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PATIENT-GUIDED INVESTIGATION OF THE RESTORATION OF HEALTH FOLLOWING TRAUMATIC BRAIN INJURY

by

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ABSTRACT

An abstract of the dissertation of Nancy Ann Carney for the Doctor of Philosophy in Systems Science: Psychology presented May 5, 1998.

Title: Patient-Guided Investigation of the Restoration of Health Following Traumatic Brain Injury

The development of emergency department medical interventions and the implementation of fast-transport trauma systems has decreased the rate of death resulting from traumatic brain injury (TBI). Without corresponding methods for long-term treatment and recovery, the prevalence of people disabled by TBI has increased, creating a growing public health problem. Investigations generated by physicians, rehabilitation programs, and social scientists, which attempt to associate standard measures of injury severity with outcome, leave unexplained variance in long-term functional status for persons with TBI.

The purpose of this investigation was to use persons with brain injury and their family members, to guide an analysis of the factors that foster successful recovery from brain injury. Three studies were conducted. In Study #1, the method for observation generated by Kurt Goldstein (1934) was adopted to conduct 20 case studies of persons who sustained brain injury. The Schema of the EsEx Couple (Maynard, 1992) was used to orient the investigation. The EsEx Couple Schema proposes that events in human life must be understood by considering the whole system of Person (Essence) in the Environment (Exchange), and the transactions that flow in a recursive loop from Person to Environment and back. Kurt Goldstein's Laws of Organismic Life (1934), a model consistent with that of the EsEx Couple, was used to evaluate the data. Strong patterns associated family and social networks, autonomy, and perceived self-determination with higher levels of recovery, and were used to generate a Model for Recovery.

In Study #2, the Motivational Analysis of Self-Systems Processes (Connell & Wellborn, 1991) was combined with results from Study #1 to generate a Development Model, and to build a survey which was administered to 248 persons with brain injury. Results (1) confirmed the model, indicating factors that contribute to recovery were hypothesized measures of Social Context, Perception, and Engagement; and (2) established a valid instrument, generated by persons with brain injury and their families, for measuring functional status.

In Study #3, results of the survey research were used to return to the case studies to consider where individual lives differ from expected patterns, and why. Deviations from expected patterns were explored to identify how individual differences operate to affect outcome. Recommendations for clinical practice include (1) directing interventions toward family as well as patient, as a method of enhancing the Social Context for the patient, and (2) using careful evaluation of each patient's idiosyncracies to consider individual interventions.

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CHAPTER I. INTRODUCTION AND LITERATURE REVIEW

Introduction

The purpose of this dissertation project was to use persons with brain injury and their family members to investigate the question: What factors foster successful recovery from brain injury? Because survivors of brain injury have not been consulted in formulating research and programs for their own benefit, I chose the case study method to initiate the project. My intention was to interview survivors and their families, to see if they held information about their recovery process that would serve to inform scientists and physicians. I used them as a team of consultants as well, to assist me in defining long-term functional status and outcome for TBI.

As will be discussed in this dissertation, research in this field has been driven by models borrowed from other pathologies that may not be appropriate for the analysis of brain injury (Johnston & Hall, 1994). In addition, there persists a gap between immediate measures of the pathology, such as injury severity, and long-term outcomes (Dikmen, Ross, Machamer, & Temkin, 1995). The ultimate goal of the research that this dissertation *initiates* is the accurate specification of proper methods and criteria for analyzing and measuring outcome from brain injury and the recovery process. The goal within the scope of this project was to build a new framework, using survivors, for conceptualizing survivorship and recovery that might move science in the direction of devising better and more relevant measures; to build a Model for Recovery. The test of the adequacy of the model would be how well it serves to explain the variation in outcome from brain injury.

The theoretical foundations for my project came from three fields. The EsEx Couple Schema (Maynard, 1992), explained fully in Chapter II, provided an understanding of all life processes in terms of Systems Theory. The general orientation allowed for the specific process of brain injury recovery to be considered for how it is governed by general laws.

The second field from which I borrowed theory was medicine, embodied in the writings of Kurt Goldstein (1934), a physician who studied people with brain injury while treating them in field hospitals during World War I. Goldstein specified a clinical method for evaluating pathology which I used to conduct the case studies. He also generated the Laws of Organismic Life, a conceptualization of life processes, founded in systems principles, which he used to analyze brain injury. I joined this theory with the EsEx Couple Schema to produce a Recovery Model I used to explain results from the case studies. This was Study #1.

The third field to provide theory was Developmental Psychology. Researchers in this field, seeking to enhance learning environments for children, have developed theories, methods for testing, and instruments for measurement, directed toward the question, what are the factors that foster or impede normal development and successful learning. I combined material from the other two fields and data from the case studies with the Motivational Analysis of Self-System Processes (Connell & Wellborn, 1991) to generate a Development Model, and to design a survey instrument to assess functional status and outcome from TBI. This was Study #2.

In Study #3, I took results from the survey and returned to the case studies. I overlaid the quantitative data of the larger sample onto the qualitative data of the case studies, to consider where the individual lives fit the patterns generated by the survey research, where they did not fit, and why.

The following section describes the current status of brain injury with respect to epidemiology, physical and psychological sequelae, evaluation methods, and treatments.

Definition and Scope of Traumatic Brain Injury

The Society

The National Head Injury Foundation (1985) defined traumatic brain injury (TBI) as "a traumatic insult to the brain capable of producing physical, intellectual, emotional, social, and vocational changes." The incidence of TBI in the United States is estimated to be 200 per 100,000 (Johnston & Hall, 1994). TBI is the third most common cause of death in America, and the primary cause of death in persons under the age of 38 (Ewing, Thomas, Sances, & Larson, 1983; Mateer, 1986).

Most TBI victims are males who were injured in car accidents (Engberg, 1995). The cost of rehospitalization and nursing homes is estimated to be $4.49 billion a year. Estimates of the annual cost of lost work and cost of disability subsidy are $20.6 billion and $12.7 billion, respectively. Lost work constitutes the largest economic cost associated with TBI (Johnston & Hall, 1994). The cumulative effect of the annually increasing TBI population has not yet been measured (LaMarche, Reed, Rich, Cash, Lucas, & Boll, 1995).

For the billions of dollars a year spent on rehabilitation, many improve, but it is not known whether the improvement reflects a natural healing process, or is the effect of the rehabilitation (Strax, 1994). Funding for TBI rehabilitation is being threatened (Hall & Cope, 1995; Johnston & Hall, 1994; Mozzoni & Bailey, 1996). Expensive specialized treatment is being denied by payers (Hall & Cope; Mozzoni & Bailey). National standards for measuring TBI rehabilitation do not exist. Assessment of deficits is now done using many different criteria, developed locally at various facilities, which is seen by courts and payers as insufficient (Johnston & Hall).

One strategy some states employ to decrease TBI is implementation of statewide Trauma Systems. They function by transporting severely injured patients to designated trauma centers where appropriate treatment is available. Emergency Medical Technicians are trained and authorized to designate "trauma system patients" at the scene of injury using predetermined triage criteria (Zimmer-Gembeck et al., 1995). Recent investigations show that mortality due to trauma in Oregon has decreased significantly since implementation of its Trauma System, and that a decrease in death with head trauma patients is the main effect of the system (Mullins et al., 1994). However, the long-term functional status of the survivors is not known, and the current ability to rehabilitate brain injury is limited. It may be that the result of the trauma system and other strategies for the acute care of TBI is an increase in the prevalence of the pathology; patients survive to be added to the growing pool of disabled.

The prevalence of TBI in the State of Oregon is estimated to be approximately 32,000 (BIAO, 1996). The Brain Injury Association of Oregon (BIAO) through its network of brain injured survivors, professionals, and family members, can account for 10% of the total TBI population. Oregon lacks a comprehensive, accurate description of its TBI population.

The Individual

The effect of head trauma on the individual varies with (1) strength and duration of the social network, (2) pre-trauma factors such as socioeconomic status, age, gender, I.Q., education, and previous traumas, and (3) severity of injury. (High, Boake, & Lehmkuhl, 1995; Lezak, 1995). These variables both directly affect outcome for the individual, and have indirect effects due to their relationship with each other (Heinemann & Whiteneck, 1995). For instance, socioeconomic status and social network are known to influence injury severity; pre-trauma I.Q. will in part determine post-trauma functional status.

Social Support

As Johnston and Hall (1994) point out, TBI causes unique cognitive impairments in memory, attention, and problem solving. It affects behaviors and disabilities differently from physical or mental health problems. Many TBI patients experience intact pre-trauma memory, with a loss of ability to integrate new information. Without a memory of the accident and subsequent events, the patients are unable to understand their deficits and move through normal phases of psychological recovery necessary to adjustment.

Also common among TBI is loss of executive function. Lezak (1995) defined executive function as follows: "The executive functions consist of those capacities that enable a person to engage successfully in independent, purposive, self-serving behavior. . . Questions about executive functions ask how or whether a person goes about doing something" (p. 42). Components of executive functions targeted in cognitive rehabilitation are initiation/inhibition, planning, organization, follow-through, and problem-solving.

Inappropriate behavior results from loss of memory and executive function and is especially a problem in sustaining employment, family relationships and friendships (Treadwell & Page, 1996). For example, in a study of 55 brain damaged people and their families, Brooks and McKinlay (1983) had relatives complete adjective profiles characterizing the patients' personalities pre-trauma and at the present time. These profiles were completed at 3, 6, and 12 months post-trauma. Results were that, as time passed, relatives' reports of TBI's personality changes became increasingly negative.

Willer, Allen, Liss, and Zicht (1991) reviewed research on long-term adjustment for brain injured people that investigated patients with injury dates up to 15 years in the past. They also found that as time passed, family members reported more behavioral and cognitive problems in TBI patients. In one study reviewed by Willer et al., which included nine people who were married at the time of injury, only two remained married at follow-up. This is consistent with other research findings that marriages are particularly vulnerable to the effects of brain injury (Lezak, 1995).

The primary component of a TBI's social network is almost always the family. During hospitalization and after discharge, professionals rely on family members to provide daily care, reminders of what is familiar to the patient, and assistance with repetitive rehabilitation tasks. The family is considered a critical determinant of successful outcome for the patient (Rosenthal & Young, 1988).

In a review and pilot study, Dunkel-Schetter and Skokan (1990) found that, in a hypothetical scenario, respondents were more willing to offer support to people who were actively coping with their situation (i.e., AIDS or cancer). They identified a possible link between empathy and motivation to help, but found the link to weaken as the cost of helping increased. In situations such as brain damage recovery, where constant attention and reminding is often required, the cost to the caregiver may overcome their willingness to help.

Kozloff (1987) used network analysis to investigate the relationship of social support systems to outcomes for TBI patients. Data were collected by observation, guided interview, and unstructured interview. Independent variables were structure, content, and function of the social network. Demographic data were also collected. Kozloff found that as time from trauma increased (chronicity), network size decreased and density increased. Also, as time progressed, the number of multiplex relationships increased. As friends and peripheral relations discontinued their association with the patient, the remaining members of the network, usually family, served multiple functions.

Pre-Trauma Factors

There is evidence that patients who have sustained other sorts of injuries have more psychological difficulties after head trauma than do patients for whom the head trauma is the first serious trauma (McKinlay & Brooks, 1984; Skord & Miranti, 1994). Thus, this pre-trauma factor, previous injuries, will have an effect on outcome.

Any change in a person's life due to a head trauma (or any trauma) must be evaluated by comparing that person's life prior to the incident with that person's life afterwards. For instance, if before an accident a person was habitually unemployed, and is likewise unemployed after the accident, then low post-trauma scores on a work-stability dimension do not implicate the accident, because there has been no change. In other words, outcome cannot be measured in an absolute way against a societal norm. Outcome for each person must be measured against that person's premorbid status (Johnston & Hall, 1994).

This measurement issue has practical implications for rehabilitation. If rehabilitation success is measured by employment, and the rehabilitation program has participants who didn't work before the trauma, then it is safe to assume that the success rate, as measured, will be low. But the meaning of a low score in this case is unclear unless pre-trauma employment is taken into account.

Injury Severity

The Glasgow Coma Scale (GCS) is the international standard for measuring severity of brain injury. A GCS of 3 to 8 is severe, 9 to 12 is moderate, and 13 to 15 is mild. Problems with using the GCS in TBI research were pointed out in a study of an alternative severity measure (Stambrook, Moore, Lubusko, Peters, & Blumenschein, 1993). Authors noted that often head trauma patients are intoxicated when treated in acute care facilities. One study reported between one-third and one-half of hospitalized head trauma patients have blood alcohol levels exceeding the legal limit for intoxication in most states (Corrigan, Rust, & Lamb-Hart, 1995). The GCS measures level of unconsciousness, but does not distinguish between alcohol-induced and trauma-induced unconsciousness.

Duration of post-traumatic amnesia (PTA), measured by the Galveston Orientation and Amnesia Test (GOAT), is another predictor of general outcomes for TBI. Early indicators of severity are (1) worst score GCS within 24 hours of injury, (2) length of coma (duration of GCS less than 9), and (3) duration of PTA.

The GCS as well as other severity measures are not predictive within the category of mild head injury (Corrigan, Rust, & Lamb-Hart, 1995). In other words, a severity measure may indicate an injury is mild, but will not predict whether the person's outcome will be consistent with the fact that the injury is not severe. Some individuals with mild head injury return to their former activities with minimal effort; others end up living on the street. Severity measures do not predict one outcome from the other.

Brooks and McKinlay (1983) found that as severity of injury increased, relatives were more likely to report a personality change in the patient, but that overall, severity of injury was not a good predictor of the magnitude of scores on the personality scale. In other words, severity level predicted personality change categorically (yes or no), but not continuously (level of change). Important in this study is the authors' measure of severity, operationally defined as "the interval between the injury and the regaining of continuous day-to-day memory" p. 340. We know that, for many patients, continuous day-to-day memory is never regained. This definition limited the sample to a higher functioning group, at least on the dimension of memory.

In Wilson's study (1992) the eight patients whose scores on the outcome measure improved over time were also those with a shorter coma period. However, improved scores and coma length did not correlate with independence. Some patients whose scores did not improve and who were in coma longer were living independently. On the other hand, Fryer and Haffey (1987) demonstrated a relationship between severity of injury and rehabilitation success.

Treatment Methods

Disposition at discharge indicates where a patient goes after acute care. Factors influencing the decision include finances, injury severity, availability of programs, and patient and family preferences. For most, funds for rehabilitation are limited, and this fact, combined with injury severity, will determine where a person goes after acute care (Brislawn, 1994).

Rehabilitation

Rehabilitation is defined as "the re-acquisition or relearning of skills and capabilities necessary to function as a member of our society" (Brislawn, 1994, p. 19-1). The definition implies that skills and capabilities were possessed in the past and lost, and may be regained through treatment. Recovery means returning to a past, healthy, state.

The current economic climate places emphasis on financial independence as the goal of rehabilitation (Smigielski, Malec, Thompson, & DePompolo, 1992). In one study (Johnston & Hall, 1994), investigators asked different rehabilitation constituencies their outcome objectives. All 165 providers/payers who responded listed "maximize functional independence" as the most important objective. The operating principle of most rehabilitation programs is that returning to work is the priority (Wehman, West, Kregel, Sherron, & Kreutzer, 1995).

Client involvement and individually designed treatment have been shown to be factors that influence success in rehabilitation (Corrigan & Deming, 1995; Mills, Nesbeda, Katz, & Alexander, 1992). However, as Johnston and Hall (1994) point out, systematic solicitation of patient and family goals is not prevalent.

Rehabilitation has been conceptualized a number of different ways, such as reductionist vs. dynamic, in-patient vs. out-patient, skills training vs. process specific.

Reductionist vs. Dynamic

The reductionist approach uses performance scores on neuropsychologic tests to diagnose deficits, and relies on practice or repetition to restore functions. The therapeutic focus is on physical, occupational, and speech therapy (Brotherton, Thomas, Wisotezek, & Milan, 1988). The dynamic rehabilitation approach places a low reliance on absolute neuropsychologic test performance, and an emphasis on individual programs which are plastic and respond to the change and growth of the individual.

In-Patient vs. Out-Patient

In general, the more seriously debilitated patients are discharged to in-patient facilities. Patients with some ability to function independently will be considered for out-patient placement. The factors that determine in- or out-patient placement are (1) injury severity and resulting functional constraints, and (2) family status. If a family is able, and is so inclined, it may elect to keep home a severely limited TBI patient.

Skills Training vs. Process Specific

Many TBI patients are unable to return to their jobs after hospital discharge, and require some form of rehabilitation (Wehman, West, Kregel, Sherron, & Kreutzer, 1995). For this group, the most common route is that of Disability Insurance and Vocational Rehabilitation (Skord & Miranti, 1994). In most states, Vocational Rehabilitation employs the skills training model. Individuals are assessed for their physical, cognitive, and emotional capabilities (usually by a neuropsychologist) and placed in a skills training milieu thought to be appropriate to their capabilities. Generally, subsidy for this kind of rehabilitation is terminated at 1 year, based on the notion that most, if not all, functional recovery will be accomplished within that time.

The process specific approach to cognitive rehabilitation is based on the information-processing model of cognition. This model conceptualizes cognition as a system of highly integrated and interdependent parts which process information at different levels (Cermak, 1982; Craik & Lockhart, 1972). Cognitive functioning is thought to be improved with rehabilitation that targets specific processes defined by the information processing model. The model assumes that different cognitive areas can be treated individually and can be directly retrained or corrected. The first step is to accurately identify the impaired process or processes. While some controlled studies demonstrated a treatment effect on intermediate outcomes (Niemann, Ruff, & Baser, 1990), others resulted in no treatment effect (Novak, Caldwell, Duke, Berquist, & Gage, 1996). Of the fifteen random controlled trials that investigated the efficacy of cognitive rehabilitation, none demonstrated a generalization of improvement from the intermediate outcome measure to practical functional status skills.

Research indicates that evaluation of the individual on many different levels (current physical, emotional, and cognitive constraints as well as pre-trauma factors) should occur in determining type of post-acute rehabilitation. Ylvisaker (1985) suggested consideration of two factors in selecting a rehabilitation program. First, consider the individual's current strengths and weaknesses, and second, match the program to the person's general intellectual level, measured both pre- and post-morbid.

In evaluating two rehabilitation program models, Fryer and Haffey (1987) found that competency on target measures was dependent on individually tailored cognitive devices. The more the individual's needs were considered, and the more the individual was involved in designing the program, the higher the scores on outcome measures. In spite of the evidence that individually tailored programs produce greater success than standard programs, finances usually dictate the type of rehabilitation a patient enters, which places most in the standard vocational rehabilitation milieu.

Traditional approaches to rehabilitation, particularly in the post-acute recovery phase, often do not result in successful community and family reintegration, or in successful employment (Smigielski, Malec, Thompson, & DePompolo, 1992). In addition, research design has not distinguished between spontaneous recovery and the effects of rehabilitation (High, Boake, & Lehmkuhl, 1995; Johnston & Hall, 1994), therefore the efficacy of rehabilitation remains unknown. Some consider the TBI rehabilitation industry to be reaping the rewards of spontaneous recovery (Lange, 1996).

Compensation

Crosson et al. (1989) defined compensation as "the deliberate application of a procedure that enables a patient to obtain a goal the realization of which would otherwise be prevented by impaired functioning" p. 46. Crosson specified four kinds of compensation.

1. Anticipatory compensation requires anticipatory awareness, an ability many TBI's do not possess. This is the ability to know in advance that a problem may occur, and to prepare for it. It requires that the survivor understand and accept the deficits.

2) Recognition compensation is triggered at the moment a problem arises.

3) Situational compensation is a kind of "blanket" technique. People are trained to respond by doing "X" whenever anything in a general set of "Y" happens.

4) External compensation consists of establishing cues in the environment and use of tools outside the cognitive process, such as memory books.

Wilson (1992) investigated use of compensatory strategies taught to 29 TBI patients in a program which varied according to individual needs. Most patients reported using more aids when reassessed at 1 year follow-up than they did during the training. Results suggested that, despite the fact that patients were introduced to a wide variety of aids during rehabilitation, they only made use of them when forced to do so by the demands of daily living.

Compensation tools can be internal or external. An example of internal compensation is the use of a mnemonic to trigger memory for appropriate action. They are cognitive tools; use of internal compensation requires some consistent facility with memory and retrieval. External compensation may be a sign pointing to the bathroom, a picture of someone placed where it is seen often, a memory book, etc.

Mateer and Mapou (1996) point out that use of compensatory strategies in management of cognitive impairments is not well researched, but possesses high face validity, and is often used in rehabilitation programs.

Backman and Dixon (1992) reviewed a variety of literature in which compensation was defined or applied from four domains of pathology: sensory handicaps, cognitive deficits, interpersonal losses, and brain injury. The value of this work is that it clearly represents how compensation is conceptualized in the applied psychological environment. The following summarizes relevant information from the review.

Taken from the English and English (1958) dictionary, one definition of compensation offered by Backman and Dixon (1992) is "action that aims to make amends for some lack or loss in personal characteristics or status; or action that achieves partial satisfaction when direct satisfaction is blocked" (p. 101). With the brain injury population, Backman and Dixon equate biological compensation with substitution of function. They state,

> "Compensation can be inferred when an objective or perceived mismatch between accessible skills and environmental demands is counterbalanced (either automatically or deliberately) by investment of more time or effort (drawing on normal skills), utilization of latent (but normally inactive) skills, or acquisition of new skills, so that a change in the behavioral profile occurs, either in the direction of adaptive attainment, maintenance, or surpassing of normal levels of proficiency or of maladaptive outcome behaviors or consequences" (p. 272).

The current literature characterizes compensation as the application of a procedure: counterbalancing for lack of a skill by using another skill. The focus is on the defective performance or performance fields.

No Treatment

"After attaining medical stability, many survivors of severe injury improve on the basis of their own efforts, aided by family and without intensive professional interventions" (Johnston & Hall, 1994, p. SC-4).

Most TBI patients receive some form of rehabilitation after hospital discharge. Those that do not may be the profoundly disabled, the mildly disabled, or those whose families will not give consent.

As Johnston and Hall (1994) pointed out, many accomplish some level of recovery without formal rehabilitation. Their knowledge of the process has not been documented. For those who participate in formal programs, spontaneous recovery is confounded with change resulting from rehabilitation. It is not known how much each contributes to the change.

Evaluation of this question is constrained by:

- Ethics. We are not able to systematically withhold treatment for someone who might benefit.
- Samples. Samples consist mainly of people with mid-range trauma severity.
- Research Methods. Most outcomes research is directed at rehabilitation, with a specific agenda of maximizing individual productivity. Methods have not systematically included patient priorities, and have not included an accurate and comprehensive measure of pre-morbid functional status as a baseline.

Evaluation Methods

Deficit Measurement

The title of Chapter Four of Muriel Lezak's neuropsychological compendium (1995) is "The Rationale of Deficit Measurement." In this chapter, Lezak explains that it is through deficiencies in control, awareness, and intellect that the results of brain insult are manifested behaviorally. She goes on to describe normative vs. individual methods of deficit assessment.

Lezak (1995) asserts that normative measures are appropriate only under the following conditions: (1) when the target being measured is functioning within average range for the normal population, and (2) when the target is not influenced by learning or general intellectual level. These criteria render normative measures alone, in most cases, inappropriate for assessing TBI.

Lezak (1995) relies on a combination of normative and individual techniques in evaluation. Individuals can be measured against themselves directly if premorbid test scores are available, such as old school records or military entrance exams. Indirect methods, that is estimating premorbid performance levels and measuring postmorbid performance against the estimate, can be accomplished by collecting historical data, or by a variety of formulas that have been developed. The Best Score Method (Lezak) assumes the highest postmorbid score from a battery of tests, or best unscored performance, is an indicator of the person's average premorbid ability. Mortensen, Gade, and Reinish (1991) found the Best Score Method systematically overestimates premorbid ability. However, as Lezak pointed out, Mortensen and colleagues used the highest score on one battery obtained by normal control subjects for their estimates.

Wilson (1992) used two methods for evaluating outcome for a group of 29 TBI patients. When using a group mean method, the result was a significant increase in scores after rehabilitation. When a more stringent, individual assessment was employed, Wilson found that eight subjects had improved, 14 had no change, and three had declined. Wilson also found that of 18 people who scored within the lowest possible category on the Wechsler Adult Intelligence Scale, 11 were living independently. These investigations suggest that the power of some normative techniques to predict functional outcomes might not be adequate.

Individual Evaluation

It is typical for a TBI patient to be evaluated by a neuropsychologist prior to discharge from acute care. Results contribute to the decision about placement, and may become part of the patient's hospital discharge record. A typical neuropsychological evaluation lasts several hours and incorporates a series of tests designed to measure deficits in specific areas. Scores on tests in those areas are thought to represent a person's capability to function.

The protocol in which I was trained divided tests into two broad categories of verbal and nonverbal. In the verbal category, patients were tested for old learning and verbal skills, reasoning and judgment, memory, arithmetic, abstract thought, and attention and concentration. In the nonverbal category, patients were tested in perception and reasoning, construction, memory, self regulation, and motor functions. Continuous scores on tests were compared to norms. That comparison determined in which performance category the score on the test placed the individual. There were nine categories, ranging from Very Superior to Defective Below Normal Limits.

Sbordonne (1995) in his work on ecological validity of neuropsychological testing, called into question neuropsychologic evaluation instruments. He asserted that the battery of tests used by neuropsychologists to test for deficits due to brain trauma were not designed to reveal whether or not, or how well, a person will function in the real world.

Goldstein (1934) stated that deficient responses make us aware that pathology exists, and then become the focus of our examination. Because deficiencies are what catch our attention, our attempts to modify the pathology are defined by our measures of the perceived deficiencies. Goldstein argued that even with clearly defined cortical injury, deficiencies are almost never confined to one performance. Rather, there are both symptomatic changes which signal pathology (incidental phenomena), and also a basic change that affects all behavior in the same way (essential phenomenon). Goldstein asserted that the behaviors that catch our attention may not be basic or key to understanding the pathology.

> "The danger arises only when this discrimination between essential and incidental phenomena is neglected . . . The incidental phenomena may have

value only for preliminary orientation and may, at best, merit the position of a crude working hypothesis. The real crisis arises when, even in the face of new findings, the investigator cannot free himself from the former theory; rather the scientist attempts to preserve it and, by constant emendations, to reconcile it with these new facts instead of replacing it by a new theory fitted to deal with both" (p. 34).

Survey and Interview Research

Researchers have used interview and survey research to evaluate the impact of TBI at the individual level. Even with cognitively intact people, survey research responses may be distorted by recall bias or other factors. With cognitively impaired people. such as TBI survivors, survey research is particularly vulnerable.

In a review article. Mckinlay and Brooks (1984) discussed three methodological issues with regard to assessing TBI survivors. Their questions. and findings. were as follows:

1. Are there systematic differences between the progress reports of survivors and those of their relatives? Results showed no significant difference in reports between survivors and their relatives on physical handicaps, but significant differences in reports on behavioral and emotional outcomes.
2) Is "lack of insight" on the part of the survivor the reason for the discrepancy in reports? Results showed no relationship between level of cognitive

ability and discrepancy on reports, suggesting that "lack of insight" is not why survivors and their relatives disagree.

3) Are personality characteristics of relatives the reason for the discrepancy in reports? Results showed a relationship between relatives' neuroticism and major behavioral problems with the survivor; however, there was no relationship between relatives' neuroticism and the discrepancy in reports.

Willer et al. (1991) found systematic differences in the views of patients vs. relatives regarding degree of impairment. There was high agreement on sensory and motor impairment, and low agreement on behavioral and emotional characteristics. Relatives reported more impairment than patients on the latter set of characteristics.

Program Evaluation

Johnston and Hall (1994) asserted that programs resist evaluation because they have limited resources, administrators question how much benefit derives from the collected data, and there is wide-spread uncertainty about how to conduct accurate outcomes research. At the same time, the increase in TBI is feeding a consumer movement in rehabilitation which is creating a demand for high quality services. The only way to provide assurance of quality is by standardization of outcome measurement. In addition, in order to justify the expense of rehabilitation, there is a need to establish that gains in measured areas go beyond what would occur from spontaneous recovery (Johnston & Hall, 1994).

Many rehabilitation programs incorporate cognitive rehabilitation and components of the process-specific approach in their protocol. That is, they include interventions based on the newer, more plastic rehabilitation models. However, systematic implementation of these methods is still too new for long-term evaluation. Fryer and Haffey (1987) reviewed results of an intensive outpatient cognitive rehabilitation program and an inpatient, community re-entry program. These models were not compared with each other. They were not equated on degree of deficit of treated patients since different deficit levels were assigned to the two different models; higher functioning to the cognitive rehabilitation program, and lower to the inpatient program.

The cognitive retraining program addressed four categories of functioning, and designed retraining to target those categories. However, at the same time, patients were trained daily in use of external compensation aids. They also participated daily in group therapy and individual psychotherapy. No control group was used. Results showed significant improvement in specified areas at the end of rehabilitation for the cognitive retraining program. It is not clear from this research, however, what accounted for the success achieved by the program - the cognitive retraining, the therapy, the external compensation, or spontaneous recovery, as these factors were confounded in the design of the study.

Outcomes Evaluation

Donabedian (1980) defined health care outcomes as follows: "Outcomes are those changes, either favorable or adverse, in the actual or potential health status of persons, groups, or communities that can be attributed to prior or concurrent care" p. 256. Johnston and Hall (1994) define health outcomes as the patient's experienced morbidity, rather than an organ system measure (e.g., mortality).

Technical ability to measure health outcomes is growing (Mills. Nesbeda. Katz. & Alexander. 1992). However. with a few exceptions, TBI outcome measures are considered by professionals to be technically inadequate. To be useful. the measure must include technically accurate severity and treatment measures. and they must incorporate the viewpoint of clients (patients and family) (Sederer & Dickey. 1996).

Mills. Nesbeda. Katz. and Alexander (1992) investigated functional outcomes from an outpatient, post-acute cognitive rehabilitation program for 42 TBI patients. Patient improvement was determined by (1) accomplishment of treatment goals. (2) differences in pre- and post-treatment functional measures, and (3) speech pathology cognitive measures. Patients' scores on functional measures increased significantly from treatment, were maintained 18 months after treatment. and were independent of age, neuropathology, injury severity, and chronicity. In contrast. cognitive measures had not changed significantly. Where the neuropsychological measures indicated no change, the functional outcome measures indicated significant gains.

Qualitative Research

Focus Groups

Willer et al. (1991) used the focus group method to collect data to identify the range and type of problems reported by TBI patients and their spouses, and to identify coping strategies. They recruited 31 couples (20 with an injured husband and 11 with an injured wife). They divided into eight small groups. A question was posed to the group and each person wrote a list of answers. Members then contributed one idea at a time until all ideas were shared and listed on a flip chart. There was a group discussion about each idea, then participants prioritized ideas by anonymous written ballot, reducing the list in size to about five or six ideas, based on priorities assigned. The questions each group was asked were, "What problems have you and your family faced since the head injury?" and "What have you and your family done that has helped you cope with these problems?" (p. 461). Using this method, authors were able to discover systematic differences in problems experienced when the husband was injured vs. when the wife was injured, and coping strategies of husbands vs. wives.

Morgan (1992) described the use of focus groups in evaluating primary care. He proposed that focus groups can be used to answer exploratory questions early in a project, or as a way to assess the effectiveness of a program or intervention that is in place; as a precursor/follow-up to other research, or as an independent source of data; and to provide support for a theory.

Interview Research

Dywan and Segalowitz (1996) researched the strength of psychometric measures in predicting adaptive functioning among TBI patients and their families. They used volunteers who were TBI survivors to assist in developing questions for their scales.

While I suspect there are other such research efforts being conducted, this is the only example I found in which patients were actively used to develop a test instrument.

Weller and Romney (1989) described the use of interviews as a method for acquiring qualitative information and for quantifying and analyzing that information.

This review indicates a predominant theme in current TBI literature is that patients have not been used to develop outcome measures either at the level of program or at the level of individual. Also, their understanding of their process of compensation has not been accessed. It is possible that focus group and structured interview research could provide the technology to acquire this information.

