Relatives' Reactions to Patients' Traumatic Brain Injury: Development and Validation of a Measurement Instrument

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Relatives’ Reactions to Patients’ Traumatic Brain Injury: Development and Validation of a Measurement Instrument

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>viii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>x</td>
</tr>
<tr>
<td>Abstract</td>
<td>xi</td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td></td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>1</td>
</tr>
<tr>
<td>Focus of the Study</td>
<td>2</td>
</tr>
<tr>
<td>Summary of Research Hypotheses</td>
<td>4</td>
</tr>
<tr>
<td>Research Hypothesis 1</td>
<td>4</td>
</tr>
<tr>
<td>Research Hypothesis 2</td>
<td>4</td>
</tr>
<tr>
<td>Research Hypothesis 3</td>
<td>5</td>
</tr>
<tr>
<td>Research Hypothesis 4</td>
<td>5</td>
</tr>
<tr>
<td>Research Hypothesis 5</td>
<td>5</td>
</tr>
<tr>
<td>Research Hypothesis 6</td>
<td>5</td>
</tr>
<tr>
<td>Research Hypothesis 7</td>
<td>5</td>
</tr>
<tr>
<td>Research Hypothesis 8</td>
<td>5</td>
</tr>
<tr>
<td>Delimitations</td>
<td>5</td>
</tr>
<tr>
<td>Relevance to Social Work</td>
<td>6</td>
</tr>
<tr>
<td>Definitions and Concepts</td>
<td>8</td>
</tr>
<tr>
<td>2. LITERATURE REVIEW</td>
<td>11</td>
</tr>
<tr>
<td>Indian Culture, Response to Trauma and Social Work</td>
<td>11</td>
</tr>
<tr>
<td>Factors that Affect the Nature of Social Work in India</td>
<td>11</td>
</tr>
<tr>
<td>Density of Population, Literacy, Fertility and Poverty</td>
<td>12</td>
</tr>
<tr>
<td>Gender, Religion and Culture</td>
<td>13</td>
</tr>
<tr>
<td>Religion and Social Work</td>
<td>15</td>
</tr>
<tr>
<td>Culture and mental health consequences of trauma</td>
<td>15</td>
</tr>
<tr>
<td>Social Work Practice, Education and Research</td>
<td>16</td>
</tr>
<tr>
<td>Casework in India</td>
<td>18</td>
</tr>
<tr>
<td>Incidence and Prevalence of Head Injuries</td>
<td>20</td>
</tr>
<tr>
<td>Incidence and Prevalence in India</td>
<td>21</td>
</tr>
<tr>
<td>Medical Aspects of TBI</td>
<td>22</td>
</tr>
<tr>
<td>Impact of TBI on Patients</td>
<td>23</td>
</tr>
<tr>
<td>Physical</td>
<td>24</td>
</tr>
<tr>
<td>Cognitive</td>
<td>25</td>
</tr>
<tr>
<td>Attention and Concentration</td>
<td>25</td>
</tr>
</tbody>
</table>

iv
Memory 26
Language 27
Perception 27
Behavior and Personality 28
Emotion 29
Social 30
Independence 30
Occupation 32
Impact of TBI on Relatives 33
  Related Theories and Models 34
  Stages of Relatives’ Reactions 38
  Emotional Reactions of Relatives 40
    Reactions of Parents 43
    Reactions of Spouses 44
Rationale for Selection of Constructs: Pilot Studies 45
  Mini-Ethnography 46
  Empirical and Technology Review 47
    Theoretical Base 49
    Hypothesis 50
    Research Design 50
    Sample Size and Type 51
    Instrumentation 51
    Statistical Analysis 52
Review of Assessment Measures 53
  Symptom Checklist 53
  Family Assessment Device 54
  Family Adaptability and Cohesion Evaluation Scale 55
  Head Injury Family Interview 55

3. CONCEPTUAL AND DEVELOPMENTAL FRAMEWORK  59
  Instrument Construction 59
  Instrument Validation 61
    Reliability 61
    Validity 66
  Rapid Assessment Instruments 68

4. RESEARCH METHODOLOGY  69
  Instrument Construction 69
   Pilot Study 70
   Item Development 70
   Data Collection Methods 71
   Opportunities and obstacles for data collection 71
   Results of the Pilot Study 71
Sample Characteristics 71
Reliability Analysis 72
Confirmatory Factorial Validity 76
Standard Error of Measurement 78
Construct Validity 78
Discussion 80

Item generation for the RBTS 81
Instrument Validation 82
Subjects 82
Rates of Usage of the RBTS 83
Informed Consent 84
Confidentiality and Anonymity 85
Measures 85
Clinical Anxiety Scale 85
Satisfaction with Life Scale 86
Beck’s Depression Inventory 87
Reactions to Brain Trauma Scale 88

Procedure of Data Collection 88
Reliability and Validity Methods 89
Reliability 89
Validity 91

5. RESULTS 94

Participant Characteristics 94
Severity of TBI of Patient 94
Duration of Hospital Stay of Patient 95
Age of the Respondent 96
Gender of the Respondent 97
Education of the Respondent 97
Income of the Respondent 98
Religion of the Respondent 98
Importance of Religion to Respondent 99
Relationship to the Patient 99
Help Received from Various Sources 100
Stress of Responsibilities 100
Caregiver Status of Respondent 101
Breadwinner Status of Respondent 102

Reliability Analysis of RBTS 102
Confirmatory Factorial Analysis 106
Final Reliability Analysis 109
Standard Error of Measurement 111
Validation Analysis of ABTPRR 111
Construct Validity 111
Convergent Construct Validity 111
Discriminant Construct Validity 114

6. DISCUSSION AND CONCLUSIONS 116
   Introduction 116
   Sample Characteristic 116
   Importance of Study Findings 119
   Reliability Analysis 120
   Validity Analysis 122
      Face and Content Validity 122
      Factorial Validity 122
      Construct Validity 123
      Scoring of the RBTS 124
   Limitations of the Study 124
   Recommendations for Future Research 126
   Implications for Social Work 127
   Utility 129
APPENDIX A: ARTICLE CATEGORIZATION 132
APPENDIX B: CRITICAL REVIEW OF TECHNOLOGY ARTICLES 133
APPENDIX C: CRITICAL REVIEW OF MEASUREMENT DEVICES 146
APPENDIX D: BRAIN TRAUMA PATIENTS’ RELATIVES 148
   REACTION - ORIGINAL 150
APPENDIX E: REACTION TO BRAIN TRAUMA SCALE 150
APPENDIX F: CONSENT LETTER 152
APPENDIX G: INTERVIEW GUIDE 153
APPENDIX H: LIST OF RESOURCES FOR RESPONDENTS 154
APPENDIX I: PERMISSION TO CONDUCT THE RESEARCH (NIMHANS) 155
APPENDIX J: PERMISSION TO CONDUCT THE RESEARCH (FSU) 157
APPENDIX K: STAGES IN CONSTRUCTION AND VALIDATION OF THE RBTS 158
REFERENCES 159
BIOGRAPHICAL SKETCH 177
LIST OF TABLES

1. Sample Characteristics 64
2. Reliability of Global Measure and Subscales 65
3. Initial Reliability Analysis of Anxiety Subdomain 65
4. Reliability Analysis of Depression Subdomain 66
5. Initial Reliability Analysis of Life Satisfaction Subdomain 66
6. Modified Reliability Analysis of Life Satisfaction Subdomain 67
7. Modified Reliability of Anxiety Domain 67
8. Modified Reliability of Depression Subdomain 68
9. Modified Reliability of Global Domain 68
10. Final Confirmatory Factorial Validity Analysis 69
11. Correlations of the Subscale scores with their respective External Scales and Single-Item Indicators 71
12. Correlations between Discriminant Demographic Indicators and the Global Domain 72
13. Age of the Respondents 87
14. Education of the Respondents 88
15. Income of the Respondents
16. Religious Preference of the Respondents
17. Initial Reliability Analysis of the Anxiety Domain
18. Initial Reliability Analysis of the Depression Domain
19. Initial Reliability Analysis of the Life Satisfaction Domain
20. Cronbach’s Alphas for the Domains and the Global Scale (RBTS)
21. Initial Confirmatory Factor Analysis of RBTS: Factors and Loading
22. Final Confirmatory Factor Analysis of RBTS: Factors and Loading
23. Initial Reliability Analysis of Global Scale (RBTS)
24. Final Cronbach’s Alphas for the Domains and Global Scale (RBTS)
25. Standard Deviation and Mean Scores of Domains and Global Scale (RBTS)
26. Standard Error of Measurement (SEM) for the Domains and Global Scale (RBTS)
27. Correlations between Convergent Demographic Indicators and Global Domain
28. Correlations between Subdomains of RBTS and the Single-item Indicators
29. Cronbach’s Alphas and SEM for the External Measures
30. Correlations between Subdomains (of RBTS) and the External Measures
31. Correlations between Discriminant Demographic Indicators and Global Domain
LIST OF FIGURES

1. Severity of TBI 86
2. Duration of hospital stay 87
3. Gender of respondent 88
4. Importance of religion 89
5. Relationship of respondent to patient 90
6. Sources of help received by the respondent 90
7. Burden of responsibility felt by the respondent 91
8. Main caregiver status of respondent 92
9. Breadwinner status of respondent 92
ABSTRACT

The cumulative effect of high incidence and long term nature of the consequences, lead to steadily increasing numbers of sufferers of the effects of TBI (Burns & Cockrell, 1993). With immediate focus on the patient’s physical and cognitive state, the relatives’ needs go unnoticed. To date, no measurement instrument has been developed which assesses reactions of traumatic brain injury patients’ relatives. The development of such an instrument, the Reaction to Brain Trauma Scale (RBTS) is the focus of this dissertation. The RBTS is a 19-item multidimensional scale scored on a 5-point Likert scale consisting of three domains. The main domain (reaction of relatives to brain trauma) is divided into sub domains of anxiety, depression and life satisfaction. The purposive, nonprobability sample (n = 279) was collected at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in Bangalore, India.

Reliability was tested by determining the internal consistency of the instrument using Cronbachs’ coefficient of alpha. Anxiety, depression and life satisfaction had reliabilities of .73, .81, and .79 respectively. Each sub domain had a low standard error of measurement (SEM). Anxiety and depression had 1.02 and .93 while life satisfaction had an SEM of 1.03. Strong evidence of factorial validity was found. Good convergent construct validity was found by correlating RBTS with three long established instruments, single item indicators and specific demographic indicators (relationship, duration and help received). Discriminant construct validity was demonstrated with correlations of RBTS with education, gender and income.
CHAPTER I
INTRODUCTION
Statement of the Problem

Brain trauma is termed as the silent epidemic by Brody in 1983. The consequences of severe traumatic brain injury (TBI) for the individuals who sustain these injuries are dramatic and long-term (Brooks, Campsie, Symington, Beattie, & McKinlay 1987; Cavallo & Saucedo, 1995; Martin, 1988; Peters, Stambrook, Moore, & Esses, 1990; Wood, 1993). With the immediate focus on the patient’s physical or cognitive state, the family’s needs go unnoticed or unrecognized (Testani-Dufour, Chappel-Aiken & Gueldner, 1992). Recent years have seen a proliferation of specialized treatment units, increased research (neurological, psychiatric and neuropsychological), rise of TBI foundations (at local and national levels), development of support groups (patient and family) and a number of other gains. There is growing recognition of the long-term implications of TBI and the need for continuing care among practitioners (Blosser & De Pompei, 1995; Urbach, 1989). With this recognition, persons with TBI can look forward to a greater likelihood of survival, a better prospect for recovery and a more comprehensive network of resources and supports.

However, this improved outlook is not adequate for the relatives of TBI patients (Hosack & Rocchio, 1995). This is especially true as relatives seek professional help at psychiatric hospitals and marriage and family clinics long after the injury incident (N. Rao, personal communication, April 1992). There is a significant change in the family structure following traumatic brain injury (Curtiss, Klemz, & Vanderploeg, 2000). Due to the cumulative effect of high annual incidence and the long-term nature of the consequences, the numbers of individuals suffering the effects of TBI are growing steadily (Bush, 1988; Waaland, Burns, & Cockrell, 1993; Stansfield, 1991; Wood, 1988). Although there is a growing industry to meet the service needs of individuals with TBI, there remains a serious gap in the available services (Bush, 1988). In 1988, it was reported that only one in 15 persons with TBI received rehabilitation (Bush,
There is no guarantee that the quality of life increases with the longer life made possible by advances in technology.

**Focus of the study**

This current work is based on the critical analysis of the literature relevant to the reactions of relatives of TBI and the assessment of instruments used to measure the reactions. The literature includes the clinical experience of researcher with Indian population and expert advice from practitioners, relatives of TBI patients and psychometricians (W. Hudson; N. Abell). The focus of the discussion is as follows.

Professional literature was reviewed and the long-term consequences of severe TBI on patients are discussed. One important contribution is the Indian setting for the formal research study. Literature pertinent to the Indian culture, reaction to trauma and social work is included to describe the Indian background and need for the study in that country.

The relevance of conducting this study in India is twofold. First it is to develop an instrument that will be used by the Indian population where there is a dearth of instruments to assess reactions of TBI patients’ relatives. Most measures used in India and the social work literature are borrowed from the West. It is for this reason that measures are slow in developing in India. The second reason is that assessing the reactions of relatives of TBI patients will be invaluable to the social work literature because there is no other study published on this subject to date in India. The only other study conducted in India was conducted to assess the anxiety of relatives of TBI patients (Rajaram, 1991, see page 40 for discussion). Many studies conducted in India have borrowed instruments and literature from the West (Kendal, 2000; Nagpaul, 1993; Segal, 1993; Kulkarni, 2000; Pathak, 2000; Jayashankar & Monterio, 2000; Srivastava, 1999; Pawar, 1999). The lack of indigenous instruments has led to the dire need for the development of assessment measures in India (I. Shariff, personal communication, August, 1991).

Previous experience with Indian subjects shows the general willingness to participate in research. Research is encouraged by institutions in India. Most subjects give their consent easily and volunteer information pertaining to their experience, thoughts, attitudes and feelings. Survey techniques used in interviewing subjects enabled the disclosure of emotionally charged personal
experience. Two subjects of Indian origin in the ethnographic study and professionals from India helped to develop the items. However, the results of this study will be viewed with caution because the performance of the measures used (in this study) is not known and a cultural leap is made in this study. The reliability scores for the external scales in this study are given on page 113.

Literature related to impact on families of individuals who sustained TBI was reviewed. Literature related to assessment of instruments used to measure relatives’ reactions to TBI was critiqued according to categories suggested by Klein and Bloom (1994). The category dealing with technology is discussed in depth. Measurement instruments used to assess the reactions of TBI patients is discussed. The methodological section details the concept and methodology of instrument validation. Prior to these discussions, the incidence, prevalence, medical aspects and uniqueness of TBI is examined. The relevance of this study to social work is emphasized.

First, the instrument is needed to assess the relatives’ reactions to TBI. The instrument was intended to be an assessment and outcome measure. One objective of this study was to develop a brief measure, intended for use with relatives of TBI patients. The construction of the instrument was assisted by the data generated from the mini-ethnography and domain analysis conducted on transcriptions of interviews (three). Three iterations revealed that the emotional responses grouped around three domains. These domains turned out to be anxiety, depression and life satisfaction of the relatives’ lives.

Once the constructs were delineated, an in-depth literature review helped in the operationalization of the construct and subdomains. The item pool was generated with input from the experts in the clinical field and measurement area. Pilot studies were conducted to test and streamline the measure. After pilot testing, experts in India reviewed the instrument. The instrument was translated into three Indian languages for administration to the target population in India. Permission was received from the head of the neurosurgical department at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in Bangalore, India. The proposal was reviewed by the Ethics Committee (NIMHANS) and approved. The director of NIMHANS then gave final permission to collect data at NIMHANS. Permission was received from the
Institutional Review Board at Florida State University.

The final part of the study consists of evaluation of the instrument using a clinical sample (relatives of TBI patients) to assess the reliability and validity of the instrument. This instrument is administered to the sample, along with other established measures, to evaluate the reliability and validity characteristics of the measure. The hypotheses for the study are described below.

**Summary of Research Hypotheses**

At the outset it was hypothesized that the current scale that is developed would produce acceptable reliability on the global scale and sub domains. This scale would also have a factor structure that divides the main domain (reactions of brain trauma patients’ relatives –see pg. 7 for definition) into three subdomains (anxiety, depression and life satisfaction). A literature review revealed that immediately after TBI of the family member, the relative responds with heightened anxiety and depression. Three related scales, Thyer's Clinical Anxiety Scale, Beck’s Depression Inventory-II and Diener's Satisfaction with Life Scale were chosen to be used as theoretically relevant correlates for convergent construct validity. Three single-item indicators were used as convergent construct validity indicators. Literature review and focus group suggestion also led to a choice of age, gender and education to be variables that establish discriminant construct validity. The global scale was chosen over the sub scales to test construct validity to be conservative and to maintain uniformity. The sub scale scores and the global scores cannot be simultaneously tested because this study claims that each represents something separate and unique in the interpretation of the RBTS. The hypotheses are given below.

**Research Hypothesis 1**

The RBTS will correlate with Thyer’s Clinical Anxiety Scale. The RBTS and the external scale (Thyer’s Clinical Anxiety Scale) should correlate positively because CAS and RBTS (has one sub scale that) measure similar constructs.

**Research Hypothesis 2**

The RBTS will correlate with Beck’s Depression Inventory II (BDI-II). The external scale (BDI-II) measures clinical depression and the depression sub scale measure a similar depression that is not clinical in nature.
**Research Hypothesis 3**

The RBTS will correlate with Diener's Satisfaction with Life Scale (SWLS). The life satisfaction subdomain is theoretically relevant to the external scale (Diener's SWLS).

**Research Hypothesis 4**

The RBTS will correlate with general item 25 of the proposed instrument. The general item 25 states that the respondent is feeling anxious. Both the subdomain anxiety and the single-item indicator 25 attempt to measure the same construct anxiety.

**Research Hypothesis 5**

The RBTS will correlate with general item 26 of the proposed instrument. This single-item indicator states that the respondent was depressed when the instrument was administered.

**Research Hypothesis 6**

The RBTS will correlate with general item 27 of the proposed instrument. This item states that the respondent is satisfied with the help received from professionals and services rendered.

**Research Hypothesis 7**

RBTS will correlate with selected demographic indicators (age, relationship of respondent with patient and time since injury). Literature reviews and the focus group of professionals and relatives agreed that specific demographic variables would or would not correlate with the RBTS.

**Research Hypothesis 8**

RBTS will not correlate with selected demographic variables (gender, education and income).

**Delimitations**

The sample was restricted to a clinical group taken from NIMHANS. This purposive sample limits the external validity of the study and the results are sample dependent. Predictive criterion validity is not established in this study due to financial and practical reasons. Test-retest reliability will not be measured because of the difficulty in readministering the measure on the sample group after a brief period. The time period between two measures would have had to be
brief due to the quick turnover at the hospital. The turnover results from patients’ continuous transfer to rehabilitation centers, discharge home and attrition.

**Relevance to Social Work and Significance of this Study**

From its inception, social work as a profession has helped the sick. Renowned social workers like Mary Richmond (1917) provided a medical model of study, diagnosis and treatment of clients. Fischer (1973) reported the lack of evidence of effectiveness in social work practice. In the United States, the managed care system has pressured social workers to see more patients and be accountable in their practice. India with its large agrarian population still relies on a centralized primary health care network. The dense population in India pressures practitioners to treat increasingly larger number of clients. Thus, social workers in the East and West need measures to effectively treat clients’ problems.

Despite commendable strides in developing assessment measures, social workers in India still look to other fields for related measures. The fields of measurement and instrument development are still in their adolescence (Springer, Abell & Hudson, 2000). Many instruments that Indian social workers borrow are from psychiatry and psychology (General Health Questionnaire, Minnesota Multiphasic Personality Inventory and Clinical Screening Scale). Even these scales are borrowed from the West. Not much published literature is available regarding the performance of Western scales in India. Despite guidance in appropriate adapting of measures, Indian social workers borrow from the West to meet their changing needs. Ideally, social workers would have their own repertoire of measurement devices best suited to their clientele.

Social workers typically treat clients who are in a vulnerable state of mind. For this reason, social workers would benefit from a brief assessment device to assess different facets of clients’ reactions to specific events. A multidimensional measure tailor made for social workers should assess different types of client reactions. Multidimensional measures must be tailor made because social workers treat clients holistically. Social workers assess the medical, physical and psychological state of the client in addition to religious, occupational, financial and other factors that impinge on clients’ adjustment. Despite its obvious importance, one critical facet of TBI clients’ adjustment, (emotional functioning of their relatives) has no measurement device.
Neurosurgical and neurological social workers would benefit from a multidimensional assessment device that could be used to assess cost-effective treatments. A short, efficient measure would help social workers assess emotional reactions of relatives of TBI patients’ relatives and develop treatments that would enable them cope with their ordeal.

In India, neurology, neurosurgery and medical personnel have dominated care of patients while families are grossly neglected. Social work in this area is restricted to giving financial aid or contact collaboration. Emotional needs of relatives were not focused upon. A dire need exists for social workers to direct their attention to relatives of TBI patients and their emotional reactions. Early intervention would prevent current adjustment and future possible emotional disorders. This study helps in providing social workers with a multidimensional tool that hastens the intervention process and fosters healthy adjustment of relatives to TBI. First, this study improves the overall body of social work knowledge by adding to literature dealing with reactions of relatives of TBI patients. Second it is hoped that the instrument developed can be used with various populations (with further in-depth psychometric study) after demonstrating its usefulness with relatives of TBI patients. Third, at the microlevel of social work intervention, development of a reliable and valid measure to assess reactions of relatives of TBI patients is of clinical value to neurological and neurosurgical social workers. Social workers would be able to quickly assess specific reactions that are maladaptive and create treatment plans focusing on specific maladaptive reactions. Fourth, at the macrolevel, this investigation would contribute to knowledge available for service system modification. Finally, by providing in-depth insight into needs of relatives of individuals who have sustained traumatic brain injury, policy-makers would have access to information that would assist them in developing meaningful policy.

In 1994, Kreutzer, et al. confirmed the earlier findings (Kreutzer, Marwitz & Kepler, 1992) that there was insufficient empirically derived information on the relatives’ responses. Earlier research called for empirical studies using standardized instruments. Thus, standardized instruments must be relevant to constructs requiring research. Therefore, rather than adapting general instruments for studies, it is crucial to have instruments that assess constructs to be researched. In addition, it is important to identify the theoretical base of research conducted so
far. Studies describing relatives were adapted from General Systems Theory, or one of its derivatives. This study is based on a strong foundation of pilot studies.

Relevance of this study to social work in India is twofold. Social workers in India need instruments to aid them in their work with clients. In addition, the need to lay a foundation for indigenous literature and research is well-documented (Nimmegadda & Couger, 1999; Kendal, 2000; Nagpaul, 1993; Segal, 1993; Kulkarni, 2000; Pathak, 2000). The following section defines some of the concepts used in the study.

**Definitions and Concepts**

Traumatic brain injury (TBI) is defined as an insult to the brain caused by external physical force that may produce an altered state of consciousness that results in impairment of cognitive abilities or physical functioning (National Head Injury Foundation, 1992).

Glasgow Coma Scale is the standard measure of scores assigned neurosurgeons, which helps to classify the severity of TBI. Developed by Jennet and Teasdale this scale relates to the level of consciousness with motor responses, eye opening and verbal responses (Jennet & Teasdale, 1981). Severe head injury in this scale is defined by a score of eight or less on the GCS. Minor head injury patients have a score on the GCS of 13 through 15. The patients who have moderate head injury have a score of nine through twelve on the GCS. Severe TBI is generally referred to in professional literature as individuals whose brain injuries result in a Glasgow Coma Scale (GCS) rating of between three and eight and post traumatic amnesia (PTA) duration of over 24 hours.

TBI patient in this study is a person who has had an injury to the head. Although injury is severe as rated by the Glasgow Coma Scale, the type of injury is not specified. The main relative in this study is a family member of the patient who has succumbed to TBI. It was necessary that this relative had no history of substance abuse or major psychiatric disorder so that the results of the study would not be biased. This member is over the age of 18 and spoke English or any of the three Indian languages (Hindi, Kannada or Tamil). It was decided at the time of analysis of data that questionnaires in Kannada would be the only ones to be retained as there were adequate number of subjects in this category and few, in the other two languages.
In this study emotional reaction to TBI is the exhibition of changes in emotions. These emotions could range from anger, anxiety, sadness, apathy, dissatisfaction or happiness. It is termed as the reaction to TBI patient and the incident itself and indicated by high anxiety, depression and low life satisfaction. It can be characterized by the exhibition of intense, diffuse feeling of shock, nervousness, apprehension, crying spells, hopelessness, loneliness, sadness, dissatisfaction (with the situation, treatment, regimen or the future).

Anxiety is defined as an intense and diffuse feeling of shock, nervousness and apprehension about the TBI of close family member. The relative worries about the effects, treatment and outcome of TBI.

Depression is an emotional disturbance occurring immediately after the TBI of the close relative. It is characterized by crying spells, feeling hopeless, lonely and sad about the TBI. The relative could have altered biological functioning (appetite, bowel movements, sleep or libido).

