.6	23	7.8	5.5	-0.3	0.71	3.1	0.06
	Tx	21	4.3	5.2	21	7.1	5.2	-2.8	0.01		
Family	C	24	0.8	5.0	24	4.4	6.2	-3.6	0.00	5.6	0.23
	Tx	20	0.6	2.1	20	2.6	3.6	-2.0	0.03		
Overall QOL	C	23	21.7	18.1	23	28.5	16.7	-6.8	0.00	16.8	0.41
	Tx	20	14.9	16.1	20	24.9	16.0	-10.0	0.00		

Table 4c.1 Differences in Pain, Nausea, Anxiety, Depression, Fatigue and Coping Among Patients Receiving ABMT
Group Differences Between During and Post- Hospitalization

Variable		During Hospitalization			Post- Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Physical											
Pain											
Sensory	C	24	3.0	5.0	24	0.2	0.5	2.8	0.01	-0.4	0.81
	Tx	21	3.3	4.7	21	0.1	0.1	3.2	0.00		
Affective	C	24	4.0	5.3	24	0.2	0.8	3.8	0.00	-0.6	-0.74
	Tx	21	4.6	6.4	21	0.2	0.5	4.4	0.00		
Total Intensity	C	24	7.0	9.7	24	0.4	1.3	6.6	0.00	-1.0	0.76
	Tx	21	8.0	10.3	21	0.4	0.9	7.6	0.00		
Overall Pain	C	24	3.5	1.0	24	4.5	1.4	-1.0	0.00	2.5	0.20
	Tx	20	3.3	1.2	20	4.8	1.2	-1.5	0.00		
Sleep	C	23	6.1	1.4	23	3.3	3.7	2.8	0.00	-4.0	0.33
	Tx	21	10.7	20.5	21	3.7	4.1	7.0	0.13		
Psychological											
Mental Health	C	24	23.5	3.8	24	24.1	5.0	-0.6	0.38	2.9	0.10
	Tx	20	23.3	3.4	20	25.6	4.0	-2.3	0.01		

Table 4c.2 Differences in Health Status and QOL Domains
Among Patients Receiving ABMT
Group Differences Between During and Post- Hospitalization

Variable		During Hospitalization			Post- Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Health Status											
Physical Functioning	C	24	3.5	1.5	24	4.7	1.5	-1.2	0.01	-0.2	0.72
	Tx	20	3.4	1.9	20	4.4	1.8	-1.0	0.03		
Role	C	24	0.3	0.6	24	1.8	1.7	-1.5	0.00	-0.6	0.19
	Tx	20	0.4	0.8	20	1.3	0.9	-0.9	0.00		
Social	C	24	3.5	1.7	24	5.5	0.9	-20	0.00	-0.8	0.19
	Tx	20	4.1	1.8	20	5.3	1.3	-1.2	0.03		
Perception	C	24	13.7	4.7	24	16.0	5.5	-2.3	0.05	1.3	0.38
	Tx	20	15.2	4.9	20	18.8	6.0	-3.6	0.00		
Overall Health	C	24	48.1	9.2	24	56.5	10.8	-8.4	0.00	2.0	0.53
	Tx	20	49.8	9.4	20	60.2	12.2	-10.4	0.00		

Table 5 **Demographic Characteristics of Primary Care Givers Between CCSP Treatment and Comparison Groups of Breast Cancer Patients Receiving ABMT at Baseline**

Factor	Tx N(%)	Ctrl N(%)	X^2	P
Marital Status				
Married	38 (97.4)	27(81.8)		
Single	1 (2.6)	6 (18.2)	4.97	0.03
Education				
HS/Some College	14 (35.9)	16(48.5)	2.07	0.35
College/Graduate Degree	25(64.1)	17(51.5)		
Living Arrangement				
With spouse	38(97.4)	25(78.1)		
With other	0 (0.0)	1(3.1)	6.63	0.04
Alone	1 (2.6)	6(18.8)		
Occupation				
Professional	26(66.7)	14(42.4)		
Non Professional	13(33.3)	19(57.6)	4.25	0.04
Employment				
Employed	33(89.2)	27(81.8)		
Unemployed	4(10.8)	6(10.8)	0.77	0.38
Income				
<50k	11(28.2)	13(40.6)		
≥50k	28(71.8)	19(59.4)	1.21	0.27
Age				
22-30	4(10.3)	2(6.1)		
31-40	7(17.9)	6(18.2)	2.79	0.42
41-50	16(41.0)	9(27.3)		
≥51	12(30.8)	16(48.4)		

Table 6 Differences in Anxiety, Depression, Fatigue and Burden Of Care at Baseline Among Primary Care Givers of CCSP Treatment and Comparison Patients Receiving ABMT

Variable	CCSP			Comparison			Diff:Between Group*	
	N	X	SD	N	X	SD	X	P
Anxiety	39	40.1	9.6	32	38.5	11.4	1.7	.52
Depression	39	7.8	6.1	33	6.2	5.1	1.6	.26
Subjective Burden of Care	39	37.9	7.2	33	36.7	4.2	1.2	.42
Objective Burden of Care	39	33.7	4.2	33	32.5	4.0	1.2	.23

* One way analysis of variance.

Table 7 Differences in Anxiety, Depression, Fatigue and Burden Of Care Among Primary Care Givers of Patients Receiving ABMT Group Differences Between Pre- and During Hospitalization

Variable		Pre- Hospitalization			During Hospitalization			Diff:Within Group		Diff:Between Group	
		N	X	SD	N	X	SD	X	P	X	P
Anxiety	**C**	26	37.4	11.1	26	34.5	11.3	2.9	0.07	0.5	0.83
	Tx	24	41.5	10.3	24	39.1	12.1	2.4	0.22		
Depression	**C**	27	5.9	5.4	27	4.5	4.8	1.4	0.05	1.1	0.29
	Tx	24	9.0	6.5	24	8.7	6.9	0.3	0.72		
Subjective BOC	**C**	27	36.4	3.9	27	37.0	2.3	-0.6	0.31	1.0	0.58
	Tx	24	37.3	2.8	24	38.9	9.3	-1.6	0.39		
Objective BOC	**C**	27	32.4	3.8	27	32.0	5.7	0.4	0.74	3.0	0.22
	Tx	24	34.2	3.5	24	36.8	10.5	-2.6	0.24		

Fig. 1 Number of Hours Slept Before and During Hospitalization Between CCSP Treated and Comparison Group

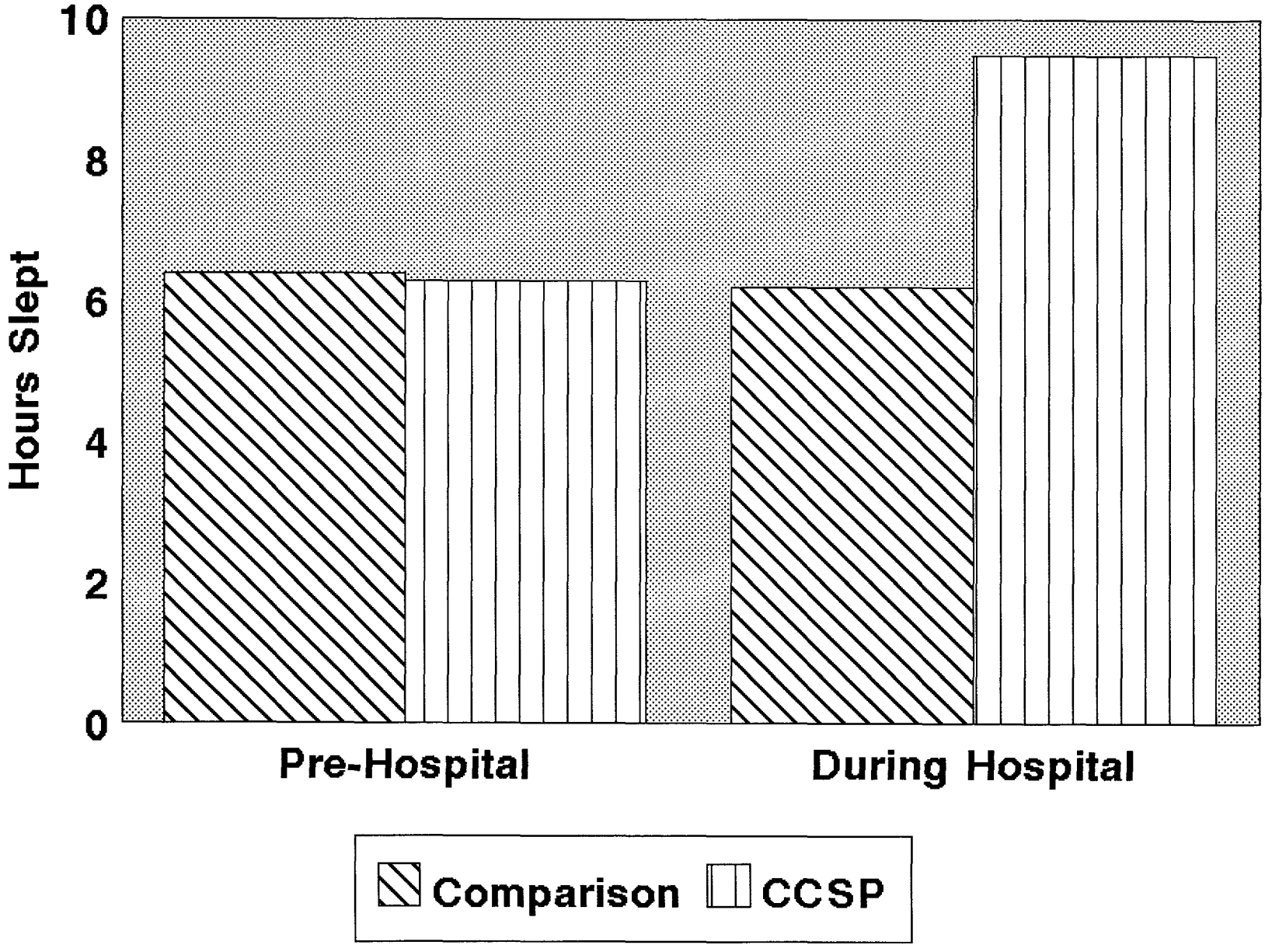


Fig. 2 Difference in Anxiety Before and During Hospitalization Between CCSP Treated and Comparison Group

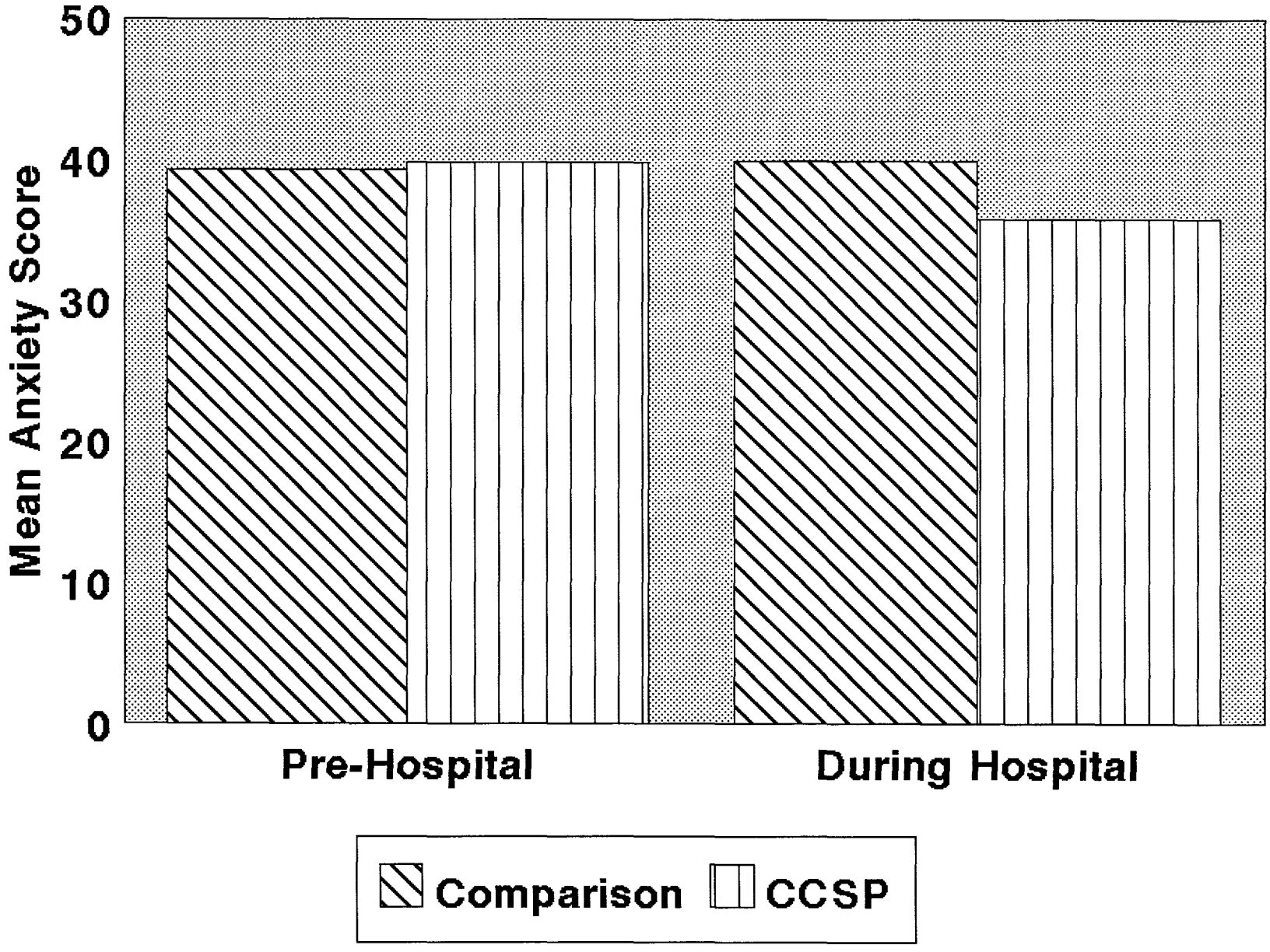


Fig. 3 Difference in Depression Before and During Hospitalization Between CCSP Treated and Comparison Group

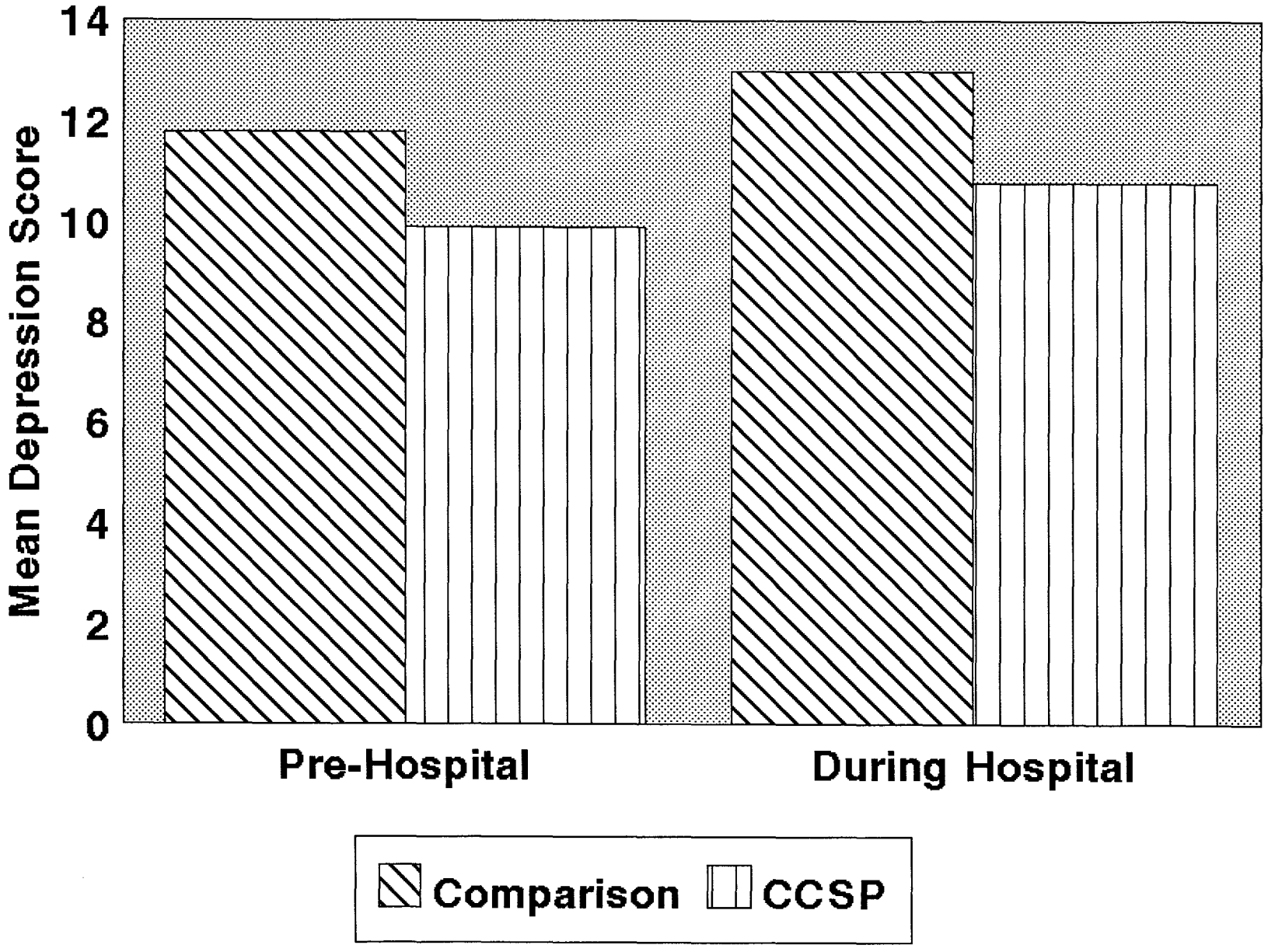


Fig. 4 Difference in Mental Health Before and During Hospitalization Between CCSP Treated and Comparison Group