Conclusion

Traumatic Brain Injury is a serious and pervasive public health problem. The effect of TBI--the long-term outcome--varies with individual differences in social support, pre-trauma factors, and severity of injury, as well as with differences in interventions. Most rehabilitation programs are based on a model of recovery developed for physical deficits, which may not be adequate for TBI. Newer methods more specific to brain injury remain untested, and their efficacy undemonstrated. The contribution of spontaneous recovery to the improvement process is unknown, and calls into question the effectiveness, and cost-effectiveness, of interventions.

Given the volume of unanswered questions in this field, together with the simple but persistent assertion in the literature that patient input has not been solicited in development of interventions, outcome measures, and research priorities, the potential value of a patient-guided investigation became evident. Previous clinical experience, described in the next chapter, contributed to the decision to propose a case study research design to conduct such an investigation.

CHAPTER II. DEVELOPMENT OF THEORY AND RESEARCH PROTOCOL

Prior Experience and Rationale for Case Study Research

I began my inquiry into the phenomenon of recovery from brain damage in 1992 when I was given the opportunity to direct a team of student volunteers who earned practicum credit for working in a group home. I had been trained in evaluation of organic brain disorders by a clinical neuropsychologist and served a year internship on the intake evaluation team of a neuropsychiatric hospital. I was then invited by my trainer to become involved in a local group home for brain damaged adult males for which he served on the Board of Directors. Through the Community Psychology program at Portland State University I organized a team of undergraduate students to serve at the home. The students were given two instructions. First, help the staff in any way you can. Second, observe with the purpose of formulating ideas for a research project.

Supported by theories and an experimental foundation from cognitive rehabilitation literature (Lezak, 1995), my students and I designed a research project. We proposed to investigate different theoretical models of memory deficit resulting from brain damage, and the effect of different forms of compensation on the deficits. Our measurement tool was a battery of neuropsychologic tests administered clinically to individuals who were brain damaged. Each test was scored, and the score compared to a scale representing normal functioning for the performance being tested.

This research produced two important outcomes. The first was that nothing I predicted occurred. Our tests were clinically sensitive, and could be counted on to identify organic deficits. The theories on which I based predictions, generated by experienced clinicians and experimentalists, were well researched. Two distinct models of memory impairment, retrieval and storage deficits (Sohlberg & Mateer, 1989), were hypothesized to foster different responses to cues. I hypothesized that people who could store but not retrieve information would be more successful using cues than people who could not store information. Still, individual performances did not conform to what should have happened. Not only did they not conform to the predicted pattern, they were remarkably without pattern, so much so that I was led to the conclusion that something else was operating to produce the observed outcomes.

The second important outcome was that, during the course of testing sessions, the patients talked. They told their stories. Although I tried to discourage the discourse, since it tended to lengthen an already long session, I had been trained to record anecdotal information as an important part of evaluation, so I took notes on what was said. Later those notes provided clues to what else was operating. Observations are summarized as follows:

1) Some patients, while profoundly impaired on both physical and cognitive

levels, presented clear communication, and unpredictably high scores on certain tests. Other patients, with what appeared to be mild impairment, were confused, unpredictable, and produced low scores on the cognitive tests.

2) Some patients were doing well in life while others were not, but the degree of success did not systematically associate itself with (a) performance on the tests, or (b) other factors which should predict recovery, such as injury severity.

3) People's methods for negotiating the circumstances of the testing session, how they compensated for their deficits in the present environment, were highly idiosyncratic.

Something else was going on. I didn't know what it was. The tests weren't telling me what it was, but the patients wanted to. As a result of this experience, I decided to conduct a case study research project. I wanted to liberate my investigation from hypotheses and theories. Questions indicating my intended direction for the research were, what are the factors that influence recovery from brain damage? Why do people with similar levels of injury severity present very different levels of recovery? What can persons with brain injury and their families tell us that might help specify the variables operating during the process of recovery?

Although I committed myself to an atheoretical approach at the start, I recognized the need for both a method for conducting the research, and for some general theoretical structure; not one that imposed extensive limitations and preconceptions, but one that would allow me to proceed consistent with the most general of systems principles.

I adopted Kurt Goldstein's theory of method (1934) to guide data collection. I adopted the Schema of the EsEx Couple (Maynard, 1992) as the structure of general systems principles within which the research would proceed. So, a specific theory of method and a general theoretical framework guided the pilot phase.

As patterns began to emerge in observations I sought more structure to assist the analysis of these patterns. During the second phase I adopted two theoretical structures, Kurt Goldstein's Laws of Organismic Life (1934), and the Motivational Analysis of Self-System Processes (Connell & Wellborn, 1991). The following section describes these two phases and the evolution from one to the other, and discusses my synthesis of the schema, method, and theories employed.

Phase 1: Atheoretical Pilot Phase

Goldstein's Theory of Method

The case study approach I used was inspired by the work of Kurt Goldstein (1934). Goldstein, born in Upper Silesia, Germany in 1878, received his medical degree in 1903 and specialized in diseases of the nervous system. He was director of the Military Hospital for Brain-Injured Soldiers during the first World War. His experiences there, and in establishing an institute for research on the after effects of brain injuries, provided the foundation for Goldstein's Organismic Theory. He was influenced by Gestalt psychology and, after moving to America, became associated with Andras Angyal and Abraham Maslow. Goldstein's many hours documenting case studies of brain damage qualified him to generate theories that ranged from the physical to the abstract. His book The Organism: A Holistic Approach to Biology Derived from Pathological Data in Man (1934) is the best known statement of Goldstein's organismic theory. He wrote the book in five weeks while waiting in Holland for his visa to the United States. Aspects of this theory, which today might be called a systems theory of the functioning of the human organism, will be discussed in the section about Phase 2. In The Organism, as well as in many other publications, Goldstein also developed and described his method for observing, diagnosing, and treating brain damaged patients. I used aspects of Goldstein's clinical method for observing and documenting to conduct the case study project. He provided direction on both general and specific modes of observation.

General Principle

As a context for observation, Goldstein asserted that the formation of a theory about observed behavior should follow, not precede, the investigation. *"This inevitably must be the case,"* he wrote, *"since the subject matter itself becomes apparent only during the process of research, as it emerges from the indefinite province in which it was embedded (p. 26)."*

Generally speaking, this is "common sense" advice for the initial phases of any research, since approaching observation with theoretical views in place implies that one knows what one expects to find. But Goldstein's advice to be open minded at the beginning is particularly important in the investigation of brain damage recovery. Although the scope of research in this area has expanded from a narrow focus on the relationship between injury severity and outcome to a broader focus that includes many social and psychological variables, a significant proportion of the variability in outcome remains unexplained (Dikmen, Ross, Machamer, & Temkin, 1995). A current trend in brain damage research is to forsake accepted theories in an attempt to discover the factors that account for the unacceptable degree of unexplained variance in outcome, and to turn to patients and families for guidance. Goldstein provided specific instructions on how to observe and document facts while conducting patient evaluations.

Specific Principles: Symptoms and Analysis

In cortical damage Goldstein identified incidental phenomena and essential phenomena. *Incidental phenomena* are the combination of disturbances or symptoms that can readily be observed. They are only useful for preliminary orientation, and may in fact conceal the fundamental defect. For example, some patients experience visual defects following brain damage. The observable symptoms may be loss of ability to draw a simple picture, running into things, or low scores on visual tests. However, more careful examination reveals the visual mechanisms to be intact, and the damage to be in the patient's ability to mentally construct what is being viewed. The cognitive process is damaged that allows the individual to piece together parts into a whole; prescription glasses will not correct the problem. But what is most obvious to the observer are symptoms which would indicate that the patient can't see well. Such symptoms become the focus of clinical attention, often leading to misdiagnosis, particularly in the case of mild brain injury where no other symptoms are presented other than those interpreted as "visual."

The *essential phenomenon* is the basic change that affects different performance fields homologously, so the essential phenomenon is expressed through various symptoms. With the patient in the previous example whose ability to mentally construct is damaged, an apparent loss of vision may be one symptom. Other symptoms may be reduced comprehension of what is being viewed or listened to, forgetting essential parts of information, or reconstructing physical objects inadequately--that is, in separate pieces rather than in one whole object. The homologous effect is that the world exists for the patient in parts, not in wholes, and this lack of ability to construct wholes can be observed in symptoms of vision, language, dressing, walking, and so forth.

Goldstein presented three methodological postulates as guidelines for patient examination that aid in revealing the true specific nature of the disturbance:

> *1) Consider initially all the phenomena presented by the organism, giving no preference, in the description, to any special one.*
>
> *2) Correctly describe the observable phenomena themselves. Diagnosis is often simplified by noting small and hitherto-unobserved deviations.*
>
> *3) When describing a phenomenon, reference the organism and the situation in which the phenomenon appears (p. 37).*

The methodological postulates provide a more specific structure for observation in the case study project. The purpose of using the postulates is to enable the distinction between incidental and essential phenomena, thus allowing for discovery of the true nature of the pathology.

In addition to these guides to method from Goldstein, one additional assumption about the nature of the observations was made. I assumed that the case histories would vary, with some characteristics shared and some unique. Observed characteristics of brain damage might then be classified as universal, generic, or unique. Universal characteristics are those all persons with TBI share. Generic characteristics are shared by specific classes within the general category of brain damage. Unique characteristics are those that are unique to the individual.

To summarize, the method for observing and documenting the brain injury cases in the pilot phase was as follows:

1) Consider theory only after conducting the observations.
2) Distinguish between incidental and essential phenomena, using the following process:
    a) Document all phenomena.
    b) Describe all phenomena correctly.
    c) Describe phenomena referencing the patient in relation to the environment.
3) Seek universal, generic, and unique characteristics across cases.

To the extent I was able, I followed Goldstein's theory of method in the pilot phase. Ideally, this meant to avoid theorizing until observations were made in order to avoid undue bias in data collection. I approached this ideal as closely as possible, given prior experience and knowledge, but some theoretical orientation was unavoidable. That orientation is embodied in a general schema for conceptualizing human life, the Schema of the EsEx Couple, developed by Hugo Maynard of the Department of Psychology, Portland State University, and communicated to me through writings, lectures, and personal communications. The following outline of the main features of the schema will illustrate the general theoretical approach assumed during the case history data collection.

The Schema of the EsEx Couple and its Application to the Analysis of Brain Damage

Origin

The EsEx Couple schema was inspired by the conflict between Aristotelian and Galilean modes of explanation in science. Aristotle proposed that an event is what it is because of the essential nature, the essence, of the bodies participating in the event. In the 17th Century, Galileo established the convention of explaining an event in terms of the external forces that act upon the bodies involved. The Galilean mode of explanation came to dominate science in the next four hundred years. while Aristotle was discredited and declined in influence. In 1931. Kurt Lewin published a classic paper describing the two modes of explanation and recommended that psychology follow Galileo, as did all other sciences. Behaviorism was then at its peak of influence. and its Galilean model of the empty organism shaped by external forces validated Lewin's position. Recently. however. the life sciences. including psychology. have turned again to an Aristotelian way of thinking. evidenced by the trend to make explanations in terms of genetics. Sociobiology is an example of this recent trend.

Restoration of the Whole

The idea that Aristotle's and Galileo's methods may not be mutually exclusive arises from modern scientific movements, like systems theory. which seek to understand contending doctrines in a new synthesis. Systems theory provides a way to restore a balance between the two opposing modes of thought.

An event may be understood as a duality of essence (Aristotle) and forces (Galileo) which is made into a systemic whole by transactions between the two domains.

Principles of the EsEx Couple

Structure. (See Figure 1). The model contains two domains and their relations. In the model's most general form, at the level of all events, Essence approximates Aristotle's notion of the inherent properties of bodies; Exchange approximates Galileo's notion of the play of forces. The transactions between the two domains are a new element. Essence affects Exchange through Transduction: Essence is read out into Exchange and gives Exchange a shape. Exchange affects Essence through Transformation: In concrete terms, objects impose their shapes onto the world, the world is changed, and that changed world imposes its shape back onto the objects, in a recursive loop. It is important to remember that Essence and Exchange are not things, but domains of explanation. The model directs that, in seeking to account for an event, both domains must be investigated. The idea that Essence and Exchange have a mutual effect on each other's shape or form gives emphasis to the informational properties of the transactions between them. The information is what determines form or shape.

In individuals, Body influences Behavior through Expression; Behavior reciprocates as Habit (see Figure 2). The expression of this system is individual development. The whole system of Body and Behavior at the individual level, and their relations of Expression and Habit, are conceptualized as Mind. In Mind, so conceived. Action is a message with the function of controlling (shaping) Experience. All living creatures encounter Mind from two perspectives: the objective and subjective. In objective mode (the Mind of another), Mind is a transaction between Body and Behavior. In subjective mode (one's own Mind). Mind is a transaction between Experience and Action. The referents are the same. but the difference in perspective (the state of the observer) makes for a difference in labels.

This particular concept of Mind - that Mind encompasses the system of body and behavior. rather than Mind being encompassed by the system - is not new to social science. It is expressed in the ideas of Mind and Self in the work of George Herbert Mead (1934). This perspective on "Mind" takes body (including brain) as the instrument of Mind. but as its necessary. not sufficient. member. It proposes that one cannot subtract the Body's exchanges with the world and still have what we would recognize as Mind. The exchanges are also necessary but not sufficient parts of a system which alone has the Mind's qualities.

I adopted this particular concept of Mind for this project for the following reason. The concept more common in current Western culture that Mind is contained in the brain and located inside Body has defined, and thus limited. inquiry into brain damage. People's behaviors are viewed as an indication of the condition of their minds, and mind as an expression of brain physiology. This linear model serves to organize evaluation linearly, into a pure cause-effect relationship. Tissue damage begets mind disorganization begets abnormal Behavior. The location to which we direct the cure is isolated to damaged tissue, or to inadequate Behavior. The problem is that this cure does not work. That is, outcomes cannot reliably be forecast from treatment. By adopting the proposed model the following is accomplished: The recursive loop allows for an effect of Behavior back onto Body, establishing a dynamic, recursive model of development. Thus an intervention anywhere can effect change in the entire system. This notion might be useful not only in designing interventions, but also in understanding why benign-appearing perturbations in the environment cause so much upheaval with the brain damaged.

In human social systems, the place where humans know each other is in Exchange (see Figure 3). Two human minds overlap in Behavior. The expression of this larger system in which the "world" explicitly appears, may be called Culture. "As the Behavior in which minds meet is behavior shared in common, it induces a like or complementary experience in the like bodies of the partners and makes for the communality of selves which we call Culture." (Maynard, 1992). Culture, in the social science meaning, is difficult to define, but is usually described as a system of shared behaviors and beliefs -- "Knowledge, belief, art, morals, custom, and any other capabilities and habits acquired by man as a member of society" (Tyler, 1958). The present schema proposes that shared experiences are also an essential part of that definition, and that shared behaviors tend to induce the entire list.

Attributes. Essence and Exchange are postulated to be equipotent in the accounting of events. The duality is made whole by the recursive loop of transactions. The whole is dynamic because Transduction and Transformation produce continuous change. This model is sensitive to individual differences because Essence and Exchange are equipotent; so the shape of Essence (body, experience, metabolism, etc.) will put its stamp upon working Mind as much as will the Exchanges (behaviors, social relations, etc.). All events will have their domains of uniqueness, as well as their universal and partial communalities.

The model also asserts that both Essence and Exchange are plastic, and responsive to shaping influences from the other. The plasticity of Body and Behavior is an important feature of this model of Mind. However, time operates to limit plasticity. For example, slow, incremental changes in a person's behavior may be met with greater tolerance (more plasticity) than the sudden, abrupt personality disruptions presented by persons with brain damage.

Because of its dynamism, the system is in constant flux. Under the right conditions of Exchange, it may achieve a steady state or equilibrium. Under other conditions of Exchange the system may go into highly unstable states. In living species these two extremes might be survival or extinction; in living individuals, successful or failed adaptation.

Equilibrium. In biological systems, a steady, renewable state - a biosphere - implies the presence of complimentary creatures, that is symbiotic relationships (e.g., plants emit oxygen and use carbon dioxide; animals emit carbon dioxide and use oxygen). For humans, culture provides a steady and renewable state of life; culture approximates a symbiosis of minds. The EsEx Couple model, therefore, suggests that the presence of symbiotic relationships can be considered an indicator of equilibrium.

The Schema of the EsEx Couple is at a high level of abstraction. Its utility is that it puts the concept of a system and its properties squarely at the center of understanding all events. In spite of many developments in scientific thinking in the 20th century which have brought systems concepts into scientific theory, a tendency persists to think of Nature in fragmented parts. The Nature-Nurture dispute continues, and we still have tendencies to account for the whole by invoking one of its parts. This schema is a reminder that attempts to account for an event like the outcome of head injury won't work if they consider only Essence (the injury, brain states) or Exchange (behaviors, social relations). Only a full account of the working system will give an understanding of the outcomes in a working life.

and both Experience and Behavior are sources of useful information.

Versions of the EsEx Couple schema already exist in biology and medicine as theories of development and of disease. Nature-plus-Nurture theories of development in Biology and Psychology, and Stress-Diathesis models of disease in medicine are examples of similar models. The EsEx Couple model merely adds certain system characteristics to schemata already in use, and generalizes the core idea to all events. All such schemata are general enough that they do not impose undue constraint on observation. They mainly serve as reminders that one must attend to both states of the body and states of the milieu to have an adequate model of biological processes. This is a restatement of Goldstein's third methodological postulate, referenced earlier.

In addition to Goldstein's recommendations on method, the EsEx Couple was the only theoretical orientation in the pilot phase. So, although the initial phase was not entirely atheoretical, the guiding theory was of the most abstract and general kind.

Transition from Phase 1 to Phase 2

In Phase 1, I conducted interviews with survivors of brain damage and their family members. Each interview provided a great deal of specific, concrete information, as well as a profound depth and quality of personal experience. Certain patterns began to emerge across cases. For example, one characteristic that distinguished patients was their level of motivation to recover. Some were motivated, and actively engaged in their recovery process; others lacked motivation and perceived themselves as victims of their circumstances. Independence and autonomy were important to all patients, but the degree of independence varied. Size and involvement of social networks also varied from patient to patient.

It became apparent that the adoption of appropriate theoretical concepts would facilitate an understanding of the emerging patterns. Two theoretical systems were adopted to provide a framework for understanding the pilot observations, Goldstein's Laws of Organismic Life (1934), and the Motivational Analysis of Self-System Processes (Connell & Wellborn, 1991). A plan to incorporate these theories into the dissertation was presented to the dissertation committee and accepted, introducing Phase 2, the Main Phase of the project.

During Phase 2 I used constructs from these two theories to focus the interviews and case analyses. I combined data from the analyses with the theories to develop two theory-specific models, one a model of Recovery and the other a model of Development. Each model was used to inform and further develop the other model. In other words, I took parts of the Development Model and inserted them into the Recovery Model, and vice versa. I used the Recovery Model as the structure for my case study analysis. I used the Development Model to build and administer a survey to evaluate factors that foster or impede successful recovery from brain damage, extending the investigation from case study to survey research. Data from the broader sample served to further inform my case study research. I returned to my cases with the Development Model and survey data to consider, on an individual basis, where their lives fit the model, where they didn't, and why.

So the theory-guided main phase grew into three separate investigations. Study #1: I conducted case study research using the Recovery Model as the theoretical structure. Study #2: I conducted survey research using the Development Model as the theoretical structure. Study #3: I used information from the survey research to perform a second evaluation of the cases. The following section describes the development of the models. The process of operationalization and measurement is presented in the Method Section.

Phase 2: Theory-Guided Main Phase

Laws of Organismic Life and Their Application to Human Life Following Brain Damage

The first body of information used to understand the pilot data was generated by Kurt Goldstein (1934). Goldstein used his observations of brain damaged soldiers to formulate theories about organismic life. He observed that living creatures strive to achieve and maintain a state of order. He proposed that all behavior can be categorized either as ordered or disordered. Effective performances belong to the ordered category. A performance is an individual's coming to terms with an environmental stimulus through a behavioral act. Disordered behavior is catastrophic in character. It is ineffective in its attempt to resolve the challenge presented by the environmental stimulus. Human beings, and all living organisms, strive to be in a condition of order, or to be in a state of equilibrium. Equilibrium is defined as "Any condition in which all acting influences are canceled by others resulting in a stable, balanced, or unchanging system." (American Heritage Dictionary, 1981).

When a person sustains brain damage, that person is thrown into a state of disorder, or thrown out of equilibrium. On one level, damage to the relationship between the brain and motor responses will render the individual unable to respond physically in certain ways. On another level, damage to cognitive processes such as memory, anticipation, imagination, monitoring, tracking, and so on will render the individual incapable of responding appropriately to various stimuli.

The lack of ability to appropriately and effectively respond impedes the process of recovery. Goldstein stated, "Order is only achievable if there is the possibility of obtaining an adequate environment. . . The fact that milieu is determined by the particular characteristics of the organism becomes especially clear in the diseased. For this altered organism, to whom the formerly normal environment has now become strange and disturbing, the basic prerequisite of existence is capability to shape once again an adequate environment" (p. 85).

The Course of Establishing a New Equilibrium

After brain damage, the patient will move through five phases characterized by specific behavior in an attempt to establish a new steady state. Patients will differ in their manifestations of these phases, and for some patients certain phases will occur simultaneously.

The phases are: (I) Initially there will be behavioral manifestations of the trauma and the subsequent immediate attempts at orientation. (II) The patient will then form adaptations for specific defects. (III) This adaptation will necessitate a shrinkage of milieu, which results in (IV) a shrinkage of performance potentialities, or, as Goldstein called it, a "loss of essential nature." This loss of essential nature coincides with (V) the reappearance of order and the restoration of health.

I. Behavioral Manifestations

1) At first the patient will be unaware of defects. Stimuli that should be disturbing seem to have no effect on behavior.

2) Performances that are not disturbed will be modified, and the patient will seek out situations in which danger due to the new disabilities is avoided.

3) Patients avoid situations that may precipitate catastrophic reactions, that is, reactions that are insufficient and inadequate.

4) When we try to force the patient into a situation earlier identified as catastrophic, the patient will seek to escape through some substitute performance.

5) Patients tend to an undisturbed state, being always occupied with something stereotypic, with little variation. This is a means of seclusion and, thereby, protection.

6) Another means for avoiding catastrophe is through orderliness. Disorder forces a choice of alternatives, rapid transition of behaviors and change of attitude, all which the brain damaged patient cannot do.

7) Patients will avoid "emptiness." A subjective experience of emptiness requires abstract thought, which is difficult or impossible for the brain- damaged.

8) The patient will attempt to maintain a performance capacity on the highest possible level compared with the former capacity.

9) There will be a distribution of energy to the outer and inner worlds of the patient consistent with demand at any particular time. This differential energy distribution explains why a patient's performance on specific tasks will vary according to well-being, fatigue, etc. Limiting external stimuli will enhance inner performance.

II. Adaptation to a Defect - Two Types

As part of the attempt to perform optimally and to regain equilibrium, the patient adapts to a defect either by yielding to it or by effecting an adjustmental shift, reorganizing the impaired performance at the expense of other performances. The type of adaptation is determined by the degree of the disturbance. In either case, there is a corresponding shrinkage of performance potentialities (essential nature) and of milieu.

Yield

In the case where the performance is damaged but not completely destroyed, patients adapt by yielding to the defect. They resign themselves to defective but passable performances, and to the corresponding change in milieu.

Shift

When the performance is completely destroyed, the patient readjusts in such a way that the defect is kept in check. This readjustment is an expression of the tendency of the patient to maintain optimal overall performance. This shift, or transformation, only occurs when a performance is impossible; it will not occur if there is some potential for partial performance. In that case, only a yield will occur. But if the performance is impossible, the patient will effect a shift, borrowing from other performances in order to compensate for what is gone.

> *What is germane is not the best possible performance in one field but the best possible performance of the organism as a whole. Therefore, transformation or modification in one field will always be oriented about the functioning of the total organism (p. 58).*

The adjustmental shift occurs consistent with four rules:

1) Within a performance field, those performances will survive that are most

important to the overall functioning of the patient.

2) The premorbid method of operating will be maintained as long as it is possible for the needs of the patient to be met in that way. If that is not possible, the shift will occur.

3) Disturbances will occur in other fields as a result of the shift in the damaged field, but the patient will tolerate those disturbances, because overall functioning is less handicapped by those disturbances than it would be by totally forfeiting the damaged performance.

4) Finally, we must call attention to a particularly important factor. The shift occurs suddenly. It is not a result of training, and it happens without the knowledge of the patient (p. 60).

An illustration Goldstein used to demonstrate the two types of adaptation is the example of one-sided cerebellar lesion. Some patients present a "tonus pull" toward the diseased side, while others pull away from the diseased side. The direction of the pull indicates the degree of damage. That is, patients with less severe damage will lean toward the damaged side; patients with more severe damage will lean away from the damaged side.

By tilting toward the diseased side, patients with minor damage reach a position in which equal stimuli on both sides produce an equal effect. Although this tilting may result in deviations in walking, poor balance, and abnormal posture, the overall effect is a feeling of ease, less vertigo, less disturbance of physical equilibrium. and so forth. This is an example of yielding to the defect.

With severe damage, a patient would fall over when tilting toward the diseased side. The yield, therefore, is impossible, and the patient will tilt toward the undamaged side of the brain. With severe damage, there is a strong "tonus pull" toward the diseased side. This strong pull is balanced by exerting abnormal effort to tilt away from the pull. In this way a new equilibrium is established. but through a change in behavior. an adjustmental shift. rather than yielding to the defect.

The patient will experience more security with the yield. It is more automatic. but does not coincide with great improvement in performance. Initially the adjustmental shift requires more volition from the patient, but eventually the new behavior becomes familiar, natural. and is practiced with little consciousness. The shift is less secure. and the system more prone to flux. However the overall performance in the field may show greater improvement than with the yield.

Since. following brain damage, the main drive for the patient is to achieve ordered behavior. as long as a performance is possible the patient will yield to the defect. The adjustmental shift only sets in when sufficient performance is not possible through yielding.

Two aspects of the yield vs. shift method of adaptation translate directly into pragmatics of brain injury management. First. mild brain injury (like mild injury in general) is considered less serious, consequently more is expected of the patient with mild TBI. However, yielding to the deficit, which is the strategy that is used with a less serious injury, requires more energy from the human system than does the shift. Therefore, all other things being equal (for instance, in the absence of other-system injuries) patients with mild brain injury will have less energy than those with severe brain injury. Yet more is expected of them in terms of being productive, goal attainment in rehabilitation, etc. It is common for persons with mild TBI to be accused of malingering. It is also common for them to present a high number of somatic complaints (van Zomeren & van den Burg, 1985), particularly fatigue, or a lack of energy. Understanding the nature of the yield, and what is required of the person to adapt in that manner, may provide information for designing more appropriate rehabilitation programs and work and home environments for persons with mild TBI.

The second pragmatic issue is that patients make behavioral and physiological modifications as an expression of their adaptation, either the yield or the shift. When they do, their experience of equilibrium is restored. But these modifications become the target of rehabilitation (either formal or informal); we try to correct the modification, to return the patients' behavior or posturing to the state we prefer. In doing so we impede their progress toward equilibrium or health, and may throw them into a catastrophic reaction.

III. Shrinkage of Milieu

Goldstein asserted the following law of behavior: *"A defective organism achieves ordered behavior only by a shrinkage of its environment in proportion to the defect (p. 56)."*

During this phase, brain injured patients will decrease the scope of their environment. The result is a reduction in number and variety of stimuli they are exposed to, allowing them to regain stability. As discussed earlier, behavioral manifestations may be a reluctance to going places, avoidance of new or unsettling experiences, and a focusing on the familiar. The greater the defect, the greater will be the diminution of the milieu.

IV. Shrinkage of Performance Potentialities (Essential Nature)

Goldstein asserted that a basic law dominating the life of the organism is the importance for the organism to attain a condition that is adequate to its "nature" and, in the case of pathology, to its modified nature.

A deficit in essence (in body and metabolism) implies an altered relation to the environment. The patient will become more dependent upon environmental events. That is, with a diminished cognitive ability to mediate, by means of intellect, the effects of stimuli, the patient will have stronger and more immediate reactions to the environment. Behavior may degenerate from rich, multiform responses to those which are compulsive and mechanical.

Further, behavior may regress from unique, complex patterns to primitive, cause-effect reactions. That is, responses will take on an automatic, stimulus-response quality. With a higher variety of alternative reactions afforded by a larger milieu, it is more probable that the patient will respond to an event uniquely, or at least less routinely. A decreased variety of possible reactions results in more predictable behavior.

A reduced potential to perform implies a loss of freedom for the patient. The American Heritage Dictionary of the English Language (1981) offers the following definitions of freedom: *The condition of being free from restraints. The capacity to exercise choice. Facility, as of motion. Originality of style or conception. Unrestricted use or access. The right of enjoying all of the privileges of membership or citizenship.* Considering this definition in light of Goldstein's descriptions of the shrinkage of performance potentialities (greater dependence; compulsive, mechanical behavior; cause-effect, more routine reactions) it is clear that people with brain damage live in a condition of restricted freedom.

V. Restoration of Health and Reappearance of Order (Equilibrium)

If regaining health meant complete restitution of the former state, this would limit the concept of health. Many people who are no longer regarded as sick have residual defects from disease and trauma. Careful analysis, and a search for essential phenomena, will reveal that the patient never returns to former methods of performance, and never returns fully to the former milieu.

> *Health is not restored . . . through compensation or substitution for disturbances as to contents. Rather it is restored if such a relation between preserved and disturbed performances is reached, which makes (in spite of residual defects) "responsiveness" possible anew (p. 331).*

Goldstein means "responsiveness" to be a function of the whole, integrated person. Thus Goldstein provides a way of recognizing equilibrium when it reappears. It manifests through the restoration of adequate responsiveness from the patient. To be well means to be capable of ordered behavior in spite of the fact that certain performances are no longer possible. However, the new state of health is different from the previous individual equilibrium.

> *To become well again, in spite of defects, always involves a certain loss in the essential nature of the organism. This coincides with the reappearance of order. A new individual norm corresponds to this rehabilitation (p. 333).*

In addition, in the new steady state, behavior will be changed, but constant. The patient will present consistent responses to consistent stimuli, although those responses may be different from what the patient would have presented prior to the trauma. A new order will be achieved.

To summarize, two behavioral indicators of the restoration of health are:

1) a new responsiveness, and
2) constancy in behavior.

Factors That Foster or Obstruct Adaptation and the Restoration of Health

The context for this discussion is the fact that, for the newly diseased patient, the basic prerequisite of existence is the ability to shape a new environment, to alter the milieu in a way appropriate to the changes in the body imposed by the disease. In terms of the EsEx Couple model, brain damage alters Essence. The body changes. It produces an interruption of the dynamic flow of information in a recursive loop between Essence and its Exchanges with environment. The result is a disequilibrium, for the information coming from the patient is changed, and no longer fits with the shape of the milieu. If recovery is to occur, the environment must be friendly to the new information and plastic enough to change under its influence, and plasticity must also be a quality of the body as it moves to a new equilibrium.

Goldstein outlined factors that foster or obstruct the restoration of health. They can be seen as aspects of culture (the place where Exchange between two or more beings takes place, see Figure 3) that allow or retard changes in Exchange. Patients with one or few essential disturbances are more likely to return to equilibrium than those with multiple essential disturbances. If patients are facilitated too much in overcoming difficulties, their performance level will not reach its maximum. Too little facilitation will result in frustration and in lower performance as well. The patient must be provided with the appropriate level of demand in order to maximize the performance level. Generally, greater demand is better, but--as with any adaptation--it must not exceed the body's ability to change. Also, adaptation will vary with the scope of the milieu. Most patients who live in hospitals will not progress as much as those who live in the community where there are more normal demands. However, for some patients, incarceration is the largest tolerable environment; a larger milieu would precipitate catastrophe.