One who can make adequate plans for the future (with a TBI patient) and is satisfied with his/her daily activities (dealing with the TBI) characterizes the satisfaction of the relatives’ life. Such a relative is also satisfied (in varying degrees) with the situation, the treatment regimen and the future in general.

Dysarthria is the physical language impairment or speech defect that is caused by focal lesions that affect muscles of the lips, tongue and jaw (Rosenthal, et al., 1983).

Loss of ability to recognize things through a particular sensory system is referred to as agnosia. Visual agnosia refers to the inability to put together visual information so that it makes sense. For example, the person may see parts of an object but not be able to put it together and see it as a whole.

The inability to express thoughts in writing is known as agraphia. Inability to read is alexia. The loss of the ability to recall the names of objects is anomia. The loss of the ability to express oneself and/or to understand language is aphasia. There are many kinds of aphasia depending on the area of head injury. It could be receptive or expressive aphasia. A person may be unable to understand what someone else is saying or be unable to express oneself to others. Still others may be able to know what to say but are unable to find words
to express their thoughts. Some patients may be able to form words that may be incomprehensible.

The above definitions describe the concepts in this study. Next, Chapter II describes the Indian culture and defends the need for borrowing from Western literature to lay a foundation for this study.
CHAPTER II
LITERATURE REVIEW

This chapter gives a broad description of Indian social work and the Indian culture that affects the way people react to trauma. Social work practice is greatly influenced by the traditional structure of society and norms prevailing in India. Despite trends and progress made in science and technology, attitudes of Indians are slow to change. This cultural lag and need for indigenous social work literature is addressed below. The incidence and prevalence of TBI in India and the U. S follow the discussion of Indian culture and social work. Medical aspects of TBI are described before discussing its impact on patients and relatives. Rationale for selecting constructs for this study is explained followed by a review of assessment measures and their significance and need.

Indian Culture, Response to Trauma and Social Work

This discussion is necessary to understand problems faced by Indian social workers’ that have curtailed the growth of research and literature in India. A few studies by Indian mental health professionals are included to show attitudes of the Indian people towards deviance (Bhattacharya, 1983). An additional discussion of Indian social work is crucial to understand the conditions existing for the Indian social workers that differ from conditions found in the West. The need for research and practice relevant to India is especially critical because social work practice in India differs from the West. Notwithstanding their differences, literature from the West is borrowed to lay a foundation for research that has not been conducted in India.

Factors that affect the attitudes and the nature of social work in India

The following discussion will begin with the general conditions existing in the Indian population that influence the nature of social work. Conditions described would include density of population, literacy, fertility, poverty, gender, culture and religion. A discussion of Indian mental health literature is included to contextualize the review of literature on social work
practice and research in India.

**Density of population, literacy, fertility and poverty**

Srinivasmurthy, (1997) noted that the fifth largest city in India, Bangalore, had a population of 4,086,548 according to the 1991 census. It was estimated that in 2001, the population would reach 5.5 – 6 million. The backlog of housing in India is estimated to be 23.2 million units. Sanitation in rural areas and urban slums is dismal. Even though the size of the cities is large, India remains one of the less urbanized countries in the world. Forty-five percent of the people live in single room shelters. The fertility rate in women aged 15 – 49 years, living in rural and urban areas is 3.7 and 2.7 children respectively. The inability of the government to provide adequate housing has resulted in the rise of urban slums (i.e. similar to inner cities in the United States). In large cities, the proportion of the population who lives in slums varies from 23 to 25 percent (Planning Commission, India, 1983).

Kanitkar and Mistry (2000) report the following data for Bangalore, India. The literacy rate was 69% that was well above the national average of 36%. There were about 47.9 % and 75.5 % for children aged 11 to 14 years in rural and urban areas respectively. In rural and urban areas, the percentage of those who completed high school in the 13 to 49 age group was 5.2 and 28 respectively. The percentage of those who were not literate was 72.4 and 32.5 in rural and urban areas, respectively. It was reported that 40% live below the poverty line (Srinivasan, 2000). Although India is self-sufficient in the production of food grains, a large number of people do not have the purchasing power to maintain a nutritionally adequate diet or a reasonable level of shelter and clothing (Hokenstad, Khinduka & Midgley, 1992). There is no national health care program or community based services in urban areas. Comprehensive rehabilitation services, social security and medical insurance for all the people are nonexistent in India. For these reasons disabled people live with their families who provide their total care. This care includes patient’s safety, hospital visits, occupational and social rehabilitation, personal hygiene and other basic needs.

The attitude of people towards AIDS is influenced by family income level (Melkote and Goswami, 2000). They add that a higher level of income was correlated with a positive attitude
toward persons with AIDS and the low level of income was associated with a negative attitude towards persons with AIDS. The factors that affect attitudes to AIDS are poverty, access to education, inequality in income, gender, and knowledge and interests of politicians (Melkote and Goswami, 2000). Social work practitioners in India believe that these factors also affect attitudes towards persons with TBI and disabilities (Reddy, K., personal communication, August 1991).

Taking these factors into consideration, a major challenge for social work practice and education in India is the need for development of preventive functions that was advocated at the 1969 United Nations’ International Conference of Ministers responsible for social welfare. A remedial approach was of limited value in India with its massive social and economic problems that are closely related to density of population. A preventive multi-pronged approach was needed to improve the prevailing conditions.

**Gender, religion and culture**

Gender differences are evident on most social development indicators, despite constitutional and legislative guarantees of equality and improvement of status of women since independence (Hokenstad, Khinduka & Midgley, 1992). The authors state that the illiteracy rate among women is far higher than that among men. The school dropout rate for girls is much higher than that for boys because families give a much lower priority to education of girls. Early childhood mortality is higher among girls than among boys, indicating that families neglect nutrition and health care access to girls. Early marriage, high fertility and social customs assign a subordinate role to women and restrain their participation in nontraditional activities (Hokenstad, Khinduka & Midgley, 1992). These factors indicate that the status of women is very low in India.

Religious scripts and epics play an important role in shaping the lifestyles in India (Epstein, 1996). The path of dharma or religion in scriptures states that a woman obtains highest heaven by serving her husband (Srinivaschariar, 1953). According to Manu, one of the earliest writers in India, in childhood a woman must be subject to her father, in youth to her husband, and when her lord is dead, to her sons. A woman must never be independent (Indian Council for Social Science Research, 1975). Even the Gita (i.e. the sacred book for Hindus in India equivalent to the Bible for Christians) places women in the same category as the lowest of castes.
and describes them as being of sinful birth (Thapar, 1975). Thapar adds that women were treated as the property of men. In the villages, families usually explain that they prefer to have sons because they lose their daughters to marriage when they come to an age when they can work on the fields and home (Epstein, 1996). The sons on the other hand, bring home the permanent woman when they marry along with dowry (bride price).

Shrinking size of family, increased modernization, globalization, mobility, migration, women’s employment, economic needs, individualism and decreased joint family obligations has changed the old order (Srinivasan, 2000). Families isolate the disabled from nine months of festivity of religious ceremonies in the community because of ostracism and stigma towards mental illness (Srinivasan, 2000). The same could be said for those who look or behave differently from what is considered culturally normative (Khan, 1993). In other words, patients who are victims of severe TBI face the same ostracism. Traditional respect for authority and professional advice has led to decreased communication. The family does not question or oppose the authority figures’ advice. Consequently, participation in treatment planning of the disabled family member is curtailed. Along with this attitude, the legacy of colonialism, submission, dependency, passive outlook, belief in Karma and decreased level of activism have added to the stress in families.

In 2000, Srinivasan remarked that there is a lack of free expression of emotions, except for the emotion displayed for role achievement and fulfillment. In other words, there is little demonstration of appreciation and encouragement. Ganguli (2000) reports that housewives, unemployed and elderly (over 60 years in age), are high-risk groups for mental disorders. Dassi and Khan, in 2000, wrote that families’ regulation of their affairs includes curbing and eliminating behavior that is inimical to survival, maintaining equilibrium and seeking improvement. The second half of the 20th century witnessed changes that have thrown time-honored traditions, norms and practices off-balance in the Indian family (Khan, 1993). The family no longer performs several pivotal functions that it used to in the past (Srivatsava, 1992). Indian families suffer when they attempt to perform a positive, proactive role as caregivers and supporters of their disabled family member (Srinivasan, 2000).
Religion and Social Work

Bhadhuri (1992) uses the transcultural approach to bereavement counseling. She has taken religious tenets from the Hindu text, the Gita, and used it in her work with clients. She puts forth the following ways that alleviate mental and emotional pain. The Gita postulates immortality of the embodied self and elaborates on our duality – a nonmaterial entity (self) inhabiting the material body. Gita advocates the law of Karma (karma yoga) that means disciplined and not egoistic action. According to the law of Karma or action, one should carry out his/her duties without being attached to rewards or motives. The identification of Karma with fatalism is misleading. The Gita also emphasizes importance of faith (Bhakti yoga). She adds that an unwavering faith stands the test of life and its sufferings. Bhadhuri uses these principles in her counseling and remarks at their success.

Culture and mental health consequences of trauma

The field of medical anthropology has influenced health research in developing countries, shifting paradigms from positivist, universalistic, scientific approach with emphasis on diagnostic methods and its accuracy to a qualitative approach. In cross-cultural psychiatry illness results from a web of causation and individuals’ sociocultural environment (Patel, 2000). However, Patel adds that studies that claim cultural causes for psychiatric illness are criticized for small-scale, less standardized methods for comparison in research. Patel, (2000) added that culture is not static but is evolving and changing.

Patel (2000) remarked that symptoms of anxiety and depression disorders are universally applicable. However, constructs of anxiety and depression are separated by international classification. A large body of evidence (Goldberg & LeCrubier, 1995; Patel, Pereira & Mann; 1998; Sen & Williams, 1987; Singh & Sharma, 1986) suggests that anxiety and depression are comorbid. The symptoms of both the disorders overlap making individual diagnosis difficult.

Keshavan, Narayan, and Gangadhar, (1989) remark that the boundary between mental and spiritual disorders is complex with the categories becoming potentially invalid in a cross cultural context. They go on to explain that dissociative disorders are a source of contemplation because of their similarity to trance and possession states as described in India. This disorder or state is
prevalent in women and could possibly provide a protective role (it could be a way of escaping from a violent male partner).

In 1999, Davar stated that trauma can have adverse mental health consequences. Research is essential to generate information that can influence health policy, practice and research should describe relevant cultural factors and their influences. The ultimate goal in mental health research according to Davar is to generate epidemiological data on prevalence, nature and outcome of mental health consequences of trauma. Such data might enhance the efficacy of various interventions. Davar stresses the importance of ensuring the criterion validity of the constructs that are measured. He adds that there are no “gold standards” for establishing criterion validity of constructs, like post traumatic stress disorder. He adds that Anglo-Americans models of illness heavily influence bio-medical categories of mental disorders. He cautions that there is a danger of medicalizing trauma and reducing its family context. A medical understanding may lead to a misinterpretation of contexts of human experiences in the face of trauma. Elaborating Davar states that disorders may superficially resemble psychiatric disorders or phenomena but may also provide a coping or healing role for the person which can only be understood through a cultural belief system. The literature given above is important because of its relevance to the current study and also points out the nuances and problems of conducting research in India. There is a lack of indigenous literature pertaining to families’ reaction to TBI and research pertaining to psychometrics in particular. It is for this reason related research was included. The following section describes the use of Western literature in Indian social work education.

**Social work practice, education and research**

Developing social work practice knowledge in the non-Western world by non-Westerners is difficult. Western models are still used and indigenized. Practitioners use culturally acceptable techniques from the West (Nimmegadda, 1999). Kendal (2000) remarked that in planning a curriculum, the Indian faculty settled on a combination of British background in social service with an American emphasis on professional social work practice. In 1936, an American missionary named Clifford Manshardt started the first school of social work in Bombay that was similar to the New York School of Social Work.
The curricula of social work programs are similar throughout India. Their development is similar to the pattern followed by U.S. social work education in the early 1960’s (Nagpaul, 1993). Most educational programs are located in urban areas and draw students from higher income urban families although 75% of Indians live in rural areas. The importance of poverty, sex-discrimination, malnutrition, illiteracy, delinquency, and abuse is stressed in curriculum development in India (Nagpaul, 1993). Kulkarni (2000) states an immediate concern is the heavy dependency of Indian social work on imported models, techniques and literature.

Medical and psychiatric social work reflects whole sale transfer from the American social work educational model (Nagpaul, 1993). Further, there is no basic text on Indian social work in part because there is a ready-made body of formulated concepts, principles, theories and techniques in the U.S. social work literature. Nagpaul reports that 90% of suggested readings were published in America. He adds that, in 1968, the Indian Encyclopedia reproduced the American social work code of ethics (1960), the curriculum policy statement (1962) and definition of practice (1956). In 1987, Indian encyclopedia was still influenced by an American format and coverage (Nagpaul, 2000). A majority of the Indian citations was not indigenous. The American texts are used for courses on Indian human development and social environment, social casework, group work and community development (Nagpaul, 1993).

This transfer seems unwise given the differences existing between the two countries. The American curriculum, according to Nagpaul (1993) is based on capitalism, social Darwinism, Protestantism and individualism. Indian philosophy, social work approaches, principles and theories on the other hand, are based on a collectivist society, with increased cooperation and dependency. Indian social work curriculum is also based on a social system that has decreased competition, decreased mobility, low conformity and ascribed status. The direct transfer of curricula is problematic because of the differences between the two cultures. To create indigenous curriculum the knowledge base of Indian social work needs to be deepened. Indian data needs to emphasize the magnitude of social problems, causes of problems, implications of existing social structure, consequences of the prevailing intervention programs, needs and priorities of different target groups and communities. Nagpaul (1993) specifies that research is
also needed in areas of resource utilization, impact of tangible indicators, feasibility of projects, and success or failure of projects. This would broaden the foundation of social work research.

Although social work in India has existed in India for more than 60 years (Pathak, 2000), there are critical lacunae in the indigenous literature. For example, author specifies that the gaps include the lack of texts on social group work, child welfare, psychiatric social work and correctional social work. Pathak adds that students rely on books published in the UK or the USA. He claims that the absence of work ethic (of academicians and practitioners who fail to publish their studies) has led to an inadequate stock of indigenous literature in the social work libraries.

The Second Review Committee on the social work education in India (University Grants Commission, 1980) found the growth of social work education to be lopsided. There was a growth at higher levels but stagnation at the baccalaureate levels where the bulk of workers are required. This may be due to the following reason. The organized sector of employment in urban settings does not recognize the baccalaureate degree as an essential qualification for social welfare positions. As a result the student either opts for poorly paid positions in nongovernmental agencies or seeks admission to graduate degree programs. Many students who specialize in a particular field of social work get positions that differ from their training (Hokenstad, Khinduka & Midgley, 1992). For positions like medical social workers or correctional welfare officers, recruitment is not confined to social workers trained in these specialties (Ramachandran, 1977).

Casework in India

Ejaz (1989) wrote that the Indian family is considered a major provider of emotional support. People are afraid of the stigma of not supporting and revealing family secrets. Middle class people are too proud to ask for help, because women and husbands are afraid that they will be blamed for their wives’ illness. Because of this fear, people needing social workers are forced to turn to their families. Many people consider social workers as outsiders. Casework practice in India is complicated because clients are uncertain of the role of social workers (Ejaz, 1989). Their clients identify social workers as doctors, nurses or other professionals. Social work
practitioners focus on problems related to crisis care, sudden illness, financial hardships, physical handicap, wife battery, moral issues and infidelity. There is no private practice and most of the clients are not charged fees, because they are poor and disadvantaged. Indian clientele is poor, poorly educated, dependant on family and seeks advice or guidance in every step of their lives. Although their clientele are impoverished, social workers come from wealthy and more educated families (than their clients). Social workers are mostly women who are more direct, less paid, less confronting than their Western counterparts. They do not follow the client-centered form of treatment. Social work services are attached to hospitals, missionaries or community centers. The social work services deal with financial problems, joint family problems, decreased knowledge, unrealistic expectations, immediate relief, finance, tangible aid, forms or concession passes for public transportation. The social workers heavy caseload included clients needing counseling, administrative work, fund raising, planning, recording and research.

There is little evidence of professional social workers responding to critical social problems (Srivastava, 1999). Social work education and practice that is oriented to the Indian culture is yet to emerge. There is little recognition of social work is a mature profession in India. Srivastava added that the major shortcoming of Indian social work education is the inability to indigenize its knowledge base. The public believes social work to be voluntary in nature. Voluntary social work is considered to be charity and therefore salary should not be paid. This leads to insecurity in social workers and a feeling of guilt for getting paid. Confusion exists in the Indian people, between social work, community-work, social service and public service. In addition, the inability to reach the impoverished could be due to the obsolete curricula and emphasis on generic social work education that does not train students to specific needs of rural Indians. Indian social work is field and not method oriented. The pattern of fieldwork and peripheral activities is not an integral part of social work education. This is in part because the practice of social work that is taught in schools does not change with needs of the Indian culture.

Over 60 years of social work in India, practitioners were educated, using dated and inadequate curricula that have led to decreased social work development (Pawar, 1999). It is for this reason that the profession of social work has not matured in the way it has developed in the
West. There is a need for a field of specialization in social work such as social work intervention in India that includes caste and class struggle (Pawar, 1999). Caste and class struggle are the problems faced by social work clients and this is ignored in Indian social work education. Social work research has low priority because it does not have prospects for practical application. Inadequate theoretical base and limited computer orientation have made it difficult for social workers to carry on social work research. The students who resort to social work because of their inability to enter into engineering or medical professions do not have the motivation or aptitude for strengthening the profession of social work. The above discussion provides a background for social work practice in India. It defends the need for conducting the research in India and lays a foundation for the current study.

**Incidence and Prevalence of Head Injuries in the United States**

Worldwide brain injury mortality rates range from a yearly 15 to 30 per 100,000 according to World Health Organization’s report (1995) on world neurotrauma. They further report that the worldwide incidence of brain injury is not known. The WHO advisory committee on neurotrauma is composed of leaders in research, care, prevention and public policy. They state that, TBI accounts for more than a third of all injury deaths. Many survivors of TBI live with impairments. TBI results in years of productive life lost and high economic costs, affecting individuals, families and society (WHO, 1995). Traumatic brain injury is a major cause of disability in the United States with incidence rate of 2 million individuals per year (Brain Injury Association of Connecticut, 1996). Every fifteen seconds someone receives a head injury in the United States, every 5 minutes one of those injured people will die and another person becomes a permanently disabled person (Brain Injury Association of Connecticut, 1996). The association adds that a survivor of a severe brain injury typically faces five to ten years of intensive services with an estimate cost in excess of $4 million. The association has also reported that annually 20% of injured people will require life long support and that only one survivor in twenty is receiving appropriate rehabilitation. The association further reports that men under thirty are twice as likely to suffer head injuries and that two-thirds of them will live a normal life span, requiring vocational and other support services. Children under five years of age are at greater

**Incidence and prevalence of head injuries in India**

In India, Bangalore is a city with a population of nearly 6 million people. Channabasavanna et al. (1994) report epidemiological statistics (in a study related to TBI) some of which are reported in the following section. The pace of population growth has not been supported by corresponding increase in related areas of social development, infrastructure and health care. Rapid development is accompanied by an increase in motor vehicles, migration and construction of buildings. This has resulted in increased rate of head injuries related to construction sites, falls and road traffic.

The incidence of head injuries actually reported in Bangalore, India, was 61 per 100,000 for a six months period. The incidence estimated was 160 per 100,000 after taking into consideration that many head injuries are not reported. Head injuries constituted 20.6% of total injuries. The highest incidence of head injuries in Bangalore was reported in the age group of 20 – 29 years. The male to female ratio of head injuries was 1:0.3. Twenty-three percent of the injured persons were educated beyond high school while 19.4% were illiterate. Some 43.5% of injured individuals were employed. The total income of 40.5% of injured persons was less than 1,000 rupees per month (one dollar is approximately equal to 50 Rupees). Injured persons who were married at the time of injury constituted 43% of total respondents. Alcohol was found to be a major risk factor for head injuries in the study conducted by Channabasavanna, et al. (1994). About 16.5% of the people with head injuries were directly attributable to alcohol consumption. Of these, 75% of injured individuals had consumed alcohol within 3 hours of the head injury.

The major external causes of head injuries in India, included road traffic accidents (61.6%), falls in various places (22.5%), assault (10.6%) and impact of variety of objects on the head (3.6%). The major external cause of mortality related to head injuries was due to road traffic accidents (68.8% of the cases). Fifteen percent of the patients used an ambulance while public transportation was used in most cases. Only 13.3% of head injured persons received first aid services at the accident scene with 83.1% of cases receiving services from medical practitioners.
Over the last three decades in India and the West, the incidence of TBI has not decreased with increased education, prevention programs and safety laws. Kraus (1993) commented that comparison across existing studies in the United States is difficult due to methodological obstacles. There is a lack of uniform definitions, clinical criteria, and mutually exclusive diagnostic criteria. Without improved definitions and criteria, social workers cannot provide essential services to the relatives of TBI patients.

**Medical Aspects of TBI**

The psychosocial aspects of TBI are difficult to study without first analyzing the medical complications. In addition to a potentially life-threatening, sudden onset of a catastrophic accident and living with chronic long-term sequelae, there is a unique and additional burden imposed by virtue of brain tissue damage (Stambrook et al. 1991). A large portion of the brain and its functioning is not clearly understood by the neurological professionals (B. Kumar, personal communication, Jan. 1991). Only a part of the brain and functions they perform are clearly studied and comprehended by medical professionals. Often prognosis for brain-injuries is poor and positive outcomes are not expected. Even if prognosis is favorable, neurosurgeons are cautious in their prognoses because complications can obscure recovery at any time. It is necessary to understand the difficult medical and psychosocial situation that surrounds TBI to appreciate the impact of TBI on relatives.

Traumatic brain injury can be the result of a traumatic accident, a vascular accident, such as anoxia, aneurysm or stroke, or diseases such as Alzheimer or Parkinson’s. TBI and degree of severity are defined earlier in the definition section (pg. 7). McCormick (1985) reported that TBI could be regarded as focal, diffuse, or secondary lesions. Focal lesions are those that occur in a limited area and are the result of direct trauma to the tissues. These traumas include contusions, subdural and epidural haematomas and intracerabral haematomas. The problems are due to the local brain tissue damage and the creation of masses in the cranium that result in brain shift, herniation and brain stem compression. Diffuse lesions, manifested over a large portion of the brain, are usually associated with a more widespread disruption of neurological functions. This can include mild concussion, classical concussion, diffuse injury or diffuse white matter shearing.
injury (Gennarelli, 1981). Secondary lesions are primarily changes within the brain as a result of either focal or diffuse lesions. These are primarily caused by a lack of blood flow to certain areas of the brain (McCormick, 1985). Severe TBI is typically followed by a period of altered consciousness may include post traumatic amnesia or coma, seizures, headaches, vomiting and/or discharge of cerebrospinal fluid from the ears or nose. The presence and intensity of symptoms are directly related to the severity of the injury which has an impact on the long-term deficits faced by patients and their families (Vogenthaler, 1987).

The medical course for TBI patients depends on the premorbid health of patients, the area injured, its severity and other complications. Severity of injury is an important factor because there is a higher occurrence of deterioration in patients with severe TBI (Rivara, Jaffee, Polissar, Fay, Liao, & Martin, 1996). Stages that describe the course are acute care, focusing on medical stabilization, rehabilitation, addressing recovery of motor, sensory, social and psychological functions, and the ‘plateau’ period where relatively slow progress is made when compared with the earlier phases (Thomsen, 1984; Vogenthaler, 1987b). The acute onset and fluctuating course are part of the complex situation that adds to the fear and helplessness of a situation removed from any previous event for patients and their relatives.

**Impact of TBI on Patients**

Victims of trauma are confronted with their own vulnerability and mortality and experience ultimate threat of their own annihilation. The suddenness of trauma, change in body image, physical helplessness, humiliation and hospital restraints all lead to overwhelming anxiety for the brain injured person (Lenehan, 1986). Bontke studies the relationship between TBI and similarity of post traumatic stress disorder in 1996. Almost all head injury victims who have been comatose for more than a few days suffer irreversible alteration of some socially important aspects of their psychological makeup (Oddy, Coughlan, Tyerman & Jenkins, 1985). The deficits in areas of cognition, socialization, psychomotor skills, physical ability, emotion, and behavior, remain long after the trauma in varying combinations (Brooks, et al. 1987; Peters, et al. 1990; Zeigler, 1987). Head injury frequently produces physical and psychological sequelae involving cognitive, behavioral and personality disturbances that are chronic, and may be permanent. The
TBI patient’s life is irrevocably changed (Hallet, Zasler, Maurer & Cash, 1992). The impact of
TBI on the industry, insurer and work of the patient is immense (Kenny, 1994). The concept of
self is totally changed after TBI (Mwaria, 1990). The National Head Injury Foundation (1986)
broadly classifies the most common sequelae of TBI into: physical, cognitive, psychological,
social, emotional, behavioral categories. This section specifically discusses physical, cognitive
(further divided as attention and concentration, memory, and language), perception, behavior and
personality, emotion, social, independence and occupation constituents of TBI sequelae.

