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UNIVERSITY OF ALBERTA

Community Integration and Quality of Life Following Traumatic Brain Injury

by

Janet L. Smith ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Master of Science

Department of Occupational Therapy
Edmonton, Alberta
Fall, 1995

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled, "Community Integration and Quality of Life following Traumatic Brain Injury" submitted by Janet L. Smith in partial fulfillment of the requirements for the degree of Master of Science.

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Abstract

Many survivors of traumatic brain injury (TBI) living in the community have impairments and disabilities that compromise their participation in expected social roles in the community. This study investigated the quality of life for 43 individuals by using the Life Satisfaction Index -A to measure life satisfaction, the Sickness Impact Profile (SIP) to measure physical and psychosocial dysfunction, the Community Integration Questionnaire (CIQ) to measure the degree of community integration, and the Quality of Social Support Scale to measure perceived social support. The impact of brain injury was evaluated through its effect on the individual's functioning and subjective quality of life using the Occupational Performance model. Psychosocial dysfunction and perceived social support were the strongest predictors of life satisfaction. As expected, the degree of community integration was lower than for a non-disabled normative group. Statistical analysis between self report and proxy reports with the CIQ and SIP measures support the reliability and importance of both sources of perception.

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CHAPTER I. Introduction

Recent advances in medical technology and improved trauma organizational systems have led to a reduction in fatalities associated with traumatic brain injury (TBI). However, with the subsequent improved survival rates, there is also an increasing number of individuals with impairments and chronic disabilities that may compromise individuals' participation in social roles, productivity, and leisure in their community. These handicaps may drastically affect their quality of life. Effective neurological interventions may be of little consequence if these individuals are unable to resume meaningful roles within their environment (Rosenthal & Muir, 1983). Successful intervention strategies by healthcare professionals rest on an understanding of the dynamic influences affecting quality of life.

Objectives of the Study:

The Occupational Performance (OP) model provides a conceptual framework for therapists to analyze behavior and activities and to guide the provision of treatment for individuals with traumatic brain injury. In order to refine and validate the concepts of this model, research is necessary to examine the underlying assumptions and principles which are applied in occupational therapy. The benefits of this research process are two: adding empirical knowledge to the literature pertaining to understanding the impact of traumatic brain injury on individuals' quality of life, and validating the conceptual basis of the Occupational Performance model. This research study utilized the the OP model to examine the relationship of the model's interacting elements to subjective quality of life. Specifically, this study investigated the level of life satisfaction of traumatically head injured survivors living in Alberta, their functional status, their degree of community integration and perceived social support and identified any association between these elements. There was also an interest in the validation of subjects' reports from the perspective of a significant other (SO). Therefore the significant others' perceptions of the subject's functional status and degree of community integration were also examined comparatively.

Research hypotheses

The following hypotheses were examined in this study:

1. That perceived social support is positively associated with life satisfaction.
2. That the degree of community integration is positively associated with life satisfaction.
3. That sickness impact scores are negatively associated with level of community integration.
4. That perceived social support is positively associated with level of community integration.
5. That sickness impact scores and perceived social support are predictive of the level of community integration.
6. That perceived social support and level of community integration are predictive of life satisfaction.
7. That individuals with TBI and their significant others will report similar ratings of the subjects' community integration and sickness impact.

CHAPTER II. Selected Literature Review

Impairment, Disability and Handicap:

Health is cited as one of the most important determinants of overall quality of life (McDowell & Newell, 1987). Our definition of health over the years has expanded significantly which has also broadened our intervention strategies. Health is defined by the World Health Organization (WHO) (1992) as "a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity." The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) presented by the World Health Organization (1980) provided a model of the disablement process which has led to the development of techniques to measure health as defined above (Minaire, 1992). This model identifies three potential consequences of disease: impairment, disability, and handicap. Each consequence represents a potential limitation in function either in using skills, performing activities or fulfilling social roles which corresponds to three levels of analysis: organ, person, and society (Turner, 1990). Impairment is "any permanent or temporary loss or abnormality of psychological, physiological, or anatomical structure or function resulting from any cause"(WHO, p.183). Disability is "any reduction or loss of functional capacity resulting from an impairment"(WHO, p. 183). Handicap is "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents fulfillment of a role that is normal for that individual" (WHO, p. 183). These three concepts are considered to be associated; however within the societal context of handicap, there is no inherent relationship between them. A person could have an impairment without a disability, a disability without a handicap and so forth. For example, a person who has a visual impairment does not necessarily have a disability or a handicap if contact lenses are worn. If the contact lenses are lost, a temporary disability results and if their occupation requires reading then a handicap also exists. On the other hand, if there is no need to read, then a handicap does not exist. The WHO model describes handicap as the net effect and interplay of many factors including the impairment or disability itself, the individual's perceptions and characteristics and several environmental factors such as societal expectations and reactions to disability, availability of services and place of residence (urban/rural) (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992). Handicaps exist when individuals are unable to fulfill expected social roles. Quality of life is most closely related to the dimension of handicap.

Quality of Life:

As our definition of health has expanded to encompass qualitative aspects of life after survival, recent evaluations of health care outcomes often include quality of life measures. The increasing participation of individuals in their health care has also shifted the evaluation of quality of life from the perceptions of the health care professional to that of the individuals concerned. The conceptual formulation which is gaining wider acceptance defines quality of life by the client's perception of function (Schipper, Clinch, & Powell, 1990). Traditionally, the term "quality of life" related both to objective circumstances and to the individual's perceptions about these circumstances (McDowell & Newell, 1987). Although some objective measures of impairments, functional limitations, or activity restrictions claim to be representative of the individual's quality of life, Minaire (1992) cogently argues that the term "quality of life" should be reserved for individuals' appraisal of their own life. Quality of life is a person-perceived entity. Fuhrer's (1994) definition of subjective quality of life as individuals' global judgements of their life experience along a continuum of positive to negative, emphasizes that these judgements of well-being reflect the individual's implicit standards rather than external objective ones. Schumaker, Anderson, & Czajkowski (1990) provide a useful framework for quality of life. Quality of life is defined as individuals' overall satisfaction with life and their general sense of personal well being. Six dimensions that determine quality of life include cognitive, social, physical and emotional functioning, personal productivity (which includes employment, homemaking and leisure involvement) and intimacy.

Attempts have been made to distinguish the terms quality of life, happiness, morale and well-being in the literature. However, changing social circumstances and orientations bring frequent alterations to the definitions of these concepts. Subjective "well being" has been described as a concept that subsumes other concepts such as life satisfaction, happiness and morale (Fuhrer, Rintala, Hart, Clearman, & Young, 1992). Although conceptual differences may be drawn between the terms of quality of life, life satisfaction, happiness and morale, current measures of quality of life generally refer to subjective feelings of well-being that are closely associated with happiness, satisfaction, and morale (McDowell & Newell, 1987). These measures are important indicators of health and adjustment to impairments and disability as they give a more integrative view and highlight the complexity of the phenomena.

Empirical studies have shown that there is no strong association between objective and subjective indicators of quality of life which has exacerbated the lack of conceptual clarity. Recent studies have found an association between measures of handicap and life satisfaction; however, there appear to be other mediating factors (Fuhrer et al., 1992; Schulz & Decker, 1985). They found that although handicap as measured by decreased mobility (ability to move about effectively in one's surroundings), social integration (ability to maintain customary social relationships) and productivity (ability to occupy time in a manner customary to one's age, sex, and culture) had a significant negative association with life satisfaction, other factors accounted for more of the variance in life satisfaction measures. Specifically, perceived control, self-assessed health and perceived social support had stronger relationships to life satisfaction. Handicap was measured against objective features of the subjects' lives. Further empirical and theoretical work is necessary to understand the relationship between subjective factors such as life satisfaction and objectifiable features of individuals' lives (Fuhrer et al.).

Occupational Performance Model:

Though the preceding discussion is illustrative of the complexity of the area intrapsychically, it does not address the major crisis occurring when there is a change in an individual's functional capacity. Therefore a conceptual framework is required which provides a forum for the mind/body integration and environmental interaction. The Occupational Performance (OP) model (Appendix I) is based on the belief that an individual's physical, mental and spiritual health is promoted through active participation in performing tasks, or directing others on one's behalf, in purposeful activity/occupation (Townsend, Brintnell, & Staisey, 1990). This model and the ICIDH are conceptually complementary in that the performance components (mental, physical, socio-cultural, and spiritual) and the areas of occupational performance (self-care, productivity, and leisure) are mirrored, although not precisely, in the categories of impairment, disability and handicap (see Appendix J) (Townsend, Ryan, & Law, 1990). Both models hold the view that health requires a holistic integration of physical and mental performance; both recognize that health involves performance; and both acknowledge that the environment defines possibilities and boundaries (Townsend, Ryan, et al.). Occupation has been defined as activities which engage a person's time and energy; specifically self-care, productivity and leisure (Reed & Sanderson, 1983). A central premise in this model is that individuals have an intrinsic need to be engaged and their engagements have a crucial effect on their quality of life. A sense of well being and self-worth is derived from a selective integration of four performance components (spiritual, physical, socio-cultural and mental) through meaningful engagement with the environment [Canadian Association of Occupational Therapy (CAOT) & Department of National Health and Welfare (DNHW), 1991]. Health is determined by an individual's purposeful engagement in occupation and by a balance of self-care, productivity and leisure (Law, 1991).

This model takes a broader view of the factors which may influence community integration and suggests a framework of how these factors may interact. The notion of health is closely related to the ideas of the ability to act to achieve one's purposes, autonomy, and the ability to live as a member of a community (Whitbeck, 1993). The underlying philosophy governing intervention through adaptation and activity are: independence is better than dependence; internal locus of control is better than external locus of control; individuals have a right to seek a meaningful existence and fulfillment of potential through purposeful interaction (Townsend, Brintnell, et al., 1990) which reflects a Western cultural bias. However, a critical element of the model is that integration and execution of occupational performance is defined and shaped by the context of the individual's social, physical and cultural environment. This environmental context includes societal rules and expectations, an individual's developmental stage and the cultural norms dictating how an individual should live (Yerxa & Locker, 1990). This model suggests that social and physical environments may also contribute to low levels of integration into the community, in addition to the individual's disabilities. The current study examined how self-assessed life satisfaction and social support (environmental factor) interacted with the individual's ability to integrate everyday activity/occupation into age-appropriate roles and functions.

Profile of TBI:

Traumatic brain injuries are defined as damage to or functional impairment of brain tissue that is caused by an acute mechanical force (Smith, 1985). Traumatic brain injuries are most often caused by motor vehicle accidents, falls, assaults, work-related accidents and recreational-related accidents. Brain damage can be classified as primary, which occurs at the moment of impact, or secondary which occurs as a result of subsequent pathologic processes. Epidemiological studies suggest that over 50% of TBI survivors are between the ages of 15 and 25 years old and the incidence of TBI is more than 2:1 for males to females (Jennett & Teasdale, 1981; Kraus & Arzemenian, 1989). In Canada, the annual incidence of traumatic brain injuries requiring hospitalization is commonly cited as 200 cases per 100,000 population (Parkinson, Stephenson, & Phillips, 1985). Based on a population of approximately 2,500,000 in Alberta, about 5000 new cases of TBI are admitted to Alberta hospitals each year.