A total loss of a performance produces greater adaptation than a partial loss. This was discussed in the section contrasting the adjustmental shift with the process of yielding. For example, Goldstein found that people whose preferred writing arm had been amputated learned to write with the remaining hand more easily than those whose preferred writing arm was partially paralyzed. The adjustmental shift requires an engagement from the patient--an active participation in the compensation process--whereas the character of yielding is acquiescence.

When the circumstances of people's lives compel them to do well, they are more likely to do so. Patients with a family they love, jobs they enjoy, and other like demands, will excel beyond those whose life circumstances are adversarial to recovery.

It is not possible for the necessary "milieu shrinkage" to occur without the assistance of others. Practical provisions must be made for a person to successfully restrict the environment consistent with new needs. The appropriate facilitation of this process is the job of the patient's family, and the goal of medical practice. Goldstein defines "rearranging the milieu" broadly, including taking certain drugs. maintaining a specific lifestyle, avoiding "indulgences in the somatic or psychological realm," and ending or initiating certain relationships.

Explicit Factors. In summary, the explicit factors that foster or obstruct the restoration of health are (1) number of essential disturbances, (2) facilitation, (3) scope of milieu, (4) total vs. partial performance loss, (5) compelling life situation, and (6) help of others.

Implicit Factors. As stated, Goldstein proposed that order following brain damage is only possible if the person can reshape the environment to conform to the new needs of the person. He also asserted that, for most patients, a return to a former state of being is impossible, and the act of trying to get them back to the former state drives them further from health, and even into a catastrophic reaction. They need permission from others to be the new and different being they have become. The people interviewed for this project's case study confirmed this idea. Therefore, two additional factors contributing to the restoration of health, which Goldstein implicitly expressed, are (1) Ability to Shape the Environment, and (2) Permission to be Different.

Goldstein's Process of Recovery as an EsEx Couple

Figure 4 represents Goldstein's process of recovery in terms of the EsEx Couple model and differentiates between the two methods of adaptation, yield and shift.. The assumption is made, for the sake of the demonstration, that prior to injury, the person was living in a state of equilibrium. Responses are effective, eliciting validation from the milieu. Immediately after injury, the person's capacity is reduced, generating behavioral manifestations that constitute ineffective action, because the milieu has not yet adjusted to the new needs of the person. In response to catastrophic reactions precipitated by ineffective action, the person will adapt to the deficits, either by yielding to them or shifting to a new mode of operating, and the milieu will shrink to accommodate the adaptation. Restoration of health occurs with the milieu allowing the person to be different, and the person having replaced lost essential nature with new adapted capacities.

The difference between yield and shift as methods of adaptation is represented in the amount of lost essential nature, and in the degree of permission to be different provided by the milieu. With yield, an adaptive response to a partially destroyed performance, less is lost, so the necessary change in milieu is smaller. With shift, which occurs after total destruction of a performance, more is lost, and the milieu must respond with greater accommodation. Important to note is the greater degree of new capacity acquired after the shift as opposed to the yield.

representing Goldstein's assertion that total performance loss will be associated with greater improvement of overall performance.

Freedom

The restriction of milieu required for the restoration of equilibrium may be, for the particular individual, so adverse that it precipitates its own catastrophic reaction. If patients perceive their freedom so restricted by milieu shrinkage that performances they deem essential are no longer possible, life becomes inadequate. There are several possible outcomes. The patient may live in a state of great suffering, never truly accomplishing a new equilibrium. The patient may be spared the catastrophe by losing awareness. Or, one extreme expression of adaptation, the patient may self-destruct.

> *The impossibility of grasping the phenomenon of disease in a way other than by introducing the factor of freedom leads us to the recognition of an important attribute of man, namely, recognition of his potentiality for freedom, his necessity to realize his nature by free decision (p. 450).*

Direction/Motivation

Goldstein considers, but to my knowledge never directly answers, the question of motivation. *"Whence comes the direction in the activity of the organism? From without? Whence does this direction come? With this question, we stand before the fundamental problem of life processes (p. 84)."*

I suggest Goldstein does not directly answer his question because, to give an answer would be to point to one part of the whole system, thereby excluding other parts. And the answer lies in an analysis of the whole system. Goldstein's indirect answer is:

> *Two answers, different in principle, seem possible. (1) The direction is effected through a specific environment in which the organism lives. (2) It is effected through a certain determination and force issuing from the organism itself.*
>
> *One could say that the environment emerges from the world through the being or actualization of the organism.*
>
> *Order is only achievable if there is the possibility of obtaining an adequate environment. But the possibility alone is of no avail. Environment first arises from the world only when there is an ordered organism. Therefore, the order must be determined from somewhere else. From where? From within the organism? We are ultimately referred back to the organism itself (p. 85).*

Goldstein, therefore, painted a picture of organismic direction and motivation reminiscent of the EsEx Couple model. There is the body of the organism (Essence). Being in a state of order, it is effective in shaping its environment. There is the environment (implied in Exchange), which is plastic and friendly to the performances of the organism. In this condition the organism, the person, the patient, is directed, motivated, to continue to perform.

Summary

All behavior can be characterized as ordered or disordered. Brain damage throws a person into a state of disorder, and at that point the basic prerequisite of existence is the ability of the person to shape a new environment appropriate to the new needs. To that end, the person will attempt to move through five phases in the process of restoration of health. The presence or absence of certain factors in the environment will foster or impede restoration of health. The behavioral indicators of health are responsiveness and constancy.

Recovery Model

Figure 5 maps key aspects of Goldstein's Laws of Organismic Life onto the structure of the EsEx Couple schema, now called the Recovery Model. The initial insult occurs in the Body, in Essence. There, two indicators of the condition of the Body are (1) number of essential disturbances, and (2) total vs. partial performance loss. These are two of the eight factors that foster or impede recovery. In this example, the Exchange side of the EsEx Couple corresponds with Goldstein's concept of Milieu. There, four indicators of the condition of the Milieu are (1) facilitation, (2) scope of milieu, (3) help of others, and (4) compelling life situation.

If the appropriate levels of these four aspects of Milieu are present, the information delivered from Milieu to Essence is that the person is able to shape the environment, and has permission to be different. This information has a transformational effect on Essence, allowing the person to turn energy away from attempts at orientation and focus on adaptation. As the person adapts, transactions from Essence back to the Milieu acquire the qualities of responsiveness and constancy.

A final indicator, to be found in the domain of Milieu or Exchange, comes directly from the EsEx Couple model. The model proposes that when the human system is in a state of order, the person will share symbiotic relationships with others. Given the reciprocal nature of the EsEx Couple model, Symbiotic Relationships could be used as an independent measure (i.e., the presence of symbiotic relationships enhances outcomes) or as a dependent measure (symbiotic relationships are an outcome).

Construction of the Recovery Model thus far gave rise to the question of measurement, which instigated a search into different bodies of literature. By identifying laws that govern all of organismic life, then using those laws to analyze recovery from brain damage, Goldstein implied that, in some ways, recovery from brain damage is like the normal developmental process. Models of social cognition and learning generated from developmental psychology have been used in the investigation of recovery from brain damage (Cicerone & Wood, 1987; Levine, van

Horn, & Curtis, 1993; Mintz, van Horn, & Levine, 1995). A review of the literature from developmental psychology provided the second theoretical system I used for Phase 2 of this project.

A Motivational Analysis of Self-System Processes and its Application to the Analysis of Brain Damage

Competence, Autonomy, and Relatedness

The social context is a facilitating or inhibitory milieu for the development of the self. Factors that foster development include *"notions of unconditional, positive regard, support of autonomy, and the channeling of motivational energies toward culturally acceptable enterprises."* (Connell & Wellborn, 1991). This notion of the effect of environment on the individual is consistent with the theory presented by Goldstein, and with the more general Schema of the EsEx Couple.

The model developed by Connell and Wellborn (1991) asserts that people have fundamental psychological needs for competence, autonomy and relatedness. These needs are defined as follows:

Competence: The need to experience oneself as capable of producing desired outcomes and avoiding negative outcomes.

Autonomy: The need to experience choice in initiation, maintenance and regulation of activity and the experience of connectedness between one's actions and personal goals and values.

Relatedness: The need to feel securely connected to the social surround and the need to experience oneself as worthy and capable of love and respect.

Development proceeds out of the interaction among these three psychological needs and the social context, or milieu. Factors in the social context that foster meeting the needs, and therefore foster development, are structure, autonomy support, and involvement.

Structure, Autonomy Support, and Involvement

Structure is provided when there is consistency in interactions with others and a clarity about expectations. Autonomy is supported when the appropriate amount of choice is provided the individual. Involvement encompasses how much time others spend with the individual, and in what spirit the time is spent (i.e., positive affect).

Engagement/Disaffection

How an individual acts (performs) is a function of inter- and intra-individual variation in the system. Modes or styles of action are conceptualized as engagement and disaffection. When the appropriate structure, autonomy support, and involvement are present in the social context, and the three psychological needs are being met, engagement will occur and can be observed in the affect, behavior, and cognition of the individual. When the needs are not being met, disaffection will occur and can be observed in the same way as engagement.

Engagement vs. disaffection is measured through ratings of a person's emotions, cognitions, and behaviors either in the normal course of events (ongoing engagement or disaffection) or when coping with perceived failure (engagement or disaffection in the face of a challenge).

Results of Empirical Studies

Perceived Competence. A direct relationship was demonstrated between perceived competence and student engagement. Students with higher scores along perceived competence dimensions were more likely to be engaged rather than disaffected. Further, there was a direct relationship between teacher reports of student engagement and outcomes in academic achievement and grades. Engaged students were more likely to have higher achievement and grades.

Perceived Autonomy. Children who reported higher levels of perceived autonomy were reported by their teachers to be more engaged in class and show higher levels of school performance.

Perceived Relatedness. Emotional security correlated with teacher ratings of engagement.

Development Model

Figure 6 illustrates the constructs and their associated indicators in the Development Model. Social Context is measured by an informant's report of Structure, Autonomy Support, and Involvement in the life of the subject.

Perception of Social Context is measured by the subject's report of their Structure, Autonomy Support, and Involvement. Engagement is measured by Strategies used and Feelings experienced by the subject when encountering new or difficult tasks. Outcomes for developmental research would be measures of academic achievement and other indicators of normal development.

As a result of findings from the case study interviews, a form of Engagement labeled Victim was added to the model. In looking for patterns among the cases, I found some patients considered themselves victims, and expressed that consistently during interview sessions and in other contexts. Others did not take that position, and expressed themselves as self-determining. Whether or not a person felt victimized appeared to associate with levels well-being, therefore the idea was added to the model as a form of Engagement.

Recovery Model and Development Model - Final Forms

Similarities Between Models

Similarities and overlaps between the Recovery and Development models can be seen at the levels of constructs and measures.

The constructs of Social Context (Development) and Milieu (Recovery) are the same. Perception of Social Context (Development) is a phenomenon of Essence (Recovery). Responsiveness and Constancy (Recovery) can be considered indicators of a particular level of Engagement (Development). Structure

(Development) approximates Facilitation (Recovery).

Differences Between Models

Differences between the models can be seen at the levels of constructs, variables, and direction of arrows.

The Recovery Model has four constructs. Two are represented as domains (Essence/Body and Exchange/Milieu), and two are represented as information flowing in one direction, from one domain to the other. Responsiveness and Constancy were specified by Goldstein as indicators of Order, and in this model can be considered an outcome measure, but the reciprocal nature of the model allows for any place to be either an independent or dependent variable. In addition, during Study #1, a specific outcome measure was not specified. The Development Model has three constructs and a clearly specified outcome.

The most significant difference between the models is the direction of the arrows, and what the arrows represent. In the Recovery Model, the arrows are associated with indicators that are actually measured. In the Development Model, all the measures are associated with domains, and the arrows only represent direction of influence from one domain to the other. The Recovery Model is reciprocal. Influence flows in one direction, creating a reciprocal loop that accounts for the movement of the system toward or away from the condition of order. The Development Model is linear. Social Context and Perception of Social Context affect each other, and affect Engagement; methods of Engagement produce the outcome.

Integration of Aspects of Both Models

Aspects of the Development Model were added to the Recovery Model, and aspects of the Recovery Model were added to the Development Model, to create two final forms.

Recovery Model. Figure 7 illustrates the Recovery Model, which was used to evaluate the case studies during Study #1.

1. The construct representing Essence is named Person, and encompasses both perception and physiology. Variables that measure Person are:

   Number of Essential Disturbances

   Total vs. Partial Performance Loss

   Perceived: Structure

   Autonomy Support

   Involvement

   Ability to Shape the Environment

   Permission to be Different

2. The construct representing the flow of information away from Person is named Engagement. Variables that measure Engagement are:

   Feelings

Strategies

Victim

3. The construct representing Exchange is named Social Context. Variables that measure Social Context are:

Structure

Symbiosis

Scope of Milieu

Compelling Life Situation

Help of Others

4. The construct representing the flow of information away from Social Context is named Validation. Variables that measure Validation are:

Autonomy Support

Involvement

Ability to Shape the Environment

Permission to be Different

Development Model. Figure 8 illustrates the Development Model, which was used to design and evaluate the survey research during Study #2, and is presented with Figure 6 so that additions and deletions can be noted.

1. The construct of Perception is measured by the following variables:

Perceived: Structure

Autonomy Support

Involvement

Symbiosis

Ability to Shape the Environment

Permission to be Different

2. The construct of Social Context is measured by the following variables:

Structure

Autonomy Support

Involvement

Symbiosis

Ability to Shape the Environment

Permission to be Different

3. The construct of Engagement is measured by the following variables:

Family Report of:	Feelings
	Strategies
	Victim
Patient Report of:	Strategies
	Victim

Patients' reports of Feelings were found to be unreliable, and that measure was removed from the analysis. Refer to the Discussion Section for an elaboration of this deletion.

4. The outcome is Functional Status, and is measured by the following:

   Functional Status Scale (FS)

   Change in Socio-Economic Status (SES CHANGE)

   Change in Independence (LIVING CHANGE)

   Refer to the Method Section for Study #2 for an elaboration of the development of these measures.

5. A mediating variable, Severity of Injury, was added to the Development Model. It is measured by the following:

   Level and Depth of Coma (LEVEL)

   Category of Injury (CAT)

   Injury Severity Score (ISS)

   Abbreviated Injury Score for Head (AIS)

   Refer to the Method Section for Study #2 for an elaboration of the development of these measures.

Summary of Model Development

Originally one model was to be used, the EsEx Couple Schema, with one sample and method, 20 case studies. Data collection at that level led to an addition to the proposal, the inclusion of a second model, and a second sample and method for investigation, survey research. Each sample and model informed the other, resulting in revisions in both. These are not competing models, but they are distinct, as described previously.

Beyond the difference in structure, the important difference is their utility. The general nature of the EsEx Couple model, it's reciprocal direction and unspecified outcome, lends itself to exploratory interviews with a small sample, particularly when one is seeking answers, rather than confirming a hypothesis. That is how it was used during Study #1, and the results led to the expansion of the investigation into a larger sample.

The specific structure of the Development Model is useful in aggregating pre-determined data from a larger sample, to look for patterns thought to be present. That is how it was used during Study #2. Its strength is its ability to show where strong trends occur with large numbers of people. Its weakness is, it doesn't illustrate the idiosyncracies of an individual life, and why one person varies from the expected pattern.

The results of the survey were superimposed upon those of the smaller sample, to look for where, in real life examples, patterns were consistent and inconsistent with those of the larger group. This was Study #3. Note that both consistencies and inconsistencies were sought. I did not attempt to construct a fit from those data that would work to validate the model. Understanding where real lives fit the pattern allowed for strong conclusions from the pattern. Noting where they did not fit accomplished the following: First, it weakened the ability to draw conclusions or generate hypotheses from the patterns. Second, it led to consideration of why the real life did not fit the pattern; what set of factors in that individual's life resulted in behaviors, circumstances, or qualities that did not fit expectations.

Summary

The initial project was a case study investigation of the question, what factors foster the recovery process for persons with TBI? Goldstein's method for individual evaluation was used for observation. The EsEx Couple Schema was used for a general orientation to the nature of the observations. The emergence of patterns led to the adoption of two specific theories, Goldstein's Laws of Organismic Life (1934), and the Motivational Analysis of Self-System Processes (Connell & Wellborn, 1991).

Goldstein's (1934) theory was used to construct a specific theoretical model, the Recovery Model, using the structure of the EsEx Couple Schema. The Recovery Model was used to evaluate data collected from the case studies, constituting Study #1. Connell & Wellborn's (1991) model was used to construct the Development Model, which was used to evaluate data collected from the survey research, constituting Study #2. Study #3 was an exploration of patterns when data from Studies #1 and #2 were considered together.

Method, Results, and Discussion are presented separately for each of the three studies. Hypotheses for Studies #2 and #3 are generated at the conclusions of Studies #1 and #2. No hypothesis was tested for Study #1. Rather, the question was asked, for 20 persons who survived traumatic brain injury, what are the factors in their lives that foster recovery?

CHAPTER III. STUDY #1 - CASE STUDIES

The case studies constitute the most important aspect of this dissertation. From the interviews and group discussions, I discovered patterns in behavior which were used to generate a model for recovery and define constructs and variables used for quantitative analysis. In addition, my interactions with these people provided an understanding of the special demand their pathology imposes upon them, which I used to explain both patterns and idiosyncracies. The salient information from Study #1 is contained in Appendix A, the case reports. This chapter is a summary of the process and outcome of producing those reports.

Method

Sample

A convenience sample of 20 persons who had sustained brain injury was acquired through the Brain Injury Support Group of Portland, Oregon (BISG). The BISG is the organization which networks the TBI community in Oregon and Southwest Washington, providing education and referral services, fund raising, and directing six distinct support group programs. Its member list consists of approximately 1,500 survivors, family members, and professionals. The survivor membership includes individuals of both genders who vary in age, type of head trauma, socioeconomic status, premorbid history, I.Q., rehabilitation, and employment. Professionals on the list are primarily people who work directly with

TBI patients in disciplines such as vocational rehabilitation and speech pathology.

Case study subjects were 9 females and 11 males who ranged in age from 23 to 69 years. Mechanisms of injury were 10 motor vehicle accidents (MVA), 2 tumor/radiation damage, 1 attack, 1 fall, 1 gunshot wound, 1 bicycle accident, 1 plane crash, 1 shrapnel wound, 1 aneurism, and 1 anoxia. Six participants lived with their spouse, 5 alone, 4 with a family member or partner, 2 in long-term maximum care facilities, 1 in the Oregon State Hospital, and 1 in assisted housing. One participant died during the investigation. Of the 19 surviving participants, 14 were unemployed, 4 were employed, and 1 was retired.

The requirement for inclusion was that subjects be willing to participate in individual and group interview sessions. Formal consent was acquired consistent with the standards of the Human Subjects Committee of Portland State University and the Investigators Review Board of Oregon Health Sciences University.

An informant for each case was also interviewed. Eleven informants were family members. Nine informants were friends.

Instruments

Interviews were tape recorded and transcribed. Interviews at this stage did not follow a formal protocol. Subjects and informants were asked to tell the story of their lives, including who they were and what they did before their injury, details of their injury, and subsequent chronology. People were interviewed in their homes when possible. In the case of Jody, who is an inmate at the State Hospital, interviews were conducted on the telephone and in writing.

Procedure

Goldstein's method of observation (1934) is described in Chapter II, and was the clinical method used to conduct the interviews. Morse and Field (1995) described data collection, sampling, and analysis as a simultaneous process. I also used their technique of analysis, a constant comparison of all aspects of data as they are collected. This comparison process fosters the emergence of theories, upon which further data collection is based. Cases were compared, and similarities and differences were documented. Patterns were identified and documented. The patterns that emerged from the first round of interviews helped determine lines of questioning for focus groups, as well as for the follow-up interviews.

Results and Discussion

Data were evaluated at three levels, characteristics which were universal, generic, and unique.

Universal Characteristics

Eighteen of the 20 cases participated in formal rehabilitation. One did not because formal brain injury rehabilitation did not exist when he was injured. The other did not because he died. In addition, all subjects reported problems with balance.

The problem with balance shared by all case study subjects can be considered using Goldstein's method of analysis. First, is the phenomenon described as "out of balance" incidental or essential? If incidental, it is a symptom of some fundamental change, and may not on its own adequately describe or lead to discovery of the fundamental change. If being out of balance is the essential phenomenon, it describes the fundamental change that happened as a result of the trauma. Second, does the symptom represent a total or partial loss of performance within a performance field? Implicit in that question is, to what performance field does balance belong? Is it auditory? Is it visual?

The answers to these questions are case-specific. They must be answered by examining each case and by considering the unique constellation of relevant factors present or absent for each person. For example, RS's balance problem may be a function of the loss of one eye from shrapnel; DF's from the profound musculo/skeletal trauma she sustained. Further, partial or complete loss of performance would have to be determined on an individual basis. Consequently, while "problems with balance" is a universal characteristic in this sample, its clinical relevance, and the appropriate intervention, must be determined by individual examination.

Generic Characteristics

The following patterns emerged from the first series of interviews. Some participants maintained strong family relationships, and were involved with family and friends. Others were socially isolated, and alienated from immediate and peripheral family. Degree of autonomy varied across subjects. Dependence was usually accompanied by feelings of being a victim of circumstance. Some participants felt free to have and express the idiosyncracies common with brain damage; others actively hid their deficits.

In sum, factors around which groups of subjects clustered were: family relationships, social networks, autonomy, victim, and (using Goldstein's [1934]) phrase) permission to be different. Referring to the first version of the Recovery Model (see Figure 5), relationships and social networks that persist post-trauma are a form of communication from Exchange to Essence, a validation that the person will continue to receive the required support, in spite of the new disabilities. Autonomy and Permission to be Different could be accounted for as a perception, and therefore reside in Essence, or as an objective reality, and reside as a validating communication between Essence and Exchange. Assuming the role of victim is a form of response which flows from Essence back into Exchange.

These factors, or indicators, were added to the original model and, together with information from the Development Model presented in Study #2, served to build the final version of the Recovery Model (Figure 7). Thus the evaluation of patterns among the case studies began to answer the research question for Study #1.

and contributed to the construction of a model for a more comprehensive inquiry.

Factors that appear to foster recovery from brain damage are family, relationships, autonomy, and permission to be different. A factor that may impede recovery is being a victim.

Unique Characteristics

Unique characteristic are described in the case reports (see Appendix A), organized by the following sections: Trauma, History, Post-Trauma Chronology, Behavioral Characteristics, and Evaluation according to (1) Person (2) Engagement, (3) Social Context, and (4) Validation (refer to Figure 7).

A full discussion of unique characteristics is presented in Study #3, after incorporating results from the Study #2, the survey research.

Transition to Study #2

The EsEx Couple model was informed by the case study analysis, and became the first version of the Recovery Model (Figure 5). Although a general model without a specified outcome, this version of the Recovery Model, derived from the case study results discussed above, generated the following hypotheses:

1) A person whose family and social network remain intact after injury will have a better recovery than one whose family and friends leave and do not provide support.

2) A person who is independent, or experiences autonomy, will have a better

recovery than one who is dependent.

3) A person who has permission to be different will have a better recovery than one who must hide deficits and try to return to a former state of being.

4) Assuming the role of victim will be associated with lower levels of recovery for the person than assuming a self-determining role.

A necessary component to continue the investigation was a method to operationally define the independent and dependent variables in these hypotheses. The need to define and measure variables, together with the hypotheses. guided the search in other disciplines of psychology to find previous work and instrumentation that could be used in this analysis. The Motivational Analysis of Self-System Processes (Connell & Wellborn. 1991) was adopted, initiating Study #2.

CHAPTER IV. STUDY #2 - SURVEY RESEARCH

Method

The process of specifying the model and instruments from developmental psychology used to design the survey is described in Chapter II. Consistent with the original purpose of this project, I used survivors and family members to assist in revising both the developmental instruments and functional status instruments used to assess brain injury outcome. The team synthesized constructs and variables, using their knowledge of the important issues of brain injury recovery, to produce the patient-guided instrument used for Study #2.

Process of Instrument Development

Selection of Established Functional Status Instruments

A review of brain injury research projects was conducted to identify instruments with demonstrated usefulness in evaluation of functional status. Selected instruments are listed in Appendix B. Selection criteria were developed to acquire a set of instruments that included (1) established scales used over a period of time on various populations, (2) established scales used in current brain injury research, and (3) scales designed to address specific interests of this project. For example, the Katz Adjustment Scales (Katz & Lyerly, 1963) have been demonstrated over a number of years and a variety of populations to be a reliable measure of Psychosocial Functioning. The Portland Adaptability Inventory (Lezak,

1987) has been used in recent brain injury research (Sbordonne, Liter, & Pettler-Jennings, 1995). The Brock Adaptive Functioning Questionnaire (Dywan & Segalowitz, 1996) is relatively new, but was developed using patient input, and incorporates pre-morbid measures, two issues of interest in this project.

Constructs for measuring functional status from the selected instruments were categorized as follows: Executive Function, Cognition, Personality/Emotionality, Social, Satisfaction, Psychological, Occupational, Activities of Daily Life (ADL), Family, Financial, Independence, Physiological, Adaptation, and Descriptive (i.e., injury severity). Lezak (1995) provided definitions for categorization.

Collection of Survivor, Family, and Professional Input

Weller and Romney (1988) specified a method for systematically collecting information from subjects in interviews in order to determine priorities within a population for a particular research question. Their Free-List and Triad Comparison techniques were used in this project.

Interviews were conducted with a convenience sample of 5 brain injury survivors, 4 relatives of survivors, and 3 professionals who work with brain injured people. Survivors were 4 males and 1 female, ranging in age from 35 to 69 years. Types of brain damage were shrapnel wound, fall, bicycle accident, brain tumor, and physical attack. Family members were 2 wives, 1 mother and 1 sister.

Professionals were a female rehabilitation therapist, a female case manager, and a male psychologist.

Interviews were tape recorded. Subjects were asked, "What attributes of life do you think are most affected when a person suffers a head injury?" Subjects were asked to generate as many responses as possible to the question, until they had exhausted all possible responses. Lists were transcribed, and total number of responses, including duplicate responses, was calculated for each subject. Lists were compiled, resulting in 141 items.

A tally for each item was made, and the relative importance was estimated, based on how often an item was mentioned, and its recency in the list generated by each participant. The importance estimate was used to eliminate items that were ranked less important by respondents, and items that were similar were combined, resulting in a condensed list of 21 items.

Items were randomly placed into three sets of 70 triads. A questionnaire was prepared with the following instruction:

> For every set of three problems, circle the problem that has been most difficult for you (for your friend or relative who has sustained brain damage)."

Twenty-one survivors and 9 family/care givers filled out the triad comparison questionnaire during a meeting of Portland's Traumatic Brain Injury

Social Club. Survivor data were analyzed separately from family/caregiver data. Three survivor surveys were eliminated due to incomplete answers or duplicate marks.

Based on frequency of times an item was marked more important than the other two items in the triad, survivors considered the most important problems to be memory, being organized, mobility and independence, physical limitations, being unproductive, and problems thinking. Family and caregivers concurred that the most important problem was memory. Other items considered important, in contrast to survivors, were social isolation, being inappropriate, and problems with friends.

The constructs of Memory, Mobility/Independence, Organization/Productivity, Inappropriate Behavior, and Physical Limitations were specified as important Patient-Guided measures of functional status.

The social items, social isolation and problems with friends, were incorporated into the measure of Social Context as a mediating variable, and not in the functional status measure.

Construction and Testing of First Draft

A 22-page survey draft was constructed incorporating variables from established instruments that reflected (1) the priorities of the target population, (2) dimensions that current research indicated were important measures, and (3) the research goals of this project.

Nine brain injured people assisted by three members of the research team filled out the survey in a work meeting, discussing items and asking questions throughout the session. Subjects were 6 males and 3 females ranging in age from 25 to 69 years. Types of brain damage were bicycle accident, birth defect, brain tumor, motor vehicle accidents, shrapnel wound, fall, and physical attack.

Items were rewritten and other changes made during the meeting. Examples of changes are:

1) Negative and positive items had been mixed together in a scale, so that for one question, the response "never" indicated good functional status, whereas for the following question, the response "always" indicated good functional status. Subjects found the mix confusing and difficult to respond to, so negative items were separated from positive items in the final form of the instrument.
2) Type-face was enlarged and page orientation changed to facilitate reading.
3) Items were added, deleted, or changed based on subjects' reports of their interpretation of the questions.

A second draft was prepared and administered to a group of 3 family members of brain injured people, 2 wives and 1 mother, assisted by two members of the research team. A second version of the survey was developed to be completed by an informant. The Survivor Survey consisted of 115 questions, and the Family Survey consisted of 119 questions. The following definition of a case was specified: A case consists of either a Family Survey, a Survivor Survey, or both. Some of the questions are identical on both surveys. These are the functional status questions and other questions that are grounded in fact rather than experience or opinion. If both surveys were returned for a case, it was assumed the factual information from the family survey was more likely to be accurate than the same information from the patient survey, and that information was recorded in the case record.

Pilot Administration

Subjects were provided through the Brain Injury Support Group (BISG) in Portland, Bend, Corvallis, and Eugene, Oregon. I attended support group meetings and administered the pilot survey to survivors and family. Results of the pilot administration are as follows: Sixty-eight cases were collected, 26 females, 36 males, and 6 unspecified. Ages ranged from 19 to 69 years, with a mean age of 39 years. Refer to Table 1 for additional demographic data.

Reliability analyses using Chronbach's Alpha were performed to determine item reliability. Due to low item reliability scores, 17 items were removed from the Survivor Survey and 13 items from the Family Survey. After removal of items, reliability analyses for the Survivor and Family Surveys produced Chronbach's alphas of .80 and .90, respectively.

Survey Constructs, Scales, and Variables

The Patient-Guided instrument (Appendix C) includes three primary constructs, an intervening construct, and an outcome measure (refer to Figure 8):

Three Primary Constructs

Construct	Variables
Perception	Perceived Structure
	Perceived Autonomy Support
	Perceived Involvement
	Perceived Symbiosis
	Perceived Ability to Shape Environment
	Perceived Permission to be Different
Social Context	Structure
	Autonomy Support
	Involvement
	Symbiosis
	Ability to Shape Environment
	Permission to be Different
Engagement	Patient Report of Strategies
	Patient Report of Victim

	Family Report of Strategies
	Family Report of Feelings
	Family Report of Victim
Intervening Construct	
Severity of Injury (SOI)	Level and Depth of Coma (LEVEL)
	Injury Category (CAT)
	Injury Severity Scale (ISS)
	Abbreviated Injury Score (Head) AIS
Outcome	
Functional Status	Functional Status Scale (FS)
	Change in SES (SES CHANGE)
	Change in Independence (LIVING CHANGE)

The following specifies the method for scoring each measurement:

Social Context

There are 17 questions, all on the Family Survey, in Social Context. They have response options of "Never, Sometimes, Many Times, Always" with numeric values of 1 through 4, respectively, when "Never" is the negative end of the scale and "Always" the positive end, and with numeric values of 4 through 1, respectively, when "Always" is the negative end of the scale and "Never" the positive end. Therefore the higher score indicates a more positive condition. A composite score was calculated by summing the scores for individual items. If missing data surpassed a threshold level (> 30% of responses within a composite), the case was not used in the analysis. Otherwise, missing data were estimated by averaging the case responses within sub-constructs and assigning the average.

Perception

There are 19 questions from the Survivor Survey in Perception. Scoring is consistent with scoring for FS.

Engagement

There are 7 questions from the Family Survey and 4 questions from the Survivor Survey in ENG. Scoring is consistent with scoring for FS.

Severity of Injury (SOI)

Level and Depth of Coma (LEVEL). LEVEL was derived from ICD-9-CM (1993) diagnoses recorded in the Hospital Discharge Index (HDI). Scores for LEVEL are 0 (Unspecified), 1 (None), 2 (<1 hr.), 3 (1-24 hr.), 4 (>24 hr. with return to previous state of consciousness), 5 (> 24 hr. without return to previous state of consciousness), and 6 (Coma of unspecified duration).

Injury Category (CAT). Categories of CAT are 1 (Closed/No Tissue Damage), 2 (Closed/Unspecified Tissue Damage), 3 (Closed/Specified Tissue Damage), 4 (Open/No Tissue Damage), 5 (Open/Unspecified Tissue Damage), and 6 (Open/Specified Tissue Damage).