Physical

When coma lasts longer than three months, return of motor function is severely affected
(Edwards, 1987). Complications of prolonged hypertension, ventricular enlargement, and
seizures significantly decrease the probability of achieving physical independence (Brink, 1983).
Physical handicaps are part of the sequelae (Peters, et al., 1990) that is often present with
differential rates of recovery and variable outcome (Bond, 1979). Loss of balance, loss of power,
muscle tone disorders, epilepsy and speech disorders are examples of physical sequelae that may
result following brain injury (Nelson, 1983). Lezak and O’Brien (1988) noted that there was
indication of continuing difficulty with physical symptoms over a five-year study period. Vision
impairments were evident in more than one-third of sample by fifth year and one-fourth had
difficulties with hand use. Ambulatory difficulties and dysarthria (i.e., physical language
impairments that are typically caused by focal lesions which affect muscles of lips, tongue, and
jaw as defined by Rosenthal et al. in 1983) were noted in 17% of individuals by the fifth year.
Having to cope with unexpected physical limitations contributes to detrimental emotional and
personality changes (Lezak & O’Brien, 1988). They added that patients and families do not
appear overly concerned about motor disabilities. Emotional disorders are a greater obstacle to
rehabilitation and community restoration than are physical deficits (Woessner & Caplan, 1995).

Vogenthaler (1987) reported that motor, speech and sensory deficits are common in TBI
patients. Motor deficits may include loss of power, either weakness or paralysis, that is typically
limited to one side of the body (i.e., hemiparesis or hemiplegia), ataxia or muscle movements
that are uncoordinated, deficits in fine and gross motor skills, poor balance and limited
endurance. Because of the serious impact of TBI, services to patients and families are emphasized in India (Gururaj, 1998). The sequelae that Bond (1984) outlined are (1) an impaired capacity for social perceptiveness, (2) an impaired capacity for control and self-regulation, (3) stimulus bound behavior and increased dependency, (4) emotional changes, and (5) inability to learn from social experience.

**Cognitive**

The effects of traumatic brain injury on cognitive functioning are measured via observational assessment techniques, neuropsychological assessment techniques, subjective reports from close family members/caregivers, or a combination of these measurement techniques. Researchers studying the effects of severe traumatic brain injury indicate that most individuals continue to experience severe cognitive impairment long after discharge from the hospital setting (Adamovich et al. 1985; Auerbach, 1986; Ben-Yishay & Diller, 1983; Prigatano et al. 1984). Cognitive defects persist much longer than physical symptoms and lead ultimately to the most debilitating consequences of TBI: economic dependence and continued need for support service (Benton, 1985).

Cognitive impairment especially on spatial motor tasks in head injury was observed by Misra in 1986 in India. Gupta and Nayak (1990) reported that brain damaged patients with frontal or temporal lobe excisions were found to be consistently inferior to controls on tasks assessing visual and constructive ability. They also documented impairment in visual tasks of synthesizing fragmented line drawing following brain damage. There was a relationship found between fantastic confabulation and head injury cases (Sabhesan, Bhaskar & Natarajan, 1988). Amateur boxers reportedly admitted for head injury were found to have developed dementia, epilepsy, respiratory arrest and neurosis (Dhamija, et al, 1988).

Patients who have sustained closed head injury, both focal and diffuse cerebral damage, sustain disorders of physical and cognitive nature. Attention, concentration, and memory are a part of cognition that affects almost all areas of the patient’s functioning. They are discussed below.

**Attention and Concentration**

Most patients with severe head injuries experience difficulty with new learning, memory
and speed of learning (Brooks, 1984; Fussey & Giles, 1988; Brooks, et al. 1987). These difficulties consist of reduced or slowed learning ability compounded by defective information retrieval. Disorders of attention are noted to be major problems caused by all forms of brain injury (Wood, 1988). Moderate to severely headinjured persons have problems with poor concentration, poor memory, and are unable to abstract or manipulate concepts. Relatives of patients in a study by Brooks, Campsie, et al. (1987) reported poor concentration in 64% of 134 cases. Deficits in concentration and attention affect an individual's ability to remain on task to completion, to follow a social conversation, to follow instructions, and to operate independently in any situation (Wood, 1988).

In India attention related middle latency components of visual and auditory evoked potentials were recorded in a group of head injury patients (Pandey, 2000). Mukundan et al. in 1990 observed a slowing of attention process in closed head injury patients.

**Memory**

The two kinds of memory dysfunction associated with traumatic brain injury are retrograde memory and anterograde memory. Memory problems identified by relatives of persons with brain injury include such behaviors as frequent misplacing things, repeating questions, losing track of conversation, forgetting names of objects, and failing to recognize friends by face. There have been reports of memory deficits as a long-term consequence of traumatic brain injury (Thomsen, 1984). Memory loss could cause problems like slowness in thinking, attention, and perception (Fryer & Haffey, 1987; Thomsen, 1987). Fryer and Haffey (1987) added that impaired attention, orientation, concentration, language processing, performance rate, impaired initiative, judgment, and problem-solving skills are common cognitive sequelae associated with serious TBI.

In a comparative study of closed head injury patients and matched controls in India, on a free scale memory task and auditory digit-span test, the former scored significantly lower than controls (Gupta & Ghai, 2000). They also found that severe head injury patients performed poorly in comparison to the mild head injury group.

Difficulties in modulating cognitive activities can show up in conceptual rigidity and
stimulus boundedness (Lezak, 1986). These patients are unaware of how they have changed. If they are aware, their judgment of change is usually not sufficiently accurate to allow them to identify and relate specific impairments to problems in everyday living (Lezak, 1986).

**Language**

In a five-year longitudinal study, 27% and 45% of the individuals studied experienced dysarthria and aphasia, respectively, during the first six months following injury (Lezak & O'Brien, 1988). Dysarthria did not decline as significantly in that 17% (from 27%) of individuals sampled still experienced this defect by the last assessment period. The past three decades of research in the area of brain damage and language disorders have found that numerous loci of the brain are important in intact language functioning (Bigler, 1988). Language deficits that are related to cognitive impairment involve problems associated "with reduced word fluency, impaired visual naming and impaired auditory comprehension of complex oral commands. Also included are anomie (inability to find the correct word), verbal paraphasia (use of incorrect words or word combinations) and associated impairments of reading and writing" (Adamovich, et al. 1985, p. 27-28). These deficits, termed aphasia, are defined as language impairments that are due to cognitive processing rather than defects in oral or aural organs (Rosenthal, et al. 1983). Physical language impairments are typically caused by focal lesions that affect the muscles of the lips, tongue and jaw, i.e., dysarthria (Rosenthal, 1983). Speech deficits include dysarthria, poor articulation of speech sounds (because of injury to the motor speech nerves) and apraxia, impairment of articulatory programming in the cerebral cortex. Sensory damage could result in perceptual, visual, auditory and tactile deficits (Vogenthaler, 1987).

**Perception**

Patients with deficits in cognition might have visual-motor coordination, figure-ground discrimination, spatial orientation, and visual field disorders (Bigler, 1987; Levin, Benton, & Grossman, 1982; Vogenthaler, 1987). An individual who experiences a visual field disorder may only perceive or see one side of a desk top, or may neglect one side of one's body (Vogenthaler, 1987). A spatial orientation problem may prevent a person from being able to maneuver even in a familiar space of two rooms or more.
Behavior and Personality

The patients’ progress in different areas (i.e., behavior, personality, emotion, social skills, independence and occupation) is usually assessed by the doctors’ observation and inference based mainly on relatives’ report of patient behavior. Relatives’ primary complaint of brain injured clients’ are of their behavioral difficulties (Brooks, 1990). The patients’ greatest handicaps come from impaired capacities for control, regulation and adaptation of complex behavior (Bond, 1984). Brooks et al. (1987) asked relatives of survivors to identify persistent disabling effects of TBI. All subjects in their study had sustained a severe closed head injury as determined by coma duration, necessity for surgery immediately following injury and by post traumatic amnesia (PTA) rating. Results strongly indicated that family members saw behavioral and personality changes as most significant. Neurobehavioral and psychological difficulties may foster persisting disability, sometimes in association with protracted litigation (Binder, 1990; McCaffrey, Williams, & Fischer, 1991; Ruff, 1993). According to Lezak and O'Brien (1988), personality and characterological problems acquired by these individuals are serious and may be permanent (Brooks & McKinlay, 1983; Levin, et al. 1982; Lezak, 1987; Oddy, et al. 1985; Thomsen, 1984). Most often these patients suffer from a complex syndrome of defects, such as being childishly self-centered and irresponsible and lacking self-direction, self-control or common sense.

Lezak (1978) delineated five broad categories of personality or character changes in individuals who sustained traumatic brain injury. These are: (1) an impaired capacity for social perceptiveness resulting in self-centered behavior in which both empathy and self-reflective, or self-critical attitudes are diminished, (2) an impaired capacity for control and self-regulation giving rise to impulsivity, restlessness and impatience, (3) stimulus-bound behavior appearing as social dependency, difficulty in planning, organizing activities or projects and decreased or absent behavioral initiative, (4) common alterations such as apathy, silliness, lability, irritability, increased sexual interest or a decreased sex drive, and (5) inability to profit from experience compromising the patient's capacity for social learning, even when ability to absorb new information may be intact. Others (Hendryx, 1989; Prigatano, et al., 1984; Oddy et al. 1985) have
recognized the seriousness of personality and behavioral changes that occur in individuals following TBI.

**Emotion**

Psychiatric problems are found in some TBI patients (Lishman, 1973; Bond, 1984). In India, few studies have examined emotional deficits in brain damaged patients (Pandey, 2000). Manic reactions following brain damage were reported by Nizamie, Nizamie, Borde, and Sharma in 1988. The same was reported by Sabhesan, Bhaskar, et al. (1988). Post traumatic neurosis and psychoses were reported following head injury (Pathak, Renjhen & Mitra, 1983). Head injured patients are more psychologically distressed than spinal cord injured patients in the U. S. (Stambrook et al., 1991). Specific psychiatric problems such as frontal lobe syndrome and dementia may develop (Stambrook et al., 1991). Secondary changes include lowered self-esteem, increased frustration, despair, depression, paranoia and suicidal ideation (Stavros, 1987). Irritability and impatience are common reflecting both an impaired capacity for self-control and persistent frustrations imposed by their mental and physical handicaps (Prigatano et al., 1984). Emotional symptoms such as depression, anxiety, irritability, apathy and lability are common problematic consequences of brain injury (Woessner & Caplan, 1995). Moderate to severely head injured persons are emotionally labile and have personality changes and perceptual disorders. Difficulties in modulation of emotional reactions can result in lability, temper outbursts or flattened affect. The head injured member is often child-like in dependence, depression, amotivation, impatience, violent outbursts or lethargy (Popper, 1987). Presence of irritability, premorbid substance abuse, longer time postinjury, greater severity of injury, longer acute hospitalizations and poor judgment were all correlated with poorer family functioning (Moore, 1993).

Depression or paranoia may be caused by an individual's awareness of their disabilities. In a study by Brooks and his colleagues (1987), individuals who had sustained severe head injury were described by relatives as being irritable, angry and depressed (Brooks et al., 1987). By contrast to relatives’ perceptions, TBI patients may be depressed because of their families’ denial and lack of acceptance. Roueche and Fordyce (1983) and Fordyce and associates (1988)
attributed disability awareness to decreasing cognitive confusion after head injury. Out of seven broad categories of deficit, family members rated the emotional change category as the most significant problem area. Within this category, subcategories were rated by over half of the relatives reporting in all subcategories (i.e., anger, 67%; irritability, 73%; impatience, 56%; depression, 63%; personality change, 76%). This high rate of reported deficits is not surprising because all the areas (e.g., emotion, behavior, cognition and personality) affect each other. These deficits in turn have an impact on patients, their relatives and family functioning.

Social

In India, patients with head injury, showed poor adjustment in family as well as personal areas (Sabhesan, Premila, & Natarajan, 1988). Although TBI patients are capable of simple tasks, they often cannot perform them independently (Lezak, 1986). Although changes may not be apparent, the disabilities tend to disrupt the patient’s life and that of his/her family permanently. There is a pattern of continuing disability on the part of TBI patient and distress by the family members (Kreutzer, et al. 1992). Deficits in cognitive, psychosocial and physical skills adversely affect an individual's ability to function in major life activities following severe TBI. Many individuals who were independent as adults find themselves unable to manage basic activities. These activities are related to living alone, staying at home alone, traveling around the community, participating as a consumer in retail stores, social organizations, recreational facilities, handling money or personal finances (Fussey & Giles, 1988; Jacobs, 1988; Jacobs, Blatnick, & Sandhorst, 1990; Prigatano, Klonoff, & Bailey, 1987). The resulting deficiencies cause varying degrees of maladjustment at home, in society and in the work place (Brooks, et al.1987; Jacobs, 1988; Thomsen, 1984; Warrington, 1981).

Independence

In many cases, family members find that their injured relative cannot be left alone (Brooks et al. 1987). Jacobs (1988) interviewed 142 families of individuals who had sustained serious brain injury. The results indicated that 20% of the individuals required assistance with their basic self-care skills such as eating, dressing, grooming, and bathing. Thirty-seven percent were dependent on others to accomplish higher order self-care skills, such as caring for health,
personal safety, purchasing or selecting appropriate clothing. In most cases, difficulties with lower order self-care skills were attributable to physical limitations, while inability with higher order skills were apparently more related to cognitive, perceptual, communication and behavioral deficits. Thirty-three percent of individuals reported to being unable to read directions on packages independently while a few were not able to read newspapers. While most individuals sampled were able to tell time (89%), only 65% demonstrated that they knew how to allocate time for specific activities and 43% were reported to be unable to get around their city without getting lost. Findings from this study indicate that most survivors lived with their families, did not work or attend school and were dependent on others for basic needs, finances and services outside home. In a study by Prigatano and associates (1987), 30 of the 89 individuals studied were considered old enough to be living alone but were living with their parents instead.

The emotional and social problems persist and appear to increase in magnitude, years after the individual has been injured and has received a regimen of rehabilitation (Brooks, 1984). Long-term consequences make it extremely difficult for TBI patients to be well adjusted with their families, to work for a living and to conform to the societal norms (Brooks, et al. 1987; Jacobs, 1988; Lezak & O'Brien, 1988). Majority of TBI patients, return home and their relatives have to cope with little support and adopt defense mechanisms such as denial. TBI patients lack judgment and sensitivity and have limited social graces. Major areas of patients’ lives that are most seriously affected include independent living, work and social relationships. Kozloff (1987) conducted a qualitative study to examine the social networks of individuals with TBI. Kozloff used an ethnographic research methodology to collect data from 37 individuals who had sustained severe TBI and 39 of their significant others. One important finding was that as time from onset increases, network size decreases and network density increases. Individuals reported a decrease in their social relationships and a feeling of isolation from their peers. In another qualitative study (Karpman, Wolfe & Vargo, 1986), individuals who were between two and five years post TBI, unanimously agreed that social isolation was a concern (Karpman et al. 1986). In India most individuals were almost totally dependent on their families for all aspects of their lives (Acharya, Pruthvish & Rajendra, 1998).
**Occupation**

Additional information (Oddy, et al.1985; Brooks, et al. 1987) pertaining to social skills or difficulties is discussed within the context of returning to social settings within the community (i.e., employment, school, and other community settings). Based on measures of motor abilities and intellectual performance, many patients are capable of earning a living, or at least performing familiar household chores. However, few patients return to the level of employment they had prior to TBI (Brooks, et al. 1987). Loss of work and alienation from friends are the most disrupted areas of patients’ lives (Brooks, et al., 1987).

In a study conducted by Brooks and his associates (1987), a poor return-to-work rate was reported for a sample of 134 individuals who had sustained severe head injuries. Five years after injury, a substantial proportion (70 %) of patients were still unemployed (Brooks, et al. 1987). The Brooks report identified cognitive and behavioral factors to be more significant in contributing to unemployment than physical deficits.

Prigatano et al. (1987) surveyed 95 individuals with a mean duration of 29 months of mild, moderate, and severe TBI. The data indicated a positive correlation between severity of injury and outcome of patients returning to work or school. Sixty-two percent of patients whose injuries were in the mild range, 50% of patients in the moderate range, and 23% in the severe range, returned to work (Prigatano, et al. 1987).

Stapleton (1986) conducted a retrospective study of 40 individuals in which discharge recommendations from a rehabilitation program were reviewed. This study documented professional expectations for vocational outcome rather than achievement of outcomes. Of this sample, 35% were recommended for sheltered workshop services, 10% for formal job training, 17.5% for work adjustment, 30% for prevocational services, and finally, 7.5% with no reasonable expectation for employment (Stapleton, 1986).

In India, the majority of the TBI patients who had severe TBI accompanied by physical and/or emotional disabilities do not get back to their previous level of employment. Many patients come from an agricultural area and therefore work at home or not at all. In urban areas, the lack of facilities and high level of social stigma towards mental or behavioral disabilities
restrict disabled patients their homes (see pg. 14 for discussion by Srinivasan, 2000). Most TBI patients discharged from hospitals, with physical and emotional disabilities were kept out of sight from neighbors, friends and relatives (P. Rajaram, personal communication, April, 1994).

Long-term psychosocial problems have a direct relationship to high unemployment and employment turnover for TBI individuals (Jellinek, Torkelson & Harvey, 1982; Prigatano, et al. 1987). Patients’ complaints of impaired cognition and emotional changes are issues that influenced return to work (Hendryx, 1989). Hendryx added that interacting factors resulting from TBI were perceived changes in employment, physical, cognitive and emotional status. Given the array of consequences of TBI on patients, it is instructive to examine the effect on relatives.

**Impact of TBI on Relatives**

TBI patients and medical service personnel rely on primary family members (Frank et al. 1990). Relatives experience major difficulties when their loved ones sustain TBI (Barry & Clark, 1992; Brooks, et al. 1987; Eisner & Kreutzer, 1989; Lezak, 1988; Mintz, 1994; Zeigler, 1987). Following acute hospital care, patients recover from serious TBI in terms of medical crisis, but still have substantial, long-term needs for assistance and services (Bush, 1988; Vogenthaler, 1987). Researchers report that continuing symptomatic sequelae of TBI patients are a major cause of burden and stress on close relatives (Eisner & Kreutzer, 1989; Jacobs, 1988; Livingston & Brooks, 1988). Head injury exposes relatives to problems that are unique to this disability (Florian, Katz & Lahav, 1991). There are increased demands on close relatives because increasing numbers of individuals with severe TBI require long-term, rehabilitation services and a shift toward community based service delivery. Even though professional rehabilitative care is widely available today, relatives are often considered primary caregivers for persons with disabilities once acute care is no longer necessary.

In India, relatives are always regarded as primary caregivers for persons with disabilities (Patel, 2000). Reliance on relatives occurs after hospital care is no longer necessary because, financial constraints have prevented community based services from being developed (Pandey, 1993). Indian relatives may be less likely to disclose emotional needs than the Western relatives. The personnel and professional interface is quite different in India that requires the meticulous
translation of measures, which can be used to enable families to help each other.

Rehabilitation specialists provide treatment and support to relatives to help them cope with the heavy burdens placed on them (Maitz & Sachs, 1995). State and local chapters of the National Head Injury Foundation across the U.S. provide support to TBI individuals and their close relatives. Relatives are called survivors of TBI (Brown & McCormick, 1988). Researchers are continuing to study impact of TBI on relatives along with strategies used for coping with stresses related to care giving roles (Graffi & Minnes, 1988). This discussion will be couched in existing theories and models. Evolution of relatives’ reactions will be discussed before narrowing the focus of the paper to consider relatives’ reactions to TBI and relevant measurement devices.

**Related Theories and Models**

Researchers have established a theoretical base to the problem that faces relatives of TBI patients. The problem of relatives reacting in an adaptive or maladaptive manner is obscured by medical needs of the TBI patient. There is a long delay before needs of relatives are regarded as important enough to warrant professional attention. Studies done on relatives of TBI patients are largely exploratory. Few studies have used relevant theories to study the complex stressors that confront the relative of TBI patient. This theoretical discussion sheds light on how relatives react to TBI patient and clarifies potentially maladaptive reactions.

Sachs (1985) used Frankl's (1969) existential approach to psychotherapy, (i.e., logo therapy), to develop a model of treatment. The essential element of this approach is ‘logos’ or knowledge of oneself. The individual’s well being is related to his/her ability to find meaning in life. Three principles describe the ways in which individuals can find meaning in life. The first is what they give to the world in terms of their creations in life. Second is what they take from the world in terms of encounters and experiences; and third is the stand he/she takes to his/her predicament in case he/she must face a fate that he/she cannot change (Sachs, 1985). Sachs added that many difficulties presented by relatives of TBI adults appear similar to despair that logo therapy addresses. Three tenets are established: recognizing the tragic aspect of life, orienting oneself to the future, and recognizing the role of personal responsibility and commitment. It is a positive approach to view TBI as not merely an event to be painfully endured, but rather one that
can be reinterpreted as a growth experience, though one can argue that it is minimizing the traumatic experience.

In close relation to this study, the Reiss' Family Paradigm (1981) suggests that the family unit develop ways to evolve a mode of perceiving, and interpret and interact with the social world through integrating various styles of its members. This is included here to understand how different types of relatives react in different ways. The three dimensions discussed in this study include configurations, coordination and closure. Configurations depict the way families differ in their experiences of the world and the belief that a reasoned search of the world can solve its mysteries. Coordination is the extent to which family members perceive that the world is equally open to all members and whether they see themselves as loosely bound, or as a tight unit. Closure is the extent to which family perceives events as familiar and, thus, interpretable or whether the family sees events as novel and in need of new means of interpretation. The three topologies which families fall into include the environment-sensitive families, interpersonal distance-sensitive families, and consensus-sensitive families (Reiss, 1981). Reiss used this model for a family coping with a handicapped child. This model is regarded as highly theoretical and difficult to measure empirically (Moore, 1993). Moore adds that the model is limited as it primarily focuses on how families view the world and their place in it.

In the trauma literature few studies have observed relatives react to a family member being treated for TBI in a hospital. Earlier studies focused on the crisis faced by the patient and the need for crisis intervention (Bartoloucci & Drayer, 1973; Spitz, 1976). Professionals need to look beyond the physical treatment of the patient to the psychological care of the patient’s family to assist them in coping with the crisis of injury or illness. In India, professionals do not really assist relatives in coping, instead the family members try to provide that function. This difference in patient or professional interface the instruments would be beneficial in aiding social workers to enable family members to effectively help patients. In India, professionals do not really assist relatives in coping, instead the family members try to provide that function.

General Systems Theory has been discussed in the literature more than any other theory and will be further examined here. Families are regarded as living, on-going entities, with
members organized in a continuous, interactive, patterned relationship with one another and extending over time and space (Goldenberg & Goldenberg, 1991). The Goldenbergs add that a change in one component inevitably is associated with changes in other components with which it is in relation. They emphasize that there is a need to focus on structure and its processes. The elements of a system act in a predictable, organized fashion with one another. The sum of their individual parts constitutes the whole through their interaction. The parts in isolation are not equal to the whole. The rules that govern family system ensure that the organization is maintained and outline the way people pattern their behavior in systems. This helps in maintaining homeostasis (internal, sustaining and dynamically interacting processes) that take place within a family and assure its internal balance. Families have boundaries that are invisible lines of demarcation that vary in their permeability with regard to the amount of influence allowed. They can be open or closed, depending on information that is allowed through.

The impact of a family member experiencing TBI has near instantaneous effects on the entire system (Rees, 1988). Family system must adapt to potential loss, shifting roles and boundary invasion. The integrity of systems is threatened when a member is lost. Although persons experiencing TBI are between the ages of 15 and 24, families may have 20 to 40 years of caretaking when injuries are severe (Williams, 1991). When able members carry on the roles of the injured member, forced transitions and added responsibilities can lead to role strain (i.e., stress that an individual experiences when they have difficulties in carrying out the expectations of various roles; Maitz, 1991). Many families have increased stress when interacting with the outside systems. The interaction of family system with the boundaries outside is important in their adjustment to current stress. As time passes, previously closed or open families tend to lose contact with their support systems (Brown & McCormick, 1988; Zarski & Hall, 1987).

Other systems theorists have expanded upon the General Systems Theory. The Beavers Systems Model classified families along a linear continuum, with respect to their competence. The extremes were centripetal and centrifugal family functioning, with optimum position at the center. Centripetal extreme position depicted relationships where satisfaction is derived from within the family and centrifugal where families look to the outside world for satisfying
relationships. This model was applied to families of retarded children (Hampson, Hulgus, Beavers & Beavers, 1988). The circumplex model classified families according to two dimensions - adaptability and cohesiveness. Families were considered to be dysfunctional if they exhibited either extreme of dimension (Olson et al., 1985). These models are discussed here inasmuch research studies (Appendix B), have implied that researchers have adapted some of these models in their studies.

The McMaster Model of Family Functioning is both theoretical and clinical. This model focuses on dimensions of family functioning that affects family members’ physical and emotional well being. The model suggests three tasks of the family. First, the basic task in which the family deals with providing basic necessities like food and shelter. Second, task deals with problems arising from developmental stages of members in the family. The third task deals with contingencies of illness, accidents or loss. This model attends to family structure, organization and transactional patterns (Epstein, Bishop & Baldwin, 1982).

De Pompei et al. applied systems theory, described by Bertalanffy, in 1987 to understand family reactions to TBI. This helped to understand family dysfunction by examining recurring patterns of family interaction instead of focusing on one individual component. De Pompei et al. suggested that if the family is viewed as a unit that contains unique individuals who relate with, rely upon and react to all other members of that unit, then the rehabilitation teams may be able to employ different approaches in their educational counseling with families. Rehabilitation team members who were aware of the individual behavioral differences of TBI patient often did not see the individuality of other family members and their relationships.

