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The relationship of perceived and observed functional abilities in patients with chronic pain

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THE RELATIONSHIP OF PERCEIVED AND OBSERVED FUNCTIONAL ABILITIES IN PATIENTS WITH CHRONIC PAIN

A Thesis
Presented to
The Faculty of the Department of Occupational Therapy
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by
Karen L. Pickett
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ABSTRACT

THE RELATIONSHIP OF PERCEIVED AND OBSERVED FUNCTIONAL ABILITIES IN PATIENTS WITH CHRONIC PAIN

by Karen L. Pickett

This study examined and describes the relationship of perceived and observed functional abilities in a sample of patients with chronic pain. It describes changes in perception after participation in a multidisciplinary treatment program including occupational therapy. Multiple methods triangulation was used, including both quantitative and qualitative data. Tools included Visual Analogue Scales, interview, Observation Checklists, and Performance Limitations Lists completed by both subjects and therapists. Previous studies have reported results of perceived function in daily activities. This study reports observed performance in functional activities. Therapists and subjects differed in their perceptions, primarily in their identified reasons for performance limitations. Therapists identified physical, psychosocial, and energy conservation related reasons for performance limitations; subjects identified physical and environmental reasons for performance limitations. Subjects showed an increase in score for their perceptions of their abilities after participation in the treatment program.

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Chapter 1

INTRODUCTION

Purpose

The purpose of this study was to examine and describe the relationship of perceived and observed functional abilities during participation in occupational therapy as part of a multidisciplinary treatment program and describe changes in perception after participation in the treatment program in a sample of patients with chronic pain.

Statement of the Problem

Increased participation in functional activities related to life roles is a goal of any multidisciplinary treatment program for patients with chronic pain, particularly the occupational therapy portion of the program (Bettencourt, Carlstrom, Brown, Lindau & Long, 1986; Padilla & Bianchi, 1990; Sullivan, Turner & Romano, 1991). The relationship between perception of abilities and actual abilities is a key component for a patient resuming healthy occupational roles and decreasing participation in the patient or sick role. The Model of Human Occupation addresses this relationship partially through the concept of *belief in skill* which is defined as "a person's conviction that he or she has a range of important abilities" (Kielhofner & Burke, 1985, p. 16). Kielhofner and Burke stated that "only when a disabled person begins to rebuild a realistic belief in skill is a more adaptive pattern of behavior likely to emerge" (p.16). Riley, Ahern and Follick (1988) found that patients with chronic pain believe that the impact of pain on their functioning is greater than pain itself in predicting actual skills. Perceived skills are believed to contribute to the ability to participate in functional activities in daily life. There is a need to study the relationship of perceived skills and actual skills, so that any discrepancy between actual and perceived skills may be better understood and effective treatment programs may be designed. Furthermore, while the discrepancy between actual and perceived skills has been studied extensively, and the literature refers to routine daily activities or daily activity functioning, no literature was found that described the relationship of perceived and observed functional abilities examined as a result of participation in purposeful, functional activities.

Research Questions

The questions studied were:

1) How do perceived functional abilities differ from observed functional abilities in patients with chronic pain during participation in a multidisciplinary treatment program including occupational therapy?

2) How do subjects' perception of functional abilities change after participation in a multidisciplinary treatment program including occupational therapy compared with their perceptions before such participation?

3) What factors, other than pain, do subjects and therapists identify as limitations to performance of functional activities?

Definitions

The definitions generated for this study were:

Activity: Levine and Brayley (1991) define activity as "any specific action or pursuit [which] can be learned [and] involve a 'doing' process." Activity is the "most basic component of the performance hierarchy...the foundation of the doing process" (p. 600). Examples given are brushing one's teeth, cooking a hot dog, and riding a scooter board. Activities may be described as diversional, functional, gender related or culturally influenced. In this study, activity is distinct from its component performance skills (e.g., physical, cognitive, psychosocial).

Chronic Pain: Sullivan et al. (1991), quoting The International Association for the Study of Pain, defined chronic pain as "...that which persists beyond the normal time of healing...the most convenient point of division between acute and chronic pain [is three months]" (p.194). In this study, this is the definition of chronic pain used. Patients with chronic pain were first identified as such by the referring physician.

Factors limiting performance: This is defined as any reason that makes the performance of a functional activity difficult or impossible in the perception of the subject or therapist. These may include fatigue, motivation, depression, concentration, unrealistic standards of performance, family stress, contractures or other deformity, endurance or other physical, psychosocial or cognitive reasons. For this study, subjects and therapists completed separate performance limitations forms listing the reasons which made the activity difficult (Appendix A).

Functional activities: Functional activities are those in which a person engages during the course of daily living which are necessary for participation in life roles. They may be categorized as "work-related, self-care, leisure, social and recreational" (Levine & Brayley, 1991, p. 602). In this study, subjects chose the functional activities they found important to address during treatment, with a predetermined list to help define activity but not limit choices (Appendix B).

Multidisciplinary Treatment Program: This includes an individual and group program of interventions from the following disciplines: psychiatry, nursing, physical therapy, occupational therapy, social work, psychology, and special consultation from orthopedics, neurology, and pain specialists as ordered. The team has regular meetings with and without the patient to review and revise the treatment plan.

Observed functional abilities: According to the American Heritage Dictionary (Boyer, Ellis, Harris, & Soukhanov, 1989) ability is "the power to do something; skill" (p. 1). Observed functional abilities are the therapists' observations of the subjects' power to perform daily life activities related to life roles. They include observations of physical, psychosocial, cognitive or environmental components of performance and requires activity analysis to observe these components. The data describing observed functional abilities were gathered through an Observation Checklist used during the performance of functional activities (Appendix C), the therapist-generated list of performance limitations, and observations of performance during the initial interview.

Occupational therapy intervention: In this study, occupational therapy intervention included individual and group instruction in relaxation techniques, energy conservation, body mechanics and work simplification/activity adaptation before and in the context of functional activities, communication skills training, and work or leisure activity exploration.

Perceived functional abilities: According to the American Heritage Dictionary (Boyer et al., 1989) perceive means "to become aware of through the senses" (p. 508). Perceived functional abilities are defined in this study as the subjects' observations of their power to perform daily life activities related to life roles. This construct includes aspects of the Model of Human Occupation's volitional subsystem described by Kielhofner and Burke (1985), especially belief in skill, belief in efficacy of skill, and expectancy of success, discussed elsewhere in this paper.

In this study, data describing perceived functional abilities were gathered by the initial interview (Appendix D), the Visual Analogue Scale for functional activities (Appendix E), statements noted by the therapist observing performance of activities, and a list of performance limitations generated by the subject.

Purposeful activities: Kielhofner (1985) described humans as open systems and stated that purposefulness is an attribute of open systems, meaning that "they act in response to inner goals" (p. 7). Fidler and Fidler (1978) contrasted purposeful activity to random activity, and stated that the goals of purposeful activity are to test a skill, clarify a relationship or create a product. Purposeful activities are those that are directed by meaningful goals for the person engaging in them. In this study, purposeful activity is incorporated into treatment through the subjects' choice of activity goals on the Visual Analogue Scales (See Appendixes B and E).

Assumptions

It is assumed in this study that, at some level, subjects wanted to return to purposeful, functional activity in their lives. It is also assumed that the nature of purposeful, functional activity is inherently different from the components of activity. Functional activity is composed of at least sensorimotor, psychosocial, and cognitive components. For example, sitting, standing, or range of motion are sensorimotor components allowing one to cook, crochet or get dressed to go to work. These activities relate to a person's life roles, daily routines, his/her values and his/her motivation, and are performed within his/her environment (American Occupational Therapy Association, 1994).

Additionally, it was assumed that most subjects who were asked to participate would do so and that they would cooperate with procedures, and that such procedures would yield useful information so that something could be learned about subjects with chronic pain.

Limitations

Several limitations are recognized. First, scoring of observed performance is difficult to compare to perceived performance because no measurement tools could be found with reliability and validity across subjects and therapists. Comparing qualitative themes did allow for description of the differences, however.

Second, while this study examines perception of abilities before and after treatment, it is not possible using this study design to determine the effects of each part of the multidisciplinary treatment program, e.g. the specific effect of the occupational therapy program on outcomes.

Third, although the study uses functional activities, the choice of functional activities was limited because of the hospital setting. Also, the activities used were performed outside of the social environment in which they are usually performed. However, every effort was made to reproduce the environment and activity characteristics for each subject.

Finally, the results of this study cannot be generalized to a larger population because of a limited, non-randomized sample. However, information was gained to suggest characteristics of the population and areas for further study.

Significance of the Study

The significance of this study lies in the observation of functional activity with both quantitative and qualitative methods to better understand the relationship of perceived and observed functional abilities, the changes in perceived functioning after a multidisciplinary treatment program and the limitations identified by patients and therapists.

If patients with chronic pain are to return to purposeful, meaningful activity in their communities, their level of functioning must be understood and improved, including their perception of their functioning (Gage, Noh, Polatajko, & Kaspar, 1994; Gallagher et al., 1989; Kielhofner & Burke, 1985; Riley et al., 1988). Occupational therapists have long assessed and treated functional deficits, including sensorimotor, cognitive and psychosocial components of such deficits, which are all relevant for the chronic pain population. Yet, the occupational therapy literature does not reflect research into functional deficits utilizing functional activities with this population. Literature outside the field of occupational therapy has especially emphasized the importance of function in this population, but has only described functional deficit components or self-report without observation of performance of functional activities (Follick, Ahern, & Laser-Wolston, 1984; Riley et al., 1988; Romano et al., 1988). An occupational therapy perspective focuses on functioning in a whole sense, in the activities that are meaningful to the patient and include consideration of sensorimotor, cognitive and psychosocial components.

That there is a difference in perception between patients and health care professionals about the patient's abilities and that this difference is important for outcomes of treatment has been established (Gage et al., 1994; Romano et al., 1988; White & Strong, 1992). However, the nature of this difference in the context of purposeful, functional activities and the change of perceptions with treatment has not been adequately studied. Yet, theoretical descriptions of occupational therapy in general and specifically with this population emphasize addressing purposeful, functional activities (Christiansen, 1991; Padilla & Bianchi, 1990; Gusich, 1984).

This study incorporates structured observation of whole functional activities, as well as interview and quantitative measurement of subject perceptions to examine perceived versus observed functioning, changes in perceived function, and limitations to functioning. Information to improve understanding about the relationship of perceived versus observed functioning of patients with chronic pain can assist in facilitating a person's return to meaningful productive participation in the community and contribute to the literature in this area.

Chapter 2

LITERATURE REVIEW

Chronic pain is distinguished from acute pain by its duration and relationship to expected healing time after injury. Sullivan et al. (1991), quoting The International Association for the Study of Pain, defined chronic pain as "...that which persists beyond the normal time of healing...the most convenient point of division between acute and chronic pain [is three months]" (p.194). Pain that becomes chronic must be treated differently than acute pain, moving from a curative model to a rehabilitative model. It is recognized by many in the field of chronic pain rehabilitation that it is not only a biological problem but a psychosocial problem as well (Fordyce, 1988; Sullivan et al., 1991; Trief, Elliott, Stein, & Frederickson, 1987). The dichotomization of pain that is created by viewing the symptoms as either somatogenic or psychogenic is "clinically counterproductive" (Sullivan et al., 1991). In addition, it is necessary to address behavior associated with chronic pain as well as each of its biopsychosocial aspects. Fordyce (1988) emphasized this concept regarding failed back syndrome by stating, "Chronic pain should always be seen, in some substantial part, as a problem of what people say or do; not simply as a symptom of some underlying neurophysiological, emotional, or motivational problem...Proper patient management calls for both disease model and learning model concepts" (p. 31). Trief et al. found that patients with psychogenic pain and patients with organic pain scored similarly on measures of anxiety, depression and social alienation. Therefore, they suggest approaching all patients with pain problems in light of current stressors and coping strategies.

Occupational therapy has traditionally viewed the human being as a whole entity through the use of purposeful activity in evaluation and therapy. "The mind and body cannot be separated when dealing with human beings. In occupational therapy, this concept is crucial to high quality intervention" (Levine & Brayley, 1991, p. 600). Occupational therapists do this by using purposeful activity and focusing on performance of activities of daily living for the individual's environment, which is consistent with the biopsychosocial approach in much of the literature.

Much of the literature supports the observation that patients with chronic pain frequently perform differently than they report they are able to perform in various activities. The literature reviewed is clear in indicating the need to assess the patient with chronic pain using a variety of measures, relying on both self-report and observation (Egan & Katon, 1987; Keefe & Dolan, 1986; Romano et al., 1988; Smith, Follick, Ahern, & Adams, 1986). In addition, there has been concern in the literature with the impact of pain on function, further emphasizing the importance of a variety of measures to the chronic pain treatment team (Brooks, Jordan, Divine, Smith, & Neelon, 1990; Fordyce, 1988; Mooney, 1988).

Several additional concepts related to perception of abilities and function with regard to pain are covered in the literature, including illness behavior, pain behavior, and cognitive distortions (Keefe, Crisson, Maltbie, Bradley & Gil, 1986; Romano et al., 1988). These each describe aspects of the patients' responses to illness or pain, reflecting their beliefs about their illness or pain and the impact on daily functioning. A description of the reviewed studies incorporating these concepts follows. Although several studies have utilized physical or psychological components of functional activities as indicators of function, no study incorporated actual observation or scoring of purposeful, functional activities in the definition or study of function in patients with chronic pain.

Patient Beliefs About Function

Many studies have dealt with an apparent discrepancy between what patients with chronic pain say versus what they do. What patients with chronic pain say about their function may not reflect what they demonstrate, as several studies point out. However, what they believe about their abilities is important for their functioning, as indicated by Gage et al. (1994) who used a tool, adapted from the Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gibson, 1981), to measure self-efficacy with specific tasks in occupational therapy in patients with a variety of chronic conditions, including but not limited to pain. The definition of self-efficacy used was by Bandura, Cioffi, Taylor, and Brouillard (1988) as "beliefs in one's capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands" (p. 479). Gage et al. found that perceived self-efficacy with specific tasks was a major determinant of actual performance of those tasks outside the clinic. They emphasized the need for therapists to be aware that the patient's ability to perform an activity in the absence of belief in ability is not sufficient to improve occupational performance. Further they described previous research which showed a high correlation of task specific measurement of self-efficacy to actual performance as opposed to global measures of self-efficacy (Bandura, 1977; Wang & RiCharde, 1988).