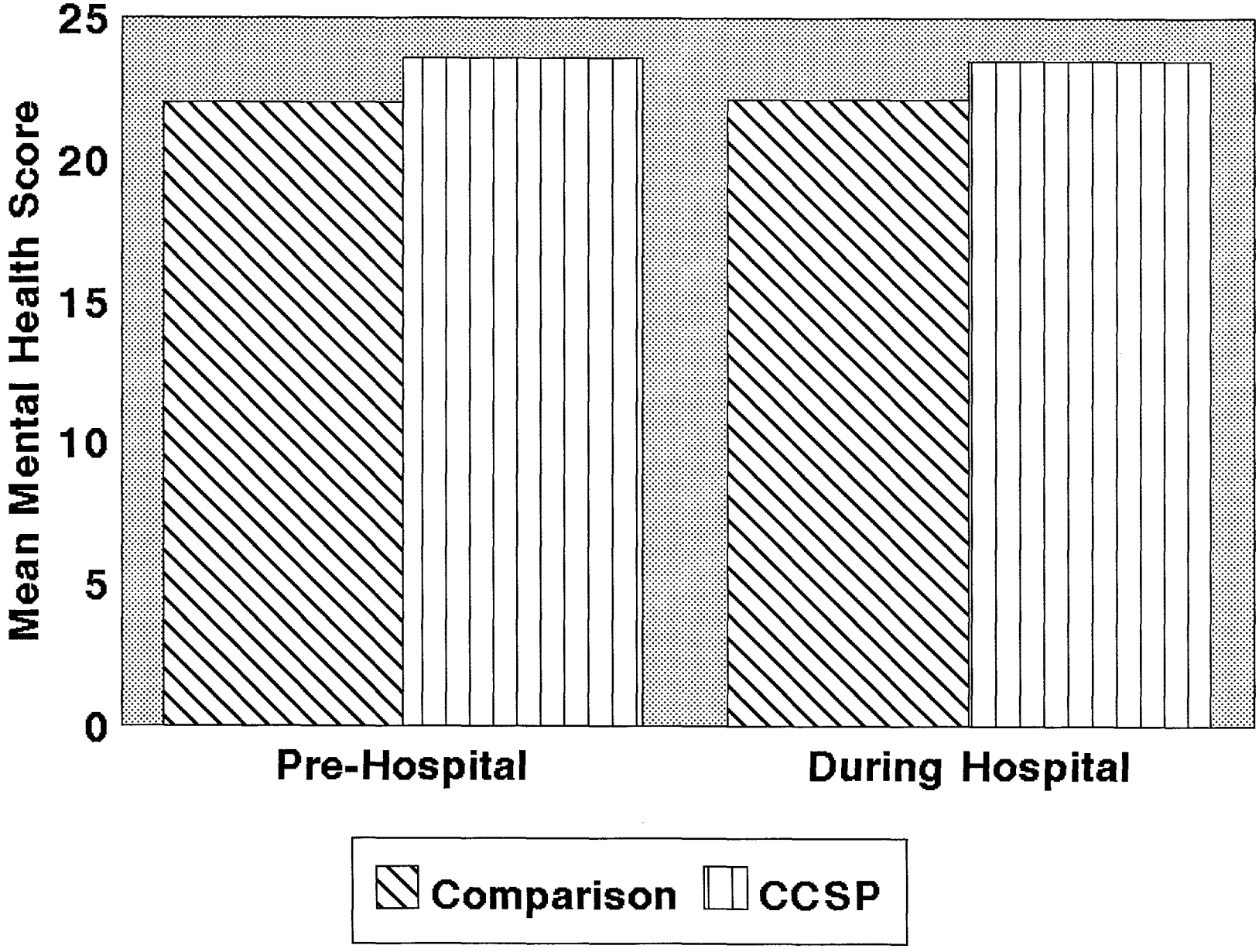


Fig. 5 Difference in Physical Functioning Before and During Hospitalization Between CCSP Treated and Comparison Group

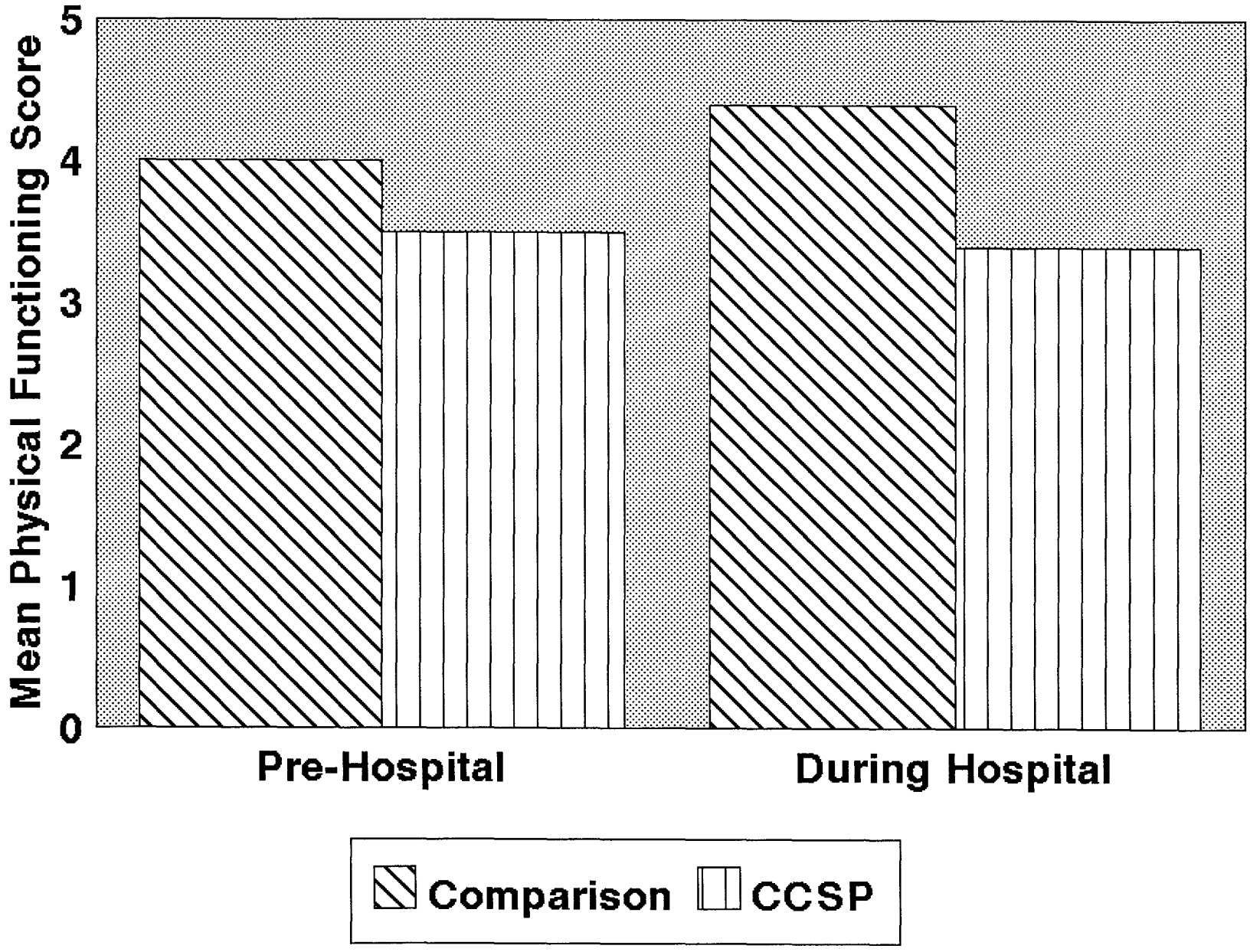


Fig. 6 Difference in Role Functioning Before and During Hospitalization Between CCSP Treated and Comparison Group

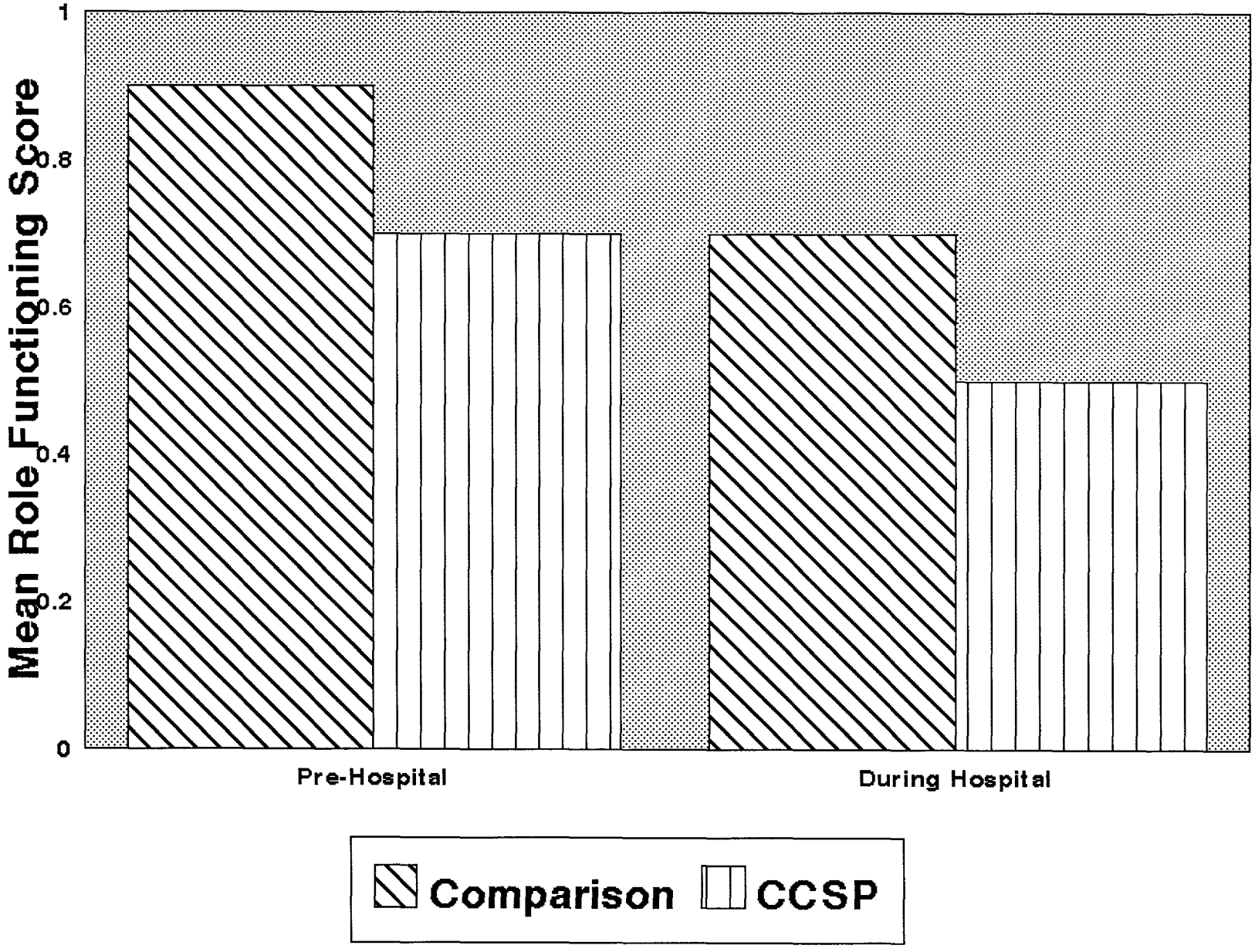


Fig. 7 Difference in Social Functioning Before and During Hospitalization Between CCSP Treated and Comparison Group

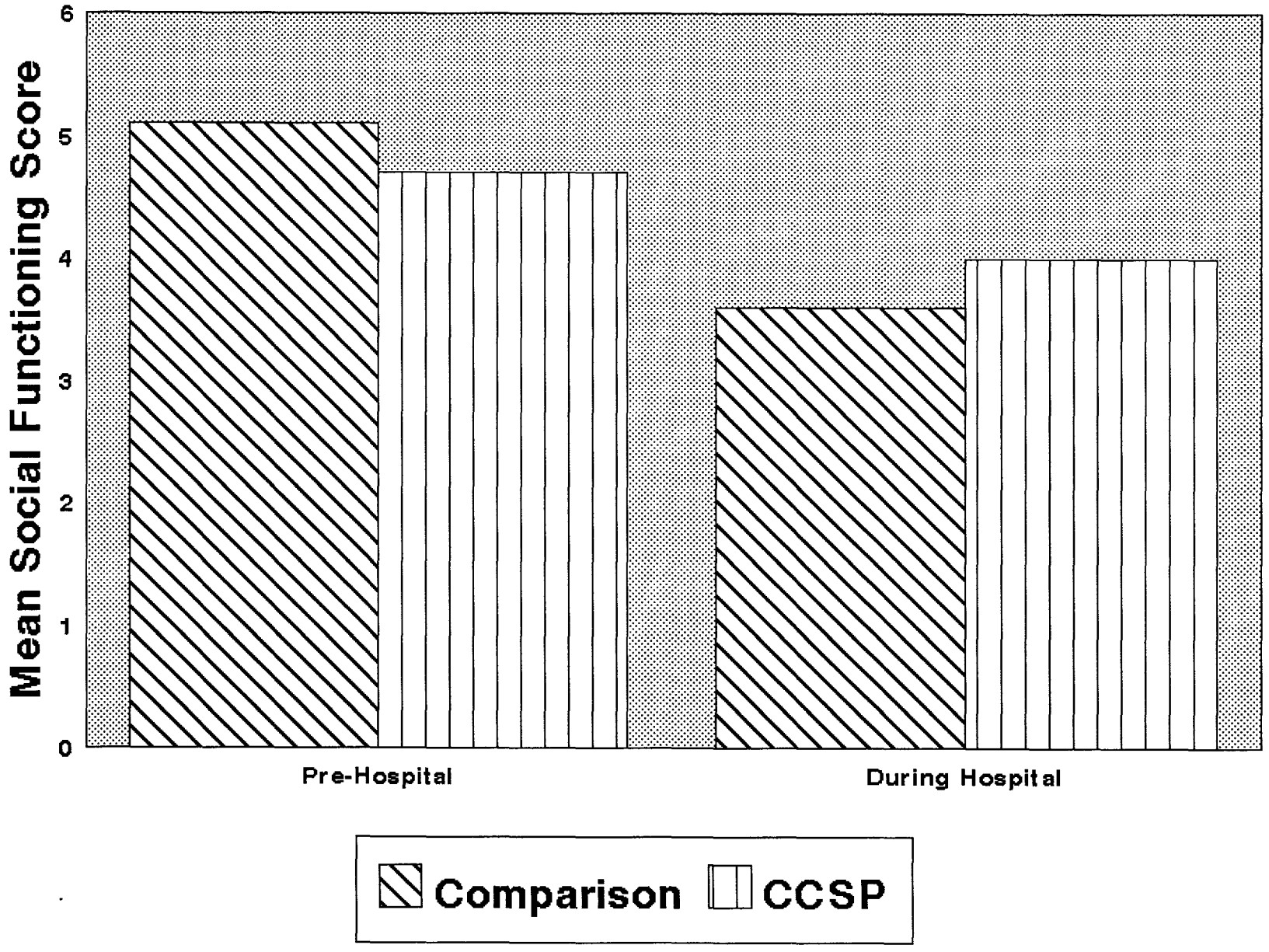


Fig. 8 Difference in Health Perception Before and During Hospitalization Between CCSP Treated and Comparison Group