General systems theory forms a strong theoretical base to understand the reactions of relatives to TBI patients’ experiences. The review of literature shows transition from focusing on individual patients, to families as useful aids in the rehabilitation. The general systems theory recognizes that relatives are important individuals in and of themselves. Systems theory suggests that if any member (TBI patient) is not functioning well, then the whole family may not be in homeostasis and thus experience a threat. As a result there could be stress that prevents in-depth intervention. There is a need to prevent these stressors at the outset, as a form of secondary
prevention. Social work intervention with relatives of TBI patient (i.e., element of whole system) can cause changes in other components of the family. In other words, family intervention would help in the recovery process of the patient and help families maintain homeostasis.

The above models are discussed because they help us understand how families of TBI patients react to the event (Reiss, 1981). These models also help in planning treatment strategies (Sachs, 1985). The models help the rehabilitation teams to employ different approaches in their educational counseling with families. Despite challenging differences between Western and Eastern cultures, the conceptualizations of the relatives’ reactions to TBI and their endeavor to readjust is similar. This similarity has made the transfer of Western models and theories to the Indian population, useful to a large extent. This is especially true because of the lack of indigenous literature dealing with models and theories created specifically for the Indian population. Despite challenging differences between Western and Eastern cultures, the conceptualizations of the relatives’ reactions to TBI and their endeavor to readjust is similar.

**Stages in the Evolution of Relatives’ Reactions to TBI**

Families of TBI patients undergo a series of reactions as their appreciation of injured patient’s condition evolves. A process conceptualized by Maus-Clum and Ryan, (1981) in terms of six different reaction patterns or stages is discussed below. Some families experience all the stages to varying degrees. Others may bypass one stage while some become bogged down for years at an early stage. The stages tend to overlap and may occur in different order. Though most of these stages are important, and can be as devastating as the next stage, the first stage is most important and will be discussed in depth. In the first stage, families must assess maladaptive reaction and behaviors that help prevent those reactions and behaviors from hampering future adaptive functioning. Depending on initial reaction, later coping strategies will be formed. It is essential for the treating team to assess initial reactions and help the relatives through the trauma in preparation for the ordeal ahead.

The onset of TBI, especially as a result of accident, stroke or cardiac disease, is a sudden life-threatening crisis that disrupts family life. TBI may be a precursor of a serious and chronic illness, like general epilepsy, total paralysis, persistent vegetative state, meningitis, or renal
infection that poses specific adjustment problems for both families and individuals (Maus-Clum & Ryan, 1981). The injured person is likely to be critically ill and hospitalized in an intensive care setting. Families are often shocked to find the person they knew as healthy only hours before to be unresponsive and corpse-like. The intensive care unit is foreign and often overwhelming to families and patients (Maus-Clum & Ryan, 1981). The initial reactions are one of disbelief, shock, guilt, fear (Williams, 1991) and increased stress (Elliott & Smith, 1985). Of the six stages described above, first stage is the anxiety stage, which lasted an average of nine months for 180 families (Bray, 1977). These families were confronted by severe disability of a family member. First stage has also been described as one of happiness because patient is alive, although families regard patient to be burdensome due to fatigue, inactivity or weakness (Maus-Clum & Ryan, 1981). In this stage families often expect full recovery by the end of one year.

Bewilderment and anxiety mark the second stage when the patient is uncooperative, unmotivated, and self-centered. Families believe full recovery is possible for patients who give effort. In the third stage, family is discouraged, guilty and depressed, as they perceive the patient to be irresponsible, self-centered, irritable and lazy. Family believes the patient could become independent with their help. In the fourth stage families are depressed and exhibit feelings of being trapped (Maus-Clum & Ryan, 1981). They expect little or no change in the patient as they see a difficult and child-like person different in comparison to the one they once knew. This condition and expectation carries over to the fifth stage during which the family goes into mourning. In the last stage family reorganizes emotionally (if not physically disengaged) with the same perception of the patient and losing hope that patient will ever improve (Maus-Clum & Ryan, 1981).

The period subsequent to what is known as the "recovery plateau" occurs approximately six to nine months postacute care (Vogenthaler, 1987a). At this point following injury, the individual's recovery slows down and family realizes that their family member will not be returning to his or her preinjury state (Warrington, 1981). At this point the service provision support typically fades to minimal levels, leaving long-term care to family members (Warrington, 1981). During these stages relatives react in a distinct manner, depending on their role and
personality. This reaction is discussed in detail below.

**Emotional Reactions of Relatives**

There is a paucity of Indian literature with regard to the general emotional reactions of relatives of TBI patients. Rajaram (1991) conducted an experimental study on emotions of TBI patients. This was the first study of its kind (concerning relatives of TBI patients) conducted in India. The research was conducted to assess the impact of structured intervention on relatives of head injured patients. The study included a purposive sample of 60 Indian relatives of severe TBI patients. Design of study was experimental, with 30 subjects each in control and experimental groups. A structured interview schedule included questions of sociodemographic data, details of the injured patient, sociodemographic details of the relative and Speilberger’s State Anxiety measure. The psychosocial package was administered following the initial interview. After 24 hours, the state anxiety measure was administered again to check for changes postintervention.

Data was analyzed using t test and descriptive statistics were used to present data. A significant reduction in state anxiety was found in the experimental group that received the psychosocial package. There was no significant change in level of state anxiety in the control group that did not receive the psychosocial package.

Several Western studies describe family members of patients who have sustained a severe TBI (Bishop & Miller, 1988; Brooks, et al. 1987; Camplair, et al. 1990; Jacobs, 1988; Livingston & Brooks, 1988; Lezak, 1988; Rodgers & Kreutzer, 1984; Zeigler, 1987). Family members report long-term adverse effects as a result of TBI. Difficulties experienced by family members of those who sustained a TBI may be more pronounced because of the late onset of disability (unlike congenital anomalies), unrealistic expectations for recovery and a lack of awareness of available support services (Warrington, 1981). In addition, descriptive research indicates a strong relationship between personality, behavioral changes and disruption to family life (Brooks, et al. 1987; Lezak, 1988).

Early investigation of impact on family was undertaken as rehabilitation practitioners tried to alleviate stresses of family members while treating the injured individual. The long-term effect of severe TBI on individuals and resulting impact on family suggests continued disruption.
of the family unit (Brooks, et al. 1987). Families of TBI patients experience a high level of subjective burden and associated psychological distress (Brooks, 1990). The general emotional reactions of relatives of TBI patients and reactions of parents and spouses will be examined below.

Often discrepancy exists between actual and apparent abilities of the person recovering from TBI. Unrealistic expectations coupled with desires of the individual to be the way they were before injury causes tension and stress among all close family members (Lezak, 1988). Families experience difficulties when they realize the level of care needed and long-term outlook. Impact on family members is substantial as they assume responsibilities of relatives, independent living skills’ trainers, services coordinators, counselors and transporters for their injured family member. Repeated frustrations with a nonresponsive, incomplete and/or nonexistent service system leaves the family to provide these services and to act as case managers, operating by trial and error to locate support services in an unfamiliar system (Warrington, 1981).

In response to the outcry of family members and clinical treatment professionals, researchers have examined impact of TBI on the family (Brooks et al., 1987; Livingston & Brooks, 1988). Empirical evidence documenting stress and disruption of social functioning on the family unit has prompted development of materials designed for family members (Colorado Head Injury Foundation, 1991; Headlines, 1990). Textbooks and textbook chapters for professionals in the field have also been developed (Camplair, Kreutzer, & Doherty, 1990; Esposito & Esposito, 1990; Kreutzer, Zasler, Camplair, & Leininger, 1990; Waaland, 1990; Williams, 1991). Using Satir’s family characterization, Watson (1987) postulates that when one member becomes disabled all other family members are affected. Families are in varying degrees of disability and disarray in post trauma (Johnson & Higgins, 1987). Relatives of severe TBI patients suffer significant psychiatric morbidity when compared to relatives of patients with minor TBI. A retrospective study of expressed emotions and emotional distress in relatives of TBI patients revealed levels of anxiety significantly higher among high expressed emotions group. It is difficult to pinpoint relationship between anxiety in relatives and TBI because these groups may have a genetic predisposition to high anxiety. There was a high level of depression in
groups with high and low expressed emotions (Flanagan, 1998).

Mood disturbance of relatives included high levels of anxiety. Those who have other disorders like depression and psychosomatic illness have a major anxiety component. Forty-five percent of relatives of severely injured men score beyond the Leeds Anxiety threshold, while 57% do the same on the General Health Questionnaire (Frye, 1982), perhaps indicating that others are suffering a more generalized disturbance. Frye (1982) noted an increased incidence of duodenal ulcers, heart attacks, depression and divorce in families of TBI patients. Lezak (1986) found that anger, frustration and sorrow are natural emotions for close relatives of TBI patients. In a study conducted by Maus-Clum and Ryan (1981), half of the TBI patients’ mothers and wives interviewed, reported experiencing frustration, irritability and annoyance. Three-fourths of spouses reported depression, anger, financial insecurity and decreased social contacts. Half indicated they were married but did not really have a husband like the one they once knew and loved, because they could not mourn for loss of the spouse and they had to care for a near total stranger who gave little in return.

As the result of TBI, financial resources are depleted, stress is increased for the breadwinner, parental roles are strained, and siblings are challenged. Caregivers’ premorbid personality and financial strain may be related to the stress (Peters, et al. 1990). Behavioral changes of the patient causes changes in marital relationship, daily routines and social activities. These changes can tax the strength of even the strongest family (Gordon, 1989). The more severely patients are injured, the more their relatives become patients as well. Relatives may (psychologically) suffer more than TBI patients themselves. A high rate of depression was found in caregivers of head injured patients and the variable most predictive of elevated depression scores was coping satisfaction (Knight, Devereux & Godfrey, 1998). Families knew less and, consequently, had more anxiety about trauma’s effects and its threat of loss (Lenehan, 1986). They have the additional burden of feeling powerless in face of a loved one’s desperate need. Epperson (1977) identified six phases of recovery for the trauma patient’s family. They include high anxiety, denial, anger, remorse, grief and reconciliation. Children of parents with TBI experienced more symptoms of depression than the comparison group (Uysal, et al.1998). Oddy
et al. (1978a) using the Wakefield Depression Inventory, found a high incidence of depression associated with relatives’ perception of patients’ problems early in the recovery phase. Unfortunately, sample was skewed towards higher socioeconomic categories and those under-40 years old. For some, depression occurs as a chronic pull on their lives that continues as a permanently fixed emotional burden. For others, depression comes and goes with patient’s ups and downs. Relatives patient are most likely to suffer at least one or two bouts of deep depression in which they lose the will to live and may become suicidal (Frye, 1982).

Brooks and McKinlay (1983), using a seven-point rating of stress, demonstrated that relatives remained moderately stressed for a year following injury. Stress was associated with relatives’ perception of patients’ problem. Livingston, Brooks and Bond (1985a) noted a significant number of family members who reported anxiety-based affective disturbances. Relatives of severe TBI patients had higher scores on anxiety/insomnia, social dysfunction and perceived burden than did relatives of mild TBI patients. This persisted throughout the year following injury. Many relatives gave evidence of significant stress even a year after injury (Oddy et al., 1978). Emotional reaction of relatives can be placed under constructs of anxiety, depression and life satisfaction.

**Reactions of Parents**

It was found that children of parents with TBI, perceived parents as more lax and less actively involved in parenting roles (Uysal, et. al., 1998). Due to high incidence of TBI occurring between ages of 15 and 24, many individuals returned to their parental family (Oddy, et al., 1985). According to theoretical perspectives of familial developmental stages and transitions, stages of adolescence and launching encompass the years between 15 and 24 (Olson et al., 1983). Parents reach a stage when they expect children to transition out of the nest. Families of individuals with disabilities undergo stress when naturally occurring transitions do not. Parents continue to be responsible for grown up children who have succumbed to TBI because they are unable to live independent lives. Families live daily with practical effects of memory loss. Mothers often become full-time caretakers (Stavros, 1987). Fathers report increased pressure to make up for lost income and increased medical expenditure (Popper, 1987). Individuality,
interests and personal needs of family members become submerged at times by patients’ needs and demands (Lezak, 1986). Other siblings may be ignored or neglected by the parent (Gordon, 1989). Stavros adds that psychosocial assessments of TBI patients’ family system often reveal a pattern of substance abuse that compounds the existing situation. A study assessing long term consequences of TBI on patients and relatives noted that mothers differed from wives in their response profiles (Santos, Castro-Caldas, & De Sousa, 1998).

Reactions of Spouses

TBI disrupts marital stability and creates stress in marriage (Resnick, 1993). In an empirical study (Peters, et al, 1990), wives reported less expressed affection, satisfaction, feelings of cohesiveness, overall marital adjustment within their marriages when compared to ratings by wives of spinal cord injury patients. A cross sectional study of primary, secondary and tertiary caregivers found wives at greatest risk of poor psychosocial outcome (Perlesz, Kinsela & Crowe, 2000). Lezak (1978) studied three wives of injured individuals who had been discharged from hospital for approximately four to six weeks. Within a two-week time period, all three women requested psychological help, expressed fears that they (the wives) were going crazy, were failing their family and were trying to fight off frustration, disappointment, fatigue, and depression (Lezak, 1978). Stern et al. (1988) reported that wives recognize conflicts when they divide their attention between husband and family. Wives of TBI patients reported more depression than do wives of paraplegics (Rosenbaum & Najenson, 1976).

A family support group network was established, through which Lezak (1978) identified numerous problems cited by family members. Family members described their spouses with TBI as dependent, demanding, irresponsible, foolish, ill mannered or dangerous in the support group. They also described emotional stress experienced by all close relatives. Wives expressed feelings of being abused emotionally, physically and of being isolated, trapped, abandoned, and subjugated by TBI member. Lezak (1978) further described special problems experienced by spouses of individuals with TBI to be overdemanding or unable to perform sexually. Many spouses assume responsibility of a primary caregiver although they may be unprepared to assume major household and financial responsibilities.
Lezak (1978) also discussed particular difficulties for spouses where children were involved, including unrealistic expectations, prevalence of depression of relatives, family counseling needs and other issues related to effects on and support services for family members of individuals seriously disabled as a result of TBI. Zeigler (1987) discussed impact on family from the perspective of a spouse rather than a parent. There are difficult adjustments to be made with a partner because of altered responsibilities of a spouse. The spouse of a person with TBI often provides physical care and supervision to the injured individual, in addition to assuming household tasks, overseeing rehabilitation, health care, social service agency activities, and making decisions for the disabled spouse (Zeigler, 1987). Unspoken social constraints are placed on a spouse of patient who may be contemplating divorce. Marriages are subject to severe strain or disintegration. The most troubling sequelae of TBI to families are labeled "psychiatric" in the broad sense: cognitive impairment, memory loss, confusion, irritability, mood instability, behavioral disturbance and personality change in their partners. Thomsen (1984) concurred with Maus-Clum and Ryan (1981) that wives have more difficulty than mothers do, in accepting family changes after TBI. One-third of Thomsen’s sample either considered or filed for divorce. It is difficult to say whether divorce was directly caused by TBI in spouses. However, it is clear that marital relationship of TBI patient is vulnerable to stress. Wives of severe TBI patients experience psychiatric problems, psychosocial dysfunction and high level of burden imposed by the injury in the year following TBI (Livingston et al. 1985a).

**Rationale for Selection of Constructs: Pilot Studies**

This section follows the general reactions of relatives to TBI and the reactions found in parents and spouses. The ensuing discussion includes selection of constructs and is followed by a technology review. Health professionals have recognized that presence of disability has a profound effect on families, although research and mental health interventions have focused on individual patients (Peters et al., 1990). There is insufficient empirical information available on psychiatric and social outcomes for relatives who live with a TBI patient (Livingston et al. 1985a). Many relatives seek professional assistance years after the accident for major psychiatric disorders, marital problems, or family discussion (P. Rajaram, personal communication, July
1992). Literature indicates that the first stage is crucial (Maus-Clum & Ryan, 1981) for families to strengthen adaptive coping skills eliminating those that are maladaptive. Later coping strategies are formed based on the initial reaction. Maus-Clum and Ryan (1981) have reiterated that relatives are bogged down for years at the early stage. It is imperative that professional social workers assess those reactions that hamper functioning of relatives and strengthen their adaptive skills. Few therapists have been trained specifically to help TBI patients’ families deal with their emotions (Stavros, 1987). A careful analysis of these emotions could signal professionals to appropriately help families over their emotional turmoil that may become a psychosomatic or a major psychiatric disorder. To date there is no measure to specifically assess reactions of relatives of TBI patients. Emotional reactions identified in the above studies include anxiety and depression, both of which have an impact on relatives’ life satisfaction. Two pilot studies were conducted because literature did not provide needed guidance. The first study was a mini-ethnography that the researcher conducted in 1995 to delineate the domains under which emotional reactions (main domain as defined on pg. 8) cluster.

**Mini-ethnography**

The purpose of the mini-ethnographic study was to delineate domains to be included in the proposed instrument. Ethnographic techniques proposed by Atkinson and Hammersley (1983) were used to explore responses based on a small number of cases using unstructured interview data. Analysis involved explicit interpretation of reactions of relatives to TBI. Interviews were conducted in the United States and taped using an interview guide (see appendix N). Subjects were included if they were relatives of a severe TBI patient, were over the age of 18, spoke English and had no prior history of substance abuse or psychiatric disorder. Two of the three subjects were of Indian origin.

Interviews were similar to feminist-based interviewing that required openness and emotional engagement, as explained by Oakley (1981). The semistructured guide contained open-ended questions covering areas of TBI and its sequelae that needed to be discussed with the relative. Open-ended questions (or areas covering TBI and its sequelae) were listed based on discussions with neurological social workers who rated the content of questions (or areas
covering TBI and its sequelae) as satisfactory or not. The researcher conducted all interviews to maintain uniformity and to prevent differential effects of interviewers.

Domain analysis was conducted on transcriptions of interviews. Three iterations revealed that the emotional responses grouped around three domains. The domains turned out to be anxiety, depression and impact on relatives’ lives. Taking into account the small sample size, results of this study are limited. However, as a pilot exploratory study, preliminary findings paved way for further in-depth research studies.

Keeping this in mind, the following sections were limited to reviewing publications focusing on empirical and technology (as defined by Klien and Bloom in 1994) and measures that assess domains of anxiety, depression and life satisfaction. It should be noted that domains of anxiety and depression differ significantly from major psychiatric disorders. Relatives of TBI patients seldom have major psychiatric disorders soon after the tragedy (K. Reddy, personal communication, July 1999). They have symptoms of depression that may affect mood, cognition, behavior and biological functioning. Often these symptoms are believed to be natural responses to stress and are ignored because symptoms are not enough to warrant a diagnostic label (of major psychiatric disorder). Relatives are burdened with tragedy and taking on extra role of patient and relative. This cumulative impact of loss, role strain and lack of external support inevitably leads to breakdown of the caregiver. This scenario is preventable if social workers can quickly assess major reactions and treat maladaptive reactions appropriately. For this intervention, appropriate measures are necessary for social workers to use with families of TBI patients.

An in-depth and structured analysis of literature concerning relatives’ reactions to TBI patients was required before assessing available instruments. Klein and Bloom's (1994) categorization system was used for the review with emphasis placed on empirical and technology categories because they are pertinent to this effort. A critical review of literature pertaining to relatives’ emotional reactions to TBI is presented here.

**Empirical and Technological Review**

This section identifies relatives’ reactions and analyzes instruments used to assess their
reaction. This section also provides a critique of literature that deals with assessment of emotional reactions of TBI patients’ relatives. The earlier presentation analyzed emotional reactions while the following paragraphs deal with the critique of emotional reactions’ assessment. Articles are specifically chosen to make this discussion relevant only to assessment of relatives’ emotional reactions to TBI (in particular anxiety, depression and life satisfaction). The inclusion criteria are articles dated from 1987 to the present that delineate relatives’ reactions to TBI, and articles that are written in English. Although the previous 10 years were given the major focus, some of the articles dating back from 1987 were important and needed to be included. Some of the Indian journals are written in English.

The above time period was chosen to focus on the current view of neurological treatment professionals that has changed dramatically from looking solely at the patient to including relatives. Articles relating to relatives’ reactions were chosen with attention given to constructs that were identified above (anxiety, depression and life satisfaction). Previous sections dealt with the broader area of sequelae of TBI on patient and magnitude of its impact on relatives. It was necessary to include previous sections to provide a foundation for need to assess emotional reactions of relatives of TBI patients. Assessment can only be done with appropriate measures. Review of technological articles will be followed by assessment of measures of relatives’ reactions to TBI. Forty-six articles were reviewed using the system of categorization presented by Klein and Bloom (1994).

The five components (Klein & Bloom, 1994) in applied social science that emerged through qualitative content analysis were empiricism, technology, conceptualization, valuation, and commentary. Klein and Bloom remark that these components are intended to be exhaustive and are conceptually mutually exclusive even if they coexist. Empirical component is reflected in articles that are defined as practice or research articles where observed events are evaluated and/or measured. It includes quantitative research, qualitative research and/or secondary data analysis. Technology component is identified in articles when clear technological devices, procedures (such as planned interview schedules using standardized scales or statistical methods), or articles where social or clinical arrangements were proposed, described or
recommended (amplifying empirical contacts). Articles classified as valuation may present values directly or indirectly. Commentary reflects professional ‘storytelling’ that often appears in the literature.

The guidelines proposed by Klein and Bloom helped to assign articles to the relevant category. The categorization of these articles is found in Appendix A. Empirical and technology sections pertinent to our purpose are discussed below. This section is in logical flow of delineating relatives’ reactions and critiquing existing measures that justify need to develop a new measure to assess relatives’ reactions to TBI. This review is divided into and discussed under theoretical base, hypothesis, research design, sample size and type, instrumentation and statistical analysis.

Articles are reviewed in accordance with guidelines presented by Klein and Bloom (1994) (see Appendix A). Articles under technology (two) and empirical (eleven) categories are reviewed in detail in Appendix B. Eleven of 26 empirical articles were chosen based on their use of standardized measures and measurement of relatives’ reactions.

These articles analyzed below were taken from the following journals: *Archives of Clinical Neuropsychology, Archives of Physical Medical Rehabilitation, Brain Injury, British Medical Journal, Journal of Clinical and Experimental Neuropsychology, Journal of Head Trauma Rehabilitation, Neurorehabilitation, Rehabilitation Nursing,* and *Archives of Physical Medicine and Rehabilitation.*

**Theoretical Base**

Several authors have discussed systems perspective and family systems theory as the theoretical base of their respective study (Kay, Cavallo, Ezrachi, & Vavagiakis, 1995; Cavallo, Kay, & Vavagiakis, 1992). It was difficult to glean the theoretical base from other studies in the technology category (see Appendix A). It seems that research studies (chosen in the technology section) implied an ecosystems’ approach. Impact of patient’s TBI on family is seen as an event upsetting the homeostasis of the family unit and implies that change in one unit of the system causes a change in all units. It is difficult to place studies that do not have a theoretical basis into an ecosystem perspective.
**Hypothesis**

Articles reviewed in the empirical and technology section (see Appendix A) have a clearly stated purpose and clearly identified variables. Three articles clearly stated their hypothesis. One article stated multiple hypotheses. Only one article aimed to describe structure, contents, rationale, development, clinical utility and research potential of head injury family interview. Three articles described differing perceptions of patients and families. Relationship between patient variables and relatives’ distress and family functioning were included in these three articles. Three other articles described needs of relatives, amount of time and therapy relatives can provide for patient and identification of predictors at risk for an intervention program. Only three articles described affective symptoms of relatives, experiences and perceptions of relatives and persons with TBI.

**Research Design**

Articles reviewed reveal a paucity of validation studies. Kay, et al. (1995) is the only instrument validation design conducted over a 10-year period. They included a pilot study in their design and mention the validation process, clearly describing the reliability and validity of the problem checklist (one of five sections of the instrument). Two studies, Livingston (1988) and Hendryx (1989) made design more rigorous with comparison and control groups. It was not evident from their report why they stated that there was no need for an intra or interjudge reliability check on questionnaire responses. It is possible that the questionnaire has built in set of responses that check for inter and intrajudge reliability. The study also required family responses to be independent of professionals. If independent responses were compared later, reliability of the study would be enhanced. A prospective research (Hall & Karzmark, 1994) conducted at 6, 12 and 24 months post injury was standardized with a staff member conducting all interviews. To provide a control group for TBI patients, researchers have used spouses of spinal cord injury patients (Stambrook, et al.1991; Hammell, 1994; Whalley-Hammell, 1991). The remaining six articles were descriptive and did not control for variables. There was no mention of training interviewers or testing for reliability. Most articles did not describe the actual process of research in their methodology section. This is an important issue for articles focusing on psychometrics.
Sample Size and Type

Sample size was relatively small (Quine, Pierce, & Lyle, 1988 used 37 patients and relatives; Cavallo, et. al, 1992 used 34 individuals). The largest samples used were by Kay, et al. (1995) with 190 interviews while Serio, Kreutzer, and Gervasio (1995) used 180 subjects raising the question of generalizability of findings in studies with smaller samples. A convenience sample was used in all studies and gathered in one interview in conjunction with regular neuropsychiatric testing. There was no mention in most articles if consent was obtained prior to interview. None of the studies used a sampling frame. Results can be generalized only to populations similar to samples in the studies. Some authors employed sampling and matching techniques to reduce threats to internal validity. Studies combined data from relatives with different kinship and considered them equivalent. If some family members are not main caregivers of patient then they may have less opportunity to interact with patients, decreasing validity of their reports. With regard to severity of injury, it is important to use a more heterogeneous (with regard to TBI patients’ severity of trauma) sample as severity is an important predictor of outcome. Mild, moderate and severe TBI patients’ relatives need to be included in research. Homogenous patient groups may decrease amount of variance to fully understand complex relationships between patient characteristics and relatives’ psychological distress. Effect of power was not mentioned in any article.