Riley et al. (1988) found that the role of chronic pain patients' beliefs about the impact of pain on their functioning is greater in predicting their demonstrated skill than their pain reports are in predicting the same. "Hence, it appears that the belief that pain necessarily implies disability is associated with actual impairment, independent of the actual contribution of reported pain" (p. 581). The Riley et al. study defines actual impairment as measured *partial movements* (less than normal range of motion), and *limitation statements* (frequency of statements related to disability during the performance of these motions). The studies by Gage et al. (1994) and Riley et al. highlight the importance of belief about skills in determining actual performance. However, do beliefs about skill tend to be higher, lower or the same as observed performance?

White and Strong (1992) compared self-report of up-time (amount of time spent standing, walking, or out of bed) with an automated electromechanical measure of up-time in hospitalized patients with low back pain. Patients were asked to keep an activity diary of the estimated time that they spent standing, lying, walking, and sitting. During the same period, patients wore an electromechanical device to measure the same motions. The study showed that patients with chronic pain in this pain clinic reported significantly lower levels of up-time than was objectively measured by the electromechanical device. Apparently, the subjects' beliefs about their skill was lower than their actual skill in this study. Previously, Sanders (1983) had found the same results using comparison of up-time measured by patients versus electromechanical device. In the studies by White and Strong and Riley et al. (1988), function is measured by specific movements. Neither study directly studied performance in functional activities.

In contrast to studies by Sanders (1983) and White and Strong (1992), Follick et al. (1984) found that the use of an activity diary was a valid and reliable method for assessment of daily activity patterns in a population of pain clinic outpatients. Self-report of up-time and down-time correlated significantly with spouse reports of the same. Self-reported down-time correlated with electromechanical measurement of the same. This is the only study found that supports the use of self-report measures. The patient population studied was outpatient, which may account for the difference in findings. MacRae and Riley (1990) describe differences between hospital and home environments and suggest that the hospital environment may contribute to increased pain because of anxiety, lack of environmental control, and unfamiliar surroundings. Perhaps this difference also contributes to patients' perception of their abilities, thereby accounting for differences in studies. Another difference between studies is the use of spouses as objective measurement. The spouse may have perceptions which are closer to that of the patient than that of the clinician.

Smith et al. (1986) found that cognitive distortions, defined as "illogical inferences or conclusions based on the information given" (p. 204), contributed to impaired functioning. Specifically, the cognitive distortion of over-generalization correlated with scores on the Sickness Impact Profile (Bergner et al., 1981). Smith et al. found that this cognitive error is most consistently correlated with disability. They proposed that if patients with chronic pain generalized disability in one area of function to other areas of function, they would likely decrease their activity level. These patients may also generalize disability over time, thereby maintaining disability and affecting self-efficacy expectations. "The resulting decreases in functional behavior are likely to confirm patients' lowered expectations and distorted cognitive style, thereby initiating a self-exacerbating cycle" (Smith et al., 1986, p. 209). Again, the measures of function were solely self-reported. In fact, since the measure of function was a questionnaire, it could be argued that it was a repeat measure of cognitive distortion applied to the subject of functional activities. Nevertheless, it appears that cognitive distortion may play an important role in the patients beliefs or perceptions about their function.

Illness and Pain Behaviors and Function

Keefe et al. (1986) studied the relationship of illness behavior to pain behavior and pain ratings during routine daily activities. These authors defined illness behavior as defined by Mechanic (cited in Keefe et al., 1986) as "the different ways that patients perceive, evaluate, and act upon their symptoms." Pain behavior was defined according to a definition by Fordyce (cited in Keefe et al., 1986) as behavior that communicates to others that pain is being experienced. These may include guarded movement, verbal complaints, decreased activity, facial expressions and body posturing. This comparison showed a significant relationship between self-reported illness behaviors and observed pain behaviors, including decreased activity levels which may mean decreased functional ability, but this is not specified. The patients' evaluations of their own symptoms on a questionnaire predicted their pain behaviors in routine daily activities. Routine daily activities were defined as sitting, standing, walking, and reclining for specified periods of time. This study did not describe the resulting performance effects of illness or pain behavior during functional, purposeful activities.

Romano et al. (1988) included observation as well as self-report in a study of pain behaviors (defined as guarding, bracing, rubbing, grimacing and sighing) and the relationship of these pain behaviors to pain ratings and functional disability. They found that observed pain behaviors correlated significantly with self-reported pain ratings, pain behaviors and physical disability, but not psychosocial disability. There was a decrease in observed pain behaviors after multidisciplinary inpatient treatment, and this decrease was strongly associated with decreased depression. Although this study incorporated structured observation as an evaluation tool, disability was measured by patient self-report.

Egan and Katon (1987) studied responses to illness in patients with chronic pain and in healthy adults. The severely impaired patients with chronic pain were most likely to report that they had gone to great efforts to maintain their health, yet did not report significantly more health related activities (increased rest, change of diet, over the counter medications, talk to friends, etc.) compared with the mildly impaired or normal populations. The severely impaired patients with pain did report more visits to the doctor than the other populations. In this case, self-report of the level of effort to maintain health was greater than self-report of actual health related activities. Again, the conclusion that self-report is different than actual behavior surfaces, though all information in the study by Egan and Katon was self-reported. Furthermore, the Egan and

Katon study was primarily focused on health related activities, not necessarily other types of activities of daily living.

Keefe and Dolan (1986) compared coping strategies in chronic low back pain patients (LBP) and myofascial pain dysfunction syndrome patients (MPD). LBP patients reported more variety of coping strategies, yet scored poorly on measures of function (activity diary used to report time spent in various positions throughout the day). The LBP patients reported they were coping better than they actually were, according to the pain diary. Not accounted for in this study was the fact that the activity diary was limited to movements, not functional activities, and that the diary was a self-reported measure. Though this study was about specific coping behaviors, like the Egan and Katon (1987) study, the patients overestimated what they actually had done in response to illness. This appears to be in contrast with White and Strong (1992) who showed that patients underestimate their abilities, however, the contrast is between illness behaviors (activities done in response to illness) versus other daily activities. It appears that patients with chronic pain may understate what daily activities they are able to do, but overstate what they have done to take care of their health in response to illness.

Occupational Therapy Intervention

In addition to the study by White and Strong (1992), Bisson (1987) studied activity levels in relation to pain and found, using a pain questionnaire and activity diary, that the patients with increased activity levels showed decreased pain perception. Garg and Walberg (1990) evaluated the relationship of specific therapeutic art activities to the perception of pain. They found that a positive relationship existed between engagement in the provided activities and the reduction of perceived pain for three out of six subjects. The authors recommended that further research utilize activities of interest for each subject instead of predetermined art activities.

Heck (1988), although studying acute, not chronic, pain, incorporated purposefulness of tasks into a study of pain tolerance. He compared pain tolerance of subjects involved in non-purposeful tasks versus pain tolerance of the same subjects involved in purposeful tasks. Both were paper and pencil tasks, one with goal orientation and problems to be solved, the other repetitive. The subjects tolerated painful stimulus significantly longer when involved in a purposeful task versus a non-purposeful task. Although these results may not be possible to generalize to a chronic pain population, they suggest the importance of studying purposeful tasks in order to obtain a more accurate measure of the impact of pain on overall function, or the impact of involvement in a purposeful, functional task on pain.

Other occupational therapy literature has covered descriptions of specific treatment methods to alleviate or manage pain (McCormack, 1988, 1990; Pavek & Daily, 1990; Southam & Cummings, 1990), description of work simulation programs (Bettencourt et al., 1986), description of the role of occupational therapy as a part of a multidisciplinary treatment program (Giles & Allen, 1986; Weinstein, 1990), and the application of occupational therapy theoretical models to chronic pain (Gusich, 1984; Padilla & Bianchi, 1990).

Occupational therapy research has primarily focused on the measurement of activity components or the use of activity or other methods to reduce pain. Occupational therapy program and theory descriptions in relation to chronic pain have emphasized the occupational therapist's role in enabling patients to function in their daily activities, managing pain and adapting to performance demands. As pain reduction has not been a primary emphasis in the general literature reviewed, rather the management of pain for functioning, more research is needed regarding improving the performance of daily functional activities in patients with chronic pain. This includes the need for improved understanding of patients' performance and perceptions of performance in the context of functional activities and measurement of the same.

The Model of Human Occupation

The Model of Human Occupation (Kielhofner, 1985) can provide a useful and thorough guide for the occupational therapist to understand the problems of patients with chronic pain, identifying subsystems which contribute to performance of daily activities (volition, habituation, performance). This model was used as a frame of reference for the conducting and analysis of this study.

In this model, the human is described as an open system interacting with and acting upon the environment. This open system has three hierarchical subsystems which contribute to the motivation, organization, and performance of occupation. The volition subsystem motivates the choice of occupational behavior. The habituation subsystem organizes occupational behavior into roles and habits. The performance subsystem enables the performance of activities through specific skills (Kielhofner & Burke, 1985). This approach addresses both physical and psychosocial aspects of disability through focusing on occupational dysfunction, thereby not dichotomizing the origin of symptoms. Padilla and Bianchi (1990) and Gusich (1984) have described the impact of chronic pain on the subsystems outlined in the Model of Human Occupation. Specifically, the impact on the volitional subsystem involves decreased sense of control in the environment, followed by decreasing activity in an attempt to regain control. Further, the chronic pain sufferer begins to doubt whether he or she has any useful skills (Padilla & Bianchi, 1990). According to this model, "adaptive persons recognize which skills they perform exceptionally well, adequately and poorly" (Kielhofner & Burke, 1985, pp. 16-17). But people with chronic pain often have distorted views of their abilities, according to the literature reviewed. Therefore, it is important to further understand this apparent discrepancy between actual skills and perception of skills, particularly as it may impact evaluation and treatment in occupational therapy.

Critique and Summary

The medical and psychological literature has emphasized a biopsychosocial approach to the treatment of chronic pain and a concern with function in daily activities. The studies reviewed have described the role of self-report, beliefs about function, measurement of up-time, cognitive distortions, illness behaviors and pain behaviors in the functioning of the patient with chronic pain. The medical and psychological literature has defined and measured function by some component of function, according to the definitions in the current study. Terms such as activity, routine daily activity, and functional disability are not defined as they are in the occupational therapy literature. Perhaps for the ease of measurement these terms are defined in terms of activity components, such as certain movements or thought patterns. However, "activities are influenced by psychosocial, physical, cognitive, sensory, and perceptual functioning, as well as environmental factors. The psychosocial component is very important and includes motivation, upon which every thing else is dependent." (Levine & Brayley, 1991, p. 608). That purposeful activity (occupation) is useful for assessment and therapeutic intervention has been a basic premise of the profession of occupational therapy since its beginning, one of the reasons being the multidimensional nature of occupation as noted (Levine & Brayley, 1991). To study one component of activities only is to overlook this multidimensional aspect of activities, and therefore study only a portion of actual functioning.

In the studies described, there is clearly a lack of instruments which measure function objectively, yet function has been emphasized as a major concern for all disciplines involved with chronic pain treatment. Some instruments measure specific activities, but rely solely on self-report. Others utilize systematic observation, but only observed component movements (walking, sitting, standing) or pain behaviors (rubbing, grimacing, bracing). Observation of a functional activity incorporates other elements of function than physical components and adds information to the patient's self-report of function. The Model of Human Occupation (Kielhofner & Burke, 1985) has been suggested as a useful guide for occupational therapists to address these aspects of treatment for patients with chronic pain.

Chapter 3

DESIGN AND METHODOLOGY

In order to answer the research questions, methodological triangulation was used. Triangulation is defined as the "use of multiple methods to study the same problem" (Polkinghorne, 1983, p. 253). Methodological triangulation is distinct from theoretical, data, or investigator triangulation in that a variety of tools is used in gathering the data, and the tools may be of different types (Polkinghorne, 1983). Methods triangulated in this study, included interview, a measurement scale, and observation of performance that yielded both quantitative and qualitative data.

The questions addressed in this study were:

1) How do perceived functional abilities differ from observed functional abilities in patients with chronic pain during participation in a multidisciplinary treatment program including occupational therapy?

2) How do subjects' perception of functional abilities change after participation in a multidisciplinary treatment program including occupational therapy compared with their perceptions before such participation?

3) What factors, other than pain, do subjects and therapists identify as limitations to performance of functional activities?

Subjects were selected from the Inpatient Behavioral Medicine Unit at Stanford University Hospital. Selection criteria included: patients diagnosed with chronic pain, between the ages of 20 and 70, with no progressive degenerative disease as their primary admitting diagnosis. Patients with affective disorders were allowed into the selection, but patients with a thought disorder, active psychosis, or dementia were excluded. Patients must have entered treatment for chronic pain willingly, and those who stated that they were not in treatment willingly were excluded. Patients also were required to have occupational therapy services ordered by their physician in order to have the option to participate in the study. Potential subjects were excluded from the study if they were unable or unwilling to participate, or if they were in the hospital for a three day evaluation only.

Methodology

According to Polkinghorne (1983), "...the very nature of the subject matter of human science suggests the value of combining the results of several systems of inquiry in order to gain a fuller understanding of topics under investigation" (p. 254). Also, the American Occupational Therapy Foundation (undated) supports the modified use of both quantitative and qualitative methods, considering the complexity of the study of human functional performance.

In order to address the questions about abilities, perceptions of abilities and limitations to performance, any one method alone would have been inadequate. A strictly quantitative method using standard tests may have measured the therapist's perception of performance, but would not have measured the subject's perception of performance in this sample size. In addition, the literature searched indicated a lack of standard tools for measurement of activity performance, except for those measuring performance of self-care activities (Convery, Minteer, Amiel, & Connett, 1977; Jette & Deniston, 1978; Wade & Collin, 1988), which would have been too limited a scope of activities for the purposes of this study. Interview alone would have addressed the subjects' perception of performance, but without therapist observation of performance, the comparison of perceptions would not have been possible. Therefore, the methods used were visual analogue scale measurements, interview, and observation of performance. "By using all of the information gained from the different procedures, the researcher can learn more than he can learn from any one procedure alone" (Polkinghorne,1983, pp. 252-3). Therefore, quantitative (the Visual Analogue Scale and Observation Checklist) and qualitative (interview, the Performance Limitations Lists, and portions of the Observation Checklist) methods were used.

Quantitative Methodology

Quantitative methods in this study were used to report subjects perceptions about their abilities and measure change in the same, with specific activities (Visual Analogue Scales, Appendix E) and to measure some of the observations made by therapists (Observation Checklist, Appendix C). The number of subjects did not yield sufficient data to calculate statistical significance, however, adequate data to report averages was generated. Trends can be revealed and the study can serve as a pilot for the tools used, particularly the Visual Analogue Scale.

