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**SOCIAL SUPPORT AS A FACTOR OF PERCEIVED
INDEPENDENCE AMONG INDIVIDUALS WITH HEAD INJURY**

**A Dissertation
Presented for the
Doctor of Education
Degree**

The University of Tennessee, Knoxville

Phyllis Herrick O'Donnell

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To my husband, John

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ABSTRACT

This study describes the relationship between variables of perceived social support and perceived independence among individuals with head injury as determined from structured interviews with them.

Perceived social support was described for both quantity and satisfaction with support. Independence was ascribed three connotations; those of (a) physical independence, (b) economic independence, and (c) perceptions of self as overall an essentially independent person.

Eight questions were asked, four were preliminary, and four were major. Findings suggest that subjects do see themselves as having support systems, with which they are generally satisfied. They see themselves to a fairly high degree as overall essentially independent persons with lessened degrees of physical and economic independence. They are satisfied with themselves as persons, but less satisfied with perceptions of their physical and economic independence. Correlation coefficient results show a relationship between satisfaction with support and satisfaction with perceived levels of physical and economic independence. Satisfaction with support is also related to perceived levels of economic independence.

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CHAPTER I

INTRODUCTION

Background

Physical and cognitive issues become obvious early in recovery from head injury. Emotional and social issues often emerge as prominent factors later in recovery. Research studies concerning persons with head injury indicate the following:

1. Emotional distress measurements often increase over time as measured in psychological testing at the acute stage and again six months later (Fordyce, Roueche, & Prigaten, 1983).
2. Overall social networks tend to decrease over time. Isolation tends to increase for the individual and sometimes the family as well (Thomsen, 1984).
3. Although independent living is a major goal of rehabilitation, residual deficits tend to place individuals at a position of increased physical, financial, and social dependency

(Brooks, Campsie, Symington, Beattie, & McKinlay, 1987).

4. Apart from physical and intellectual impairment, some emotional factors seem to be related to the degree of supportiveness within the family and to the larger social framework such as social support groups, professional friends, personal friends, etc. (Kozloff, 1987).

Most research addresses psycho-social concerns, independence factors, and client need from the perceptual point of view of the facility, the professional, the family or the vocational placement personnel. There is a need for psycho-social research which includes more information about social support as individuals with head injury perceive it, and more information about independence as they perceive it.

Social Support Research

Research studies cite the need for more information about the support system of the individual with head injury in order to integrate the individual and the family into the regimen for maintenance of

positive outcomes for brain-injured persons (American Congress of Physical Medicine and Rehabilitation, 1989).

Independence Research

Rehabilitation assumes independence as a critical and essential goal. However, the term independence has several definitions within the traditional rehabilitation setting. Within acute settings, the term usually denotes the maximization of physical functioning (feeding, dressing, moving one's self). In the vocational setting, independence is usually defined in terms of the levels of ability to work. Pfluger (1979) has defined independent living as control over one's life based upon choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. If Pfluger's definition can be construed as consumer driven, then independent living services as a programmatic part of rehabilitation must be seen partly from the perceptions of the client. This is especially true in light of the power of belief systems to effect change. That is, head injury decreases individual independence. The

transition from dependence at the beginning of rehabilitation to maximum independence as an end is the goal of rehabilitation. Systems of rehabilitations which really can and do empower the individual toward functional and perceptual realization of independence by increasing the individual's ability to choose may be more effective than traditional systems (Ylvasaker & Gobble, 1987). Functional increases in choices may require adjusted physical and environmental services, and is outside the scope of this study. The head-injured person's perceptions about the availability and ability to choose may be influenced by social support, social services, and social systems.

Perceptual Approach to Research

Currently most research studies encompass functional, behavioral, or psychological test data administered to or derived from behavioral observation of the individual. Few studies have attempted to directly document the perceptions of the individual with head injury. Of the research using perceptions as part of the study, one study (Rappaport, Herrero-Bache, Rappaport, & Winterfield, 1989) used both report of the

subject and, also sometimes, that of a cohort. However, cohort responses were used in that study only when it was impossible to make direct contact with the subject. In another study (Kaplan, 1990), perceptions of social support were associated with degrees of emotional distress as measured on a psycho-educational self-report tool, i.e., the Sixteen Personality Factor Inventory (16PF). Results of that study indicated that perceptions of available social support were also related to client vocational outcome one year after evaluation. More research was cited as needed to focus on the factors of social support for vocational and other outcome needs. The present study used social support as one of three dimensions of psycho-social research. The three dimensions were those using social support, independence, and client perceptions.

Statement of the Problem

As noted previously, research cites social support as increasing the prospect of effective rehabilitation and community re-entry. Achievement of independence is a factor important for effective rehabilitation and community re-entry. However, data concerning the

possible relationship for persons with head-injury between support systems and independence factors is not available. Therefore, the focus of the present study was to investigate this relationship. The present study was designed to determine perceptions of social support, as they related to perceptions of independence, among persons with head injury who were post-discharge from a rehabilitation center.

Research Questions

A total of eight research questions were studied. The first four were preliminary research questions. Four other research questions constituted the major research questions. These explored the possible relationship between head-injured former client's perceptions about support systems and perceptions about independence.

Preliminary Research Questions

1. To what degree do former clients view themselves as having support systems?

2. To what degree do former clients feel satisfied with their perceived support systems?
3. To what degree do former clients view themselves as independent persons?
4. To what degree are former clients satisfied with their perceived independence?

Major Research Questions

5. To what degree does support system number (quantity) relate to levels of perceived independence?
6. To what degree do levels of satisfaction with support systems relate to levels of perceived independence?
7. To what degree does support system number (quantity) relate to levels of satisfaction with degree of independence?
8. To what degree do levels of satisfaction with support systems relate to levels of satisfaction with degree of independence?

Definition of Terms

Social Support

According to Caplan (1974) overall social support implies a lasting pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time. A social network provides psychological resources and supplies for the maintenance of mental and emotional health. Social support, (Sarason, Levine, Basham, & Sarason, 1983) is the existence of available people on whom we can rely, people who let us know that they care about, value, and love us.

According to Sarason et al. (1983) social support requires two basic elements: (a) the perception that there is a sufficient number of available others to whom one can turn in time of need, and (b) a degree of satisfaction with the available support. These two factors may vary in their relation to one another depending on individual differences in personality. In the present study, social support was measured by a structured interview using items from Sarason's Social Support Questionnaire (SSQ). Two kinds of questions

were asked. One question was about the number of people who provide social support. The other question was about the degree of satisfaction with social support.

Independence

An independent person is described as one who perceives him/her self to be assertive, self-sufficient, and able to make his/her own decisions (Moos & Moos, 1988). Independent living, according to Pfluger (1979), is control over one's life based upon choices of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. Independence was used in this study as an internal referent, the perception of which was defined in terms of the individual's responses to the structured interview. Two kinds of questions were asked. One kind of question was asked about degree of independence, the other was asked about satisfaction levels with independence. With respect to this study independence was ascribed three connotations; physical independence, economic independence, and self-overall as an essentially independent person.

Physical Independence

This term was used in the sense of the perceived absence of physical impairment which would, in some way(s), be handicapping to everyday functioning of the individual. Operationally it was defined in terms of the individual's responses to the interview as outlined in Appendix A.

Economic Independence

This term was used in the sense of financial or material well being that allows for ordinary maintenance and planning for the individual. Operationally this was defined in terms of the individual's responses to the structured interview outlined in Appendix A.

Self Overall As Essentially An Independent Person

This term was used in the sense of social, emotional, or psychological ability to have control or make decisions that are typical within the common choices of an everyday adult citizen. Operationally

this was defined in terms of the individual's responses to the structured interview outlined in Appendix A.

Significance of Study

Rehabilitation seeks, as part of its theoretical existence, to re-establish the individual as a fully functioning, empowered person. Achievement of congruence between recipient perception of need and available choices of rehabilitative services can enhance the recovery process. Rehabilitation practices can be improved, with documentation of opinions, perceptions, and mind sets of those individuals as consumers. Research studies which encompass consumer/client considerations, among them client perceptions of social support, independence, and satisfaction levels, might provide documentation.

Social support is cited to be a beneficial influence for effective rehabilitation, though further information is needed for an integrated or systematic approach to the therapeutic processes. Increased independence is an on-going objective for physical, cognitive, and emotional domains, but client perceptions are often ignored. Research and

documentation of a relationship between social support and independence, using client perceptions, might benefit attempts for more effective standards. Additional documentation could support present efforts for increased social services and systems. Furthermore, documentation could provide a rationale for research on a larger scale. The social support and independence measures might add to what is cited as needed research in psycho-social areas. The perceptual approach could add to the literature as a consumer-driven method. The present study investigated the perceptions about two related psycho-social measures, i.e., social support, and independence in order to provide some additional information toward needed research.

Limitations of Study

Several limitations are presented, which may have affected described results. They are as follows:

1. The sample group was small; therefore they may not represent the larger population from which they were drawn.

2. The group studied were interviewed in terms of their discharge dates; therefore they did not constitute a randomized sample.
3. Some members of the sample population were not interviewed because they could not be contacted by phone.
4. Some members of the sample population were not interviewed because they did not wish to be part of the sample.
5. One cohort of a member of the sample population was not interviewed because the subject did not wish to designate a cohort.