Cultural differences (Asian, Native Americans, Hispanics, Black Americans or Caucasians) in family structure and roles and differences in caretaking and rehabilitation services may make findings less generalizable. Studies did consider controlling for preexisting conditions, like prior substance abuse or preexisting psychiatric disorder that increases control of extraneous factors.

Instrumentation

Studies reviewed used measures to assess degree and severity of patients’ injury. These measures were standardized and administered as a self-report. Objective and reliable clinician rating systems were seldom-used (Kreutzer, Gervasio & Camplair, 1994). Two studies assessed family reactions using questionnaires (Hendryx, 1989; Campbell, 1988). Quine, et al. (1988)
used trained observation and structured recording. Five articles used standardized measures, like the General Health Questionnaire, Family Needs Questionnaire, Head Injury Family Interview, Family Assessment Device, Support for Significant Other, Perceived Stress Scale and Social Readjustment Scale. Reliability and validity of measures were not mentioned in eight articles. The only articles that mentioned psychometric properties were Serio, et al. (1995) and Kay, et al. (1995). Measures of relatives’ psychological distress often consisted of single questions with unknown reliability and ambiguous meaning. Relationship between burden, strain and psychological distress were not delineated. Family reactions were assessed as major psychiatric disorder (as labeled under DSM IV), with specific reactions forming part of the syndrome (anxiety reaction or major depression). Specific reactions need to be studied as separate constructs that differentiate from major psychiatric disorders. Instruments used are applicable to global syndrome (a psychiatric disorder like major depression) which was not relevant to families of TBI patients. Where instruments were used, there was no description of reliability, validity or norms.

**Statistical Analysis**

Studies reviewed did not mention if assumptions of the statistical test employed were met. This becomes important when studies used parametric tests (Linn, Allen, & Willer, 1994; Livingston, 1988; Kay, et al., 1995; Kreutzer, et al, 1994; Serio, et al, 1995) without stating if their sample was randomly selected or if the dependent variable was normally distributed in the population. It was difficult to determine from instruments used if level of measurement was, at least, interval in the above articles. Two articles used nonparametric statistics appropriately when conditions for parametric tests were not met (Hall & Karzmark, 1994; Hendryx, 1989).

Descriptive statistics were used more widely than analytic or inferential statistics in articles. Limitations discussed above seriously affect credibility of any study. It is difficult for readers to regard recommendations with enthusiasm. This section (to study relatives’ reactions of TBI patients and to examine adequacy of instruments available to assess these reactions) focused on instruments measuring relatives’ reactions.
Review of Assessment Measures

Instruments are assessed below to identify their conceptual clarity, operationalization, adequacy, psychometric evidence and suitability for use with relatives of TBI patients. The first four instruments discussed are those frequently used in TBI research studies. They are Symptom Checklist (SCL-90-R), Family Assessment Device (FAD), Family Adaptability and Cohesion Evaluation Scale (FACES-III) and Head Injury Family Interview (HIFI). The Family Burden of Injury Interview (Burgess, et al. 1999) designed to assess impact of childhood traumatic head injury on family is not discussed here. This scale does not measure symptoms of anxiety and depression or life satisfaction that is the focus of the study. Constructs measured by these instruments are different from reactions to TBI. Second, target group for this scale is the whole family and not the main relative. For these reasons, three standardized instruments that assess anxiety, depression and life satisfaction are also discussed.

Symptom Checklist (SCL - 90 - R)

The SCL-90-R is a 90-item self-report symptom inventory developed by Derogatis (1983). A five-point scale is used, with 0 = ‘not at all’ and 4 = ‘extremely’. Scores on nine individual dimensions are derived, as well as three summary indices: Positive Symptom Total, Positive Distress Index and Global Severity Index. Standardized scores are based on the normative group of 960 individuals, described as a stratified random sample from a diversely comprised county. Test-retest stability and internal consistency coefficients are reported to be acceptable, ranging from .77 to .90. While, there was criticism of the stability and validity of SCL-90-R factors (Cyr, Doxey & Vigna, 1988; Payne, 1985) it was reported to be a sound self-report of psychopathology (Tennen, Affleck & Herzverger, 1985). Woessner and Caplan (1995) concluded that this scale has some items with neurological content. Consequently, subjects displayed marked elevations on five dimensions containing brain injury symptoms (BIS). These authors agree with Di Cesare, Parente & Anderson-Perente (1990) who report the existence of pervasive elevations on the SCL-90-R among TBI patients. Psychometric properties of this tool appear to be weak. Only two of nine dimensions deal with anxiety and depression. Other dimensions include various mental disorders found in the Diagnostic and Statistical Manual of
Mental Disorders- Fourth Edition (DSM-IV; 1994). Using two of nine dimensions in this study affects the reliability of the SCL90-R.

**Family Assessment Device (FAD)**

Epstein, Baldwin, and Bishop (1983) designed a 60-item questionnaire to evaluate family functioning according to the McMaster Model. This model describes structural, occupational and transactional properties of families. It identifies six dimensions of family functioning: problem solving, communication, roles, affective responsiveness, affective involvement and behavior control. Accordingly, FAD consists of six subscales to measure these dimensions and a seventh subscale dealing with general functioning.

FAD has fairly good internal consistency, with alphas for subscales ranging from .72 to .92. Global reliability has not been reported. Subscales could be reliable independent scales, even without adequate global reliability. FAD demonstrates some degree of concurrent and predictive validity. In a separate study of 178 couples in their sixties, the FAD was moderately correlated with the Locke-Wallace Marital Satisfaction Scale and showed a fair ability to predict scores on the Philadelphia Geriatric Morale Scale. FAD has good known-groups validity, with all seven subscales significantly distinguishing between, individuals from clinical families and nonclinical families.

FAD was used with success in research studies of families of TBI patients. There is no assessment of emotional reactions of relatives of TBI patient. Items assess reactions of family as a whole. However at neurosurgical centers the whole family is seldom present (T. Hegde, personal communication, Sept. 2000). Often the main relative has different opinions about family dynamics from that of other members, thereby questioning reliability of rating. This relative feels the brunt of the whole traumatic process and needs preventive diagnosis and intervention. Specific symptoms of the main relative’s emotions need to be understood. It should be noted that the main relative of TBI patient is not always clearly identified. However, researcher has found that in India it is usually spouses who comes for partners, mother for children, off-springs for elderly parents and only when these persons are not available, the fathers and siblings become the main relatives of TBI patients.

54
Family Adaptability and Cohesion Evaluation Scale (FACES-III)

Olson, Bell, and Portner (1985) developed a 20-item instrument designed to measure two dimensions of family functioning: cohesion and adaptability. It is based on the Circumplex Model of family functioning and its dimensions of family behavior: cohesion, adaptability (ability to change) and communication. FACES-III is designed to assess family members’ perception of their family and how they would like it to be. It is normed on families with adolescents and young couples in different stages of their life cycle. FACES-III has fair internal consistency with an overall alpha of .68 for the total instrument and .77 and .62 for subscales. It is reported to have good face validity that is not important in relation to other forms of validity. Data demonstrating other types of validity were not found. However, studies have shown that FACES-III has fair known groups’ validity in being able to discriminate among extreme, midrange and balanced families in several problem categories. With the purpose of this study and questionable validity of this instrument in mind, this is not a relevant measure of constructs of anxiety, depression and life satisfaction. None of the items assess emotional reactions of the main relative. It is discussed here because it is one of the most frequently used instruments in studies of families with a TBI patient.

Head Injury Family Interview (HIFI)

Kay, et al. (1995) describe the HIFI as a five-part structured interview designed to gather clinical and research data on persons with TBI and their family members. Over a 10-year period it was developed to track outcomes of persons recovering from TBI (with input from both injured person and significant others) and to document impact of injury on family. Current version reflects revision, expansion and fine-tuning based on experience with multiple samples of families and feedback from clinicians in a multicenter study. Authors state that one component of the HIFI (The Problem Checklist of patients’ symptoms) has been extensively explored. Psychometric properties of the global scale and the component used for assessing impact on family are not given.

HIFI was designed for a longitudinal study of recovery from brain injury in adults and is appropriate for use with nonhospitalized adolescents and adults. All questions presuppose that
the person with head injury has some experience living at home and is attempting to reintegrate into the community. One section assesses progress of patient from the significant other’s point of view while the second component deals with impact on the significant other. It does not focus on emotional reactions of the significant other. HIFI is not appropriate because it is designed for longitudinal studies where the main relative has formed various coping strategies. This study needs an instrument that assesses relatives’ immediate reactions that can help develop preventive interventions.

Three measures that assess anxiety, depression and life satisfaction were critically analyzed to examine currently available instruments (p. 85). These measures were chosen over other existing ones based on their wide usage and relevant psychometric properties. Additionally these instruments assessed constructs similar to constructs in the current study. Most important these scales were reviewed to defend their use in this study.

Review of scales, reveals that most of them have acceptable reliability (internal consistency), displaying that items cluster around construct of study. There is a strong correlation among items. This homogeneity among items in a scale is necessary for measurement of a construct. However, actual description of construct is not given in many studies. One cannot be sure that the instrument measures the construct it sets out to measure. In some cases, like clinical anxiety and major depression, one can infer that the construct is the syndrome (collection) of all symptoms. The syndrome is made up of a cluster of symptoms (that indicate if one has the disorder or not). Most important, however, one is not sure that the constructs measured, despite their accuracy, are similar to the constructs desired (anxiety and depression in relatives of TBI patients). Despite the likeness of the items to relatives’ reaction of TBI many items are not relevant to TBI of patients. The domain from which those items are sampled may be similar to the domain of relatives’ reactions of TBI. In the current study emphasis is on a similar anxiety, depression and life satisfaction that is a specific reaction to TBI in family member. Items specifically relate to trauma (see definitions of anxiety, depression and life satisfaction as used in the current study, pg. 8). All three constructs together form the main domain reaction to TBI.

The type of sample for which above scales are validated, seem to differ from relatives of
TBI patients. Relatives of TBI patients are different from psychiatric patients or geriatric samples. Relatives of TBI patients may suffer from depression, anxiety or disturbed life satisfaction similar to psychiatric patients. However, genetic predisposition or cumulative stresses may not cause the emotional reaction. It is true that subjects could have predisposing conditions to make them react in a certain manner. Nurses in the current study screened subjects for preexisting mental illness and substance abuse. A need exists to assess combinations of symptoms of major disorders. It is necessary to develop a multidimensional instrument that specifically measures anxiety, depression and life satisfaction that are the three domains of construct reactions’ relatives of TBI patients. A specific instrument would help in focusing social work intervention in a result-oriented manner. There is no scale developed as yet to assess relatives’ reactions to TBI. Research done to date assesses constructs with different lengthy instruments or inadequately deals with multidimensional instruments like the HIFI. Measurement tools employed have been modified from those developed for use in other areas. No global scale exists to assess relatives’ reactions to the brain injury that include anxiety, depression and life satisfaction. There is a need for a brief, multidimensional measure to assess emotional reactions of relatives of TBI patients.

Given the focus of the study, it is crucial to develop an instrument that measures the relatives’ reactions to TBI. Studies conducted to date have used measures more appropriate for related, but distinctly different populations. The only instrument developed for relatives of TBI patients is actually a subscale of the global scale used to assess the neurological, medical and psychosocial picture of the TBI patient. For immediate diagnosis and help in intervention of maladaptive reactions of relatives of TBI patients, it is important to develop an appropriate assessment tool, for the Indian population where specific published studies related to relatives’ reaction to TBI are not present. Most studies conducted by social workers focusing on relatives’ reactions to any illness have used instruments that are borrowed from the West. They are usually used in the form of surveys, due to the low rate of literacy. For this reason, translations that have been made in research conducted so far may not be psychometrically tested. Self-report questionnaires are rarely used. There is no scale developed to assess the reactions of TBI
patients’ relatives. There is a need for developing an instrument that caters to Indian researchers and social workers, in general and to Indian relatives of TBI patients specifically.
CHAPTER III
CONCEPTUAL AND DEVELOPMENTAL FRAMEWORK

This chapter delineates conceptual process of the study. A brief discussion of the classical measurement theory from which this study draws its basis will be followed by a description of the process of instrument construction. The instrument construction process includes identification of the main domain, specification of constructs and their operationalization. This chapter includes a section of rapid assessment instruments because the instrument under study is intended to be brief. A delineation of research methodology used in validation of the instrument being developed, Reaction to Brain Trauma Scale (RBTS) follows.

The initial part of instrument development process included an in-depth study of the construct (reactions of TBI patients’ relatives) and generation of item pool with help of a focus group (colleagues). Deciding the validation process, subjecting instrument to expert review and determining measurement format followed the above. The Human Subjects Committee of the Institutional Review Board (IRB) at Florida State University approved the pilot study. To streamline the revised instrument it was pilot-tested. Items were revised based on pilot study findings, further literature review and input by panel of experts (in the neurosurgical and measurement fields). The Human Subjects Committee of the IRB at Florida State University approved data collection in India. Permission was received from the Ethics Committee at the National Institute of Mental Health of Mental Health and Neuro Sciences (NIMHANS) in Bangalore, India to collect data. The scale was then administered to a sample of relatives of TBI patients at NIMHANS. Data was analyzed to establish reliability and validity of the instrument.

Instrument Construction

Measurement is the act of observing, classifying and quantifying in a structured manner that object which is observed. Stevens, in 1946, described measurement as the assignment of numerals to objects or events according to specific rules. Weitzenhoffer (1951, p. 387), defined...
measurement as “an operation performed on the physical world by an observer”. According to Lord and Norvich in 1968 and Crocker and Algina in 1986, measurement applies to properties of objects rather than to objects themselves. Crocker and Algina (1986) state that test theory provides a general framework for viewing instrument development process.

This research study followed the guidelines for developing the measure provided by Fischer and Corcoran (1994). The guidelines are utility, directness, and applicability to client, sensitivity and reactivity. Utility refers to usefulness of instrument to social workers dealing with families of TBI patients. Directness refers to straightforward nature of the measure, indicating that items are ambiguous and capture the construct (i.e., reactions of relative of TBI patient) that the device is intended to measure. Applicability to client system is important in terms of culture and diversity. This is crucial given that the target population was located in India. Sensitivity refers to ability of the measure to capture change over time. Measure should be sufficiently sensitive to detect any differences that might take place if the measure was administered twice over a time period to the same group. This guideline was financially and practically impossible to follow in this study. Reactivity deals with items that are offensive in nature to relatives or those producing strong reactions from respondents of the measure. To avoid this, input of relatives was included to delineate constructs (two ethnographic study subjects were of the Indian culture) and later expert review in India determined relevance of items.

A process of instrument construction is broken down variably by many authors (Allen & Yen, 1979; DeVellis, 1991; Spector, 1992). Five steps suggested by Allen and Yen in 1979 included planning the test, writing items for each area planned and administering items to a sample of individuals similar to that of the population on which the final version will be used. Fourth step involved conducting an item analysis and final step was to readminister the instrument on the target population. DeVellis broke down the process of instrument construction into eight steps in 1991. Initially, what one wants to measure is determined, followed by the generation of an item pool and the determination of format for measurement. Experts review the initial item pool and validation items to be included are determined after which sample group is administered the measure. Items are evaluated and finally one arrives at the scale that is
appropriate. Spector (1992) outlines the following steps. First, the construct is defined and operationalized. Next, the scale is designed, after which a pilot test and item analysis are conducted. Finally the instrument is validated and normed. In addition, it is necessary to continuously administer the measure to various samples for norming and establishing construct validity. This was not possible in the current study due to time and financial constraints. The authors mentioned above, emphasize different steps depending on their strategies. In general, a process of test construction includes the following: (1) defining construct of interest, (2) formulating the measure including format and items, (3) submitting items to expert review for content and format, (4) administering the tool and (5) analyzing data to establish reliability and validity of the tool. The current study follows the general steps culled from steps suggested by the authors mentioned above.

**Instrument Validation**

Measurement consists of rules for assigning symbols to objects to represent quantities of attributes numerically (i.e., scaling), or to define whether objects fall in same or different categories with respect to a given attribute (i.e., classification) (Nunnally & Bernstein, 1994). Attributes of objects, or people, are measured keeping in mind that a good measure is reliable (i.e., consistent) and valid (i.e., measures what it purports to measure). Carmines and Zeller (1979) described measurement as ‘process of linking abstract concepts to empirical indicants’ (p. 10). The process can be the structure through which indicants or information that the researcher possesses are classified and quantified. Nature of connection between abstract concept and indicant(s) is dictated by theory. Study of reliability and validity includes determination of quality of structure that leads to classification and quantification. The structure provides consistent results and adequate connection between abstract concept and empirical indicant (i.e., validity). Process of instrument validation involves determining whether the researcher can rely on the instrument under various circumstances and whether the connection between empirical data (i.e., what the client is reporting) and theoretical construct is sound.

**Reliability**

The classical measurement model by Crocker and Algina (1986), which assumes that the
individual items are comparable indicators of the underlying construct, provides conceptual framework for validation work conducted as part of this study. It is one of the most significant issues from Charles Spearman’s (1904) fascination with the concept of correlation. The classical true score model is widely accepted and most used in scientific efforts to measure constructs associated with human behavior. In essence this model is concerned with how well observed scores reflect corresponding true scores. Reliability is established by calculating the ratio of true to observed score variance. Equivalence of content, means, variance and intercorrelations of measures are considered.

Reliability theory is concerned with variance of quantification of empirical indicants. The explanation of this definition and discussion of reliability as used in the present study is drawn from various authors (Carmines & Zeller, 1979; Crocker & Algina, 1986; DeVellis, 1991; Kerlinger, 1986; Nunnally & Bernstein, 1994; Spearman, 1904; Spector, 1992). Total of obtained variance of a set of scores, derived from the administration of an instrument, consists of systematic variance and error variance. The intent of this model (originally proposed by Spearman in 1904) is as follows. Each individual score contributing to the variance, \(X_t\) (where \(t\) stands for total) is the composite of two hypothetical components - the true component and the error component. Each person’s total score, therefore, contains a true score, \(X_p\) (where \(p\) stands for true), and an error score \(X_e\) (where \(e\) stands for error). \(X_e\) indicates an increase or decrease in the quantification of the empirical indicant that results from factors responsible for error of measurement. This is represented by the equation:

\[
X_t = X_p + X_e
\]

\(X_p\) can be thought of as the score possible under ‘perfect’ conditions or it can be thought of as the average of sum of an infinite number of scores, \(X = (X_1 + X_2 + X_3 + \ldots \ X_n) / n\).

Through algebraic substitution the equation \(X_t = X_p + X_e\) can be substituted to variance terms, \(V_t = V_p + V_e\). Errors of measurement are always present. The theory assumes that if we know error scores and subtract them from obtained scores, we would obtain ‘true’ scores. However, we can never really know the true scores. The concept of a true score and error score is theoretical. Error variance (once estimated) can be substituted in the above variance term equation and the
equation can be solved resulting in an estimate of reliability. Based on this reasoning ‘reliability is defined through error’ (Kerlinger, 1986, p. 408). The greater the error, the lesser is the reliability and vice-versa. Alternatively, ‘... reliability is the proportion of variance attributable to the true score of the latent variable’ (DeVellis, 1991, p.24). The definition leads to various assumptions or basic principles of the classical true score model. The basic principles of error scores (Crocker and Algina, 1986) are that the mean of the error scores from a population of subjects is zero ($\mu_E = 0$) and the correlation between error scores from two tests (when subjects take two separate tests and each subjects’ scores on the two tests or, two testing occasions with the same form are assumed to be randomly chosen from two independent distributions of possible observed scores) is zero ($P_{E1E2} = .0$). These general principles describe the basic properties of true and error scores which make it possible to apply the classical true score model to the study of test score reliability.

There are four basic methods for estimating the reliability of empirical measurements. The conceptualization and operationalization of reliability differs between these computational methods. The four methods include test-retest, alternative form, split-halves, and internal consistency. Test-retest requires giving the same test to the same people twice with an intervening period of time. Reliability is then equal to the correlation between scores obtained at two points in time. The classical true score theory defines two tests as parallel when each respondent has the same true score on both forms of the same test. Alternative form method, or parallel form method, also involves two testing situations with the same people but uses different forms of the same test to measure the same construct. Correlation between the two tests provides the reliability coefficient estimate of reliability. Division of the total number of items into halves and correlating their respective scores for analysis is called split-halves method of estimating reliability. This estimate of reliability is the correlation between two distinct halves of the instrument.

The fourth method, like the third, is the estimation of internal consistency. It is dependent on how well each individual item of an instrument reflects some underlying construct. Coefficient alpha or Cronbach’s alpha is the most common method of calculation of an estimate
of internal consistency reliability. It is not of primary importance to researcher in most testing situations to know how subjects score on specific items. It is more important for researcher to generalize from specific items to a larger domain of content that includes all possible items asked. For this purpose, it is vital for researcher to determine how consistently subjects performed across items or domains of items on the form. This helps to establish how consistently subjects perform on a specific test. Such procedures designed to estimate reliability are also called internal consistency methods. Item homogeneity is indicated when a respondent performs consistently across items within a measure or domain of that measure. Cronbach’s alpha is used to determine internal consistency of the index. Cronbach’s coefficient partitions observed variation into portion attributable to true score and portion attributable to error. Cronbach’s alpha is based on average correlation among all items. Cronbach’s coefficient alpha is characteristic of a test reflecting positive correlation of items composing it (Kuder & Richardson, 1937).

Various authors have given acceptable reliability rates. (Hudson, 1982) indicated a loading of .60 for nomothetic research. Springer, Abell and Nugent (2002) set .80 - .84 as minimally acceptable and .85-.89 as respectable. The authors add that .70 - .79 is undesirable and less than .70 is regarded as unacceptable. They explain the reason for setting higher standards is because there is no opportunity to average out the measurement error that is contained in the scale when working with individuals. While group research averages out the measurement error when computing group means and mean differences. Nunnally & Bernstein (1994) suggested .70 as “modest” for reliability. They remark that the standard set is really dependent on test scores when important decisions are made regarding individuals. In other words, if test scores determine whether a subject receives treatment or not, then a higher standard is required. In this study, all the subjects are theoretically given treatment and the scores subjects receive would affect the type of treatment received. The scores direct the social worker to focus on reactions that are maladaptive. This measure is designed to help social workers to focus his/her treatment plan for quick efficient work with clients. This instrument is designed to help social workers focus his/her treatment plan towards alleviating anxiety, depression or enhancing the life satisfaction of the respondent.
All four approaches to reliability are designed to determine proportion of error in the observed scores of the measure. Reliability coefficient is influenced by difference in the variance or standard deviation of a measurement scale (Springer et al., 2002). This difference they state could occur between samples. The authors add that reliability is affected by homogeneity of respondents’ responses to the measurement items. Thus standard error of measurement (SEM) can compensate for the reliability coefficient’s weakness because it is less affected by difference in variance of responses between samples. It is used to estimate amount of error in the instrument. It is basically an estimate of standard deviation of error. SEM can be used to determine what change in scores may be due to error. In general, smaller the SEM, more reliable the instrument and lower the measurement error. This method is derived from classical test theory that describes the expected variation of each respondent’s observed score about the respondents’ true score. Theoretically, each respondent has a distribution of possible observed scores around the respondents’ true scores. These possible observed scores have standard deviations which are averaged for the group and results in SEM. Thus, it shows how far the true score may be from the observed score for an average respondent in the population. The formula for calculating SEM is as follows:

\[ \text{SEM} = s \sqrt{1-r_\alpha} \] (standard deviation of root of 1- \( r_\alpha \) or coefficient alpha).

It is impossible to determine the exact amount of error in a given test score. There are no clear criteria for judging small or large SEM (Springer, Abell & Hudson, 2002). These authors recommend a general rule stating that SEM should be approximately five percent or less than the range of possible scores. A good measure should possess a large coefficient of reliability and a small SEM. The SEM will be computed for each final subscale. Reliability is present when the instrument measures something consistently and holds together well with all the items as a whole. Good validity ensures that the instrument measures what the clinician or researcher intends to measure. Reliability though important and necessary is not enough for a good measure. A useful measure should have validity. An increase in reliability coefficient indicates that the subjects’ score is consistent while validity ensures that the researchers’ inferences are defensible.
**Validity**

An instrument can measure something similarly, but if it does not measure what the researcher intends to measure then the instrument will lack usefulness. Validity cannot be established easily, quickly or definitively. Validity is the process by which a test developer collects evidence to support types of inferences that are to be drawn from test scores (Cronbach, 1971). Validity is intimately associated with the underlying construct that the instrument is intended to measure. The task of instrument validation involves interpretation of what the scale scores actually represent. One hopes that scores are representative of construct as intended by researcher. Therefore, validity is a theoretical issue. An instrument is useful to the extent that it reflects its intended theoretical concept.