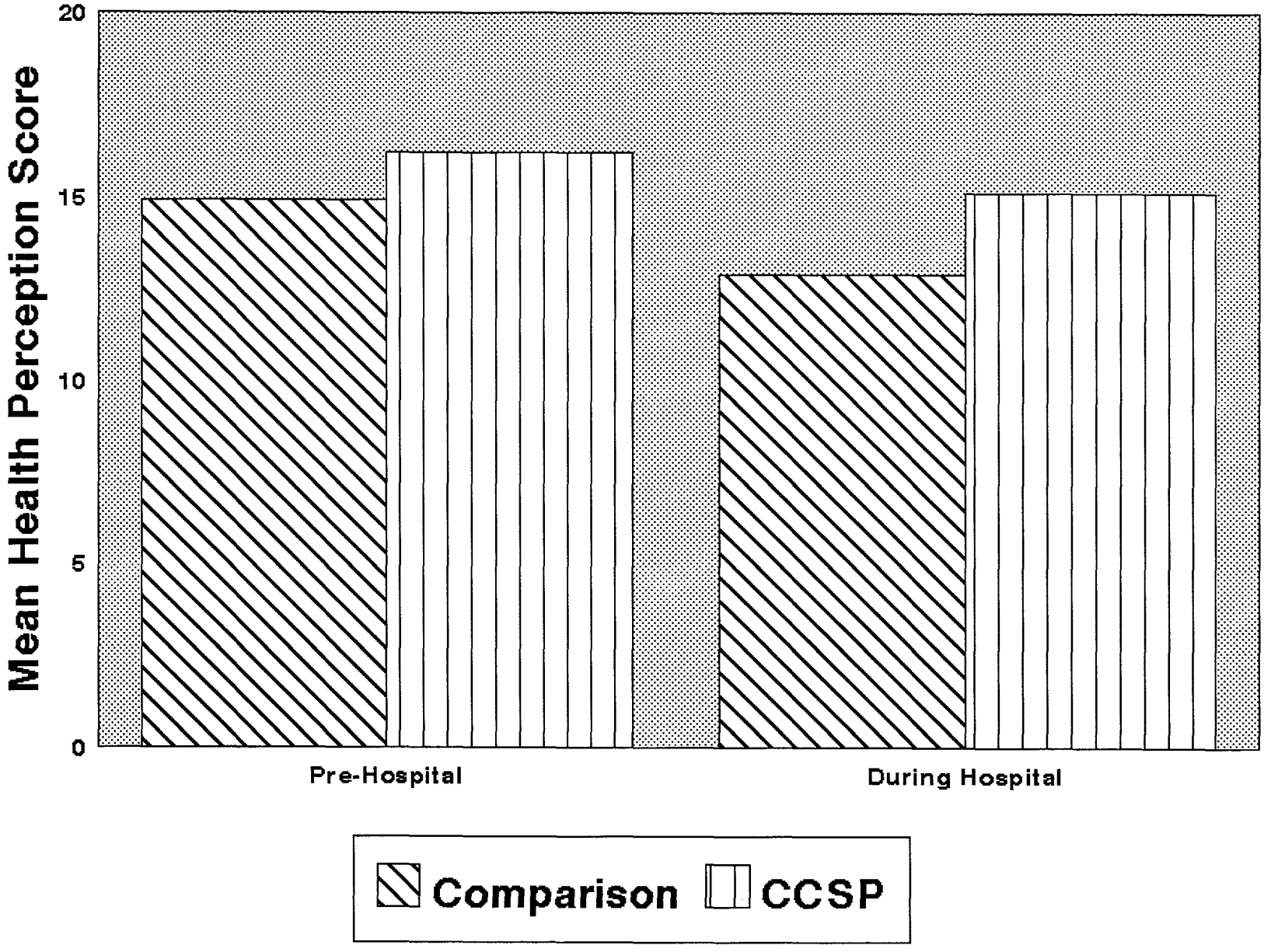


Fig. 9 Difference in Pain Before and During Hospitalization Between CCSP Treated and Comparison Group

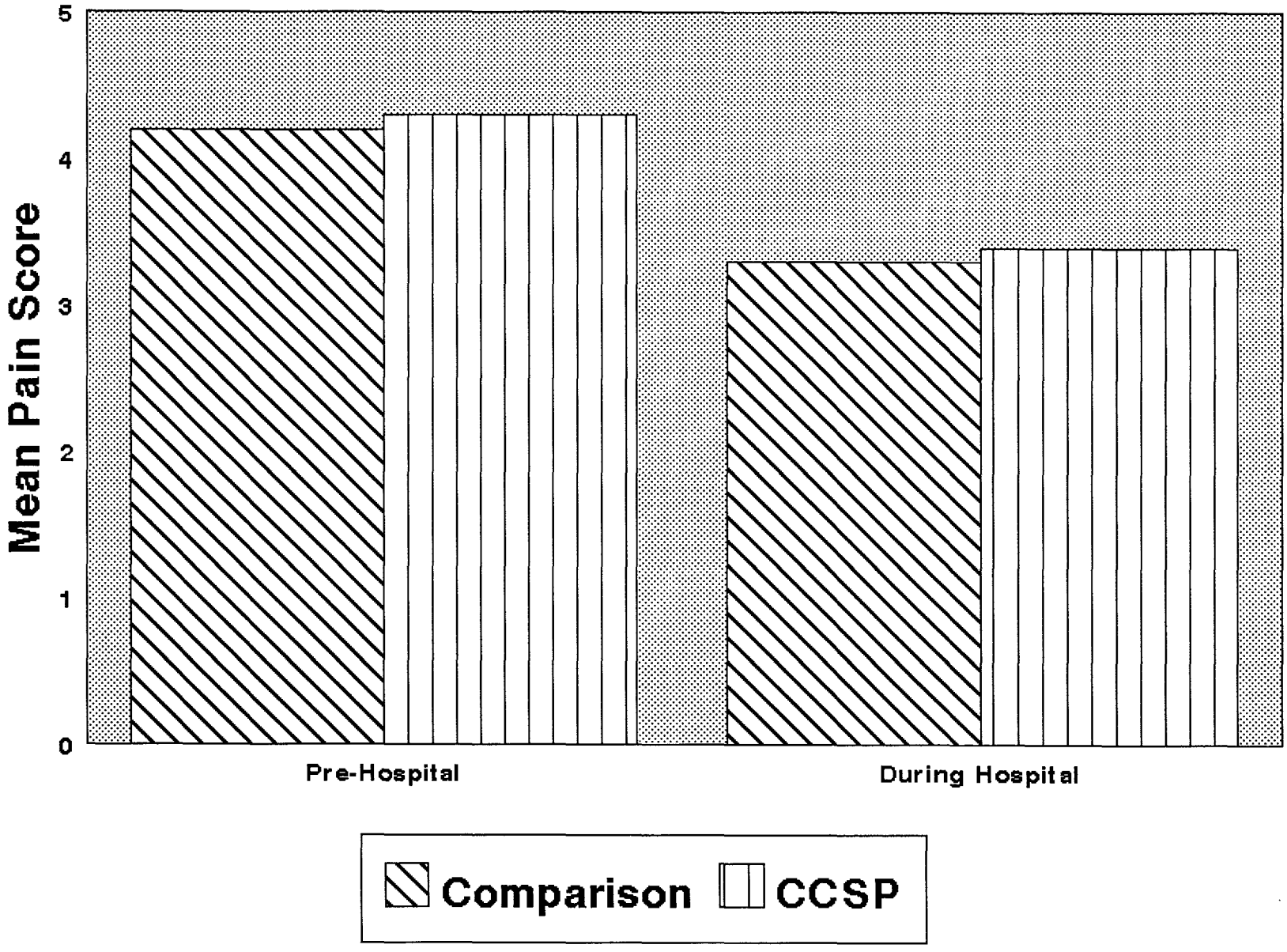


Fig.10 Difference in Overall Health Status Before and During Hospitalization Between CCSP Treated and Comparison Group

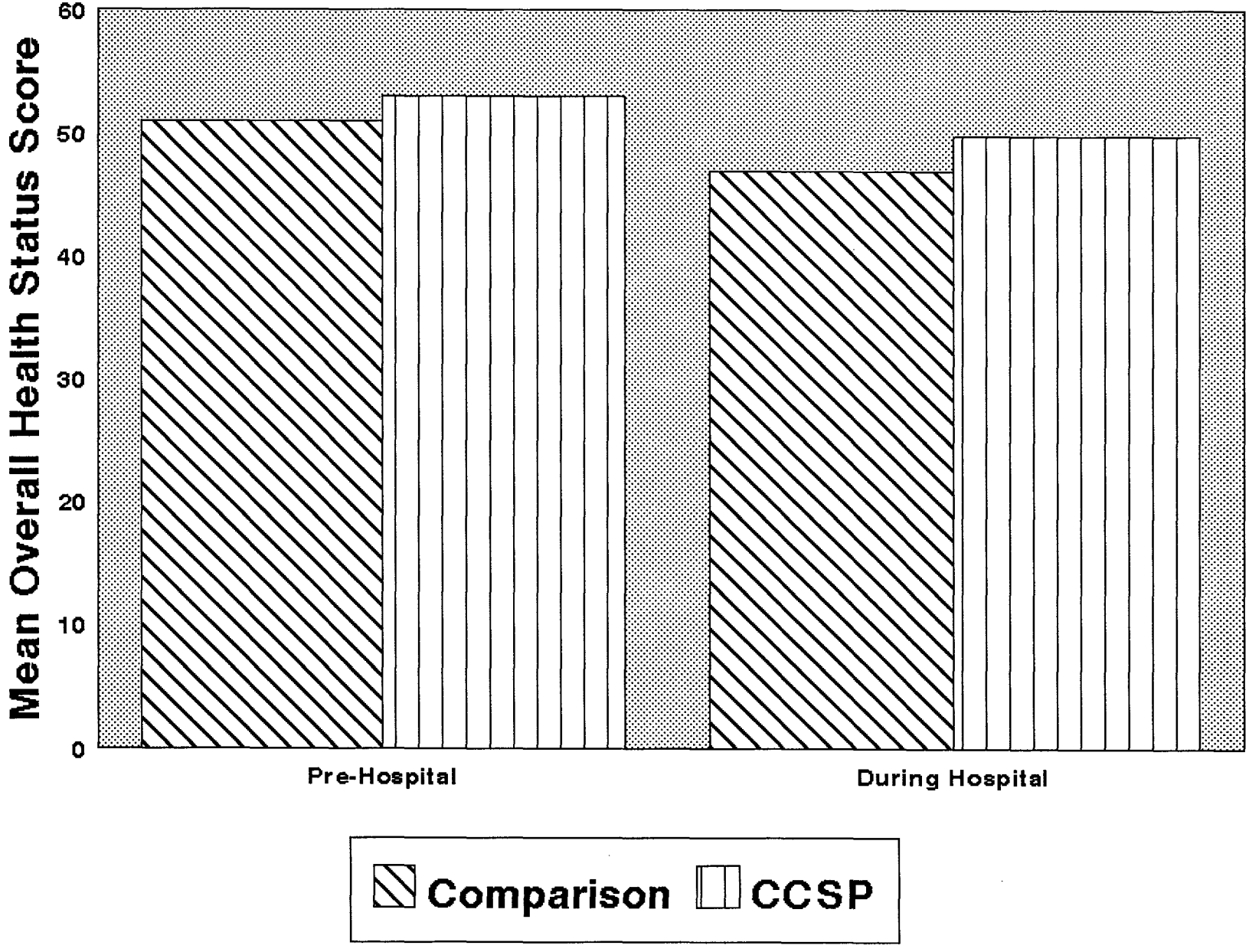


Fig.11 Difference in Avoidance of Catastrophizing Before and During Hospitalization Between CCSP Treated and Comparison Group

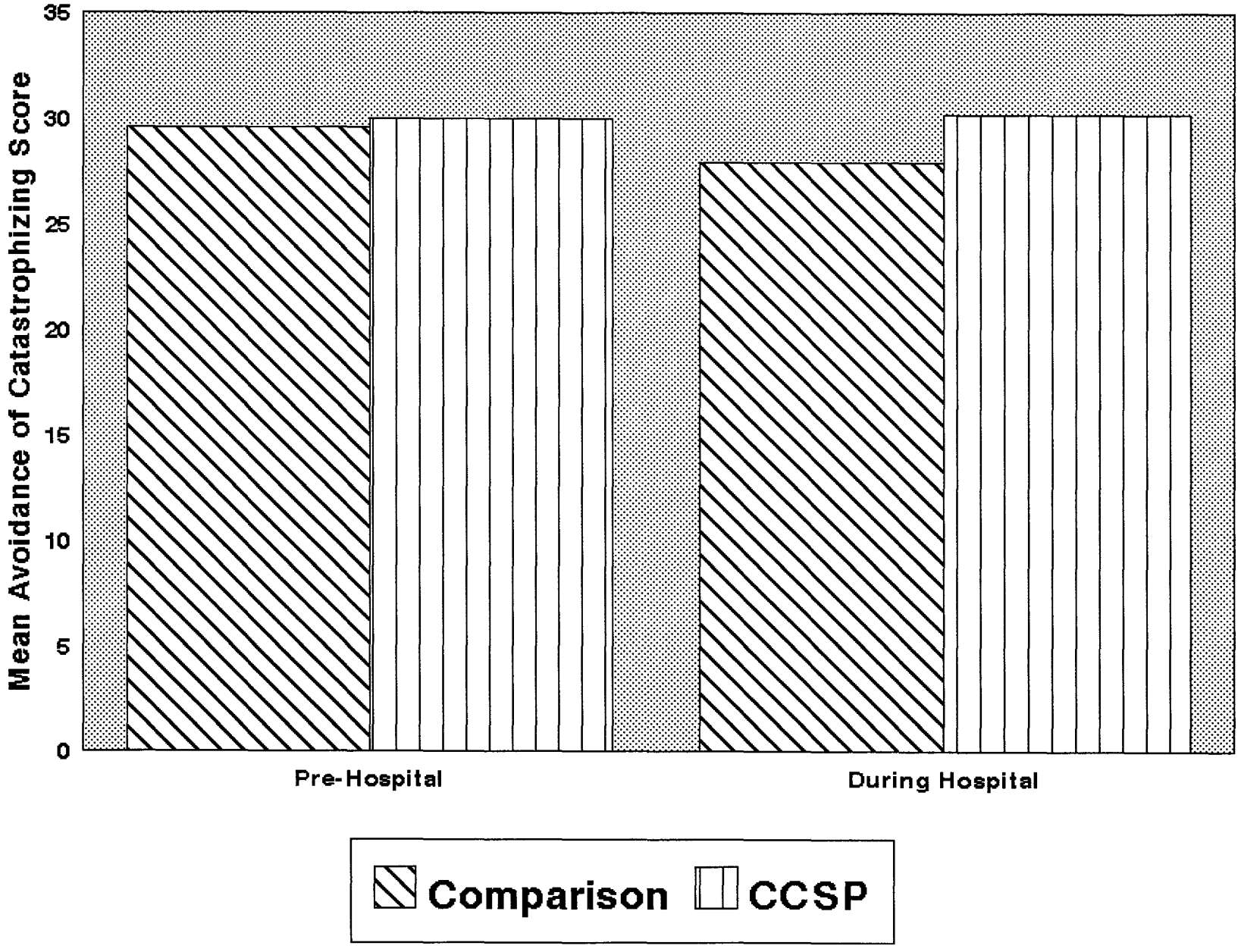


Fig.12 Difference in Mental Health Before and After Hospitalization Between CCSP Treated and Comparison Group