Reliability and validity have been established in many previous studies using the Visual Analogue Scale. "For the most part, investigators have deemed the [Visual Analogue Scale] to be a reliable and valid measurement tool" (Wewers & Lowe, 1990, p. 230). However, it is recognized that for broader use and statistically significant data, reliability and validity should be established for the particular use of the Visual Analogue Scale (Lee & Kieckhefer, 1989). This was beyond the scope of this study.

The Observation Checklist (Appendix C), was developed based on the clinical experience of the principal investigator and the research questions. The checklist was used to quantify some of the observations made by the therapist, to make recording observations easier, and to ensure that when different therapists observed they were observing the same aspects of performance. When used by other therapists in the course of the study, those therapists were individually trained by the principal investigator.

Qualitative Methodology

Qualitative methods added descriptive information and depth to the quantitative measures. Qualitative tools used were the initial interview, which was audio taped, parts of the Observation Checklist, and the Performance Limitations Lists.

Merrill (1985) described the lack of qualitative studies in occupational therapy, and also described a fit between the values in occupational therapy and those in qualitative research. Kielhofner (1982b) identified similarities between qualitative research and occupational therapy: "Both focus on the realities of everyday life. Both appreciate the deep richness of mundane affairs. And both attempt to gear their techniques to the realities of the people involved" (p. 162). The realities of everyday life and the richness of mundane affairs were sought in this study to add depth to the understanding of the perceptions of patients with chronic pain, and those of the therapists involved with them.

With qualitative methods, reliability and validity are achieved during and after the gathering of data. This is in contrast to quantitative methods, which must have established such assurances prior to the gathering of data. Kielhofner (1982a) identifies three important processes to ensure validity of data gathered with qualitative methods: (a) the role of the participant-observer in accessing relevant everyday meanings, rationales and actions of the subjects, (b) the fit between the situation and the methods in use, and (c) documentation of methods (p. 73).

According to Kielhofner (1982a), the role of the participant-observer has been questioned in the past, particularly with respect to bias that may be created by active participation with subjects being studied. On the contrary, Kielhofner has argued that such participation actually is necessary for optimal reliability and validity. This will increase awareness of bias which may be present. In this study, the principal investigator was the primary therapist for all subjects involved, and prior to data collection, a technique called "bracketing" was used to recognize and set aside biases which may have influenced interpretation of the data prematurely. Originally defined by Husserl (1907/1964) and later described by MacRae (1993), bracketing involves "a conscious attempt on the part of the interviewer to achieve a pre-theoretical state. It does not mean denying or suppressing one's beliefs; just the opposite. Bracketing can be successfully accomplished when theoretical bias is purposely brought to consciousness, acknowledged and then temporarily set aside" (MacRae, 1993).

Secondly, Kielhofner (1982a) stated that the application of methods that fit the situation enhances reliability and validity. For example, an interview for a colleague would be different in nature than an interview with a retarded adult client. The methods for this study, interview and rating scales, are consistent with a patient unit which has goals of behavioral change, and in fact such methods are a part of everyday experience for patients on this unit.

Thirdly, the handling of the data themselves are an important aspect of reliability and validity for qualitative research. Kielhofner (1982a) has recommended that notes regarding the research process be kept. In this study, notes were kept during collection and analysis of the data. Also, the data were well documented, using the forms described and audio-taping and professional transcription of interviews. During analysis, tapes were listened to 2-3 times and transcription checked against the tapes. The data were studied thoroughly before interpretations were made.

Instruments

Visual Analogue Scale

A visual analogue scale is a vertical or horizontal line of any length, with distinct anchor points at the ends, used for subjects to rate some subjective phenomenon. The most reliable and valid visual analogue scales have been 10 centimeter, horizontal lines (Wewers & Lowe, 1990).

The Visual Analogue Scale was used to provide a quantitative measure of the subjects' perceptions of their ability to perform certain chosen activities before and after participation in a multidisciplinary treatment program. Visual analogue scales are objective, valid, and reliable means to measure subjective phenomena, such as pain or mood. They have been used to measure these as well as anxiety, alertness, cigarette cravings, sleep quality, and other clinical symptoms (Wewers & Lowe, 1990). Padilla et al. (1983) used a visual analogue scale for measurement of quality of life factors in cancer patients. These factors included measurement of physical condition (pain, nausea, strength, appetite), ability to perform important human activities (work, household tasks, sexual activity), and general quality of life (hobbies, feeling useful, worry about medical costs). The study by Padilla et al. is the only one found in this literature search which uses the visual analogue scale for categories related to performance of functional activities.

It is clear that chronic pain impairs occupational functioning in the areas of self-care, work and leisure as well as social relationships. Assessment of the extent of functional impairment is difficult because of the noted problems with self-report by patients with chronic pain and availability of adequate rating scales, especially for activities related to work and leisure. The use of a visual analogue scale allowed the researcher to examine perception of function in activities which were unique to the subject and chosen by the subject, while using a reliable tool to do so (Wewers & Lowe, 1990).

Observation Checklist and Performance Limitations Lists

Observation was used throughout the research process, particularly and most systematically during the subject's performance of activities in therapy. Tools used were the Observation Checklist and Performance Limitations Lists.

The Observation Checklist, developed specifically for this study, was used to guide the researcher in specific observations to be made with each subject (Appendix C). The Observation Checklist delineates areas that are typically observed in a treatment session, including cognitive, physical and psychosocial skills as well as pain complaints and use of energy conserving strategies. Next to the categories are columns to check within normal limits (WNL), cues given, or training needed. Original study procedures were to include performance of the first activity to be observed without intervention by the therapist; however, the time constraints in the hospital and desire to not withhold treatment made it necessary to include treatment in the form of cues and training as soon as the need was noted.

With regard to the Model of Human Occupation, observations on the Observation Checklist related to the performance (e.g., problem solving, planning, strength, range of motion), habituation (e.g., activity organization, role relatedness), and volitional (e.g., standards for performance, meaningfulness of activity) subsystems are included.

In addition to the Observation Checklist completed by the therapist, the subject and therapist listed performance limitations after the performance of each activity, using their respective Performance Limitations Forms (Appendix A). Subjects and therapists did this separately, so as not to influence each other. There was one primary therapist, the principal investigator, who worked with all subjects; however, other therapists also contributed to the data.

Interview Format

Interview was used throughout the study before, during, and after the performance of activities in the course of therapy. Only the initial interview, however, was systematically recorded and analyzed. The interview format was considered unscheduled and standardized (Jones, p. 142-50, 1985), meaning the interviewer utilized an a list of interview questions (standardized), yet allowed for rewording of questions or different questions to fit the subject or situation (unscheduled). This format is in contrast to a scheduled standardized interview which requires consistent question presentation, wording and sequence. The interviews were all conducted by the principal investigator, who was the primary treating occupational therapist. According to Polkinghorne (1983), "The face-to-face encounter provides the richest data source for the human science researcher seeking to understand human structures of experience. This interaction takes place in the context of a relationship. The more comfortable and trusting a person feels with the researcher, the more open and giving he or she will be concerning his or her own experiences" (p. 267).

The initial interview, during the initial assessment, yielded information such as the subjects' life roles, typical day prior to admission, pain description, mobility status, cognitive and psychosocial skills, values and rehabilitation goals (Appendix D). Initial questions were developed and adapted from the Assessment of Occupational Functioning Screening Instrument (Watts, Kielhofner, Bauer, Gregory, & Valentine, 1986) and the Occupational Case Analysis Interview and Rating Scale (Kaplan & Kielhofner, 1989). Subsequent interviewing focused on perception of abilities during and after performance of chosen activities (Appendix D), and responses were recorded on the Observation Checklist (Appendix C).

Procedures

Initial verbal contact with subjects who met the criteria for entrance to the study included the following explanation by the principal investigator:

> I am one of the occupational therapists on this unit, and your doctor has asked me to see you. Have you had occupational therapy before? [pause for answer] In occupational therapy we are

> concerned with one's ability to function in every day life activities, including work, leisure, and self-care activities. Before we proceed with the usual evaluation and treatment, I would like to ask if you are interested in taking part in a research study which is seeking to understand the experience of people with chronic pain better, specifically in how they see their abilities. Whether you choose to participate in this study or not will not change your occupational therapy treatment, but it would involve me asking you more questions about your experience and having you complete two additional short rating scales, which may or may not usually be done. Would you like more information?

Prior to study participation and after initial verbal agreement, the occupational therapist issued the consent form (Appendix F), a list of functional activities (Appendix B), and the first Visual Analogue Scale (Appendix E). An appointment for the initial interview was arranged.

The initial meeting consisted of an interview and observational assessment (Appendix D) that yielded information such as the subject's life roles, typical day prior to admission, pain description, mobility status and rehabilitation goals. This initial interview was no different than usual occupational therapy evaluation in this setting and was completed by the principal investigator, the primary therapist in all cases. Considering the subject's statements and performance in the initial interview, the therapist developed treatment addressing the problems. The therapist and the subject collaborated in developing a plan to address treatment concerns in the context of at least one of the activities listed by the subject on the Visual Analogue Scale. During or after performance of each activity, the therapist intervened to provide cues and training as necessary. The therapist and subject then completed their respective Performance Limitations Lists (Appendix A) simultaneously but in separate locations. Some subjects completed only one activity in treatment, others three, depending on need and length of stay.

At the time of discharge, the subject was again asked to rate his/her perception of function in all three activities on a second Visual Analogue Scale (Appendix E). Throughout the study, the therapist asked the subject questions to gather information related to the research questions (Appendix D).

The initial interview was audio taped for the most accurate transcription. The tapes and other documentation were secured separate from any identifying information, accessible only to the principal investigator.

Three registered occupational therapists, including the principal investigator, and one occupational therapy intern were involved in the data gathering process. The initial contact and instructions, initial interview and treatment plan were completed by the principal investigator. The other therapists completed Observation Checklists and Performance Limitations Lists for a few of the activities performed by subjects. These therapists were trained to use the forms in a meeting with the principal investigator.

In summary, subjects were asked to rate their ability in functional activities which had been a part of their life at some time prior to hospitalization, participate in interviewing about their perceptions of their performance, perform one to three of these activities in the hospital as a part of usual occupational therapy intervention, list performance limitations, and rate their abilities again at the time of discharge.

Data Analysis

Visual Analogue Scale

Wewers and Lowe (1990) described methods of statistical analysis for the Visual Analogue Scale, including parametric and non-parametric procedures. Parametric procedures require data to be continuous and include the calculation of means, standard deviation, T-ratio among other procedures. Non-parametric procedures treat the data as categorical and include chi square among other procedures. Both are used to determine statistical significance, and Maxwell (cited in Wewers & Lowe, 1990) stated that "generally it makes little difference whether parametric or non-parametric tests are used to analyze visual analogue scale data" (p. 233). Both are most accurate and meaningful with samples larger than the sample in this study. While statistical tests such as the t-test or chi square were not used, the data were treated as continuous, then as categorical and results are described accordingly.

The Visual Analogue Scales completed by subjects were compiled on a list according to subject number, activities chosen, initial and final scores in centimeters from the left anchor point, and the difference between initial and final scores. Activities were studied for what types of activities subjects chose to rate, and those activities that were done in therapy were noted. Scores on the Visual Analogue Scales were first treated as continuous data, allowing the calculation of averages. But because of the small sample no further parametric statistics were performed. Average initial and final scores for all subjects together were calculated. The average difference in scores for each subject was also calculated. Second, the data were treated as categorical and all initial and final scores were put into the categories of below or above the half way point on the Visual Analogue Scale. Again, because of the small sample size, no further non-parametric statistics were calculated.

Observation Checklist and Performance Limitations Forms

Observations were recorded on the Observation Checklist and the Performance Limitations List by the therapist. These were organized into categories. The Observation Checklist had predetermined categories which served to organize the data, but the Performance Limitations List data was used to develop its own organizing system. Responses in each category were counted, described and compared and summarized.

Interview

Tesch (1990) identified that there are at least 26 different methods of analyzing qualitative data, some more defined than others, and most adapted in some way by the specific researcher. The methods used here are best described as descriptive interpretational analysis as opposed to theory-building interpretational analysis as described by Tesch. These methods involve the identification of themes through the categorization of data followed by interpretation in order to better understand the phenomena being studied, particularly in light of the research questions and current theories related to the research questions. "When concentrating on description the categories are used to discover the commonalities across cases, or the constituents of a phenomenon" (Tesch, 1990, p. 114).

In addition to Tesch's (1990) described method, concepts from Giorgi's (1985) phenomenological methodology were used. Both describe steps to be taken for data organization and analysis, and these steps were studied, outlined and combined to create the following procedure which was followed to organize and analyze the data.

1) The audio tapes were listened to by the principal investigator and compared with transcription in order to gain a "sense of the whole" (Giorgi, 1985, p. 10; Tesch, 1990, p. 142) and to assure correct transcription.

2) Meaning units were determined by dividing the text at each topic switch.

3) Meaning units were clustered into themes and each theme given a code. This created the organizing system for the remainder of data analysis (Tesch, 1990). An organizing system allows for more effective data management and understanding, and "the data themselves remain the most suitable and the richest source for the development of an organizing system" (Tesch, 1990, p. 142)

4) The data were coded according to themes, and documents of each theme with relevant sections from interviews were developed.

5) Each category of themes was summarized according to the data contributed to that theme by the subject interviews.

6) Themes were prioritized according to relevance to the research questions and studied, referring back to the original interviews as needed.

Chapter 4

DATA AND RESULTS

In order to answer the questions, several instruments were used, some of which helped to address more than one question. The instruments offered both quantitative and qualitative data. They included the Visual Analogue Scale, the Observation Checklist, and the Performance Limitations Lists for subjects and therapists, and interview. The data are presented here according to each subject's information from each instrument. Then the data yielded by each instrument are presented. Results are presented to answer each question.

Subject Data

Twelve subjects from the Inpatient Behavioral Medicine Unit at Stanford University Hospital were presented with the opportunity to participate in the study. Five subjects were subsequently eliminated from the study because of insufficient data gathered or the subject having left before treatment could be provided. All seven subjects who continued in the study reported back pain as one area of pain. Five subjects had a work related injury that precipitated their back pain. The other two had back pain from arthritis and costochondritis. Other areas of pain were present as well for several subjects.

Length of hospitalization ranged from 4 to 78 days, the average being 18 days. However, six of the seven subjects stayed less than 17 days. Subjects were started in the occupational therapy program within two days of admission and completed the final paperwork for the study on the day before or the day of discharge from the hospital.