Validity has been conceptualized in four basic ways: content validity, construct validity, criterion-related validity (Crocker & Algina, 1986) and factorial validity. Nunnally and Bernstein (1994) state that content validity is established when items are adequately sampled from the pool of the required domain. Face validity is similar to content validity, but not precisely the same. Face validity is the extent to which items appear to measure a construct. More than to researchers, face validity is meaningful to respondents or lay persons. Content validity can be thought of as the degree to which items of a scale represent the domain of items that would define the construct under consideration. Good subjective evidence for content validity can be obtained by the conceptual inspection of item/definition fit for each domain (Abell, 2001). In this study, content validity is tested by the agreement of item content (among colleagues and practitioners) and matched to the clear definition of the target construct. Modification of items with help of focus group helps to remove ambiguity and superfluity.

Factor validity is described as items on a scale having a much higher positive correlation with the scale’s total score than with the total score of any other scale. Factor validity indicates that a test is properly classified but not necessarily useful as a valid predictor of a particular criterion. It can be either confirmatory or exploratory in nature. Confirmatory factor validity is determined by examining the degree to which items on an instrument correlate with the constructs that they are intended to measure (Nunnally & Bernstein, 1994). Factor structure is
determined by the clustering of variables. It is determined when variables have a higher correlation with the hypothesized subscale score than with any other subscale score. Multiple group or group-centroid method of confirmatory factor analysis (Nunnally & Bernstein, 1994) is sometimes preferred for the relative ease with which it can be understood, employed and communicated.

If the number of subdomains is not determined apriori, and there is no predetermination of factors, then an exploratory factorial analysis must be conducted. Exploratory factorial analysis is considered to be more of a theory generating factor analysis (Stevens 1996). In exploratory factorial analysis, the researcher needs to decide if he or she wants to conduct an orthogonal (i.e., uncorrelated) rotation (i.e., Varimax rotation in SPSS) or the alternative which is an oblique (i.e., correlated) rotation (i.e., Oblimin in SPSS).

Criterion validity is established when the proposed measure is empirically associated with some standard. Correlation between criterion measurements and test scores taken at the same time refers to criterion validity. Criterion validity could either be concurrent or predictive criterion validity. Concurrent criterion validity could be classified as known instruments or known-groups concurrent criterion validity. If the instrument currently being developed can be empirically associated with the standard, then known instruments criterion validity is established. Correlation coefficient, or validity coefficient, is the quantification of empirical association. If the instrument distinguishes between groups that possess the construct being measured and groups that do not possess it, then criterion known-groups validity is established. Finally, predictive criterion validity is defined as establishing a statistical relationship with a particular criterion (Nunnally & Bernstein, 1994). Predictive criterion validity is useful when predicting clients’ behavior based on score received by the client on an instrument. A predictor measure is related to a criterion measure with the nature of the problem, determining when measurements are obtained.

Construct validity is the type of validity with closest ties to theoretical considerations. It is concerned with theoretical relationship of a variable to other variables. Construct validity can either be convergent or discriminant constructs validity. Variables hypothesized to correlate with
this instrument need to correlate, either positively or negatively, to establish convergent construct validity. Variables that are not hypothesized to correlate should not correlate with this instrument to establish discriminant construct validity. Hypotheses theoretically proposed, of the instruments’ scores in relation to that of the established instruments’ scores must be confirmed for an instrument to have construct validity.

**Rapid Assessment Instruments**

Rapid Assessment Instruments (RAIs) are brief and easily administered (Fischer & Corcoran, 1994). In general, RAIs are an avenue to the evaluation of social work practice. The purpose of this study is to create and validate the instrument intended for use in clinical practice and research. To be useful it is important, the instrument is short, easily administered and scored. RAIs are measurement tools that can have both social work research and clinical purposes. RAIs can be easily integrated into clinical practice because of their brevity and ease in administration. These characteristics distinguish RAIs from other measurement devices. Levitt and Reid (1981) described RAIs as follows: (1) short (no more that two pages), (2) easily administered, (3) easily completed, (4) written in straight forward simple language, (5) easily scored and (6) easily interpreted. Intrusiveness of these measures is minimized by the rapidity of their use. Use of RAIs in clinical research takes advantage of the lessened intrusiveness. There is less for clinicians to worry about clients with intrusiveness of research procedures minimized by the RAIs’ brevity.

Essentially, a RAI provides a structured and systematic method of self-reporting for a client. Methods of self-report can be used in pursuit of various goals. Toseland and Reid (1985) summarized several reasons given for using RAIs in social work practice. These include less time required for information collection, provision of a systematic analysis of symptoms and revealing of information that is missed in clinical interviews. Uncovering patterns in the client’s problems that are both an estimation of extent of clients’ problems and determination of changes in clients’ problems is included. To this point, this chapter has dealt with conceptual framework for the study. Next, methodology used in the current research will be described.
CHAPTER IV
RESEARCH METHODOLOGY

Construction of the instrument required an in-depth study of the construct (i.e., reactions of relatives of TBI patients) and generation of an item pool. Deciding on the validation process, subjecting the instrument to expert review and testing it in a pilot study to streamline the instrument were part of the instrument construction process. These steps were followed by the administration of the instrument on the sample of intended population. Data analysis followed and included reliability and validity estimation to assess the usefulness of the measure.

Instrument Construction

The subdomains of the main construct (i.e., reactions of TBI patients’ relatives) were determined by conducting a qualitative study (see p. 46). Review of existing measures revealed the need for a brief, multidimensional measure that assessed relatives’ reaction to TBI. Item pool generation was guided by review of literature which provided a thorough understanding of the constructs and delineated the limits of the constructs. Group process initiated a flow of thought and development of the instrument. Colleagues in social work profession (i.e., PhD students) formed a focus group to brainstorm ideas and generate the item pool (see Appendix K).

Items were given to professionals and practitioners in the field of neurology and neurosurgery for their approval and suggestions. The neurosurgeon, neurologist and neurological social workers were Indian. In addition the focus group of professionals helped to ensure compatibility with measurement format. DeVellis (1991) suggested simultaneous conduct of item generation and measurement format.

A five-point Likert scaling (i.e., ranging from strongly agree to strongly disagree) of responses was agreed upon by professionals. Relatives of TBI patients considered the five-point Likert scale less confusing than the seven-point scale. At the pilot phase, the initial development intended the RBTS to be a self-report instrument with a Likert scaling of up to seven-point range.
Language experts (V. K. Sundaravadanan; G. Anandhi; Sreedevi; K. Anil, personal communication, June, 1998) suggested that this would not be wise due to the difficulty in translating the scale into three Indian languages. After data collection, for the sake of simplicity, questionnaires translated to one language only would be retained in this study). With a seven-point scale, there was an increased risk in corrupting the reverse translation. The five-point Likert scale was adopted for sake of clarity and precision.

There were 98 items at the outset of the research study. The group of social workers who first helped to create items initially decided upon 57 of the items. The group of clinical experts further narrowed this number down to 45 items. Each of the three domains had 15 items. A pilot study was conducted on 165 college students. The results of the data analysis of this pilot study could not be generalized because the nonprobability sample was not similar to the target population. The subjects were asked to read a case vignette that helped to create the traumatic scenario. During the analysis of this pilot study, items that were ambiguous, and those items that did not capture the intended domain, were deleted or shifted as appropriate. Details of the pilot study are given below.

**Pilot Study**

This section deals with the initial revisions of the instrument. It was pilot tested on a group of undergraduate students (n = 165) in social work, sociology and psychology departments at Florida State University. Initial version of the instrument (see Appendix D) called the Brain Trauma Patients’ Relatives’ Reactions (BTPRR) contained three domains of nine items each. The three domains, anxiety, depression and life satisfaction, were collectively intended to provide an overall measurement of the global domain named ‘reactions of relatives of TBI patients’.

**Item development**

Items were initially inspired by previous instruments and from transcribing interviews of relatives of TBI patients (see qualitative study discussion on page 46). A focus group of colleagues at Florida State University provided input to increase the comprehensiveness and lessen ambiguity of the items. The list of items was also discussed with a neurological social
worker (Barancho, personal communication, April, 1996). As a result of these discussions items were modified a number of times to remove ambiguity and superfluity.

Data collection method

Inquiries were first made at the local hospital (Tallahassee Memorial Hospital) and those in Yuma (AZ), Boston (MA) and Gainesville (FL) to get a sample of relatives of TBI patients. It was disheartening to note that the turnover of patients averaged about three per day in smaller hospitals. Permission was not received by larger hospitals at the time the study commenced. Therefore, students at Florida State University were requested to participate in the study. Professors were contacted to use 15 minutes of their class time to conduct pilot data collection. Students were asked to read the case vignette that attempted to place them in the scenario of a TBI patients’ relative. They were then asked to answer the questions that followed, keeping the case scenario in mind.

Opportunities and obstacles for data collection

Many professors were enthusiastic about the project. One asked the researcher to use the entire class time to enlighten the students about the research project and answer questions. This session was conducted after the questionnaires were completed to avoid any bias that might be introduced in the study. Two social workers stated that their hospitals might be open to research. Forty-nine questionnaires were eliminated because students were not properly instructed and, thus did not answer the instrument with the case vignette in mind. Some students remarked that it was not easy to put themselves in the position of relatives of TBI patients.

Results of the Pilot Study

Sample Characteristics

The total sample size of 165 comprised of 119 female and 46 male subjects, including 123 Caucasians, 33 African Americans, 5 Asians, and 2 others (1 Hispanic and 1 Native American). Average age was 23.43 years and average education was 15.32 years as presented in Table 1. Scale frequencies were run to check the data for any mistakes and missing values. Frequencies of demographic variables were taken to get the description of sample. Frequencies for the external scales were generated for the same reason.
Reliability Analysis

Cronbach’s alpha coefficient was computed as an index of reliability for the new scale. This pilot study considered a reliability of .70 as adequate. The standard is less rigorous as the score is meant to indicate the direction of the treatment (see p. 64 for discussion on standards of reliability). In the pilot study, as seen in Table 2, the global scale and two of the subscales exceed the criteria while the anxiety subscale falls below the standard for individual clinical application. Taking into consideration the Indian setting and nature of the study, the reliability is acceptable (N. Abell, personal communication, June 16, 2003).

### Table 1 Sample Characteristics

<table>
<thead>
<tr>
<th>Demographic Indicators</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>23.43</td>
<td>5.70</td>
<td>6.00</td>
<td>51.00</td>
</tr>
<tr>
<td>Education</td>
<td>15.32</td>
<td>1.89</td>
<td>2.00</td>
<td>20.00</td>
</tr>
</tbody>
</table>

### Table 2 Initial Reliability of Global Measure and Subscales

<table>
<thead>
<tr>
<th>Measures</th>
<th>Reliability</th>
<th>Number of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety Subscale</td>
<td>.75</td>
<td>7</td>
</tr>
<tr>
<td>Depression Subscale</td>
<td>.83</td>
<td>9</td>
</tr>
<tr>
<td>Life satisfaction Subscale</td>
<td>.91</td>
<td>8</td>
</tr>
<tr>
<td>Global scale</td>
<td>.92</td>
<td>24</td>
</tr>
</tbody>
</table>

Table 2 displays total alphas for subscales and global scales. Item total correlation and alpha of the scale if that single item were deleted will be presented below. Original reliability and the modified reliability alphas are shown in the following section.

### Table 3 Initial Reliability Analysis of Anxiety Subdomain

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Total Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My hands and legs tremble all the time.</td>
<td>-</td>
<td>.60</td>
</tr>
<tr>
<td>2. I feel shocked at the trauma of my relative.</td>
<td>.19</td>
<td>.48</td>
</tr>
<tr>
<td>3. I sweat every time I think of the incident.</td>
<td>.27</td>
<td>.45</td>
</tr>
</tbody>
</table>
Original reliability of .50 shown in Table 3 turned out to be very low for anxiety subscale. Items 1 and 8 were the weakest. The alpha if item deleted (i.e., the alpha coefficient of the scale if specific items were deleted from the scale) rose noticeably to .60 and .56 respectively. Factorial validity also showed these items’ weakness, as will be seen later. Therefore, a study of the items showed that if these weak items were removed the other items would still measure the subdomain of anxiety adequately. Consequently, items numbered 1 and 8 in the anxiety subdomain were removed.

Table 4 shows that the alpha of .84 was adequate. Deleting any of the items in the depression subscale or moving it to another subscale would not have increased the subscale or
overall global alpha. Therefore, the depression subscale was left as it was. Alpha of .91 of the subscale life satisfaction was high (Table 5).

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Tot Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. I consider committing suicide.</td>
<td>.32</td>
<td>.92</td>
</tr>
<tr>
<td>18. I have made adequate plans for the future.</td>
<td>.55</td>
<td>.90</td>
</tr>
<tr>
<td>19. I get dissatisfied often.</td>
<td>.51</td>
<td>.91</td>
</tr>
<tr>
<td>20. I am in a better position than other caregivers.</td>
<td>.75</td>
<td>.89</td>
</tr>
<tr>
<td>21. This situation could have been worse.</td>
<td>.75</td>
<td>.89</td>
</tr>
<tr>
<td>22. I expect things to change for the better.</td>
<td>.85</td>
<td>.88</td>
</tr>
<tr>
<td>23. The things I used to do before still interest me.</td>
<td>.84</td>
<td>.88</td>
</tr>
<tr>
<td>24. I am satisfied with the treatment.</td>
<td>.83</td>
<td>.88</td>
</tr>
<tr>
<td>27. I am satisfied with life right now.</td>
<td>.66</td>
<td>.90</td>
</tr>
<tr>
<td>TOTAL ALPHA</td>
<td></td>
<td>.91</td>
</tr>
</tbody>
</table>

Table 6. Modified Reliability Analysis of Life Satisfaction Subdomain (After Removing Item L17)

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Tot Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. I have made adequate plans for the future.</td>
<td>.57</td>
<td>.92</td>
</tr>
<tr>
<td>19. I get dissatisfied often.</td>
<td>.49</td>
<td>.92</td>
</tr>
<tr>
<td>20. I am in a better position than other caregivers.</td>
<td>.75</td>
<td>.90</td>
</tr>
<tr>
<td>21. This situation could have been worse.</td>
<td>.76</td>
<td>.90</td>
</tr>
<tr>
<td>22. I expect things to change for the better.</td>
<td>.86</td>
<td>.89</td>
</tr>
<tr>
<td>23. The things I used to do before still interest me.</td>
<td>.85</td>
<td>.89</td>
</tr>
<tr>
<td>24. I am satisfied with the treatment.</td>
<td>.83</td>
<td>.89</td>
</tr>
<tr>
<td>27. I am satisfied with life right now.</td>
<td>.67</td>
<td>.91</td>
</tr>
<tr>
<td>TOTAL ALPHA</td>
<td></td>
<td>.92</td>
</tr>
</tbody>
</table>

To keep the subscale items equivalent, item 9 was removed from the depression scale and added to the anxiety subscale. This was not absolutely necessary but was considered to be appropriate because adding it to the anxiety subscale increased the alpha level of anxiety subscale. The depression subscale alpha fell by .01, which is minimal in comparison to the increase in alpha in the anxiety sub scale, when item 9 is added to the anxiety subscale.
Reliability of the anxiety scale rose to .75, while reliability of the depression scale fell to .83 (see Table 7 and 8) from the previously calculated .84 (see Table 4) after removing item 9 from the depression subscale.

The alpha coefficient of the global scale, after removing items 1, 8 and 17 rose from .90 to .92 (see Tables 2 & 9).
Table 9. Modified Reliability of Global Domain (Deleting Items A1, A8 & L17)

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Total Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. I feel shocked at the trauma of my relative.</td>
<td>.10</td>
<td>.92</td>
</tr>
<tr>
<td>3. I sweat every time I think of the incident.</td>
<td>.34</td>
<td>.92</td>
</tr>
<tr>
<td>4. I worry about the treatment.</td>
<td>.55</td>
<td>.91</td>
</tr>
<tr>
<td>5. I am worried about the effect of the trauma.</td>
<td>.30</td>
<td>.92</td>
</tr>
<tr>
<td>6. I have negative thoughts about the incident.</td>
<td>.43</td>
<td>.92</td>
</tr>
<tr>
<td>7. I am so preoccupied that I cannot work as usual.</td>
<td>.46</td>
<td>.92</td>
</tr>
<tr>
<td>9. I feel alone in the world.</td>
<td>.63</td>
<td>.91</td>
</tr>
<tr>
<td>10. My heart feels heavy and sad.</td>
<td>.45</td>
<td>.91</td>
</tr>
<tr>
<td>11. My appetite and sleep patterns have changed.</td>
<td>.45</td>
<td>.92</td>
</tr>
<tr>
<td>12. This is the saddest time of my life.</td>
<td>.55</td>
<td>.91</td>
</tr>
<tr>
<td>13. I feel devastated thinking of the futility.</td>
<td>.44</td>
<td>.92</td>
</tr>
<tr>
<td>14. I feel there is no hope in the future.</td>
<td>.55</td>
<td>.91</td>
</tr>
<tr>
<td>15. I feel tired and listless.</td>
<td>.61</td>
<td>.91</td>
</tr>
<tr>
<td>16. I cannot stop crying.</td>
<td>.45</td>
<td>.92</td>
</tr>
<tr>
<td>18. I have made adequate plans for the future.</td>
<td>.46</td>
<td>.91</td>
</tr>
<tr>
<td>19. I get dissatisfied often.</td>
<td>.64</td>
<td>.91</td>
</tr>
<tr>
<td>20. I am in a better position than other caregivers.</td>
<td>.65</td>
<td>.91</td>
</tr>
<tr>
<td>21. This situation could have been worse.</td>
<td>.63</td>
<td>.91</td>
</tr>
<tr>
<td>22. I expect things to change for the better.</td>
<td>.72</td>
<td>.91</td>
</tr>
<tr>
<td>23. The things I used to do before still interest me.</td>
<td>.69</td>
<td>.91</td>
</tr>
<tr>
<td>24. I am satisfied with the treatment.</td>
<td>.70</td>
<td>.91</td>
</tr>
<tr>
<td>25. I feel anxious.</td>
<td>.71</td>
<td>.91</td>
</tr>
<tr>
<td>26. I feel depressed in general.</td>
<td>.64</td>
<td>.91</td>
</tr>
<tr>
<td>27. I am satisfied with life right now.</td>
<td>.57</td>
<td>.91</td>
</tr>
<tr>
<td><strong>TOTAL ALPHA</strong></td>
<td></td>
<td><strong>.92</strong></td>
</tr>
</tbody>
</table>

Confirmatory Factorial Validity

Confirmatory factor analysis was employed to find out if item responses group into three subscales as hypothesized, after detailed literature review conducted as part of the research study.
<table>
<thead>
<tr>
<th>Item</th>
<th>ASUB</th>
<th>DSUB</th>
<th>LSUB</th>
<th>Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>A2</td>
<td>.39</td>
<td>.17</td>
<td>.04</td>
<td>.15</td>
</tr>
<tr>
<td>A3</td>
<td>.55</td>
<td>.40</td>
<td>.18</td>
<td>.39</td>
</tr>
<tr>
<td>A4</td>
<td>.63</td>
<td>.56</td>
<td>.41</td>
<td>.40</td>
</tr>
<tr>
<td>A5</td>
<td>.52</td>
<td>.34</td>
<td>.17</td>
<td>.38</td>
</tr>
<tr>
<td>A6</td>
<td>.64</td>
<td>.48</td>
<td>.24</td>
<td>.48</td>
</tr>
<tr>
<td>A7</td>
<td>.67</td>
<td>.49</td>
<td>.29</td>
<td>.52</td>
</tr>
<tr>
<td>G25</td>
<td>.68</td>
<td>.68</td>
<td>.58</td>
<td>.74</td>
</tr>
<tr>
<td>D9</td>
<td>.62</td>
<td>.61</td>
<td>.50</td>
<td>.66</td>
</tr>
<tr>
<td>D10</td>
<td>.47</td>
<td>.62</td>
<td>.26</td>
<td>.50</td>
</tr>
<tr>
<td>D11</td>
<td>.45</td>
<td>.68</td>
<td>.23</td>
<td>.50</td>
</tr>
<tr>
<td>D12</td>
<td>.58</td>
<td>.70</td>
<td>.33</td>
<td>.59</td>
</tr>
<tr>
<td>D13</td>
<td>.44</td>
<td>.66</td>
<td>.23</td>
<td>.49</td>
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<tr>
<td>D14</td>
<td>.47</td>
<td>.66</td>
<td>.43</td>
<td>.60</td>
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<tr>
<td>D15</td>
<td>.51</td>
<td>.71</td>
<td>.46</td>
<td>.65</td>
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<tr>
<td>D16</td>
<td>.52</td>
<td>.65</td>
<td>.22</td>
<td>.49</td>
</tr>
<tr>
<td>G26</td>
<td>.60</td>
<td>.72</td>
<td>.47</td>
<td>.68</td>
</tr>
<tr>
<td>L18</td>
<td>.22</td>
<td>.28</td>
<td>.65</td>
<td>.52</td>
</tr>
<tr>
<td>L19</td>
<td>.53</td>
<td>.58</td>
<td>.59</td>
<td>.68</td>
</tr>
<tr>
<td>L20</td>
<td>.35</td>
<td>.44</td>
<td>.81</td>
<td>.70</td>
</tr>
<tr>
<td>L21</td>
<td>.35</td>
<td>.39</td>
<td>.83</td>
<td>.68</td>
</tr>
<tr>
<td>L22</td>
<td>.39</td>
<td>.46</td>
<td>.90</td>
<td>.76</td>
</tr>
<tr>
<td>L23</td>
<td>.38</td>
<td>.42</td>
<td>.90</td>
<td>.74</td>
</tr>
<tr>
<td>L24</td>
<td>.40</td>
<td>.44</td>
<td>.88</td>
<td>.75</td>
</tr>
<tr>
<td>G27</td>
<td>.36</td>
<td>.35</td>
<td>.76</td>
<td>.63</td>
</tr>
</tbody>
</table>

Note.  
A = anxiety item  
D = depression item  
L = life satisfaction item  
G = global item

Factor structure was determined by clustering of variables with higher correlations, with the hypothesized subscale score, rather than with any other subscale score. Table 10 shows clustering of items under three subdomains of anxiety, depression and life satisfaction. Anxiety items have lower correlations with the subscale score of anxiety, again pointing to relative weakness of the subscale. The life satisfaction items are correlated highly with their subscale.
score. Item 9 is the weakest item under the depression subscale. However, the alpha if it was removed is not higher than the present alpha. It correlates higher under the anxiety subscale than under any other subscale.

This could mean that it is more of an anxiety item than a depression item. That is to say item 9 assesses anxiety, more accurately than it does depression. Item 4 correlates more with the anxiety subscale total than with any other subscale total. However, it correlates quite highly with the depression subscale total. This indicates that item 4 assesses anxiety better than it assesses depression which it does to some degree. The global item 25 that is supposed to assess anxiety has the same correlation with depression subscale total. These scores show that there is a strong relation between anxiety and depression. Many patients who have a major depressive (or anxiety disorder) have some anxiety (or depression) symptoms too. Psychiatrists often diagnose depressive-anxiety or anxiety-depressive neurosis. There is an overlap in the diagnosis of anxiety and depression.

**Standard error of measurement**

The criteria used to assess SEM are given in detail on page 65. According to this standard, SEM should be approximately five per cent or less of the range of all possible scale scores. This would be a SEM of \( < / = 4.8 \) for global scale and 1.6 for the sub scales. The standard error of measurement was low for the external scales (CAS = .98, BDI-II = .56, SWLS = .17) Standard error of measurement was considerably low for the subscales and global scale that is under construction (ASUB = .11, DSUB=.13, LSUB=.14, GLOBAL = .08). This shows that the measurement error is low indicating that it is a good scale.

**Construct Validity**

To examine convergent construct validity, RBTS scores were hypothesized to correlate with three single-item indicators (of the constructs anxiety, depression and life satisfaction) and three established scales (CAS, BDI–II & SWLS). To examine discriminant construct validity, the global scale (general emotional reaction) score was theoretically proposed not to correlate with age, education, and gender. A low correlation between the global scale score and demographic variables (that were hypothesized not to correlate with the global scale) would empirically test
the hypothesized relation and help establish discriminant construct validity.

<table>
<thead>
<tr>
<th>Table 11</th>
<th>Correlations of the Subscale scores with their respective External Scales and Single Item Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subscale scores (anxiety, depression and life satisfaction)</td>
</tr>
<tr>
<td></td>
<td>r</td>
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<tr>
<td>External Scales</td>
<td></td>
</tr>
<tr>
<td>CAS</td>
<td>.36</td>
</tr>
<tr>
<td>BDI-II</td>
<td>.34</td>
</tr>
<tr>
<td>SWLS</td>
<td>.43</td>
</tr>
<tr>
<td>Single-Item Indicators of the constructs anxiety, depression and life satisfaction</td>
<td>Subscale scores (anxiety, depression and life satisfaction)</td>
</tr>
<tr>
<td>General Item 25</td>
<td>.64</td>
</tr>
<tr>
<td>General Item 26</td>
<td>.60</td>
</tr>
<tr>
<td>General Item 27</td>
<td>.49</td>
</tr>
<tr>
<td>MEAN CORRELATION</td>
<td>.48</td>
</tr>
</tbody>
</table>

In Table 11, subscales (anxiety, depression and life satisfaction) scores correlate highly, as hypothesized, with single-item indicators (of the constructs: anxiety, depression and life satisfaction) showing good convergent construct validity. It is also seen that subscale scores correlate more modestly with the external scale scores. As hypothesized, the RBTS correlates highly with the external scales (CAS, BDI-II or SWLS). RBTS correlates more with their respective external scales than with other subscales. This emphasizes that the subscales capture the construct as hypothesized. The demographic variables (i.e., age, education & gender) in Table 12 do not correlate highly with the global scale scores as hypothesized. Age and education do not correlate as much as gender does.