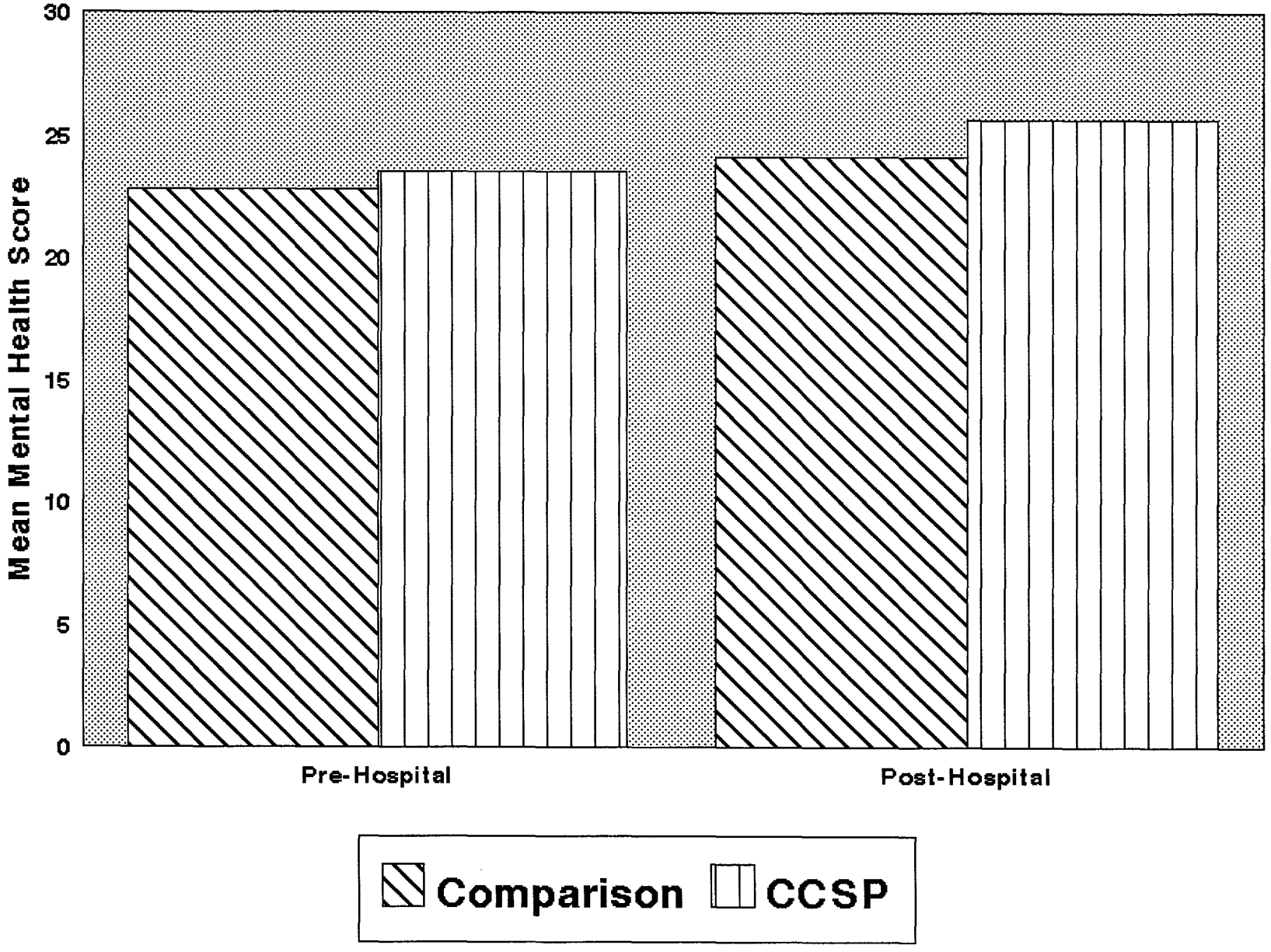


Fig.13 Difference in Physical Functioning Before and After Hospitalization Between CCSP Treated and Comparison Group

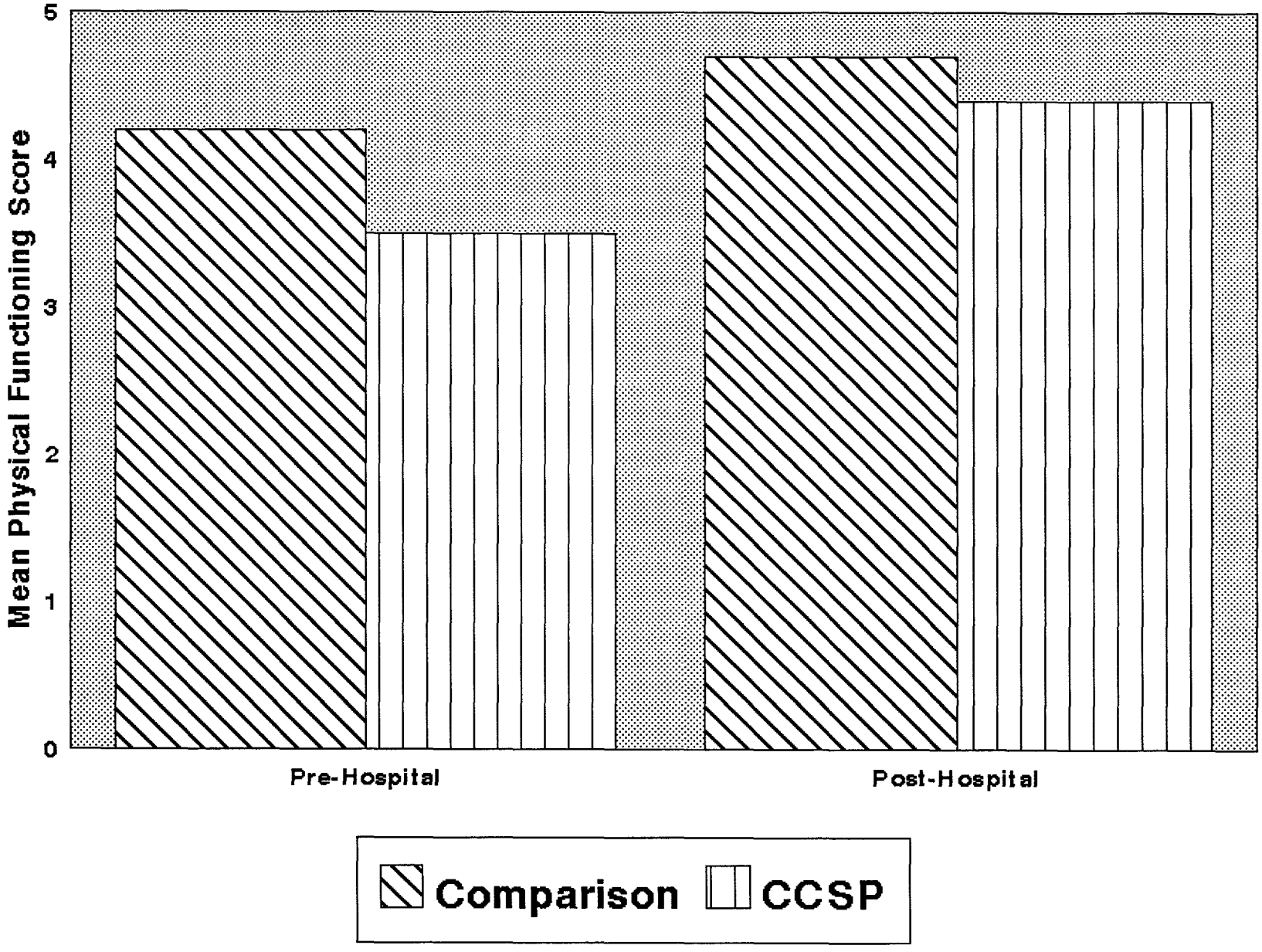


Fig.14 Difference in Role Functioning Before and After Hospitalization Between CCSP Treated and Comparison Group

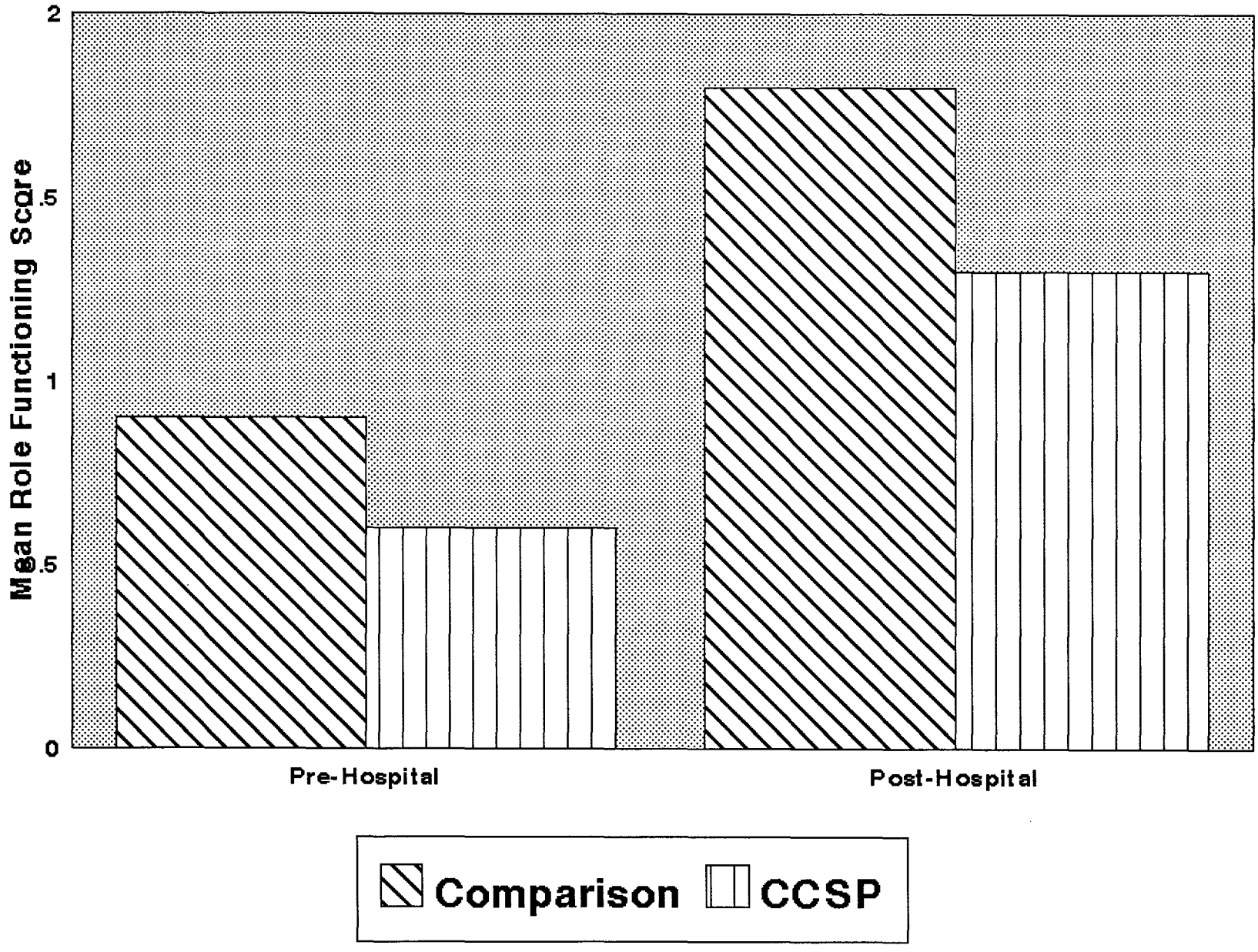


Fig.15 Difference in Social Functioning Before and After Hospitalization Between CCSP Treated and Comparison Group

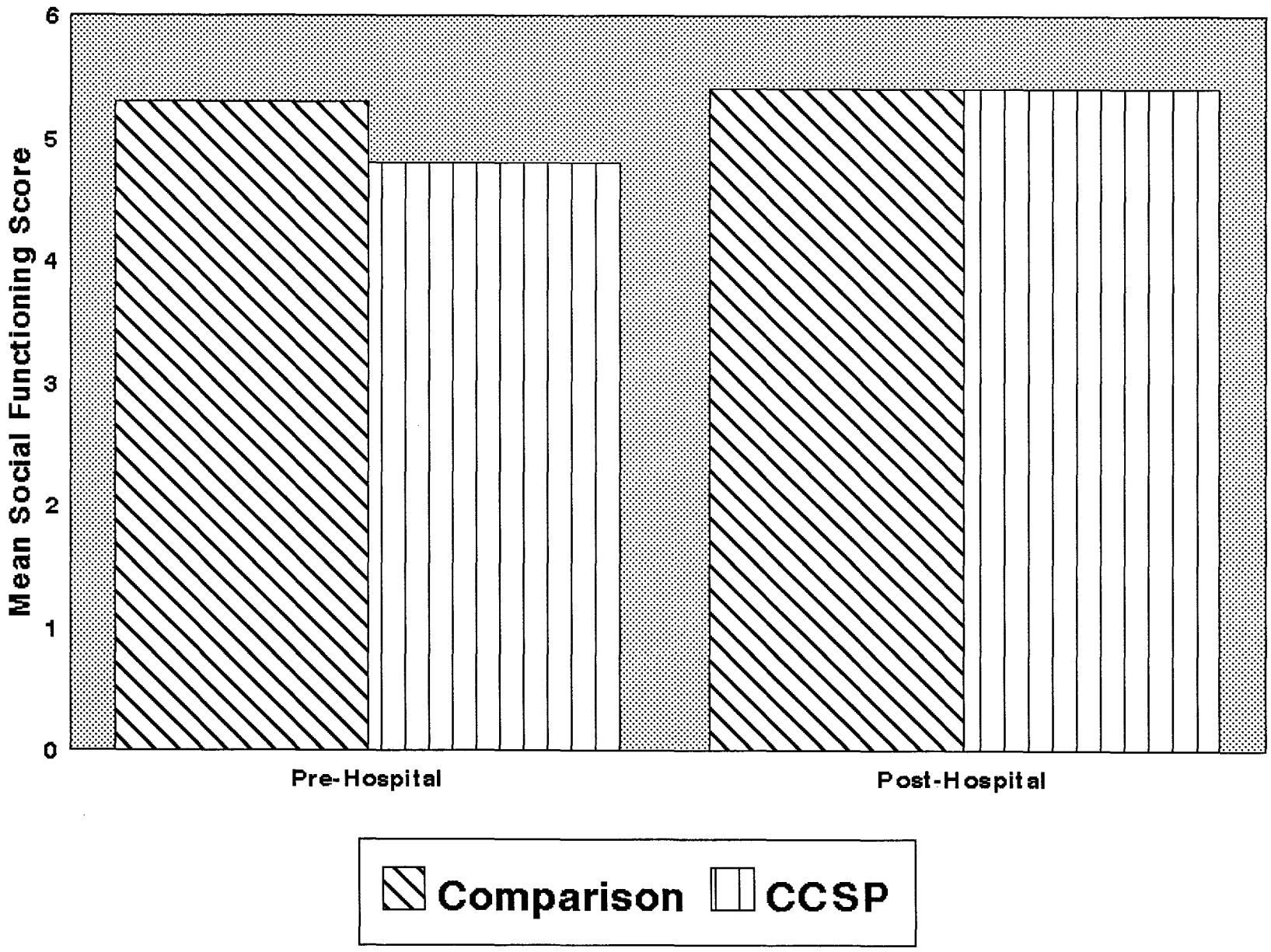


Fig.16 Difference in Pain Before and After Hospitalization Between CCSP Treated and Comparison Group