CHAPTER II

REVIEW OF LITERATURE

Current medical technology increasingly saves the lives of individuals who have sustained serious injury. However, many of those individuals may spend the remainder of their lives in reduced physical, cognitive, or psycho-social circumstance. The injury to the brain that might once have killed now often destines long years of possible social isolation, dependency on others, and subtle (therefore not easily resolvable) devaluation of person. It is the goal of rehabilitation processes to rebuild, by retraining, physical, cognitive, or psycho-social skills and facilitate the restoration of as much independence of living as is possible for the individual.

Background

Earlier studies of head injury have indicated that about 50% of severe head injuries resulting in coma would also cause death (Plum & Posner, 1982). Results of later studies have indicated that close to 97% of those reaching the hospital alive would survive

(Aronow, 1987). Of those surviving, many remain, and will remain, in comas or persistent vegetative states. Others will awake and recover. But they must live with disabling results of injury for a short time, a long time, or always.

Recovery Levels

There is a common pattern of recovery events from a traumatic head injury. The series of events often occur in stages that are roughly predictable. These are usually documented via varying tools of functional/cognitive levels in the patient's recovery record. Three of the most common measures are the Glasgow Coma Scale used after acute (initial) injury, the Disability Rating Scale (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982), and the Ranchos Los Amigos Scale used in acute and later stages of recovery (Slater, Kendrick, & Zoltan, 1987). The Ranchos Los Amigos Scale is one outlined into eight stages of recovery (Malkmus, Booth, & Kodimer, 1980). The lowest level on the scale describes unconsciousness with no response to the environment. The pattern of recovery from unconsciousness to a comatose stage gives way to

lethargy and then a period of agitation and hyperactivity. This stage is followed in turn by one of increased lucidity with automatic behaviors that may be irrelevant situationally. Often, increasing clarity of thought and alertness is interrupted by periods of confusion, forgetfulness, and disturbed emotionalism and behavior. Persons may recover, seemingly steadily, or may realize a number of deficits within varying functional areas (Vogenthaler, 1987).

Levels of Re-Entry

The seventh and eighth stages (Ranchos Levels VII and VIII) are ones descriptive of emerging appropriate behaviors. The level VII stage describes increased automatic but sometimes robot like ability to interact with the environment. Attentional memory, insight, and problem-solving skills may still be deficient but minimum supervision and structure is needed for activities of interest. Level VIII is a stage of recovery that implies increased purposefulness, insight, and environmental independence. Memory and processing speed may still be decreased from normal levels but are functional for society. These two

levels, especially the last, are ones typical for community re-entry, when the individual is expected to integrate past, present, and future life events. But social, emotional, and intellectual limitations may be present for a long time.

Determinants for long term recovery have been reported to depend on severity, type of injury, timely admission to medical facility, environmental support systems, personal support systems, and personal perseverance (Burke, Wesolowski, & Guth, 1987). In one ten-year follow-up, long term recovery was related to level of disability, discharge placement (home or extended services) and social environmental factors (Rappaport et al., 1989). At the end of the ten year period, the study also indicated that for 63 of 101 patients interviewed from five to ten years post injury there was still an overall moderate disability. Also reported was loss of employment status and loss of socio-economic independence with 24% of follow-up cases living in bed and board or skilled nursing facilities, and 14% requiring around the clock care. Jacobs' report (1988a) on 142 survivors found that 34% reported

as functioning independently, while 39% required the total support of someone else.

Traditionally, the duration of significant active recovery following traumatic head injury was expected to be approximately a year, or, at most, two (Cope, Cole, Hall, & Barkan, 1991). Outcome evaluations at that earlier point in time focused upon medical, physical, and basic cognitive therapy (Goethe & Levin, 1984; Jennett & Bond, 1975; Schleuderer, Short, & Crisler, 1988) as a part of the multiple acute problems to be addressed. However many professionals then and later underscored the need to address social, emotional, and behavioral components as critical issues (Rossi, & Rusk, 1981; Ruff & Nieman, 1990). The need for more research about optimum models of effectiveness was argued (Jacobs, 1988b; Koontz, 1983).

Outcome results of emerging models including day care programs (Ben-Yishay, Silver, Piasetskey, & Rattock, 1987), post-acute and transitional programs (Jacobs, 1988b) and independent living programs (Cordeluci & Gretz-Lasky, 1987) reported the benefits of extended rehabilitation for these and other deficits. Empirical reports (New Medico Head Injury

Systems, 1988) indicated increased functioning and decreased long term cost for individuals receiving extended care as opposed to those who did not.

Presently, the National Head Injury Foundation cites categories of persisting deficits from traumatic head injury to include those of physical, cognitive, and psycho/social/behavioral impairment. Among these, outcome research has increasingly indicated that it is the psycho/social/behavioral areas of impairment that often constitute the most persistent and the most perplexing problem for head-injured individuals (Lezak, 1987). It has been a critical area of concern for rehabilitation professionals, family, and vocational personnel as the individual seeks to reintegrate into work and community life (Oddy, 1985). An area of continuing research need is that pertaining to social adjustment and social support as factors for optimal recovery.

Socialization And Adjustment

For individuals with head injury, it seems increasingly clear that socialization can be a problem (Blair & Lanyon, 1987). Research has indicated that

emotional and personality adjustment following head injury can have a significant effect on rehabilitation outcome (Brooks et al., 1987). Often, such adjustment appears roughly parallel to cognitive recovery. That is, initially there is usually a clearing of both cognitive and emotional confusion (Deboskey, & Morin, 1985). For many people, however, increasing cognitive awareness results in the realization of post-injury limitations and causes increasing emotional distress. Fordyce et al. (1983) reported that individuals referred for neuropsychological testing as acute level patients and then again six months later actually indicated increased emotional distress on the later scores. These differences in emotional functioning appeared to be independent of the level of neuropsychological impairment or the initial length of coma. Overall, it often happens that friends disappear as they notice, more and more, an apparent permanent inability for the patient to communicate well, and to do physically or intellectually the things that were so easy and enjoyable before the injury (Bergland & Thomas, 1991).

In traumatic head injury there is often generalized trauma (McClelland, 1988). Swelling and hemorrhage may cause both localized damage and introcranial pressure. Personality change was often reported (Brooks et al., 1987). Depression, irritability and obsessional traits are frequently observed and are among the most common emotions after affects of head injury.

According to Blackerby (1984), emotional characteristics may be seen emerging from differing sources. There may be affective exaggeration of some pre-injury personality characteristics. Such traits often include aggressiveness, tension, depression, hostility, and resistance to authority. Some organic head injury related factors include those of insensitivity, egocentrism, and defective inhibition. All or any of these can easily lead to poor judgement, impulsivity or its opposite, lower spontaneity. Blackerby states that still other factors may develop situationally during recovery. These may include decreased self-confidence, uncertainty, and fear. These last may be reflected as belligerence, hostility, denial, or rationalizations.

To a large degree, families suffer the major brunt of many of these changes (Frank, Hunt, Smick, Haut, & Chaney, 1990; Linge, 1984; Zeigler, 1990). Initially families rarely understand the intellectual, social, or emotional consequences of brain injury. At first, they may fear that the injury may have caused the individual to become permanently "crazy" (Sbordone, 1984). Later, they may also feel convinced that behaviors exhibited during the acute phase will give way to spontaneous recovery once the individual is discharged and returns to his everyday life and activities. When this, early on, does not occur, hopefulness may give way to discouragement. Family members may interact with ambivalence, impatience, or an overly critical attitude towards these behaviors. They may act out their own anxiety and/or depression which may exacerbate the head injured person's own fears and thus further breakdown family cohesiveness. Studies on family reactions to head injury consequently show ongoing patterns of family disfunctioning with emotional and social breakdown within family members and within the extended family system. Other studies have indicated that change occurs in intrafamily dynamics, roles,

expectations, with distress and breakdown as common outcomes (Brooks et al., 1987).

Apart from physical and intellectual impairment, freedom from factors such as irritability and aggressiveness, anxiety, or agitation may be in some cases related to the degree of cohesiveness and supportiveness within the family and larger social network (Kaplan, 1990). Pre-injury social networking may include organizations, professional friends, and extended family members. When impairment results in a delay/stoppage in a return to work, professional ties are broken. Extended peer and family ties may also be broken as a function of newly imposed limitations. Lessening of personal and professional ties tend to place more focus and more strain on the individual and his family. The breakdown of social supports has been reported as common. However, less information is available about the importance of maintaining a social network.

Social Support

Kaplan (1990) found that both social network and family cohesiveness become extremely important as

issues for implication of vocational outcomes. Higher levels of suspiciousness, insecurity, tension, and lower levels of emotional stability and self-discipline have been reported as being related to negative evaluations of available social support. On the other hand, perceived feelings of social support appear related to less emotional distress and a greater likelihood of positive vocational outcome. Needs identified from Kaplan's studies were those for exploration of determinates of social support and emotional negation of distress among persons with traumatic brain injury in a diverse number of samples. He also cited the need for identification of specific aspects of social support which may be facilitated.