Subject 1

Subject 1, a 49 year old married male, lives with his wife and college age daughter. He has been trained as a licensed vocational nurse but stopped working in 1980 because of drug abuse. Since then he has worked as a security guard and an attendant for a quadriplegic, the latter position ending in 1992. At the time of admission he was spending most of his time at home while his wife worked full time. This subject was admitted for pain management due to his chronic low back pain, which resulted from a 1978 injury while digging, then a reinjury while working as a nurse lifting a patient. He was admitted with pain disorder associated with psychological factors, dysthymic disorder, generalized anxiety disorder, and myofascial pain syndrome. The treatment team's goals for hospitalization were detoxification from pain medications through a methadone taper and teaching other pain management techniques. In the past he had tried trigger point injections, epidural steroids, traction, physical therapy, and massage without relief.

Subject 1 was hospitalized for 17 days. Prior to admission he spent a typical day waking early because of pain, taking pain medication, watching television, reading, caring for his dogs, transporting his wife to work, shopping occasionally and on weekends visiting his mother. During the initial interview he identified several activities which he was able to do including dressing, grooming, personal hygiene, shower transfers, cooking, cleaning, and yardwork. In the same interview, Subject 1 identified several activities he found difficult and the reasons he found them difficult including cooking (because it was hard to think of things to make), driving (low sitting tolerance), home repair (pain, not enough help available), tying shoes (back pain), and getting on and off the bed (back pain). His participation in the difficult activities varied. Methods of adaptation for difficult activities included changing positions, buying a new bed, doing lighter wood projects or, in his words, "just get by." Activities that Subject 1 identified as unable to do were reaching for pots and pans ("can't bend and reach"), painting the house (reaching and climbing difficult), and doing heavy carpentry work (equipment too heavy).

Subject 1 identified his hospital goals as: a) to find ways of coping with pain and b) to participate in a good treatment program, as he was not pleased with a previous program. He expressed a desire to be "self-supporting" within a year and to be able to contribute something to his family. "I want to do my part with my wife and my family, you know, taking care of things. I just want to...contribute to it." When asked about more specific vocational and leisure goals, he identified being a counselor and "something with my wife", respectively. Then, he stated that he couldn't work unless his blood pressure was controlled, and there wasn't enough time to participate in leisure with his wife. Later, when asked about the likelihood of reaching his goals, he stated "I'm going to do it. If it's not here, I'll find someplace else...even though I don't seem to finish things, I'm not a quitter."

For participation in the occupational therapy program, Subject 1 chose yardwork, sitting in a classroom, and painting as activities to rate on the Visual Analogue Scale. Initial ratings for all three activities on the Visual Analogue Scale were below the halfway point. All final ratings were above the halfway point, with an average difference of 5.4 centimeters between final and initial ratings, indicating an overall increase in the subject's rating of his abilities by the end of his hospitalization.

Subject 1 displayed mixed perceptions of his abilities with at least two activities, cooking and yardwork. In the interview, cooking and yardwork were identified as activities he was able to do. But he also stated that cooking was difficult, and he identified yardwork on the Visual Analogue Scale as an activity he wanted to be able to do again and rated his ability below "completely able."

Based on the initial interview, observations, and the subject's activity choices on the Visual Analogue Scale, the treatment plan included body mechanics, energy conservation, and relaxation training with application to the chosen activities. Sitting in a classroom was addressed in the context of participation in an occupational therapy group and yardwork was set up in the unit garden during individual treatment. Observations made by the therapist during the initial interview and listed on the Observation Checklist during subsequent performance of a yardwork activity indicated a need for cues about proper body mechanics and energy conservation measures, difficulty taking rest breaks once involved in an activity, and the subject's verbalization of mixed messages about the importance of the activity.

On the Performance Limitations List the subject identified improper clothing and wet soil as limitations after the yardwork activity was performed. The therapist identified performance limitations of decreased pacing, poor body mechanics, and improper clothing due to the subject not asking his wife to bring proper clothing as was planned.

Assessment of these data indicate that although Subject 1 verbalized motivation and confidence about returning to specific activities, these reports were mixed and he readily identified external barriers to performance that he believed were out of his control. Furthermore, there were clear differences between the subject's perceptions and the therapist's perceptions at the beginning of treatment, especially related to reasons for performance difficulties. However, despite the perceived barriers, this subject indicated a perception of increased abilities as reported on the Visual Analogue Scale ratings at the end of the treatment program.

Subject 2

Subject 2, a 32 year old married mother of four children, had previously worked as a physical therapist and was pursuing a Ph.D. in biomedical engineering. She was admitted after noticing some memory problems associated with her current pain medication, which was prescribed for chronic neck, shoulder, back and knee pain which she had had for ten years. In addition, she was having some syncopal episodes resulting in falls that increased her shoulder pain. The treatment team's goals for hospitalization were detoxification from all pain medications and teaching non-pharmacological methods of pain management. The subject identified her goal for the hospitalization as "to adjust my lifestyle." She was admitted with the following diagnoses: rule out psychological factors affecting physical condition, rule out dysthymia, history of lupus (self-report), status post moving vehicle accident in September 1993, rule out arthritis, myofascial neck pain, bleeding ulcers. In the past she was treated for the pain with physical therapy including heat packs and ultra sound, with little success. The patient explained that, prior to admission, housework was taking twice as long as it had previously. She was having difficulty lifting things and walking up stairs, and had begun to use a cane. Until May 1994, six months prior to this hospital admission, she had two part time jobs, went to school, and cleaned house meticulously, reportedly because of her children's asthma.

Subject 2 was hospitalized for six days. In the initial interview she gave a detailed description of a typical day and week prior to this hospitalization, including specific times at which each activity took place. She emphasized the necessity of routines for her children. She described her day starting at 5:45 in the morning and listed many activities she does for her children including, making their meals, driving them to school, giving them baths, helping them with homework, playing with them and cleaning the house very thoroughly because of their asthma. Cleaning included daily or twice daily dusting and vacuuming and weekly "deep cleaning" including closet reorganization and scrubbing windows, screens, walls and floors. Subject 2 stated that her self-care activities, including showering and dressing, helped her to move easier later in the day. She also listed taking medication as an activity occurring at least twice a day. She noted that she does get time for herself, occasionally in the evening and some Sundays. In these times she "does nothing."

Activities she described being able to do were her basic hygiene, grooming and dressing needs, cooking, cleaning and driving. She noted that some of these increased her pain. She described playing with children, lifting children, and keeping her balance as difficult activities. Her reasons for difficulty were mobility and her knee "giving out," and she attributed the latter partially to the habit of working on her knees. Methods of adaptation included holding her children in her lap, using a cane, and getting help from her husband. Her primary method of attempting to adapt was to perform activities despite the pain and only take rest breaks at the end of the day or week. Regarding this latter method of adaptation she stated, "It's a matter of saying [no] to the pain, until it just gets unbearable."

Subject 2 identified her hospital goal as increasing mobility. In a few months she wanted to be "getting ready for Christmas." Work related goals included returning to school full time to complete her degree in Biomedical Engineering. She identified leisure goals as sky jumping, motorcycle racing, and woodwork, which she had not pursued recently because her husband did not want her to and the activities "are not very 'motherly' to do." With regard to the likelihood of her reaching her goals in general, she stated, "Oh, I'm going to do them. It just depends on the time frame. Instead of taking maybe three years, it might take five or six years, but I -- it will be accomplished."

Subject 2 chose long walks, child care (bathing and dressing children, specifically), and manual crafts to rate on the Visual Analogue Scale. Initial ratings were all below the halfway point. Final ratings on all three activities at the time of discharge were above the halfway point, with an average difference of 4.8 centimeters between initial and final ratings.

Based on interview, initial observations, and activity choices on the Visual Analogue Scale, the treatment plan was developed and included practicing energy conservation techniques with household and child care tasks, relaxation training, and problem solving about expectations and standards for performance of tasks. Therapist observations during the initial interview and performance of simulated bathing of children, recorded on the Observation Checklist, included the need for cues for proper body mechanics and positioning, training to use energy conservation techniques, and that the subject had very high standards of performance for activities.

On the Performance Limitations List, after the performance of simulated bathing of a child, the subject attributed difficulties in performance to difficulty bending, reaching, and lifting. The therapist listed endurance, body mechanics, physical weight limiting mobility, and unrealistic standards of performance coupled with reluctance to seek help for tasks. Limited shoulder range of motion was noted, but did not interfere with the tasks addressed.

Some differences in perception between the subject and the therapist were evident during treatment. These differences were related to reasons for performance limitations. The subject and therapist agreed on physical reasons for limitations, but the therapist also identified psychosocial reasons that were not independently identified by the subject. Completion of many tasks to an extremely high standard was clearly important to this subject and was not negotiable because of her perception of children's health needs. The standard had reportedly come from a physician but had not been confirmed by a physician during this hospitalization. This standard was unrealistic and ultimately limited her performance in the assessment of the therapist, but she believed it was her physical state which was the limitation.

Although Subject 2 expressed confidence in future goal attainment, she rated her abilities in some activities more closely to "completely unable" than "completely able" on the Visual Analogue Scale. However, this subject showed perceptions of improved abilities on the Visual Analogue Scale by the end of hospitalization.

Subject 3

Subject 3, a 43 year old divorced mother of one son, lives with her partner who also has one son. Until May of 1994, the subject had worked as a ranch worker. At that time she fell and injured her back and had not worked since, although she described some activities in the home. She was admitted with the following diagnoses: major depression, chronic pain syndrome, L4-L5 spondylolisthesis, history of knee arthroscopic surgery in 1988, and history of polydrug abuse. The treatment team's hospital goals were to taper her off of pain medications, decide if surgery is indicated, and teach pain management skills.

Subject 3 was hospitalized for eight days. A typical day's activities at home prior to hospitalization included doing personal care activities, watching TV, carrying out some household chores such as cleaning the bathroom, doing the laundry, and making the bed. Activities outside the home included driving her and her partner's sons to school if she felt well enough, walking to the post office occasionally, and going to psychotherapy or recovery groups. On weekends, she would rest, walk, and occasionally go camping. The last camping trip occurred about one month prior to hospitalization. She stated that sometimes during the week or weekend she would paint, write poetry, care for her bird, and read about homeopathic medicine, but recently she seldom participated in these. Activities she identified as those she was able to perform were driving (though it increased her pain), housework (though it took more time than it did previously), money management, bathing and dressing with the help of adaptive equipment, and basic in-home mobility. In the same interview Subject 3 identified driving, cleaning the bathroom, managing money, tying shoes, dressing, and getting into the tub as activities which were difficult to perform. Reasons for difficulty stated in the interview were the type of vehicle she had to drive (too high and standard transmission), and increased pain. Her primary methods of adaptation were driving a different car, the use of special equipment (reacher, dressing stick, hospital bed, reclining chair, and special cushions), changing how the activity is performed or the time frame in which it is completed, asking for help, and changing positions.

Subject 3 identified her hospital goals as: a) to know her capabilities especially related to work and leisure tasks, b) to learn pain management skills, and c) to be able to talk to doctors more effectively. Her ideal vocational goals were to work full time as a ranch worker again, but she thought that working three-fourths time may be more realistic. Leisure goals included camping and traveling more and having increased recreation time with her son. She saw her leisure goals as more long term than work goals. Regarding the likelihood of reaching her goals Subject 3 stated, "Well, I'm pretty persistent and I work pretty hard, and I believe that I'm going to be able to go back and do some of my work, but I also know that I'm going to have limitations. I know that I will never be able to lift a railroad tie on my shoulder with [my partner] you know, and walk...I know that I'll have to compensate. I believe that I can still actually probably do 80 percent of the work."

Subject 3 chose using hand tools, yardwork, and camping (setting up tent, walking and sleeping on uneven ground) to rate on the Visual Analogue Scale. Initial ratings for all three activities were below the halfway point. All the activities were rated higher at discharge, but only the ratings for using hand tools and doing yardwork were above the halfway point. The average difference in ratings from initial to final was 2.8 centimeters.

Based on the initial interview, observations and activity choices on the Visual Analogue Scale, the treatment plan included further evaluation of equipment needs for self-care to consider use of less equipment, instruction in positioning and body mechanics training with activity, relaxation training with focus on coordination of breathing with activity, assertiveness training, and allowing the subject opportunities to explore abilities with the activities chosen. A driving evaluation as an outpatient was discussed. As noted on the Observation Checklist, during performance of a wood working task using hand tools, the subject was observed to need occasional cues for positioning and techniques for pacing the activity. The subject was goal-directed, organized and showed realistic expectations during the activity, which was wood carving. The subject stated, "I don't have to be perfect--that's what I like about it... I can do a good job...I love this activity." She readily identified this activity as one of the only ones left related to her role as a hobbyist, and she found meaning in it by making a gift for her partner who had helped her so much. The subject demonstrated no pain behaviors during engagement in the activity, but was rubbing her buttocks and leg during ambulation to and from the room where the activity was performed.

The subject identified only time as a performance limitation, and the therapist identified time (cut short by a schedule conflict) and the need for positioning cues as performance limitations.

Subject 3 presented mixed perceptions about her abilities. While she listed several activities she felt able to do and was hopeful about future performance, she described at length the adaptations she has had to make to perform most activities during a typical day, including the use of many pieces of special equipment and long rest breaks. These adaptations, aimed at pain relief, may have limited the amount of actual activity in which the subject was able to participate in a day. Observations of her actual performance showed fewer pain behaviors during involvement in purposeful, meaningful activity than when not engaged in such activity.

There was agreement between subject and therapist on some external factors in performance such as time and the use of a different car, but the therapist identified additional physical and psychosocial areas to address in treatment such as positioning and exploring decreasing the use of equipment. The subject clearly thought that she could perform many illness-related activities she listed, but was more limited in activities related to other roles, which the therapist thought she could perform. However, this subject described confidence in future goal attainment and showed an overall perception of increased abilities on the Visual Analogue Scale by the end of the treatment program.

Subject 4

Subject 4, a 52 year old divorced mother of two grown children, lives with her partner of eight years. She was admitted for evaluation and treatment of her chronic pain syndrome. She had had chronic pain of both shoulders and hands (left greater than right), left hip and knee, and back (from work injury 15-20 years ago). She had last worked in 1985 and had experience in factory assembly work, ranch and landscaping work, and planning and scheduling work. She had been disabled since 1985 after a near fatal suicide attempt which resulted in respiratory and cardiac arrest and subsequent gangrene and amputation of three fingers on her right hand in 1985, with revision of the amputation for pain control in 1994. She learned compensatory techniques and left hand dominance after her amputations, but now was experiencing pain in the opposite upper extremity, likely due to overuse. The hospital team's goals were detoxification from pain medications and teaching non-pharmacological pain management skills. Admitting diagnoses included: pain disorder associated with psychological factors, major depression, rule out chronic dysthymic disorder, rule out post traumatic stress disorder, chronic pain syndrome, history of pulmonary edema, deep venous thrombosis, and alcohol and cocaine use.