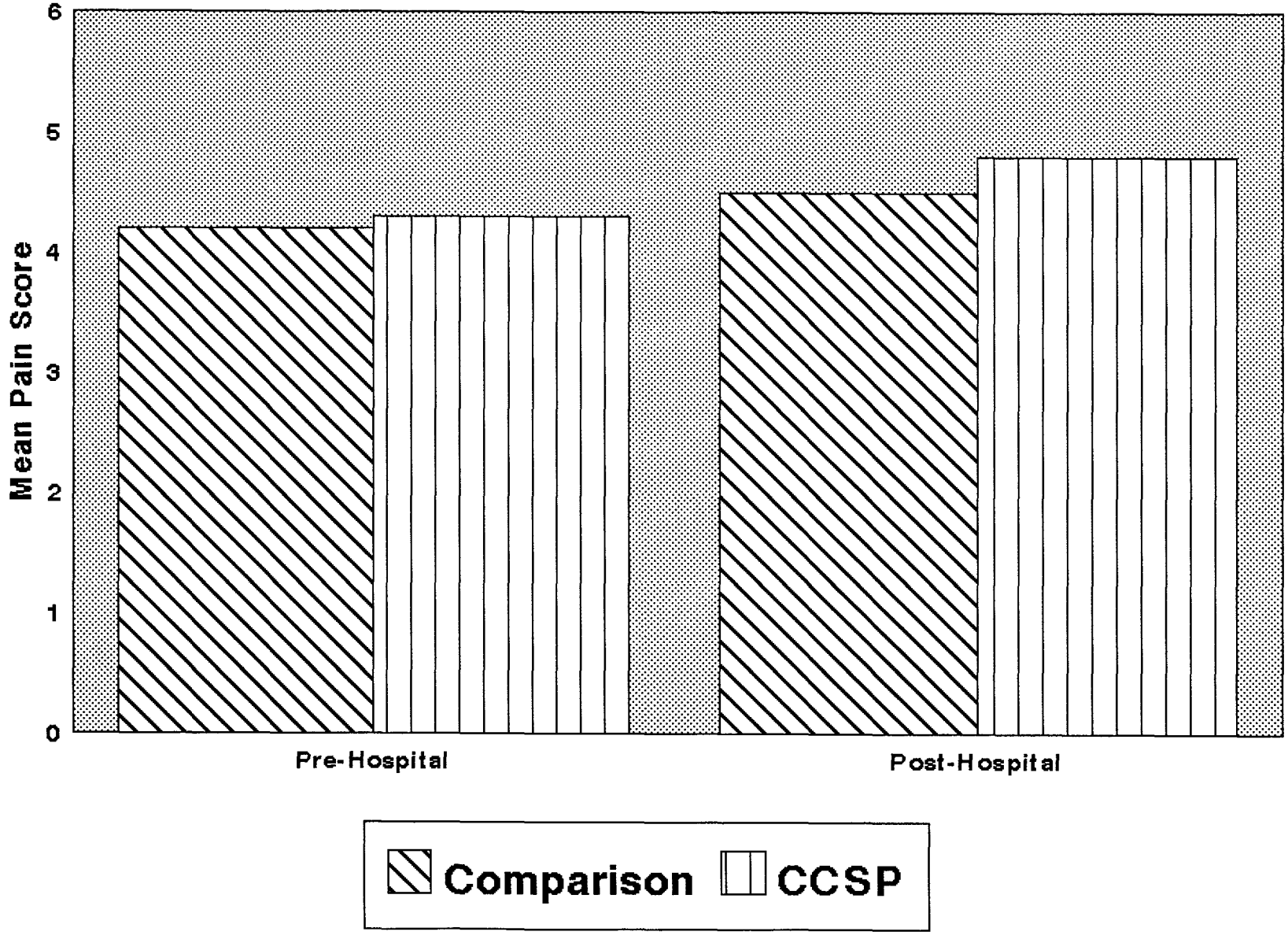


Fig.17 Difference in Health Perception Before and After Hospitalization Between CCSP Treated and Comparison Group

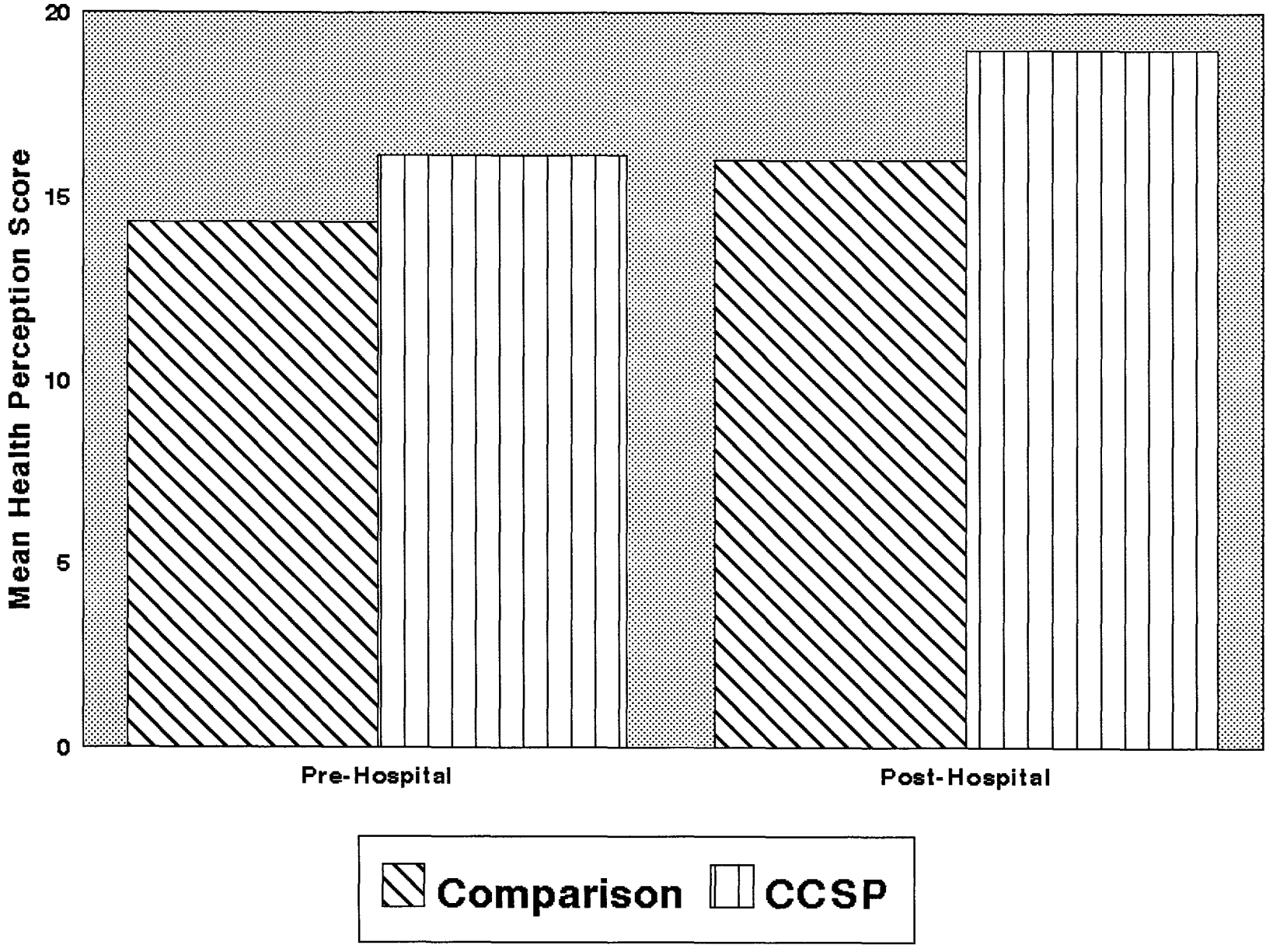


Fig.18 Difference in Overall Health Status Before and After Hospitalization Between CCSP Treated and Comparison Group

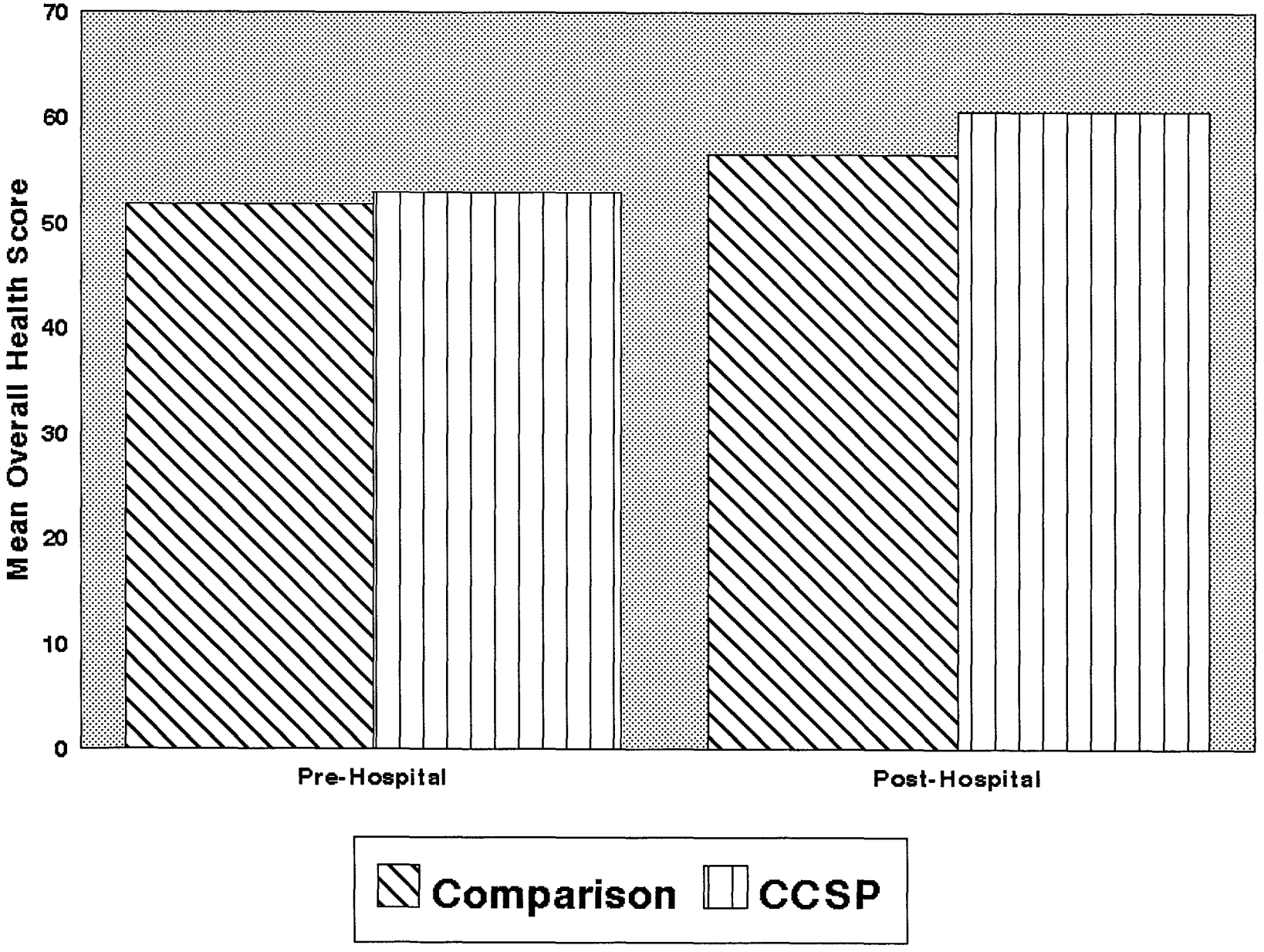


Fig.19 Difference in QOL (Health) Before and After Hospitalization Between CCSP Treated and Comparison Group

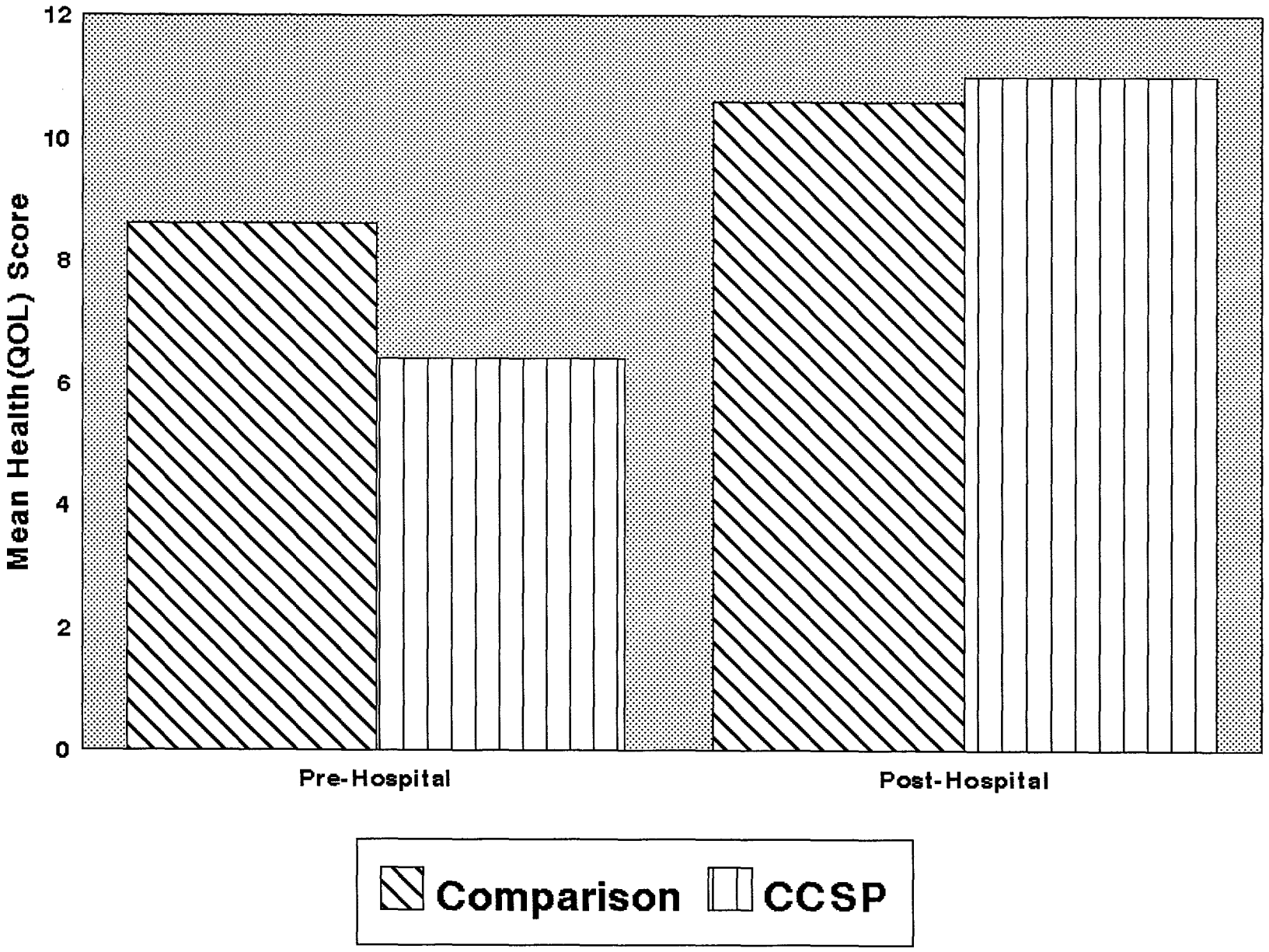


Fig.20 Difference in QOL(Socioeconomic) Before and After Hospitalization Between CCSP Treated and Comparison Group