Kozloff (1987) stated that social support has a positive effect on the process of long term recovery. His study used an anthropologic approach (interview guides and unstructured interviews) to explore the opinions of the patient and his/her family regarding sources of help. He suggested that social networks are linked to a sense of well being, to definitions of health, and to the utilization of services. He has suggested that health care providers and community

services be more aware of this positive effect in order to evaluate the personal resources of the person with head injury.

If there is evidence to indicate the probable beneficial effect of available support systems then an investigation of the individual's appraisal of that support may be also important (Sarason & Sarason, 1986). Therefore, a measurement that could identify both the number of available others as well as the degree of personal satisfaction with social support might be useful.

Perceptions From The Field

Most groups working with the person with head injury have agreed about ultimate goals for that individual. But perceptions about assessment techniques; short term goals and methods for success have often differed. Congruence among professionals in decisions about the individual is important but has often been lacking (Zingale, 1985). A study by Matte, Crisler, Campbell, and Woodruff (1991) was designed to determine congruence of the clients, facility counselors' and referral counselors' perception of

client functioning level. Overall results indicated significantly different perceptions of client functioning levels. According to the authors it was a general lack of agreement among all groups. In that study a strong suggestion was made to find ways to reduce incongruences to better operate from the same baseline of reference.

Assessment of factors which constitute common emotional patterns for persons with head injury has also been affected by differing perspectives. As indicated earlier, rehabilitation professionals and researchers have sometimes cited an unawareness or denial of limitation on the part of the individual of his/her limitations (Lezak, 1987; McClure & Flynt, 1991; Ridley, 1989).

One study of response styles on the Minnesota Multiphasic Personality Inventory (MMPI) for subjects with head injury indicated that, of 44 profiles, between 18% to 30% were identified as biased to look good. The primary implication cited in that study was the need for careful scrutiny of consistency and bias to look good when interpreting such self-report measures (Burke, Smith, & Imhoff, 1989). That study

indicated subject sample to be those in a post-acute program, tested as part of admissions processing. It did not include length of time since injury or approximate neuropsychological functional level at time of testing. This may have been an important omission in evaluating the reliability of these self-report results. The length and complexity of the MMPI in its language and report style (566 questions) necessitates a high level of visual and cognitive attentional skill which in this study was not reported. Its results raises questions of test suitability to cognitive functioning level. Other studies of personality profile, although reporting elevated profiles for individuals with head injury, have not reported such bias. A study of personality traits completed with the Millon Clinical Multivariate Inventory (MCMI) were compared with self-reports of personality change following head injury (Tuokko, Vernon-Wilkinson, & Robinson, 1991). The MCMI is like the MMPI, a self report personality measure, and is composed of questions to which the examinee answers true or false. It is a shorter length (175 questions), the construction of questions is more simple as is its

language and terminology. In that study, personality trait scales and clinical scale evaluations correlated with self-reports of dysfunction.

In another study, subjects involved with drivers training models were reported to often overestimate their aptitude in relation to objective driver skill score results (Pendergrass, 1990, 1991). This was noted as especially true for their perception of visual and motoric speed response.

Ridley (1989) stated that rehabilitative staff's perception of denial on the part of the client and the family was frequently used in a too simplistic way. She suggested that denial is a complex issue, and often misunderstood in a rehabilitative setting. She indicated that staff members fail to respond to family concerns appropriately. Poor communication and an unsuccessful relationship among family, client, and staff often results.

Perceptions From The Person

The rehabilitation client is a consumer whose views, if known, are sometimes more negatively evaluated than used as instruments of value. This may

be common to areas of other kinds of disability as well as head injury.

Havranek (1991) indicated that, though its foundation may be medical, disability is a socioeconomic problem because of its interaction with societal resources. He stated that it is often a vocational handicap. Most people see employment as indispensable to independence and hence disabled individuals are often regarded as little more than dependent children. This kind of reaction may be encultured as a negative myth about the abilities of disabled people. A study by Holmes and Karst (1990) showed many ways by which disability myths have become institutionalized as negative reactions in the general population and also in the vocational rehabilitation service delivery system. Goodwin (1990) has stated that the role of disability is traditionally restrictive and patronizing. It is a role where expectations, those of dependency, are reinforced by American policies and laws which fund only dependent behaviors.

Studies that have focused on clients perceptions of client functioning have reported the tendency of

individuals with disabilities to stereotype other persons with disabilities in the same way non-disabled people do (Shurka & Florian, 1984). However, when these disabled persons were asked to rate themselves, Beail (1983) reported a consistent tendency for them to rate themselves more favorably than others would.

Specific to head injury, a study by Prigatano, Altun, and O'Brien (1990) reported that 64 subjects with traumatic brain injury and their relatives completed a questionnaire which required judgements by both the subject and their relatives concerning the degree of competency the subject currently demonstrated in carrying out daily tasks. The purpose of the questionnaire was to determine how realistic the patient was in self evaluating behavioral strengths and limitations. Results generally indicated agreement between subjects and relatives concerning tasks of daily living. Areas of differences cited were in abilities of emotional and social interactions which in this study was reported as probable limitations of awareness on the part of the subject.

Perceptions of individuals with head injury and their families were used in a case study approach

(Bergland & Thomas, 1991). In this study, 25 subjects who had sustained head injury during adolescence and who were currently over age 18, were asked about their perceptions about events and experiences following the subjects discharge from hospital. The results were loosely fitted into five categories, (e.g. self, family, friends, school, and work). In that study, the individuals reported a change in the aspect of self as well as changes in moods and emotions. Decreased stamina and endurance were also reported, more often by families than the individual. Ninety-two percent of the individuals reported hurt and disappointment when social relationships were broken, once the long term deficits were realized.

Persistence of a search for help from a neuropsychology office by individuals with head injury long after head injury also provides an indirect view of some individuals' perceptions (Karol, 1989). This retrospective review of patient records indicated they sought help for years and sometimes decades for residual difficulties. The mean number of years after injury was 9.9. The main complaints were listed as cognitive, job/school, medical, emotional, social

relationships, living, and behavioral. The study's results suggested a need for increased attention to long term care. Results also implied possible misperceptions and underestimations on the part of medical professionals about long term outcome needs.

Towards Independence

An area of common agreement between most groups in rehabilitation is the pursuit of ultimate maximum independence of living for the disabled individual. There are several views, perspectives and perceptions regarding the methods and models for achievement of that goal. One current view, already discussed, is that for increasing time as a rehabilitation patient. There are increased efforts to facilitate rehabilitation through extended care. An analysis of outcome in a post-acute setting (Cope et al., 1991) showed increases of 16% in employment from admission to follow-up, 17% increase in non-competitive educational involvement, a reduction of no productive activity from 91% to 37.1%, and an increase in 24 hour/day independence from 23.5% to 77.1%. All these changes were at statistically significant levels and suggested

further recovery toward independence occurred in the late post-injury phase for individuals serviced within a rehabilitation model.

A report by Ostby, Sakato, & Leung (1991), conducted to describe the relationship between rehabilitation services and perceived persistence of problems following services suggested findings quite different. They suggested that greater exposure to rehabilitative services and post-acute care narrowed achievable goals and produced an expectancy set which precipitated the generation of more identifiable problems. The authors presented as one suggestion, a more active role on the part of the client and family in problem solving. A second implication stated was the possibility that problem identification is a positive indicator of progress.

Burke, Zencius, Wesolowski, and Doubleday (1991) suggested that future treatment models should focus on reducing dependency on external persons such as job coaches and attendants. He suggested this kind of reduction focus of treatment rather than cognitive training for elimination of problem behaviors such as poor planning or initiation. Such treatment could use

checklists of vocational tasks, rather than verbal cues, as a way to increase independence in both living and working. He suggested that checklists become internalized without deterioration of performance, and at less cost than attendants. Another suggestion within the post-acute rehabilitation scene was that of increased feedback to clients from staff, within a community setting model. The suggestion was made that feedback should be given from within a neuropsychological framework in order to increase patient understanding, decrease burn out of the staff, and increase overall team-patient interaction as in a real-world setting (Prigatano, 1989).

A study by Hallaner, Prosser, and Swift (1989) suggested the patient return to work within community based programs as early as possible. They suggested using supported employment with reality oriented goals which simulate real working conditions.

Many studies suggest the inclusion of family system into the social and vocational rehabilitation of the individual (DePompei, Zorski, & Hull, 1988; Kaplan, 1990; Kozloff, 1987). Pfluger (1979) suggested the offering of choices to the individual. He stated that

even under severe physical and cognitive limitations there are possibilities of alternative ways of implementing goals and that the choice should be those, or approach those, of the client. He suggested that the freedom of choice in alternatives promotes, in the individual a perception of increased independence.

Head injury is a complex and not totally understood disability (Blackerby & Gualtieri, 1991). However, it is one disability among many others that can affect an individual in a lifetime. Its clinical handicapping descriptors may not be as overwhelming as the cultural and societal burdens that sometimes occur. As friends drop away, physical or economic independence disappears, and the self may be left vulnerable to fear, uncertainty, and a perception of devaluation (Prigatano, 1991). If support systems and networks are important links to lessened emotional stress, to increases in feelings of health and to more positive vocational outcomes, (Kaplon, 1990; Kozloff, 1989), they may be also linked to perceptions of independence and empowerment. It is a question the answers for which are worth exploration.