The most common form of brain injury involves a loss of consciousness following a rapid acceleration/deceleration injury. Individuals who sustain severe diffuse axonal brain injury will typically become comatose for many hours, days, weeks or even months (Sbordone, 1992). The severity of brain injuries is most commonly determined by the length and depth of coma as measured by the Glasgow Coma Scale (GCS) or the interval between the occurrence of the head injury and the return of full consciousness and continuous memory of ongoing events as measured by the Post-Traumatic Amnesia (PTA) scale (Rimel, Giordani, Barth, & Jane, 1982). Severe injury occurs when loss of consciousness and/or PTA exceed 24 hours or there is demonstrable cerebral contusion, intracranial hematoma, or laceration. Moderate injury occurs when loss of consciousness and/or PTA lasts for more than 30 minutes but less than 24 hours without cerebral laceration or intracranial hematoma; cerebral contusion is usually present. Mild injury occurs when the loss of consciousness and/or PTA is less than 30 minutes without cerebral contusion, laceration, hematoma. These categories correlate well with the GCS (Bermann & Kovich, 1991). Studies suggest that less severe trauma, younger age and higher education are associated with increased probability of functional independence (Timming, Orrison, & Mikula, 1982; Jennett & Teasdale, 1981), social rehabilitation (Lundholm, Jepsen, & Thornval, 1975) and higher employment rates (Brooks et al., 1987; McMordie et al., 1990). Although severity measures are useful in tracking emergence from coma and they do correlate with outcomes, they have limited use for categorizing post-coma patients (Gouvier, Blanton, LaPorte, & Nepomuceno, 1987). Other scales have been developed for this purpose based on functional capabilities post-coma. The Disability Rating Scale (DRS) is a 30-item scale commonly used to classify post-coma outcome levels for traumatic brain injury patients from "coma to community" (Rappaport et al., 1977). Individuals can be classified into categories of disability ranging from death to no disability.

The range of possible physical and cognitive deficits resulting from brain injury have been extensively documented in the literature. Although the neuro-behavioral sequelae resulting from TBI are heterogeneous, there is a constellation of phenomena that characterizes this group of individuals. Memory deficits are the hallmark of closed head injury resulting in a reduced learning capacity for new information and impaired performance in many daily activities (Kay, 1986). In addition, impairments in executive functions can result in difficulties in organizing integrative thinking or behavior (especially in new and unstructured environments), initiating new activities, problems with flexibility of thinking, reduced abstract reasoning capacity, impaired complex information processing skills, and problems with judgement (Kay; Lezak, 1982). Longitudinal studies suggest that personality change and emotional problems such as irritability, mood changes and decreased frustration tolerance are the most serious social problems (Brooks, Campsie, Symington, Beattie & McKinlay, 1986; Lezak, 1987). This often results in loneliness, social isolation and a loss of identity (Krefting, 1987). Although the physical problems have been minimized relative to psychosocial problems, they may relate to the ability to participate in some psychosocial activities such as recreation (McLean, Dikmen, & Temkin, 1993). All these problems can present barriers to successful social and vocational readjustment and dramatically change the level of integration of the individual into the community.

The changes that occur in an individuals' life after a traumatic brain injury are exponential. Numerous changes in an individual's life have often been associated with increased levels of stress and secondary stress related illness. Many persons with TBI experience important role changes in their lives that result in feelings of lowered self-esteem and quality of life (Hallet, Zasler, Maurer & Cash, 1994). Therefore, specific changes in the subjects' life were documented in this study.

One goal of post-acute rehabilitation for persons with TBI is to improve their quality of life by effectively eliminating or reducing deficits in functional areas required to successfully participate in occupational performance roles. Although rehabilitation efforts demonstrate successes with physical and some cognitive deficits, integration into the community remains problematic (Ben-Yishay, Silver, Piasetsky, & Rottock, 1987) because it requires a complex synthesis of biopsychosocial skills within the environment. This is reflected in the term, "walking wounded", which aptly describes many individuals with moderate to severe brain injury who may appear physically recovered but who unfortunately have residual cognitive problems which interfere with important outcomes such as return to employment, independent living and social integration. Therefore, this study measured the functional manifestations of these residual biopsychosocial problems.

Measurement of disability resulting from TBI

The most appropriate measure of disability is one in which the individual rather than the organ becomes the unit of analysis. Pathology is evaluated indirectly through its effect on functioning of the individual. The Sickness Impact Profile (SIP) is a behaviorally based self-report measure of sickness-related dysfunction (Bergner, Bobbitt, Carter, & Gilson, 1981). The SIP is not intended to measure the presence of disease, nor the experienced discomfort or feeling state of the respondent (illness); rather it is intended to measure sickness-impacts which are defined as changes in a person's behavior associated with carrying out one's daily life activities that are related to his or her (lack of) health.

The SIP has been used as a self-report measure of functional status and as a measure of quality of life. In an overview of existing measures of quality of life, Spitzer (1987) highly recommended the SIP as a measure of behavioral or performance aspects of illness. The SIP items address the three major aspects of health recommended by the WHO: physical, mental, and social. Of interest in this study are the physical and psychosocial dimensions of the SIP as a measure of subsequent dysfunction in occupational performance components (socio-cultural, physical and mental) following traumatic brain injury.

The SIP has been used in studies examining functional outcomes post- TBI. The psychometric properties will be discussed later. Although modifications have been attempted to increase the sensitivity of the standard SIP for use with individuals with TBI, authors conclude that the SIP performed well as a measure of psychosocial and physical functioning of individuals with TBI (McLean et al., 1993; Temkin, McLean et al., 1988; Temkin, Dikmen, MacHamer, & McLean, 1989). The SIP was able to differentiate between individuals with brain injury, non-injured controls (Temkin, McLean, et al.) and non-brain injured trauma control patients (Temkin, Dikmen, et al.). The SIP also related significantly, although modestly, to both neurological and neuropsychological severity of the brain injury (Temkin, McLean, et al.). The SIP scores are affected by factors relevant to the functioning of these individuals (i.e., head-injury severity, the severity of other system injuries and the time since injury) (Temkin, Dikmen, et al.). McLean et al. (1993) found that although physical problems did show more recovery over the first year relative to psychosocial problems, physical problems may contribute to problems in participation in some recreational activities.

Sickness impact is an intersubjective construct in that it is also influenced by cultural aspects of the individual such as conceptions of health, the self and clinical reports of dysfunction. This means that changes must be recognizable by both the patient and his or her social surroundings (De Bruin, De Witte, Stevens, &

Diederiks, 1992). Although a person's perception of his/her deficits is no less important than the external observation of that deficit, given that sickness impact is an inter-subjective construct, the comparison of subject and proxy respondents is an important aspect of the SIP's construct validation. The use of proxy respondents to complete the SIP has shown some promising initial data but has not been sufficiently explored (De Bruin et al., 1992). Krenz, Larson, Buchner, & Canfield (1988) recommend that proxy respondents' SIP scores be used for patients with cognitive impairments such as Alzheimer's disease. The correlations between two validated measures of dementia severity (the Mini Mental State Exam and Dementia Rating Scale) and the SIP scores rated by two sources [family members versus the individuals with alzheimers-type dementia (ATD)] resulted in consistently higher correlations with family reporting (Krenz et al., 1988). The authors conclude that this discrepancy is most likely attributable to the cognitive deficits of the individuals with ATD rather than sampling differences (e.g., the degree to which the proxy knows the subject).

The comparison of SIP scores using proxy respondents versus respondents with TBI has not been reported in the literature to date. Given that individuals with brain injury may lack awareness of social behaviors, the investigation of proxy respondents with individuals with TBI is important to validate its use with this population. Both the individual with the TBI and the significant other completed the total SIP questionnaire, to permit the calculation of the physical and psychosocial dimensions and the total score of the SIP.

Measurement of Life Satisfaction:

Approaches to measurement of life satisfaction include summing up the individual's satisfaction ratings with a number of specific life domains (Spitzer et al., 1981) to reflect overall life satisfaction. Although this approach may provide insight into some of the bases of life satisfaction, it has been criticized in that specific lists of domains fail to capture the individual's global appraisal of life experience (Fuhrer, 1994). Another approach uses single item measures such as the Self-Anchoring Ladder developed by Cantril (1965). Compared to multi-item scales, single-item scales tend to be less reliable. The current study used a multi-item life satisfaction measure (Life Satisfaction Index - A) as a subjective indicator of general well being as perceived by the individual with TBI.

Measurement of Community Integration

The success of community integration represents the degree to which the individual performs developmentally appropriate roles and functions (Willer, Linn, & Allen, 1994) and gets satisfaction through the experience. Wood-Dauphinee et al. (1988) suggest that reintegration means the ability to function, to do what one wants to do or feels one has to do, not that one must necessarily be free of symptoms or even disability. Despite efforts aimed towards community integration for those with TBI, there are few measures that actually operationalize and assess this outcome, particularly from the individual's perspective.

The Community Integration Questionnaire (CIQ) was recently developed in response to this measurement need and specifically to assess the degree of integration into the community as a measure of reduced handicap in accordance with the WHO definition (Willer, Linn, & Allen, 1994). The CIQ does not assess specific integration skills (performance components in the OP model); rather it globally assesses integration outcomes (occupational performance areas). The domains are conceptually similar to the occupational performance activities (productivity and leisure).

The CIQ consists of a sample of activities in the domains of leisure and productivity in which the client is expected to participate independently in the community. These activities have been cited in the literature as problematic for some survivors of TBI. The CIQ is worded such that survivors can reliably describe their own level of community integration. The present form of the CIQ does not directly assess the individual's satisfaction or sense of control over integration, nor the degree to which the individual chooses to be engaged in these various activities (Willer, Linn, & Allen, 1994). The importance of involvement in all three domains is acknowledged in that the level of integration is taken as an aggregate score of the three domains.

A recent study by Willer, Rosenthal, Kreutzer, Gordon, and Rempel (1993) examined the level of community integration of two groups of individuals with TBI compared with a non-disabled group of subjects. Results of this study demonstrate the CIQ's validity and potential for use in program evaluation. Individuals with brain injury were significantly less integrated on the total CIQ score than individuals in the non-disabled sample. Significant differences were also found on every subscale, except for females with TBI whose home integration scores were not significantly different than the non-disabled females.

Measurement of social support

Whether or not disability results in a handicap depends upon the environment and various factors which can modify the results of disablement (CAOT & DNHW, 1991; Minaire, 1992). Adjustment implies coming to satisfactory terms with the environment and oneself and it involves both a personal and social reference (Katz & Lyerly, 1963). Of interest in this study are the effects of the social environment, specifically social support, on the subject's degree of integration into the community and life satisfaction. A number of empirical studies have indicated that social support is associated with mortality/morbidity (Berkman & Syme, 1979), well being (Schulz & Decker, 1985), life satisfaction (Fuhrer et al., 1992) and home and family functioning (Goodenow, Reisine, & Grady, 1990).

The literature relevant to social support distinguishes between two concepts: 1) social network (social integration), i.e. the number of relationships a person has and frequency of contact, and 2) perceived social support, i.e. the person's perception of the supportive importance of social interactions

(Schaefer, Coyne, & Lazurus, 1981). The former concept emphasizes the support derived from the embeddedness within a social network which is thought to promote physical and mental health (Berkman & Syme, 1979). The approach used in the CIQ to measure social integration is similar to this concept in that quantity and not quality of social contacts is obtained. Perceived social support has been described as including positive effects such as tangible, emotional and informational support and negative effects of relationships such as constraints, conflicts and disappointments (Schaefer et al.). In studies examining adjustment to illness, when measures of both social network and perceived social support have been obtained, the perception of the adequacy of support has had stronger associations than social network with psychological and social functioning and life satisfaction (Fuhrer et al., 1992; Goodenow et al., 1990; Shulz & Decker, 1985). Holosko and Heuge (1989) found that perceived social support was positively related to self-esteem, life satisfaction and major life adjustments of clients with TBI. A growing number of studies suggest that during times of stress, the individual needs to perceive that others are available to help cope with demands posed by the environment. Given the stressful nature of adjusting to the residual impairments of TBI, one would expect that a sense of well-being or life satisfaction would also be related to perceived social support. Therefore, in this study, in addition to the social integration measure on the CIQ, perceived social support was measured using the Quality of Social Support (Goodenow et al.).