Injury Severity Score (ISS). Scores for the ISS range from 5 to 75, with a higher score indicating a higher level of severity.

Abbreviated Injury Score (Head) (AIS). Scores for the AIS range from 0 to 5, with a higher score indicating a higher level of severity.

Functional Status

Functional Status Scale. There are 18 questions, identical on both the Survivor and Family Surveys, in the Functional Status scale. Twelve have response options of "Never, Sometimes, Many Times, Always." Six questions assess physical functioning, and can be scored between 1 (poor) and 4 (no problem). Scoring is consistent with scoring for Social Context. For cases with both Survivor and Family surveys, or with only the Family survey, the Family Report of Functional Status was used as the Functional Status score. For cases with only the Survivor survey, the Survivor Report of Functional Status was used as the Functional Status score.

Change in Socio-Economic Status (SES CHANGE). Hollingshead's (1975) method was used to estimate Socio-Economic Status, with possible scores ranging from 8 (lowest) to 66 (highest). Post-Trauma SES was subtracted from Pre-Trauma SES to calculate change. A decrease was scored 1, no change was scored 2, and an increase was scored 3.

Change in Living Circumstances (LIVING CHANGE). Respondents' report of change in living circumstances was categorized based on independence level. A score of 1 indicated a decrease in independence from pre- to post-trauma. A score of 2 indicated no change in independence; a score of 3 indicated an increase in independence.

Procedure for Survey Administration

Instrument packets were mailed to 829 people on the membership list of the Brain Injury Support Group of Portland, Oregon. An instrument packet contained a cover letter with instructions for completing the surveys, a Family Survey, a Survivor Survey, an Informed Consent Form, and postage-paid return envelopes. Support Group staff identified members on the list who were either a survivor of brain injury, or a family member of a survivor, for the mailing. Additional instrument packets were mailed to people who called the research office and asked to participate. The final distribution number, after accounting for packets that were returned undelivered, was 837.

Sample

Four-hundred two surveys were returned, 210 from survivors and 192 from family members. The response rate was 24%. One-hundred fifty-four cases had a response from both a survivor and a family member. Fifty-six cases had only a survivor response, and 38 cases have only a family member response. There were 248 cases in the sample, 103 females, 143 males, and 2 unspecified. Average respondent age was 40 years (St. Dev. = 12.92, N = 241). Refer to Table 1 for additional demographic data. Eighty-four cases were linked to hospital data from the Hospital Discharge Index.

Mean number of years since the injury (chronicity) is 11.65 (St. Dev. = 8.73, N = 231). Two-hundred twenty-four survivors participated in some kind of rehabilitation after injury. For 83 survivors, the level of independent living (LIVING CHANGE) decreased after injury; for 81 there was no change, and for 22 the level of independent living increased. Mechanisms of injury were: Motor Vehicle Accident (MVA), 116; Impact, 56; AVM/Hemorrhage/Stroke, 22; Surgery, 7; Tumor, 6; Anoxia, 4; Gunshot Wound (GSW), 3; Shrapnel, 1; Other, 9; Unspecified, 24. Of the 84 cases linked to hospital data, 21 were fractures and 42 were non-fracture brain injuries resulting from some form of impact.

Refer to Table 2 for means and standard deviations for the composite scores of the constructs and outcome measures.

Results

Reliabiity and Validity of the Survey Instrument

Chronbach's alpha was used to evaluate item reliability for scales in the survey (refer to Table 3). Highest coefficients were for the Functional Status scales (.91). Lowest coefficients were for Family and Survivor reports of Engagement (.60 and .61, respectively).

Constructs measured by the instrument were correlated to evaluate their shared variance (refer to Table 4). Statistically significant correlations ranged from .57 (LEVEL with AIS) to .29 (Functional Status with Patient Report of Engagement).

As a measure of validity, severity questions from the instrument were correlated with severity measures obtained from the independent data source of the Hospital Discharge Index. Statistically significant correlations ranged from .40 (Days in Hospital with Abbreviated Injury Score) to .25 (Days in Hospital with Level of Unconsciousness).

Universal Characteristics

For the survey sample. 224 of 248 participated in rehabilitation. This result reflects the bias in the samples. which consist of survivors with mid-range severity of injury. The profoundly disabled were not able to be respondents in this research. The mildly disabled probably did not participate in rehabilitation. This was the single universal characteristic found in the survey sample.

Generic Characteristics

Constructs and variables were correlated to evaluate the associations for this sample (see Table 4). As scores for Functional Status increased, scores for the following increased: Social Context, Perception, Family Report of Engagement. Patient Report of Engagement, SES CHANGE. and LIVING CHANGE.

A One-Way Analysis of Variance revealed a significant difference in Functional Status across levels of LIVING CHANGE, F(2, 171) = 9.39, $p < .001$ (see Table 5). A Tukey's HSD with a significance level set at .05 indicated a significant difference in Functional Status between people who became less independent (M = 46.94, SD = 9.46, n = 73) and people who stayed the same (M = 52.93, SD = 10.11, n = 77), and between people who became less independent and people who became more independent (M = 54.91, SD = 9.77, n = 22).

A Two-Way Analysis of Variance conducted to evaluate the effect of LEVEL and CAT on Functional Status revealed main effects for LEVEL, F(6, 58) = 3.52, p = .007, and CAT, F(5, 58) = 3.91, p = .006 (refer to Table 6; see Table 7 for means and standard deviations). There was no interaction between independent variables. For LEVEL, the highest Functional Status scores were for Unspecified Coma, and Coma of more than 24 hrs. with return to previous state of unconsciousness. Lowest Functional Status scores were for Coma of less than 1 hr. and Coma of more than 24 hrs. without return to previous state of consciousness. For CAT, highest Functional Status scores were for Closed/Unspecified Tissue Damage. Lowest Functional Status scores were for Open/Unspecified Tissue Damage.

The same independent variables were used in a second Factorial Analysis to evaluate their effect on SES CHANGE (refer to Table 8; see Table 9 for means and standard deviations). A main effect was found for LEVEL, F(6, 61) = 3.55, p = .006. There was no main effect for CAT, however there was a significant interaction, F(9, 61) = 2.34, p = .03 (see Figure 9). The interaction occurred between LEVEL 1 through 4, and CAT 2 (Closed/Unspecified Tissue Damage) and 3 (Closed/Specified Tissue Damage). As duration of unconsciousness increased, SES decreased from pre- to post-trauma for patients with Closed/Unspecified Tissue Damage, and increased from pre- to post-trauma for patients with Closed/Specified Tissue Damage. With unconsciousness greater than 24 hours and no return to previous state, patients from both Injury Categories decreased in SES from pre- to post-trauma. With unconsciousness of unspecified duration, SES increased from pre- to post-trauma for patients with Closed/Unspecified Tissue Damage, and decreased for patients with Closed/Specified Tissue Damage.

A One-Way Analysis of Variance verified the significant effect of LEVEL on SES CHANGE, F(6, 61) = 3.22, p = .009 (see Table 10). A Tukey's HSD with a significance level set at .05 showed significant differences between Unspecified Coma (M = 2.6, SD = 0.55, n = 5) and: Coma less than 1 hr. (M = 1.7, SD = 0.41, n = 6), Coma of 1 to 24 hrs. (M = 1.4, SD = 0.65, n = 13), and Coma > 24 hrs. with no return to previous state of consciousness (M = 1.4, SD = .59, n = 20).

Discussion

Sample Characteristics

This sample was obtained by soliciting members of a support group, therefore they are survivors with a functional status high enough to enable support group participation, and they are survivors with some form of support in their lives. Furthermore. the Injury Severity measures indicate the sample does not include extremely mild or profoundly disabled cases, but represents intermediate to severe cases. As the mean scores for Functional Status, Social Context, Self Report of Social Context, and Engagement indicate, on average both survivors and family score survivors around 3 on a scale of 1 to 4 with 4 being the highest score. However, the ranges of scores indicate considerable variability: Functional Status scores assigned by family ranged from 1.17 to 4, and by survivors from 1.11 to 4. Therefore, while the sample is limited to support group membership, it represents the variability in functional status expected from a group of survivors who sustained intermediate to severe injury, and provides an appropriate data set for this investigation.

Reliability and Validity of the Survey Instrument

Results of the item reliability analyses for scales are strong (refer to Table 3), with the highest coefficients coming from the Functional Status scales. This result verifies the assertion that a strong measure could be built by using survivors and their family to work on previously established and tested scales. The lowest coefficients came from the Inappropriate Behavior component of the Functional

Status scale (Chronbach's Alpha = .60), and the Family and Survivor Reports of Engagement (Chronbach's Alpha = .69 and .61, respectively). The low coefficient for Inappropriate Behavior could be the result of the limited number of items (two) in that subscale. With respect to Engagement, the Engagement construct was generated by developmental psychologists. A question for future investigation is, where do the models for brain injury recovery and the models for normal development converge, and where do they diverge? It is possible that engagement modes for brain injured people differ enough from those of children that unique questions must be developed to capture the process, rather than borrowing questions from developmental psychology.

Reliability for the Social Context and Perception constructs, also from developmental psychology, was strong (Chronbach's Alpha = .82 and .83, respectively), indicating a convergence of models. It is possible that the Engagement construct represents a divergence of models. It is also possible that selection and wording of items resulted in the lower reliability coefficients. Further investigation is necessary.

Correlation of constructs within the instrument indicate the Functional Status scale shares acceptable variance with expected constructs, based on previous research. Highest correlations were with Family Report of Engagement and Social Context (Pearson's r = .51 and .43, respectively). As survivors engage more positively, and have more structure, autonomy support, and involvement in their social context, their functional status increases.

Generic Characteristics

Construct Correlations

High Functional Status scores were associated with positive reports of methods of Engagement from both survivors and informants. As components of the Social Context such as Autonomy Support, Structure, and Involvement were present, and perceived as being present, Functional Status increased. As SES changed for the worse and as independence (LIVING CHANGE) decreased, Functional Status decreased.

These results serve to support aspects of the Development Model, specifically the effect of Engagement on Functional Status, and the effect of Social Context on Functional Status (see Figure 8). These are associations, however, from which no causal inferences can be made.

Analyses of Variance

A one-way ANOVA was used to test the difference in Functional Status across levels of LIVING CHANGE. A significant difference was found in Functional Status between people whose independence decreased and people whose independence stayed the same, and between people whose independence decreased and people whose independence increased. As independence decreased, Functional

Status decreased.

Difference in Functional Status according to level of severity of injury (LEVEL) and category of injury (CAT) was tested with a 2-way Analysis of Variance. There were main effects for both independent variables, with no interaction. Level of severity was determined using the ICD-9-CM classifications for coma. The highest Functional Status was reported for people whose classifications were for unspecified coma, and for coma of more than 24 hrs. with return to the previous state of consciousness. Lowest Functional Status was reported for coma of less than 1 hr., and coma of more than 24 hrs. without return to the previous state of consciousness. The variability among physicians and hospitals in assigning ICD-9-CM codes, as well as misdiagnosis or malingering, may be factors contributing to the low Functional Status scores for people with coma of less than 1 hr.

Functional Status scores across categories of injury were consistent with expectations. Highest Functional Status was for people who sustained closed head injuries with unspecified tissue damage. Lowest Functional Status was for people who sustained open head wounds with unspecified tissue damage.

The results of the 2-Way ANOVA to evaluate change in SES according to Level of Severity of Injury and Category of Injury are complex, and given the sample size, extensive interpretation is unfounded. The results are worth discussing because they bring to light the controversy about the severity of closed circumscribed damage vs. closed diffuse damage. For this sample, when duration of unconsciousness was minimal, patients with circumscribed tissue damage and a closed head injury had poorer outcomes than those with diffuse damage and a closed head injury. However, as duration of coma increased, the outcome reversed and patients with diffuse tissue damage had poorer outcomes than those with circumscribed tissue damage. This suggests that both duration of consciousness and type of damage (circumscribed vs. diffuse) need to be considered in diagnostics and prognostics. When the level of unconsciousness extended to greater than 24 hours without return to the previous state of consciousness, both groups had poor outcomes. Many factors would need to be considered before making inferences suggested by these data. For example, confounding procedures, alcohol or drug intoxication, and other system injuries may impact both levels of unconsciousness and outcome measures.

A follow-up one-way ANOVA was performed to verify the significant effect of level of unconsciousness on change in SES. If there was no coma specified in the ICD-9-CM classification, outcomes in terms of change in SES were significantly better than if there was a coma of less than 1 hr., 1-24 hrs., or more than 24 hrs. without return to the previous state of consciousness.

Summary and Transition to Study #3

Expected Results

Hypotheses generated from Study #1 were:

1) A person whose family and social network remain intact after injury will have a better recovery than one whose family and friends leave.

2) A person who is independent, or experiences autonomy, will have a better recovery than one who is dependent.

3) A person who has permission to be different will have a better recovery than one who must hide deficits and try to return to a former state of being.

4) Assuming the role of victim will be associated with lower levels of recovery for the person than assuming a self-determining role.

The Development Model asserts that high scores for variables in the constructs of Social Context and Perception will be associated with high scores for variables in Engagement, which will lead to high outcome scores.

Results

The strongest results from the survey research were the direct relationships between Functional Status and Engagement, Social Context, LIVING CHANGE, and SES CHANGE. These results validate parts of the Development Model, and confirm exploratory findings from Study #1. Those results indicated that presence of family, social networks, autonomy, and permission to be different--all components of Social Context--should associate with high Functional Status. They indicated that not being a victim--a component of Engagement--should associate with high Functional Status. The survey results confirmed those expectations.

Study #3

Participants in the case studies and their informants also completed surveys. The results from the larger (survey) sample were compared to those of the smaller (case study) sample. Inconsistencies between samples were of particular interest. There was a strong advantage in the data collected from the case studies, in that they were much more complete than those of the survey. With the case studies, I was able to observe and document individual idiosyncracies in a number of social contexts. Therefore, when a measure for one of them varied from what was expected based on the survey patterns, I could consider on an individual basis what, in that person's life, could account for the deviation. When subsets of the 20 deviated from the survey patterns, I could take into account what the subset had in common.

This process of identifying and explaining patterns and deviations was the basis for Study #3. Study #3 was a return to exploratory research, and had no formal hypothesis. The research question was: When a case study subject deviated from the expected pattern generated by the survey data, what idiosyncratic characteristic of that person's life could be found to explain the deviation?

CHAPTER V. CASE STUDIES REVISITED

The purpose of Study #3 was (1) to identify among the case studies when individual behavior was consistent or inconsistent with expectations generated by the survey research from Study #2, and (2) to seek explanations in the details of the case reports for consistencies and inconsistencies in behavior.

Method

Results from the survey sample were used to make changes in variables for Study #3 (specified below). A true outcome, Order, was specified, and a measure of Order derived for each subject. A final model was assembled and used to orient the analysis. Measures of variables in the constructs of Perception, Social Context, and Validation were then examined to see where, on an individual basis, the person's life was consistent with Order or Disorder. Explanations for consistencies and inconsistencies were explored.

Revision of Variables

A survey response was acquired from each person in the case study. Results from the larger sample led to the following changes in variables from Study #2 to Study #3:

Perception

Items used to measure Ability to Shape the Environment were separated into two distinct indices, Ability to Shape Life and Ability to Shape Rehabilitation.

Items used to measure Involvement were separated into two distinct indices, Involvement in Life and Involvement in Rehabilitation. Perceived Access to Services was added to this construct.

Social Context

Opinion of Rehabilitation, as reported by the informant, was added to this construct.

Validation

Items used to measure Ability to Shape the Environment were separated into two distinct indices, Ability to Shape Life and Ability to Shape Rehabilitation. Items used to measure Involvement were separated into two distinct indices, Involvement in Life and Involvement in Rehabilitation.

Outcome Measure

The outcome measure was specification of whether or not the person was in a state of Order. Order was derived from (1) clinical evaluation, (2) measures of Engagement, and (3) measures of Functional Status.

Each case report was reviewed to consider who presented qualities of responsiveness and constancy in their Engagement modes; whose actions were netting the desired results; who complained that they were dissatisfied and unfulfilled; who presented consistent response, and who was erratic and unpredictable. Answers to those questions provided a list, based on clinical evaluation, of people in a state of Order and those in a state of Disorder.

Individual scores from the survey for the variables in the Engagement construct were reviewed. People with scores above the median for a variable were assigned a positive value for that variable; those with scores below the median were assigned a negative. Scores on the median were labeled "on." Positives and negatives were summed to calculate a total, resulting in a categorical assignment of a state of Order or Disorder for each person. These quantitative categories were compared with clinical evaluations. Clinical evaluations for four people specified them in a state of Order while their survey scores specified them in a state of Disorder. In one case, the clinical evaluation was a state of Disorder while scores indicated a state of Order. For eight people, the clinical evaluation agreed with the survey scores. For five people, there were insufficient data for a quantitative specification of Order or Disorder. In two cases, all variable scores were on the median, rendering their quantitative specification questionable.

To further define Order, two Functional Status composites from the survey were examined, Family and Patient Reports of Functional Status. People with scores above the median were assigned a positive for the composite; those with scores below the median were assigned a negative. Scores on the median were labeled "on." Positives and negatives were summed to calculate a total. For six cases, both scores were either positive or negative. In two cases the Patient

Functional Status score disagreed with the Family Functional Status score. In two cases one or both composites were on the median. In ten cases there were insufficient data for one of the composite scores.

These results were compared to clinical evaluations and scores from the Engagement construct to determine a final assignment of Order or Disorder for each person. Positives and negatives for the three methods of evaluation were given equal weight. In 18 cases the assignment of Order or Disorder was based solely on the total across these three measures, even when the clinical evaluation disagreed. Missing data for 2 cases, combined with strong clinical evidence, resulted in the specification of their state of Order based solely on clinical data. Eleven people were categorized in a state of Order. Nine people were categorized in a state of Disorder. Within these categories people were ranked from highest to lowest based on their cumulative scores on measures of Functional Status and Engagement. This ranking was consistent with clinical evaluation for all subjects except Ann D., who gave herself high scores in spite of circumstances and the presentation of behaviors that clearly place her in a state of Disorder. Refer to Table 11 for subjects' Order/Disorder categories, and ranking within categories.

There is no presumption that these states are true for a lifetime, or for any period of time other than that period when the measure was taken. However, events and lives as represented in the EsEx Couple can enter into stable states, and maintain those states over extended periods of time. For this project, a read was taken of the state of Order for 20 people at one point in time, in order to conduct an analysis of significant factors that relate to states of Order. The utility of the exercise is limited by the dynamic nature of life processes.

Model for Order

Constructs and variables in the Model for Order are as follows:

Construct	Variable or Composite
Perception	Perceived Structure
	Perceived Autonomy Support
	Perceived Involvement in Life
	Perceived Involvement in Rehab.
	Perceived Symbiosis
	Perceived Ability to Shape Life
	Perceived Ability to Shape Rehab.
	Perceived Permission to be Different
	Perceived Access to Social Services
Social Context	Structure
	Help of Others
	Opinion of Rehab.
	Symbiosis

Validation	Autonomy Support
	Involvement in Life
	Involvement in Rehab.
	Ability to Shape Life
	Ability to Shape Rehab.
	Permission to be Different
Order	Functional Status Composite
	Engagement Composite
	Clinical Evaluation

Refer to Figure 10 for an illustration of the Model for Order. The purpose of this model is to provide an exploratory structure for bringing information from the survey research back to the case study research, to consider consistencies, inconsistencies, and patterns. It is not intended to be a merge of previous models or a competing model. It is not intended to be quantitatively tested. While quantitative data from Study #2 is used here, the nature of Study #3, and the Model for Order, is qualitative.

Results

Subjects were categorized in a state of Order or Disorder, and individuals' scores for each variable index within each construct were noted. The expected pattern was that people in Order would score above the median on each index, and those in Disorder would score below the median. Table 12, the Chart Highlighting Failed Predictions, illustrates for each subject when the scores met expectations and when they did not. Shaded cells show where classification of Order/Disorder failed to predict scores.

Percent Correct, the proportion that subjects scored consistent with their Order/Disorder classification, was calculated for each measure, and for each construct. Percent Correct was derived by dividing [the number of times scores met expectations] by [the number of possible scores]. Following are the results:

Construct	% Correct	Variable	% Correct
Perception	77%	Perceived Structure	69%
		Perceived Autonomy Support	81%
		Perceived Involvement in Life	65%
		Perceived Inv. in Rehab.	100%
		Perceived Symbiosis	81%
		Perceived Ab. to Shape Life	81%
		Perceived Ab. to Sh. Rehab.	69%
		Perceived Perm. to be Diff.	71%
		Perceived Access	65%
Social Context	80%	Structure	69%
		Help of Others	83%

		Opinion of Rehab.	90%
Validation	74%	Autonomy Support	58%
		Involvement in Life	69%
		Involvement in Rehab.	100%
		Ability to Shape Life	75%
		Ability to Shape Rehab.	80%
		Permission to be Different	69%
		Symbiosis	58%

An examination of the Chart Highlighting Failed Predictions (Table 12) demonstrates that, for the case study sample, some constructs and measures were more reliable than others in their association with Order.

1. Social Context - The strongest construct was Social Context. These responses were provided by family, not patients. For questions asked of family members about Structure, Rehabilitation, and Help, positive responses correlated with the state of Order and negative responses correlated with the state of Disorder more than for other constructs (80% of the time). Consistent with both Goldstein (1934) and Connell and Wellborn (1991), Structure questions were designed to determine if patients had the amount and kind of Structure appropriate to their particular needs. Over-facilitation is considered an impediment to recovery as much as under-

facilitation. The Rehabilitation component was the family's opinion of the value of the rehabilitation program. Help is a measure of just that - does the patient have the practical assistance required to function?

2. Symbiosis - Patient Report of Symbiosis was strong. Eighty-one percent of the time, positive responses from patients correlated with the state of Order and negative responses correlated with the state of Disorder. Patients' perception of symbiotic relationships in their lives, therefore, is a strong indicator of Order.

3. Involvement in Rehab. and Help - The strongest variables, evaluated independent of their constructs, were Perceived Involvement in Rehab. (reported by patients), Involvement in Rehab. (reported by family), Family Opinion of Rehab., and Help (reported by family). High Involvement of others in the patients' rehabilitation program, as reported by both patients and family, correlated with the state of Order 100% of the time, and low Involvement correlated with the state of Disorder 100% of the time. The same pattern was true for Family Opinion of Rehab. 90% of the time, and for Help 83% of the time.

Missing Data

A considerable degree of data are missing from the surveys acquired from the case study subjects. For 7 subjects there was no informant survey. Three subjects did not provide their own version of the survey. In examining reasons for missing surveys, the following pattern presented itself: For the 7 missing informant surveys, 4 were for people in Disorder and 3 for people in Order. For all 4 in Disorder, the informants refused to provide a survey. For all 3 in Order, the subject refused to allow an informant to provide a survey.

It is possible the informants' refusal to provide a survey illustrates a general lack of support and understanding of the needs of the subject, indicating a negative condition in Social Context, and accounting for the state of Disorder. For the subjects in a state of Order, refusal to acquire informants' surveys might represent a high level of independence, an indicator of Order.

For the 3 surveys not provided by subjects, all 3 subjects were not able to complete the survey. The state hospital did not give permission for Jody to receive the survey. Because of their profound memory deficits, Dan and DZ could not perform the task.

Discussion

This section (1) discusses patterns from the case studies that are both consistent and inconsistent with expectations, and (2) explores individual lives to find explanations for behaviors.

Consistencies

Social Context

People in the Ordered group whose Social Context was consistent with Order are Bob. Greg, and BH. Bob and Greg have strong, attentive family members who are aware of the particular needs of their survivor. There is less evidence of strong family ties with BH. However, her injuries are less severe, so she does not require as much help in order to maintain Order.

The person in the Disordered group whose Social Context was consistent with disorder is Mike T. However, Mike T. is one of the cases for whom the low scores contradicted the clinical evaluation of an ordered, working life. In other words, in spite of informant reports and scores on the survey, I don't think Mike T. is in a state of Disorder. His life is made workable by his wife, Julie, who is also brain damaged (and one of our cases), but whose Functional Status is high. The informant data on Mike T. was provided by a relative who knew him prior to his brain damage. Julie met Mike T. after his surgery, in the brain injury support group. It is probable Julie's evaluation of Mike T.'s Functional Status would be higher than that provided by the relative. In addition, around Julie, there is no pressure for Mike T. to go back to being the way he used to be, since Julie didn't know him then, and fell in love with him the way he is now. Consequently, Mike T. has a high degree of autonomy and permission in his life.

Validation

People in the Ordered group whose Validation was consistent with Order are Bob and Greg. They are also in the Ordered group whose Social Context is consistent with Order. As reported, Bob and Greg have strong family support systems.

The person in the Disordered group whose Validation is consistent with Disorder is Jody, who was sentenced to 30 years in the state mental hospital.

Perception

People in the Ordered group whose Perception was consistent with Order were MH, David, and John. All three cases present a low number of essential disturbances. For Validation, which is the informant's version of the same inquiry as Perception, John's informant, his wife, gave him a low rating. She said he did not have much autonomy, Involvement, Ability to Shape Life, and so forth. And yet John's report is the opposite. His experience at the time of the report was that he was autonomous, and that experience, whether it reflects reality or not, is consistent with his categorization as Ordered; his wife's report, although probably more real, does not adequately describe John's state of Order. This changed for John, however, as his disease progressed, resulting in an intolerable diminution in the scope of John's Social Context.

MH's low severity level combines with a close spousal relationship--she divorced her first husband after her accident and remarried--to compensate for the reduction in her Perception. David's wife, on the other hand, divorced him after his accident, and he does not have much contact with his children as well. Yet he rates himself high in Perception. David is severely impaired, but his deficits are primarily physical, so he uses the mental capacity he has to compensate for his physical limitations. He volunteers, uses public transportation, and is a member of the TBI social club. David's form of adaptation is "yield" as opposed to "shift" which suspends him in a state of suffering. Performances have been damaged but not destroyed. There is no possibility for a brand new orientation.

People in the Disordered group whose Perception was consistent with Disorder were Mick, Sandy, and Mike T. Mick's family provides support with an agenda that Mick should be grateful for their help. Interviews with Mick and his mother revealed that this dynamic was present prior to his accident. Mick resented his family then and he resents them now. Mick's perception of their lack of support is a barrier to the usefulness of the assistance they provide.

Sandy's injury severity is relatively low, which in the past has not limited her ability to create a life for herself. However, at the time of her report, her husband was suggesting divorce, which probably threw her out of a state of Order, and accounts for her low self-report for Perception.

Mike T.'s report of Perception is low, which is consistent with his Disordered category. I have maintained he is not Disordered, that I have miscategorized him, yet his own report suggests he experiences diminished

Perception. On the other hand, Mike T. is an activist. He runs the support group program for Eastern Oregon. His brain damage is the result of the miscalibration of radiation equipment when he was being treated for a brain tumor. He and others sued the hospital and won a financial settlement. These facts illustrate that Mike T., although severely disabled, is aware and intelligent, which may account for his low evaluation of Perception. On the other hand, his high number of essential disturbances may be the simple and concrete explanation for his low scores for Perception.

Inconsistencies

Social Context

People in the Ordered group whose Social Context was inconsistent with Order are Jean, John, RS, Ann C., Becky, and Julie. These people received low scores by informants on measures of Structure and Help, and they did not have a compelling life situation. However, they are categorized in a state of Order. It is possible the informants, having known the survivors prior to their brain damage, gauged their responses against some premorbid standard, resulting in a low evaluation of their current Social Context. I believe this is a fundamental problem with the research design, and may point to a place where the developmental model does not work well with brain damage evaluation. The developmental model specifies that we accept informant data as the objective description of the Social

Context. For example, we make the assumption that if the informant reports low scores on questions about Structure, there is inadequate Structure present. But the informant may be providing a low evaluation of Structure relative to a Structure that was present prior to the injury. Perhaps informant data for children is more reliable than for brain damaged people. With children, the complication of having known the person in a prior state is not introduced. There is no comparison between the current status and some former status.

People in the Disordered group whose Social Context was inconsistent with Disorder are JB, Jody, Dan, and DZ. Informants rated them high in Structure, Help, and reported they had a compelling life situation. Dan's parents committed him to a long term care facility and moved to another state, so as to begin a new life without Dan. Their high evaluation of Dan's Social Context could reflect their need to believe he is being taken care of. DZ's injury is the newest of the twenty cases, and he has lost all ability to integrate new information. The informants who provided the high evaluation of DZ's Social Context, his parents, have not fully accepted the loss. Like Dan's parents, they need to believe DZ is all right; unlike Dan's parents, their need is driven by their daily involvement, rather than by distance.

Validation

People in the Ordered group whose Validation was inconsistent with Order are RS, Ann C., Jean, John, BH, and Julie. RS, Jean, John, and Julie are also in the

Ordered group whose Social Context is inconsistent with Order. Because data for Validation is provided by an informant, the viability of informant data comes into question. On the other hand, low scores on these indices may reflect that the informant knows and understands the amount of work required to provide adequate Validation. For example, RS works, has an involved family, experiences himself as being in control of his life, understands that he has deficits and believes he has permission to have them and still be loved. Yet his wife rated him low on Autonomy Support, Involvement, Ability to Shape Life, and so forth. This may be because she is the choreographer of RS's life; she is the person who makes sure on a daily basis that all components necessary to RS's experience of autonomy are in place. She knows he isn't truly autonomous; his freedom is an illusion for him that she creates in order to maintain his stability.

People in the Disordered group whose Validation was inconsistent with Disorder are Mike T., DZ, Dan, and JB. They received high scores from informants for Validation. I maintain that I have miscategorized Mike T., and that he leads an ordered life. The high scores for Dan and DZ are probably a function of the parents' reporting the information, as discussed above. JB's informant was her sister, who is also disabled. In this case, their pre-trauma status may help explain the high evaluation of indices like Ability to Shape Life, and Autonomy Support. In discussing their life before JB's accident, her sister described a relatively limited scope of Social Context. For example, for recreation they shopped at second hand stores or visited friends. The components of their life that constitute the construct of Validation were not drastically diminished by JB's accident.

Perception

People in the Ordered group whose Perception was inconsistent with Order were Jean. Julie, RS, DF, Ann C.. Bob, BH, and Greg. For Jean, Julie, DF, and Ann C.. although their mechanisms of injury and essential phenomena differ, these four survivors share an awareness of the loss in their lives that operates to diminish their Perception. They represent Goldstein's distinction between yielding and shifting with respect to adaptation. This of course varies among the four people. For example, some of DF's physical performances have been completely destroyed. Consequently she has abandoned pre-trauma methods for certain activities, and developed prostheses to compensate. But her cognitive abilities, while damaged, remain intact, rendering her aware of the limitations in her life.

Jean, on the other hand, presents no obvious characteristics of brain damage, or any type of damage. Jean sustained a brain stem hemorrhage, which resulted in loss of speech and certain motor activities, but not much, if any, loss of awareness. Because all damage was partial, there was no possibility for her to adapt through shifting. She was sentenced to years of struggling to restore the parts of herself she lost. In addition, Jean reported that her family never acknowledged the extent of her loss. They maintained a pretense that everything was all right, even through the years when Jean could not complete a sentence. This family dynamic isolated Jean; she buried her experience of loss and carries it still. But minutes into my first interview with Jean, her grief surfaced as if the accident were quite recent. Her experience is that she lost a part of herself she will never regain, and no one knows about it. This isolation may explain her low self-report of Perception, as well as those of Julie, DF, and Ann C.

People in the Disordered group whose Perception was inconsistent with Disorder were Ann D., JB, and Hal. Ann D. has lost everything. Little is known about her pre-morbid life. She lives in a nursing home, and cannot walk. She presents a constant state of agitation and self-concern, and has a diminished capacity to commit new information to memory. I think her high self-evaluation for Perception reflects her inability to negotiate the interview and survey instrument.