Subject 4 stayed in the hospital for nine days. She began her description of a typical day prior to hospitalization by stating,

> Well, on a weekday, I did a lot -- I needed a lot of sleep since I had that last surgery in April. So on a weekday I've been -- I wake up maybe at 11:00 or 11:30 in the morning and of course... if I have an appointment or I'm awakened, then I can pull myself together and if I have to get up, I can. Then in the afternoon I take a longer nap... [After getting up] I have something to eat so I can take my medicine. And -- this sounds awful, but I kind of have to sit down and rest after I've had something to eat and my medicine before I go get dressed or anything.

Other daily or semi-daily activities included self-care, embroidery, gardening, seeing friends, talking with her sons, going to the theater where one of her sons performs, and cooking with her partner. Subject 4 described embroidery, walking, gardening, tub transfers, dressing, and dusting as activities she was able to perform. Upon further questioning, she stated that sitting in the theater, driving and getting in and out of the shower were difficult for her, and as a result she had been walking more places and asking her partner for help in the shower because of feeling "wobbly." She went to the theater despite increased pain because it was very important to her. Other activities which were difficult for Subject 4 were vacuuming, dusting under heavy objects, and changing a bed ("just can't do it..I could if I forced myself"), and she wanted to be able to do more household chores to help her partner who worked full time and had taken on many of the household tasks. Methods of adaptation included changing positions, decreasing travel distances by foot or car, asking for help, buying precut vegetables to help with cooking, using adaptive equipment such as a cutting board with nails, changing the environment for easier access to supplies, and taking a bath instead of a shower. About these adaptations, this subject stated "need is the mother of invention...I just was craving to do something with my hands."

When asked about her hospital goals, Subject 4 described being in the process of redefining her goals from pain relief to pain management as she has been talking to members of the treatment team. "I would like to be doing at least what I have been doing with less pain, and maybe more -- you know, eventually more but I would like to do at least what I have been doing." Specifically, she identified more household activities, more leisure walking on the beach, more social activity, and some volunteer work. "I'd like to do something to -- I will do something to, you know, keep in the world, you know, get me involved in people and things, but I don't think I can make any commitment on a regular -- you know, what you can call work." She described reaching her goals as "doable."

Subject 4 chose yardwork, changing a bed, and manual crafts as activities to rate on the Visual Analogue Scale, and all of the ratings were below the halfway point on the scale. All three activities were performed as a part of therapy. Final ratings were all above the halfway point, each at 9.8 centimeters from the left anchor point. This represents an average increase of 7.6 centimeters on the 10 centimeter line.

The treatment plan for Subject 4 included exploring ways to use both upper extremities during functional activities such as the ones she identified on the Visual Analogue Scale, learning relaxation and energy conservation techniques, and reviewing proper body mechanics in the context of activities.

During performance of a yardwork activity, it was noted by the therapist that the subject needed cues for planning and problem solving as well as one for safety with tool use because of the unfamiliar environment. Cues and training for body mechanics were required, and diminished hip strength was noted. The subject complained of pain with the activity and spoke of the value of the activity being diminished by having to take rest breaks and to be aware of positioning. The same cues were required for participation in manual crafts, except for the safety cue. Participation in bed making required a few positioning recommendations. Pain was noted because of the metal frame which is unique to the hospital bed. The subject participated in discussion about the meaning and role relatedness of each activity, specifically her roles as homemaker and hobbyist.

For the yardwork activity, Subject 4 and the therapist both identified limited strength, pain and decreased use of energy conservation as limitations to performance. The subject added the external factor of cold weather, and the therapist added the psychosocial impact of having to take breaks before she was invested in the activity. For the manual craft activity, the subject and therapist both identified physical and external/environmental limitations to performance, but the subject added pain as a limiting factor. For the bed making activity, both subject and therapist identified limiting factors as the decreased use of energy conservation and external/environmental factors such as the metal bed frame. The subject added the difficulty with changing old habits as a limitation.

Subject 4 maintained independent participation in most self-care and some leisure activities, and she maintained the desire for additional purposeful activities. She presented a mixed perception of some activities, stating that she was able to do them but they were also difficult, and she sometimes needed help. In some activities she indeed needed assistance, according to the therapist. In addition, some routine activities may have changed in their meaning, such as eating in order to take medications or having to force herself to get up because of appointments.

There was agreement as to the type of performance limitations although the specifics were sometimes different. When identified limitations were different, the subject identified pain or external limitations out of her control and the therapist identified psychosocial and energy conservation limitations. However, this subject was able to identify some psychosocial limitations as well. Also, she expressed confidence about future goal attainment and at the end of treatment increased her rating of her abilities on the Visual Analogue Scale.

Subject 5

Subject 5, a 66 year old, twice married father of two grown children and retired entrepreneur/business man, had sold his successful company prior to his hospital admission. He has been active in civic and social life associated with museums and politics. He was admitted to a local hospital after a fall thought to be secondary to neuropathy, use of pain medications and alcohol. He was discharged and then admitted to Stanford for pain control and evaluation of his depression and chronic pain. He had cervical spondylosis, a pulmonary embolus (treated), history of multiple orthopedic surgeries of foot and knee (and used a cane for mobility), and major depression. The hospital team's goals for Subject 5 were detoxification from pain medications, pain management, and adaptation to long term disability.

Subject 5 was in the hospital for 78 days. He described his typical day prior to hospitalization as follows: get up, go see his psychiatrist, go home and go back to bed, go to see his psychiatrist again in the afternoon sometimes, return home and have dinner with his wife or go out to dinner, his wife would go to the opera some nights and he would stay at home though he had gone with her at previous times, and sometimes he would get together with a friend. He contrasted this with a typical day prior to his illness which included an early morning meeting (7:30 or 8:00), go to the office, out to lunch with colleagues, traveling, and numerous evening and weekend civic and social activities. His wife was responsible for running the home with her personal secretary, and they had a private cook and chauffeur. He identified being able to get himself in and out of a tub or shower independently, but did not list any other activities he felt he was able to do. He identified getting dressed as a difficult activity, half because of motivation and half because of being slowed by arthritis. "[Before this disability, I'd] come flying home and change my clothes in 15 minutes -- take a bath, change my clothes and go out to the museum." He had been interested in cooking in the past, but had no interest at the time of interview. Rather, he wanted to get back into activities which were "99% mental," rather than physical activities. Yet when barriers to "mental activity" such as business meetings or museum work were explored, he stated he could not because of mobility. Alternatives for increasing independent mobility were explored, including a motorized scooter or increased use of his chauffeur, but he refused such suggestions. Subject 5 was unable to describe any attempt he had made at adaptation to be able to do the activities he stated he wanted to do again. He also rejected attempts to assist him with adapting his lifestyle. Such attempts included a meeting with a hospital volunteer who had a motorized scooter that had greatly increased her independence and walks around the hospital viewing and discussing the artwork. During these sessions, Subject 5 showed decreased pain behaviors and held pleasant, positive conversation, but afterward was unable to plan to incorporate such activity into his lifestyle.

Subject 5 had the hospital goal of eliminating his depression and resuming all of his activities as before. His long term goals were to resume his activities like "before" some unspecified time. The likelihood of success in meeting his goals he stated was "1%."

Subject 5 rated personal care, social activities or "working the room" and business/civic work on the Visual Analogue Scale. The latter two activities were rated below the halfway point initially, and further below the halfway point at the time of discharge. Personal care was rated above the halfway point initially and further above it at the time of discharge. The overall average difference between initial and final ratings was - 0.4 centimeters, indicating an overall decrease in perception of abilities. Because of the long hospitalization, and possible imminent discharge, a mid-hospitalization measure on the Visual Analogue Scale was taken on all three activities. When the middle measures are compared with the final measures there is an overall increase in perception between two weeks prior to discharge and actual discharge.

In observing a dressing activity during the initial interview, it was observed that Subject 5 moved quickly and did not pace his level of activity, readily acknowledging that his prior lifestyle involved a rapid pace. Although he identified personal care as an activity on the Visual Analogue Scale, when this was addressed in treatment, he explained that he did not want to be "bothered with such minutia." The treatment plan then focused on his being able to "work the room" and be involved in business and civic activities in individual and group sessions. "Working the room" involved maneuvering around a room full of people, with a drink in one hand, and initiating conversations. He demonstrated good body mechanics and ability to manage a glass of water in one hand while walking around obstacles and initiating conversation in an individual session. In a later group session requiring the same skills in an actual group of people, he adapted by sitting most of the time and calling to others. As endurance was identified as a problem by the therapist, the use of a scooter or wheelchair was explored in later sessions, but rejected by the subject. He continued to state that he could not "work the room," with or without a wheelchair.

Both Subject 5 and the therapist identified mobility as a performance limitation, but the therapist noted that physical adaptations and assertiveness skills were could be used to enable performance. Both subject and therapist identified psychosocial performance limitations; the therapist listed self-perception and the subject listed depression, limited "thinking and scheming skills", a waning sense of humor, and not having active goals. In addition, the therapist identified lack of use of energy conservation strategies as a performance limitation.

Although some of the same performance limitations were identified, Subject 5 and the therapist clearly had differing perceptions of his abilities and of the possibility for adaptation. The various suggestions and even practice with specific adaptations were not sufficient for this subject to plan for the application of such adaptations to his lifestyle and resuming activities that were apparently important to him. Although he described valuing his prior lifestyle very highly, his standards for current performance of the activities associated with his previous lifestyle could not include anything that was different from the way those activities had been performed previously. By the end of hospitalization his final Visual Analogue Scale ratings showed perception of decrease in ability in the activities at which therapy sessions were aimed to assist him with adaptions. He had made it clear that he did not want to be "bothered with such minutia" as adaptations to personal care activities, and apparently he could not "be bothered" with adaptations to "working the room" or business or civic work either.

Subject 6

Subject 6, a 34 year old divorced, unemployed female receives disability compensation. She had sustained a back injury, including fracture of T7 and T8 vertebra and subsequent fusion of T6-10 and placement of Harrington rods in 1982. She subsequently reinjured her back in 1994. She was admitted for chronic pain and depression. The patient had become suicidal prior to admission, but denied such ideation during her hospitalization. She had worked as a nightclub singer, and prior to that was employed in computer and secretarial work. She also served in the United States Air Force. The initial back injury occurred from a fall from a balcony while in the Air Force stationed in another country. The goal of hospitalization was to detoxify from pain medications and teach non-pharmacological management of her pain.

Subject 6 was hospitalized for seven days. She described a typical day prior to hospitalization as including: doing yoga and stretching first thing in the morning for pain; taking pain medication and if that didn't work, walking for pain; doing dishes; lying down; going to aquatic therapy; playing guitar a little; reading about chronic pain, yoga or visualization; and watching television. On the weekend she described not doing as much. Subject 6 identified taking the bus, driving, aquatic therapy, showering, grooming, dressing, and in-home functional transfers as activities she was able to do. Upon later questioning, she described showering, grooming, dressing, driving, housework, cooking and bicycling activities as difficult. She explained that if she showered, groomed, and dressed in the same day, that would be all that she could do for the day because of the pain. She stated that driving was difficult because of limited neck range of motion, which was not tested. She tearfully identified interest in surfing and experience with other physical activities and inability to do them now. Methods of adaptation included using a taxi or asking friends for rides, asking for help with household tasks, writing to her congressman for additional funds to get more help, adding shock absorbers to her bicycle seat, and watching surfing rather than doing it.

Short term goals identified by Subject 6 were: a) to learn more ways to distract from pain and b) to be able to do yoga for two hours a day. She described ideas she has had for longer term goals including getting into an independent living skills/vocational training program, becoming a music therapist or doing volunteer work, returning to mountain biking and becoming more physically active in general. She stated that she felt she "could do anything" with regard to confidence in herself, but also that she needed to "take one day at a time...I don't know how I'm going to feel each day when I wake up. Some days I have good days and some days are bad. So I really don't think about the future much."

Subject 6 rated shaving her legs, cooking, and working with computers on the Visual Analogue Scale. Both initial and final ratings were below the halfway point on the scale, but all three final scores were higher than the initial scores. The average difference between initial and final scores was 2.3 centimeters.

The treatment plan was to teach energy conservation techniques and positioning with the activities identified on the Visual Analogue Scale. This was done and observed with shaving her legs. The subject needed cuing for problem solving and safety, body mechanics, and taking short rest breaks while shaving her legs in the shower.

On the performance limitations forms, the subject listed positioning and having to bend because of no seat in the shower. The therapist identified the same factors on the Observation Checklist and added on the Performance Limitations List that the subject did not "think through" body mechanics options thoroughly and had questionable motivation to perform the activity independently.

Subject 6 described mixed perceptions of abilities, stating several activities that she was able to do but were also difficult and describing the inability to predict day to day performance. She was able to identify several future goals and described having confidence in herself, but the inability to predict day to day performance and the presence of many activities for pain control, which appear to have given structure to her day, may have been limiting factors in her progress toward stated goals. However, she did show an overall increase in her perceptions as reported on the Visual Analogue Scale but not above the halfway point.

Subject 7

Subject 7, a 35 year old married father of two children, has received disability compensation for the previous two years. He was admitted for chronic low back and left leg pain which he has had since 1986. He worked from 1987 to 1991 after retraining from assembly work in printed circuits to computer technician work through vocational rehabilitation, but has been unable to work since 1992. Admitting diagnoses included: psychological factors affecting physical condition, lumbar laminectomy with fusion in 1993, obesity, and chronic obstructive pulmonary disease. The hospital team's goals were to decrease medication use and increase pain management skills.

Subject 7 stayed in the hospital for 4 days. Prior to hospitalization, he spent a typical day waking up with pain, "lying around," going for a walk at noon, watching television, playing computer games, making the bed, and sometimes doing some vacuuming or laundry. On the weekend he would perform the same activities and go with his wife to do the grocery shopping but was only able to push the cart. He stated that he was able to do these activities, but later listed bed making, vacuuming, and laundry on the Visual Analogue Scale to be able to do again. In the interview, he identified getting on and off the toilet, fishing and watching his son play football as difficult activities because of leg weakness and low sitting tolerance. He has adapted with toilet transfers by using one leg to get up and down. Other techniques were discussed with him for this task. For household activities he has asked for help, except for bed making which he would start doing while he was still in bed. He was observed to be able to do this activity with adequate body mechanics. He had not been fishing in three years, but regarding his child's ball games he stated "I'll do anything for my kids."