<table>
<thead>
<tr>
<th>Table 12</th>
<th>Correlations Between Discriminant Demographic Indicators and the Global Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Global Domain</td>
</tr>
<tr>
<td></td>
<td>r</td>
</tr>
<tr>
<td>Demographic Indicators</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.06</td>
</tr>
<tr>
<td>Education</td>
<td>.08</td>
</tr>
<tr>
<td>Gender</td>
<td>.22</td>
</tr>
<tr>
<td>MEAN CORRELATION</td>
<td>.13</td>
</tr>
</tbody>
</table>
Even though correlation between gender and global scale score is lower than other correlation scores of variables which converge (i.e., single item indicators and external scales with subscale scores), it is not low enough to indicate that gender does not correlate with the global scale as hypothesized. Therefore, it can be said that gender could have some correlation with the global scale score. Literature review conducted for this study does not reveal ages and gender to be variables that correlate positively or negatively with reactions of relatives to TBI.

**Discussion of Pilot Study Results**

This section deals with the discussion of results of pilot study conducted with students. It is for this reason that it is placed in this section of the dissertation. This is not the discussion of results of assessment of the final measure conducted with relatives of patients of TBI patients.

In developing the instrument to assess reactions of relatives of TBI patients, reliability and validity were assessed. The scale adequately assesses stressful reactions of relatives of TBI patients. It further quantifies anxiety, depression and life satisfaction. A cut-off indicator for stress should be developed to record the degree of stressful reaction. Future research should take into consideration different sample groups, larger samples and also, norm it to other cultures. The most important need is for this instrument to be administered on the actual population. In other words, it is crucial that this instrument is tested on relatives of TBI patients. Given the purpose of this study to provide Indian social workers with a measurement device, the instrument must be tested on a sample comprised of Indians. The above steps are needed to strengthen this preliminary evidence.

A minimum of eight items per subscale were retained to maintain minimum standards of reliability (Ferketich, 1991) while allowing the computation of reliability coefficients and exploratory factor analysis to streamline the final scale of 24 items. There were three items in the form of single item indicators of the constructs. The scale was intended to be as brief as possible.

This pilot study does not indicate that the measurement device is consistent and accurate enough to be used on relatives of TBI patients at this point. However, the pilot study has been invaluable in understanding the conceptual and analytic outcome of this study. This pilot study has suggested that the device can be tested on the relatives of TBI patients. Within the constraints
of the research design, the pilot study findings provide a starting place for content and structure of scale employed in the dissertation. The pilot study findings helped in a very preliminary way.

**Item Generation for the RBTS**

Although items of the Reactions to Brain Trauma Scale (RBTS) were pilot tested and revised, there still was a need to refine it. Focus groups of experts in the field were included from the very initial development of this instrument. Focus group included neurosurgeons, neurologists, neurological/neurosurgical social workers, and nurses. The neurosurgeons were the heads of the different specialized units of neurosurgery at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in India. Neurological and neurosurgical social workers were consultants working with TBI patients at NIMHANS. Groups of nurses consulted at NIMHANS were those working at the casualty department, short-stay wards, pre and postsurgery wards, intensive care unit and male/female wards. Various experts were sent the list of revised items (after pilot study and further Indian literature review) for their comment and suggestions. The focus group members agreed on the appropriateness of domains of instrument for the study.

Changes were made to the list of items that improved its clarity and relevance to the target group. The instrument was named the Brain Trauma Patients’ Relatives’ Reactions (BTPRR) at the outset. For the sake of brevity, it was changed to Reactions to Brain Trauma Scale (RBTS). Members agreed that the format was ideal for subjects for whom the instrument was intended. They decided that a seven-point Likert scale would be confusing. When it came to the process of translating the questionnaires into the three Indian languages and then again translating them back into English (to check for the correctness of the original translations) another group of experts in the three languages was consulted. These experts were professors who teach at various schools in India. The three languages were chosen based on the suggestion of the head medical officer at NIMHANS who indicated that these three major languages are spoken by most patients and their family members who are admitted to NIMHANS. This format was agreed by the language experts who suggested that translating the seven points of the Likert scale into the three different languages would be difficult and may not say the same thing as it does in English. The language experts translated the questionnaire in consultation with their
colleagues in their respective departments. The language experts who originally translated the questionnaire into the three Indian languages were different from those who made the reverse translations (from three Indian languages to English).

**Instrument Validation**

**Subjects**

Subjects were relatives of TBI (i.e., a close family member of the patient who has succumbed to TBI). The family member was over the age of 18, who spoke any of the three Indian languages (i.e., Hindi, Kannada or Tamil). It was also necessary that relatives had no history of substance abuse or major psychiatric disorder so that the test results would not be biased by relatives who had major mental disorders as they would be likely to score high on the RBTS. TBI patients were admitted at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in Bangalore, India. NIMHANS is a multidisciplinary organization which works simultaneously on three fronts: caring for those with mental or neurological disorders, training social work, psychological, neurological, neurosurgical and nursing staff and conducting research in several cognate fields. Established in 1954, NIMHANS is currently an autonomous body and receives grants from central and state governments for maintenance and development activities (Channabasavanna, 1991).

The institute’s main philosophy is the multidisciplinary team approach towards prevention and curative aspects of health. It has an out-patient facility, 24-hour casualty and emergency service, 150 faculty, over 100 resident doctors, other residents and postgraduates in various fields of mental health (i.e., social work and psychology), neurosciences and specialized nursing care (Channabasavanna, 1991). Research activities encompass a large spectrum, from cellular mechanisms to social systems associated with various neurological and behavioral disorders, which help explain not only the disease processes but also the basic issues of brain behavior relationship. An important objective of NIMHANS is to cooperate with agencies (international and national) engaged in mental health, neurosciences research and training (Channabasavanna, 1991). Another objective is to arrange for the exchange of personnel, material and data. The Institutes’ neurosurgical center caters to the needs of patients with
neurological and neurosurgical problems. It has 155 beds with an average of 15 admissions per day of patients with severe TBI.

Permission was obtained to conduct the study at the neurosurgical center at NIMHANS. The Ethics Committee at NIMHANS approved the study (see appendix I). The researcher collected the data. The limited generalizability due to use of purposive sample was offset, to a small degree, by maximizing the sample size. DeVellis (1991) stated that it is not uncommon to find factor analysis done in smaller samples. However, larger samples increase the ability of factor structure to emerge from an analysis. Replicating factor analysis on a separate sample is the best way of demonstrating generalizability. Given the high turnover at NIMHANS, a set goal of 270 subjects for the sample seemed reasonable. This would ensure the standard suggested for factor analysis (i.e., 10 subjects for each item on the scale) according to Nunnally and Bernstein (1994).

It was a purposive sample as the subjects were those with whom the researcher was specifically interested. The subjects all met the criteria required in the research study. Total sampling period was around six weeks with the number sampled varying daily (with the admission rate of severe and moderate TBI patients and the availability of their relative for interviews). An epidemiological study (G. Gururaj, Head of Department of Epidemiology at NIMHANS) in TBI was carried out at the same time. Relatives of TBI patients were referred to the researcher after the epidemiological interview. Interviews were conducted in the nurses’ station in each ward.

Rates of usage of the RBTS

The subjects (279) answered the questionnaire in one language - Kannada. There were 18 subjects who completed the Hindi questionnaire and 15 who answered the Tamil questionnaire. Of the 22 subjects who refused to respond to the questionnaire, 19 subjects had reasons that had nothing to do with their attitude towards the study. Some could not be there at the time of the interview because they had to be elsewhere. Some had to fill the “never-ending” prescriptions from pharmacies that were far from the hospital. A few relatives had to attend to care of their TBI family member and there were important home matters to attend to for others. Three
relatives, however, had other reasons to not comply. One relative looked at the questionnaire and refused to answer, another said that it was a waste of time while the third walked away after answering a few questions. For analysis purposes only those questionnaires completed in Kannada were retained. Those completed in the other two languages and those with missing data were not included in the analysis.

**Informed Consent**

Participation in this study was voluntary. Informed consent was obtained from participants. Participants were given a full description of study and their role in it. In the event participants had further questions, name and telephone number of contact person (researcher) were provided. The interviewer explained to the participants that by filling out the instruments they automatically demonstrate their agreement to participate in the study. The ethics committee at NIMHANS required a consent form (see appendix F) to be presented along with the questionnaire.

The consent form was read to the participants at the outset giving them adequate time to refuse to participate if they so wished. It was explicitly communicated that at any point in the interview, participants could decline to continue if they changed their mind about participating. Those who did not wish to participate in this study were not in any way coerced. There was no material incentive for participating in this study. It was made clear that nothing untoward would happen if participants chose not to participate. However, participants were told that their participation would help in the instrument development and in the focused treatment of TBI patients’ relatives. Signatures or thumbprints of respondents were not taken as it was found to be appropriate to get their verbal consent after the form was read to them.

There was less than minimum risk of the participants being emotionally disturbed with the items in this study. Steps were taken to ensure that the subjects who were emotionally upset by participating in this study were referred to appropriate professionals. A list of hotlines, contact persons and institutions (see Appendix H) were made available for those who required emotional support. Contacts included hospitals and clinics located in close proximity to the institution (NIMHANS) where the data was collected.
Confidentiality and Anonymity

The participants did not write their names or identification number on the questionnaire. The identity of the respondents was not tied to the questionnaires in any way. There was no way of tracing individuals from the completed forms. Personal documentation like tapes or pictures of the participants was not collected. Thus, anonymity was maintained. The researcher securely maintained the records at all times. After research is successfully completed all hard copies will be destroyed.

Measures

The researcher did not find evidence of performance of these measures on the Indian population. An earlier study done by the researcher, Rajaram in 1992 (see results on page 40) revealed that Speilberger’s Anxiety Scale’s performance was similar to its performance in the West. It is anticipated that these scales will perform as well as they do in the West, since the researcher has administered the instrument. Care was also taken to bridge the language gap with good translation done by language experts (as revealed by the reverse translation). Even though the researcher was fluent in speaking, and could read and write in these languages, she had not conversed in these languages in the past six years. The researcher went through a thorough training in administering the questionnaire.

With all these precautions, it has to be noted that there is a cultural leap using a foreign measurement device to measure reactions of relatives to TBI of their family member. However, a first step must be made in order to develop indigenous instrument devices and literature. There was a need to borrow from Western literature to develop tools that are specially designed for the Indian population. The following section deals with description of measures that were administered to subjects. Psychometric properties available will be mentioned. The purpose of this discussion is to defend the use of measures in this study. Even though there are many existing scales that measure the three constructs (anxiety, depression and life satisfaction), these three instruments were specifically chosen for their content, structure and ease of administration.

Clinical Anxiety Scale (CAS)

Thyer (1987) developed a 25-item scale that focused on measuring amount, degree and
severity of clinical anxiety. Excellent internal consistency was reported with a coefficient alpha of .94. Standard error of measurement of 4.2 was relatively low, suggesting minimal amount of measurement error. Two-week test-retest correlations ranged from .64 to .74. Concurrent construct validity was reported to discriminate between groups suffering from anxiety and lower anxiety control groups. This device had good psychometric properties to assess general anxiety in clinical practice. Items are not specifically related to relatives’ reactions to TBI. Experience in working with this group (Narayan, personal communication, October 1992) revealed that, unlike generalized anxiety, relatives’ anxiety was more related to the traumatic event. Anxiety formed part of the general reaction that encompasses depression, anxiety and life satisfaction. Even though the scale is long (keeping in mind anxiety is one dimension of the construct general reaction to TBI and that relatives are not in a position to answer lengthy measurement devices) it is used for its good psychometric properties to establish convergent construct validity. The current study aimed to develop a brief multidimensional instrument to be administered on relatives of TBI patients.

**Satisfaction with Life Scale (SWLS)**

Diener, Emmons, Larsen, and Griffin (1985) developed a five-item scale as part of a body of research on subjective well being. The scale referred to cognitive judgmental aspects of general life satisfaction. It has good reliability and criterion validity. The authors clearly operationalized the construct, emphasizing cognitive judgmental aspect of life satisfaction. Clinical utility with adolescents undergoing identity crisis or adults experiencing midlife crisis was suggested. It was normed on a sample of undergraduates and a sample of elderly citizens. Internal consistency was acceptable with an alpha of .87. Test-retest reliability was established with a correlation of .82 for a two-month period. Convergent construct validity was also reported using correlations with nine measures of subjective well being, scores ranging from .37 to .75. Discriminant construct validity was implied by a weak correlation with a measure of affect intensity and with the SWLS not evoking a social desirability response set. Condensing the scale (five items) made reporting and scoring easier. It could be restrictive in tapping the whole construct of life satisfaction, as envisioned, to assess the reactions of TBI patients’ relatives. For
relatives of TBI patient, life satisfaction items should be more relevant to trauma and immediate life after injury. This instrument is chosen in this study to establish convergent construct validity for its ease in administration and brevity.

**Beck Depression Inventory - Second Edition (BDI-II)**

Beck, Steer and Brown (1996) developed a 21-item self-report instrument for measuring severity of depression in adults and adolescents aged 13 years and older. This version was developed for assessment of symptoms corresponding to criteria for diagnosing depressive disorders (listed in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders- Fourth Edition) (DSM-IV, 1994). Internal consistency (measured using coefficient alpha) was .92 for 500 outpatients and .93 for 120 college students. For outpatient sample, correlations ranged from .39 to .70. Range of corrected item-total correlations for student sample ranged from .27 to .74. Test-retest correlation was significant (p < 001) at .93. This stability over time was estimated based on responses of a subsample of 26 outpatients who were administered the BDI-II at first and second therapy sessions held a week apart. Construct validity coefficients were noted as follows: .93 with BDI-II; .68 with Beck Hopelessness Scale (BHS); .37 with Scale for Suicide Ideation (SSI); .60 with Beck Anxiety Inventory (BAI); .71 with the Revised Hamilton Psychiatric Rating Scale for Depression (HRSD-R) and .47 with Revised Hamilton Anxiety Rating Scale (HARS-R). With respect to convergent validity, the BDI-II is positively related (.001) to both the BHS and the HRSD-R. Discriminant validity is seen with lower rate of correlation between the BDI-II and the HARS-R.

Factorial validity evidence was provided by the intercorrelations among the 21 BDI-II items. Kaiser’s measure of sampling adequacy was .95. BDI is sensitive to clinical changes. However, some items with somatic content are not relevant for assessing relatives’ reactions. The multiple-choice format makes it difficult for respondents to rate and indicate presence of symptoms. These limitations are minimal in comparison to the good psychometric properties of this measure. For this reason, the measure is chosen to establish convergent construct validity in this study.
Reactions to brain trauma scale (RBTS).

The focus of this study is RBTS and it consists of 27 items, with 9 items each assessing anxiety, depression and life satisfaction of relatives of TBI patients. Items were changed after the pilot study and by the focus group in India. It was also recommended that a few items be added to the demographic data section of the questionnaire. It is intended for use by relatives of TBI patients as a rapid assessment self-report instrument. Its item pool intends to reflect the above purpose. It is believed that there will be a few items that can be discarded following data analysis. The instructions include the statement asking how respondents feel at that moment. They will be asked to honestly give their personal views, including items that ask about relationships with the injured. Respondents will be asked to indicate the response that best describes the way they feel. The Flesch-Kincaid grade level recorded 8.0 indicating that a student of eighth grade and above can read and understand this questionnaire in English. It was the same for the external scales too.

Procedure of Data Collection

Recruitment efforts began with successful completion of pilot study. The head of the neurosurgical department of NIMHANS was contacted and clearance to collect data was granted. The questionnaire was read to the respondents using the survey technique. The instrument package was administered by appointment by the researcher after admission of patient (mild and moderate TBI) to the ward. Care was taken to ensure that the relatives were not given false information by the interviewer regarding the patients’ recovery and any question answered about the patient was done in consultation with the treatment team. The researcher refrained from giving examples, clarifying or elaborating on the questions in the questionnaire. If subjects were confused, the questions were repeated and not elaborated.

The package (questionnaire administered to the subjects) contained the current instrument under study, Beck’s Depression Inventory, Clinical Anxiety Scale and the Satisfaction with Life scale. One of the three languages, the questionnaire in Kannada was used the most in this study. Completed questionnaires translated in the other two languages were few and therefore not retained for analysis in this study but will be analyzed in the future. Demographic data collected
consisted of participant characteristics and patient details that could have a bearing on the study. Participants were asked if they had any prior history of substance abuse or mental illness at the outset. It should be noted that some of the participants could have had neurotic anxiety or neurotic depression that was not diagnosed. It is possible that some of the participants who scored highly on the depression or anxiety scale could be diagnosed as neurotic depressive or neurotic anxiety patients. However, the same could be said of the general population. Data collected with regard to the instruments will be analyzed using the following methods.

**Reliability and Validity Methods**

Earlier, conceptual aspects of reliability and validity were discussed. The following section provides explanation and rationale of reliability and validity estimation techniques used in this study. Data was analyzed using the Statistical Package for the Social Sciences (SPSS).

**Reliability**

Cronbach’s coefficient was used as the method of estimating reliability for both the subscales and the global scale. Other methods, parallel forms and split-halves, were not chosen because they lacked sophistication and accuracy. Test-retest method of estimating reliability (which relies upon stability of scores from one administration to another) was not conducted for logistical and logical reasons. It was not possible financially and it was also difficult to administer the instrument package on the same sample after a time period has elapsed. Further, it is hoped that the instrument is sensitive to change over time, treatment and coping mechanisms. If it is sensitive to change, then trying to establish reliability through test-retest method did not seem logical because for test-retest method of establishing reliability one hopes to get consistent results over a time period. In this case, the constructs are expected to change over time. According to N. Abell (personal communication, May 2002), “an instrument which is sensitive to change over time could produce different scores in a circumstance where subject(s)’ experience of a particular problem had changed. That is, if one’s depression is different at various times a sensitive scale (one which tracks level of their problem as it actually exists) would produce different scores at each time. A related complication for test-retest reliability is that if the technique requires consistency of scores over time, it is unlikely to be established for
problems that are inherently changeable (and thus likely to differ, rather than remain the same). Consequently, a scale might have high internal consistency but low test-retest reliability.

Alternate or parallel forms, method required two different forms of instrument. Construction of parallel forms is not very easy (Carmines & Zeller, 1979). It entails creation of a shorter form of original measure and administering it along with the original measure. Construction of one instrument is an arduous task by itself, so due to time constraints the construction of another form of the same instrument was not undertaken.

Split-halves method of reliability is indicated with high correlations between answers of two halves of all the items. Correlation between two halves varies depending on how items are split (Nunnally & Bernstein, 1994). Split-half method is part of the underlying calculations for Cronbach’s coefficient alpha. Coefficient alpha is the average of all possible split-half reliability estimates or average of all alpha coefficients obtained for all possible combinations of items in two half tests (Carmines & Zeller, 1979).

Cronbach’s coefficient partitions observed variation into the portion that is attributable to true score and portion that is attributable to error. It is based on average correlations among all items. Cronbach’s alpha determines internal consistency of individual item scores with total index (Crocker & Algina, 1986). This was established in this study using SPSS. This analysis was used to determine stability of the global index and consistency for the three subdomains individually. The process analyzed how strongly items load (correlate) with their domains. ‘Alpha if item deleted’ option in SPSS helped determine what items needed to be deleted from their respective domains. Deleting certain items was beneficial, when deletion increased overall alpha level for the domain (especially when the items did not load onto domains that they were intended to). In terms of internal consistency, when an instrument has a high alpha (maximum of 1.0) it indicated that items were capturing the same domain and therefore, reliable. This study considers .80 - .84 as an acceptable range for reliability (see p. 64 for the discussion on setting this standard for the current study).

All four approaches to reliability are designed to detect absence of error in the measure. Reliability coefficient is influenced by difference in the variance or standard deviation of a
measurement scale (Springer et al., 2002). A detailed discussion is given on page 65. A good measure should possess a large coefficient of reliability and a small SEM. Reliability though important and necessary is not enough for a good measure. A useful measure has validity.

**Validity**

Three types of validity were used in evaluation of the instrument. They were content, construct (convergent construct and discriminant construct) and factorial validity. As a method of testing theory, establishment of construct validity is an ongoing process. It could turn out to be an elusive endeavor.

Content validity is the degree to which items of a scale represent the domain of items that would define the construct under consideration. It is related to the manner in which the instrument is developed (Walz & Bausell, 1981). A scale has content validity when its items represent a randomly chosen sample of items from the universe. There is no universally acceptable means of assessing content validity (Carmines & Zelle, 1979). An instrument with good content validity would be very useful for a practitioner. Nunnally and Bernstein (1994) state that content validity is established when items are adequately sampled from the pool of required domain. Content validity is established when items of a scale represent the domain of items that would define the construct under consideration. In this study, content validity was established by agreement of item content (among colleagues and practitioners) and matched to the clear definition of target construct emotional reaction of TBI patients’ relative (definitions provided on pg. 8). Modification of items with help of focus group helped remove ambiguity and superfluity.

Criterion validity is the degree to which the instrument being constructed can be empirically associated with some standard. Correlation coefficient is used for quantification of the empirical association. There are as many correlation coefficients as there are criteria for the instrument. Hudson (personal communication, July, 1997) suggests the use of convergent construct validity instead of criterion concurrent known-instruments validity. If the instrument under construction is better than the established instrument used as the criterion, researcher must attribute resulting poor correlation to the instrument under construction. This is because once the instrument is established as a criterion, with which the measure under construction should be
compared. It cannot later be discarded as a criterion due to poor correlation between the two instruments. Therefore, the instrument, which is endeavoring to reach a standard based on the criterion measure, must assume cause for poor correlation.

The above risk is great enough to avoid administration of external instruments, along with the current measure being developed for establishing criterion known-instruments validity. In this study, therefore we did not try to establish criterion known instruments validity. However, external instruments were administered to test convergent construct validity. Correlating external scale scores with subscale scores (that were hypothesized to correlate) can test convergent construct validity. A high correlation supports arguments for convergent construct validity.

Construct validity is most closely related to theory. A tie to theory of construct validity lies in testing of hypotheses associated with the extent to which some particular measure relates (convergent validity), or does not relate (discriminant validity), to other measures in accordance with some theory. Theoretically, immediately after TBI of family member the relative responds with heightened anxiety and depression. From a detailed review of long established instruments, Thyer’s Clinical Anxiety Scale, Satisfaction with Life Scale and Beck’s Depression Inventory-II were chosen to be used as theoretically relevant correlates for convergent construct validity. If the new scale correlated highly in magnitude with the scales’ (long known for their reliability and validity) responses, then convergent construct validity exists. Three single-item indicators were used as convergent construct validity indicators. The measure should correlate with single-item indicators that asked if the relative feels anxious, satisfied with life or depressed to establish convergent construct validity. Age, gender and education were used as discriminant construct validity indicators as it was hypothesized that they are variables that should not correlate with the global scale. Hypotheses (p. 5) show the relation between results and hypotheses of this study.

Indepth literature review helped make the choice of which demographic variables to choose for the purpose of establishing convergent and discriminant construct validity. Reaction to Brain Trauma Scale will correlate with selected demographic indicators (age, relationship of respondent with patient and time since injury). Reaction to Brain Trauma Scale will not correlate positively with selected demographic variables (gender, education and income).
Pearson’s r was used to test convergent and discriminant construct validity. Pearson’s r is used to measure strength of linear relationship between items. Either positive or negative relationships between items were detected. Pearson’s r values range from -1 to +1 (perfect negative linear to perfect positive linear relationships). Where appropriate, calculated r values were squared to indicate shared variance or the magnitude of linear relationship between the two factors. One main requirement is to have a normal distribution of population from which the sample is drawn (which this study lacks). However, this study has a relatively large sample size. The need for this requirement diminishes, based on the central limit theorem that states that as sample size increases (number of observations) sum of independent observations (regardless of type of distribution possessed by each independent observation) approaches a normal distribution.

Factorial validity is demonstrated by using either exploratory factor analysis or confirmatory factor analysis. Confirmatory factorial validity is determined by examining the degree to which the items on an instrument correlate with constructs that they are intended to measure (Nunnally, 1978). Confirmatory factor validity is used in this study because items and factors are derived from theoretical thought (in-depth literature review). Previous studies included mini-ethnography, in-depth literature review and pilot study. Number of factors was fixed at three (i.e., anxiety, depression and life satisfaction). This type of validity is also described as items on a scale having a much higher positive correlation with the scale’s total score than with the total score of any subscale (Hudson, 1982). Items were fixed to load onto their predetermined domains. Multiple group or group-centroid method of confirmatory factor analysis was used for the relative ease with which it was understood, employed and communicated (Nunnally, 1978). Pearson’s r was used to correlate item responses with subscale totals. Factor structure was determined by clustering of variables that had a higher correlation with the hypothesized sub scale score (than with any other subscale scores). It was determined apriori that there should three subdomains (each with nine items) under one global domain. The following chapter will deal with results of study and analysis as required for validation of the Reactions to Brain Trauma Scale (RBTS).
CHAPTER V
RESULTS

This chapter consists of results of the study. At the outset, participant characteristics and results of reliability analysis conducted on the Reaction to Brain Trauma Scale (RBTS) will be presented. The findings of confirmatory factor analysis (CFA) will be discussed next. Results of convergent and discriminant construct validity will follow the above presentation. These results produce the final version of RBTS. The following are relevant characteristics of participants and their TBI family member collected in the form of demographic data.