CHAPTER III

METHODOLOGY

Research Design

The present study described the relationship between variables of social support and independence as determined from structured interviews with head-injured former clients who have sustained head injury who are 6-18 months post-discharge and who were at above Rancho levels of a rehabilitation center (see Appendix A). Background status information, including approximate levels of current physical, economic, and social involvement, were described from a telephone interview with a cohort (see Appendix B).

The aim of the research was descriptive. No cause and effect relationship was sought. No null hypothesis was stated. Eight questions were explored. Four of them were preliminary research questions. Four others made up the major research questions for the study. Preliminary questions were examined using descriptive statistics, e.g., means and ranges. The four major research questions used a correlation coefficient

(Pearson product-moment) measure. Possible gender differences were tested with a Mann-Whitney U test.

Pilot Study

Before the research letters were sent to subjects targeted for the project a pilot study was undertaken. Cover letters were sent and interviews were conducted with five individuals who had sustained head injury and who were estimated to be at a level of community re-entrance (above Ranchos level VII). Letters and interviews were also conducted with three individuals who had never sustained head injury, in order to determine any superficial differences in response.

Results of the pilot study indicated that completion of the interview took more time for persons with head injury than with ones who had not sustained injury. There was a slightly lower perceived level of independence for all three connotations of independence among the sample with head injury than in other persons, as was expected. Based on the pilot study findings, the cover letter and instructions were retained in their original formats, except that the

estimation of time for interview was extended by fifteen minutes.

Subjects

Permission was obtained from a major rehabilitation center, which specialized in programs for individuals with head injury who had passed the stage of hospital in-patient status, to work with a sample of their former patients (see Appendix C).

Subjects were estimated to include approximately thirty individuals who represented:

- (a) Former clients who had sustained traumatic brain injury, and were
- (b) six months to eighteen months post discharge and
- (c) were estimated to be at or above Rancho Amigos Level VII (Malkmus et al., 1980).

Since this was a rehabilitation service center (as opposed to a hospital), individuals referred to it were generally at the post-critical stage of recovery at admission time.

The number of subjects who met criteria was 25 former clients. Two were not contacted because they had no phone service. Three declined to be part of the

sample. One could not be contacted despite several attempted phone calls over the period of a month.

The final group sample consisted of 19 individuals. Of those 12 were male, and 7 were female. The mean ages at time of interview was 26. The mean age at time of injury was 23.5. Overall these subjects were approximately two and a half years post injury. For most subjects, the cause of injury was vehicular in nature. Diagnosis for injury was in all cases that of traumatic brain injury. Original records depicting type (closed, open, depressed) or periods of post-traumatic amnesia were not included as part of the data from the post-acute rehabilitation center, and this information from cohorts was sometimes imprecise or lacking. Education level ranged from high school levels (10) to post high school (6) to college graduate (3). Interviews with cohorts indicated that at the time of interview 3 of the group were competitively employed, 13 were unemployed. Of those unemployed, 3 were in an educational program of some kind; 1 was retired with disability, and 9 were receiving some kind of financial assistance of a personal or government-sponsored kind. Most subjects (15) were under their

own daily living care. Four used a helper of which 3 were unpaid family members and one a paid attendant. Two subjects lived alone. All others were with spouse or other family members. Most cohorts indicated a time loss for students in school or a job skill level loss for subjects formerly employed. No report was made for job level advancements or educational level advancement at the time of the interview.

Instrumentation

The primary instruments for this study included a structured interview which contained within it questions from the Social Support Questionnaire (SSQ) (see Appendix A). The Social Support Questionnaire (SSQ) was developed by Irving G. Sarason (Sarason et al., 1983) as one of the measures used to explore the belief on the part of individuals that they are supported emotionally by, and involved with, others (Kaplan, 1990). The measures introduced in this study were developed to explore two elements which Sarason found most important to the concept of social support; (a) the perception that there is a significant number (SSQN) of available others to whom one can turn to in

need; and, (b) a degree of satisfaction (SSQS) with the available support. A family score could also be acquired for people described as family members. A professional non-family score could also be obtained.

Additional interview questions were included to explore the area of perceived social independence (INDD) and perceived satisfaction levels of independence (INDS). These questions were part of the structured interview as indicated earlier and followed the same format within the interview as the SSQ.

The Social Support Questionnaire has been widely used in clinical settings (Sarason, Sarason, & Shearin, 1986). Original validation used college student samples. Other correlations were found to be significantly related ($p < .05$ to $p < .001$) to the Beck Depression Scale, Multiple Adjective Affect Check List, Inventory of Social Supportive Behaviors, Family Environment List, Eysenck Personality Inventory, Marlowe-Crowne Scale, and Life Experience Scale (Sarason, Sarason, Hacker, & Basham, 1985). It has been found to relate to various individual difference variables in ways consistent with samples in the original validation work ($p < .001$).

The present shortened SSQ was developed by Sarason, Sarason, Shearin, and Pierce (1987) to meet the time barriers that a lengthier assessment presents. It has been researched for test, retest reliability ($p < .001$), internal reliability (range .96 to .98) and correlation to the original version of the SSQ ($p < .001$). It was found to be psychometrically sound as an acceptable substitute. This shorter version of the SSQ is reported to be highly similar in correlation by its two scores (number and satisfaction correlations ranged from .96 to .98) with comparable scores of the longer SSQ and in its relationship to a variety of personality and social competence variables. Both the test-retest, and the internal reliability ($p < .05$) of the shorter SSQ were reported by Sarason as highly satisfactory.

A cohort telephone interview was also completed. The interview followed an outline for factual information about current status information outlined in Appendix B. Information regarding medical and demographic background were obtained as much as possible from medical information given by the

rehabilitation center according to the items outlined in Appendix B.

Procedure

Permission was obtained from a major rehabilitation center to work with a sample of their population which met subject criteria (see Appendix C). Portions of their records were obtained and reviewed for medical background and demographic information.

A notice of request for telephone interview (see Appendix D) was sent to each subject from the sample selected. Informed consent was a part of the notice and was designed to alert and protect subjects from any known risks. Official consent from the subject was requested by a follow-up call approximately two weeks later. Upon giving consent a structured telephone interview based upon questions from the SSQ (see Appendix A) was conducted.

Responses were audio taped for consent purposes only. Information received was transferred to records by number so that anonymity was maintained. After responses were recorded, all audio tapes other than

those parts with specific indication of verbal consent were destroyed.

During the same interview a request was made from the subject for a designated cohort. The designated cohort was to be used to establish the factual data of current status. Mutual confidentiality of response for either or both subject or cohort was stated.

After the subject interview, a notice of request form was sent to each of the designated cohorts (see Appendix E). Approximately two weeks later a follow-up cohort interview was conducted. Perceptions taken earlier from subjects were handled as confidential. Cohorts responded primarily to factual questions of present status of the subject.

Total information obtained constituted general trauma history information, current status information, and perceptual information. Perceptual information constituted the basic data for the research study. Other data were considered background information.

Statistical Procedures

As noted earlier, eight research questions were tested. The first four were preliminary research

questions and were analyzed using descriptive statistics, such as ranges and means. Four major research questions were tested using a Pearson product-moment correlation measure.

With respect to both primary and major research questions the variable of independence (INDD) was ascribed three connotations; physical independence (INDD_p), economic independence (INDD_e) and self overall as essentially an independent person (INDD_s). Parallel to that, satisfaction with level of independence (INDS) was ascribed three connotations also; satisfaction with physical independence (INDS_p), satisfaction with economic independence (INDS_e), and satisfaction with self overall as essentially an independent person (INDS_s).

Preliminary Research Questions

Question #1

To what degree do former clients view themselves as having support systems (SSQN)?

There were six interview items that addressed availability of support persons. For each item, from

zero up to nine individuals could be listed as support resources. The total constituted the number or quantity for any individual. A total of 54 support persons could be listed for all 6 questions for each individual. To answer this question, mean and ranges of quantity for each question were determined, as was the overall mean.

Question #2

To what degree do former clients feel satisfied with their perceived support systems?

For each of the six items about the number of support resources there was a parallel item regarding the level of satisfaction with the support system. Levels ranged from 1 to 6. The maximum possible score for satisfaction was 36. To answer this question, the mean and range for satisfaction for each item were determined. The overall mean was also determined.

Question #3

To what degree do former clients view themselves as independent persons?

Independence was ascribed three connotations in the study, physical independence, economic independence and self overall, as essentially an independent person.

The subject response for each connotation could range from 1 to 6. A maximum score of 6 could be listed for each connotation of independence. To answer this question mean and ranges were determined for each connotation.

Question #4

To what degree are former clients satisfied with their perceived independence (INDS)?

For each connotation of perceived independence there was a parallel connotation regarding the level of satisfaction with it. There were listed levels of satisfaction with perceived physical independence, perceived economic independence, and perception of self overall, as essentially an independent person. Levels for each ranged from 1 to 6. The maximum level of satisfaction for any one connotation was 6. To answer this question ranges and means were determined for each of the three connotations. Three overall means were also determined.

Major Research Question

Question #5

To what degree does support system number relate to levels of perceived independence?

To study this question, number (quantity) scores were used with perceived economic independence scores, perceived physical independence scores and scores for perceptions of self overall as an essentially independent person, respectively. These three sets of scores were used as input for three Pearson product-moment correlation measures.