Summary:

The Occupational Performance Model and the WHO disablement model provide the conceptual framework to understand the link between occupational performance, social environment, and life satisfaction. Quality of life, as assessed by the individual, is an important outcome of the available health care. For the purposes of this study, the Life Satisfaction Index - A, a subjective measure of life satisfaction was used to measure general well being (see Appendix G). An increasing number of individuals' lives are affected by residual impairments of TBI which become manifest when they attempt to resume important social roles in the community. The degree of handicap or the social disadvantage which is associated with the fulfillment of occupational roles, rests not only on the deficits in occupational performance components or disability but also on environmental influences. Interaction with the community is seen as an indicator of a functional life style. It follows that the level of community integration will be influenced by both the degree of dysfunction in the physical and psychosocial dimensions following a TBI and the socio-cultural environment. In order to cope and adjust to the consequences of TBI, individuals draw on both personal and social resources. The socio-cultural environmental aspects of interest in this study are social support in the environment as perceived by the individual. Social support is associated with positive aspects but may contain negative aspects such as strain/conflict. Relationship strain is often reported by both the individual with TBI and the significant other (Brooks et al., 1986). Previous literature suggests that satisfaction with life is derived from individuals' ability to engage in meaningful activity, their congruence between their expected and actual performance, and their qualitative evaluation of social support from the environment (Goodenow et al., 1990; CAOT & DNHW, 1991). A better understanding of these dynamic factors is essential in effectual program planning and providing appropriate rehabilitation interventions.

CHAPTER III. Methods and Procedures:

Study Participants:

Subjects were identified through the Northern Alberta Brain Injury Society (NABIS), the Southern Alberta Brain Injury Society (SABIS), the Central Alberta Brain Injury Society (CABIS), the Lloydminster and Area Brain Injury Society (LABIS), the Peace River Area Brain Injury Society (PABIS), and the Drayton Valley Association for Community Living. These agencies contacted subjects according to the inclusion/exclusion criteria which follows to ask if their names could be given to the researcher to arrange an interview (see Appendix K). Subjects: 1) had sustained a traumatic brain injury as an adult between the ages of 18 and 60; 2) were at least one year post-injury; 3) were discharged from any inpatient rehabilitation programs at least one year (subjects may be attending an outpatient program or community support groups); and 4) lived within 100 kilometers of urban centers in Alberta i.e. Edmonton, Red Deer, Calgary, Grande Prairie or Lloydminster. Persons with receptive/expressive aphasia or a previous history of head injury with loss of consciousness, psychiatric history requiring hospitalization, or substance abuse prior to the TBI were excluded.

All participants were given an introductory letter by the agencies describing the purpose of the study and the requirements (Appendix B). The agency only released their name and telephone number to the researcher with their agreement. The subjects named a significant other when initially contacted by the researcher. In order to obtain a broad representation of living arrangements and social constellations, a significant other was defined as any individual who either lived with or had at least 10 hours of direct contact per week with the individual with TBI. Both the individual with TBI and a significant other had to agree to participate and signed separate consent letters (see Appendices C & D). The relationship with the significant other is described in Table 1. The subjects lived with their significant other in 54% of the cases.

Forty-four interviews were arranged with subjects and their significant other. Of these, one subject was excluded because he became agitated and refused to complete the screening test; therefore a sample of 43 was obtained. The sample of convenience may limit generalizability of the findings.

Socio-demographic Information:

Socio-demographic characteristics (see Appendix E) were obtained from the subject and their significant other during the interview. The sample was characteristic of epidemiological information reported in the literature. Subjects' average age at the time of injury was 27 years old, ranging from 18 to 51 years old. Almost half of the sample had suffered their injury at age 25 years or younger, similar to the findings of Jennet & Teasdale (1981). The ratio of males to females (1.9:1) is comparable to the 2:1 ratio reported in the literature (Jennet & Teasdale; Kraus & Arzemenian, 1989).

Approximately half of the subjects had some post-secondary education. The sample included subjects who lived in various locales in Alberta and different types of accommodations as described in Table 2. The majority of subjects were from urban centers.

The subjects ranged in age from 22 to 54 years old at the time of the interview ($\underline{M}$=34.6, $\underline{SD}$=7.6). One to eighteen years ($\underline{M}$=7.8, $\underline{SD}$=8.6) had passed since their injury. Most subjects had been involved in a motor vehicle accident (see Table 3). Days in coma ranged from less than one day to 240 days ($\underline{M}$=37.8, $\underline{SD}$=46.7). Table 4 summarizes the severity of their injury and level of disability. The majority of the subjects were classified as severe traumatic brain injuries using the length of time in coma (Rimel et al, 1982).

TABLE 1

Distribution of the subjects according to socio-demographic characteristics.

	%	n
Gender:		
male	65.1	28
female	34.9	15
Marital Status:		
never married	48.8	21
married/common-law	28.0	12
divorced	23.3	10
Level of Education:		
7 - 11	27.9	12
high school	25.6	11
college	23.3	10
trade/technical	16.3	7
university	7.0	3
Children:		
none:	53.5	23
independent:	18.6	8
dependent:	27.9	12
Relationship of Significant Other to Subject:		
parent	32.6	14
sibling/son/daughter	11.6	5
spouse/common-law	27.9	12
friend	18.6	8
case worker/attendant	9.3	4

TABLE 2

Distribution of the subjects according to living arrangements

Locale	%	n
urban	67.4	29
town	18.6	8
rural	9.3	6
Residence		
room and board with family	27.9	12
rent apartment/house	41.9	18
own house/condominium/trailer	23.3	10
other	7.0	3
People in household		
alone	30.2	13
with spouse	32.6	14
with parents	25.6	11
hired attendant	4.7	2
friend	7.0	3

TABLE 3

Type of Accident

	%	n
Motor vehicle accident	72.1	31
Horse accident	11.6	5
Fall	9.3	4
Falling object	4.7	2
Assault	2.3	1

TABLE 4

Distribution of subjects according to severity indices of injury

	%	n
Severity of injury: (Loss of consciousness)		
mild (<30 minutes)	7.0	3
moderate (30 minutes to 24 hours)	4.7	2
severe (> 24 hrs)	88.3	38
Disability Rating Scale:		
none	4.7	2
mild	51.2	22
moderate	39.5	17
severe	4.7	2

Changes Post-injury:

Marital status had changed following their injury for approximately one quarter of the subjects (n = 10). Of these ten subjects whose marital status had changed, seven had been married and were now divorced and 3 subjects had been single and were now married. Almost half of the subjects had never married and remained single.

Employment status had changed for the majority of the subjects (84%). Table 5 includes the percentages of the sample for pre-injury and post-injury occupational categories. Two-thirds of the group had been unable to secure steady employment for more than 2 months after their accident. This contrasts remarkably to their premorbid employment status where 93% engaged in paid employment. Employment status was not analyzed in relation to self-report measures because the majority of subjects were unemployed. Several subjects had attempted to return to work unsuccessfully; others had not attempted work. Of the total, only a few subjects (n=4) had additional training post-injury which led to employment requiring more skill than required on their jobs pre-injury. The pattern of employment post-injury is similar to the findings of Holosko and Huege (1989).

TABLE 5

The distribution of subjects according to occupations pre-injury and post-injury

	Pre-Injury		Post-Injury	
Occupations:	%	n	%	n
homemaker	4.7	2	4.7	2
unskilled/semi	72.1	31	18.6	8
clerical	0.0	0	2.3	1
skilled	18.6	8	7.0	3
professional	2.3	1	0.0	0
not working	2.3	1	67.4	29

Rehabilitation:

The average time spent in acute care was 69.6 days, ranging from 0 to 624. The length of time spent in post-acute care ranged from 0 to 260 weeks, with an average of 31.2 weeks. Many of the subjects (60.5 %) had been involved in some form of community based rehabilitation, once they had been discharged from an inpatient setting. This included traditional rehabilitation outpatient services (primarily physiotherapy), specialized brain injury programs (such as Head Injury Relearning Centre, Rebuilding, Glenrose Brain Injury Program), general programs for a variety of disabilities (Beehives, Life Skills) and individual rehabilitation in the home (homecare, rehabilitation worker). The majority of subjects (72%) had been involved in a support group, usually offered through one of the Alberta Brain Injury Societies.

Methods and Procedures:

Screening:

All participants were screened for severe cognitive impairment using the Mini-Mental Status Examination (MMSE) (Folstein, Folstein & McHugh, 1975) at the initial meeting. The scores on the MMSE ranged from 21 to 30 with an average score of 26.93 (SD = 2.63). None of the individuals scored less than 20 on the MMSE, a score which would have indicated cognitive deficits severe enough to impair their ability to provide valid information on questionnaires.

Interview schedule: Pilot interviews with three subjects were done. The Wide Range Achievement Test - Revised (Jastak & Wilkinson, 1984) was administered to determine if their reading levels were adequate to read the questionnaires themselves or whether the questions should be read to them. The three pilot subjects did not have adequate reading proficiency and therefore the interviewer read the questions to the subject and the proxy. The subject and the proxy were positioned so that they could hear the interviewer but they were unable to see each other when completing the questionnaires. As there were no changes in the subsequent protocol, the data from the pilot subjects were included in the study. The interviews took an average of one and a half hours to complete. The measurement instruments were given in the order in which they are described below.

Measurements:

The Sickness Impact Profile: This measure was developed by Bergner et al. (1981) was used to measure the impact of brain injury on the physical and psychosocial dimensions of function. The SIP is rated at a Grade 5 reading level. The SIP questionnaire consists of 136 items grouped into 12 categories. Three categories (Ambulation, Mobility, Body Care and Movement) are aggregated into a physical dimension; four other categories (Social Interaction, Communication, Emotional Behavior, Alertness Behavior) are aggregated into a psychosocial dimension. The remaining groupings (Eating, Work, Sleep and Rest, Household Management, and Recreation and Pastimes) are independent categories. Since the last revision in 1981, the SIP has been widely used with various conditions, demographic and cultural subgroups.

DeBruin et al. (1992) reported satisfactory test-retest reliability with correlations ranging from .90 to .91 on physical dimension scores, .79 to .87 on psychosocial dimension scores and .75 to .92 on overall scores. The internal consistency of the SIP shows that the overall instrument (.91), the psychosocial (.84) and physical (.90) dimensions and the separate categories (.74) have sufficiently high alphas. Cronbach's reliability coefficient for the total score in the current study was .93. The categorical structure of the SIP and its robustness permits measurement of specific dimensions of functional status or behavior (DeBruin et al., 1992). The SIP appears to have satisfactory validity. DeBruin et al. concluded that SIP scores measure a concept in which psychological factors play a part, but are not dominated by them. The SIP displayed sensitivity in detecting small changes in health over time (Bergner et al., 1981) and the effects of recovery with TBI over time (Temkin et al., 1988). The SIP correlated with overall function at 1 year (.71) and has been able to differentiate individuals with TBI versus control groups (Temkin et al.; Temkin et al., 1989).

The SIP has been used as a self-administered questionnaire providing reliable and valid data (DeBruin et al., 1992). The interviewer-delivered self-administered form of the SIP showed consistently higher correlations with other measures of dysfunction and sickness than interviewer-administered SIPs (Bergner et al., 1981). In this study, the questionnaire was interviewer-delivered and self-administered. As recommended, the interviewer read the instructions to both the subject and the SO, answered questions, and read each statement to assure comprehension.

Community Integration Questionnaire: Global community integration was measured using the Community Integration Questionnaire (Willer, Linn, & Allen, 1994), designed specifically for individuals who have suffered a brain injury. The reading level of the CIQ is Grade 10. The CIQ consists of 15 items each with a choice of responses. The items are grouped into three categories: home integration, social integration, and productivity (refer to Appendix F for items). The CIQ has acceptable internal consistency (.76) for the overall CIQ (Willer, Linn, & Allen). With this sample of subjects, the Cronbach's reliability coefficient for the overall CIQ (total) scores was .45, indicating low internal consistency. The test-retest reliability coefficient for the CIQ administered with an average of 10 days between assessments ranged from .91 to .97 for the total score, and from .83 for productive activities to .97 for home integration. Correlation coefficients between patient and significant other ranged from .74 for social integration to .96 for productive activities. The CIQ differentiated between disabled and non-disabled populations, except for females on the home integration subscale (Willer et al.) The overall CIQ scores between females and males with TBI did not differ significantly. The overall CIQ scores demonstrate that individuals with TBI are significantly less likely to be integrated than those who have not experienced a TBI. The subjects with TBI and the significant other were given the instructions for the CIQ together and they then completed the CIQ with the interviewer reading each item with the possible responses.