Patterns in Inconsistencies

Individual scores on variables were examined for each subject to further evaluate inconsistencies. Jean, John, RS, and Julie, all in a state of Order, were evaluated as low in measures of Social Context. Jean, John, and RS all have less-than-adequate Structure. Julie has inadequate Help. This result, suggests that Structure and Help may be exceptionally strong variables contributing to Social Context, and a common thread in threatening the condition of an Ordered person's life.

Conversely, Dan and DZ, both in Disorder, were evaluated as high in measures of Social Context. The scope of their Social Context is appropriate to the degree of their deficits. The quality of their Social Context may be inadequate, but the limitations in size are necessary to their safety and that of others. This result suggests that appropriate scope elevates the condition of a Disordered person's life.

Six people, over half the Ordered group, received low evaluations for Validation. A closer look at their reports shows that to some degree, they all have limits to their Ability to Shape their Life and/or their rehabilitation programs. This finding is consistent with Goldstein's assertion that the ability to shape a new environment is essential to the restoration of Order.

All people in a state of Disorder who received high evaluations of Validation have one thing in common. They all have adequate Permission to be Different. This suggests that Permission to be Different may be a strong factor in stabilizing the life of a Disordered person.

Idiosyncratic Explanation for Inconsistencies

The informal hypothesis for Study #3 was: When a case study subject deviated from the expected pattern generated by the survey data, something idiosyncratic about that person's life could be found to explain the deviation. The following discusses deviations noted earlier, and presents possible explanations founded in individual differences.

While family has been shown to be an important influence in recovery, BH demonstrated that, with less severe injury, family is less important in establishing a state of order. It appears she has limited involvement with her family, yet she is functional enough on her own, given her mild impairments, to continue to lead a stable and productive life.

The partnership between Mike T. and his wife illustrates the power of Permission to be Different. In this case, Julie's full acceptance of Mike the way he is operates to elevate his autonomy, allowing him more independence than would be expected, given his low Functional Status.

Some low post-trauma measures must be considered in relation to the pre-trauma measure, in order to understand a deviation from the expected pattern. For example, JB's informant scored JB high in Social Context indices, although she is in a state of Disorder. But in many ways JB's life now, her Social Context, is not different from her life prior to her injury. The scope of her Social Context was relatively limited then, and not greatly reduced since her injury.

Level of awareness appears to play a strong role in accounting for deviations from expected patterns. For some subjects, high awareness of the loss they sustained appeared in company with low scores on measures of Perception, a self-reported construct, and could be directly related. One subject's life illustrates that high awareness can result in isolation and loneliness, which was captured in her low scores on measures of Perception.

The usefulness of the Family Survey--the informant's report--is challenged in considering deviations from expected patterns. It is possible that limitations in using informant data account for some of the deviation. For example, a family member may base a response to a question on knowledge of the subject prior to injury. A subject may have entered a state of post-trauma Order, but because the relative knew the subject's pre-trauma level of functioning, the relative assigns low scores on measures of functional status. Another source of inaccurate informant data may be the informant's need to believe the subject is being cared for. Finally, low Autonomy scores may be a function of the fact that the informant, the family member, is the person doing the work necessary to provide the autonomy. The low score reflects the informant's understanding that, without help, there would be no autonomy.

Summary

Percent Correct

Case study subjects' behavior, as measured by their own and their families' survey responses, was most consistent their Order/Disorder category in the following:

Social Context

Opinion of Rehabilitation

	Help
Perception	Involvement in Rehabilitation
	Autonomy Support
	Symbiosis
Validation	Involvement in Rehabilitation
	Ability to Shape Life
	Ability to Shape Rehabilitation

Strong Constructs/Measures

Based on proportion of behaviors that were consistent with expectations, the strongest constructs and measures in the Model for Order are Social Context, Perceived Symbiosis, Perceived Involvement in Rehabilitation, Involvement in Rehabilitation, Opinion of Rehabilitation, and Help.

Consistencies

Strong family operates through Social Context and Validation to contribute to Order. Low number of essential disturbances operates through Perception to contribute to Order. High awareness of loss operates through Perception to contribute to Disorder.

Inconsistencies

Patterns in Inconsistencies. Lack of Structure and Help accounts for low Social Context for people in Order. Diminished Scope accounts for high Social

Context for people in Disorder. Limited Ability to Shape Life accounts for low Validation for people in Order. High degree of Permission to be Different accounts for high Validation for people in Disorder.

Idiosyncratic Explanations. For individual cases: Low Severity of Injury reduced the need for family. High degree of Permission to be Different provided Autonomy. Limited pre-trauma Social Context accounted for low post-trauma Social Context. High awareness of loss added to the adaptation of Yield to result in isolation, and low Perception. Informant reports distorted by (1) knowledge of work required to create the illusion of autonomy, (2) need to believe the patient is all right, and (3) use of pre-trauma standard to gauge post-trauma status.

CHAPTER VI. CONCLUSIONS

This project was initiated as a case study investigation of factors that contribute to the recovery from brain injury. Kurt Goldstein's (1934) method for observation was used to conduct the investigation. The EsEx Couple Schema (Maynard, 1992) was used as a general theoretical orientation.

The project evolved into three distinct studies that related to and informed each other. During Study #1, case histories were constructed for 20 survivors. Qualitative evaluation of those data led to the development of the Recovery Model, and to generation of the hypotheses that recovery may be enhanced by family, social networks, autonomy, permission to be different, and the feeling that one is not a victim.

The interest in testing the hypotheses, along with the need to operationalize measures, led to Study #2, and the adoption of two specific theories, one for recovery and one for development: Kurt Goldstein's Laws of Organismic Life (1934), and the Motivational Analysis of Self-Systems Processes (Connell & Wellborn, 1991). A survey was constructed and administered. Results indicated that hypothesized factors in the Social Context and hypothesized modes of Engagement were strongly associated with Functional Status.

For Study #3, the aggregated data from the survey were used to reexamine the individual cases, to consider how idiosyncracies account for deviations in expected behavior and outcomes.

Two important products are the result of this research. A new way of conceptualizing recovery was developed, integrating theory and practice from Systems Science, Medicine, and Developmental Psychology, and was articulated in a Model for Recovery. An instrument for measuring post-trauma functional status and the recovery process, created with the assistance of people who have sustained brain injury and their families, was designed and validated.

The following is a summary of the findings of this project, with recommendations for how to use the information in clinical practice.

Universal Characteristics

All subjects in the case study experienced a problem with balance. For the survey sample, 47% of family respondents reported an explicit problem with balance for the patient in question. An additional 26% reported related problems with walking, increasing the proportion with balance problems to 73%. Forty-four percent of patient respondents reported an explicit problem with balance. An additional 23% reported related problems with walking, increasing the patient-reported proportion with balance problems to 67%. While the problem with balance was not universal for the survey sample, the majority of the sample has the problem.

The most useful place to deliver this information is into the arena of primary care practice, and other medical fields that may lack an understanding of the signs and symptoms of brain injury, such as opthomology or psychiatry. The misdiagnosis of brain injury is a particular problem with mild cases that may have no history of admission to an emergency room for the trauma. When a patient presents with a balance problem but a negative Magnetic Resonance Image (MRI), the physician could request a neuropsychologic evaluation that would be sensitive enough to detect the organic damage, if present (Lezak, 1995). Further investigation of universal, or near-universal characteristics, could be used to develop a simple but useful checklist for primary care practice of the major signs and symptoms of brain injury.

Generic Characteristics

Social Context

The strongest relationship between construct and outcome demonstrated by the case study sample was between Social Context and the state of Order. Family Opinion of Rehabilitation and Help were strong measures of Social Context that associated with Order. The survey results confirmed the overall finding, in the strong relationship between Social Context and Functional Status.

Perception

Case study patients who perceived that others were Involved in their Rehabilitation were more likely to be in a state of Order. Perceived Autonomy

Support and Symbiosis also contributed to the state of Order

Validation

Case study patients who had Autonomy Support, were able to Shape Life and Rehabilitation, had Permission to be Different, and had Involvement from others in their rehabilitation program were more likely to be in a state of Order. Also, patients who were able to Shape their Life were more likely to have positive Engagement Strategies, and those with Involvement were more likely to have positive Feelings about engaging in new and difficult tasks.

These patterns have practical application, in the following way:

1. Appropriate Structure and enough Help are important facilitators of recovery. Families can be informed early about how to establish a structure for the patient that will maximize the potential for recovery. They can also be assisted in preparing for and providing the necessary level of Help.
2. The scope of the patient's environment must be appropriate to the level of deficit and not dictated by what the patient or family can afford.
3. Families can be trained to provide autonomy support for patients, so that patients will experience being independent. Support systems for family members need to be established and maintained so they can remain involved in the lives of the patients.
4. Families can be trained to recognize behaviors that are the patient's attempt

to shape the environment, and supported in allowing the patient to succeed in those efforts. Families can be informed of the potential harm in pushing a patient to try return to some former state.

5. Reciprocal relationships in which the patient feels needed must be established, or maintained if already present.
6. Family participation in rehabilitation must be encouraged and facilitated.
7. Physicians need to be trained to fully disclose information to family members, so they understand the implications of the severity of the trauma.

Refer to Figure 12 for a representation of important results illustrated within the Model for Order.

Unique Characteristics

The unique characteristics of the case study sample have been described. While the uniqueness of the survey respondents cannot be described, we can understand that it is there through the twenty people who contributed their stories to this dissertation. For this section, I will draw conclusions first, then elaborate on two case studies that were most interesting to me, and that illustrate the profound influence of the unique on the working system.

A glance at Table 12, the Chart of Failed Predictions, reveals the strongest and most important result, which is the overwhelming individual variability in the cases. Some patterns were found, and they hold potential clinical meaning.

However, the most clinically relevant result is the lack of consistent pattern, and what this implies for clinical practice. In the end, the clinician will face the patient and make decisions about care, and the patient's well-being and opportunity for recovery is in the hands of the clinician, and depends upon the skills and experience that can be brought to bear.

The large part played by individual differences in the recovery of TBI survivors may cast light on a subject which has been hard to understand. It has never been easy to define what is meant by good clinical skills in psychology and medicine. Clinicians can be found who reliably produce good results in their patients, but it is not easy to say how they differ from those who are less successful. Often they have the same training and length of service as less able colleagues, but they seem to get better results. In addition, almost all clinicians improve with experience.

It is likely that many factors are at work to make a good clinician, like intelligence, education, interest, temperament, and much more. But perhaps the results of the present study show how accumulated experience in a clinical setting makes its contribution. Perhaps successful clinicians come to realize the importance of individual differences to such a degree that they learn to search the specifics of a patient's life and situation for the unique opportunities and hazards that exist for that person. Long experience may also generate more effective strategies for finding the details of the patient's life and for creating unique solutions for unique problems. Goldstein (1934) believed the fundamental job of the physician is to come to know the individuality of the patient, so as to understand how much restriction of freedom the patient can tolerate and still maintain essential nature. Because prescribed interventions always, at least initially and sometimes permanently, produce a restriction of freedom.

It is beneficial to know about the universal and generic characteristics of a population of patients undergoing treatment. Those features provide the basic ground against which the person's uniqueness shows in high relief. One might even say that knowing the properties of a population is essential if one is to discern exactly how each patient is different. But the central point remains that in clinical work--as distinct from epidemiology--one must treat patients one at a time. And, when people are met individually, all bets are off and all population statistics become abstractions. A knowledge of populations is useful when setting up the routine practices of a clinical setting because *clinics* are institutions which treat populations, but *clinicians* are practitioners who treat patients, and the effective treatment of each patient must depend on the readiness and ability of the staff to grasp and understand personal uniqueness and make that the basis of their intervention in each case.

If it is true that individual differences account for as much variability in the outcome of TBI survivors as seems to be the case in the present study, then they become crucial for understanding how a survivor's life works or not. This may not be welcome news for those who hope to find a basis for treatment and intervention which is simple and powerful and can be made into effective routines of treatment. But it may show why clinicians need to develop an alertness for the unique character of each patient, and it may direct their attention to the actual impediments to successful survivorship, and it may aid in finding the truly effective resources that will work for that particular survivor. This may be one of the essential skills of the successful clinician--to recognize and work with uniqueness.

Individual differences is arguably the first topic in American scientific psychology. It was the subject chosen by J. McKeen Cattel for his dissertation with Wilhelm Wundt in Leipzig. Since that time, individual differences has never disappeared as a field of study in psychology, but it has not occupied the central place of more nomothetic science. However, in applied psychology, the study of uniqueness must become more salient. It is here that applications of systems theory may play a new part. Even in the operation of uniqueness, with all its particular variation and play of variables, the same systemic processes may be at work. It has been the thesis of this work that this is the case: that basic systems principles still underlie the operations of survivorship, but that the particularities of each human life will stamp each survivor with a unique character which must be appreciated to make treatment and intervention genuinely helpful.

The next section is a narrative of two of the case studies. I selected them for elaboration because they illustrate the complexity of the individual life and the influence of individuality on the restoration of health. Also, they illustrate what I consider to be the two most important factors that contribute to a working system. the heart of my dissertation findings, family and freedom.

The interplay of the survivor's personal autonomy and its paradoxical dependence on family support. evokes reference to the operation of the EsEx Couple as a model of the social self. The idea of the social self was introduced into scientific psychology by William James in 1890 and later extended most famously into the work of George Herbert Mead (1913. 1934) and his students. The basic idea of the social self is that of a system formed by the person-in-social context. seen as a functional unit. As a model of the relation of Self and Other. it was a systems idea in its inception. and it may be conceptualized as an instance of the EsEx Couple as shown in Figure 11.

This representation of the social self originates in the idea that humans have the two discriminable needs of personal autonomy and social connection: a need for solitude and a need for human company. All human society exists in a tension between these two needs, and makes some particular compromise between them. In solitude. one has the experience and the benefits of one's own uniqueness. This is the domain of creativity and free expression which Maslow (1962) called self-actualization (Maslow derived this idea from the work of Kurt Goldstein). But solitude also entails the risks of alienation and loneliness, of autism and madness, so a successful state of Liberty depends--paradoxically--on the other aspect of the social self, the company of the Other. If the Essence side of the social self represents the state of person in Liberty, then the Exchange side represents the nature of the social exchange, here called Love. This first representation of the social self in Figure 11 (called Ease, or Innocence, or Friendship) shows the idealized form of a "successful" life in progress. But the social self may also reach "unsuccessful" states, as shown in the corresponding system in Figure 11 (called Dis-ease, or Experience, or War). An actual human life might tend to one state or the other, and typically is lived somewhere in the space between the two extremes.

From this abstract vantage we can consider the unique characteristics of two real lives, one which represents a condition of Ease, the other a condition of Disease.

The Working System - Bob and John

Bob

Bob has the longest chronicity, 67 years. He fell ten stories when he was 18 months old, fracturing his skull and sustaining profuse tissue damage. The result was delays in walking and speaking, cognitive and developmental delays, perseverative behavior, and pain. TBI was not a defined phenomenon; formal rehabilitation was not available. Bob lived in a rural mid-west environment among a large, extended family of Scots and Tuscarora Indian heritage. They provided rehabilitation by walking with him to the river to fish and by reading the newspaper to him. His cousins brought him to school, protected him from the cruelty of other children, and explained his aberrations to the teacher. Aunts and uncles took care of him during summer vacations, providing him with diverse stimulation and his parents with a respite from the routine of his care.

Initially Bob's number of essential disturbances was overwhelming. It is unclear, because his trauma is so old, whether he suffered total or partial performance loss. However, it appears that the facilitation provided him was appropriate; he was not overprotected, but he had the support necessary to be safe and avoid catastrophic reactions. Help was provided him and his parents by peripheral members of the family. As a child, his compelling life situation was the opportunity to fish; it was the motivation for his learning to walk. His father walked him to the river. If Bob fell, which he often did, his father would not help, but would wait as long as it took for Bob to get up and carry on. Bob's family, then, created for Bob an illusion of autonomy, which strengthened him as he grew and ultimately allowed him true freedom.

Bob has moved through the phases of recovery and currently lives in a restored state of health.

Bob's first love, fishing, was encouraged, which may account for the fact that he developed other interests as he grew that motivated him to achieve. The interest in fishing was an expression of Essence; his willingness to learn to walk in order to get there was an expression of Engagement. The Social Context responded with the appropriate kind and amount of facilitation, resulting in concrete validation of his autonomy and ability to affect his environment. What is important here is not what motivated Bob, but the fact that his ability to be motivated was fostered by the positive response he received from his Social Context when he expressed interest.

Bob's case is unique in many ways. He was injured prior to developing language, so his recovery process occurred as he grew. He was injured before complex and expensive methods of rehabilitation would be developed, so his recovery process was not complicated by medicine. He had a devoted family, and one strong figure, his father, whose intuition guided him to facilitate Bob's environment appropriate to his needs. Although Bob's specific circumstances were unique, they serve to illustrate and validate principles for recovery discussed in this project.

John

John is the person who provided insights into loss of cognitive function before his brain damage, as opposed to the retrospective reports of the other 19 cases. John had small cell carcinoma. He was receiving chemotherapy and radiation therapy; his disease was in remission. At a family gathering John presented symptoms of aphasia. Subsequent brain scans revealed several tumors. His deficits were minimal, but were expected to increase due to damage from the prescribed treatment, brain radiation. At this point he was entered into the study, and was interviewed on a weekly basis while both the progression of the disease and the radiation therapy reduced his cognitive abilities.

Early in the process John expressed his strongest concern over losing his ability to imagine. He pointed out that his joy in life was the ability to think; the content of his thought was secondary to the simple ability to have thoughts. He also pointed out that, although forgetting is a part of cognitive dysfunction, a person may still know he is forgetting. He stated, "When you don't remember something you know you should know, you know you don't know." In other words, unless brain injured people experience loss of memory to the most profound degree, they are to some extent aware when they are forgetting something, and this awareness is a source of great discomfort, probably a precipitator of catastrophic reaction.

John was a union electrician, a Viet Nam veteran, a member of a large extended family of Italian and Irish immigrant descent. He was married and had two children, one of whom was married and a parent of two daughters. John's compelling life situation was his family, in particular his granddaughters. John was a strong influence in the family; the person who made most decisions, large or small. His ability to be in control and autonomous was at least as important to him as his ability to think.

As John's disease progressed his number of essential disturbances increased. It is not possible, nor would it be particularly productive, to separate his brain damage deficits from those caused by his other-system disease and therapy process. In general, his condition deteriorated slowly over time, and with it came the reduction in his Social Context.

There is a question with regard to whether John received the appropriate facilitation in his Social Context. John's strong personality overwhelmed attempts to support him in the way his family considered necessary. It appeared that John perceived attempts at facilitation to be further restrictions of his autonomy, thus he rejected them, and reacted with anger. He regressed into a state of Dis-Ease, in which transactions acquired qualities of anxiety and deceit. Over the course of time, family members either stopped trying to facilitate, or began disguising their efforts. In fact, John required the support of others. He lost the ability to work, drive, walk unaided, locate the bathroom, etc. At one point, members of the family most involved in John's care formally discussed how to proceed. Should they take steps to force John to understand his limitations, or should they continue to conceal their assistance? The former would be easier for them, but would probably result in a catastrophic realization for John. The family chose not to force John to awareness, and continued to conceal their intricate, daily routine of taking care of him while pretending not to.

However diminished John's awareness became, it was not reduced consistent with his reduction in Social Context. As Goldstein pointed out, shrinkage of Social Context is a necessary phase in the restoration of health, but with it comes either a reduction of awareness or great suffering. For many brain injury survivors, particularly those whose injury was traumatic and severe, awareness is diminished at the point of trauma, sparing them the suffering that comes with understanding that freedom is lost.

John remained aware that his world was diminished, both the inner-world of his imagination which he so loved and the outer-world of being a free man able to play with his grand children. His path was to end his suffering; at some point now lost to memory John suspended eating and drinking.

Why is John discussed in the context of the working system? Two answers are possible. One answer is, all systems work. There is no such thing as a system that is not working. A system may be in a condition in which its responses do not facilitate its purpose, but then the dynamics of the system, as defined by the EsEx Couple model, make alterations in processes that change actions, essence, Social Context, and so forth, and move it back to a state of equilibrium. This perspective serves to caution the clinician. Order is not synonymous with "working," and Disorder with "not working." Disorder is an outcome of a working system that encountered a stimulus to which it had an inadequate response. If only one thing is gained from this dissertation effort, it should be the understanding that, in treating brain injury, the clinician must throw out preconceptions of what equilibrium looks like: to try to return the patient to a former state is to guarantee failure.

Another reason for considering John in the context of the working system is to use his case to emphasize the importance of freedom, and to illustrate Goldstein's assertion that fundamental to all humans is the need to realize and actualize the self through free choice. More than most, John's freedom was precious to him. Losing it was intolerable. Being aware of the loss precipitated intense suffering. Ending his life was his final act of autonomy.

The Model from Developmental Psychology and Brain Injury Analysis

Divergence

John's case is a good place to start in considering the developmental model, since he provided the first clue about where the model works for children but does not for brain injury. John talked about imagination, a form of abstract thought. Imagination is lost to varying degrees in the wake of brain damage. Children, on the other hand, are rich in imagination. We first got evidence of this difference in samples when designing the survey instrument. In the pilot, we had incorporated a number of questions borrowed from the developmental instrument about feelings. Measures of feelings contribute to the construct of Engagement. Questions about how a person feels when engaging in new or difficult tasks are asked of both children (or in our case, survivors) and teachers (or in our case, family members). Results of reliability analyses required that we eliminate questions about feelings from the survivor survey. Survivors' response patterns to those questions were unreliable. An examination of the questions showed that answers required abstract thought. A person must imagine himself in a particular situation, and consider how he might react. The task was beyond the capability of the brain injured sample.

Another difference between children and brain injured people that reduces the usefulness of the model is awareness. It is possible that children, in general, are more aware than many survivors of brain injury. Finally, the Social Context of school is probably very different from that of rehabilitation. In school, there is no effort to return a child to some former state of being.

Convergence

Early in this document results were discussed of empirical studies conducted with children and teachers using the instruments designed by developmental psychologists to evaluate children. Results showed a direct relationship between perceived competence and Engagement, between perceived autonomy support and Engagement, and between perceived autonomy support and academic outcome. In the developmental model, perceived competence and Autonomy Support contribute to Structure, an aspect of Social Context. In this model, Perception stands alone. In any case, both models demonstrate a strength of association between perception and Engagement. In the brain injury sample, there was a direct relationship (1) between Perception of Permission to be Different and Patient Report of Strategies (Engagement), and (2) between Perception of Ability to Shape the Environment and Patient Report of Strategies (Engagement).

Research results with children showed a relationship between Engagement and academic outcomes. Our research showed a relationship between Engagement and Functional Status, and equivalent to academic outcomes. High scores on Family Report of Engagement Strategies correlated with high Functional Status scores as reported by family. This result must be considered tempered by the fact that both reports are from the informant. Still, the result is consistent with the developmental research.

Finally, emotional security, an indicator of Involvement, was related to Engagement in the developmental research. Likewise, there was a direct and strong relationship between Involvement and Engagement in our research with brain injury.

Future Research

Use of the Developmental Model

The results of this project indicate that brain injury rehabilitation may benefit if informed by developmental psychology. Two directions for research are warranted. First, rehabilitation environments should be evaluated to determine where and how they violate the principles for appropriate development. That is, do they provide appropriate Structure, Autonomy Support, and Involvement? Do they foster positive methods of Engagement? Second, a comprehensive evaluation of the convergence and divergence of the developmental model and brain injury rehabilitation model, beyond what we have accomplished in this project, should be conducted. This evaluation could be used to develop measures for tracking individual progress in rehabilitation, and to learn more about the developmental process of recovery from brain injury.

System for Prospective Evaluation

Most of the data used in this project, and most previous research referenced here, are retrospective. A prospective study is needed to gather information about brain injury recovery. Prospective data collection structures for tracking TBI exist in other cities that have been operating for over 10 years, providing valuable sample pools for investigation. Oregon is in a unique position to have a population-based sample for a data collection project. Oregon's trauma system mandates that all traumas triaged as severe be transferred to one of two Level-1 trauma centers, OHSU or Emanuel Medical Center. This investigator received a grant from the

Medical Research Foundation of Oregon to fund a pilot project that will establish a structure for tracking the progress of brain injury patients in both of Oregon's Level-1 trauma centers from the emergency department, through ICU and acute care treatment, and into rehabilitation. The pilot will operate for one year. Data will be collected from hospital records, family members, and patients. The outcome instrument developed in this dissertation will be used to measure Functional Status. Variables will be added in order to facilitate sharing information with other cities.

Random Controlled Trial of the Effect of Social Support

The Brain Injury Support Group of Portland supported efforts to establish a TBI Social Club. The clubhouse model is an intervention considered effective in improving outcomes for other disadvantaged populations, and has recently been used for brain injury survivors. The clubhouse model mandates that survivors design and operate their own social club, with the assistance of facilitators if necessary. Members believe that people who participate in the social club have better outcomes than those who don't, because the club provides a place where survivors can share resources, teach each other how to negotiate the world anew, and give encouragement. Variants of this model exist in formal rehabilitation programs. For example, the in-patient rehabilitation program at the Mayo Clinic utilizes patients who are almost ready to graduate as mentors for the newly admitted patients.

While clinical observation supports the belief that social support systems such as the social club enhance survivors' Functional Status, there are no controlled experiments to provide direct evidence. The data collection project previously described will provide a structure with which to conduct a randomly assigned, controlled experiment to determine if participation in the TBI social club enhances outcomes. The framework for the experiment will be based on the Lodge and Ward studies (Fairweather, et al.), a series of random controlled trials conducted to investigate the effect of autonomy on the outcomes for the chronically mentally ill. The Lodge and Ward studies demonstrate that true experiments can be conducted with disadvantaged populations without violating the ethics of science or medicine.

The results of this dissertation project are encouraging with respect to the potential power of social support in fostering recovery from brain injury. An effective intervention at the level of family and social network could prove to be cost-effective as well. Without a prospective, random assigned, controlled trial, we lack evidence strong enough to be used to develop practice guidelines. A uniform standard of care is the ultimate goal for the care of persons who sustain brain injury. Practice guidelines will provide a foundation for standard of care in brain injury rehabilitation. The first step to guideline development is strong, controlled research.

Table 1

Demographics of Pilot Administration

Variable	Mean	Std. Dev.	Min.	Max.	N
Age at Inj.	25.17	11.83	1.50	49.50	54
Days in Coma	38.26	45.42	0.0	183	54
Days in Hosp.	100.78	127.56	0.0	553	50

Pre-Trauma Education Mean: High School Graduate

Annual Pre-Trauma Income Mean: $20,000 to $25,000

Demographics of Final Administration

Variable	Mean	St. Dev.	Min.	Max.	N
Age at Inj.	28.03	13.45	.02	65.32	228
Days in Coma	55.85	254.22	.00	3650	230
Days in Hosp.	79.28	138.81	.00	1616	209

Pre-Trauma Education Mean: High School Graduate

Annual Pre-Trauma Income Mean: $20,000 to $25,000

Table 2

Means and Standard Deviations for Survey Constructs and Outcome Measures

Constructs	M	SD	Range	N
Social Context	50.26	7.38	27 - 66	186
Perception	57.58	8.33	33 - 76	201
Family Rep of Eng.	19.42	3.85	11 - 28	184
Patient Report of Eng.	12.24	2.36	5 - 16	194
Outcome Measures	M	SD	Range	N
Injury Severity Score	23.45	9.38	5 - 75	67
Family Report of FS	49.45	11.58	21 - 72	177
Patient Report of FS	54.30	10.40	20 - 72	192
Abbreviated Injury Score	3.97	1.35	1 - 5	71
Change in SES	1.53	.75	1 - 3	212
Change in Independ.	2.14	1.11	1-3	233

Note. FS = Functional Status.

Table 3

Survey Reliability Analyses

Scale	Chronbach's Alpha	Items	N
FS Scale Subscales			
Memory	.83	6	142
Mobility/Independence	.95	10	126
Organization/Productivity	.81	6	135
Physical	.87	12	139
Inappropriate Behavior	.60	2	144
Family Report of FS Composite	.91	18	151
Patient Report of FS Composite	.91	18	167
Social Context	.82	17	155
Perception	.83	19	158
Family Report of Engagement	.69	7	165
Patient Report of Engagement	.61	4	194

Note. FS = Functional Status.

Table 4

Pearson's r Correlations for Constructs From Survey Administration

	Social Context		Perception		Patient Engagement		Family Engagement	
	r	N	r	N	r	N	r	N
Soc. Context	1.00	186	.47*	147	.35*	142	.69*	184
Perception	.47*	147	1.00	201	.66*	194	.47*	146
Patient Eng.	.35*	142	.66*	194	1.00	194	.46*	141
Family Eng.	.69*	184	.47*	146	.46*	141	1.00	184
Family FS	.45*	174	.36*	140	.31*	135	.53*	173
Patient FS	.30*	137	.44*	187	.44*	180	.34*	137
AIS	.02	64	-.03	59	-.04	58	.05	64
ISS	-.02	59	.05	55	.03	54	.12	59
SES CH	.18*	169	.08	174	.03	169	.20*	167
LIV CH	.11	178	.07	191	-.05	186	.09	176

Table 4 (Continued)

Pearson's r Correlations for Constructs From Survey Administration

	Family Funct. Status		Patient Func. Stat.		AIS		ISS	
	r	N	r	N	r	N	r	N
Soc. Context	.45*	174	.30*	137	.02	64	-.02	59
Perception	.36*	140	.44*	187	-.03	59	.05	55
Patient Eng.	.31*	135	.44*	180	-.04	58	.03	54
Family Eng.	.53*	173	.34*	137	.05	64	.12	59
Family FS	1.00	177	.81*	134	-.17	60	-.07	56
Patient FS	.81*	134	1.00	192	-.15	56	-.03	53
AIS	-.17	60	-.15	56	1.00	71	.76*	66
ISS	-.07	56	-.03	53	.76*	66	1.00	67
SES CH	.37*	160	.33*	165	-.16	71	-.13	66
LIV CH	.28*	170	.22*	181	-.03	70	-.09	67

Table 4 (Continued)

Pearson's r Correlations for Constructs From Survey Administration

	SES CHANGE		LIVING CHANGE	
	r	N	r	N
Social Context	.18*	169	.11	178
Perception	.08	174	.07	191
Patient Engagement	.03	169	-.05	186
Family Engagement	.20*	167	.09	176
Family Funct. Status	.37*	160	.28*	170
Patient Funct. Status	.33*	165	.22*	181
AIS	-.16	71	-.03	70
ISS	-.13	66	-.09	67
SES CHANGE	1.00	212	.28*	200
LIVING CHANGE	.28*	200	1.00	233

Note. FS = Functional Status. AIS - Abbreviated Injury Score. ISS = Injury Severity Score. SES CH = Change in Socio-Economic Status. LIV CH = Change in Living Status. * $p < .05$.

Table 5

One-Way Analysis of Variance - Effect of LIVING CHANGE on Functional Status (FS)

Dependent Variable FS - Patient Guided Functional Status Composite

By Independent Variable LIVING CHANGE - Change in Level of Independence

Source	DF	Sum of Squares	Mean Squares	F Ratio	F Prob.
Betw Grps	2	1802.6531	901.3266	9.3904	.0001
With Grps	169	16221.2404	95.9837		
Total	171	18023.8935			

Group 1 - Decrease in Independence.

Group 2 - No Change.

Group 3 - Increase in Independence.