Question #6

To what degree do levels of satisfaction with support systems relate to levels of perceived independence?

Support system satisfaction scores were compared with scores for perceptions of physical independence, perceptions of economic independence, and perceptions of self overall as essentially an independent person. These three sets of scores were used as input for three Pearson product-moment correlation measures.

Question #7

To what degree does support system number relate to levels of satisfaction with degree of independence?

Support system satisfaction scores were compared with scores for satisfaction with physical independence, satisfaction with economic independence and satisfaction with perception of self overall as essentially an independent person, respectively. These three sets of scores were used as input for three Pearson product-moment correlation measures.

Question #8

To what degree do levels of satisfaction with support systems relate to levels of satisfaction with degree of independence?

To explore this question, satisfaction with support system scores were used with three independence scores: physical independence, economic independence, and self overall as essentially an independent person. These three sets of scores were used as input for three Pearson product-moment correlation measures.

CHAPTER IV

RESULTS

Research Questions

Presentation of data analysis for this study is listed according to each research question asked. A total of eight research questions were tested. The first four were preliminary research questions and were analyzed using descriptive statistics, e.g., ranges and means. Four other major research questions, were tested using a correlation coefficient (Pearson product-moment) measure (Gardner, 1975). Related questions for analysis such as gender, and family as a number score (quantity) are also discussed.

Preliminary Research Questions

Question #1

To what degree do former clients view themselves as having support systems (SSQN)?

There were six items that addressed the availability of support persons. For each item up to

nine individuals could be listed as support resources. The same individual could be listed for each of the six items. A total of fifty-four support persons (quantity) could be listed for all six questions for each subject. Specific subject response ranged from a total quantity of 7 to 39 with a mean score of 18.947 for the group. The responders did, in fact, use the same support persons for different items. Mean scores from subject responders for each of the six questions indicate the number of persons identified as supports as shown in Table 1.

The response means for the separate items show the highest number ($\bar{M} = 5.63$) of support persons for item number 1 and lowest ($\bar{M} = 2.13$) number for item number 9. Item number 1 required a response about general help only, while the items 3 through 11 asked for responses from support persons who would give help for more specific emotional issues.

In all items, responses indicated that subjects viewed themselves as having some support systems when in emotional need. For a subject, the mean number (18.95) indicated those support persons who could be counted upon to help, to care, to console, to help one

Table 1

Means and Ranges for Items as Listed on SSO as Quantity

Items	<u>M</u>	<u>SD</u>	Range
1. Number you can count on to be dependable when you need help.	5.63	2.31	3 - 9
3. Number you can count on to help you feel more relaxed when you are under pressure or tense.	2.32	2.29	0 - 9
5. Number who accepts you totally including your worst and best points.	2.47	1.65	0 - 6
7. Number you can count on to care about you regardless of what is happening to you.	2.42	2.41	1 - 9
9. Number you can count on to help you feel better when you are feeling down in the dumps.	2.37	2.39	0 - 9
11. Number you can count on to console you when you are very upset.	2.53	2.63	0 - 9
Total	18.95	8.55	

Note: odd numbered items measured quantity of support

feel better, to accept one's best and worst points, and to relax one, as listed in items 1, 3, 5, 7, 9, and 11 in Table 1. However, subject responses varied. For a few subjects a zero ("no one") response was given for some of the items. In one case "God" was given as a support.

Question # 2

To what degree do former clients feel satisfied with their perceived support systems (SSQS)?

For each of the six items about the number of support resources there was a parallel item regarding the level of satisfaction with support system. Levels could range from 1 (very dissatisfied) to 6 (very satisfied). Subject responses indicated an overall mean of 4.91 on the 1 to 6 scale. This indicates that, generally, subjects rated the levels of satisfaction as "fairly satisfied" in their overall perceived support systems. Response means reflected differing levels of satisfaction for particular items as is indicated in Table 2.

Generally scores indicate a consistent high level of satisfaction with support systems across all

Table 2

Means and Ranges for Items as Listed on SSQ as Satisfaction Levels

Items	<u>M</u>	<u>SD</u>	Range
2. Satisfaction with support for when you need help	5.37	.83	3 - 6
4. Satisfaction with support for when you are under pressure or are tense	4.79	.92	3 - 6
6. Satisfaction with support for total acceptance including best and worst points	4.95	.97	2 - 6
8. Satisfaction with support for caring about you regardless of what is happening	5.05	.85	3 - 6
10. Satisfaction with support for help for when you are feeling down in the dumps	4.74	1.45	1 - 6
12. Satisfaction with support for consolation when upset	4.58	1.67	1 - 6
Overall	4.91		

Note: even numbered items measure satisfaction with support

questions asked. However, specific responses for some items differed. The highest mean (5.37) was for item 2. This item requested a response about satisfaction with support for general help. Questions #4 through 12 asked for responses about satisfaction with support about more specific emotional issues.

Question #3

To what degree do former clients view themselves as independent persons (INDD)?

Independence was ascribed three connotations in the study, that of (a) physical independence, (b) economic independence, and apart from these two, (c) self overall as essentially an independent person. Subject responses for each item could range from 1 (very dependent) to 6 (very independent). Results are shown in Table 3.

Generally among these questions perceptions of least independence were economic. A response mean of 3.74 reflected that the subjects rated this as "a little independent" on the interview rating scale. The perception of greatest independence was for perception of self overall as essentially an independent person.

Table 3

Means for Level of Perception of Independence (INDD

Satisfaction	<u>M</u>	<u>SD</u>
INDD _p (physical)	4.63	1.57
INDD _e (economic)	3.74	1.76
INDD _s (self)	5.16	1.26

A response mean of 5.16 indicated that the subjects gave ratings of being overall "fairly independent."

Question #4

To what degree are former clients satisfied with their perceived independence (INDS)?

Satisfaction with independence was given three connotations parallel to perceived level of independence. The three connotations were (a) satisfaction with physical independence, (b) satisfaction with economic independence, or (c) satisfaction with self overall as essentially an independent person. Results are shown in Table 4.

The subject ratings that indicated least satisfaction were those for degree of perceived economic independence ($\bar{M}$ =3.90). Ratings for greatest satisfaction overall were those for satisfaction in level of self overall as essentially an independent person ($\bar{M}$ =5.26).

Major Research Questions

The following questions address relationships between support system number (SSQN), support system

Table 4

Means for Level of Satisfaction with Degree of Independence (INDS)

Satisfaction	<u>M</u>	<u>SD</u>
INDD _p (physical)	4.37	1.57
INDD _e (economic)	3.90	1.82
INDD _s (self)	5.26	1.15

satisfaction (SSQS), perceived levels of independence (INDD), and satisfaction with levels of independence (INDS). A correlation coefficient (Pearson product-moment) measure was used to analyze these relationships.

This was an exploratory study. It contained no null hypotheses and used a small sample. To control for a Type II error (Gay, 1976) and to facilitate statistical clarity, the magnitude of correlation results are described and levels of significance are stated. Descriptors are stated as similar to the conventions suggested by Davis (1971, p. 49) who suggests them as useful to a reader in agreement as to "what is a strong value and what is a weak one." Some probability findings not beyond the .05 significance level are also reported.

In this study, levels of perceived independence are presented with three connotations whenever used; (a) levels of perceived physical functioning (INDD_p), (b) levels of perceived economic functioning (INDD_e), and (c) levels of perception of self overall as an essentially independent person (INDD_s). Satisfaction with degree of independence is also shown in the

following questions with three connotations: (a) satisfaction with degree of physical independence ($INDS_p$), (b) satisfaction with degree of economic independence ($INDS_e$) and (c) satisfaction with degree of self overall, as essentially an independent person ($INDS_s$).

Question # 5

To what degree does support system number (SSQN) relate to levels of perceived independence (INDD)?

The correlation between support system number and levels of perceived physical independence was low and positive ($r=.15$). The correlation between support system number and levels of perceived economic independence was low and positive ($r=.25$). The correlation between support system number and perceived self overall as essentially an independent person was low and negative ($r=-.12$).

There was no notable relationship between the number of support persons available and the perceived degree of physical independence or economic independence or perceptions of self overall as essentially an independent person.

Table 5

Support System Number (SSQN) versus Levels of Perceived Degree of Independence (INDD)

SSQN	r	p
INDS _p (physical)	.15	.536
INDS _e (economic)	.25	.309
INDS _s (self)	-.12	.616

Note: df=17

Question #6

To what degree do levels of satisfaction with support systems (SSQS) relate to levels of perceived independence (INDS)? Results are shown in Table 6.

A moderate positive correlation was obtained when comparing levels of satisfaction with support systems and levels of perceived economic independence ($r=.49$). There is a significant relationship ($p<.034$) between the variables. To the degree that subjects were satisfied with their support systems they tended to perceive their level of economic independence to be high.

A moderate positive correlation was obtained when comparing levels of satisfaction with support systems and levels of perceived physical independence. However, the relationship was not a significant one ($p<.127$).

There was a negligible negative correlation obtained between support system satisfaction and perceptions of self overall as essentially an independent person ($r=-.07$). There was no notable relationship satisfaction with support systems and

Table 6

Levels of Satisfaction with Support Systems (SSQS)
versus Levels of Perceived Independence (INDD)

SSQN	r	p
INDS _p (physical)	.36	.127
INDS _e (economic)	.49	.034
INDS _s (self)	-.07	.771

Note: df=17

perceptions of self overall as essentially an independent person.