The Quality of Social Support Scale : The significant other was asked to leave during this part of the interview to allow the subject to be free in commenting on social support. Subjects were asked to name all the people to whom they would go for support or help if they needed it and indicate the type of relationship, i.e., spouse or partner, family member, friend, co-worker, professional, religious leader, or support group. This information was not analyzed. The question gave them an opportunity to reflect on the people in their lives who provided some type of support, prior to administering the perceived social support measure.

The Quality of Social Support Scale (QSSS) was developed for a telephone interview by Goodenow, Resine & Grady (1990) was used to measure perceived social support (see Appendix H). The reading level of the QSSS is rated as Grade 7. The QSSS consists of 17 statements related to the support received from others which subjects rate on a Likert-type scale. The items are not categorized into subscales, rather a single score is calculated. The total score can range from 17 (no social support) to 68 (complete social support). The scale includes several dimensions of social support: information and feedback, task assistance, opportunity for confiding, physical affection, affirmation and relationship strain (Goodenow et al.). Cronbach's alpha for the QSSS with individuals with rheumatoid arthritis was .87, similar to the reliability coefficient found in this study of .85. Preliminary evidence of concurrent and discriminant validity was demonstrated with two instruments: the Arizona Social Support Interview and the Global Adjustment to Illness Scale indicating that the QSSS captures the concept of social support and can discriminate individuals in adaptation to illness (Fifield et al., 1988). The interviewer read each statement followed by potential responses to the subjects who indicated one of four responses typed on a card.

Life Satisfaction Index-A: The 18 item version of the Life Satisfaction Index-A (LSIA) (Adams, 1969), modified from the original LSIA scale developed by Neugarten, Havighurst and Tobin (1961), was used to measure life satisfaction. The LSIA is rated as a Grade 5 reading level. Internal consistency is reported as .90 (Edwards & Klemack, 1973), .84 (Wolk & Kurtz, 1975) and .82 (this study). Neugarten et al. conceptualized the original scale as measuring various components of life satisfaction. Factor analysis confirms the multi-dimensional nature of the scale with an elderly group. The central concepts identified are mood tone, zest for life and congruence (Adams, 1969; Hoyt & Creech, 1983). Factor analysis has not been done using a sample of younger individuals. The LSIA correlates well with other measures of life satisfaction in a geriatric population (Lohmann, 1977). This study used the three point scoring system for the LSIA. Scores can range from 0 to 36, with the highest score indicating maximum life satisfaction.

The LSIA was chosen for a number of reasons. Although the LSIA scale was originally developed as a multi-dimensional measure of life satisfaction for elderly persons (Adams, 1969), it has been used in an extensive survey examining life satisfaction of Americans over age 18 (Louis Harris & Associates, 1975). The LSIA has been used to measure life satisfaction of a group of individuals with spinal cord injuries (SCI), ranging in age from 19 to 77 years old (M = 37) (Fuhrer, Rintala, Hart, Clearman, and Young,1992). They reported a negative relationship between life satisfaction as measured by the Life Satisfaction Index-A (LSIA) (Adams, 1969) and the degree handicap as conceptualized by the WHO model. Although the LSIA has not managed to overcome the conceptual uncertainties common to measurements of this type, it appears to be more thoroughly evaluated than other instruments. A review by McDowell & Newell (1987) indicates that the scale has adequate psychometric properties including reliability, concurrent validity and some construct validity. The interviewer read the instructions and each statement of the LSIA and the subjects checked the appropriate column.

Disability Rating Scale: The level of disability was categorized according to the Disability Rating Scale (DRS) developed by Rappaport et al. (1982). Eight dimensions of ability are rated and the cumulative total score is classified into four categories of disability. The levels of disability are mild (DRS = 1 - 3), moderate (DRS = 4 -6), severe (DRS = 7 - 20) or very severe (1 - 29) (Cope, Cole, Hall, Barkan, 1991). Several studies on DRS report high interrater reliability ranging from .87 to .98 (Holosko & Huege, 1989; Gouvier et al., 1987; Rappaport et al.) and test-retest reliability of .98 (Gouvier et al.). The interviewer completed the DRS with the significant other immediately after each interview was conducted (see Appendix M). Based on their responses, the subjects' disabilities ranged from none to severe, with the majority categorized as mild to moderate (see Table 4).

Chapter IV. RESULTS

The results of the investigation are presented in this chapter. Data was analyzed using Statistical Package for Social Sciences (SSPS Inc., 1986) with the alpha level set at .01 to reduce the potential for an inflated incidence of Type 1 errors (Ottenbacher, 1983). Summary statistics (e.g., percentages, frequencies, means, standard deviations, and ranges) are presented for each of the self-report measures (see Table 6). The results are compared with existing normative data using t-tests as this was the only method of analysis possible.

Scores on the Life Satisfaction Measure

The mean score on the LSIA measure of 20.19 found in this study was significantly different (t (1, 41) = 5.4, $p < .01$) from the mean LSIA score of 26.7 found by Louis Harris & Associates (1975). The findings indicate that this sample of subjects was less satisfied with their lives than a comparison group of non-disabled adults. Individuals with TBI are similar to those with SCI in that both groups come from a similar at-risk population and experienced a traumatic event (potentially life threatening) typically in early adulthood which led to significant changes in abilities and frequently life roles (Brooks, 1991). therefore a t-test was used to compare this sample's mean LSIA score with the mean score of 17.6 in the Fuhrer et al. (1992) study of persons with SCI. The difference was not significant; t(1,42) = 2.15, p= .05.

Subjects' scores on the Quality of Social Support scale:

The mean score of 52.8 on the QSSS (which has a maximum of 68) indicates that most subjects did feel supported by others most of the time. The mean is similar to the mean score of 54.3 found in a study of 194 women with rheumatoid arthritis (Goodenow et al., 1990). No other group was available for comparison purposes.

Scores on the Sickness Impact Profile:

The mean scores for subject and the proxy on the SIP measure are described in Table 6 and Figure 1. The psychosocial area was twice as likely to affected relative to the physical dimension.

T-test comparisons of this sample with another sample of individuals with TBI (McLean et al., 1993) were performed. The Alberta sample did not differ significantly from the comparison group on physical and total dysfunction. The Alberta mean score (M=22) on psychosocial dysfunction was significantly greater (t(1,42)=6.1, $p < .01$) than the comparison group (M=6). This Alberta sample differed in the severity of injury from the comparison group studied by McLean et al. which was characterized as having less severe injuries on average according to the GCS (60% mild, 11% moderate, and 29% severe) and the subjects were only one year post-injury.

Scores on the Community Integration Questionnaire

The mean scores for the subjects' and the proxies' CIQ totals and subscales are described in Figure 2. A t-test comparison was performed between the CIQ scores from this sample and scores reported in a study which included one sample of non-disabled individuals (Willer, Ottenbacher, & Coad, 1994). The mean CIQ total score of 18.9 in this Alberta sample was significantly lower than the mean score of 20.7 for the non-disabled group (t(1,42)= 8.9, $p< .01$). The comparison group of adults with no disabilities were slightly younger and a greater percentage of them had completed high school.

The available data in the 1993 study by Willer et al. using the CIQ measure with two groups of individuals with TBI is described in Table 8 along with this Alberta sample. The latter group was comparable to the Ontario community sample of 352 subjects with age, years since injury, and severity of injury.

TABLE 6

Mean scores on measurement instruments

MEASURE:	M	SD	minimum	maximum
Life Satisfaction Index	20.2	7.9	6	33
Quality of Social Support	52.8	8.9	30	67
Sickness Impact Profile (subjects' ratings)				
Physical dysfunction	12.4	13.5	0	52
Psychosocial dysfunction	22.2	17.5	0	73
Total SIP	18.4	13.0	0	59
Sickness Impact Profile: (proxies' ratings)				
Physical Dysfunction	13.6	14.9	0	54
Psychosocial Dysfunction	25.4	18.8	0	77
Total SIP	20.0	13.6	1	57
Community Integration Questionnaire: (subjects' ratings)				
CIQ total	18.9	4.3	10	28
Home Integration	5.8	2.8	0	10
Productivity	4.9	2.8	0	11
Social Integration	8.5	2.0	0	12
Community Integration Questionnaire: (proxies' ratings)				
CIQ total	19.1	4.8	7	11
Home Integration	5.8	3.1	0	10
Productivity	4.5	2.5	1	11
Social Integration	8.7	1.8	5	12

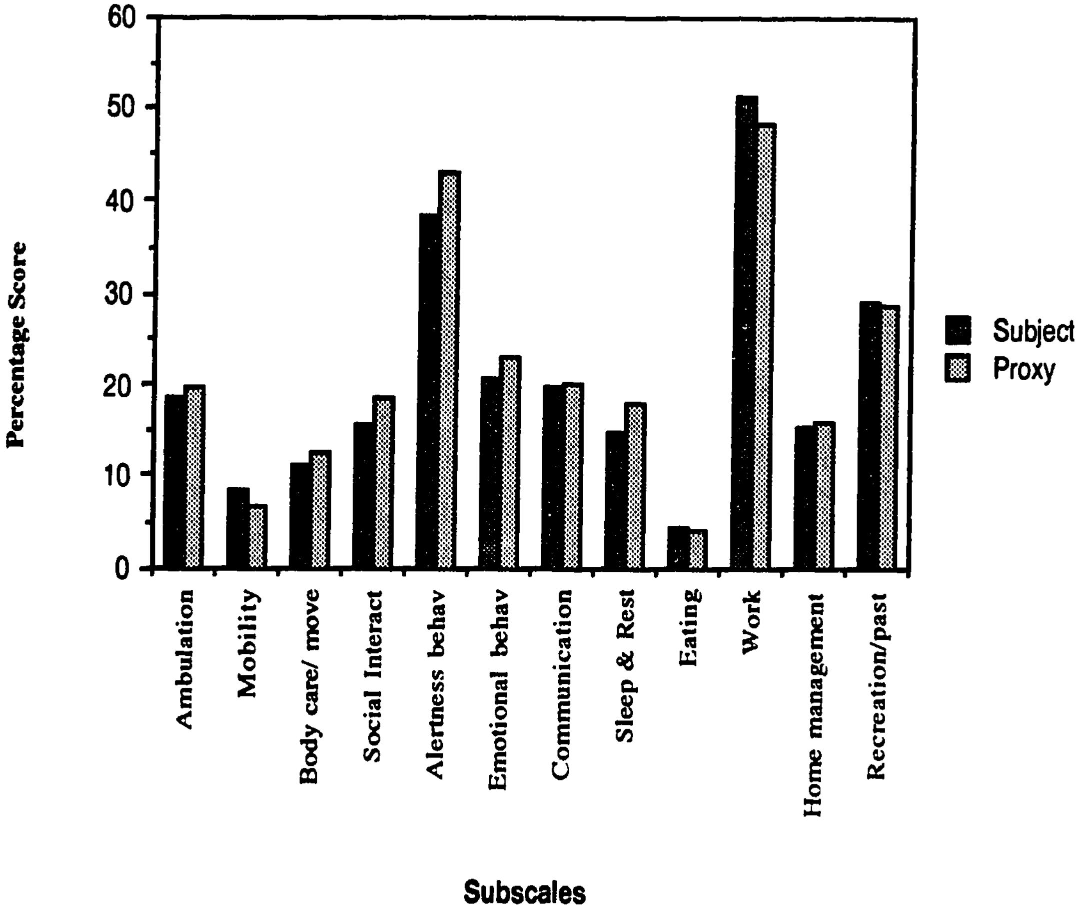

Figure 1. Mean percentage scores of subject versus proxy on the Sickness Impact Profile subscales.