Regarding his goals for hospitalization, Subject 7 said he didn't know. "My only goal right now is, you know, living day by day and just taking it day by day and I'll worry about it as it comes." He did state that he might like to help out around the house more, but that it didn't really matter to his family. " The situation at home is satisfying. I mean I always ask my wife, I go, you know -- I always talk to her about it, you know, and she always says, '...don't worry, things are fine'." He stated he would like to fish again, and someday win the lottery. The likelihood of reaching these goals was "Hah, the lottery, the odds are too high. Fishing's got better odds than that, I mean -- I'd say good...I'll probably go out there and force myself to stay out there, you know. All I want is [to catch] just one fish and then I can go home."

Initially, Subject 7 rated only bed making, vacuuming and laundry on the Visual Analogue Scale, but later the importance of fishing again became evident, so an additional rating was completed. The initial rating for bed making was above the halfway point, but the other activity ratings were below halfway. All final ratings were above the halfway point and higher than the initial ratings, and the average difference was 2.7 centimeters.

The two activities chosen for participation in therapy and observation by the therapist were bed making and simulated fishing. Techniques for vacuuming were discussed briefly, but performance was not observed because of his short hospitalization. The subject demonstrated adequate body mechanics for both bed making and simulated fishing, but he needed cues for energy conservation and coordinating breathing with activity. Simulated fishing was done with a real fishing pole in an outdoor area with open space. Together the subject and therapist participated in problem solving about the barriers to fishing, while casting the line toward targets on the grass. The subject needed cues to use energy conserving techniques such as resting before fatigue or pain and using a chair. He was receptive to such ideas. During the activity he related the importance of the activity to his being a father to his son and was reminded that fishing for him was "relaxing, peaceful and fun" and he was able to find humor in the simulation. Afterward he stated, "I think maybe I can do this now."

For the bed making and simulated fishing activities, the subject identified difficulty bending, reaching, lifting, low sitting and standing tolerance as performance limitations on the Performance Limitations List. For the bed making activity, the therapist identified poor coordination of breathing, a low bed, and difficulty bending as performance limitations. However, it was noted by the therapist that the subject was able to use appropriate movements in place of bending to accomplish making the bed. The therapist identified poor knowledge of energy conservation strategies as a performance limitation for the simulated fishing activity.

Subject 7 gave mixed reports of his abilities, and in general participated in very few activities on a daily basis. He initially was non-committal about future goals, but later was more positive in his statements about his abilities and future activity possibilities. There was agreement about some physical limitations to performance, but although the therapist noted additional energy conservation reasons, the therapist thought that the subject overcame physical limitations adequately. There was an overall perception of increased abilities as reported on the Visual Analogue Scale.

Instrument Data

Visual Analogue Scale

The Visual Analogue Scale was used to measure the subjects' perception of their abilities in three chosen activities prior to the initial interview and at the end of participation in the multidisciplinary treatment program (Appendix E). In one case an intermediate measure was taken because of a prolonged hospital stay and possible imminent discharge, which did not occur until two weeks later. A final measure was taken at actual discharge. All measurements were recorded, but it is the difference between initial and final scores which were calculated into the average difference. Another subject was allowed an additional activity to rate because of the importance of this activity for focus in the occupational therapy program. This was not discovered until after the initial three activities were chosen. A total of 22 activities were rated by the seven subjects. Results from the Visual Analogue Scales are compiled in Table 1.

The measurements in Table 1 represent the distance in centimeters of the subjects' mark from the left anchor point, completely unable, toward the right anchor point, completely able, on the 10 centimeter Visual Analogue Scale. The difference measurements indicate the difference between the position of the mark at discharge minus the mark at admission, indicating the amount of change in self-rating for each activity. A positive number for the difference indicates an increase in the rating of subjects' perceived level of ability by self-assessment. The total average difference among subjects is 3.6, a 36% increase in perception of ability. The range of average difference measurements

Table 1

Visual Analogue Scale Measurements: Distance from Left Anchor Point

Subject #	Activity	Initial		Final	Difference
1	Yardwork*	1.8cm		7.1cm	5.3cm
	Sitting in classroom*	2.6		8.6	6.0
	Painting	4.5		9.6	5.1 (Avg.=5.4)
2	Long walks	0.3		6.2	5.9
	Child care*	3.4		7.2	3.8
	Manual Crafts*	2.4		7.2	4.8 (Avg.=4.8)
3	Use hand tools*	2.1		5.3	3.2
	Yardwork	2.2		5.2	3.0
	Camping	2.1		4.3	2.2 (Avg.=2.8)
4	Yardwork*	1.8		9.8	8.0
	Changing a bed*	2.4		9.8	7.4
	Manual Crafts*	2.5		9.8	7.3 (Avg.=7.6)
5	Personal care	5.8	4.7	8.7	2.9(Final - Initial)
	Social/Work the room*	4.5	0.6	1.2	-3.3
	Business/Civic work*	2.3	0.5	1.5	-0.8 (Avg.=-0.4)
6	Shave my legs*	1.3		4.4	3.1
	Cook meals	0.6		4.5	3.9
	Work with computers	2.3		2.1	-0.2 (Avg.=2.3)
7	Making bed*	6.0		7.6	1.6
	Vacuuming	4.7		6.6	1.9
	Laundry	2.7		5.2	2.5
	Fishing*	2.0		6.9	4.9 (Avg.=2.7)
	Total	60.3		138.8	78.5
	Average	**2.7**		**6.3**	**3.6**

Note. Asterisk (*) indicates activities that were done during OT sessions.

for subjects is -0.4 to 7.6 centimeters. Statistical significance was not calculated because of the small sample size, but some observations were made.

Activities were chosen based on having been performed in the past and the presence of desire to be able to return to them in the future. Subjects chose a variety of activities to rate on the Visual Analogue Scale including self-care, household, leisure, and work-related activities which included school and parenting. Overall, out of 22 activities, 2 activities could be classified as self-care, 6 as household, 7 as leisure, and 7 as work. Few chose the same activities, and in some cases they chose the same activity for different purposes. For example, Subjects 1, 3 and 4 all chose yardwork, but Subjects 1 and 4 chose it as a leisure activity while subject three chose it as a potential work activity. Similarly, Subjects 2 and 4 both chose manual crafts, but for Subject 2 it was related to a caretaking role as parent, and for Subject 4 it was a solitary leisure activity.

One subject stood out from the rest. Subject 5 is the only one who indicated a perception of decreased abilities with two activities when initial and final measurements were compared. However, comparison of middle and final measurements showed an increase for all three activities.

Among the other subjects, most activities were rated higher at the final rating than the initial rating, whether the activity was done in therapy or not. However, the subject with the highest average difference in Visual Analogue Scale measurements is the one who participated in all three activities in occupational therapy during her hospitalization. The subjects with the next highest average difference participated in two of the chosen activities.Tests for statistical significance were not applied here because of the sample size, but the results suggested additional areas for study. Further study could explore the effects of doing the actual activities in therapy on overall outcomes.

During analysis the Visual Analogue Scale was divided in half and subjects' ratings for all 22 activities were placed in either the completely unable (less than 5 centimeters from the left anchor point) or completely able (greater than 5 centimeters from the left anchor point) categories (see Appendix E). Twenty of the 22 activities were rated in the completely unable category at the initial rating, and 16 of the 22 activities were rated in the completely able category at the final rating (see Table 2). This method of analysis also shows a perception of increased abilities for all subjects.

Observation Checklist

The Observation Checklist (Appendix C) was used during the subjects' performance of an activity from the activities chosen for the Visual Analogue Scale. The Observation Checklist allowed observations of performance to be recorded systematically, documenting observations, subject statements, and treatment that was provided. Items on the checklist formed five categories: cognitive skills, physical skills, energy conservation/ pacing skills, psychosocial issues, and pain related issues. Observations for ten activities were recorded for the seven subjects. Compilations of scores were achieved for the two subjects whom were observed in more than one activity, e.g., if one subject's checklist was marked by the therapist as needing cues in body mechanics for more than one activity, only one check was entered in the results for that subject.

Table 2

Categorization of Visual Analogue Scale Ratings as Completely Able or Completely Unable

	Completely Unable	Completely Able
Initial ratings	20 activities	2 activities
Final ratings	6 activities	16 activities

Observation of cognitive skills (planning and problem solving, organization, following directions, safety judgment) showed that subjects generally performed within normal limits (WNL) for the activities performed. Two subjects showed poor planning, problem solving or safety judgment problems, but these were isolated events, observed once in one activity for each subject. Of 30 checks made in the cognitive area 25 were in the WNL column and 5 were in the cues given column.

In the area of physical strength, range of motion, and body mechanics, subjects showed strength and range of motion that were within normal limits for the activities performed, except for two instances of self-reported decreased strength, and one instance of observed decreased range of motion. Subjects were observed to need more cues for body mechanics than training for strength or range of motion. Sixteen of 17 checks for cues needed in the physical category were for body mechanics. Also, 12 of 23 checks in the WNL column were for body mechanics; however, only 2 subjects had no noted problems with body mechanics. Most needed cuing or training in body mechanics.

With regard to the pacing and energy conservation items that included breathing with activity, rushing vs. pacing activity, rest breaks, and other energy conservation techniques, 22 of the 29 marks in this area were in the cues given or needs training columns. Notes added to this area included that subjects tended to rush through activity, take no or few short rest breaks, hold their breath with parts of activity, and complain of fatigue.

In the psychosocial area that included standards for performance, verbalizations about ability/inability, meaningfulness of activity, and role relatedness, there were fewer marks than in the other areas but more notes were written on the side. The marks that were made were in the WNL (8) or cues given (2). Six subjects were able to identify the role relatedness of the activity, in response to questions and spontaneously. One subject gave mixed messages about the meaningfulness of the activity, i.e., "I feel like I'm on a chain gang..." versus "this is therapeutic..." (Subject 1). Six of the seven subjects made statements related to having to adjust standards for performance because of pain. Three subjects indicated that they had made those adjustments with such statements as "It's not perfect, but it's good enough" (Subject 3) or "I know I may not do it as well as before" (Subject 2). The other three were still having difficulty with the adjustments, indicating that changing the standards compromised the role to which the activity was related. One of these subjects observed during the activity that her difficulty performing it was due to having to make so many adjustments to the way the activity was done that it lost meaning for her. Just when she would "get into it" she would need to change positions or take a break (Subject 4). Five subjects expressed a sense of ability following performance of the activity in therapy , i.e., "I think maybe I can do this now," (Subject 7) or "I can do a good job" (Subject 3).

During the performance of activities, one subject verbalized complaints of pain and one demonstrated pain behaviors. Outside the context of the activity (e.g., walking to the activity) however, one subject complained of pain, and four demonstrated pain behaviors.

In summary, in the context of a functional activity, almost no cognitive impairment was reported on the Observation Checklist. Few strength and range of motion impairments were reported. The lack of adequate use of body mechanics and energy conservation techniques were reported. Subject awareness of the meaning of activities and a need for adjusting performance standards were reported. Few pain complaints or behaviors were reported on the Observation Checklist.

Performance Limitations Lists

Performance Limitations Lists for subject and therapist (Appendix A) were used simultaneously after the subjects' performance of one to three of the activities that had been rated on the Visual Analogue Scale. The total number of activities performed with appropriate data collected was 10. The Performance Limitations List was completed by the subject and the therapist separately after the therapy session that included the performance of an activity.

Subjects

Categories were formed during data analysis by grouping similar responses together from subjects' lists of reasons (total 34) for limitations as follows (see also Table 3):

1) External/Environmental--Three subjects reported a total of nine responses in this category. They included the soil being too wet or wearing inappropriate clothing for gardening, time and space limits, type of bed for bed making, the weather causing hand discomfort, having an IV in one arm, and dust from sanding wood.

2) Psychosocial--Two subjects listed a total of five psychosocial reasons. These included trying to change old habits, depression, low energy limiting the

Table 3

Categories of Identified Performance Limitations

Category	Subjects' Lists		Therapists' Lists	
	#R	#S1	#R	#S2
Environmental	9	3	5	4
Psychosocial	5	2	7	5
Physical	12	6	7	6
Energy/pacing	4	2	8	5
Pain	4	1	2	1

Note. #R is the number of reasons identified for that category.
#S1 is the number of subjects who identified limitation(s) in that category.
#S2 is the number of subjects for whom that category was identified as a limitation by therapists.

use of ideas, no active goals and waning sense of humor. Four of five were reported by one subject.

3) Physical--Six subjects gave 12 responses in this category. Reasons included bending, reaching, lifting, positioning and decreased strength.

4) Energy/Pacing--Two subjects gave four responses in this category. These included endurance for sitting and standing, "needing to do the activity slower and not get out of breath," limited mobility and fatigue.

5) Pain--One subject identified pain as a limiting factor. Although the research questions asked what factors other than pain do subjects identify, this category was included because the performance limitations form did not state *other than pain*. However, subjects were informed of this verbally.

The most cited reasons for limitations to activities by subjects were physical and environmental reasons; however, the physical category drew a large total number of responses from six of the subjects, whereas the environmental category drew many responses from three subjects.

Therapists

There were a total of 29 therapist responses, which is five less than those obtained for the subjects. The same categories used for subjects' lists of limitations were used to classify therapist lists for greater ease of comparison.

1) External/Environmental--Five limitations related to external or environmental issues were identified for four subjects. Specific limitations identified included adaptive equipment, time and space limits and interruptions by other medical personnel.

2) Psychosocial--Seven psychosocial limitations were noted for five

subjects. These included the need for external motivation, lack of follow through with preparation, extremely high performance standards, difficulty delegating tasks, self perception and difficulty sustaining interest in an activity especially when rest breaks were needed.

3) Physical--Seven physical limitations were identified for six subjects. These included mobility, body mechanics, positioning and bending.

4) Energy/Pacing--Eight reasons related to energy or need for pacing were identified for five subjects. These included low endurance, rushing, planning ahead, coordinating breathing with activity and needing to change positions before pain and fatigue started.

5) Pain--Pain was identified as a limitation twice for one subject. Right hand pain limited the amount of time the subject could grasp objects, and hip pain limited use of proper body mechanics which led to back pain.

Therapists identified physical, psychosocial, and energy/pacing issues most as limitations to the performance of functional activities. External/environmental reasons were identified also. However, all but one reason given were different from those given by subjects.

In comparing therapists' and subjects' lists of limitations several observations can be made. Overall, subjects listed more limitations than therapists. Subjects listed more limitations in the environmental and physical categories than any other category; whereas, therapists listed more limitations in the physical, psychosocial and energy/pacing categories. Neither subjects nor therapists identified many cognitive reasons limiting performance. Five subjects identified at least one of the same limitations as therapists identified;

no subject identified more than two of the same limitations as therapists; two subjects had no identified limitations in common with therapists. Agreement between subject and therapist occurred at least once in each category. Where there was not agreement between subjects and therapists, therapists identified additional psychosocial or energy/pacing limitations, and subjects identified additional pain, physical or environmental limitations.