Question #7

To what degree does a support system number (SSQN) relate to levels of satisfaction with degree of independence (INDS)? Results are shown in Table 7.

The correlation between support system number and satisfaction with levels of perceived physical independence was low and positive ($r=.13$). There was a moderate positive correlation between support system number and levels of satisfaction with perceived economic independence ($r=.34$). The correlation between support system number and levels of perception of self overall as an essentially independent person was low and positive ($r=.10$).

The number of support resources available to the subject was not notably related to the client's level of satisfaction with perceived physical independence or satisfaction with level of self overall as essentially an independent person. The number of support resources available to the subject was not significantly related to the client's satisfaction with perceived level of

Table 7

Support System Number (SSQN) Versus Levels of
Satisfaction with Degree of Independence (INDS)

SSQN	r	p
INDS _p (physical)	.13	.600
INDS _e (economic)	.34	.157
INDS _s (self)	.10	.683

Note: df=17

economic independence ($p < .157$), although the correlation magnitude was a moderate positive one.

Question #8

To what degree do levels of satisfaction (SSQS) with support systems relate to levels of satisfaction with degree of independence (INDS)? Results are shown in Table 8.

Results showed a substantial positive correlation between the subject's satisfaction with perceived support systems and the satisfaction with their perceptions of physical independence ($r = .68$). There is a significant relationship ($p < .002$). Results indicated a moderate positive correlation between the subjects' satisfaction with perceived support system and satisfaction with their perception of economic independence ($r = .49$). The relationship is significant ($p < .032$). To the degree that subjects were satisfied with their support resources, they tended also to be satisfied with their perceived levels of physical and economic independence. A negligible positive correlation was obtained when comparing satisfaction with support resources and satisfaction with

Table 8

Levels of Satisfaction with Support Systems (SSQS)
Versus Levels of Satisfaction with Degree of
Independence (INDS)

SSQS	r	p
INDS _p (physical)	.68	.002
INDS _e (economic)	.49	.032
INDS _s (self)	.06	.801

Note: df=17

perceptions of self overall as an essentially independent person ($r=.06$). No notable relationship was found between satisfactory support systems and levels of satisfaction with perceptions of self overall as essentially an independent person.

Related Questions for Analysis

Family as Quantity

A question specific to the number of support systems available (quantity) involved the number of family members represented within that number. Of the number of persons listed as support resources family membership ranged from 10% to 100%, per client response. The overall mean percentage of family members for the total client group was 63.8%.

1. Correlation was tested to analyze the relationships between support system number (specific to family members only) and levels of perceived independence. Results are shown in Table 9.

(a) Correlation between support system family number and that of physical

independence was as low and negative ($r=-.20$). There is no notable relationship.

(b) Correlation between support system family number and that of the economic independence was negligible and positive ($r=.08$). There is no notable relationship.

(c) Correlation between support system family number and that of the perception of self overall as essentially an independent person was moderate and negative ($r=-.38$). There is no significant relationship ($p<.105$).

2. Correlation was tested to analyze the relationships between support system number (specific to family members only) and levels of satisfaction with perceived independence. Results are shown in Table 10.

a) Correlation between support system family number and that of satisfaction with physical independence is low and

Table 9

Support System Family Number (SSQN) versus Levels of Perceived INdependence (INDS)

SSQNf (family)	r	p
INDS _p (physical)	-.20	.422
INDS _e (economic)	.08	.746
INDS _s (self)	-.38	.105

Note: df=17

negative ($r = -.21$). There is no notable relationship.

- (b) Correlation between support system family number and that of satisfaction with economic independence is low and positive ($r = .22$). There is no notable relationship.
- (c) Correlation between support system family number and that of satisfaction with perception of self overall as essentially an independent person is moderate and negative ($r = -.37$). There is no significant relationship ($p < .124$).

No significant relationship is indicated between family number of support and other variables in this sample study. There are however correlations of modest negative magnitude between support system family membership and perception of self overall as an essentially independent person. Future research might include these variables.

Table 10

Support System Family Number (SSQNf) versus Levels of Satisfaction with Degree of Independence (INDS)

SSQNf (family)	r	p
INDS _p (physical)	-.21	.401
INDS _e (economic)	.22	.369
INDS _s (self)	-.37	.124

Note: df=17

GENDER

As indicated earlier there were 12 males and 7 females. Gender factors were analyzed using a Mann-Whitney U test. In this study there were no significant differences between male and female samples. Results are shown in Table 11.

Table 11

Social Support and Independence Mean Ranks for Male and Female Subjects

Variable	Male	Female	Z ^a
SSQN	10.42	9.29	.424
SSQN (family)	9.75	10.43	.254
SSQS	9.13	11.50	.891
INDD			
INDD _p (physical)	9.75	10.43	.265
INDD _e (economic)	8.29	12.93	1.761
INDD _s (self)	11.17	8.00	1.325
INDS			
INDS _p (physical)	9.17	11.43	.872
INDS _e (economic)	8.50	12.57	1.559
INDS _s (self)	10.42	9.29	1.325

^aZ is corrected for ties; level of significance ($p < .05$) requires a z of 1.96

CHAPTER V

DISCUSSION AND IMPLICATIONS

Discussion

Summary

The purpose of this descriptive study was to examine the relationship between perceptions of social support and perceptions of independence among former clients of a rehabilitation center specializing in head injury. As a consumer, the client's recovery to independence is the focal goal of the rehabilitation process. However, the client's own perceptions and preferences are often not a major part of the process.

Inclusion of client perceptions could facilitate the achievement of congruence of outcome goals among the client, the rehabilitation personnel, the family caretakers, and the community. Documentation of a relationship between social support and independence, using client perceptions, could be beneficial to achievement of such congruence. In addition, benefits might be gained in attempts for increased research

toward more consumer focused programs within the standards of therapeutic processes. Documentation could also support present efforts toward increased social systems and services.

Subjects were 19 former clients of a rehabilitation center who had sustained traumatic brain injury, were six to eighteen months post discharge and were estimated to be at or about Rancho Amigos Level VII. Telephone interviews were first conducted with them and later with cohorts assigned by them. One individual declined to specify a cohort.

Cohort information was given for demographic background purposes only and answers given did not constitute data for research study. Conversations with subject or cohorts were held mutually, and globally, as confidential, and only after deliverance of informed consent requirements.

Discussion of Data Analysis

Eight research questions were tested. The first four were preliminary research questions and were analyzed using descriptive statistics, such as ranges

and means. Four major research questions were tested using a Pearson product-moment correlation measure.

With respect to both primary and major research questions independence (INDD) was ascribed three connotations; physical independence (INDD_p), economic independence (INDD_e), and self as essentially an independent person (INDD_s). Parallel to that, satisfaction with level of independence (INDS) was ascribed three connotations also; satisfaction with physical independence (INDS_p), satisfaction with economic independence (INDS_e), and satisfaction with self as essentially an independent person (INDS_s). Related questions for analysis such as family (e.g. quantity) and gender were also explored. This study was an exploratory one with a small sample and with description of relationships as its goal. In order to avoid Type II errors, modest correlations were reported descriptively. Relationships that were statistically significant were stated. The following summarizes the results.

Preliminary Research Questions

- (1) Responses indicated that subjects perceived themselves as having support systems, although for specific questions subject responses were "no one" or "God."
- (2) With respect to satisfaction with support systems, subject response indicated satisfaction level to be high, or "fairly satisfied."
- 3) Among perceptions of independence subjects responses indicated the perception of self overall as an independent person to be the highest level of independence levels rated. The level of perceived economic independence was rated lowest of the three measures.
- 4) Subjects rated greatest satisfaction with perceptions of themselves overall as essentially independent persons. Least satisfaction was indicated for levels of perceived economic independence.

Major Research Questions

These questions addressed relationships between support system number (quantity), support system satisfaction, perceived levels of independence, and satisfaction with levels of independence.

- (1) The subjects' satisfaction with perceived support systems showed a significant relationship to perceived economic independence. To the degree that subjects were satisfied with their available others, they rated their perceptions of economic independence to be high. Since this was a correlational, rather than a causal-comparative study, relationships found cannot be predictive. Therefore, this correlation could indicate a number of things including an increased perception of economic independence (rather than objective independent economic states) as a function of adequate support systems. It could indicate, conversely, that those who have adequate economic independence, are also financially able to maintain a social network in a

socially/financially viable way that is satisfactory to them. The data indicated a moderate positive correlation between satisfaction with support systems and levels of perceived physical independence, but the relationship was not statistically significant in this study and inferences cannot be made within the scope of this sample study. It may be a question for future studies, however.

- (2) A significant relationship was obtained when comparing levels of satisfaction with support systems and levels of satisfaction with perceived physical and economic independence. To the degree that subjects were satisfied with their support resources they indicated satisfaction with both their physical and economic perceptual levels of independence. Background information for the subjects indicate physical and economic hardship for the group as a sample. This is not uncommon in the larger population of head-injured individuals, who are often placed in a

position of increased physical, financial, and social dependency (Brooks et al., 1984.). The relationship between perceived satisfactory social supports and satisfaction with (possibly) altered physical and economic status suggests the beneficial relationship of social networks despite decreased physical and financial independence.