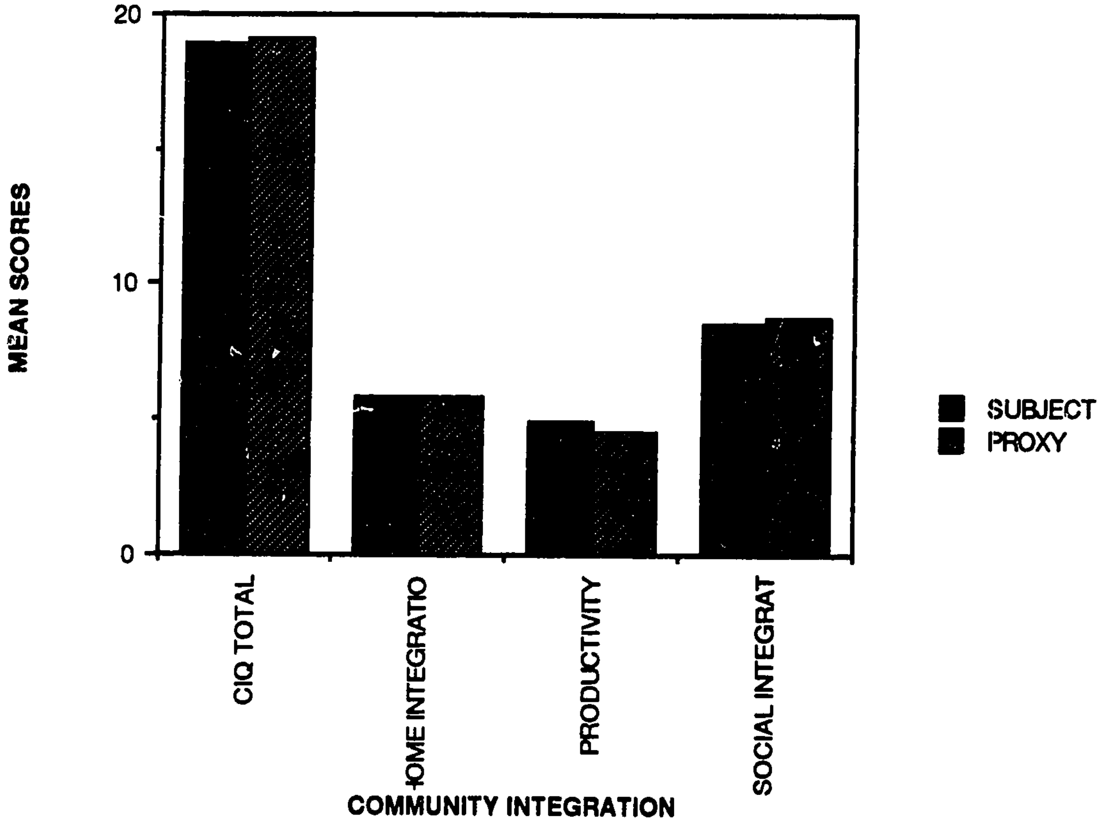

Figure 2: Mean scores of Community Integration Questionnaire subscales and total for subject versus proxy.

Hypotheses

The hypotheses were tested using a one-tailed test. The correlation matrix between the four measures used in this study is found in Table 7. The results are as follows:

1. A correlational analysis was used to determine if there was a positive relationship between perceived social support and life satisfaction. The correlation between these two measures was .49, significant at $p = .002$.

2. A correlational analysis was used to determine if there was a positive relationship between community integration and life satisfaction. This hypothesis was not supported using the subjects' CIQ rating in that the correlation between these two measures was not significant $r = .16$, $p = .31$.

3. A correlational analysis was used to determine if sickness impact scores were negatively associated with level of community integration. This hypothesis was not supported using the subjects' SIP ratings in that the correlation between the total scores on these two measures was -.22 ($p = .16$). The CIQ productivity subscale score was negatively correlated with the SIP physical dysfunction ($r = -.48$, $p = .001$).

4. A correlational analysis was used to determine if perceived social support would be positively associated with the level of community integration. This hypothesis was not supported ($r = -.06$, $p = .71$).

5. A multiple regression analysis was used to determine if sickness impact scores and perceived social support would be predictive of the level of community integration. Neither of the two measures accounted for a significant proportion of the variance found in the subjects' CIQ scores.

6. Multiple regression analyses were used to determine if perceived social support and the level of community integration would be predictive of life satisfaction. The results of the multiple regression analysis can be found in Table 8. This hypothesis was supported in that the LSIA variance accounted for by the two measures was .25, although the QSSS was the only independent variable statistically significant.

TABLE 7

Correlational analyses between self report measures

	SIP Psycho-social	SIP Total	CIQ Home	CIQ Social	CIQ Product-ivity	CIQ Total	QSSS	LSI-A
SIP Physical	*.53	*.83	-.16	.08	*-.48	-.32	.02	-.26
SIP Psycho-social		*.89	.10	.03	-.20	-.03	-.23	.16
SIP Total			-.02	.03	*-.39	-.22	-.15	*-.44
CIQ Home				.26	.02	*.69	-.15	-.15
CIQ Social					-.13	.52	.27	.09
CIQ Product-ivity						.49	-.09	.09
CIQ Total							-.05	.15
QSSS								*.47

*p < .01

TABLE 8

Multiple regression LSIA: 2 independent variables (QSSS, CIQ)

LSIA: $R_2 = .25$

	B	Beta	T	Significance
QSSS	.32	.48	3.5	.001
CIQ	.34	.19	1.4	.183

7. Correlational analyses were done to determine if the subjects' perception of their level of sickness impact (SIP) and community integration (CIQ) was positively associated with their significant others' perception. Correlation coefficients between the two sources of information are: .84 for SIP physical dysfunction, .56 for SIP psychosocial dysfunction, .69 for SIP total, .87 for CIQ home integration, .70 for CIQ productive activities, .42 for CIQ social integration, and .57 for CIQ total. All correlations were significant at $\underline{p} < .01$ except social integration. A Hotelling T_2 test with 5 dependent variables (3 CIQ subscales and 2 SIP subscales) revealed no significant differences between the means for the subjects' and proxies' scores. $\underline{F}$ (5,84) =.287, $\underline{p} = .91$.

Supplementary Analysis

Associations between demographic variables and measures

Correlational analyses were done to see if there was any associations between the demographic characteristics (age at injury, time since injury, education, mental status) and the measures (see Table 9). Only two correlations were significant. The subject's age at injury and quality of social support measure were negatively correlated (r = -.44, p = .003) indicating that the younger the individual when injured the more perceived social support. The scores on the MMSE negatively correlated with the QSSS measure (r = -.50, p = .001), indicating the greater the cognitive impairment, the lower the perceived quality of social support.

Associations between life satisfaction and sickness impact scores

Although a direct association between sickness impact as measured on the SIP and life satisfaction was not hypothesized, overall life satisfaction could be affected by the perception of loss of abilities on a personal level. A significant negative correlation of -.51 ($p < .001$) between the subjects' SIP subscale of psychosocial dysfunction and the LSIA scores was found. Given that there was a significant association between the SIP scores and the LSIA scores, the SIP and the QSSS scores were used as an independent variables to regress on the dependent variable of LSIA. The subjects' SIP scores and QSSS scores accounted for 34.6% of the variance of the LSIA scores. Both independent variables were significant as described in Table 10. The SIP psychosocial subscale and the QSSS scores accounted for 37.5 % of the variance of the LSIA scores. Both independent variables were significant, with the psychosocial scores accounting for slightly more variance in the LSIA relative to the QSSS scores.

Living Arrangements

The living arrangements were examined to determine if this was associated with the outcomes on the level of community integration. A Hotelling's T_2 test with 3 dependent variables (CIQ subscales) found a significant difference between the mean scores for subjects living alone, subjects living with spouse, and subjects living with family, F(6, 64) = 3.07, p = .01). The only significant univariate F - test was on the home integration subscale F(2,35) = 8.19, p = .001. A post-hoc Scheffe test found that subjects living alone scored significantly higher (M = 20.9, SD=3.9) than both subjects living with spouse (M = 18.5, SD=3.3) or living with parents/family (M = 18.0, SD=4.7) and the latter two groups were not significantly different.

TABLE 9

Correlational analyses of measures and demographic information

	CIQ	SIP	QSSS	LSIA
Age at injury	-.27	.17	*-.44	-.19
Months since injury	.20	-.13	.09	.06
Education level	.13	.05	-.09	.06
Days in coma	-.21	-.28	.19	-.03
MMSE	.12	-.09	*-.50	-.03

MMSE:	Mini-Mental Status Examination
CIQ:	Community Integration Questionnaire
SIP:	Sickness Impact Profile
QSSS:	Quality of Social Support
LSIA:	Life Satisfaction Index -A

* p < .01

TABLE 10

Multiple regression LSIA: 2 independent variables (QSSS, SIP)

LSIA: $R_2 = .36$

	B	Beta	T	Significance
QSSS	.36	.41	3.12	.001
SIP	-.21	-.35	-2.63	.012

Chapter V. DISCUSSION

The purpose of this study was to investigate quality of life for traumatically head injured adults living in the community. This was done by the investigation of four variables from the perspectives of the survivors and their significant others. The four variables included life satisfaction of the survivors, their degree of community integration, their perceived social support, and their perceptions of sickness impact. In the following chapter the results of the study are discussed and placed within the context of the literature reporting studies of person with TBI and the underlying theory guiding the study. Implications for intervention are discussed.

Life Satisfaction

Quality of life has been defined as an individual's overall satisfaction with life and a general sense of personal well being. A multi-item single measure, such as the LSIA provides a global view of the client's life satisfaction. It does not, however, provide specific reasons for different levels of life satisfaction Identifying factors which are associated with life satisfaction may lead to a better understanding of how clinicians can facilitate positive change in the quality of life for the individual with TBI.

Given that individuals with TBI typically experience several losses of previously acquired abilities and psychosocial roles, they are expected to be less satisfied with their lives than individuals living without the challenge of disabilities. Overall, this was the case in this study. However, several individuals had scores on the life satisfaction which were actually higher than the average individual in the comparison group of non-disabled individuals. Factors which are associated with these variations in life satisfaction may provide insight into areas of the client's life which could be altered by rehabilitation intervention to indirectly enhance their satisfaction with life.

The degree of the impact of injury in the psychosocial area as measured on the SIP was significantly associated with an individual's life satisfaction, indicating that the greater the psychosocial dysfunction, the less satisfied they were in their global appraisal of their life. The association between physical dysfunction and life satisfaction was not as strong. The results suggest that people who were more satisfied with their life perceived less psychosocial dysfunction. An alternative explanation is that health or lack thereof (i.e., disability) is an important factor in overall perceived quality of life. The scores on the SIP reflect directly the individual's disability and indirectly the individual's handicap or role losses which are essential in the measurement of quality of life (Spitzer, 1986). The most problematic residual difficulties for individuals with TBI are in the psychosocial area which appear to have a pervasive effect on the individual's life. The ratio of psychosocial to physical dysfunction was approximately 2 to 1, similar to the recovery pattern reported in the literature (McLean et al., 1993; Temkin et al., 1988), suggesting that a greater degree of psychosocial dysfunction is identified relative to physical dysfunction in the long-term outcome. Psychosocial skills are required to meet the demands associated with assuming social roles which in turn provide opportunities for meeting basic needs of self-worth, meaningful existence, and social affiliation. The impact of psychosocial deficits on an individual's ability to fulfill basic needs may contribute to the strength of this association to life satisfaction. These results corroborate the conclusions of a meta-analysis of 124 studies which found that health and subjective well-being were positively correlated (Okun, Stock, Haring, & Witter, 1984).

The impact of TBI on the individual's abilities did account for some but not all of the variation in life satisfaction. An environmental factor was also associated with these variations in life satisfaction. Survivors who reported higher levels of life satisfaction perceived a better quality of social support. This relationship could be bidirectional. As quality of social support increases so does life satisfaction or alternatively as life satisfaction increases, an individual may socialize more and subsequently perceive more social support.