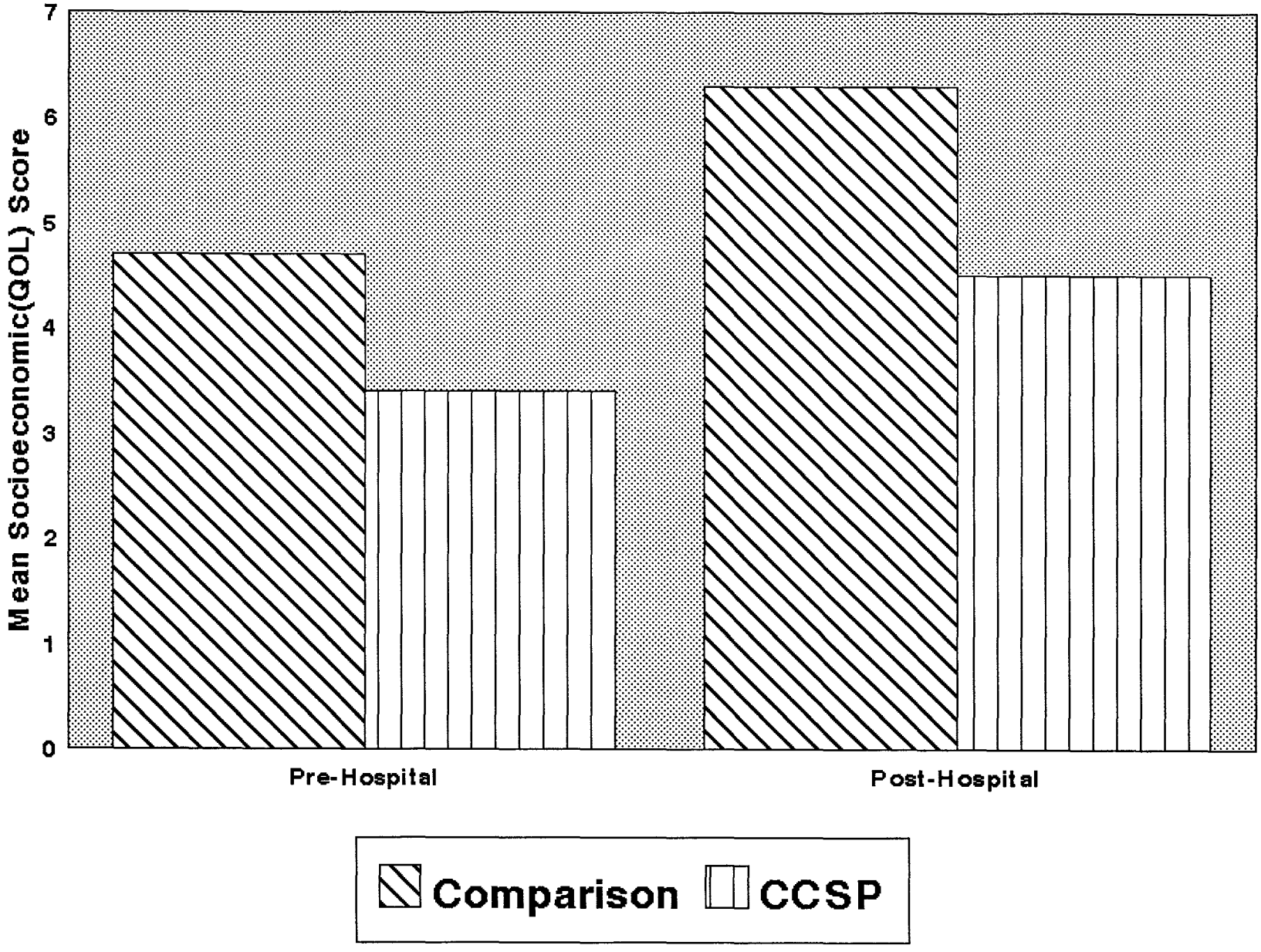


Fig.21 Difference in QOL (Psychological/Spiritual) Before and After Hospitalization Between CCSP Treated and Comparison Group

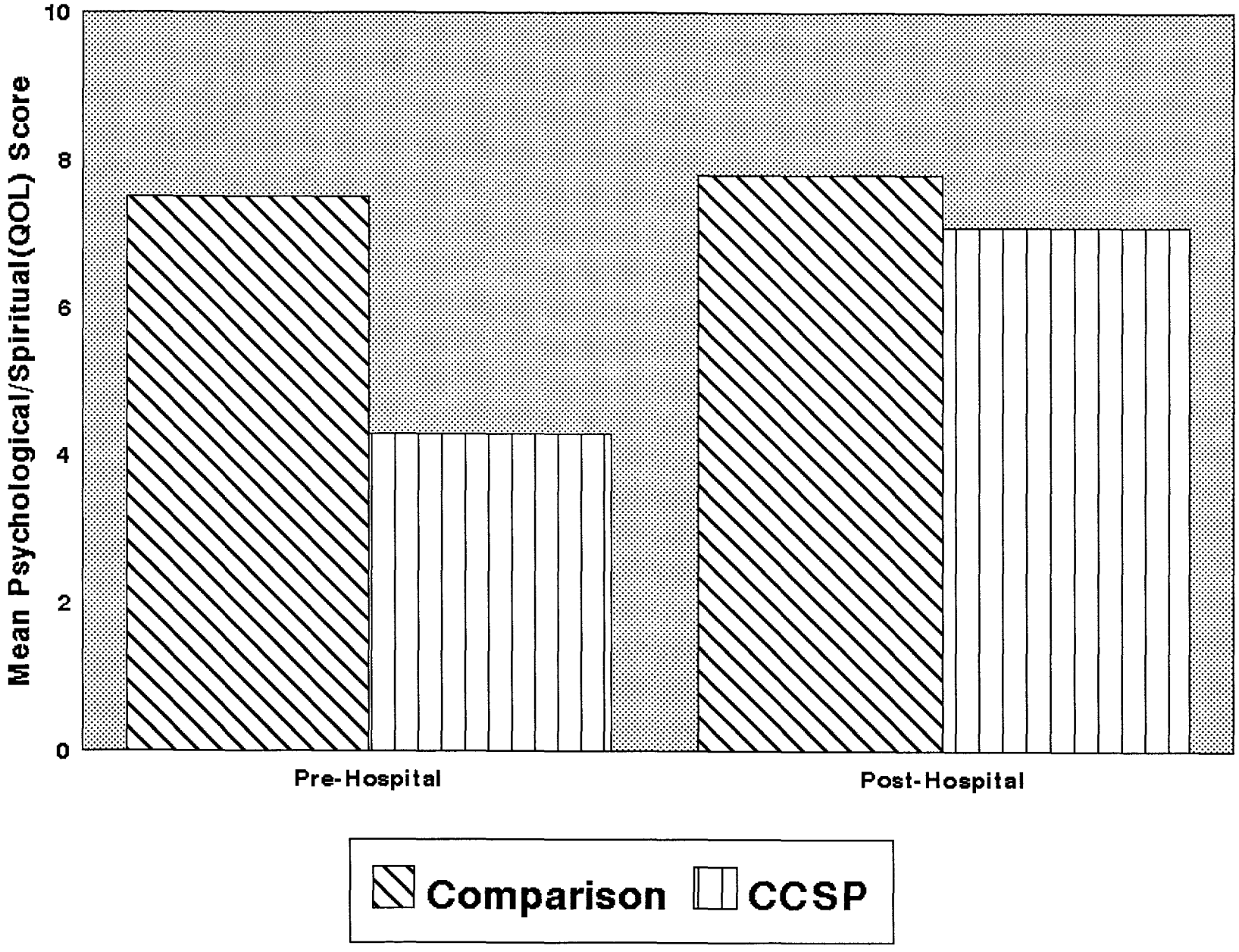


Fig.22 Difference in QOL (Family) Before and After Hospitalization Between CCSP Treated and Comparison Group

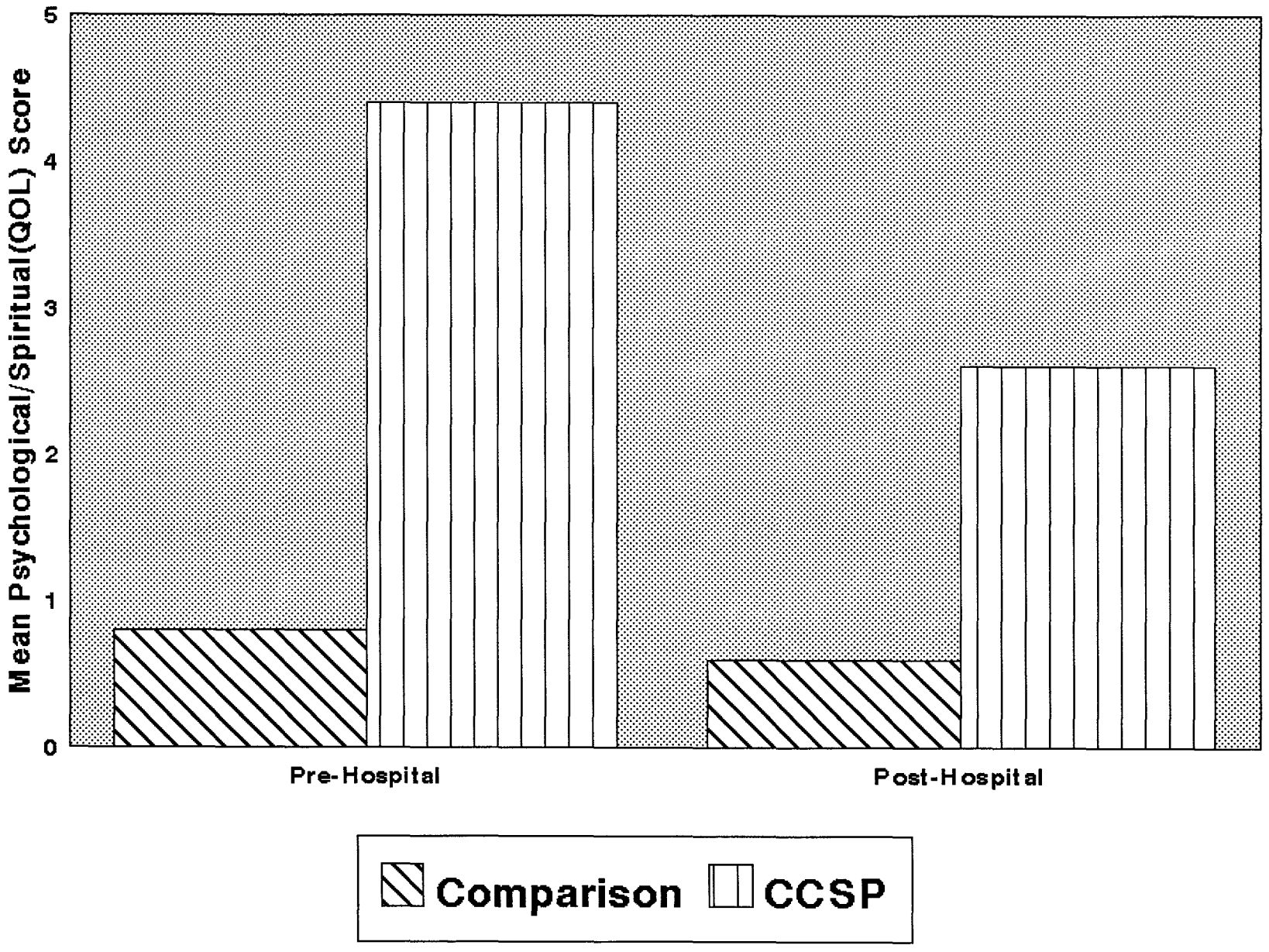
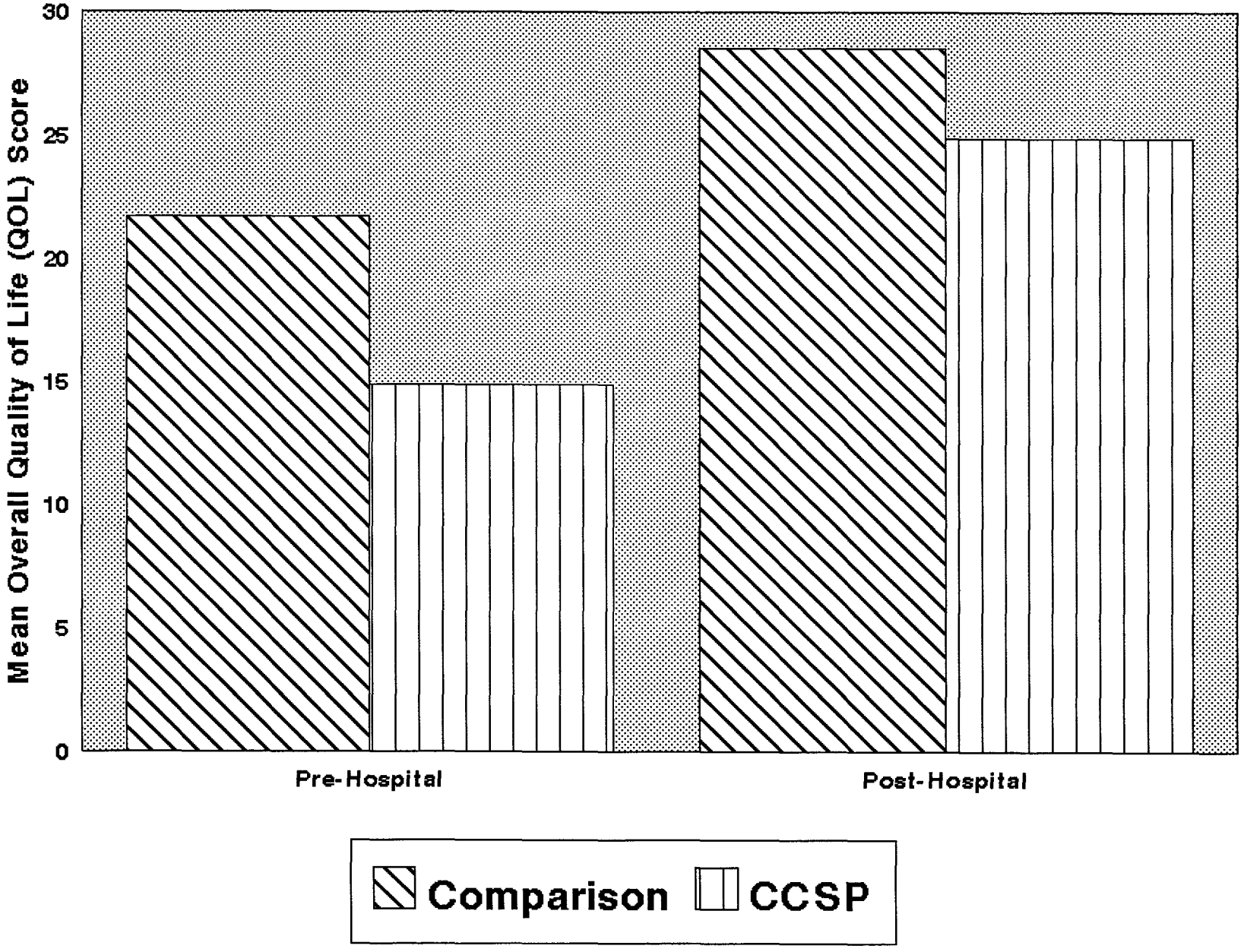


Fig.23 Difference in Overall Quality of Life (QOL) Before and After Hospitalization Between CCSP Treated and Comparison Group



Pain, Psychological Distress, Health Status, and Coping in Breast Cancer Patients Scheduled for Autologous Bone Marrow Transplantation

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Purpose/Objectives: The purpose of this study was to describe pain, psychological distress, health status, and coping experienced by breast cancer patients who are scheduled for autologous bone marrow transplantation (ABMT). Strength and direction of relationships among pain, psychological distress, health status, and coping were explored. The percentage of variance within the concept of health status which was explained by age, pain, psychological distress, and coping (ability to control pain and catastrophizing) was also examined.

Design: A descriptive, correlational design was used.

Setting: The setting was an urban, National Cancer Institute designated Comprehensive Cancer Center located in the eastern United States.

Sample: A convenience sample of 83 female, breast cancer patients scheduled for ABMT was used. The population age ranged from 22 to 59 years ($\times$ = 44.47 years) and was composed of 72 Caucasian (87.8 %), 6 African American (7.3 %), and 4 other minorities (4.9 %) patients.

Methods: The data were collected by an oncology clinical nurse specialist in the outpatient medical oncology clinic during a regularly scheduled visit approximately 20 days pre-hospitalization for intensive chemotherapy and ABMT. Sociodemographic data were collected using the Patient Demographic Data Form. The following self-report instruments were used: Gaston-Johansson Painometer®; State-Trait Anxiety Inventory; Beck Depression Inventory; MOS Short-form General Health Survey; and Coping Strategies Questionnaire.

Main Research Variables: Pain, psychological distress, health status, and coping.

Findings: The sample characteristics consisted of a select group of highly educated, primarily Caucasian patients, who were married, living with their spouse, and employed in professional occupations with yearly incomes of greater than $50,000. The subjects experienced low pain intensity. However, the range of reported pain intensity ratings was wide indicating that some patients experienced at least moderate pain intensity. Pain locations were varied; pain was experienced primarily in the vagina, chest, shoulder, and arm and described most frequently as aching, sore, dull, annoying, tiring, nagging, and troublesome. Subjects reported mild depression and moderate state anxiety. The range of depression and state anxiety was wide, indicating that some subjects experienced severe depression and severe anxiety. Coping strategies used most frequently to deal with pain included use of positive coping statements, diverting attention, praying and hoping, increasing activity level, ability to control pain, and ability to decrease pain. Subjects reported a moderate total health status and a low role functioning. High, significant correlations were seen between state anxiety and depression, and physical functioning and role functioning. High, significant, negative correlations were seen between state anxiety and mental heath, depression and total health status, and depression and mental health. Sixty-five percent of the variance in health status was explained by sensory pain, depression, and catastrophizing.