Table 5 (Continued)

One-Way Analysis of Variance - Effect of LIVING CHANGE on Functional Status (FS)

Group	Count	Mean	Standard Deviation	Standard Error
Grp 1	73	46.9418	9.4599	1.1072
Grp 2	77	52.9286	10.1126	1.1524
Grp 3	22	54.9091	9.7732	2.0837
Total	172	50.6410	10.2666	.7828

Table 6

Two-Way Analysis of Variance - Effect of LEVEL and CAT on FS

Dependent Variable FS - Patient-Guided Functional Status Composite

By Independent Variables LEVEL - Level of Unconsciousness

and CAT - Category of Injury

Source of Variation	Sum of Squares	DF	Mean Square	F	Sig of F
Main Effects	3508.718	11	318.974	3.699	.001
LEVEL	1823.656	6	303.943	3.524	.007
CAT	1685.062	5	377.012	3.908	.006
2-Way Interactions	1591.156	9	176.795	2.050	.060
	1591.156	9	176.795	2.050	.060
Explained	5099.874	20	254.994	2.957	.002
Residual	3277.145	38	86.241		
Total	8377.019	58	144.431		

N=59

Table 7

Means and Standard Deviations From Two-Way Analysis of Variance

Effect of LEVEL and CAT on FS

Level of Unconsciousness	Mean	St. Dev.	N
Unspecified Coma	60.60	10.98	5
None	50.33	9.61	3
Less than 1 hr.	45.50	5.98	5
1 to 24 hr.	52.87	13.18	13
> 24 hr./return to previous state	60.60	5.36	10
> 24 hr./no return to previous state	46.81	12.53	18
Coma of Unspecified Duration	52.60	13.54	5

Table 7 (Continued)

Means and Standard Deviations From Two-Way Analysis of Variance

Effect of LEVEL and CAT on FS

Category of Injury			
Closed/No Tissue Damage	47.35	8.99	5
Closed/Unsp. Tissue Damage	55.58	11.39	20
Closed/Spec. Tissue Damage	52.50	11.44	30
Open/No Tissue Damage	43.00		1
Open/Unsp. Tissue Damage	23.00		1
Open/Spec. Tissue Damage	45.50	20.50	2

Note. LEVEL = Level of Unconsciousness. CAT = Category of Injury. FS = Functional Status.

Table 8

Two-Way Analysis of Variance - Effect of LEVEL and CAT on SES CHANGE

Dependent Variable SES CHANGE - Change in Socio-Economic Status

By Independent Variables LEVEL - Level of Unconsciousness

and CAT - Category of Injury

Source of Variation	Sum of Squares	DF	Mean Square	F	Sig of F
Main Effects	10.688	11	.972	2.298	.027
LEVEL	1.683	5	.337	.796	.006
CAT	9.005	6	1.501	3.549	.559
2-Way Interactions	8.895	9	.988	2.337	.031
	8.895	9	.988	2.337	.031
Explained	19.583	20	.979	2.316	.011
Residual	17.337	41	.423		
Total	36.919	61	.605		

N = 62

Table 9

Means From Two-Way Analysis of Variance

Effect of LEVEL and CAT on SES CHANGE

Level of Unconsciousness	Mean	N
Unspecified Coma	2.6	5
None	2.0	3
Less than 1 hr.	1.17	6
1 to 24 hr.	1.38	13
> 24 hr./return to previous state	1.91	11
> 24 hr./no return to previous state	1.35	20
Coma of Unspecified Duration	1.75	4

Table 9 (Continued)

Means From Two-Way Analysis of Variance

Effect of LEVEL and CAT on SES CHANGE

Category of Injury	Mean	N
Closed/No Tissue Damage	1.20	5
Closed/Unspecified Tissue Damage	1.60	20
Closed/Specified Tissue Damage	1.64	33
Open/No Tissue Damage	2.00	1
Open/Unspecified Tissue Damage	1.00	1
Open/Specified Tissue Damage	2.00	2

Note. LEVEL = Level of Unconsciousness. CAT = Category of Injury. SES CHANGE = Change in Socio-Economic Status.

Table 10

One-Way Analysis of Variance - Effect of LEVEL on SES CHANGE

Dependent Variable SES CHANGE - Change in Socio-Economic Status

By Independent Variable LEVEL - Level of Unconsciousness

Source	DF	Sum of Squares	Mean Squares	F Ratio	F Prob.
Betw. Groups	6	9.6000	1.6000	3.2212	.0088
With. Groups	55	27.3193	.4967		
Total	61	36.9194			

Group 0 - Unspecified Coma

Group 1 - No Coma

Group 2 - Less than 1 hr.

Group 3 - 1 to 24 hr.

Group 4 - > 24 hr./return to previous state

Group 5 - > 24 hr./no return to previous state

Group 6 - Coma of Unspecified Duration

Table 10 (Continued)

One-Way Analysis of Variance - Effect of LEVEL on SES CHANGE

Dependent Variable SES CHANGE - Change in Socio-Economic Status

By Independent Variable LEVEL - Level of Unconsciousness

Group	Count	Mean	Standard Deviation	Standard Error
Grp 0	5	2.600	.5477	.2499
Grp 1	3	2.000	1.000	.5774
Grp 2	6	1.1667	.4082	.1667
Grp 3	13	1.3846	.6504	.1804
Grp 4	11	1.9091	.9439	.2846
Grp 5	20	1.3500	.5871	.1313
Grp 6	4	1.7500	.9574	.4787
Total	62	1.5968	.7780	.0988

Table 11

Order/Disorder Categories for Case Study Sample

Order	Disorder
Bob	Hal
MH	Mick
Ann C.	JB
David	Mike T.
Julie	Sandy
John	Jody
Jean	DZ
Greg	Dan
BH	Ann D.
RS	
DF	

Table 12

Chart Highlighting Failed Predictions: Effects of State of Order or Disorder

		(self report) Perceptions									(family report) Social Context			Validation									
Subject[1]	O/D	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	# Fail	% Fail	Ave % Fail
Bob	O			n/a	■	■			n/a			n/a	m	m	n/a		m		n/a	m	2	20	
MH	O										m	m	m	m	m	m	m	m	m	m	0	0	
Ann C.	O			■		■		■							■					■	5	26	
David	O										m	m	m	m	m	m	m	m	m	m	0	0	
Julie	O		■				■	■					■	m							4	22	
John	O			n/a			m		n/a		■	n/a		m	n/a		■		n/a		2	16	
Jean	O		■		■	■		■		■	■	■					■				8	42	
Greg	O						■														1	5	
BH	O				■			■		■		m			m			■	m	■	5	31	
RS	O			■							■			■	■	■	■	■		■	8	42	
DF	O	■		■	■	■	■				m	m	m	m	m	m	m	m	m	m	5	55	23
Hal	D			m			m	■	m		m	m	m		m	m	m	m	m	m	1	14	
Mick	D	m	m							m	m	m	m	m	m	m	m	m	m	m	0	0	
JB	D	■		■		m											■	■		■	5	28	
Mike T.	D													■		■					2	10	
Sandy	D										m	m	m		m	m	m	m	m	m	0	0	
Jody	D	m	m	m	m	m	m	m	m	m										■	1	10	
DZ	D	m	m	m	m	m	m	m	m	m			■	■		■	■				4	40	
Dan	D	m	m	m	m	m	m	m	m	m	■					■		■		m	3	30	
Ann D.	D	■	■	m	■	■		■	m	■	m	m	m	m	m	m	m	m	m	m	6	85	24
# fail/# possible %correct		3/16 81	3/16 81	4/13 69	5/17 71	5/16 69	3/15 80	6/17 65	0/13 100	3/16 81	4/13 69	1/10 90	2/12 83	3/12 76	2/10 80	4/13 69	5/12 58	4/13 69	0/10 100	5/12 58			
# fail/# possible % Failed										32/139 23			7/35 20							23/82 28			62/256 24

[1] All Subjects listed in order of score on Order/Disorder, with most ordered person at top of list

Shaded cells show where classification of Order/Disorder failed to predict scores on scale. m=missing data n/a not applicable

Please see the following page for a key to the variables numbered in the top row of this table

Table 12

Chart Highlighting Failed Predictions - Key

Perception

#1	Autonomy Support
#2	Able to Shape Life
#3	Able to Shape Rehab.
#4	Permission to be Diff.
#5	Structure
#6	Access to Services
#7	Involvement in Life
#8	Involvement in Rehab.
#9	Symbiosis

Social Context

#10	Structure
#11	Opinion of Rehab.
#12	Help

Validation

#13	Able to Shape Life
#14	Able to Shape Rehab.
#15	Permission to be Different
#16	Autonomy Support
#17	Involvement in Life
#18	Involvement in Rehab.
#19	Symbiosis

Figure 1

The EsEx Couple in General Form

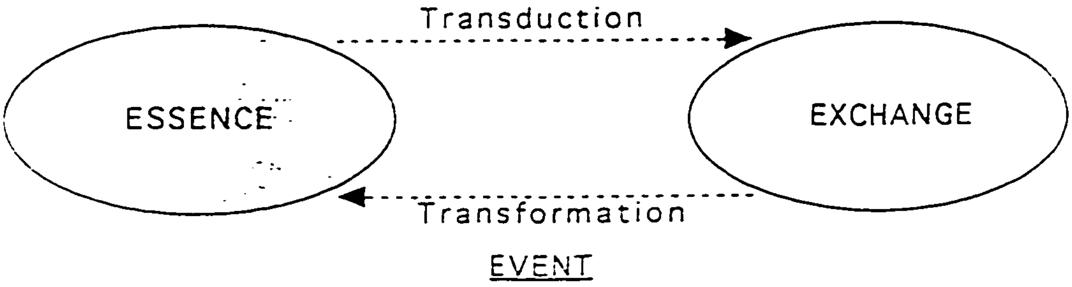
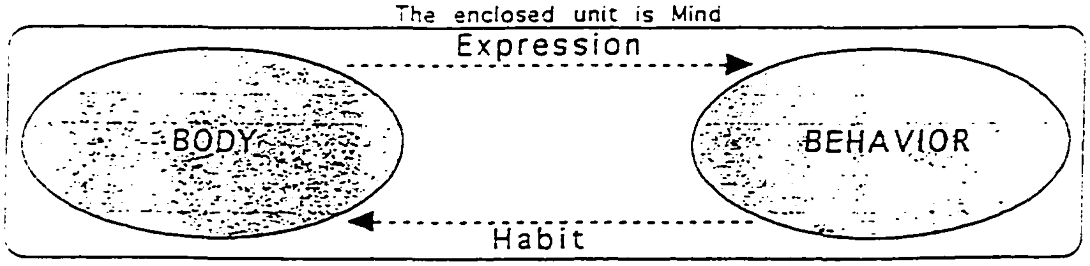


Figure 2

The EsEx Couple as Individual Development



INDIVIDUAL: Development

Figure 3

The EsEx Couple in Socios

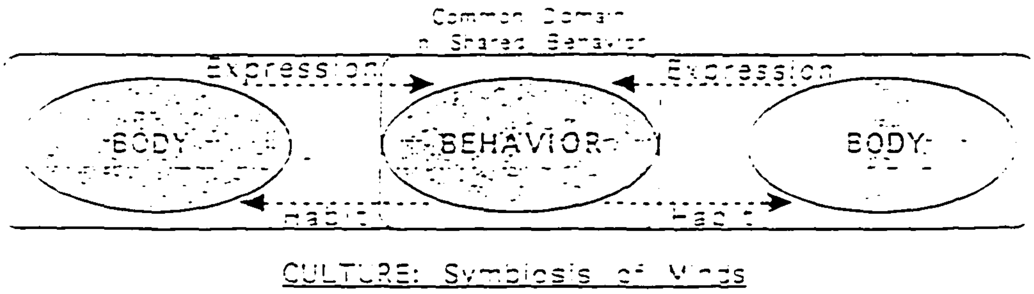


Figure 4

Goldstein's Process of Recovery as an EsEx Couple

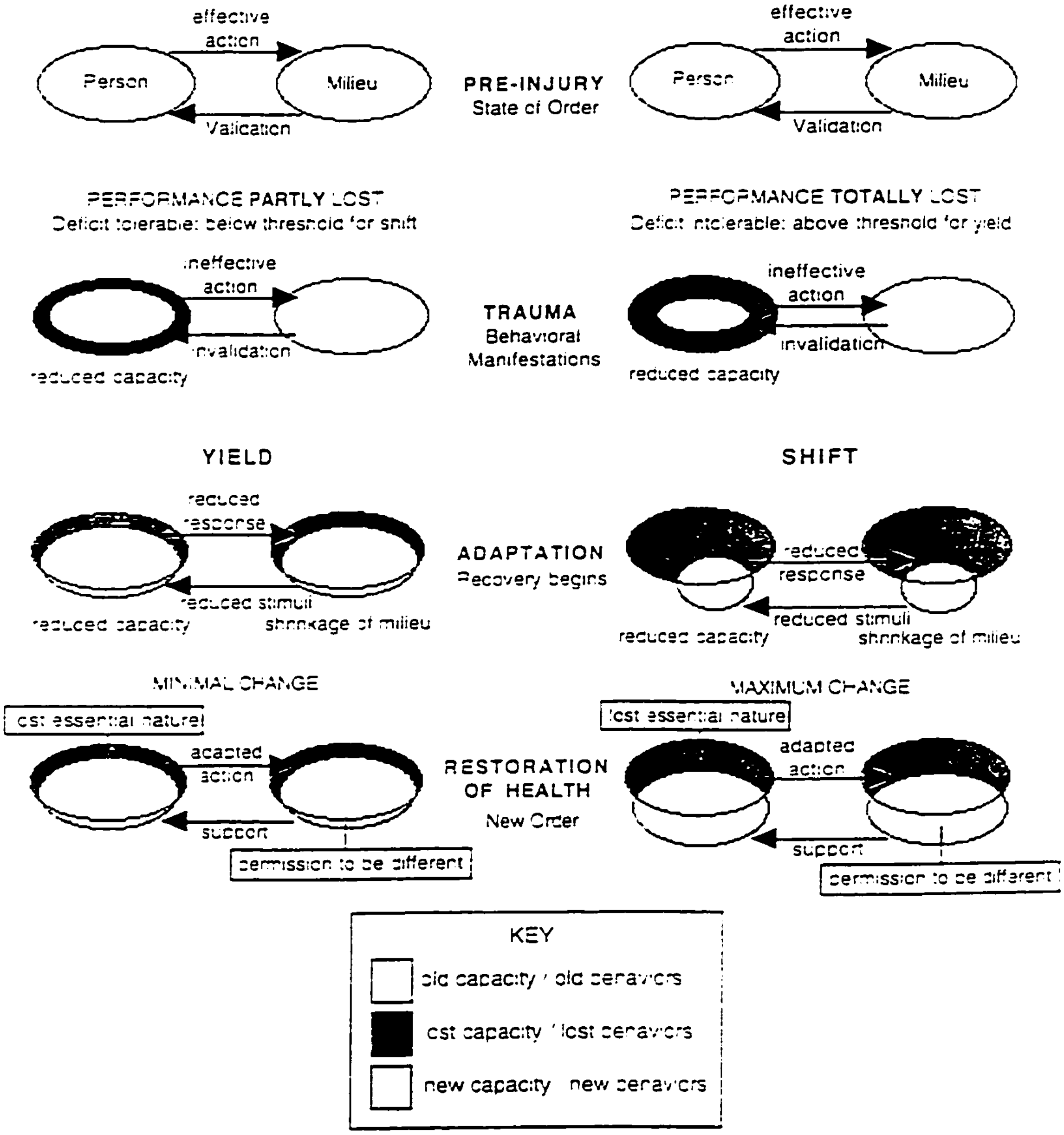


Figure 5

Recover Model - Initial Form

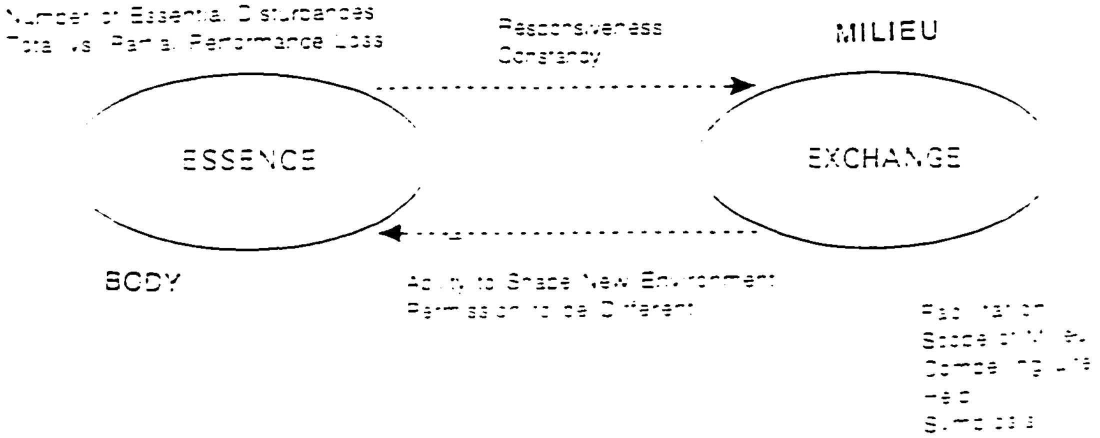


Figure 6

Development Model - Initial Form

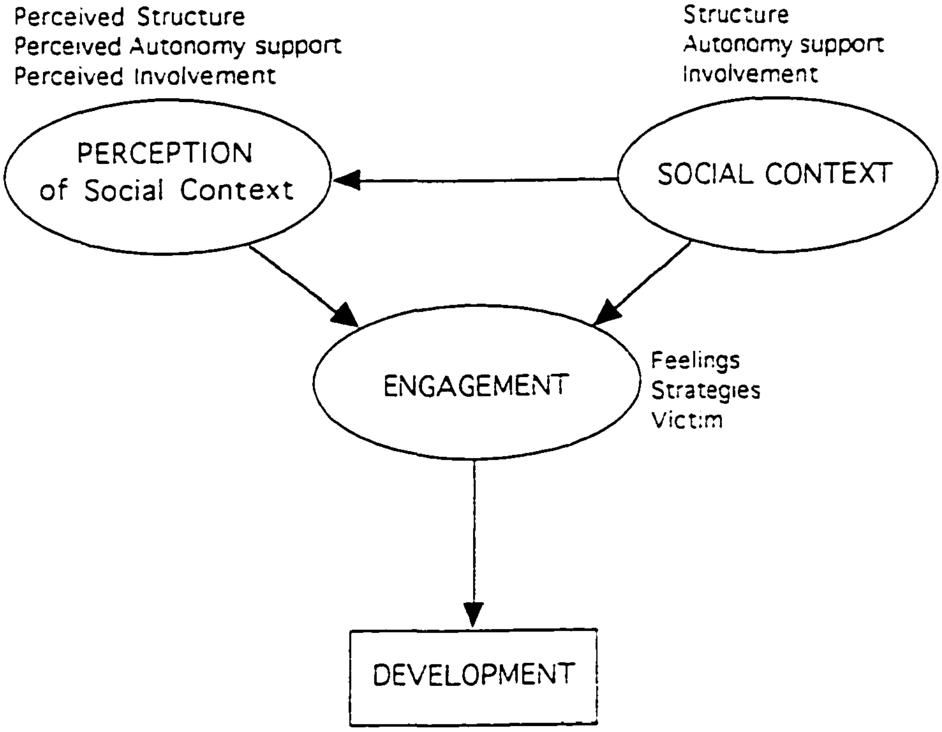


Figure 7

Recovery Model - Final Form

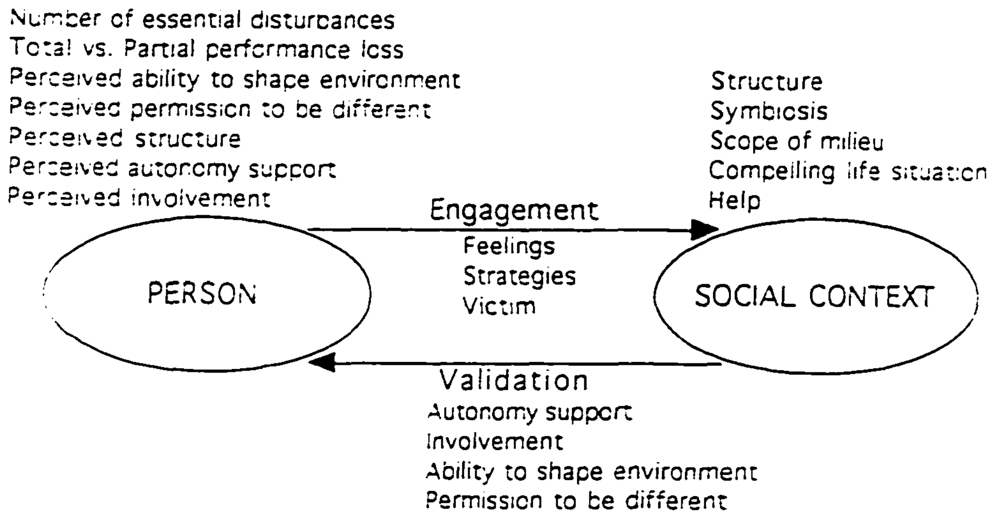


Figure 8

Development Model - Final Form

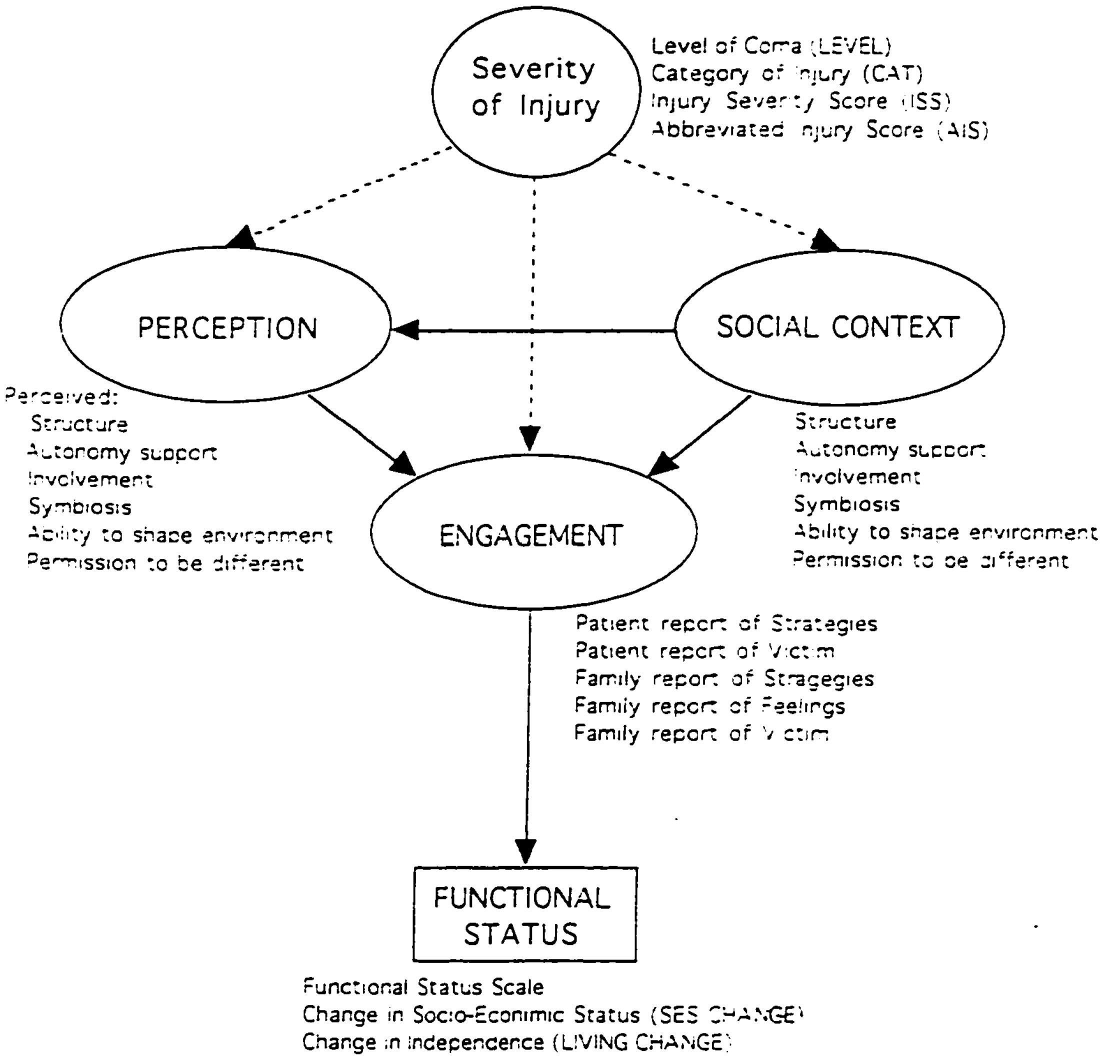


Figure 9

Interaction Chart - Two-Way Analysis of Variance - Effect of LEVEL and CAT on SES CHANGE