Life satisfaction was not associated with the general level of community integration (CIQ) nor with the social integration subscale of the CIQ. The CIQ measures integration in terms of quantity and not quality of social interactions. The CIQ does not assess the degree of satisfaction the individual feels over integration outcomes or the personal relevance of the activities. The CIQ measures the level of independence and social contacts quantitatively but not the qualitative aspects of doing these activities nor does it assess integration skills (mastery). For example, one question on the CIQ asks "who usually looks after your personal finances?" (Willer, Linn, & Allen, 1994). The questionnaire does not ask how successful these transactions are, nor whether the individual has the organizational skills to manage his/her funds, nor if the individual is satisfied with how finances are managed. Other studies with different populations have also found that perceived quality of social support and not quantity is the salient factor (Fuhrer et al., 1992; Goodenow et al., 1990; Shulz & Decker, 1985). Therefore, clinicians need to consider the quality of social support when addressing the social needs of clients with TBI to facilitate meaningful social contacts in the community.

Community Integration:

Willer et al. (1993) indicate that the fairest assessment of community integration includes three domains of role function: home integration, social integration and productive activities. The authors suggest that the activities associated with these three areas reflect the values and goals of both disabled and non-disabled individuals in our society. They are seen as essential for meeting role expectations thereby creating a sense of personal satisfaction. The expected degree to which an individual participates in these activities with reintegration varies according to the individual's previous level of integration.

In this study the individual's perceived physical and psychosocial dysfunction as measured by the SIP was not significantly related to their level of community integration as measured on the CIQ. The only significant association was between the productivity subscale of the CIQ and the physical dimension of the SIP; in other words, the more integrated the individual was in productive activities, the less perceived physical dysfunction. Most study participants did have psychosocial and cognitive dysfunction which would naturally affect their employability. However, as the findings suggest, level of productivity (including paid and unpaid work) varied significantly only with the addition of differing degrees of physical dysfunction. One explanation is that prior to their injury, 72% of these individuals were employed in unskilled or semi-skilled jobs (Table 7) which typically require intact physical functioning. Many individuals did attempt to return to their premorbid employment; however, in addition to difficulties meeting the psychosocial demands of their job, their physical functioning was an important determinant of whether they could manage the physical requirements of the job. Those individuals whose cognitive deficits limited their return to employment of a skilled or professional nature were also be restricted to jobs which relied on performing physical tasks. Therefore, in these cases the degree of physical dysfunction again becomes an important factor in their ability to secure and maintain work.

The CIQ is currently the best simple scale available to assess the level of functional independence in the community for persons with TBI (Hall & Johnston, 1994). However, one limitation of the CIQ as a measurement of community integration is that the individual may not have done an activity independently prior to their injury, but would score lower on the CIQ if they were not engaged independently in the activity at the time of the interview. For example, many activities such as shopping, or bill paying may have been shared with a spouse pre-injury. If the individual does resume sharing a task in the same manner as they had managed the activity pre-injury, according to the CIQ measure, the individual would be less integrated. Successful community integration should relate to the restoration of an individual to his/her preinjury status. The CIQ does not use the premorbid functioning as a reference to judge current functioning.

The stronger association of life satisfaction with the sickness impact profile as compared to the community integration measure may be reflective of the emphasis of the SIP on the individual's subjective opinion of the changes in behaviors as a result of the TBI. In order to overcome this limitation of the CIQ, Hall & Johnston (1994) recommend that a retrospective pre-injury assessment be incorporated to use as a baseline by which current status could be compare. Alternatively, a scoring method which would encompass current level of community integration relative to premorbid functioning should be developed to enhance the utility of the CIQ measure.

Although not hypothesized, living arrangements appear to have an effect on one aspect of integration, namely, the degree of home integration. Individuals who lived alone versus those who lived with someone else were rated as more integrated into the home activities. Although it is natural to assume that these individuals lived alone because they were able to manage their household activities, the individuals who lived with a significant other may in fact be able to perform equally as independently in home activities if the family division of roles and labor required them to do it, if there was no one to do it for them, or they were encouraged to do so. The significant other may do things for the injured individual for efficiency. This may unintentionally limit the injured individual's integration into home activities and their chance of regaining skills for independent living. Whether or not an individual with TBI lives with a significant other post-injury is not determined solely by the degree of their residual problems, but rather by the existing social network the injured individual has established prior to their injury. Members of the social network can vary considerably by factors such as their degree of altruism, obligation, protectiveness, and control towards the injured individual. The social response to take care of an individual recovering from any illness or injury is natural, however, dependency can be fostered if this is prolonged. An injured individual should be put in situations of less reliance on significant others to facilitate more independent living. If they cannot cope with this independence, then a more supportive living situation could be orchestrated.

Social Support:

The results indicate that on average these individuals felt supported by their social network. Several respondents reported that they would not have done so well without these supports. The social supports that the subjects identified typically included a professional in the formal support network; and four individuals identified them as their significant other which was allowable given the definition of significant other. However, many of the key persons identified were family and non-kin sources of support. The findings suggest that more perceived social support was associated a greater degree of life satisfaction. This is similar to the results of a study by Holosko and Huege (1989) of a group with TBI with comparable characteristics on the DRS and who were on average, 5.5 years post injury. Their research suggested that social support seems to be an important variable in adjustment to major life changes and community integration of individuals who become disabled by life threatening trauma. Smith (1979) found that informal social networks such as family, friends, and community associations were instrumental in individuals' social adjustment after a cerebral vascular accident. Similarly, in this study perceived social support was associated both with level of social integration in the community and life satisfaction.

The greater the individual's cognitive dysfunction, the less the individual's perceived social support from the environment. Individuals with more severe cognitive deficits and personality changes would most likely have more difficulty resuming and sustaining social relationships and therefore perceive less support. Another explanation for this finding is that individuals with greater cognitive deficits and personality changes may have a greater need for social support. This need may not be fulfilled to their desired expectations even though they may have equivalent support to someone with less severe deficits.

The younger the person was at the time of injury, the greater their perceived social support. Although the influence of age and patterns of support was not examined specifically in this study, the impression during the interviews was that younger individuals (at the time of injury) were often more reliant on parental involvement especially during the initial stages of recovery compared to older individuals. Many of the younger males identified their mother as a key social support, whereas their friends had gradually stopped visiting. Kozloff (1987) found that the pattern of dependency on primary kin to meet social and financial needs gradually increases over time and can often create strain in the family. A parent-child relationship is typically one in which there is an inherent expected dependency from the child on the parent, which may allow the younger injured individual to return to dependency on parents than an older individual. Individuals who are older at the time of injury often have established significant relationships with spouses and friends. They typically receive less support from their aging parents (Kozloff, 1987). The transition from a relationship of expected reciprocity to one of dependency over an extended period of time by one individual on another can increase relationship strain. This may account for the differing perceptions of perceived social support between older and younger individuals.

Subject and proxy reporting on SIP and CIQ:

The results of this study suggest that meaningful information about sickness impact or illness behaviors can be obtained from two different sources, i.e. self and proxy. The subjects' scores were non-significantly lower, i.e. less reported impact, than the proxy scores in all three dimensions of the SIP. Some studies have found that some individuals with TBI tend to underestimate the functional effects of cognitive, emotional and other deficits when compared to relatives' perception (McKinlay & Brooks, 1984). The results also suggest that meaningful and similar information on community integration can be obtained from two different sources, i.e. self and proxy. Therefore, clinicians should obtain information from both the individual with TBI and significant others when possible to obtain a more global perception of both the impact of the injury and level of community integration.

Occupational Performance Model

The Occupational Performance model provided the framework to examine how subjective quality of life interacts with an individual's ability to integrate everyday activity/occupation into roles and functions within the context of the social environment. The findings indicate that subjective quality of life (self-assessed life satisfaction) is related to the degree of dysfunction in the psychosocial dimensions following traumatic brain injury and the perceived social support available.

The O.P. model is based on the belief that an individual's social, physical, spiritual and mental well being is promoted through active participation in performing tasks, or directing others on one's behalf, in purposeful activity/occupation (Townsend et al., 1990). This may provide a theoretical explanation for the minimal association between life satisfaction and level of community integration as measured. The CIQ proved not to be compatible with the O.P. model. If the person did not do the activity themselves then someone else either assisted with an activity or did the task for them. This would result in lower CIQ scores but a higher life satisfaction score because this help permitted the need of the subject to be met. In cases where someone else assists or manages certain activities which are viewed as unimportant to the individual, then again the individual's life satisfaction will not be affected. It is important to remember that all of these subjects were able to live in the community, although there was no comparison group living in an institution in this study. The findings support the client-centered approach of the O.P. model and highlights the importance of acknowledging the client's value system and their personal priorities.

The subjective quality of life as measured by life satisfaction can be viewed as an individual's global appraisal of their life or general well-being (Fuhrer, 1994). It is therefore compatible with the model's definition of spirituality (CAOT & DNHW, 1991). Spirituality is best considered to be pervasive to the individual's occupational performance rather than a component which requires interaction with other elements to produce an effect. Rather than being a specific performance component, performance area, or environmental influence, the quality of life becomes a client-centered view of their integrated occupational performance.

Client-centered practice is the cornerstone of occupational therapy interventions (CAOT & DNHW, 1991). The concept of client-centered focus has been applied in this research to examine quality of life. The individual with TBI ultimately is the only one who can gauge their life satisfaction and how they perceive their social support. Their perceptions and level of satisfaction must be of equal consideration in judging functional status. This shifts the global evaluation of quality of life from the health care provider to the individual client. The client's view then provides important feedback to service providers and also directs the process of rehabilitation.

Changes in psychosocial roles and function following a TBI have a pervasive effect on the gestalt of an individual's life and subsequently have a substantial impact on subjective quality of life. A major role change for individuals with TBI experience is a loss in their productivity roles along with the supplementary benefits such as income, prestige, identity, mastery, and a sense of accomplishment. In this sample, over two thirds of individuals had not resumed steady employment post-injury. Rehabilitation strategies must optimize the client's chances to gain some form of productivity role. Often residual psychosocial dysfunction is problematic in the work place and strategies to improve social skills use are needed. The association between physical dysfunction (SIP) and the individual's level of productivity, suggests that practitioners should not overlook the physical dimensions. Given that there is minimal physical recovery to be gained several years post-injury, a focus on reducing barriers in the physical and social environment to accommodate the client's physical deficits may increase the chances of attaining paid employment.

The Occupational Performance model identifies the social influence within the socio-cultural environment of the individual. As seen in this study, there is a strong relationship between perceived social support and life satisfaction. The results revealed that survivors of head injury were able to acknowledge social supports in their lives, and the help extended to them was perceived as generally positive. The client's perception of strain in relationships and social support in the environment may directly impact resources that the individual uses to cope with community living.

The social element is also acknowledged on the individual level as a basic performance component. There is an interplay between the social component and the social environment. The individual has social needs and through occupation have developed a level of social skills. These are expressed through interaction within their environment. The individual's social skills are affected by a variety of behaviors some of which are a result of personality change. The environment specifically provides the "other" required for social engagement. It is through social interaction (verbal and non-verbal) that support is received contributing to the sense that someone else is available for support. The social interaction also provides encouragement, prompts and the cueing which can increase the level of occupational performance through greater engagement with the environment. Engagement in occupational performance areas (actual or directed) provide feedback to the individual and is fundamental to a sense of internal satisfaction and mastery. The findings are in keeping with the Occupational Performance model in that occupational performance components and the socio-cultural environment affect chances to engage in self-care, productivity and leisure.

The importance of the relationship of social support with life satisfaction indicates that therapists need to provide specific treatment strategies to develop the social skills of the individual with TBI to enhance their social interaction effectiveness and reduce social isolation. As well, professionals should look at how these supports may be integrated into treatment and program planning. The model alerts professionals to address the social element in goal setting with the client and program planning to achieve social abilities necessary to engage successfully in psychosocial roles in the community. Meaningful engagement with the social, cultural, and physical aspects of the environment are essential to derive a positive sense of well-being.