- (3) No significant relationships were obtained when comparing support system number with (a) perceived independence or (b) satisfaction with perceived independence, in any of its three connotations. In this exploratory study, subjects did not report data that showed any notable relationships between the quantity of support resources available, and their perceptions of, or satisfaction with, physical independence. Data did not show a significant relationship between support system number and levels of perceived economic independence either. However, there was a modest correlation between support system number and levels of satisfaction with

degree of economic independence. For this sample study, it was not a significant relationship. Future research might address this question.

- (4) Negligible correlations were obtained when comparing levels of satisfaction with support systems with (a) perceptions of self overall as essentially an independent person or (b) levels of satisfaction with self overall as essentially an independent person.

Generally, the perceived level of self overall as essentially an independent person, and the satisfaction level with self overall as essentially an independent person were rated as being the highest of the preliminary questions asked. It appeared that the subjects generally answered these questions in isolation from consideration of relative physical or economic perceptions. A specific request to (a) consider the three aspects of perceptions of independence and then, additionally, (b) evaluate a separate overall level of independence may have had further descriptive benefits. The pilot study initial to this research study did not suggest a possible

researchable difference between self, as essentially an independent person, and self as overall an independent person. Further delineation is not possible in this study, but is a suggestion for future research studies.

Related Questions

A question specific to the number of support systems available (quantity) involved the family members represented within that number. That question and a question about gender difference are discussed below.

Family. In this sample study, when family membership was used (SSQN_f) to compare support system number with levels of perceived independence, in any of its three connotations, or with satisfaction with independence in any of its three connotations, no significant relationships were found. However, there was a moderate negative correlation found between support system family number and perceptions of self overall as essentially an independent person. Also there was a moderate negative correlation obtained between support system family number and satisfaction with level of

self overall as essentially an independent person. Further inference about family membership cannot be made in this study, but may be a question for future research.

Gender. There was no significant difference between gender groups in this sample. However, because of the possible masking effect such gender issues might have in other studies, testing for gender is a continuing recommendation in consideration for future studies.

Implications for Practitioners

Social supports, in this study had two elements (a) the perception of a sufficient number of available others (quantity) and (b) a degree of satisfaction with the available support. Data analysis for this sample showed different results when comparing the number (quantity) of supports with independence variables than when comparing satisfaction with independence variables. No significant relationships were found with regard to the number (quantity) of support systems and perceptions of, or satisfaction with, any of the three aspects of independence studied. However,

results show that the subjects' satisfaction with social supports was related to several aspects of independence; that of perception of economic independence, and that of satisfaction with both economic independence and physical independence.

These results may indicate a need for rehabilitation personnel to focus more efforts on the individuals perception of a satisfactory support system as opposed to number (quantity).

- (1) For instance, despite the opportunity for the individual to name past therapists, social service personnel, case managers or current vocational counselors as support for help, only one therapist was mentioned, and one psychologist who was, in fact, a private psycho-therapist outside the rehabilitation process. Rehabilitation as an industry, places value on personnel acting as, or facilitating social supports, but clearly, within this sample, they were not represented as past or present perceived supports, nor were other clients. Theoretically, there are many rehabilitative personnel available in a

rehabilitation center. There are many other clients going through similar difficulties within the same rehabilitation center. Further effort may determine the kind of strategies needed to utilize available professional personnel or commonalities between clients in a way that will result in increased perception of these persons as potential support systems.

- (2) Conversely, the lack of significant relationship between the number (quantity) of supports seen as needed and any perceptions of independence may suggest the need for greater focus on counseling techniques in rehabilitation centers to nurture, facilitate and maintain in a cohesive way those supports already within the individual's network. This would tend to change the focus of techniques now used which (a) emphasize counseling for the individual subject(s) and (b) attempt support groups for family members, but (c) rarely (if ever) attempt formalized consistent, on-going counseling

groups for subjects and their perceived support systems (whoever they may be), together. Since once discharged, the individual must fall back on those on whom s/he can count for help, benefits could accrue to that individual if these important others are made part of the in-facility rehabilitation process.

- (3) Finally, results of this study did not show significant relationships between any kind of social support and perceptions of, or satisfaction with, self overall as essentially an independent person. This concept for the subject seemed isolated from consideration of either physical or emotional independence. Subjects' ratings for self were at the highest levels of any perceptions asked and may reflect descriptions of themselves as held over time (and before injury). The ratings may also reflect coping mechanisms. Research studies indicate denial as a factor often noted in head-injured

individuals (Prigatano, Altman, & O'Brien, 1990).

In summary, social support and independence are words commonly used by rehabilitation personnel, family caretakers, and vocational re-entry planners. However, the perceptions about social support and independence expressed by the subjects in this study present a different way of viewing such issues. Those views may be beneficial as input to further effort, for more congruent comprehensive rehabilitation programs.

Recommendations for Further Research

This study was one whose purpose was an exploratory, descriptive one. A small number of former clients was sampled, from one rehabilitation center. Even among the sample group, three could not be contacted because of the lack of a phone. Furthermore, the cognitive requirement of Rancho's Amigos Cognitive Level VII narrowed the sample. Therefore the sample may not represent the population of individuals with head injury. In addition, since correlations, not predictions, between variables were sought, those correlations found cannot be considered causal or

predictive. Significant relationships found could, indeed, be spurious results of factors not considered. However research correlations found between satisfaction with a subject's support system and aspects of (a) perceived economic independence, and (b) satisfaction with perceived physical and economic independence does point out the need for future research because of it's seeming beneficial value.

In addition the data indicate no significant relationship between the number (quantity) of support persons and perceptions of independence. Future research should address the distinction between these two variables. Data presented here did not usually include rehabilitation personnel as part of support, past or present. In the perceptions of the head-injured individual a satisfactory support system is indicated to be an important difference from that of support number.

It should be added, however, that among the perceptions of independence there was a moderate negative, not significant, correlation between support system number and perceptions of, and satisfaction with, economic independence. No inference was made for

this sample study but future research might address this question among perceptions of independence.

Although relationships between support systems and perceptions of self overall as an independent person were not established, further research which distinguishes the self as essentially an independent person from the self as an overall independent person may be helpful. For instance, in this study the structured interview (see Appendix A) used as part of its language a description of the self as socially, or emotionally or psychologically able to make his/her own decisions. Future research might ask to what degree the self is overall independent as influenced by constraints of physical, economic, or other dependencies which prevent action in decision results. Any study which compares effectiveness of subject identified supports using a measure like the SSQ, in a group counseling milieu, as compared with current individual or family group counseling techniques might be fruitful.

Finally, future research which further delineates factors of clients' perceptions of social support and independence can be helpful in increasing the value of

their input to the rehabilitation process. Such input can increase congruence to the many issues and perceptions involved in comprehensive rehabilitation of the individual who has sustained traumatic head injury.

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APPENDICES

APPENDIX A

Name _____

Age: _____ Sex: _____ Date: _____

INSTRUCTIONS: The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials, and their relationship to you. Do not list more than nine people.

For the second part, rate how satisfied you are with the overall support you have. If you have had no support for a question, just say "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the question as best you can. All your responses will be kept confidential.

Example

Who do you know whom you can trust with information that could get you in trouble?

_____ No one	1) T.N. (brother)	4) T.N. (father)	7)
	2) L.M. (friend)	5) L.M. (employer)	8)
	3) R.S. (friend)	6)	9)

How satisfied?

6- very satisfied	5- fairly satisfied	4 - a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1 - very dissatisfied
----------------------	------------------------	---------------------------	-----------------------------	---------------------------	--------------------------

1. Whom can you really count on to be dependable when you need help?

_____ No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

2. How satisfied?

6- very satisfied	5- fairly satisfied	4 - a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1 - very dissatisfied
----------------------	------------------------	---------------------------	-----------------------------	---------------------------	--------------------------

3. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

_____ No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

4. How satisfied?
6- very satisfied 5- fairly satisfied 4 - a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1 - very dissatisfied
5. Who accepts you totally, including both your worst and your best points?
____ No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)
6. How satisfied?
6- very satisfied 5- fairly satisfied 4 - a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1 - very dissatisfied
7. Whom can you really count on to care about you, regardless of what is happening to you?
____ No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)
8. How satisfied?
6- very satisfied 5- fairly satisfied 4 - a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1 - very dissatisfied
9. Whom can you really count on to help you feel better when you are feeling generally down-in-the -dumps?
____ No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)
10. How satisfied?
6- very satisfied 5- fairly satisfied 4 - a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1 - very dissatisfied
11. Whom can you count on to console you when you are very upset?
____ No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

12. How satisfied?
- | | | | | | |
|----------------------|------------------------|---------------------------|-----------------------------|---------------------------|--------------------------|
| 6- very
satisfied | 5- fairly
satisfied | 4 - a little
satisfied | 3- a little
dissatisfied | 2- fairly
dissatisfied | 1 - very
dissatisfied |
|----------------------|------------------------|---------------------------|-----------------------------|---------------------------|--------------------------|

The next few questions ask about your perceptions of independence.