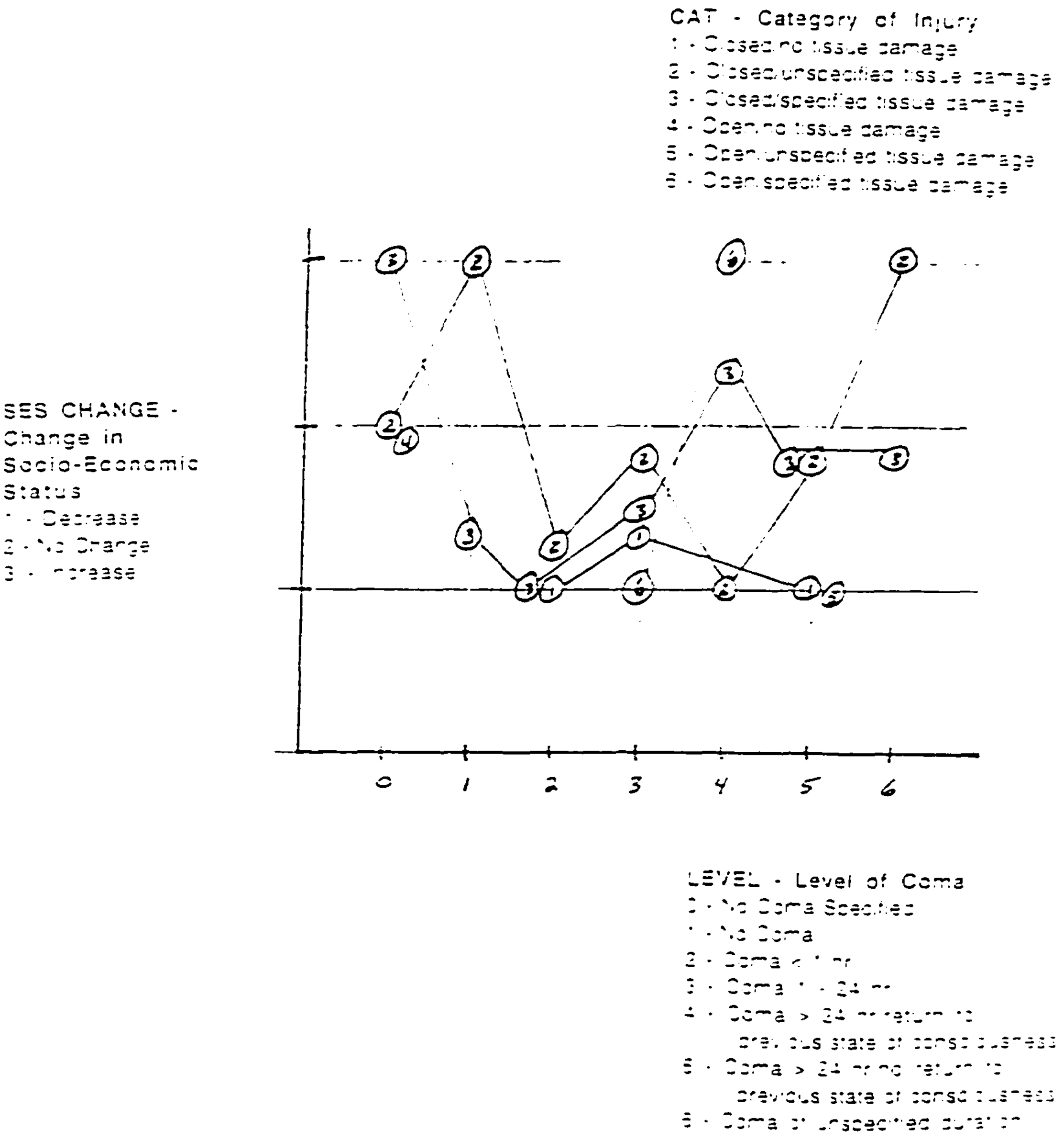


Figure 10

Model for Order

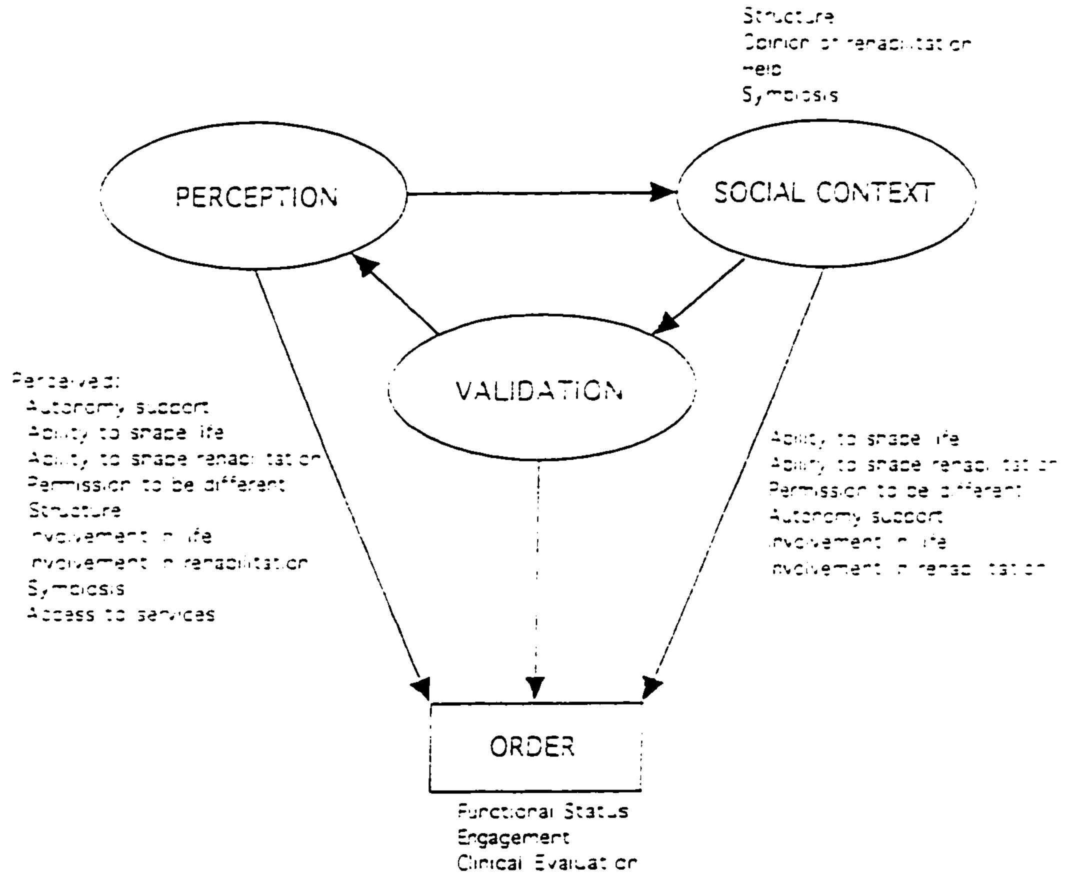


Figure 11

The EsEx Couple as the Social Self

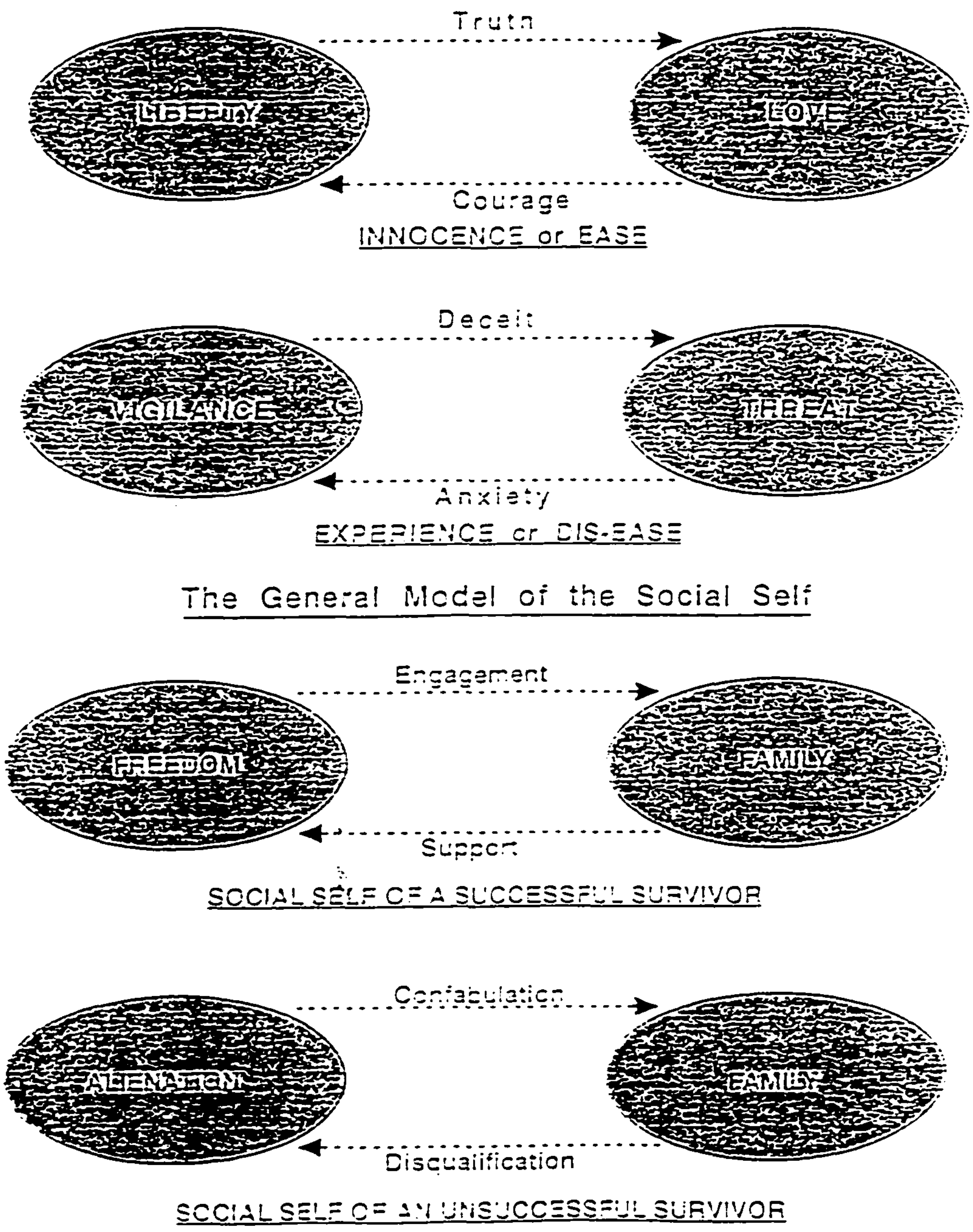


Figure 12

Results Displayed in the Model for Recovery

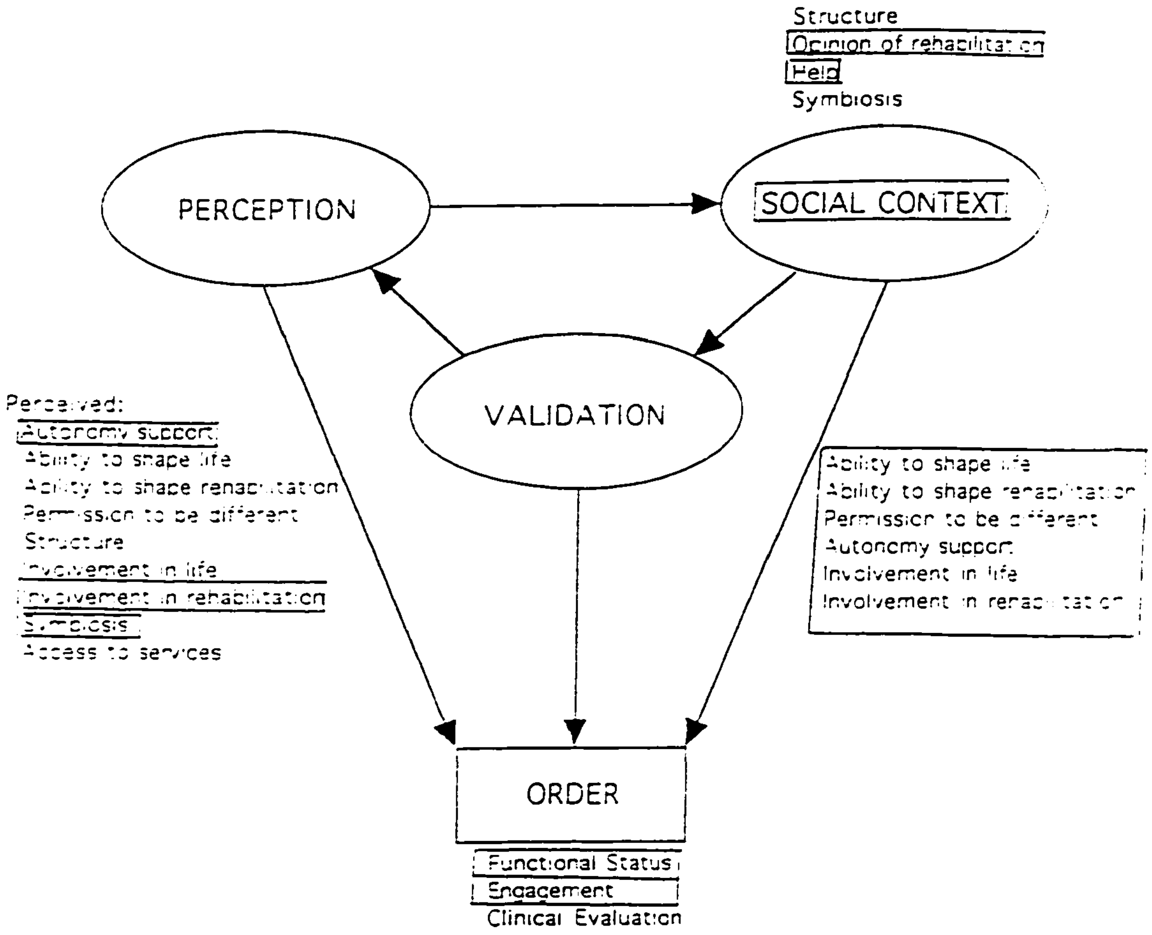
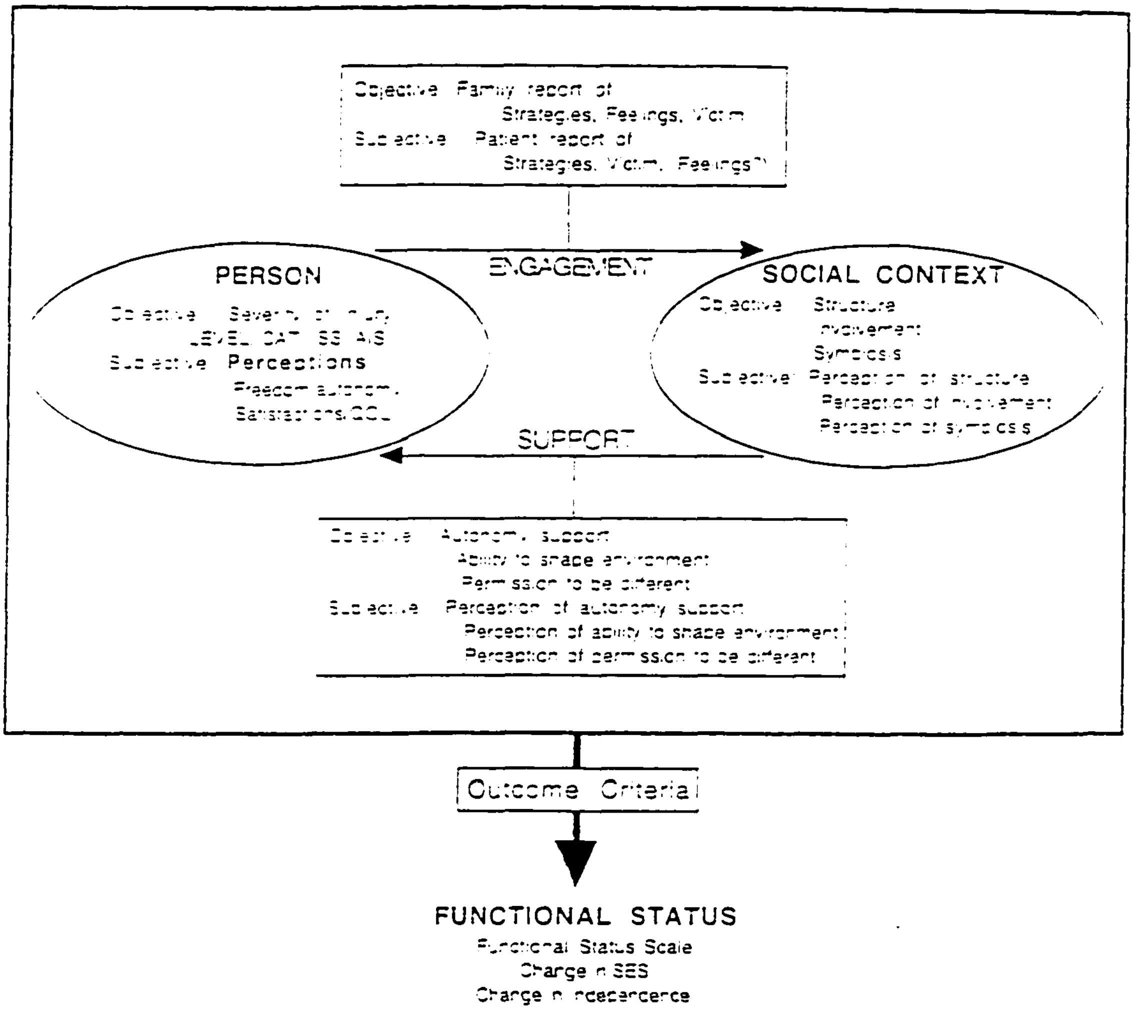


Figure 13

A Return to the EsEx Couple - Future Research



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Appendix A

Case #1 - JB Trauma

JB is a 58 year old Caucasian female. In January of 1985, when she was 46, she was admitted to the emergency ward of a Miami, Florida metropolitan hospital. She had been driving her car, and while at a stop light, a man attempting to steal her car threw a concrete brick through the window. The concrete struck JB in the head.

JB was in a coma for 14 days. She did not sustain a fracture and did not receive neurosurgery. No ICP monitor or shunt was used. JB presented seizures during and after hospital stay. She was in the acute care hospital 40 days.

JB was discharged to home, but could not function at work. A precise record of her course is not clear. She was admitted into a drug and alcohol rehabilitation facility, although she and her sister report she was not abusing either drugs or alcohol at the time. Apparently the admission was an act of desperation, as she had no other options for in-patient care. There was a report from that program that JB attempted suicide, and a recommendation for commitment to a psychiatric hospital. Her sister, recognizing the extent of JB's deficits, contacted an in-patient rehabilitation program for brain injury, and arranged JB's admission.

History

Prior to being attacked JB lived in Florida close to two sisters and her mother. She had an associate's degree in laboratory technology, and was employed in that field. Her annual income was approximately $20,000. Her leisure activities consisted of shopping at second hand stores and gardening. She was divorced and lived alone. In 1981 she began participating in Alcoholics Anonymous. JB's sister provided this information; JB did not talk about it. The sister was in the program. and JB began going to meetings with her.

Post-Trauma Chronology

JB was in the in-patient rehabilitation facility for approximately 18 months when her funding was discontinued. She move into a trailer with another woman who cared for her. but became depressed as well as physically ill, and was subsequently admitted to a psychiatric hospital. She was discharged from the hospital to a nursing home. From the nursing home, in 1988, she moved to California to live with one of two sons. They moved to Oregon, and the son returned to California. JB's sister moved from Florida to Oregon to live with and care for her.

The source of JB and her sister's income is Disability. Her annual income is approximately $15,000. JB currently participates in an out-patient rehabilitation program through Sister's of Providence health system. JB fell in her apartment and sustained a second head injury. She is involved in litigation associated with the accident. Several years ago her mother and son died.

JB has participated in physical therapy, speech therapy, cognitive retraining.

vocational rehabilitation, training in ADL's, psychological counseling, and occupational therapy.

Behavioral Characteristics

JB reported a complete loss of pre-trauma memory. Unlike many diffuse brain damage cases, she is able to integrate new information, but has no history prior to her accident. She did, however, recognize members of her family after the attack. JB said she is unable to be in crowds and unfamiliar places. She characterizes her experience as "going on overload" and relies on her sister to recognize the problem when it arises and extricate her from the situation. JB reports being slow to recognize and learn, and being emotionally unstable and unpredictable.

The sister's report is consistent with that of JB. She added that JB used to be a very dynamic, social person, and since the accident is a recluse.

JB rocks constantly and has a problem with balance. She lives in a small, cluttered apartment. She keeps as many objects as possible on the surface of tables and chairs, possibly to facilitate locating them. JB has adopted the language of the psychiatric counseling and self-help programs to which she has been exposed, both pre- and post-trauma, and speaks about her experience in those terms.

Most remarkable about JB's narrative is that she characterizes herself as the victim in every account of incidents of her life, both pre- and post-trauma.

Evaluation

Person

JB's perception of her ability to shape her life, permission to be different, structure, and involvement of others in both her life and her rehabilitation program are low. Her perception of her ability to affect her rehabilitation program is high, as is her perception of her autonomy support.

JB has sustained many physical as well as cognitive and psychological damages, thus her number of essential disturbances is high. I can't say whether she has yielded or shifted in her adaptation process. While she reports a total loss of pre-trauma memory, I am not sure this is the case. I am unable to evaluate whether she experienced total vs. partial loss of certain performances.

Engagement

JB's scores for strategies she uses to engage were below the median. She scored above the median for measures of how she feels when she engages in new or difficult activities. While these data, combined with her low functional status score, sum to a classification of disordered for JB, my clinical evaluation of her is that she is in a state of order, for the following reasons. JB is responsive to interactions from her environment, and constant in her mode of response. She seeks opportunities to be a victim, and uses her victim status to obtain services from others to fulfill her needs. While her interactions with the environment appear to be catastrophic, they are not. They serve to provide her with what she needs, by eliciting the care of others. While she reports she does not have symbiotic relationships, her sister reports she does. However, for purposes of the evaluation, I maintained JB's quantitative classification of disordered.

Social Context

JB scored below the median for structure, facilitation, and help of others. However, it appears the scope of her social context is appropriate to her disabilities. As noted, she keeps many objects out and on the surface of tables and chairs, to facilitate locating them. In addition, she has mastered use of public transportation for the handicapped to ensure she can attend her day program, the TBI support group, and other activities. Both JB and her sister report that JB does not have a compelling life situation.

Validation

Consistent with being in a state of disorder, JB scored below the median for the informant's report of her ability to shape her life and her rehabilitation program, permission to be different, and others' involvement in her rehabilitation program. However, she scored above the median for autonomy support and involvement.

Case #2 - Bob

Trauma

Bob is a 70 year old Caucasian and Native American male. When he was

18 months old he fell ten stories onto concrete, fracturing his skull. The hospital data are sparse, given the chronicity of this case. He was admitted to a hospital in Detroit, Michigan, where he stayed 3 months. He was in a coma for approximately two months. Bob does not know if he experienced seizures. He never participated in formal rehabilitation.

History/Post-Trauma Chronology

Because Bob was a baby when he sustained his head injury, his post-trauma chronology and history are one in the same. Bob was a member of a large extended family of Scots and Tuscarora Indian descent. His immediate family consisted of himself and a brother along with his parents, but he had many aunts, uncles, and cousins, located in both urban and rural environments of the midwest. Consequently Bob was raised in both rural and urban traditions. Bob reports his family's annual income was approximately $20,000.

Bob's development of the ability to walk and talk was delayed. He was transported in a wheelbarrow by cousins until his father decided to get rid of the wheelbarrow in order to force Bob to learn to walk. Bob loved to fish, and his father used that as a motivation to teach Bob to walk. They would walk to the river to fish. Bob would fall; his father would wait for him to pick himself up and continue.

Bob's father taught him to read and write by reading him the newspaper, and having Bob follow the sentences as he read. Bob started grade school with his age group, able to read but unable to speak. He reports his attempts to speak were high pitched squeaks, but he was unaware of the sounds he was making. I don't know how he developed speech.

Bob's cousins would escort him to school and protect him from the unkindness of other children. His aunts and uncles took him into their homes during summer vacation, providing respite to his parents, and exposing Bob to a variety of environments.

When Bob was seventeen he lied about his age and history and joined the army. He served during World War II and achieved the rank of sergeant. After the military he married, and attended college, receiving a degree in forestry management. He was a forester until retirement several years ago. No one in his professional life knew he was brain damaged. He kept detailed records of each day's activities in order to remember from day to day what had transpired. He had seven children. He did not tell his wife of his accident or deficits until many years into their marriage, when the demands of working and raising a large family served to diminish his ability to hide his problems.

Bob is currently retired. His annual income is approximately $25,000.

Behavioral Characteristics

Bob has limited ability to commit new information to memory. He compensates by keeping detailed written records of activities and commitments. Bob reports problems with anger, and a tendency to withdraw when he has been exposed to too much stimuli. Sometimes when driving he forgets where he is going, and ends up miles from his destination.

Bob's wife's description of Bob is consistent with the patient report. She added that his withdrawal from the family became a critical problem in their marriage, precipitating a depression for her.

Bob stutters intermittently, and sometimes delays in responding to questions. These are the only manifestations of his deficits.

Evaluation

Coherence

Bob's coherence is consistent with being in a state of order in all measures with the following exceptions. Bob does not perceive he has permission to be different, or a structure appropriate to his needs. This is understandable considering he was injured in 1928, and achieved in his life by becoming skilled at hiding his deficits.

Engagement

Bob scored above the median on strategies and feelings about engaging in new or difficult tasks. His functional status score is also above the median. Clinical evaluation agreed with objective measures that Bob lives in a state of order. Neither Bob nor others consider him a victim, and he and others agree that he has symbiotic relationships.

Social Context

On measures of Social Context, Bob never deviated from the expected pattern for a person in a state of order. He has help from others, and a level of facilitation appropriate to his deficits.

Validation

On measures of validation. Bob never deviated from the expected pattern for a person in a state of order. Unlike Bob, his informant believes he has permission to be different, as well as the ability to shape his life, autonomy support, and involvement.

Case #3 - Ann C.

Trauma

Ann C. is a 53 year old Caucasian female. In June of 1983, when she was 40, she was admitted to the emergency department of a hospital in Eugene, Oregon with a gunshot wound to the head. Her husband shot her. The bullet passed through the right side of her skull.

Ann was in a coma 39 days, and in the acute care hospital six months. She seized and was given anticonvulsant medication. She was shunted. Her hospital discharge index record for Abbreviated Injury Score is 5, and Injury Severity Score is 25.

During and after hospital discharge, lasting approximately four years, Ann received the following rehabilitation: physical therapy, cognitive therapy, speech therapy, psychological counseling, and occupational therapy.

History

Prior to her injury Ann was married and had two children. She has a bachelor's degree in elementary education, and a teaching certificate. She had been employed as a secretary for four years. Her annual income was approximately $40,000. She enjoyed camping, sewing, reading, ethnic cooking, and parties.

Post-Trauma Chronology

Ann divorced her husband. After discharge from rehabilitation, her children moved out of the home. She currently lives alone. She is financially supported by social security, investments and savings, and alimony. Her annual income is approximately $25,000. She is unable to be very active, but returned to school to take a class, Psychology of the Disabled. She is a homemaker who will never be able to return to work. For leisure, she watches television and exercises at a fitness center.

Behavioral Characteristics

Ann reports problems with balance and pain. She was left-handed prior to her injury, and switched to using her right hand during occupational therapy. She reports problems with concentration, particularly when others are speaking. Ann is not satisfied with her ability to express herself verbally.

Ann's informant added that Ann is easily fatigued, and sleeps more than prior to the accident.

Ann requires a cane to walk, and wears a leg brace.

Evaluation

Coherence

Ann does not perceive that she has the involvement of others in her life. She also does not perceive her structure to be appropriate to her disabilities, and believes she had limited ability to shape her rehabilitation program. She feels she can shape her own life, has permission to be different, autonomy support, and access to social services.

Engagement

Ann scored above the median on measures of strategies she uses when engaging in new or difficult tasks, and on measures of her feelings when doing so. She has a high functional status score. These measures confirm the clinical evaluation that Ann is in a state of order. While she feels she has symbiotic relationships, her informant did not agree. Neither Ann nor her informant perceive she is a victim.

Social Context

Ann never deviated from the expected pattern for a person in a state of order on measures of Social Context.

Validation

The two places where Ann deviated from the expected pattern were her ability to shape her rehabilitation program, and involvement of others in the program. Ann reported that she couldn't have accomplished independent living without rehabilitation, but that is her perception, which is a measure of coherence. Her informant reported that no one participated with her in the program, and that the family insisted she go through rehabilitation. While Ann agreed that no one attended her program with her, she did not perceive that anyone was insisting she go.

Case #4 - Ann D.

Trauma

Ann D. is a 45 year old Caucasian female. In 1983, when she was 32, she was admitted to the emergency department of a hospital in South Dakota with multiple system injuries from a motorcycle accident. She was in a coma ten months. She does not know how long she was in the hospital, or any other details of the trauma. Ann does not know how she came to live in Oregon. She has no family that we were able to locate. Consequently there is no informant report for Ann.

History

Prior to her injury Ann was an employed administrative assistant. She had taken college courses but was not degreed. She earned between $10,000 and $15,000 a year. She was not married, and lived alone. For leisure activity she enjoyed camping, water skiing, and swimming.

Post Trauma Chronology

As stated, little is know about Ann both prior to and since her accident. She lives in a skilled nursing facility. Policies prohibited the facility from releasing information to us about Ann. She is supported by social security and is unable to be very active. She reports her annual income is less than $10,000. For leisure activity she plays bingo and attends the TBI support group and TBI club. Ann's course of rehabilitation included physical therapy, occupational therapy, and speech therapy. She is also trained in the use of a memory notebook.

Behavioral Characteristics

Ann is unable to walk and ambulates in a wheelchair. She is unable to use her preferred hand, and has double vision resulting from the accident. She is coherent and does not appear to have problems speaking. She reports a mild problem with fatigue.

Evaluation

Coherence

Ann rated herself above the median on measures of her perception of her ability to shape her life, permission to be different, structure, autonomy support, and involvement. These ratings may reflect her inability to understand her situation, or a lack of awareness. They do not reflect reality. It is possible that, as Goldstein described, her awareness has diminished, sparing her the suffering that would happen if she fully understood her circumstances.

Engagement

Ann's evaluation of her engagement strategies is above the median. We do not have an informant evaluation for her, which limits the analysis. Ann has a very low functional status score, and based on that and clinical observation, she is categorized in a state of disorder.

Ann states she believes she has symbiotic relationships - that there are others in her life that need her. Responses to probes indicate she does not consider herself a victim.

Social Context

There are no choices about Social Context for Ann. She has no family or support system provided by friends. She is financially dependent upon social security, so she has limited options for living arrangements. The best she can afford is a skilled nursing facility. The scope of her Social Context is diminished by the combination of her disabilities and the circumstances of her life.

Validation

Without an informant report for Ann, there is nothing except observation from which to construct her validation. In my opinion, she has no ability to shape her environment, no autonomy support, and no involvement of others. Her participation in the TBI social club and support group allows her some permission to be different, and may provide a place where she sustains symbiotic relationships.

Case #5 - DF

Trauma

DF is a 49 year old Caucasian female. In September of 1977, when she was 30, she was admitted to the emergency department of a Portland, Oregon metropolitan hospital, the victim of a hit-and-run accident. She was in a coma six months. She sustained multiple system injuries. We were unable to obtain medical records for DF, and do not know how long she was in the hospital.

History

DF was an employed secretary prior to her accident, with an annual salary of approximately $25,000. She had taken college courses but was not degreed. She lived with her son. For leisure she socialized with friends.

Post-Trauma Chronology

DF was not willing to share much information about herself since the accident. She lives with a full-time care giver, with whom, her informant reports, she is in a relationship. Her source of income is Social Security. Her annual income is less than $10,000. She participated in cognitive therapy, vocational rehabilitation, training in ADL's, and occupational therapy. She reports it was a waste of time. Her family did not participate in her rehabilitation program.

Behavioral Characteristics

DF cannot walk, and has limited use of her hands. She ambulates in an electric wheelchair. She postures to one side, and has trouble speaking. Her speech deficits appear to be physiological rather than cognitive. That is, she knows what she wants to say, but has some muscular deficits that limit her ability to move air across her larynx. It is almost impossible to understand her speech. She is practically blind in one eye. She reports no problems with fatigue.

Evaluation

Coherence

DF perceives she has the ability to shape her life, but this ability does not extend to her rehabilitation program. Further, she does not believe she has permission to be different, autonomy support, or appropriate structure in her life.

Engagement

DF's scores were on the median for measures of strategies employed when she encounters new or difficult tasks. Her opinion of rehabilitation is low, and her functional status is low. However, clinical observation reveals a person in complete control of her environment. DF has mastered the ability to direct other people to facilitate her requests and needs. In spite of her extreme difficulty with speaking, she is able to tell people where she wants to go, what she wants to do, and how she wants her affairs handled.

I categorized DF as being in a state of order, although her quantitative data do not support the diagnosis. Many of her scores in measures of constructs such as coherence are low, possibly indicating she lives in a state of disorder, and my diagnosis is wrong. However, I suspect the ratings are low because they are self ratings, and her cognitive abilities are enough intact for her to be keenly aware of her disadvantages.

DF believes she has symbiotic relationships in her life, and does not consider herself a victim.

Social Context

As described, DF has the type and degree of facilitation she dictates. She also is gregarious, likeable, and optimistic, which engenders a great deal of help from others. She says her compelling life situation is video poker.

Validation

Much of DF's validation--the true, objective ability to dictate her own destiny--is a function of her relationship with her caregiver. It appears he is as dependent upon her as she is on him. They did not reveal the technical aspects of their relationship. I don't know if or how much he is paid to take care of DF. There is some reciprocal need involved, evidence by his responsiveness to her requests, and the length of time he has remained her assistant. She is the source of his livelihood. In return, he is DF's arms, legs, vocal chords, driver, cook, and many other things. It is from this symbiotic relationship that DF actually receives power over her environment, as embodied in the construct of validation.

Case #6 - Mick

Trauma

Mick is a 35 year old Caucasian male. In June of 1989, when he was 28, he was admitted to the emergency ward of a Portland, Oregon metropolitan hospital classified as a Level I trauma Center. He crashed his bicycle on his way to work and was discovered unconscious, in a ditch, some hours later.

In the hospital Mick seized and was treated with medication that required his being placed on life support. Therefore his state of unconsciousness was drug-induced as well as trauma-induced. He remained on medication and life support for 3 days, and was unconscious 2 days following removal of life support, for a total of 5 days of unconsciousness. He had no surgery. A catheter was used to monitor inter-cranial pressure, but drainage was not necessary.

Mick was in in-patient rehabilitation for 3 months, where he received physical and vocational rehabilitation.

History

Prior to his accident Mick has attended college, but was not degreed. He owned a bicycle shop, and had an annual income of approximately $25,000. He lived alone. Biking was his source of social and leisure activity.

Post-Trauma Chronology

After discharge from RIO Mick moved into his parents' home. He was 27 year old. His parents decided against long-term rehabilitation, explaining that it was expensive and they weren't convinced it would be worthwhile. He acquired janitorial work through a temporary agency, but was unwilling to continue, feeling the work was beneath him. During this time he became so despondent he attempted suicide by cutting his wrists. He had previously made contact with the local support group, and when they were notified of Mick's suicide attempt they helped him find a house to move into, a rental owned by the father of another brain injury survivor.

Mick has been unsuccessful at maintaining a job. His current source of income is disability. His annual income is less than $10,000. He has taken some college courses since his accident. He lives alone and reports he does not have a social life.

Behavioral Characteristics

Mick reported a loss of sense of touch and loss of balance. He readily gets car-sick. He says he lost one inch from his height. He is susceptible to what he called mental overload. He has a problem with fatigue.

Evaluation

Coherence

Mick didn't deviate from the expected pattern for a person in a state of disorder with respect to scores for Coherence. He believes his ability to shape his life is limited. that he has little structure, autonomy support, and involvement, and limited permission to be changed.

Engagement

Mick provided little information on his survey regarding engagement. I observe his engagement strategies lead him to a state of disaffection as opposed to engagement. He considers himself a victim, however, his informant believes that Mick's bad circumstances are a result of his own actions.

Mick's functional status, measured as an outcome of his injury, is high. However. he is insulin-dependent diabetic. His categorization as disordered is based almost entirely on clinical evaluation.

Social Context

While Mick's informant consented to an interview, she would not agree to provide a survey response. During her interview she asserted she provides a high degree of facilitation and help to Mick.

Validation

Mick's informant also asserts Mick has a high degree of autonomy support, involvement, permission to be different, and ability to shape his life.

This case is an example of the weakness of the method we use for acquiring information about participants. We make the assumption that the informant provides the objective information about social context, and use their data to specify the condition of the subject's Social Context. However, the needs and prior history of the informant can affect their perception, and distort their report. Mick's informant, his mother, has a perception of Mick that precedes his injury, and influences her assessment of Mick's social context.

Case #7 - Greg

Trauma

Greg is a 40 year old Caucasian male. In May of 1989, when he was 32, he was admitted to the emergency department of a Level 1 Trauma Center in Portland Oregon with multiple system injuries, including a closed head injury, from a motor vehicle accident. He sustained multiple cerebral contusions and a subarachnoid hemorrhage. His Injury Severity Score derived from the Hospital Discharge Index was 29. His Abbreviated Injury Score for head was 5. Greg was in acute care two months. He was in a coma eleven days, and was shunted. He did not seize.

Greg spent approximately two years in rehabilitation, both in- and out-patient. He received physical therapy, speech therapy, cognitive retraining, vocational rehabilitation, training in activities of daily living, and occupational therapy. Both he and his parents report that this therapy helped him both physically and mentally. Greg's parents attended rehabilitation sessions with him, and helped him practice his exercises.

History

Prior to his accident Greg was the manager of an auto parts store. He had a high school degree. He had been married and divorced, and was living with his son and brother. His annual income was approximately $35,000. His leisure activities were sports and cars.

Post-Trauma Chronology

Greg and his son live with Greg's parents in a modest home in a working-class neighborhood. After rehabilitation Greg returned to his job, but was fired after several outbursts of anger and inappropriate behavior. Greg reported that he would become overwhelmed when several people needed assistance at one time. He is financially supported by disability. He does volunteer work in a hospital, which he and his parents report he enjoys. He is able to ride public transportation alone. He has not returned to school. For leisure he enjoys movies, working out, and bike riding.

Behavioral Characteristics

Greg walks with a limp. He was in a wheel chair for three months and crutches for a year. He has a mild problem with fatigue. Greg's most profound deficit is lack of ability to commit new information to memory, although his parents report he has learned ways to compensate. Greg has a good sense of humor, and has developed a way of covering for his uncertainty by making a joke of the situation. It is an effective strategy in that it relieves everyone's tension, and serves to put people on notice that Greg is not tracking.

Evaluation

Coherence

Of the eight sub-constructs used to measure coherence, Greg deviated from the expected pattern on one, Access to Social Services. Although Greg has access to services, he would not be able to use most of them by himself, and relies on his parents to mediate. Otherwise, Greg perceives himself autonomous, able to shape his life, with permission to be different and a structure appropriate to his deficits. This perception probably represents both his limited awareness as well as objective reality; his parents are committed to supporting Greg in maximizing his potential.

Engagement

Greg's objective scores on strategies he uses when engaging in new or difficult tasks are above the median, and his scores on feelings when he engages are on the median. He has a functional status score above the median. These scores agree with the clinical evaluation that Greg lives in a state of order. He and his parents report he has symbiotic relationships, the most significant one being with his son. While Greg does not perceive himself as a victim, his parents do. They have been involved in the support group programs and advocacy movement for many years, and are aware of the limitations in services and understanding about head injury.