Assumptions and Limitations:

This study assumes that the sample is representative of survivors of severe TBI living in Alberta communities, as there was insufficient representation of individuals with mild and moderate TBI. Although a sample of convenience may limit the generalizability of results, this group is typical of the literature's description of the type of patient with TBI seen in rehabilitation. Comparison to other studies of persons with TBI has helped to address the limitation due to having no control group. Individuals were recruited through community agencies that had provided some support for the survivors or their families, therefore introducing an inherent bias in the sample. The study does not examine the reasons for the pattern of integration, but rather gives a snap shot of community integration outcome indicators several years post-injury. There was a finite number of indicators of outcomes which embody widely held societal values and represent common ground between clients and society. There may be other factors which affect community integration and life satisfaction that were not measured.

CHAPTER VI. SUMMARY AND RECOMMENDATIONS

Summary

The quality of life for individuals with traumatic brain injury living in the community appears to be reduced. Often these individuals experience profound changes in their psychosocial role performance which may lead to social alienation. The WHO definition of health guides service providers to address the physical, mental and social well-being of individuals with a more holistic view of health. The Occupational Performance model provides a framework for occupational therapists to incorporate this expectation in their approach to service provision. The Occupational Performance model can provide a framework for developing research studies and interpreting the results.

A combination of measures is important to capture a holistic view of the rehabilitation outcomes for these individuals in a community setting. This study utilized measures of life satisfaction, sickness impact, perceived social support and community integration to evaluate dimensions related to quality of life. The findings are subject to inherent limitations of selecting a finite number of indicators. These instruments were assumed to be conceptually compatible with the Occupational Performance model, although the CIQ did not prove to be as compatible as expected. The results can increase our knowledge about quality of life and the application of functional abilities of survivors of TBI to achieve satisfaction in their life.

A primary difficulty in research with individuals with TBI is often the concern that this group may be unable to provide reliable and valid estimates of their situation. The client-centered approach was reflected in the focus on the individual's perceptions of their situation and their quality of life. A significant positive association between the perceptions of the survivor and the significant other about sickness-related behaviors and community integration demonstrates that both sources of information identified similar areas of dysfunction. Both the person with cognitive impairments and a significant other can provide judgements and understanding about areas of dysfunction which impact the life of the individual with TBI. Only in extreme cases or in early stages of recovery would client involvement appear unreliable, necessitating reliance solely on a proxy.

Rehabilitation has traditionally presumed that restoring functional independence yields a more satisfying life; however, as this data has suggested the level of independence in the community (CIQ) may not directly influence an individual's global appraisal of their life as measured by their life satisfaction. A definitive set of functional items may not capture the experiences of greatest importance to the individual, nor reflect their relative value perceived by the individual. Rather, each individual has a unique background of experiences and abilities which is often used as a reference to gauge recovery and adjustment and from which to view his/her current life. Therefore, it is important to incorporate the individual's perspectives. Health care providers can provide interventions and resources to assist the individual in reaching their optimum level of function relevant to their values and environment by involving the individual in goal setting. Client involvement and empowerment are especially crucial to maintain motivation in the rehabilitation process in the community and to sustain outcomes. The assessment and development of client autonomy in rehabilitation is a continuous process involving clinical skill and understanding of the individual's perspectives (Banja & Johnston).

Some individuals in the disability movement see themselves as normal individuals labeled as abnormal as a result of prejudices, architectural, and social barriers (Whiteneck, 1992). This is not to deny that handicaps occur in the presence of impairments or disability; however, in every case a handicap is identified, the external reference point is the society in which the individual lives. The Occupational Performance model includes environmental factors as an important influence in the outcome of impairment and disability which must be considered in program planning. The current study examined only one aspect of the social environment. The social, physical, and cultural environments can potentially present both opportunities and barriers to the individual with TBI to fulfill their psychosocial roles.

Recommendations for future study

The Occupational Performance model has provided a useful framework for the design and interpretation of results of this research study. Future research using the O. P. model will provide further empirical knowledge necessary to refine and or alter the concepts of the model. The results of this study have supported the use of subjective reports from individuals with traumatic brain injury as reliable sources of information.

Future more discriminative research on the interaction and role of environmental barriers (physical, social, and cultural) will be valuable to understand the external influences that modify occupational performance. Investigation into the concept of handicap, an externally influenced factor and the client's view of role loss is needed to clarify its relationship to quality of life.

The Sickness Impact Profile has proven to be a useful measure of physical and psychosocial dysfunction both from the perspective of the individual with TBI and of a proxy to identify the behavioral changes resulting from the injury. Clinically, this measure helps to target salient issues for the client which can then be used as a focus for goal setting. The outcome measurement of community integration may require a retrospective component to demonstrate a stronger link between the concepts of handicap and quality of life which was not achieved using the CIQ as is. In this study, perceived social support was utilized as an aggregate score of various types of social support. With larger samples, the effect of the different types of support which make up the Quality of Social Support scale could be examined. The differences between the patterns of social support and the effect of living arrangements on the level of integration could be explored further.

This study used a global measure of quality of life to capture an individual's general appraisal of their life in relationship to the occupational performance. Examination of both domain-specific and global measures of subjective quality of life simultaneously may provide further insight into the individual's occupational performance as it relates to the quality of life.

Based on this study, the following questions need to be addressed in future research:

1. What is an appropriate measure of community integration which is compatible with the Occupational Performance model?
2. What factors (intrinsic and extrinsic) induce identified members of social network to provide social support?
3. What are the productivity roles of the non-competively employed persons with TBI which contribute to life satisfaction?
4. Are there differences in life satisfaction between individuals living in the community versus in an institutional setting?
5. How does the make-up of the social network (relative proportion of kin versus non-kin) influence the individual's life satisfaction and perception of social support in the environment?

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APPENDIX A

SAMPLE SIZE CALCULATION

Power test (after Cohen & Cohen, 1983)
Ho: $R2 < .2$
Ha: $R2 \geq .2$

At a alpha level of .05 and a study power of .80, given 2 independent variables, $L = 9.64$.

$$F2 = \frac{R2}{1 - R2} = \frac{.2}{.8} = .25$$

Where K equals the number of independent variables and N is the number of subjects required:

$$N = \frac{L}{F2} + k + 1$$

$$= \frac{9.64}{.25} + 2 + 1$$

$$= 38.56 + 2 + 1$$

$$= 41.56$$

APPENDIX B: INTRODUCTORY LETTER

Dear

The University of Alberta and the ____________ are interested in studying the life satisfaction of persons after brain injury. We also want to know what activities they do in the community. This study will us understand what may affect quality of life. It will help us to improve programs.

The ____________ is contacting individuals living in the community. If you want to participate, someone will call you to set up a meeting. She will ask about the help you get from family and friends. You will be given three questionnaires. One is about your activities in the community. Another is about changes in yourself. One is about how you feel about life. The questions take about 1 1/2 hours. The interviewer will help if you don't understand. It can be done in your home or at the__________. We will also need some basic information from you. We would like to ask similar questions of someone who is close to you.

All information will be kept confidential. Only the researchers will see your responses. Any publications will only have group responses. If you want, you may have a summary of the findings. Your participation in the study is voluntary. Refusal or withdrawal will not affect the services you receive.

This study is very important to help improve the life satisfaction of people with brain injury. <u>We really need your help</u>. Thank you for your consideration. If you want to help with the study or if you have any additional questions, please phone Janet Smith at 454-4710. You can call collect if you are phoning long distance. Please leave your name and phone number after the recorded message. I will return your call as soon as possible.

Sincerely

Janet Smith
Graduate Student
Department of Occupational Therapy
University of Alberta

APPENDIX C: CONSENT FORM (SUBJECT)

Title: Community integration and life satisfaction after a traumatic brain injury.

Investigators:
Janet Smith, Masters candidate, Rehabilitation Medicine, University of Alberta. Tel. 454-4710
Sharon Brintnell, Professor and Supervisor, Dept. of Occupational Therapy, University of Alberta. Tel. 492- 2067
Joyce Magill-Evans, Professor, Dept. of Occupational Therapy, University of Alberta. Tel. 492-0402

Purpose: This study will look at things that may affect the quality of life for people after brain injury. You will be asked questions about the activities you do. You will also be asked about your feelings about life. The interview will take about 1 1/2 hours total time.

Consent:
I, ____________________, agree to participate in this.
I understand that my participation is voluntary. I may refuse to answer any questions. I may withdraw from the study at any time without any consequences. I understand that I may not benefit directly from the study.

I also understand that all information will be kept confidential. My name will not be on any of the questionnaires. A code number will be used instead. My name will not be used in any publications which may result from the research.

I am satisfied with the answers to my questions about the study. I understand what is involved in the study. At any time I will be free to ask further questions of the interviewer. I will receive a copy of this form. I sign this consent form freely.

______________________________ ________________
Participant's signature Date

In my opinion, this participant understands the requirements of this study.

______________________________ ________________
Interviewer's signature Date

APPENDIX D: CONSENT FORM (SIGNIFICANT OTHER)

Title: COMMUNITY INTEGRATION AND LIFE SATISFACTION AFTER TRAUMATIC BRAIN INJURY

Investigators:
Janet Smith, Masters candidate, Rehabilitation Medicine, University of Alberta. Tel. 454-4710
Sharon Brintnell, Professor and Supervisor, Dept of Occupational Therapy, University of Alberta. Tel. 492- 2067
Joyce Magill-Evans, Professor, Dept. of Occupational Therapy, University of Alberta. Tel. 492-0402

Purpose: This project will look at the factors that may affect the quality of life for people after brain injury. You will be asked to complete two questionnaires. One is about ___________'s daily activities. One is about how the brain injury has affected ___________'s behaviors. This will take about 1 hour.

Consent:
I, ____________________, agree to participate in this study. I understand that my participation is voluntary. I may refuse to answer any questions. I may withdraw from the study at any time without any consequences to my friend or my relative. I understand that neither I nor ______________may benefit directly from the study.

I also understand that all information will be treated confidentially. My name will not appear on any of the questionnaires. A code number will be used instead. My name will not be used in any publications which may result from the research.

I am satisfied with the answers to my questions about the study. I understand what is involved in the study. At any time I will be free to ask further questions of the interviewer if I want. I will receive a copy of this consent form.

____________________ ____________________
Participant's signature Interviewer's signature ________________

____
DATE DATE

APPENDIX E: INTERVIEW

Date of interview:____________

Socio-Demographic characteristics:

Column

1-3 Code I.D.

4 Gender: (1) female
(2) male

5-8 Birthdate: (month, year)

9 Relationship with "significant other"
(1) parent
(2) sibling or relative
(3) spouse or common-law
(4) friend
(5) other (specify)__________

10 Living with "significant other" (1) yes (2) no

11 Marital status
(1)_never married
(2)_married
(3)_common-law
(4)_formerly married: (separated,divorced, widowed)

12 Same marital status before TBI (1) yes (2) no

13 ____ Living arrangement:
(1) ___alone
(2) ___with spouse
(3) ___living with parents/relatives
(4) ___with hired attendant
(5) ___with friend

14 ____ Residence:
(1) room & board with family
(2) rent apartment/house
(3) own house/condominium/townhouse
(4) other_________

15 _____Same arrangement before TBI (1) yes (2) no

Children:
16, 17 __independent
18, 19 __ dependent

20 Ethnic background: (generate)

21 Education:
(1) Incomplete high school or grade school___
(2) High-School completion__
(3) College__
(4) vocational/technical, business or trade school___
(5) professional/graduate___

22 Pre-injury occupation:
(1) homemaker__
(2) unskilled/semi-skilled__
(3) skilled laborer__
(4) clerical/sales__
(5) professional/executive__
(6) none__

23 Pre-injury occupation:
(1) homemaker__
(2) unskilled/semi-skilled__
(3) skilled laborer__
(4) clerical/sales__
(5) professional/executive__
(6) none__

24, 25 months since injury:__

27 Type of accident:

28-30 Number of days in coma (severity of trauma)___

31, 32 Glasgow Coma scale score at 24 hours____

33-35 Number of days in acute rehabilitation___

36-38 Number of days in post-acute rehabilitation
e.g.,. Glenrose

39 Involvement in community based rehabilitation:
(1) yes___
(2) no___
40 Currently? (1) yes ____
(2) no ____

What did/does the program involve?