1. How independent in physical functioning and doing everyday things do you see yourself?

- | | |
|------------------------|----------------------|
| 6 very independent | 3 a little dependant |
| 5 fairly independent | 2 fairly dependent |
| 4 a little independent | 1 very dependent |

- 1a. How satisfied?

- | | |
|----------------------|-------------------------|
| 6 very satisfied | 3 a little dissatisfied |
| 5 fairly satisfied | 2 fairly dissatisfied |
| 4 a little satisfied | 1 very dissatisfied |

2. How independent economically (or financially or materially) do you see yourself?

- | | |
|------------------------|----------------------|
| 6 very independent | 3 a little dependant |
| 5 fairly independent | 2 fairly dependent |
| 4 a little independent | 1 very dependent |

- 2a. How satisfied?

- | | |
|----------------------|-------------------------|
| 6 very satisfied | 3 a little dissatisfied |
| 5 fairly satisfied | 2 fairly dissatisfied |
| 4 a little satisfied | 1 very dissatisfied |

3. Overall to what degree do you see yourself as essentially an independent person (socially or emotionally or psychologically able to make your own decisions) ?

- | | |
|------------------------|----------------------|
| 6 very independent | 3 a little dependant |
| 5 fairly independent | 2 fairly dependent |
| 4 a little independent | 1 very dependent |

- 3a. How satisfied?

- | | |
|----------------------|-------------------------|
| 6 very satisfied | 3 a little dissatisfied |
| 5 fairly satisfied | 2 fairly dissatisfied |
| 4 a little satisfied | 1 very dissatisfied |

APPENDIX B

Background and Status Information - Medical and Demographic

SEX

Male

Female

MARITAL STATUS

Single

Married

Divorced

Separated

AGE AT ONSET**AGE AT ADMISSION TO THIS
FACILITY****CAUSE OF INJURY**

MVA (bike, plane)

Fall

Assault

Gunshot

Pedestrian

Other

TYPE INJURY

Closed

Open

Depressed

OCCUPATION PRIOR TO INJURY

Employed

professional

skilled

clerical

other

Unemployed - no assistance

Unemployed - with assistance

EDUCATION

College years

High School level

Elementary level

LIVING ARRANGEMENT

Home

Board & Care

Transitional Living

Rehab Facility-Other

Others

LIVING WITH

Alone

Family/Relatives

Attendant

Other

ECONOMIC

Job

Assistance

Student

Other

HEALTH MAINTENANCE

Own Care

Unpaid Helper

Paid Attendant

Paid Professional

APPENDIX C

New Medico Rehabilitation Center of Tennessee

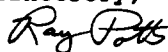
10-10-90

Dear Ms. O'Donnell,

Your dissertation proposal, as we discussed over the telephone, appears to have good potential for increasing the body of knowledge about the long-term aspects of recovery following rehabilitation. This knowledge should enable head-injured individuals and their families to better cope with the long-term effects of their injury, and should educate treatment facilities such that they can better perform their functions as well.

We are happy to offer assistance to you in the endeavor to study the issues described in your proposal. Please contact me so that we can coordinate efforts and get your research study implemented.

Sincerely,



Ray Potts, Ed.D.
Program Director
Licensed Psychologist

205 Westgate Drive
Springfield, Tennessee
37172

Telephone
(615) 384-8686

APPENDIX D

Facility
Street Address
City, State, Zip
Client Information

Notification of Telephone Interview Follow-Up for _____

During your rehabilitation stay, you and the staff of this facility worked together in improving your ability to perform important activities of living, working with others, and becoming more independent. Your progress was monitored from admissions time to discharge. In order to study some long term benefits from rehabilitation, we ask that you allow us to contact you again, so that we may ask your opinion about some areas of your daily living situation now. Some of the things we hope to ask you about concern your opinion about your independence. Also, we will ask your opinion about the people in your environment who give you help or support.

Your participation is of course, totally voluntary. The telephone interviewer will identify herself as representing our facility. The interview will take about thirty minutes. Your responses will be kept confidential in accordance with standard rules of confidentiality and consent outlined below. The interviewer will ask you if you are willing to give your opinion about your current status. If you do not wish to participate, simply let her know. Questions about the results of this study will not be answered for several months. Other questions may be addressed to:

William Poppen, Ph.d., Project Director
Education & Counseling Psychology

108 Claxton Education Bldg.
University of Tennessee
Knoxville, TN 37996-3400 (615) 974-5131

Ray Potts, Ed.D., Licensed Dept. of
Psychologist, Program Director

New Medico Rehabilitation Center
205 Westgate Drive • Springfield,
TN 37172 (615) 384-8686

We hope you will participate in this important follow-up study.

Statement of Consent and Confidentiality

This study constitutes outcome research. Participation is totally voluntary and confidential. Refusal to respond carries no penalties and individuals may withdraw or discontinue participation at any point. No foreseeable risks or discomforts are indicated. No direct or indirect benefit to the individual is foreseen other than that of verbal input towards possible future directions for facility rehabilitation efforts.

Responses will be audio taped for consent purposes only. Information received will be transferred to records by number so that no one other than the researcher will be able to identify you by name. After responses are recorded, all audio tapes other than specific indications of verbal consent for participation will be destroyed. All data will be treated confidentially.

Only the project director, his representative, and the program director of this facility will have access to the response records, which will be kept in a locked file cabinet in the project director's office. Only overall responses for all results will be reported, thus preserving individual confidentiality.

APPENDIX E

Facility
Street Address
City, State, Zip

Client Information

Notification of Telephone Follow-Up for

Dear Friend or Family Member:

During the rehabilitation stay of _____, we all worked together to improve many important daily activities. We carefully monitored progress from admission to discharge. In order to study the long term benefits of rehabilitation we have contacted _____ to ask about some opinions regarding present status. You are a person as suggested by _____ as a source of information and assistance. We ask that you allow us to contact you, also, regarding some issue's of _____ present living status. Permission has been given for you to do so.

Your participation is of course, totally voluntary. The telephone interviewer will identify herself as representing our facility. The interview will take about thirty minutes. Your responses will be kept confidential in accordance with standard rules of confidentiality and consent outlined below. If you do not wish to participate, simply let her know. Questions about the results of this study will not be answered for several months. Other questions may be addressed to:

William Poppen, Ph.d., Project Director
Dept. of Education & Counseling Psychology

Ray Potts, Ed.D., Licensed
Psychologist, Program Director

108 Claxton Education Bldg.
University of Tennessee
Knoxville, TN 37996-3400 (615) 974-5131

New Medico Rehabilitation Center
205 Westgate Drive • Springfield,
TN 37172 (615) 384-8686

We hope you will participate in this important follow-up study.

Statement of Consent and Confidentiality

This study constitutes outcome research. Participation is totally voluntary and confidential. Refusal to respond carries no penalties and individuals may withdraw or discontinue participation at any point. No foreseeable risks or discomforts are indicated. No direct or indirect benefit to the individual is foreseen other than that of verbal input towards possible future directions for facility rehabilitation efforts.

Responses will be audio taped for consent purposes only. Information received will be transferred to records by number so that no one other than the researcher will be able to identify you by name. After responses are recorded, all audio tapes other than specific indications of verbal consent for participation will be destroyed. All data will treated confidentially.

Only the project director, his representative, and the program director of this facility will have access to the response records, which will be kept in a locked file cabinet in the project director's office. Only overall responses for all results will be reported, thus preserving individual confidentiality.

APPENDIX F

THE UNIVERSITY OF TENNESSEE
KNOXVILLE



CRP #: 3379 A

DATE: 11/30/90

Title: Social Support as a Factor of Perceived Independence Among
Head-Injured Individuals

Research
Administration

Compliances

Grants &
Contracts

Proposal
Development
Services

O'Donnell, Phyllis
Educational & Counseling Psych
1411 Anderson Ave.
Maryville, TN 37801

Poppen, Dr. William A.
Ed. & Counseling Psychology
108 Claxton Ed. Bldg.
Campus

The project listed above has been certified exempt from review by the
Committee on Research Participation and is approved.

This certification is for a period ending one year from the date of
this letter. Please make timely submission of renewal or prompt
notification of project termination (see item #2 below).

The responsibilities of the project director include the following:

1. Prior approval from the Coordinator of Compliances must be
obtained before any changes in the project are instituted.
2. Submission of a Form D to request renewal, report changes
during the approval period, or report termination of the
project.

We wish you success in your research endeavors.

Sincerely,

Edith M. Szathmary
Edith M. Szathmary
Coordinator of Compliances

cc: Dr. Steve McCallum
108 Claxton Ed. Bldg.

Attachment: Copy of Form A

404 Andy Holt Tower / Knoxville, Tennessee 37996-0140 (615) 974-3466 / FAX (615) 974-2805

VITA

Phyllis Herrick O'Donnell was born to Raymond and Cora Herrick in Ashford, Connecticut on February 11, 1935. She completed elementary school in Preston, Connecticut and graduated from Norwich Free Academy in June, 1953.

O'Donnell received the Bachelor of Arts degree from the University of Connecticut. She received a Master of Science degree from Central Connecticut State College in May of 1975.

Her professional work experience includes that of teacher, consultant, writer, and licensed psychological examiner. She has received two scholarships in education achievement and research, and has been a co-author of numerous articles.