Interview Data

The interviews yielded very rich data, far more than can be explored here. At least thirteen different categories were discovered during data analysis, some more relevant to the questions than others. Not all are explored in detail here, but all have been reviewed for their content. The most relevant categories are: Observation/Treatment; Specific Activities-Unable/Difficult; Specific Activities-Able; Adaptation; Daily Routine; and Accomplishments, Goals, and Confidence.

Observation/Treatment

This category describes the observations and planned treatments stated by the therapist during the interview. During the interviews subjects were often asked to demonstrate an activity to the therapist. This category summarizes the therapist's comments. However, it was kept in mind that some therapist statements or lack thereof were primarily to build trust with the subject. For example, if a subject spoke about difficulty performing an activity, the therapist may not have immediately suggested solutions, although possible solutions may have been in the process of developing in the therapist's mind.

Examination of this category indicates that all subjects were independent in most self-care activities. In fact, one subject indicated that performing her self-care was what "loosens me up" for the day (Subject 2). Exceptions to this included the subject with amputated fingers on her right hand buttoning her left sleeve cuff. However, she had adapted to this limitation by avoiding wearing such clothing or asking her partner to help, and was satisfied with this solution (Subject 4). Also, one subject wanted to work on being able to shave her legs and demonstrated some difficulty problem solving with this activity, but then was able after one session to do so (Subject 6). Another subject found self-care activities tiring and pain inducing, but intended to go on doing them as he always had because he did not want to "be bothered with the minutia" of changing such habits (Subject 5).

The interview data revealed that all subjects were provided with an occupational therapy program that included at least two of the following interventions: training in body mechanics, energy conservation, positioning, relaxation, time management or breathing coordination with activity, among other interventions. One subject needed to learn how to pace his activities after a lifetime of rushing through them. Another needed to reconsider standards for the performance of the activity as, in her mind, it had to be done perfectly or not at all. Yet another needed to review principles of proper body mechanics and practice with functional activities. At least part of the process of setting up this plan with the subjects was recorded for every interview.

Specific Activities-Unable/Difficult

This category began with the label "specific activities-unable" because subjects initially described certain activities in terms of inability. However, upon further questioning subjects talked about very few activities that they absolutely could not perform. They described performing some activities with difficulty rather than being unable. The activities that three subjects indicated they were unable to perform were: bending and reaching for pots and pans, painting the house, doing large scale wood projects, lifting children, changing a bed, dusting under heavy objects, and driving long distances. Subjects identified ways they had adapted when faced with inability, including getting someone's help, doing lighter wood projects, holding children in lap or simply not doing the activity anymore. The success of these adaptations varied for each subject. Adaptation is another category explored here.

Specific activities which were difficult according to subjects were some self-care activities such as getting dressed or tying their shoes, many household tasks and driving. Only three leisure activities were mentioned by two subjects as difficult: playing with children, watching son play ball and fishing. No work activities were mentioned. Daily routine descriptions indicated that only one subject participated in regular leisure activity, and none were involved in work activities, although all had goals in both of these areas. This lack of leisure activities may indicate that most subjects were not dealing with leisure activity on a daily basis, and may not have been concerned with the difficulty involved in participating in them, as they were largely concerned with more basic survival tasks.

Every subject identified pain or physical disability as reasons for difficulty with activities. The next most common reason for difficulty was environmental or external factors out of their control. Only one subject identified psychosocial reasons for difficulty. Another stated that the fact that her self-care took her all day limited other activities.

Specific Activities-Able

Primarily self-care and household activities were listed as activities that subjects were able to do. Again, very few leisure or work activities were mentioned. When comparing each subject's input regarding activities they were able to perform versus those that were difficult, generally those who identified being able to perform self-care activities identified more household activities as difficult. Those who identified being able to perform self-care and household activities listed some leisure activities that are difficult. In a few cases, subjects described activities both as very difficult and as something they were able to perform.

Adaptation

All except one subject described ways in which they have attempted to maintain the activities that were important to them by adapting various aspects of the activity. Of the methods of adaptation mentioned by subjects the most commonly noted were (a) using special equipment or altering the household environment, for example, using reachers, adapting kitchen utensils, buying a new bed or hospital bed, or putting shock absorbers on a bicycle seat, (b) asking friends or family for help and, (c) trying to do the task a new way, for example, holding a child in lap instead of lifting, cleaning the bathroom on knees instead of bending, driving a car with an automatic instead of manual transmission. The least mentioned methods were (a) stopping the activity, (b) taking rest breaks, (c) increasing or decreasing the time spent for certain tasks,

(d) changing positions, (e) doing related tasks of interest and, (f) continuing the activity anyway. Subjects had tried many appropriate methods of adaptation to maintain involvement in purposeful activity, some of which were satisfactory to them, others which were not, hence their presentation to the chronic pain program.

Daily Routine

Because it was asked of them directly, all subjects described a typical day in the month prior to hospitalization. This category, as some of the previous categories, yielded much more information than time allowed for analysis for this study. Subjects primarily described involvement in household activities or assisting others in the household, by driving them places or by completing household tasks. Essentially, they described a role of homemaker, and for some this was a role reversal or change. A few described involvement in leisure activities; most described only leisure time. None of the subjects worked outside the home, although several had goals for school or vocational activities in the future. All of the subjects mentioned television as a regular part of their daily routine, and all made some mention of other people in their lives, often immediate house mates or people that help them. All subjects included taking medication, or going to doctor or therapy appointments as part of their daily routine. It appears that much of the subjects' lives are made up of activities that are medical or illness related, sedentary, or household tasks. For one subject, the ordinary activity of eating took on new meaning, enabling medicines, which may or may not have in turn enabled other activities. A more exact time study would be helpful in deepening the understanding of this topic.

Accomplishments, Goals and Confidence

Subjects were asked about their past accomplishments and about self-care, leisure and vocational goals as well as generally about their goals for the future. All subjects identified areas of past accomplishment, primarily in the area of work and family relationships, e.g. specific jobs or raising a family. All were able to identify short and long term goals, the latter being less specific. Most subjects included goals relating to "the way things were before [the injury or pain]," as well as other vocational or leisure goals. All but one subject expressed confidence in the likelihood that they would meet their goals.

Results

Question 1

How do perceived functional abilities differ from observed functional abilities in patients with chronic pain, during participation in a multidisciplinary treatment program including occupational therapy?

Data from the Visual Analogue Scales, interviews, Observation Checklists, and the Performance Limitations Lists were used to answer this question. According to the Visual Analogue Scale ratings, subjects initially rated their abilities as more unable than able, but no subjects rated their ability as completely unable to do an activity. There is not a correlating measure for therapist ratings, since no tool with reliability between subjects and therapists could be found; however, in no instance did therapists indicate that a subject was completely unable to perform an activity.

During interviews subjects described difficulty rather than inability most of the time, although there were a few subjects who identified activities that they were unable to perform. The interviews revealed that subjects achieved varying levels of participation in functional activity, and all subjects stated that they wanted some change in their activity status, even those subjects with few goals. All subjects described some level of involvement with the health care system on a daily or weekly basis, and for many this involvement structured their time. All except one of the subjects described that they had a desire for more functional purposeful activity, that they had confidence in their ability to achieve future goals, and that they had made many attempts to adapt to their situations. However, they could not independently resolve the barriers that remained which, according to their interviews and Performance Limitations Lists, were largely external or physical and out of their control.

Observations by therapists which were recorded in the interview and on the Observation Checklist during the performance of activities, indicated that subjects were more able than they thought, especially if they used some recommended adaptations. Examples of these recommendations include the adjustment of standards for performance, energy conservation, and positioning, all of which involve habit changes and lifestyle adjustments. Although subjects varied in their acceptance of these recommendations, therapists viewed the adaptations as possible and within the control of the subjects.

Subjects and therapists agreed that there were limitations, although they identified different reasons for the limitations and made conclusions about the functional abilities accordingly. Where there is disagreement, subjects perceived that they could perform with less ability than therapists observed that they could. Generally, patients with chronic pain perceived their functional abilities to be less than their observed functional abilities. Differences in perception regarding the nature of performance limitations are presented in the answer to Question 3.

Question 2

How do subjects' perception of functional abilities change after participation in a multidisciplinary treatment program including occupational therapy compared with their perceptions before such participation?

The Visual Analogue Scale ratings were used to answer this question. Prior to participation in the multidisciplinary treatment program for chronic pain, most of the activities that the subjects chose to rate on the Visual Analogue Scale were rated more closely to "completely unable" than "completely able." At the end of the program most of the activities were rated more closely to "completely able" than "completely unable." Nineteen of 22 activities were rated higher at discharge than admission, and six of seven subjects rated themselves overall higher on the Visual Analogue Scale at discharge than at admission. Overall average increase was by 3.6 centimeters on the 10 centimeter Visual Analogue Scale, more than a third of the total distance. According to this measure of perceived ability, most subjects perceived themselves as more able to perform the activities that they chose as important to be able to perform again compared with their perception at admission. In addition, most of the activities that had the highest increase of scores were those that were actually performed in the context of occupational therapy.

On the Visual Analogue Scale Subject 5 rated two of his three activities lower at discharge than at admission, and the average difference between discharge and admission ratings was a negative number. Many factors may have influenced this outcome. This subject's hospitalization (78 days) was four and a half times longer than the next longest (17 days) hospitalization in this study. All others were nine days or less. This was also the only subject with a degenerative condition, having entered the study because this was not the primary focus of treatment. Subject 5 was also the only subject who did not describe any attempts to adapt activities because of the pain. In addition, he is the only one who described very minimal likelihood of achieving his goals, stating that the likelihood was "about 1%."

Certainly many factors contributed to the change in scores including the subjects' expectancy of success or failure, the types of activities chosen, and the many aspects of multidisciplinary treatment that were not possible to separate in the scope of this study. However, the primary question was how the subjects' perceptions changed after treatment. Subjects overall indicated they had a more positive perception of what they were able to do after participation in a multidisciplinary program than before such participation.

Question 3

What factors, other than pain, do subjects and therapists identify as limitations to performance of functional activities?

Data from the interview, Observation Checklist, and Performance Limitations Lists were used to answer this question. Similarities and differences in perceptions regarding the reasons for problems in performance of functional activities were identified. Subjects identified physical and environmental reasons for limitations most often, and their attempts at adaptation were aimed at such reasons, with variable success. The environmental reasons were primarily seen as unchangeable by subjects. Therapists identified physical, psychosocial and energy conservation problems as reasons for limitations. In several cases what subjects viewed as unchangeable environmental limitations, therapists viewed as changeable psychosocial or energy conservation issues.

The primary area of limitation agreed upon by subjects and therapists was the physical category, although the perceptions about type and severity of impairment were sometimes different. Physical components identified by therapists were primarily body mechanics rather than pain or limited strength or range of motion for the activity which were identified by subjects. Even in the identification of physical limitations, subjects and therapists differed. The therapists identified limitations that required lifestyle or habit changes rather than only a change of physical status.

Subjects identified physical or environmental factors most often as limitations to performance of functional activities. Therapists identified physical, psychosocial and energy conservation factors as limitations to performance of functional activities.

Chapter 5

DISCUSSION, IMPLICATIONS, RECOMMENDATIONS AND SUMMARY

Discussion

Previous studies have shown self-report of abilities to be lower than other measurements of abilities (Keefe & Dolan, 1986; Smith et al., 1986; White & Strong, 1992). The current study supports this conclusion, as observed through interview and performance of functional activities. However, this study showed that despite perceptions of inability or difficulty, patients demonstrated continued interest in pursuing purposeful, functional activity. This was evident in the subjects' identification of goals, expectancy of success for meeting their goals, and their attempts at adaptation in order to maintain involvement in valued functional activities.

The discrepancy between the perceptions of subjects and observations of therapists indicated that subjects had a limited belief in their current skills. Padilla and Bianchi (1990) described this observation in their application of the Model of Human Occupation for patients with chronic pain. Further supported by the current research was the observation that patients with chronic pain "increasingly lose a sense of personal control and pain becomes an overpowering feature of everyday living" (Padilla & Bianchi, p. 50). These findings were especially evident in the subjects' descriptions of their daily routine and in their identified performance limitations. However, although they may have perceived decreased current skills, all but one subject in this study expected success in meeting future goals. This is in contrast to Padilla and

Bianchi's observation that "the poor prognosis of [pain] relief makes it difficult for persons to expect future success" (p.50). Expectancy of success exhibited by the subjects in the current study may have been an important factor in the change in perceptions following multidisciplinary treatment demonstrated by the Visual Analogue Scale ratings.

Although the findings of this and other studies suggest that patients with chronic pain believe they can do less than they actually can, Egan and Katon (1987) reported that patients with chronic pain were likely to report that they had gone to great efforts to maintain their health, but did not necessarily participate in more health related activities. It is possible that the current study's finding of subjects reporting methods of adaptation is reflective of the Egan and Katon study. However, the methods of adaptation described in the current study are not included in the health related activities described in the Egan and Katon study. Furthermore, in contrast to the Egan and Katon study, the current study found that there was no indication that subjects were overstating the adaptations they had attempted.

The current study described the nature of the adaptations attempted by subjects. That subjects, during interview, most often identified equipment, or asking for help is not surprising given that most also gave performance limitations as environmental or physical. Although they were attempting adaptations, and this indicated a desire to continue certain activities, the methods chosen most by subjects were not those that therapists recommended most for optimal performance.

Many previous findings related to perceived and observed function were supported by this study which used actual functional activities. The methods in this study provided the opportunity for such findings to appear in the context of actual treatment. Also, it may be concluded that the use of functional activities presented the opportunity for various types of limitations to be observed simultaneously, allowing comparison of therapist and subject perceptions. As previously stated, therapists identified more psychosocial limitations and subjects identified more physical and environmental limitations to performance. The fact that different limitations were identified by subjects and therapists supported the use of functional activity in treatment because physical and psychosocial limitations were addressed. Furthermore, the dichotomization of symptoms as physical or psychosocial, which was described as "clinically counterproductive" by Sullivan, et al. (1991), was avoided. Further, Gage et al. (1994) emphasized the importance of self-efficacy, a psychosocial variable, in the performance of specific tasks for their actual performance outside the clinic. The use of specific tasks and rating of ability with those specific tasks in this study may have been another important factor in the change of perceptions with the use of the Visual Analogue Scale.

Professional Implications

Several points may be highlighted related to professional implications of the results of this study. They are as follows.