Social Context

Greg has facilitation appropriate to his deficits, as well as enough help from others. He never deviated from the expected pattern for a person in a state of order.

Validation

Greg also never deviated from the expected pattern for a person in order on measures of validation. His parents' report confirms his perceptions of his permission to be different, ability to shape his life, and be autonomous, with involvement of others in his life.

Case #8 - Jody

Trauma

Jody is a 26 year old Caucasian male. In January of 1987, when he was 16 years old, he was admitted to the emergency department of a metropolitan hospital in Long Beach, California, having been in a motor vehicle accident. He was diagnosed with diffuse frontal lobe damage. He was not shunted. He was in a coma three weeks. He seized while in the hospital, but is not on seizure medication. For approximately two years Jody received physical therapy, speech therapy, cognitive retraining, training in activities of daily living, and psychological counseling. His mother reports rehabilitation helped Jody both physically and mentally.

History

Jody was in high school when he had his accident. He enjoyed cars and socializing with friends. He lived with his mother, and worked at part-time jobs.

Post-Trauma Chronology

After Jody's accident, his mother and he moved to Eugene so he could be placed in a rehabilitation facility there. He began presenting behavioral problems and anger. He did not have medical insurance, and did not qualify for Medicaid. Consequently, after five months, he was discharged from the facility.

Jody and his mother moved back to California, and Jody re-entered high school, but was placed in a class for mentally retarded children. He tested for his GED, but because making choices is particularly difficult for him, he was unable to manipulate the multiple choice exam. He was placed in the Job Corps, and ran away.

Jody began presenting inappropriate sexual behavior. He was given

Depoprovera, a hormone used to suppress sexual behavior in males. Jody and his mother returned to Oregon. He was placed in a foster care home. He had been removed from his Depoprovera treatment, apparently due to potential liver damage. During a day when a care-giver had her daughter with her at the home, Jody allegedly attempted to molest the child.

In court Jody pleaded not guilty. He was found guilty but insane, and placed in the state mental hospital, where he lives today.

Behavioral Characteristics

Jody has a problem with balance, and lost one eye in the accident. He has trouble listening when more than one person is speaking, and presents aphasia. Jody has a problem with fatigue, particularly in stressful situations. He is unable to plan and track, says inappropriate things many times, and has a problem committing new information to memory. He is a friendly and accommodating person.

Evaluation

Coherence

I was unable to obtain permission to visit Jody, therefore my interviews with him were conducted by telephone. Also, he was not allowed to fill out the research instrument. Consequently we have no self-reported measures of Jody's coherence. To the extent that his awareness allows, he is depressed, suggesting perceptions of inadequate structure, autonomy support, involvement, etc.

Engagement

Jody's scores on strategies he uses when engaging in new or difficult tasks fall below the median, although his feelings about engaging fall above the median. His functional status is low. I categorized him in a state of disorder. Jody lives in an environment where punitive measures are used to control behavior, a particularly cruel situation for one who cannot remember the rules from day to day.

Jody's family strongly believes he is a victim of the system that determined his fate. However, they report that he has symbiotic relationships, in that they depend on his presence in their lives, even though he is incarcerated.

Social Context

Jody's scores on measures of Social Context are consistent with the expected pattern for a person living in a state of disorder. His structure is wholly inappropriate for a person with brain damage.

Validation

Jody's scores on measures of validation are also consistent with the expected pattern. He scored below the median on measures of ability to shape his life, autonomy support, permission to be different, and involvement.

Case #9 - BH

Trauma

BH is a 37 year old Caucasian female. In November of 1993, when she was 34, BH was admitted to the emergency department of a Level 1 Trauma Center in Portland Oregon with a closed head injury from a motor vehicle accident. She was unconscious for one day. She was shunted, and did not seize. BH was in acute care for one month. Her post-discharge rehabilitation consisted of visual therapy and psychological counseling. BH's Injury Severity Score from the Hospital Discharge Index was 2, and her Abbreviated Injury Score for head was 1.

History

Prior to her injury BH had a Master's degree in Education, and was a special education teacher in a high school. Her annual income was approximately $35,000. She lived with her fiance, and enjoyed dancing for leisure activity.

Post-Trauma Chronology

BH occasionally works as a substitute teacher at a community college. Her other sources of income are investments, rental property, disability, and a financial settlement from her car accident. Her annual income is approximately $35,000. BH's fiance left her; she lives alone. BH volunteers in work camps in Europe. She writes, studies karate, takes piano lessons, enjoys music, and travels.

Behavioral Characteristics

BH has relatively minor deficits. She has tinnitus, limited visual recall, and a mild problem with fatigue. She is functionally independent. She speaks rapidly, and occasionally speaks inappropriately. It does not appear she has a severe problem with memory.

Evaluation

Coherence

BH deviated from the expected pattern for a person in a state of order on two of eight measures of coherence. She does not perceive that she has permission to be different since her accident, and she does not perceive that people are involved in her life. She feels alone. She does perceive she has the ability to shape her life, and that she has adequate structure, autonomy support, and access to services.

Engagement

BH's scores are on the median for measures of strategies she uses and feelings she has when engaging in new or difficult tasks. Her functional status is high. She has a low number of essential disturbances; limited other-system damage. Based on her high functional status and her level of activity and autonomy, she was categorized as living in a state of order. Of interest, both BH and her informant report that she does not have symbiotic relationships. Also, BH perceives herself as a victim.

Social Context

BH never deviated from the expected pattern on measures of Social Context for a person in a state of order. She has facilitation and help, as well as scope of Social Context, appropriate to her deficits.

Validation

BH deviated once form the expected pattern on measures of validation for a person in a state of order. Her informant considers she does not have involvement in her life. This is consistent with BH's report that she has lost friends, and most significantly her fiance, since her accident.

Case #10 - MH

Trauma

MH is a 54 year old Caucasian female. On March of 1981, when she was 39, she was admitted to the emergency department of a rural hospital after dumping her motorcycle on the freeway. She lost her helmet in the accident and hit her head on the concrete divider. She sustained a cerebral hematoma, but no fracture. She has seizures, and takes anti-convulsant medication. MH was in the hospital 21 days, and unconscious less than one day. She was discharged to home. Her post-discharge rehabilitation consisted of psychological counseling.

Pre-Trauma Status

MH was an educational assistant in a public school. She had a high school degree. Her annual income was approximately $40,000. She lived with her husband and her son. For leisure activity she enjoyed camping, snowmobiles, and motorcycles.

Post-Trauma Chronology

MH divorced her husband and remarried. Her sources of income are her husband's job and disability. Her annual income is approximately $35,000. She is a homemaker. She volunteers in the school where she was employed before her accident. For leisure activity she camps, reads, and socializes.

Behavioral Characteristics

MH has some problem with balance, and mild problems with speaking and fatigue. It does not appear that she has extensive essential disturbances. If her memory was impaired, she has learned to compensate, as she does not appear to have profound memory problems.

Evaluation

Coherence

MH never deviated from the expected pattern for a person living in a state of order. She perceives her structure, autonomy support, involvement, and permission to be different all appropriate to her needs.

Engagement

MH scored below the median on measures of strategies she uses when engaging in new or difficult tasks. Her functional status is high, and that combined with clinical evaluation resulted in her being categorized in a state of order. MH believes she has symbiotic relationships, and does not perceive herself as a victim.

Social Context/Validation

MH would not allow us to interview or collect data from an informant, therefore we do not have measures of Social Context and validation for her other than our observation. It appears, with her new husband, she has more permission to be different, ability to shape her life, autonomy support, and involvement, than she did prior to her accident. She reports her personal life has been enhanced since her injury, but this is a perception, and therefore a component of Coherence.

Case #11 - Jean

Trauma

Jean is a 41 year old Caucasian female. In December of 1980, when she was 25, she was admitted to the emergency department of a Portland metropolitan hospital with multiple system injuries sustained in a motor vehicle accident. She had a closed head injury, and was diagnosed with a brain stem hemorrhage. She was not shunted, and did not seize. She was in a coma five days, and in the acute care hospital 27 days. Jean's post-discharge rehabilitation, lasting approximately four years, consisted of physical therapy, speech therapy, and psychological counseling, both in- and out-patient.

Pre-Trauma Status

Jean had a Bachelor's degree and worked as an administrator for a social service agency. Her annual income was approximately $50,000. She lived with her husband, and for leisure activity she enjoyed dancing and entertaining.

Post-Trauma Chronology

Jean and her husband, who was also in the car accident, divorced after the accident. Jean returned to school, and received her Master's degree in Psychology. She is an administrator for a business, with an annual income of approximately $35,000. She lives with her boyfriend, and for leisure activity she entertains, listens to music, and skis.

Behavioral Characteristics

The most severe damage Jean sustained was in her speech. She had extensive speech therapy to correct the slowness and aphasia. Although she is articulate, slight deficits can still be detected. She has trouble concentrating when more than one person is talking, has tinnitus, and has a mild problem with fatigue. It is more difficult for her to speak when she is fatigued. Jean is functionally independent. She does not appear to have problems with memory.

Evaluation

Coherence

On measures of coherence Jean deviated from the expected pattern for a person in a state of order 50% of the time. She has a low perception of her ability to shape her life, permission to be different, perception of structure, and perception of involvement.

Engagement

On measures of strategies and feelings when engaging in new or difficult tasks, Jean scored on the median. Her functional status is high. Results of her clinical evaluation placed her in a state of disorder, but for the purposes of this analysis, I maintained, based on other measures, that Jean was in a state of order. She does not perceive that she has symbiotic relationships, although her informant believes she does. She perceives herself as a victim, and her informant does not.

Social Context

Based on informant reports, Jean does not have facilitation adequate to her new state of being. She does, however, have the help of others, to the extent she reveals she needs the help.

Validation

On measures of Validation, Jean deviated once from the expected pattern for a person in a state of order. Her informant believes she does not have adequate autonomy support in her social context. She does, however, have the ability to shape her life, permission to be different, and involvement.

Case #12 -David

Trauma

David is a 45 year old Caucasian male. In March of 1991, when he was 40, he was admitted to the emergency department of a Level 1 Trauma Center in Portland, Oregon, with multiple system injuries sustained when hit by a car as a pedestrian. He was not in a coma, and did not seize. He was in the acute care hospital ten days. Of interest, David's Abbreviated Injury Score for head from the Hospital Discharge Index was 0. His Injury Severity Score was 10. David had sustained injuries, including a head injury, from a previous motor vehicle accident in 1979, after which he was in a coma ten weeks. It is unclear how much his current deficits are a function of the first or second accident. David's post-acute rehabilitation, lasting approximately six months, consisted of physical therapy, speech therapy, vocational rehabilitation, psychological counseling, and occupational therapy.

Pre-Trauma Status

David was a truck driver who had taken some college courses but was not degreed. His annual income was approximately $35,000. He lived with his wife, and enjoyed traveling and music.

Post-Trauma Chronology

David's wife divorced him; he lives alone. He returned to school to take business courses. He is self-employed in market research. His other sources of income are investments and savings, disability, and settlement money from his accident. He reports he has no social life or leisure activities. He volunteers at the

Brain Injury Support Group.

Behavioral Characteristics

David has profound multiple-system injuries. He walks with a cane and has problems with balance. He has limited use of his preferred hand. He has mild problems with speaking and fatigue. In spite of his physical limitations, he is able to ride public transportation, and is functionally independent. Although he may have problems with planning and initiation, it does not appear he has profound memory problems.

Evaluation

Coherence

David never deviated from the expected pattern for a person in a state of order on measures of Coherence. His perception is that he has the ability to shape his life, permission to be different, and appropriate structure, autonomy support, and involvement.

Engagement

David's self-report scores are on the median for measures of strategies he uses when engaging in new or difficult tasks. His feelings about his rehabilitation were positive. His functional status is high. These measures combined with clinical evaluation resulted in categorizing David as being in a state of order. He perceives he has symbiotic relationships, and does not believe he is a victim.

Social Context/Validation

David would not allow us to interview an informant or collect informant data with the survey instrument, therefore we have no measures for him on Social Context or Validation other than our own observation. It appears that David has little help from others. He has worked to establish a structure for himself that works and is appropriate to his deficits. Any ability to shape his life he has carved out for himself. He has symbiotic relationships through the TBI network, but not in his family, and it appears he has limited involvement from his family, and limited permission to be the changed being that he is. David is a lonely person.

Case #13 - Dan

Trauma

Dan is a 42 year old Caucasian male. In June of 1983 he was admitted to the emergency department of a Level 1 Trauma Center in Portland, Oregon, after surviving a plane crash. His father was flying the small aircraft. Both survived. Dan sustained multiple system injuries and a closed head injury. He was shunted, and did not seize. He was in a coma six weeks, and in the acute care hospital over three months. His Injury Severity Score from the Hospital Discharge Index was 43, and his Abbreviated Injury Score for head was 5. Dan received approximately six months of rehabilitation, including physical therapy, speech therapy, cognitive retraining, vocational rehabilitation, training in activities of daily living, and occupational therapy. He was discharged from acute care into a long-term care facility.

Pre-Trauma Status

Dan had a high school degree and had served in the military. At the time of his accident he was a waiter. His annual income was approximately $15,000. He lived with a roommate, and enjoyed socializing for leisure activity.

Post-Trauma Chronology

Dan lives in a skilled nursing facility. He is unable to work. His source of income is disability. His annual income is less than $10,000. He watches TV and plays board games. He enjoys getting out of the foster care facility. Dan's parents moved to another state. They recorded a video of themselves telling him they were leaving, and why. They explained that there was no reason for three lives to be ruined, and they were leaving to start over. Because Dan has lost his ability to commit new information to memory, he doesn't remember anything since his accident. The video is played for him from time to time to remind him that his parents are gone.

Behavioral Characteristics

As stated, Dan has no ability to commit new information to memory. Consequently, he can meet a person, talk with them, leave the room to go to the bathroom, return and not remember the person he just met. He has, however, developed a way of pretending he knows people. If a person interacts with him as if they are familiar with him, he responds in kind. Dan cannot walk and ambulates in a wheelchair. He repeats himself often, stating that he doesn't understand how he could be so brain-damaged if he never bled from his head. He has been known to escape from the foster care home, to be discovered hours later either on the road somewhere, or in some coffee shop talking with strangers. He is aggressive with one other member of the home, threatening to trip him when he walks by. He responds positively to attention, however, and is an accommodating and likable person.

Evaluation

Coherence

Dan was unable to fill out our research instrument, therefore we have no self-reported measures of Coherence for him. He has a high number of essential disturbances, and his profound memory loss is the hallmark of his limitations. When asked about his perceptions of his life, he responds optimistically.

Engagement

Dan's scores are below the median on measures of strategies he uses when engaging in new or difficult tasks. His functional status is low; his clinical evaluation combined with these measures place him in a state of disorder. Dan's informant does not believe he has symbiotic relationships, and perceives him as a victim.

Social Context

While Dan's informant does not think Dan has enough help in his life, the informant reports Dan has adequate facilitation.

Validation

Of the six measures of Validation, Dan's scores were consistent with the expected pattern for a person in a state of disorder for four. He does not have the ability to shape his life or his rehabilitation program, he does not have autonomy support, and does not have involvement in his rehabilitation. His informant reported, however, that Dan has permission to be different, and has involvement. His informant was one of his parents, and these positive reports could simply reflect the parent's need to believe Dan has a good circumstance.

Case #14 - RS

Trauma

RS is a 49 year old Caucasian male. In March of 1968, when he was 20, he stepped on a land mine in Viet Nam. A piece of shrapnel entered his skull through his left eye. He was in a coma six weeks, and in the acute care hospital seven months. He seized and is currently taking anti-convulsant medication. He participated in rehabilitation for six years, but his formal rehabilitation commenced ten years post-injury. He received physical therapy, speech therapy, cognitive retraining, vocational rehabilitation, training in activities of daily living, psychological counseling, occupational therapy, and family counseling, all in the out-patient setting.

Pre-Trauma Status

RS was a high school graduate, and a Lance Corporal in the Marine Corps. His annual income was less than $10,000. He enjoyed skiing and baseball. He lived in a military barracks in Viet Nam.

Post-Trauma Chronology

RS married after returning to his home town from the military hospital in which he convalesced. While it was known he had sustained the shrapnel wound, little was known about brain injury, and his deficits as a function of brain damage would not surface until RS attempted to live a normal life. RS returned to school and earned a Bachelor's degree in business. His pattern was to be fired from jobs after a year or two of employment. He was able to perform up to a limit, but not beyond. RS and his wife adopted one child, and gave birth to a second child. After approximately twenty years of marriage, RS and his wife separated. They remain married, and are closely involved in each others' lives. RS is a custodian at a university/hospital campus. He is employed there through a program that hires and trains people with disabilities, and provides ongoing support for their special needs as a way of improving their ability to maintain employment.

Behavioral Characteristics

RS has a problem with balance, and his vision is limited by the loss of one eye. He has a mild problem with fatigue. RS's primary deficits have to do with his lack of initiation. He requires prompting to perform daily activities, which is probably the reason he has in the past been unable to maintain employment.

Evaluation

Coherence

Of the eight measures of Coherence, RS deviated from the expected pattern for a person in a state of order on one. He does not perceive a strong ability to determine his own rehabilitation program. Otherwise he perceives he can shape his life, has permission to be different, structure, autonomy support, and involvement.

Engagement

RS's scores on measures of strategies and feelings when engaging in new or difficult tasks are all on the median. Also, his functional status is on the median. Given the autonomy he enjoys as a function of the support he receives from his family and network of therapists, he is categorized in a state of order. He perceives he has symbiotic relationships, but his informant does not. He does not perceive himself as a victim, but his informant does.

Social Context

RS has the help of others, but his informant reports less-than-adequate facilitation.

Validation

Of the six measures of Validation, RS deviated from the expected pattern for a person in a state of order on five. His informant does not believe he has the ability to shape his life or rehabilitation program, permission to be different, autonomy support, or involvement. RS's informant is his wife, who spent many years attempting to get the VA system to provide the support necessary for RS to function. His structure and autonomy are a function of her efforts. Therefore, these low scores are a result of her perspective of the system that is not readily available to support TBI.

Case #15 - John

Trauma

John was a 48 year old Caucasian male. In October of 1996 he was diagnosed with brain cancer. He never experienced a coma or seized. During a family meal he began speaking in fragmented syllables, without knowing that he was not speaking whole words. Prior to this incident he had been diagnosed with small cell carcinoma in lungs and lymph glands. A brain scan revealed tumors in the brain. In January of 1997 John died of cardiac arrest.

Pre-Trauma Status

John had an Associate's degree and was a union electrician. His annual income was approximately $50,000. He lived with his wife and one son. His other son was married and had two children, John's grandchildren. John enjoyed sports.

Post-Trauma Chronology

It is not possible to separate the deficits John experienced as a function of his brain tumors from those of the treatment for his cancer. He was unemployed after several months of chemotherapy, although his business continued paying him a full salary until his death. Therefore his annual income remained approximately $50,000. He was unable to be very active, remained living with his wife and son, and watched T.V. and read for leisure activity.

Behavioral Characteristics

John had a problem with balance, and profound difficulty with fatigue. He struggled to maintain his position of control within the family, managing the finances and making decisions until he died. However, in spite of his assertions that he would do whatever it takes to live, at a particular point in his disease process he did two things. First, he eliminated certain people from his life who were supportive both psychologically and functionally. Second, he stopped eating and drinking liquids.

Evaluation

Coherence

John never deviated from the expected pattern for a person in a state of order on measures of Coherence. He perceived he was able to shape his live, had permission to be the way he was, had structure, autonomy support, and involvement.

Engagement

John scored above the median on measures of strategies and feelings when engaging in new or difficult tasks. His functional status was high at the time the measures were taken, although it diminished as his disease progressed. His clinical evaluation placed him in a state of disorder, but for the purposes of this analysis we specified his category as ordered. John had many symbiotic relationships. Neither he nor his informant perceived him as a victim.

Social Context

John's informant, his wife, considered that John had adequate help, but not adequate facilitation.

Validation

Of the six measures of Validation, John deviated once from the expected pattern for a person in a state of order. John's informant did not consider that John had adequate autonomy support.

Case #16 - Julie

Trauma

Julie is a 39 year old Caucasian female. In June of 1987, when she was 30, she was admitted to the emergency department of a rural hospital having repeated seizures. She was diagnosed with an aneurism. She was transferred to a major neurosurgical center where surgery was performed. She never experienced a coma, and does not currently take anti-convulsant medication. She was in the acute care hospital under one month. After discharge she received approximately six months of physical therapy, speech therapy, cognitive retraining, and vocational rehabilitation.

Pre-Trauma Status

Julie had one year of college with no degree. She worked in a mill. Her annual income was approximately $40,000. She lived with her husband and son. She enjoyed skiing, bowling, baseball, and movies.

Post-Trauma Chronology

Julie is currently a custodian. She is divorced from her husband, and remarried a person who is also a survivor of brain damage, and another subject in this research. Julie's son lives with the first husband. Her annual income is approximately $45,000. Other than her job, she receives disability, has savings, and her husband receives and annuity. Julie enjoys skiing, movies, friends, shopping. She and her husband operate the local support group for brain injury survivors.

Behavioral Characteristics

Julie has a problem with balance, has limited use of her non-preferred hand, has visual deficits, and a mild problem with fatigue. She is functionally independent, although she reports having problems learning new skills. Julie affect is limited and almost always unexpressive.

Evaluation

Coherence

Of the eight measures of Coherence, Julie deviated on three from the expected pattern for a person in a state of order. She does not perceive a strong ability to shape her life, involvement of others, and access to social services. She feels she has permission to be different, and appropriate structure and autonomy support in her life.

Engagement

Julie scored below the median on self-report of strategies she uses in new or difficult situations, but above the median on feelings and informant-report of strategies. She has a high functional status. These measures are consistent with her clinical evaluation as being in a state of order. She has symbiotic relationships, and neither she nor her informant consider her a victim.

Social Context

Whereas Julie has adequate facilitation, she does not have adequate help from others.

Validation

Of the six measures of Validation, Julie deviated once from the expected pattern for a person in a state of order. She scored below the median on measures of others' involvement in rehabilitation. Otherwise she has the ability to shape her life, permission to be different, autonomy support, and involvement.

Case #17 - Mike T.

Trauma

Mike T. is a 30 year old Caucasian male. In February of 1987 he was admitted to an acute care hospital in a rural area of Oregon for radiation treatment for a brain tumor. A mistake in calibration resulted in extensive brain damage from over-radiation. Mike T. was in the hospital 13 days. He was never in a coma. He seized, and currently takes anti-convulsant medication. He has had neurosurgery four times. Mike T. received over six years of rehabilitation, consisting of physical therapy, speech therapy, cognitive retraining, vocational rehabilitation, psychological counseling, and occupational therapy, all in the out-patient setting.

Pre-Trauma Status

Mike T. had one year of college with no degree. He was not working prior to his surgery. He lived alone. His annual income was less than $10,000. His sources of income were disability and welfare. School was the source of his social activities.

Post-Trauma Chronology

Mike T. continues to be unemployed. His annual income is approximately $45.000. Sources of income are his wife's job, investments and savings, disability, and settlement money from the over-radiation. Mike T. married a woman who is also a survivor of brain damage. They own their own home. Mike T. helps with operation of the local support group for brain injury survivors. He hunts for leisure activity.

Behavioral Characteristics

Mike T. has a problem with balance, and is functionally blind. He has problems with aphasia and fatigue. Mike T. has a problem with tracking, but has learned to compensate for other memory deficits. Although he does not drive, he appears to be functionally independent, although this may be a function of the support provided by his wife.

Evaluation

Coherence

Mike T.'s scores on measures of Coherence are consistent with his category of disordered. His perceptions of his ability to shape his life, permission to be different, structure, autonomy support, and involvement are low.

Engagement

Mike T.'s scores were below the median on self-report of strategies he uses when engaging in new or difficult tasks. His informant-report scores, and scores on feelings, are on the median. Mike T. has a low functional status score. His clinical evaluation places him in the category of ordered. However, for the purposes of evaluation, we maintained his summary score of disordered. Mike T.'s informant does not believe he has many symbiotic relationships, and both Mike T. and his informant perceive he is a victim.

Social Context

Mike T.'s informant reports inadequate facilitation and help for Mike T..

Validation

Of the six measures of Validation, Mike T. deviated from the expected pattern for a person in a state of disorder on three. Mike T.'s informant reports Mike T. has the ability to shape his life, has permission to be different, and has involvement in his rehabilitation program.

Case #18 - Hal

Trauma

Hal is a 41 year old Caucasian male. In December of 1977, when he was 22, he was admitted to the emergency department of a metropolitan hospital in California with a severe closed head injury sustained from a motor vehicle accident. He was in a coma one week, and in the acute care hospital one month. He did not seize. We do not know if he was shunted. Hal did not receive formal rehabilitation. However, his father, a physician, took him to Europe for treatments for visual problems. Also, Hal participated in meditation training.

Pre-Trauma Status

Hal had taken several years of college courses but was not degreed. He was a student, and a carpenter. His annual income was under $10,000. He participated in college social activities, and enjoyed backpacking. He lived with his girlfriend.

Post-Trauma Chronology

Hal returned to school and received a Bachelor's degree as well as an Associate's degree in drafting. He also took classes in auto-CAD. He currently works as a drafter in space planning for a large medical/educational institution. He has had trouble maintaining employment, and has lost jobs because of inappropriate behavior. His annual income is approximately $25,000. Other than his job, his sources of income are his spouse's job and an inheritance. Hal married after his accident, and has two children. He enjoys reading, family activities, and walking.

Behavioral Characteristics

Hal's most obvious deficit is visual. He experiences double vision. He presents himself as happy and optimistic. However, in conversation he occasionally inserts comments that are sexually suggestive or otherwise out-of-context.

Evaluation

Coherence

Of the eight measures of Coherence Hal deviated from the expected pattern for a person in disorder once. He perceives he has the involvement of others in his life. Otherwise, he evaluates himself low in ability to shape life, permission to be different, structure, and autonomy support.

Engagement

Hal's scores are on the median for self-report measures of strategies he uses when encountering new or difficult tasks . He has a low functional status. These measures combined with clinical evaluation resulted in a category of disordered. Hal's perception of symbiotic relationships places him on the median. He considers himself a victim.

Social Context/Validation

While Hal wanted an informant to provide information, his wife was not willing to be the informant. Because Hal has had problems maintaining employment, both he and his wife did not want others to know he has sustained brain damage. Hal's father is dead. Consequently we did not obtain informant data. It is my opinion that Hal does not have appropriate structure or facilitation, given his deficits. He has not been able to shrink his Social Context appropriate to his needs. He is being placed repeatedly into contexts too large for him to negotiate, resulting in a pattern of failure.

Case #19 - Sandy

Trauma

Sandy is a 41 year old Caucasian female. In October of 1989, when she was 34, she was admitted to the emergency department of a Level 1 Trauma Center in Portland, Oregon, having sustained multiple system injuries from a motor vehicle accident. She was semi-conscious, and did not seize. Her Injury Severity Score from the Hospital Discharge Index is 18. Her Abbreviated Injury Score for head is 0. She was in the acute care hospital five weeks. Sandy received in-patient rehabilitation for less than one month, consisting of physical therapy, speech therapy, vocational rehabilitation, and psychological counseling.

Pre-Trauma Status

Sandy had taken post-high school vocational classes. She was a driver for Domino's Pizza. Her annual income was approximately $25,000. She lived with her husband and son. She enjoyed horseback riding, driving, and hiking.

Post-Trauma Chronology

Sandy remains married and lives with her husband and son. She took some business and clerical classes after her accident. However, she is unemployed, and is a homemaker. Her annual income is approximately $30,000. Sandy coordinates activities at the local TBI club.

Behavioral Characteristics

Sandy has a problem with balance, and difficulty with her non-preferred hand. She can't concentrate when more than one person is speaking, and has tinnitus. She presents mild aphasia, and has trouble with fatigue. Sandy is functionally independent, but has deficits with short-term memory.

Evaluation

Coherence

Sandy never deviated from the expected pattern on measures of Coherence for a person in a state of disorder. She does not perceive she has the ability to shape her life, permission to be different, autonomy support, involvement, and appropriate structure.

Engagement

Sandy's scores from her self-report fall below the median on measures of strategies she uses when encountering new or difficult tasks. She has a low functional status. These measures agree with her clinical evaluation that she is in a state of disorder. She believes she has some level of symbiotic relationships, and perceives herself as a victim.

Social Context/Validation

We could not locate a person willing to provide informant information on Sandy, therefore our evaluation of her Social Context and Validation is limited. It does not appear that her husband provides facilitation or help. Sandy reports her husband feels that her head injury is her problem to deal with. I can't say that this is accurate, only that he would not consent to an interview. I would guess that, with her husband, Sandy has limited permission to be different.

Case #20 - DZ

Trauma

DZ is a 23 year old Caucasian male. In August of 1992, when he was 19, he was admitted to the emergency department of a small metropolitan hospital due to cardiac arrest. The anoxic episode resulted in severe brain damage. He was in the hospital approximately four months. He was in a coma three weeks. He received approximately one year of rehabilitation, both in- and out-patient, including physical therapy, occupational therapy, speech therapy, cognitive retraining, training in activities of daily living, and visual therapy.

Pre-Trauma Status

DZ was a college student at the time of his cardiac arrest. He lived with his parents. The family's annual income was approximately $40,000. DZ was supported by his parents, worked, and had scholarships for school. He liked to bicycle, lift weights, and ski.

Post-Trauma Chronology

DZ lives in an apartment that is part of an assisted housing complex for survivors of brain damage. He is provided with access to 24-hour care. He is taking one class a quarter in college, and is unemployed. His annual income is less than $10,000, provided by disability and welfare, and supplemented by his parents. He volunteers, and participates in the day program provided by the facility in which he lives.

Behavioral Characteristics

DZ has a slight problem with balance, and tinnitus. Although he does not have significant visual problems, it appears he has deficits in construction. He has a mild problem with fatigue. Most profound are his problems with memory, tracking, and initiation.

Evaluation

Coherence

DZ did not provide a survey response. His perceptions are limited by his awareness. His cognitive ability prevents his being able to assess his own situation.

Engagement

DZ's scores fell below the median for strategies he uses when encountering new or difficult tasks. Scores for feelings were on the median. DZ's functional status is low. We categorized him in a state of disorder. his informant reported DZ does not have symbiotic relationships, and that he is a victim.

Social Context

DZ does not have adequate facilitation, but does have help of others in his life. His Social Context is minimized appropriate to his deficits. He is functionally dependent.

Validation

DZ's scores on measures of Validation were consistent with being in a state of disorder, with the following exceptions. He has maintained some ability to shape his life, he has permission to be different, and he has autonomy support. He does not have much involvement of others in his life, and received scores below the median for involvement in and ability to shape rehabilitation.

Appendix B

Established Instruments Used to Develop Scales

Portland Adaptability Inventory (Lezak, 1987)

Psychosocial Rating Scale

(Horowitz, Fredda, Cohen, Skolnikoff, & Saunders, 1970)

Quality of Life Interview (Lehman, 1983)

Patient Competency Rating (Roueche & Fordyce, 1983)

Brock Adaptive Functioning Questionnaire

(Dywan & Segalowitz, 1996)

Family Burden Interview Schedule

(Tessler & Gamache, 1994)

Global Assessment of Functioning

(Spitzer, Gibbon, Williams, & Endicott, 1994)

Katz Adjustment Scales (Katz & Lyerly, 1963)

Life Skills Profile

(Rosen, Hadzi-Pavlovic, & Parker, 1989)

Neurobehavioral Rating Scale

(Levin, Overall, Goethe, High, & Sisson, 1987)

Neuropsychology Behavioral and Affect Profile

(Nelson, Satz, & D'Elia, 1994) .82

Appendix B (Continued)

Established Instruments Used to Develop Scales

Teachers As Social Context

(Belmont. Skinner, Wellborn, Connell. & Pierson. 1992)

Rochester Assessment of Intellectual and Social Engagement