Conclusions: Breast cancer patients scheduled for ABMT may experience pain, psychological distress, and alterations in coping and perceived health status during the pre-hospitalization for ABMT time period. Total pain intensity, sensory pain, depression, and catastrophizing appear to be important variables related to the perceived health status of the patient.

Implications for Nursing Practice: Oncology nurses need to include assessment of pain, psychological distress, health status, and coping in their routine patient assessment prior to ABMT. These patients may experience difficulty in coping not only with the breast cancer diagnosis, but also with previous surgical treatment and related pain, as well as anticipatory psychological distress

regarding the future scheduled intensive chemotherapy and ABMT process. Health care providers need to be cognizant of these potential patient psychological and physiological problems to provide appropriate care and make necessary referrals. Future nursing research should be directed toward the testing and implementation of comprehensive and increasing the use of positive coping strategies to decrease anxiety and depression.

Introduction

The American Cancer Society estimates 180, 200 new cases of breast cancer in the United States in 1997 (Parker, Tong, Bolden, & Wingo, 1997), and 43, 900 women will die from this disease (U. S. Department of Health and Human Services, 1997). Although the 5 - year survival rate is presently 97%, this rate decreases to 20% when the cancer is diagnosed with distant metastases (U. S. Department of Health and Human Services). Clearly, innovative treatment strategies are needed to increase these survival rates. One such treatment modality is the use of autologous bone marrow transplantation (ABMT) for women with metastatic or high-risk, early stage breast cancer. Autologous BMT uses high dose chemotherapy and/or radiation therapy to achieve maximum tumoricidal dose followed by bone marrow rescue with reinfusion of the patient's own cryopreserved bone marrow cells. This treatment modality has become wide-spread (Whedon, 1996); more than 5,000 ABMTs are performed annually worldwide (Buschel, Leum, & Randolph, 1996).

The purpose of this study was to describe and explore relationships among pain, psychological distress, perceived health status, and coping in breast cancer ABMT patients during the preadmission phase. The direction and strength of relationships was explored among pain, psychological distress, perceived health status, and coping. The percentage of variance within perceived health status which can be explained by pain, psychological distress, and coping (catastrophizing, control of pain, and positive coping statements) was also examined.

Literature Review

Six psychosocial stages corresponding to the medical management of BMT have been identified (Brown & Kelly, 1984; Haberman, 1988). The initial two stages--making the decision to undergo a BMT and the preadmission stage-- are contextually appropriate for this study. The decision-making stage represents a major turning point in the patient's life (Haberman). Numerous factors influence the patient's decision to undergo a BMT. The cost/benefit ratio of achieving increased survival time versus potential acute and chronic negative sequelae is a major factor (Haberman). Uncertainties may linger after this decision-making stage and may be present during the pre-admission stage and other stages. The preadmission stage presents the breast cancer patient with unique psychological demands and concerns. The patient may experience stress from numerous sources such as recent breast cancer surgery, knowledge of a life-threatening diagnosis, and uncertainty regarding the future ABMT treatment process and outcome (Jenkins, Limington, & Whittaker, 1991). Other challenges to coping are the change to outpatient status, potential geographical dislocation, and the preparation of significant others for the possibility of morbidity and death. Behavioral issues such as decreased pain tolerance and pain related to procedures, disease and/or prior treatment may be evident (Syrjala, 1995). Coping issues related to decision-making regarding treatment and access to and use of psychological supports may be present. Psychological responses, such as distress, may be operational (Syrjala).

The literature presents research regarding the pain, psychological distress, and coping experienced by these patients during and after the ABMT hospitalization period (Ford & Ballard, 1988; Gardner, August, & Githens, 1977; Gaston-Johansson, Franco, & Zimmerman, 1992; Hill et al., 1990; Jenkins & Roberts, 1991). However, there is a paucity of research conducted exploring these variables during the pre-hospitalization period. Meyers et al. (1994) explored the cognitive and emotional functioning of 61 adult patients before, during, and after BMT. Results demonstrated nearly 40% of the sample experienced significant anxiety pre-BMT (Meyers et al). Pre-hospitalization data are extremely

significant because a patient's anticipatory response to the ABMT procedures and associated intensive chemotherapy may be an important predictor of subsequent or long term quality of life (QOL) (Gaston-Johansson & Foxall, 1996) and the development of neurobehavioral disorders (Meyers et al.).

Pain

Pain has been shown to be a significant problem for a large number of stage I and stage II breast cancer patients (Arathuzik, 1991; Miaskowski & Dibble, 1995a; Miaskowski & Dibble, 1995b). Pain may be acute, as experienced prediagnosis, following lumpectomy or mastectomy and axillary node dissection, or may be chronic and long-term in nature (Gorrell, d'Angelo, & Bagley, 1988). Treatment-related breast pain from surgery and chemotherapy is related to breakdown of the skin integrity. This treatment-related pain has been characterized as irritating (Gorrell, d'Angelo, & Bagley), constricting, burning, or throbbing sensations localized to the posterior arm, axilla, and anterior chest wall (Assa, 1974; Eliott & Foley, 1989; Johnson, 1994; Wood, 1978). Only one published study to date could be found that examined the pain experienced by breast cancer patients and its effects on their lives in the outpatient setting (Miaskowski & Dibble, 1995a). The study results found that 47% of breast cancer patients receiving treatment in the outpatient setting reported cancer-related pain. The majority of patients in this group were found to have treatment-related pain from post-surgical neuropathic pain syndrome (56%) and cancer-related pain from bone metastasis (26%). Patients rated their pain as moderate to severe on a daily basis.

Patients who experience cancer pain are found to have significantly more depression, anxiety, and decreased QOL scores than pain-free patients (Ferrell, Dow, Leigh, Ly, & Gulamsekaram, 1995; Ferrell & Funk, 1995; Miaskowski & Dibble, 1995a). Many patients suffering from chemotherapy related pain in the outpatient settings have reported using non-pharmacologic approaches such as relaxation, massage, and imagery to reduce discomfort. Pilot studies by Arathuzik (1994) found that educating breast cancer patients in relaxation techniques and cognitive coping skills was effective in decreasing pain. These non-pharmacologic approaches used separately have proven to be effective in relieving pain in both breast and lung cancer patients (Arathuzik, 1994; Ferrell-Torry & Glick, 1993; Wilkie, 1990; Wilkie, 1991). However, these approaches have not been evaluated in combination in a randomized controlled clinical trial (Arathuzik; Ferrell-Torry, & Glick; Wilkie 1990; Wilkie, 1991).

Psychological Distress

Anxiety and depression are common responses to the diagnosis of and treatment for breast cancer (Gobel & Donovan, 1987; Maraste, Brandt, Olsson, & Ryde-Brandt, 1992; Schain, d'Angelo, Dunn, Lichter, & Pierce, 1993). Elevated levels of depression and anxiety may persist in a minority of breast cancer patients even years after the diagnosis (Spiegel, 1997). Adjuvant chemotherapy represents a prolonged threat to a patient's mortality and functioning leading to additional psychological distress after breast surgery. One study indicated that 14% of patients who underwent adjuvant chemotherapy after breast-conserving surgeries and mastectomies experienced severe anxiety (Maraste et al., 1992). Coscarelli-Shag et al. (1993) identified the following major sources of psychological distress for breast cancer patients at one month post diagnosis: a) anxiousness while waiting for test results and having to undergo additional diagnostic tests; b) worries over whether the cancer was progressing; c) concern about ability to take care of self; and d) concern about how the family would manage if the patient died. Assessing patients' anxiety and depression during the pre-admission period is of

paramount importance to provide appropriate interventions and because it is critical that the ABMT patients adhere to the strict treatment protocol schedule.

Perceived Health Status

Frequency and severity of pain, psychological distress, and fatigue influences a patient's perceived health status, QOL, and length of hospital stay (Chielens & Herrick, 1990). Preliminary data from a study performed by the principal investigator (PI) involving 24 patients who underwent ABMT, showed that the patients' perceived health status was significantly negatively correlated with pain (-60, $p < .01$), depression (- .83, $p < .001$), and fatigue (- 71, $p < .001$), and positively correlated with QOL (.75, $p < .001$). A patient's beliefs about his health status have been shown to be an important determinant of health outcomes (Wolcott, Wellisch, Fawzy, & Landsverk, 1986). Preliminary data from a second study by the PI showed that health perception was predictive of fatigue ($F (2, 24) = 8.07$, $p < .05$) , of anxiety ($F (2, 24) = 8.24$, $p < .05$) and of the QOL family subscale of the QOL Index-Cancer Version (Ferrans, 1990) ($F (2, 24) = 5.52$, $p < .05$). The health status of ABMT patients varies. Some breast cancer ABMT patients leave the hospital within three weeks, while others stay 2 to 3 months. About 35% of patients utilize emergency room services and about 15 to 50% require one or more rehospitalizations (Chielens & Herrick).

Coping

Coping is defined as constantly changing cognitive and behavioral efforts used to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person (Lazarus & Folkman, 1984). Positive coping strategies refer to internal thoughts and behaviors people use to manage their pain, or their emotional reactions to the pain, and to reduce emotional distress. Catastrophizing, a negative coping strategy, is defined as a method of cognitive coping characterized by negative self-statements and thoughts about the future (Keefe et al., 1987; Keefe, Brown, Wallston, & Caldwell, 1989).

Conceptual Framework

The Gate-Control Theory of Pain developed by Melzack and Wall (1965) and the Stress, Coping, and Adaptation Paradigm formulated by Lazarus and Folkman (1984) provided the theoretical framework for this study. Pain is defined as a multi-dimensional sensory and affective experience associated with discomfort (International Association for the Study of Pain, 1979). According to the Gate-Control Theory of Pain, the central system located in the brain can be stimulated by cognitive processes such as past experiences, anxiety, anticipation, and attention, which opens the gating mechanism permitting the transmission of nociceptive impulses to the brain (Melzack and Wall).

Research Objectives

The study had the following research objectives:

1. Describe the perception of pain and psychological distress by breast cancer patients during the pre-hospitalization for ABMT time period.
2. Describe the perception of health status by breast cancer patients during the pre-hospitalization for ABMT time period.
3. Explore the relationships among pain, psychological distress, catastrophizing, coping, and perceived health status, for breast cancer patients during the pre-hospitalization for ABMT time period.
4. Describe the percentage of variance within the concept of health status which was explained by pain, psychological distress, and coping (catastrophizing and ability to

control pain).

Methods

Design

The study used a descriptive, correlational design.

Sample

A convenience sample of 83 women with stage II, stage III, or stage IV breast cancer scheduled for ABMT was recruited for the study.

Setting

The setting was an urban National Cancer Institute designated comprehensive cancer center located in the eastern United States.

Instruments

The **Sociodemographic Questionnaire** included the following information: age; gender; race/ethnicity; marital status; educational level; religion; patient living arrangements; average yearly household income; occupation; work status; and household income. Clinical data were also collected: breast cancer stage; metastatic sites; past treatments for breast cancer; use of medications; laboratory data; and past care from a psychiatrist, psychologist or other mental health professional; and use of relaxation techniques and coping strategies within the past year.

Pain was measured using the **Painometer®** (POM), which was designed by the PI to assess patients' overall pain intensity, intensity of the sensory and affective components of pain, as well as the quality of pain (Gaston-Johansson, 1996). The POM is a hard, white plastic tool which measures 8 inches long, 2 inches wide, and 1 inch thick. It is light weighted and is held easily by the subject. A list of 15 sensory and 11 affective pain descriptors are located on the front side of the POM and a 100mm visual analogue scale (VAS) with a moveable marker (POM-VAS) is located on the back side of the POM. An intensity value (from a low of "1" to a high of "5") is predetermined for each sensory and affective word located on the POM-WDS. A maximum score of 36 can be obtained for the sensory component of pain and of 34 for the affective component. A total score can be obtained by adding the sensory and affective scores. High correlations were found between the initial and the repeat pain intensity ratings on the POM-VAS ($r = 0.88$, $p < 0.001$) and the POM-WDS ($r = 0.84$, $p < 0.001$) (test-retest reliability). Correlations between the POM-WDS and the McGill Pain Questionnaire ($r = 0.69$, $p < 0.001$) and POM-VAS ($r = 0.85$, $p < 0.001$) supported the concurrent validity of the POM-WDS. Construct validity was also supported for the POM by showing that pain scores decreased significantly from POM-WDS ($t = 5.53$, $p < 0.001$), and POM-VAS ($t = 6.18$, $p < 0.001$) after the treatment with pain medication. The POM took about 2 minutes to complete. The **Painometer® Questionnaire** was used to record pain intensity, pain quality, pain locations, duration (whether the pain was continuous or periodic), and length of present pain episodes.

The **Beck Depression Inventory** (BDI) was used to measure depression in subjects. The BDI consists of 21 items that describe particular symptoms of depression (Beck & Steer, 1987). Subjects respond to a Likert-type scale by rating each item 0 (no symptom) to 3 (severe or persistent presence of the symptom). Scores may range from 0 to 9 (normal), 10 to 15 (mild depression), 16 to 23 (moderate depression), and 24 to 63 (severe depression). The total possible score (range 0 to 63) is obtained by summing the 21 responses. Reliability and validity have been reported for the BDI. The BDI took 5 to 10 minutes to complete.

The **State-Trait Anxiety Inventory** (STAI) was used to measure anxiety (Spielberger, 1983).

The STAI consists of two separate self-report scales for measuring state and trait anxiety (Spielberger). State anxiety is a transitory emotional response to a stressful situation. Trait anxiety reflects a stable predisposition to anxiety as determined by a personality pattern. Each scale consists of 20 statements as related to emotions and respondents rate themselves in relationship to each statement on a Likert-type scale from 1 to 4. The total score is the sum of all 20 responses and ranges from a minimum score of 20 to 39 (low anxiety), 40 to 59 (moderate anxiety), to a maximum score of 60 to 80 (high anxiety). Scores are reported to be considerably higher under stressful conditions than under normal conditions (Spielberger). Reliability and validity have been demonstrated for this test. The STAI took about 5 to 10 minutes to complete.

The **Coping Strategy Questionnaire** (CSQ) developed by Keefe et al. (1987) was used to assess the patient's use of coping strategies. The categories of coping strategies assessed by this measure include: a) diverting attention; b) reinterpreting pain sensations; c) ignoring pain sensations; d) praying and hoping; e) catastrophizing; and f) increasing activity level. For each category of coping strategies there are 6 items on the CSQ with scores ranging from 0 to 36. Each item is rated on a 7 point scale to indicate how often that strategy is used to cope with pain (0 = "never", 3 = "sometimes", and 6 = "always"). Reliability of the CSQ has been demonstrated with alpha coefficients ranging from .71 to .85. Cronbach's alpha ranged from .71 to .88 in chemotherapy patients. The CSQ also includes 2 items which measure overall effectiveness of those strategies used by asking the subjects to rate on a 7-point scale (with scores ranging from 0 to 6) how much control they have over the pain, and how much they are able to decrease their pain (Keefe et al. , 1990). Construct validity has been demonstrated by factor analysis (Keefe et al., 1990; Carey & Burish, 1987). The CSQ took about 5-10 minutes to complete.

Perceived health status was measured by the **Medical Outcomes Study Short-form General Health Survey** (MOS-SF) (Stewart, Hays, & Ware, 1988). This instrument was chosen as opposed to other established instruments used to measure health status because of administration ease, and the fact that reliability has been demonstrated in acute and chronically ill patients (Rock et al., 1987). The 20-item survey assesses physical functioning (6 items), role functioning (2 items), social functioning (1 item), mental health (5 items), health perception (5 items), and pain (1 item) (Stewart et al., 1988). Physical functioning refers to limitations in a variety of physical activities. Role and social functioning are defined as limitations related to health problems. Mental health is assessed in terms of both psychological distress and well-being. Health perception is assessed by the patient's perceptions of their own health in general, and pain refers to differences in physical comfort. The total health perception score is obtained by summing all of the mental health scales (Stewart et al., 1988) for a possible score range of 0 to 91. The Pain and Social Functioning scores have a possible score range of 1 to 6. The Role Functioning has a possible range of 0-6. The Physical Functioning measure has a possible score range of 1 to 18. The Mental Health measure has a possible score range of 1 to 30, and the Health Perception measure has a possible score range of 1 to 25.