Patient Role and Adaptation

The data suggest that the patient with chronic pain has developed a new role, the role of patient, which has as a part of the role various habits and priorities. This role involves activities that center around illness or disability such as regular and frequent doctor or therapy visits, working daily activities around medication taking, and new daily routines aimed at pain relief. The data also show that this is not the only role left for any of the subjects, although it may have become a primary organizing role. These patients with chronic pain have preserved most of their abilities related to personal self-care and are primarily occupied with household activities, and a few have developed leisure activities within their ability, and most have a great deal of leisure time and little or no work. The occupational therapy clinician working with the patient with chronic pain ought to know this pattern but not make assumptions about any individual case. This information might form the structure of an interview during the evaluation phase.

It is important to note that most of the subjects in the study made many attempts to adapt their lifestyle and approach to activities with varying degrees of success. The fact that subjects tried alternative ways of performing activities may suggest that they maintained some motivation for participation in purposeful activity. For some the adaptation enabled the activity; for others it decreased the meaning of the activity; and for others it became a barrier or a symbol of the role of disability. Attempts made toward adaptation need to be recognized in the patient, while assistance is offered for improved adaptation.

Treatment Addressing Functional Goals and Using Functional Activities

There could exist a conflict of goals or treatment approaches given that patients tend to identify physical and external limitations and therapists identify more psychosocial and energy conservation limitations. There is common ground, however: both subjects and therapists identified physical limitations.

The use of functional activity in therapy presents the opportunity to address any of the components which need to be addressed. However, it may be best to first focus on the physical components in order to gain the patients trust in addition to actually addressing the physical need, gradually introducing other factors. This presents the challenge to the therapist to address both the physical and psychosocial in the same treatment. The greatest increases in ratings on the Visual Analogue Scale were with those activities that were performed in therapy and subjects showed less pain behaviors in the context of functional activity, thus reinforcing the value of using functional activity in therapy. However, the patient's primary concern with physical limitations may suggest the importance of placing some focus on performance components, perhaps before involvement with functional activities. Here is a place for collaborative work with physical therapy. However, an exclusive focus on physical components would not be advised, since physical impairment was not always associated with functional status and the goal of treatment is increased functioning in daily life activities.

Visual Analogue Scale use

This study suggests many benefits for the use of the Visual Analogue Scale. It allowed for the individualization of goals and measurement of progress. Subjects chose a variety of activities related to a variety of roles. This variety emphasizes the importance of meaning of activities for each individual, and suggests the importance for the occupational therapist to develop treatment based on the meaning of activities rather than a set of predetermined tasks. The Visual Analogue Scale can provide a measurement tool for such activities. It can be used as a clinical tool with the patient to set goals, show progress and illustrate the continuum of ability in functional activities. Or, it could be used as a tool for the whole treatment team to focus on functional outcomes. Gage et al. (1994) pointed out the importance of perceived self-efficacy related to specific tasks in determining actual performance of activities outside the clinic. The Visual Analogue Scale may be a helpful tool for evaluating patient perception of ability related to the tasks that have been a focus in therapy.

Patient-Centered Care

The discrepancy between perceived and observed abilities found in this and other studies emphasizes the importance of observation as a part of assessment. This brings into question the value of the current and extensive use of patient self-report in "patient-centered care" (Brumfield, 1994; Zimmerman, Crosier & Taylor, 1993). This question was not considered during the initial literature review because it emerged after data analysis. Therefore, additional sources are cited here. Certainly patients are customers and ought to be satisfied, but perhaps evaluation of functional outcomes as a part of patient satisfaction ought to include observation in functional activities. This may give more accurate results, especially for patients with chronic conditions such as chronic pain. In order to accomplish assessment of functional outcomes including observation after hospitalization, occupational therapists may need to provide more of their services in the community.

Additional Questions

New questions were raised by the participation and results provided by Subject 5 which were in some ways distinct from all the rest. Subject 5 was the only one who stated poor expectancy of success ("about 1%") and had a negative score on his average Visual Analogue Scale difference. What is the role of expectancy of success in goal attainment for predicting outcomes? These may be some factors that influenced the positive outcomes for the other subjects. Depending on the relationship between expectancy of success and self-efficacy, this may be supported by Gage et al. (1994) who found that a high score on sense of self-efficacy correlated with improvement after treatment.

Subject 5 stayed much longer than the rest of subjects and had a degenerative condition, though it was stable and not the primary focus of treatment. What roles do length of stay and type of disability play in outcomes? How do these interact with each other and with expectancy of success? Is there an optimal length of stay for functional outcomes? These are questions to be answered in subsequent research.

Subject 5 was diagnosed with major depression as were some of the other subjects; however, Subject 5 continued to exhibit more severe depressive symptoms throughout his hospitalization than the other subjects. Major depression may have been a significant influence on his perception of his abilities. A thorough review of the psychiatry treatment plan was outside the scope of this study; however, close collaboration between occupational therapy and psychiatry is suggested by this observation.

Recommendations

Four areas are recommended for further study based on the findings of this study.

Patient Role Development

Further study is recommended regarding the nature and development of the patient role in patients with chronic pain, especially as it impacts perception of functioning. A qualitative study using role development and acquisition theories (Christiansen, 1991) as guides for data analysis is recommended and may be useful for making recommendations regarding promotion of optimal adaptation in patients with chronic pain.

Use of the Visual Analogue Scale for Function

The Visual Analogue Scale has many current uses and has potential for several more. For it to be more reliable and useful in comparing therapist and subject perceptions, interrater reliability for therapists and subjects should be established. Also, comparison measures could be taken with developed self-efficacy instruments to determine if this easily used tool is a way to measure this construct. The Visual Analogue Scale could be used with a larger sample population to measure improvement after treatment that would be generalizable. Also this tool could be used immediately after the performance of activities to more closely measure the effects of activity on perception of function. Lastly, it could be sent to patients as follow-up to measure the longevity of functional outcomes, particularly in the perception of the patient.

Factors Influencing Outcomes

How do factors such as expectancy of success with goals, amount of participation in functional activity in therapy, amount of patient education or focus on components of activity performance influence functional outcomes? Expectancy of success could be compared to self-efficacy in relation to functional outcomes. Recipients of occupational therapy with direct use of functional activities versus focus only on activity components could be compared for their effectiveness in functional outcomes.

Chronic Pain and Depression

Given the severity of depression and decrease in visual analogue scale scores for Subject 5, a thorough literature review about the relationship of depression and chronic pain is suggested. This should be followed by research regarding the impact of this relationship on functional activities as indicated by the literature.

Summary

The purpose of this study was to examine and describe the relationship of perceived and observed functional abilities during participation in occupational therapy as part of a multidisciplinary treatment program and describe changes in perception after participation in the treatment program in a sample of patients with chronic pain. Perceived and observed functional abilities, changes in the same, and limitations to performance were studied using interview, observation and measurements on the Visual Analogue Scale. Many other studies have reported results about function in daily or routine activities in relation to perception; however, this study utilized observed functional activities as the arena for data gathering. Subjects showed an increase in scores for their perceptions of their abilities, and differences and similarities between therapists' and subjects' perceptions were described.

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APPENDIX A

PERFORMANCE LIMITATIONS FORMS

Date________________ #________

Performance Limitations-Client

Please list three or more factors which limited your performance of the activity you just participated in:

1)

2)

3)

4)

5)

Presented on separate form:

Date________________ #________

Performance Limitations-Therapist

List three or more factors which limited the clients performance of the activity:

1)

2)

3)

4)

5)

APPENDIX B

ACTIVITY LIST

Activity List

The following is a list of activities to assist you to complete the Visual Analogue Scale for functional activities. You are not limited to these choices; this is intended to help you think of specific activities. If you have questions, ask the occupational therapist.

Personal Care:

- Bathing/Showering
- Getting dressed
- Grooming (shave, hair care, face care, nail care)
- Other

Home Care:

- Cooking
- Laundry
- Making a bed
- Ironing
- Dusting
- Vacuuming
- Mopping/sweeping
- Yardwork
- Shopping
- Other

Leisure/Avocational:

- Sewing
- Manual crafts
- Artwork
- Puzzles
- Reading
- Gardening
- Shopping
- Games
- Computers
- Any others that may be done on the hospital grounds

Vocational

If desired, list a specific task related to your work or desired work. This may be volunteer work or school also.

APPENDIX C

Observation Checklist

Date_______________ #_______

Observation Checklist

Activity:	WNL	Cues given	Needs trng		Comments
Planning and problem solving					
Organization					
Following directions					
Safety judgement					
Strength limitations					
ROM limitations					
Body mechanics					
reaching above head					
reaching below waist					
working position					
back/neck position					
Breathing with activity					
Rushing vs. pacing activity					
Rest breaks					
Other energy conservation					
Standards for performance					
Verbaliz. re: ability/inability					
Meaningfulnes of activity					
Role relatedness					
Verbal c/o pain					
Pain behaviors					
Other verbalizations					

APPENDIX D

INTERVIEW QUESTIONS

Initial Interview Questions

1) Please describe a typical weekday in the month before you came into the hospital:

Please describe a typical weekend day in the month before you came into the hospital:

What changes would you like to make in the way you spend your time?

2) Are you able to take care of your basic self-care needs independently (bathing, dressing, grooming, hygiene)? If not, who helps you?

Are you able to get in and out of bed, shower, on and off of the toilet or chair without assistance?

What about home maintenance tasks (cooking, cleaning, yard or outdoor care)?

Do you use any special aids for the completion of any of the above tasks (reacher, shower bench, etc.)?

What would you like to be able to do again in the areas of self-care and home maintenance?

3) What work/vocational activities have you done in the past, starting with the most recent first?

What are your work goals?

4) What leisure interests do you have? In the past? How frequent? When was the last time you did these?

What leisure activities would you like to do again? What new leisure activities are you interested in for the future?

5) How do you get from one place to another in the community you live in (for shopping, leisure, social activities, etc.)?

6) What other roles do you have in your life (beyond the ones described)?
What do they require of you?

7) Whom do you turn to for support?
How well do you communicate your needs to them?
Do you ever have difficulty getting others to understand you?

8) Describe your pain to me. When is it worse and when is it better?
What does it keep you from doing?
What have you been doing to decrease or manage the pain?

9) What are your goals for this hospitalization?
What would you like to be doing in one or two months?
What would you like to be doing one year from now? Five years from now?
How likely do you think it is that you'll be able to do these things?

10) What accomplishments, skills, or talents are you most proud of?
How are these useful now?
Are there any activities you do in which you lack confidence or feel unsuccessful?
Have you taken steps to develop confidence in this area?

11) Do you have any questions for me?

12) Further assessment:
Depending on above information, assessment will continue with range of motion, strength, bed mobility, transfers, bathing, dressing, cognitive screening task, or performance of household, leisure, or work simulation task.

Questions for Subjects During Activity Performance

What is most important to you about this activity?

Why do you do it?

How could you change this activity?

How have you already changed it at home?

To what role is this activity related?

When was the last time you felt like you could do this activity adequately?

How do you know when it is adequate?

APPENDIX E

Visual Analogue Scales

Date________ #________

Visual Analogue Scale for Functional Activities-#1

Please choose three activities which have been a part of your daily activities in the past and which you would like to be able to do again. You may use the attached activity list for ideas. List each activity on the lines below and rate yourself according to your ability to do each task today. Use a single vertical line to mark the appropriate place on the continuum from *completely unable (left)* to *completely able (right).*

Completely Unable |————————————————| Completely Able

Activity: ________________

Completely Unable |————————————————| Completely Able

Activity: ________________

Completely Unable |————————————————| Completely Able

Activity: ________________

Date_________ #_______

Visual Analogue Scale for Functional Activities-#2

Using the same activities you listed on the first Visual Analogue Scale, rate yourself according to your ability to do each task today. You may ask the occupational therapist for this list. Use a single vertical line to mark the appropriate place on the continuum from *completely unable (left)* to *completely able (right).*

Completely Unable |———————————————| Completely Able

Activity: ________________

Completely Unable |———————————————| Completely Able

Activity: ________________

Completely Unable |———————————————| Completely Able

Activity: ________________

APPENDIX F

CONSENT FORM

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

College of Applied Sciences and Arts • *Department of Occupational Therapy*
One Washington Square • San José, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

AGREEMENT TO PARTICIPATE IN RESEARCH
CONSENT FORM

RESPONSIBLE INVESTIGATOR: Karen Pickett, OTR, Rehabilitation Services, R-203, Stanford University Hospital, 300 Pasteur Drive, Stanford, CA 94305. Phone: (415) 723-6701.

TITLE OF PROTOCOL: Occupational Therapy Research in Chronic Pain

I have been asked to participate in a research study that is investigating the experience of people with chronic pain, especially in relationship to their daily life activities. The results of this study should further the understanding of how people with chronic pain view their abilities in daily life activities. I understand that:

1) I will be asked to rate myself according to my abilities in specific daily activities and participate in evaluation and treatment using those same activities by an occupational therapist. I will be asked questions about the effect of chronic pain in my daily life. This does not entail more than would usually be done for assessment and treatment, except it may be more systematic and detailed. My participation may take two to three hours in addition to usual occupational therapy treatment, spread over my whole hospitalization.

2) The risks involved with participation in this study are no greater than the risks of entering the hospital for chronic pain treatment. No additional risks are anticipated.

3) The possible benefits of this study to me are more systematic, detailed evaluation and the opportunity to assist in the development of understanding of chronic pain. No additional compensation will be necessary.

4) No standard treatment will be withheld from me. Should I decide not to participate in the study, I will receive the usual assessment and treatment, with no loss of service needed while I am in the hospital.

5) The results of the study may be published, but without any means for my identification as a part of the study. My identity will be kept confidential, unless I give written permission for disclosure.

6) Questions about the research may be directed to the principal investigator:
Karen Pickett, OTR (415) 723-6701.
Complaints about the research may be presented to:
Amy Killingsworth, Assistant Professor, Interim Chairperson, Department of Occupational Therapy, San Jose State University, at (408) 924-3070.
Questions or complaints about research, subjects' rights, or research-related injury may be presented to:
Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research, San Jose State University, at (408) 924-2480, or
Human Subjects Office, 125 Panama St., Stanford University, Stanford, CA 94305-4125, (415) 723-4697 (collect, and I may remain anonymous).

7) My consent is given voluntarily without being coerced. I may refuse to participate in this study or in any part of this study, and I may refuse to answer particular questions, or I may withdraw at any time without adversely affecting my relationships with affiliated institutions, San Jose State University and Stanford University Hospital.

My signature indicates full voluntary consent to participate in the above-described research study, that I have read and understand the above statements, and I have received a copy of this signed and dated consent form.

X_______________________Date_________ X__________________________Date_________
Subject's Signature Investigator's Signature