41 Involvement in a support group
    (1) yes
    (2) no

42 What did/does the program involve?

APPENDIX F: COMMUNITY INTEGRATION QUESTIONNAIRE:
(Willer, Linn, & Allen, 1994)

1. Who usually does shopping for groceries or other necessities in your household?
____yourself alone
____yourself and someone else
____someone else

2. Who usually prepares meals in your household?
____yourself alone
____yourself and someone else
____someone else

3. In your home who usually does normal everyday housework?
____yourself alone
____yourself and someone else
____someone else

4. Who usually cares for children in your home?
____yourself alone
____yourself and someone else
____someone else
____not applicable/no children under 17 in the home

5. Who usually plans social arrangements such as get-togethers with family and friends?
____yourself alone
____yourself and someone else
____someone else

6. Who usually looks after your personal finances, such as banking or paying bills?
____yourself alone
____yourself and someone else
____someone else

Can you tell me approximately how many times a month you now usually participate in the following activities outside your home?

7. Shopping
___Never ___1-4 times ___5 or more

8. Leisure activities such as movies, sports, restaurants....
___Never ___1-4 times ___5 or more

9. Visiting friends or relatives
___Never ___1-4 times ___5 or more

10. When you participate in leisure activities do you usually do this alone or with others?
____mostly alone
____mostly with friends who have head injuries
____mostly with family members
____mostly with friends who do not have head injuries
____with a combination of family and friends

11. Do you have a best friend with whom you confide?
____yes
____no

12. How often do you travel outside the home
____almost every day
____almost every week
____seldom/never (less than once per week)

13. Please choose the answer below that best corresponds to your current (during the past month) work situation:
____full-time (more than 20 hours per week)
____part-time (less than or equal to 20 hours per week)
____not working, but actively looking for work
____not working, not looking for work
____not applicable, retired due to age

14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:
____full-time
____part-time
____not attending school or training program

15. In the past month, how often did you engage in volunteer activities?
____never
____1-4 times
____5 or more

Scoring Guidelines for CIQ:

Items 1 to 6:
2 = the activity is performed alone
1 = the activity is performed with someone else
0 = the activity is performed by someone else
note: if there are no children under 17, the average (mean) score for items #1,2,3 & 5 should be substituted

Items 7 to 9:
2 = the activity was performed 5 or more times in the past month
1 = the activity was performed 1 - 4 times in the past month
0 = the activity was not performed in the past month

Item 10:
2 = mostly with friends without head injury or combination of family and friends
1 = mostly with friends who have head injuries or with family
0 = mostly alone

Item 11:
2 = yes
0 = no

Items 12:
2 = almost every day
1 = almost every week
0 = seldom/never (less than once per week)

Items 13 to 15:

These items, although collected individually, will be combined to form one variable, Job-school. The following scoring will apply:

0 = not working, not looking for work, not going to school, no volunteer activities
1 = volunteers 1 to 4 times a month and not working, not looking for work, not in school
2 = actively looking for work and/or volunteers 5 or more times per month
3 = attends school part-time or working part-time (less than 20 hours per week)
4 = attends school full-time or works full time
5 = works full-time and attends school part-time OR attends school full-time and works part-time (less than 20 hours per week)

Summary Scores of the CIQ

Home Integration: Summation of items 1 through 5

Social Integration: Summation of items 6 through 11

Productivity: Summation of items 12 through 15

Total CIQ = Home integration + Social integration + Productivity.

APPENDIX G:
The Life Satisfaction Index A: (Adams, 1969)

		Agree	Disagree	?
1.	As I grow older, things seem better than I thought they would be.	2	0	1
2.	I have gotten more of the breaks in life than most of the people I know.	2	0	1
3.	This is the dreariest time of my life.	0	2	1
4.	I am just as happy as when I was younger.	2	0	1
5.	My life could be happier than it is now.	0	2	1
6.	These are the best years of my life.	2	0	1
7.	Most of the things I do are boring or monotonous.	0	2	1
8.	I expect some interesting and pleasant things to happen to me in the future.	2	0	1
9.	The things I do are as interesting as ever.	2	0	1
10.	I feel old and somewhat tired.	0	2	1
11.	As I look back on my life, I am fairly well satisfied.	2	0	1
12.	I would not change my past life even if I could.	2	0	1
13.	Compared to other people my age, I make a good appearance.	2	0	1

14. I have made plans for the things I'll be doing a month or a year from now.	__2__	___0__	__1
15. When I think back over my life, I didn't get most of the important things I wanted.	__2__	___0__	__1
16. Compared to other people, I get down in the dumps too often.	__2__	___0__	__1
17. I've gotten pretty much what I expected out of life.	__0__	___2__	__1
18. In spite of what people say, the lot of the average man is getting worse, not better.	__0__	___2__	__1

TOTAL

SCORE:_____

APPENDIX H

<u>Quality of Social Support Scale</u> (Goodenow, Reisine, & Grady, 1990).

For each statement, would you indicate whether the statement is: never true (1), sometimes true (2), mostly or usually true (3), or always true (4).

1. There is someone who will take over my tasks or chores when *I am unable to. (modified)* (task assistance)

2. There are people with whom I can expect to have unpleasant disagreements, people who make me angry or upset. (Relationship strain; reverse for coding scale).

3. The important people in my life accept me as I am, including both my worst and my best points. (Affirmation or Ego support)

4. There is someone who will give me a hug or hold me in their arms when I need comforting. (physical affection)

5. It's hard to find someone who can give me objective feedback on how I'm handling problems. (information and feedback; reverse for coding scale)

6. There is someone whose advice I really trust. (information and feedback).

7. I can count on someone to listen to my innermost feelings, even when I'm angry at someone or depressed about something. (opportunity for confiding)

8. Some of my friends or relatives are hard to get along with and seem like more trouble than they're worth. (relationship strain; reverse for coding scale)

9. The people I'm closest to are willing to use their skills and abilities to help me out in my everyday life. (task assistance)

10. The people I'm close to treat me like a worthwhile person and make me feel I have something positive to contribute. (affirmation or ego support)

11. When I need good information on how to get things done, I know that I can get it. (information and feedback)

12. I find it hard to be the sort of person I'd like to be when I'm around relatives or friends. (affirmation or ego support; reverse for coding scale)

13. The people I'm close to are physically affectionate toward me. (physical affection)

14. Someone would loan me money ($) or loan me something else of value if I needed it. (task assistance)

15. No one will really listen when I need to talk about personal problems. (opportunity for confiding; reverse for coding scale)

16. I can find someone to take me somewhere or run an errand for me if I need to. (task assistance)

17. It is easy to talk to my friends and relatives about things going on in my life. (opportunity for confiding)

TOTAL

SCORE:____

APPENDIX I: Occupational Performance Model:

SOCIAL ENVIRONMENT

Leisure

Self care

spiritual

physical

THE INDIVIDUAL

socio-
cultural

mental

Productivity

PHYSIC
ENVIR
ENVIRO

CULTURAL

INTERACTING ELEMENTS OF THE INDIVIDUAL IN A MODEL OF OCCUPATIONAL PERFORMANCE

APPENDIX J: Mirror Categorization

ICIDH	**OP MODEL**
IMPAIRMENTS: DISABILITIES PERFORMANCE COMPONENTS	
HANDICAPS	AREAS OF OCCUPATIONAL PERFORMANCE

ICIDH <u>HANDICAP CLASSIFICATIONS</u>	**OP MODEL** <u>AREAS OF OCCUPATIONAL PERFORMANCE</u>
PHYSICAL INDEPENDENCE ORIENTATION MOBILITY	SELF CARE
OCCUPATION ECONOMIC SELF-SUFFICIENCY	PRODUCTIVITY
SOCIAL INTEGRATION OTHER HANDICAPS	LEISURE

APPENDIX K

Telephone Follow-up:

1. Did you receive a letter requesting your participation in a study looking at the life satisfaction of individuals with brain injury?

2. If no, read the introductory letter.

If yes, the ______ would like to know if I could give your name and telephone number to the principal investigator so that she could tell you about the study and answer any questions that you may have.

3. Thank-you very much for your time. (whatever the response is)

Telephone follow-up (principal investigator)

1. I am phoning about the study on the life satisfaction and community integration for individuals who have had a brain injury. Did you have any questions about the study?

2. The study will require that you answer some questionnaires that will take about 1 1/2 hours of your time. Would you be willing to participate in this study?

3. Thank you very much for your time.

APPENDIX L: Reading Levels of Measurement Instruments

Sickness Impact Profile:

Readability statistics	**Interpretation**
Reading ease score: (Flesch)	This represents 6 to 10 yrs. schooling. 76
Grade level: 5 (Flesch-Kincaid)	Easy for most readers.
Avg. sentence length: 11 words	May indicate choppiness or lack of sentence variation.
Avg. word length: 1.41 syl.	Most readers could easily understand the vocabulary used in this document.
Avg. paragraph length: 1.0 sentences	Avoid 1-sentence paragraphs in business or technical writing.

Community Integration Questionnaire

Readability statistics	**Interpretation**
Reading ease score: 51 (Flesch)	This represents 6 to 10 yrs. schooling.
Grade level: 10 (Flesch-Kincaid)	Preferred level for most readers.
Avg. sentence length: 15.6 words	Most readers could easily understand sentences of this length
Avg. word length 1.66 syl.	Most readers could easily understand the vocabulary used in this sentence.
Avg. paragraph length: 0.8 sentences	Avoid 1-sentence paragraphs in business or technical writing.

Quality of Social Support:

Readability statistics	Interpretation
Reading ease score: 76 (Flesch)	This represents 6 to 10 yrs. schooling.
Grade level: 7 (Flesch-Kincaid)	Preferred level for most readers.
Avg. sentence length: 16.7 words	Most readers could easily understand sentences of this length.
Avg. word length: 1.34 syl.	Most readers could easily understand the vocabulary used in this document.
Avg. paragraph length: 1.0 sentences	Avoid 1-sentence paragraphs in business or technical writing.

Life Satisfaction Index - A:

Readability statistics	Interpretation
Reading ease score: 81 (Flesch)	Easy for most readers.
Grade level: 5 (Flesch-Kincaid)	Easy reading. Less than 6th grade level.
Avg. sentence length: 11.7 words	Choppiness or over use of short sentences may be indicated.
Avg. word length: 1.35 syl.	Most readers could comprehend the vocabulary used in this document.
Avg. paragraph length: 0.9 sentences	Avoid 1-sentence paragraphs in business or technical writing.

APPENDIX M:

Disability Rating Scale (Rappaport et al., 1982)

1. Arousability, awareness and responsivity:

Eye opening:	spontaneous	0
	to speech	1
	to pain	2
	none	3
Best verbal response:		
	oriented	0
	confused	1
	inappropriate	2
	incomprehensive	3
Best motor response:		
	obeying	0
	localizing	1
	withdrawing	2
	flexing	3
	extending	4

2. Cognitive Ability:

for feeding:		
	complete	0
	partial	1
	minimal	2
	none	3
for toileting:		
	complete	0
	partial	1
	minimal	2
	none	3
for grooming:		
	complete	0
	partial	1
	minimal	2
	none	3

3. Level of functioning:

4. Employability:

not restricted	0
selected jobs competitive	1
sheltered workshop/non-competitive	2
not employable	3

Disability categories:

Total DR Scores	Level of Disability
0	none
1 - 3	mild
4 - 6	moderate
7 - 20	severe
21 - 29	very severe
30	death