Construct validity was demonstrated by showing that poor health was significantly greater ($p < .001$) in a patient sample than a general population sample regarding physical and role functioning, mental health and health perceptions. Statistically significant ($p < .01$) correlations were found among all health measures. Cronbach's alpha estimated for the four multi-item scales ranged from .81 to .88 (Stewart et al., 1988). In a preliminary study by the PI, Cronbach's alpha for the MOS-SF in ABMT patients ranged from .58 to .98 for the subscales. The MOS-SF took less than 5 minutes to complete.

Procedure

The study was approved by the Institutional Review Board prior to participant accrual. All participants were recruited by either the physician co-investigator or the oncology clinical nurse specialist co-investigator during a regularly scheduled pre-ABMT Medical Oncology Outpatient Clinic visit. All participants had been accepted into the ABMT program prior to the invitation to participate in this study. Written informed consent was obtained from each participant.

Data analysis

Data analysis was conducted using the Statistical Analysis System (SAS) (SAS Institute, Cary, NC, 1993) and Statistical Package for Social Sciences (SPSS, Inc., Chicago, IL, 1995) computer packages. Descriptive statistics (frequency, percent, mean, mode , and standard deviation) were used to describe the sample and responses to the instruments. Strength and direction of relationships among pain intensity and quality, psychological distress, catastrophizing, coping, and perceived health status were explored, as measured using the POM-VAS and POM-WDS, BDI, STAI, CSQ, and MOS-SF using Pearson product moment and Spearman's Rho correlations as appropriate. The percentage of variance within the concept of health status which was explained by age, psychological distress, and coping (ability to control pain and catastrophizing) was also examined through the entry of these variables into the model.

Results

Sample Characteristics

The sample of 83 female subjects, ranging in age from 22 years to 59 years ($x = 44.47 \pm 7.29$), was composed of 72 Caucasians (87.8%), 6 African Americans (7.3%), and 4 other minorities (4.9%) ABMT patients (Table 1). Most of the subjects were married (74.4%) and living with their spouse (72.8%), with an average yearly household income of over $50,000 (67.6%). The sample was primarily Protestant (51.3%), college educated (52.4%), and employed (72.5%) in a professional position (61.6%). Most of the sample was diagnosed as Stage III disease (42.2%) (Table 2). Previous treatment was most frequently multimodal with 61 subjects (73.5%) having received surgery and chemotherapy (Table 2). Viewing treatment modalities individually, 78 subjects had previous breast cancer surgery (94%), 78 subjects had received chemotherapy (94%), 18 subjects had received previous radiation therapy (22%).

Pain

Locations of pain experienced by the study participants were primarily in the vagina (19.3%), chest (14.4%), shoulder (13.3%), and arm (9.6%) (Table 3). Other varied locations, each noted by only 1 to 5 subjects, were the neck, abdomen, breast, joint/hand, mouth, head (ache), rectum, eyes, hips, foot and generalized. All mean pain intensity scores were low: sensory pain intensity score was 3.45 (SD = 4.14; range 1-14); affective pain intensity score was 4.47 (SD = 3.67, range 1-20); total intensity score mean was 6.91 (SD = 6.86, range 1-44); and the POM-VAS overall pain intensity score was 7.47 ± 13.99 (Table 4). Although, the mean pain scores were low for sensory, affective, overall intensity, as well as for the POM-VAS, the range of reported scores was wide indicating that some subjects did experience at least moderate pain intensity. The words chosen most frequently using the POM-WDS to describe the sensory quality of pain were aching (25.3 %), sore (24.1 %), and dull (13.3%), and the words chosen most frequently to describe the affective quality of pain were annoying (26.5%), tiring (16.9%), nagging (9.6%), and troublesome (9.6%) (Table 5). Sensory words not chosen using the POM-WDS were splitting and searing and the affective word not chosen

was sickening.

Psychological Distress

Subjects reported depression and anxiety. Anxiety ranged from mild (49%), moderate (24%) to severe/high (26%). Depression ranged from mild (36%), to moderate (17%), to severe/high (7%). The mean state anxiety score was 41.43 with a standard deviation of 12.67 and a range 20 to 67. The mean depression score was 11.66 with a standard deviation of 7.73 and a range of 0 to 37 (Table 6).

Cognitive Coping Strategies

The subjects used a variety of coping strategies to cope with pain (Table 7). Ignoring pain sensations, using positive coping statements, diverting attention, praying and hoping, and increasing activity level, and ability to control pain, and ability to decrease pain were used most frequently. Reinterpreting pain sensations and avoiding catastrophizing were used least frequently.

General Health Status

Subjects reported a mean total perceived health status rating of 50.30 (SD = 10.67, range 18 - 72), out of a possible total rating range of 0 to 91. A high mean rating was reported for mental health (x = 22.10, SD = 4.5, range 8 - 29). A moderate mean rating was reported for pain (x = 4.11, SD = 1.28, range 1- 6), social function (x = 4.73, SD = 1.44, range 1 - 6), and health perception (x = 14.66, 4.98, range 5 - 25). The lowest mean was reported for role functioning (x = .79, SD = .87, range 0 - 2).

Correlations Between Pain and Selected Variables

Correlations between pain, anxiety, depression, catastrophizing, coping, and health status are presented in Table 9. High, significant positive correlations were seen between the following variables: state anxiety and depression (.61, $p < .001$); and physical functioning and role functioning (.65, $p < .001$). High, significant, negative correlations were seen between state anxiety and mental health (- .66, $p < .001$); depression and total health status (- .73, $p < .001$); and depression and mental health (- .71, $p < .001$).

The variables of interest (pain, anxiety, depression, ability to control pain, and catastrophizing) were all significantly correlated to each other and to total health status. Correlation co-efficients among variables and total health status ranged from $r = 0.33$ ($p < .01$) to $r = 0.73$ ($p < .001$). The results showed $R^2 = 0.65$, F value = 22.48, $p < .05$. Of the variables entered into the model, sensory pain ($T = - 2.58$, $p < .05$), depression ($T = - 5.59$, $p < .001$), and catastrophizing ($T = -2.57$, $p < .05$) were significant. Therefore, 65% of the variance in health status was explained by sensory pain, depression, and catastrophizing.

Discussion

The sample characteristics describe a select group of primarily highly educated Caucasian ABMT patients, who were married and living with their spouse, and employed in professional occupations with average yearly incomes greater than $50,000. Most of the sample had received surgery and chemotherapy prior to the planned ABMT. The pain locations chosen of chest, shoulder, and arm and the pain descriptors of dull, sore, and aching may be related to previous breast cancer surgery (lumpectomy or mastectomy), or a previously placed and removed central venous catheter used for the prior chemotherapy. It is interesting to note that this sample of patients experienced pain before any procedures such as central line placement or bone marrow aspiration were performed.

Psychological distress was evident through the reporting of mild through severe depression and

state anxiety. This fact demonstrates the necessity of screening for anxiety and depression in this population before admission for the ABMT. Positive coping strategies used to cope with pain were chosen by the majority of the subjects. However, the use of catastrophizing was present. Pre-admission data are important as a potential prognosticator of long-term QOL (Gaston-Johansson & Foxall, 1996) and future neurobehavioral disorders (Meyers et al., 1994). Assessing patients' anxiety and depression during the pre-admission period is also of paramount importance to provide appropriate interventions and because it is critical that the ABMT patients adhere to the strict treatment protocol schedule. The subjects reported a moderate total perceived health status. However, the range of scores was very wide with some subjects reporting very low total health status scores. The low mean rating for role functioning may be related to the change from a previously perceived role to the status of ambulatory care breast cancer patient awaiting ABMT. The high, significant, negative correlations between state anxiety and mental health, depression and total health status, and depression and mental health, and the high, significant, positive correlation between state anxiety and depression, as well as the variances in total health status explained by pain, state anxiety, and depression, demonstrate the importance of the timely assessment and treatment of these components of psychological distress.

Implications

Nursing Practice

Breast cancer patients scheduled for ABMT may experience pain, psychological distress, and alterations in coping during the pre-hospitalization period. These patients may experience difficulty in coping not only with the breast cancer diagnosis, but also with recent surgical treatment, and the anticipatory anxiety regarding the future scheduled intensive chemotherapy and ABMT process. The preadmission stage presents the breast cancer patient with unique psychological demands and concerns. Oncology nurses need to be cognizant of these potential complex psychological and physiological challenges to make appropriate assessments, perform effective nursing care, and make necessary referrals. The fast-paced clinic environment in which many patients are seen pre-ABMT necessitates that oncology nurses perform very focused patient assessments. Nursing assessments for anxiety, depression, and alteration in health status and coping should be a routine part of this pre-ABMT patient assessment. The national health care economically driven trend toward earlier discharge for the BMT population makes this early assessment even more important. Many ABMT patients are currently expected to achieve effective self-care skills during a stressful time period. Interventions to decrease anxiety, depression, and alterations in health status and coping may prevent the ABMT patient from becoming overwhelmed later in the ABMT treatment process and after discharge.

Research

Nursing research regarding interventions using findings from this and other relevant research targeted at the specific needs of breast cancer ABMT patients during the pre-hospitalization period regarding pain, psychological distress, and alterations in coping and health status is needed. Cognitive restructuring to change perception of pain and psychological distress, and decrease the use of catastrophizing, may be a useful component of this intervention. Research also needs to be directed toward discovering the reasons for the very low role perception. This role perception may become very important to the patient's ability to cope with the physiological and psychological challenges engendered by the ABMT treatment process.

Recruitment of increased numbers of minority patients into nursing research focusing on the ABMT experience for breast cancer patients is needed. External reliability of the research findings is compromised when such a select sample is used. We are unable at present to state precisely why this under representation of minorities exists in patients recruited for ABMT nationwide. One potential reason may be economic barriers related to the cost of ABMT. ABMT may cost between $80,000 to over $150,000, as compared with the cost of conventional chemotherapy which is between approximately $15,000 to $40,000. (United States General Accounting Office, 1996). Clearly we need to assess why minority populations are under represented in this treatment modality and to develop and test appropriate intervention strategies to increase minority accrual.

Conclusions

Breast cancer patients scheduled for ABMT experience pain, psychological distress, and alterations in health status and coping during the pre-admission period. Health care providers need to be aware of these potential breast cancer patient experiences in order to promote appropriate assessments, provide effective care, and make necessary referrals. Further research needs to be directed toward appropriate interventions to assist ABMT patients to cope with the many challenges related to pain, psychological distress, and alterations in coping and health status which they experience during the pre-ABMT phase.

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Table 1. Demographic Characteristics of the Sample (n = 83)

Demographic Characteristics	n	%
Sex		
Female	83	100
Ethnicity		
Caucasian	72	87.8
African-American	6	7.3
Other Minorities	4	4.9
Marital Status		
Married	61	74.4
Single	11	13.4
Divorced	10	12.2
Education Completed		
High School	16	19.5
Some College	23	28
College Graduate	26	31.7
Graduate Degree	17	20.7
Religion		
Catholic	19	23.8
Protestant	41	51.3
Jewish	6	7.5
Other	11	13.8
None	3	3.8
Patient Lives With		
Spouse	59	72.8
Other	9	11.1
Self	13	16
Average Yearly Income		
< $50,000.	24	32.4
≥ $50,000.	50	67.6
Occupation		
Professional	45	61.6
Non-Professional	28	38.4
Unknown	10	12
Work Status		
Employed	58	72.5
Unemployed	22	27.5
Age		
Mean	44.47	
SD	± 7.29	
Range	22-59	

Table 2. Clinical Characteristics of the Sample (n = 83)

Clinical Characteristics	n	%
Breast Cancer Stage		
Stage II	3	3.6
Stage III	35	42.2
Stage IV	20	24.1
Past Treatment		
Surgery	2	2.4
Surgery and Radiation	1	1.2
Surgery and Chemotherapy	61	73.5
Radiation and Chemotherapy	1	1.2
Surgery, Radiation, and Chemotherapy	16	19.3

Table 3. Locations of Pain Complaints During Pre-ABMT Period (n = 83)

Pain Locations	n	%
Vagina	16	19.3
Chest	12	14.4
Shoulder	11	13.3
Arm	8	9.6
Neck	5	6.0
Abdomen	4	4.8
Generalized	4	4.9
Breast	3	3.6
Joint/Hand	3	3.6
Other	3	3.6
Mouth	2	2.4
Head (ache)	2	2.4
Rectum	1	1.2

Table 4. Mean Pain Intensity Ratings During the Pre-ABMT Period (n = 83) (54% of the Subjects Experienced No Pain)

Pain Intensity	Mean	SD	Median	Range
Sensory	3.45	4.14	2.5	1 - 24
Affective	4.47	3.67	4.0	1 - 20
Total Score	6.92	6.86	6.0	1 - 44

Table 5. Sensory and Affective Words Chosen to Describe the Quality of Pain During Pre-ABMT Period (n = 83)

Sensory Words	n	%	Affective Words	n	%
Aching	21	25.3	Annoying	22	26.5
Sore	20	24.1	Tiring	14	16.9
Dull	11	13.3	Troublesome	8	9.6
Hurting	6	7.2	Nagging	8	9.6
Burning	5	6	Agonizing	3	3.6
Shooting	4	4.8	Terrifying	2	2.4
Tearing	3	3.6	Miserable	2	2.4
Stabbing	2	2.4	Torturing	1	1.2
Radiating	2	2.4	Unbearable	1	1.2
Sharp	2	2.4	Killing	1	1.2
Cramping	2	2.4			
Crushing	1	1.2			
Pressing	1	1.2			

Table 6. Mean Psychological Distress Ratings in Patients During Pre-ABMT Period (n = 83)

Psychological Distress	Mean	SD	Range
State Anxiety	41.43	12.67	20 - 76
Depression	11.66	7.73	0 - 37

Table 7. Mean Coping Strategies Questionnaire (CSQ) Ratings During Pre-ABMT Period (n = 83)

Items on CSQ	Mean	SD	Range
Ignoring Pain	14.26	7.37	1 - 34
Coping Statements	22.15	6.19	7 - 36
Reinterpreting Pain	6.79	6.81	0 - 27
Diverting Attention	17.08	7.66	1 - 34
Praying and Hoping	19.31	8.23	2 - 35
Catastrophizing	6.22	5.87	0 - 26
Behavioral Activity	17.36	5.73	3 - 31
Ability to Control Pain	3.99	1.11	1 - 6
Ability to Decrease Pain	3.80	1.29	1 - 6

Table 8. Mean Medical Outcomes Survey Short form General Health Survey (MOS-SF) Ratings During Pre-ABMT Period (n = 83)

Items on MOS-SF	Mean	SD	Range
Total Health Status	50.30	10.67	18 - 72
Pain	4.11	1.28	1 - 6
Physical Functioning	3.80	1.68	0 - 6
Role Functioning	.79	.87	0 - 2
Social Functioning	4.73	1.44	1 - 6
Mental Health	22.10	4.52	8 - 29
Health Perception	14.66	4.98	5 - 25

Table 9. Correlation Between Pain and Selected Variables (n = 83)

	Pain (Overall Intensity)	Pain (Sensory)	Pain (Affective)	Anxiety (State)	Depression	Catastrophizing	Coping	Health Status (Total)	Physical Functioning	Role Functioning	Social Functioning	Mental Health	Health Perception	Pain
Pain (Overall (Intensity)	1													
Pain (Sensory)	.67***	1												
Pain (Affective)	.71***	-.04	1											
Anxiety) (State)	-.07	.03	-.13	1										
Depression	.02	.17	-.12	.61***	1									
Catastrophizing	.08	.22	-.09	.29**	.29**	1								
Coping	.16	-.006	.22*	-.22*	-.19	-.20	1							
Health Status (Total)	-.20	-.33**	.004	-.56**	-.73***	-.43***	.12	1						
Physical Functioning	-.16	-.24*	-.0005	-.12	-.22*	-.23*	.10	.44***	1					
Role Functioning	.03	-.19	.21*	-.18	-.33**	-.21	.23	.50***	.65***	1				
Social Functioning	-.15	-.33**	.11	-.33**	-.57***	-.30**	.17	.73***	.42***	.47***	1			
Mental Health	-.05	-.16	.08	-.66***	-.71***	-.27*	.13	.76***	.04	.17	.44***	1		
Health Perception	-.23*	-.27*	-.06	-.41***	-.54***	-.39***	.04	.85***	.23*	.30**	.49***	.49***	1	
Pain	-.16	-.28**	.04	-.09	-.32**	-.39***	.02	.57***	.40***	.37***	.59***	.20	.41***	1

*p < .05 **p < .01 ***p < .001