Participant Characteristics

The total sample included in this study consisted of 279 subjects. The sample was collected from the National Institute of Mental Health and Neuroscience in Bangalore, India. Subjects were relatives of TBI patients. These patients were admitted to the casualty department, the intensive care unit, short-stay ward, the pre and postoperative wards or the surgical wards. The relatives were parents, spouses, siblings or children of the patients. The relatives related some of the benefits of participating in this study. The expression of feelings was cathartic and did alleviate some stress. Even when such expression was found to be awkward by some respondents, it was beneficial in the long run (as reported by some respondents). Three of the respondents voluntarily informed the researcher that the interview process helped in some way. When probed the respondents added that they felt a relief, some understanding of their own feelings and a general feeling of “weight lifting off their shoulders”. There is a possibility that if there had been a formal follow up, more respondents might have added to this sentiment.

Severity of TBI of the patient

Relatives’ reaction may vary with degree of severity of their family members’ TBI. Patients who had suffered severe TBI totaled to 223, while 56 had moderate TBI. Severity of TBI
was measured by neurosurgeons using a Glasgow Coma Scale. This scale had a total score of 13. A patient scoring 13 is considered normal. Lower the score on this scale, greater the severity of injury to the brain. This score varies from the first day to a later time, depending on progress, or lack of progress, that the TBI patient makes. TBI patients’ medical chart typically has different Glasgow Coma Scale (GSC) scores on different days of his/her stay in hospital because the medical staff calculates GSC scores recording daily changes in medical condition of the patient. The score used for this study was the one taken on patients’ admission to hospital. As shown in Figure 1 below, 80% of patients had severe TBI on admission. Only 20% of patients had moderate TBI.

![Figure 1 - Severity of Brain Trauma of Patient as Indicated by the Glasgow Coma Scale](image)

**Figure 1 - Severity of Brain Trauma of Patient as Indicated by the Glasgow Coma Scale**

**Duration of hospital stay of the TBI patient**

Duration of stay of patient was considered in this study. Change in patients’ condition depended on factors like treatment process and patients’ pre trauma condition. Change in the patients’ condition would most likely affect relatives’ reaction to TBI.

Figure 2 indicates that 50% of patients included in this study were interviewed on the first day of admission to hospital. About 10% of relatives were interviewed on the third day after admission of their family member to hospital. Almost 13% of patients who had stayed in hospital for nine days were included in the study. The remaining 27% of respondents interviewed had
their family member with TBI in hospital for no more than 15 days. Duration of hospital stay is important because longer the patient stayed in hospital, more likely it is that relatives’ responses would change. This change in relatives’ reactions may be due to the attitude of hospital staff, reactions or other TBI patients’ relatives, change in patients’ condition or acceptance of trauma.

![Figure 2 - Duration of Hospital Stay of TBI Patient](image)

**Figure 2 - Duration of Hospital Stay of TBI Patient**

**Age of the respondent**

Table 13 depicts the mean age of the subjects as 38 years. The age range was 54, with a minimum of 18 years and a maximum of 72 years. There were 78 subjects between the ages of 18 years and 27 years. There were 49 subjects between the ages 28 and 36 years. For the age groups of 37 to 45 years and 46 to 54 years, there were 61 and 63 subjects in each interval, respectively.

<table>
<thead>
<tr>
<th>Age Range (in years)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-27</td>
<td>78</td>
</tr>
<tr>
<td>28-36</td>
<td>49</td>
</tr>
<tr>
<td>37-45</td>
<td>61</td>
</tr>
<tr>
<td>46-54</td>
<td>63</td>
</tr>
<tr>
<td>55-63</td>
<td>24</td>
</tr>
<tr>
<td>64-72</td>
<td>4</td>
</tr>
</tbody>
</table>
Gender of the respondent

The sample was divided by gender into 103 males and 176 females (Figure 3). The higher rate for women is consistent with earlier study findings (Rajaram, 1991). Most Indian women still stay at home. Therefore they would be likely to stay at the patient’s bed-side while men went to work. Women usually do not go out to buy medicine or food when men are available. It is proper for women to remain in the confines of the hospital while men do the outside chores. If a male member was around the female would stay behind while the male responded to the questions.

![Gender of the Respondent](image)

**Figure 3 - Gender of the Respondent**

Education of the respondent

Rates of education of respondents are shown in percentages in Table 14. One hundred and thirty-two of subjects indicated that they had not attended any formal school. ‘Informal’ schools attended by some subjects included agricultural workshops held by village-head farmers.

<table>
<thead>
<tr>
<th>Education</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (N)</td>
<td>279</td>
</tr>
<tr>
<td>None</td>
<td>132</td>
</tr>
<tr>
<td>Completed 10th Grade</td>
<td>75</td>
</tr>
<tr>
<td>PreUniversity</td>
<td>47</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (N)</td>
<td>279</td>
<td>100.0</td>
</tr>
<tr>
<td>None</td>
<td>132</td>
<td>47.3</td>
</tr>
<tr>
<td>Completed 10th Grade</td>
<td>75</td>
<td>26.9</td>
</tr>
<tr>
<td>PreUniversity</td>
<td>47</td>
<td>16.8</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>25</td>
<td>9.0</td>
</tr>
</tbody>
</table>
Some women’s groups held meetings to teach women about banking, gainful employment, education and leadership. Many respondents were not educated and it was appropriate for researcher to read the instrument and not use it as a self-report measure.

**Income of the respondent**

<table>
<thead>
<tr>
<th>Table 15. Income of the Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Image of table]</td>
</tr>
</tbody>
</table>

Table 15 illustrates various income groupings of respondents with 225 subjects reporting an annual income below 10,000 Rupees (Indian currency equivalent to approximately $200). Fifty-one subjects claimed that their annual income was between 10,000 to 30,000 Rupees. Forty-two subjects reported an annual income between 30,000 to 50,000 Rupees. The interviewer reiterated (to the subjects) that there was no relation of their disclosure of income, to the hospital charges. However, hospital staff stated that many respondents were under the firm impression that they should give a low annual income figure to any hospital staff who asks about it in the hospital to avoid the large hospital bills. The researcher was considered to be a hospital staff member by many respondents.

**Religion of the respondent**

<table>
<thead>
<tr>
<th>Table 16. Religious Preference of the Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Image of table]</td>
</tr>
</tbody>
</table>

98
**Importance of religion to the respondents**

![Importance of religion to the respondents](image)

**Figure 4 - Importance of Religion to the Respondent**

Figure 4 displays the importance of religion in the respondents’ lives. Two hundred and forty-six (about 88%) of the sample insisted that religion played an important role in their lives. Thirty-three (about 12%) of the subjects said that religion played a moderate role in their lives.

**Relationship to the patient**

Of the total sample, 156 subjects (87%) were parents, while 81 subjects (29%) were spouses and 42 subjects (15%) were children of the TBI patient. The relationship of the respondent to the patient is depicted in Figure 5.

![Relationship to the patient](image)

**Figure 5 - Relationship of Respondent to the Patient**
Help received from various sources

One hundred and fifty-four subjects (55%) stated they received help mainly from family and some help was also sought from friends and relatives (Figure 6). Sixty-four respondents (23%) revealed that relatives helped them more than friends and family. Friends helped 61 subjects (22%) to a large extent.

Figure 6 - Sources of Help Received by the Respondent

Institutions (other than hospital) did not play a large role in help to families of TBI patients at that initial phase of recovery process (R. Narayan, personal communication, Feb. 1999, personal communication). For this reason tertiary source of support were not included in the questionnaire (demographic portion). Sources from where help was received are displayed in Figure 6.

Stress of responsibilities

When questioned if additional responsibilities were physically and mentally wearing subjects down, 249 respondents (89%) replied in the affirmative. Remaining 30 subjects said they were not worn out by additional responsibilities. Figure 7 shows the above percentages for respondents admitting that responsibilities were either wearing them down or not wearing them down. This particular information was collected to see if the stress of additional responsibilities was directly related to the amount of anxiety or depression exhibited by the respondent. This would be useful for future research was not dealt with in this study.
Figure 7 - Burden of Responsibilities Felt by Respondent

Caregiver status of the respondent

About 143 subjects (51%) claimed to be the main caregiver, while 136 identified themselves as secondary caregivers (see Figure 8). A main caregiver is one who devotes more than six hours a day or night in the exclusive care of the TBI family member. This main caregiver is not just a member who comes during visiting hours.

Figure 8 - Main Caregiver of the Respondent
Breadwinner status of the respondent

![Graph showing breadwinner status](image)

Figure 9 - Breadwinner Status of the Respondent

Figure 9 represents the breadwinner status of the respondents. About 45% of the respondents claimed to be breadwinners while 55% of the respondents said that they were not the breadwinners of their families. It is to be noted that most respondents lived in rural areas where the joint family system is still in existence. In such joint families, the head of the family is still considered the sole breadwinner. Although the rest of the members may help on the agricultural land, they are still considered dependents of the family head. It is only when there is a break in the joint family and members start their own households with separate incomes they are considered as separate breadwinners. The preceding section dealt with the characteristics of the participants and patients. The reliability and validity of the RBTS is given below.

Reliability Analysis of RBTS

At the outset, reliability analysis was used to inspect individual item characteristics. The next step in reliability analysis involved examination of the relationships between each item and the entire instrument. Reliability coefficients were also scrutinized. All these tasks were carried out in a step-by-step manner. Reliability or internal consistency of the Reaction to Brain Trauma Scale (RBTS) is affected by item-total correlations.

Item total correlations were inspected first to detect existence of negative correlations.
between items and item total, and to list those items (with negative correlations) as potential items for deletion. These negative correlation values suggest bad wording, sampling error or wrong keying according to Nunnally and Berinstein (1994). Item to item correlation matrix was also checked. Patterns of negative correlations that were related to a failure to reverse-score any item were not seen. Items that exhibited a positive correlation with some items and a negative correlation with other items were tentatively listed as potential items for deletion. Items that exhibited the above properties were items numbered 1 and 8 of the anxiety subdomain. The problem with these two items was confirmed by the items’ poor performance on other indicators, such as its ‘item corrected item-total scale correlation’ and ‘alpha if item deleted’ figures within the respective domain.

Item-total scale correlations and Cronbach’s alpha levels are important factors related to the overall instrument reliability. Items performing poorly on these indicators were deleted if it was determined (perhaps subjectively) that such deletion would not result in a substantial conceptual loss. Items that have a low item total correlation are likely to be difficult, ambiguous or may have little relevance to the domain. Each individual item must correlate substantially with rest of the items in its domain in order to have good reliability. Items with item-total scale correlations below .40 within a domain were evaluated on an individual basis for deletion. This was in keeping with standards suggested by Nunnally and Bernstein (1994). Increase in alpha level with relation to deletion of an individual item from a domain was taken into consideration. Various authors have given acceptable reliability rates. This study considers .80 - .84 as an acceptable range for reliability (see p. 64 for discussion of standards of reliability). Deletion of items was considered for those items marked by an asterisk (*) in reliability analysis for each domain (see Table 17). Item two was also listed as a potential item for deletion with the low correlation of .31.
Table 17. Initial Reliability Analysis of the Anxiety Domain

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Total Scale Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am able to think clearly and make plans for the day. *</td>
<td>.17</td>
<td>.73</td>
</tr>
<tr>
<td>2. I feel shocked at the trauma of my close family member.</td>
<td>.31</td>
<td>.69</td>
</tr>
<tr>
<td>3. I feel nervous about the incident.</td>
<td>.45</td>
<td>.67</td>
</tr>
<tr>
<td>4. I am unable to make plans to look after the patient.</td>
<td>.43</td>
<td>.67</td>
</tr>
<tr>
<td>5. I am worried about the effect of the traumatic incident.</td>
<td>.42</td>
<td>.67</td>
</tr>
<tr>
<td>6. I keep worrying about the treatment teams' efficiency.</td>
<td>.56</td>
<td>.65</td>
</tr>
<tr>
<td>7. I am so preoccupied that I cannot carry on with routine as usual.</td>
<td>.54</td>
<td>.65</td>
</tr>
<tr>
<td>8. I feel calm and at peace.*</td>
<td>.12</td>
<td>.73</td>
</tr>
<tr>
<td>TOTAL ALPHA</td>
<td></td>
<td>.71</td>
</tr>
</tbody>
</table>

The depression domain was initially constructed with items from numbers 9 through 16. There were no items deleted because the item-total correlations were not below .40 and the figures in the ‘alpha if item deleted’ did not show substantial increase in the total alpha when any item was deleted from this domain (see Table 18).

Table 18. Initial Reliability Analysis of the Depression Domain

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Total Scale Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. I feel alone in the world since the trauma.</td>
<td>.53</td>
<td>.79</td>
</tr>
<tr>
<td>10. My heart feels heavy and sad about the incident.</td>
<td>.57</td>
<td>.79</td>
</tr>
<tr>
<td>11. My appetite and sleep patterns have increased or decreased.</td>
<td>.49</td>
<td>.80</td>
</tr>
<tr>
<td>12. This is the saddest time of my life.</td>
<td>.57</td>
<td>.79</td>
</tr>
<tr>
<td>13. I feel devastated at the thought of losing my loved one.</td>
<td>.43</td>
<td>.80</td>
</tr>
<tr>
<td>14. I feel there is no hope in the future for me.</td>
<td>.46</td>
<td>.80</td>
</tr>
<tr>
<td>15. I feel tired and listless since the trauma.</td>
<td>.45</td>
<td>.80</td>
</tr>
<tr>
<td>16. I cannot stop crying when I think of the incident.</td>
<td>.47</td>
<td>.80</td>
</tr>
<tr>
<td>TOTAL ALPHA</td>
<td></td>
<td>.81</td>
</tr>
</tbody>
</table>

Total alpha for the life satisfaction scale is .79 (see Table 19). This level exceeds all the values in the ‘alpha if item deleted’ column. This shows that removal of any item would not increase the alpha level over the existing .79. Therefore, no item in the life satisfaction subscale
was deleted.

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item- Total Scale Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. I regret wrong decisions made regarding relatives’ treatment.</td>
<td>.45</td>
<td>.77</td>
</tr>
<tr>
<td>18. I have made plans for the immediate future adequately.</td>
<td>.44</td>
<td>.77</td>
</tr>
<tr>
<td>19. I get dissatisfied, often thinking about the trauma.</td>
<td>.36</td>
<td>.78</td>
</tr>
<tr>
<td>20. I am in a better position than other caregivers.</td>
<td>.33</td>
<td>.79</td>
</tr>
<tr>
<td>21. This situation could have been worse.</td>
<td>.54</td>
<td>.76</td>
</tr>
<tr>
<td>22. I expect things to change for the better in the future.</td>
<td>.56</td>
<td>.75</td>
</tr>
<tr>
<td>23. The things I used to do before this traumatic event still interest me.</td>
<td>.49</td>
<td>.77</td>
</tr>
<tr>
<td>24. I am satisfied with the treatment regimen and patient care.</td>
<td>.53</td>
<td>.76</td>
</tr>
<tr>
<td><strong>TOTAL ALPHA</strong></td>
<td></td>
<td><strong>.79</strong></td>
</tr>
</tbody>
</table>

The overall alpha levels increased for each domain after items marked by an asterisk (*) were deleted from its respective domain (see Table 17). As mentioned previously, for current research purposes, an alpha of .80 - .84 is considered acceptable. The anxiety domain did not reach this level with an alpha coefficient of .73. The depression domain had an alpha between .80 and .85 that is an acceptable range for application with individual clients (Corcoran & Fischer, 1987). The life satisfaction domain has a coefficient alpha of .79 that can be rounded to .80. Additionally, there was the possibility that items would need to be deleted based on findings from confirmatory factor analysis. Deletion of selected items from respective domains after considering the findings of confirmatory factor analysis would possibly increase or decrease alpha levels for each domain.

The table below (Table 20) gives total reliability coefficients for the domains and global scale (details of computation are shown later in this section).

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Depression</th>
<th>Life Satisfaction</th>
<th>Global Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>.73</td>
<td>.81</td>
<td>.79</td>
<td>.90</td>
</tr>
</tbody>
</table>
Confirmatory Factor Analysis

Confirmatory factor analysis was used to determine the degree to which specific items on the RBTS correlated with domains with which they were intended to measure (see Table 24). Multiple groups or group centroid method (Nunnally & Bernstein, 1994) was employed to conduct confirmatory factor analysis. The revised, version of each domain was further analyzed after selected items were deleted based on reliability analysis and initial confirmatory factor analysis. The selected and deleted items were not included in the final confirmatory factor analysis. There were three domains fixed at the outset. The domains were titled anxiety, depression and life satisfaction.

Item correlations with factors are considered moderately high when they fall around .60 (Nunnally & Bernstein, 1994). This analysis used these criteria and appropriately moved or deleted items to the domain with which they correlated best. In other words, those items which had a lesser correlation with their respective domain, which had a stronger association with another domain or which did not seem to represent a major conceptual loss to that domain were deleted from the RBTS. Items that had misplaced loading or items that were weak were marked with an asterisk (*). Results of confirmatory factor analysis reveal that items load well onto domains with which they were intended to load onto at the outset. Factor loading indicates this for each item highlighted in bold under its respective domain (see Table 21). Some items load strongly onto domains that they were not intended to load onto. However, these items have strongest loading on domains that they were intended to load onto. Anxiety item 2 and depression item 13 are weak. They loaded more heavily on their respective domains than with any other domain.

Anxiety item 4 loads with .54 onto depression domain even though it has a loading of .59 on the anxiety domain. This means that item A4 has characteristics that are similar to the depression construct. Item D9 similarly loads onto depression and anxiety domains with a .66 and .62 respectively. Item L18 loads with .54 and .60 onto depression and life satisfaction domains. Item L19 loads with .50, .49 and .51 onto anxiety, depression and life satisfaction domains respectively.
While previous reasoning would be the same for items D9 and L18, item L19 has strong loading on both anxiety and depression domains. Item L19 was problematic, with similar loading on all three domains. This shows that item L19 does not contribute to life satisfaction domain exclusively or even to a large extent. It would be wise to delete L19 altogether. It was noted that anxiety items 1 and 8 do not load onto anxiety domains as strongly as other items. While most anxiety items load onto anxiety sub domain, with loading ranging from, .45 to .70, A1 and A8 have low loading scores of .39 and .34. This was in keeping with results discussed earlier.

<table>
<thead>
<tr>
<th>Table 21. Initial Confirmatory Factor Analysis of ABTPRR: Factors and Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Item</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Anxiety 1</td>
</tr>
<tr>
<td>Anxiety 2</td>
</tr>
<tr>
<td>Anxiety 3</td>
</tr>
<tr>
<td>Anxiety 4</td>
</tr>
<tr>
<td>Anxiety 5</td>
</tr>
<tr>
<td>Anxiety 6</td>
</tr>
<tr>
<td>Anxiety 7</td>
</tr>
<tr>
<td>Anxiety 8</td>
</tr>
<tr>
<td>Depression 9</td>
</tr>
<tr>
<td>Depression 10</td>
</tr>
<tr>
<td>Depression 11</td>
</tr>
<tr>
<td>Depression 12</td>
</tr>
<tr>
<td>Depression 13</td>
</tr>
<tr>
<td>Depression 14</td>
</tr>
<tr>
<td>Depression 15</td>
</tr>
<tr>
<td>Depression 16</td>
</tr>
<tr>
<td>Life Satisfaction 17</td>
</tr>
<tr>
<td>Life Satisfaction 18</td>
</tr>
<tr>
<td>Life Satisfaction 19</td>
</tr>
<tr>
<td>Life Satisfaction 20</td>
</tr>
<tr>
<td>Life Satisfaction 21</td>
</tr>
<tr>
<td>Life Satisfaction 22</td>
</tr>
<tr>
<td>Life Satisfaction 23</td>
</tr>
<tr>
<td>Life Satisfaction 24</td>
</tr>
</tbody>
</table>
Final confirmatory factor analysis consisted of 19 items remaining in the RBTS. This was because item 1 and 8 were selected for deletion based on review of reliability analysis, confirmatory factor analysis and review of items. Items A2, D13 and L19 had low scores on confirmatory factor analysis and were removed. Their scores were well below .60, the standard accepted for this study. Items A3, A4, A5, D14, D15 and L19 had scores very close to .60 and were retained because they loaded strongly onto their respective domains.

<table>
<thead>
<tr>
<th>Item</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Life Satisfaction</th>
<th>Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety 3</td>
<td>.59</td>
<td>.45</td>
<td>.36</td>
<td>.51</td>
</tr>
<tr>
<td>Anxiety 4</td>
<td>.59</td>
<td>.54</td>
<td>.49</td>
<td>.68</td>
</tr>
<tr>
<td>Anxiety 5</td>
<td>.58</td>
<td>.48</td>
<td>.39</td>
<td>.53</td>
</tr>
<tr>
<td>Anxiety 6</td>
<td>.69</td>
<td>.51</td>
<td>.39</td>
<td>.58</td>
</tr>
<tr>
<td>Anxiety 7</td>
<td>.67</td>
<td>.60</td>
<td>.47</td>
<td>.65</td>
</tr>
<tr>
<td>Depression 9</td>
<td>.60</td>
<td>.66</td>
<td>.49</td>
<td>.66</td>
</tr>
<tr>
<td>Depression 10</td>
<td>.48</td>
<td>.68</td>
<td>.50</td>
<td>.62</td>
</tr>
<tr>
<td>Depression 11</td>
<td>.44</td>
<td>.62</td>
<td>.44</td>
<td>.56</td>
</tr>
<tr>
<td>Depression 12</td>
<td>.58</td>
<td>.68</td>
<td>.50</td>
<td>.65</td>
</tr>
<tr>
<td>Depression 14</td>
<td>.43</td>
<td>.59</td>
<td>.41</td>
<td>.54</td>
</tr>
<tr>
<td>Depression 15</td>
<td>.39</td>
<td>.59</td>
<td>.32</td>
<td>.48</td>
</tr>
<tr>
<td>Depression 16</td>
<td>.45</td>
<td>.60</td>
<td>.35</td>
<td>.52</td>
</tr>
<tr>
<td>Life Satisfaction 17</td>
<td>.41</td>
<td>.51</td>
<td>.59</td>
<td>.57</td>
</tr>
<tr>
<td>Life Satisfaction 18</td>
<td>.47</td>
<td>.54</td>
<td>.60</td>
<td>.61</td>
</tr>
<tr>
<td>Life Satisfaction 21</td>
<td>.33</td>
<td>.33</td>
<td>.65</td>
<td>.45</td>
</tr>
<tr>
<td>Life Satisfaction 22</td>
<td>.34</td>
<td>.31</td>
<td>.68</td>
<td>.50</td>
</tr>
<tr>
<td>Life Satisfaction 23</td>
<td>.31</td>
<td>.32</td>
<td>.62</td>
<td>.48</td>
</tr>
<tr>
<td>Life Satisfaction 24</td>
<td>.26</td>
<td>.35</td>
<td>.65</td>
<td>.48</td>
</tr>
</tbody>
</table>

Overall Cronbach’s alpha was computed for the global domain (entire instrument) to see how well the items hold together. The instrument needs to be reliable as a whole instrument regardless of the internal consistency within each domain. It has been cautioned, however, that the overall alpha can be misleading in a multidimensional instrument representing an “elevation” parameter in the multivariate space of domains (Hudson, personal communication, 1997). This is
because the overall alpha represents the mean of all scores for an individual (which is all the item scores for that individual). Mean shows the profile elevation for the domain as a whole and produces a positively biased statistic.

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item- Total Scale Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am able to think clearly and make plans for the day. *</td>
<td>.22</td>
<td>.89</td>
</tr>
<tr>
<td>2. I feel shocked at the trauma of my close family member.*</td>
<td>.32</td>
<td>.90</td>
</tr>
<tr>
<td>3. I feel nervous about the incident.</td>
<td>.47</td>
<td>.90</td>
</tr>
<tr>
<td>4. I am unable to make plans to look after the patient.</td>
<td>.55</td>
<td>.91</td>
</tr>
<tr>
<td>5. I am worried about the effect of the traumatic incident.</td>
<td>.49</td>
<td>.90</td>
</tr>
<tr>
<td>6. I keep worrying about the treatment teams’ efficiency.</td>
<td>.54</td>
<td>.90</td>
</tr>
<tr>
<td>7. I am so preoccupied that I cannot carry on with routine as usual.</td>
<td>.60</td>
<td>.91</td>
</tr>
<tr>
<td>8. I feel calm and at peace.*</td>
<td>.17</td>
<td>.88</td>
</tr>
<tr>
<td>9. I feel alone in the world since the trauma.</td>
<td>.61</td>
<td>.90</td>
</tr>
<tr>
<td>10. My heart feels heavy and sad about the incident.</td>
<td>.58</td>
<td>.90</td>
</tr>
<tr>
<td>11. My appetite and sleep patterns have increased or decreased.</td>
<td>.51</td>
<td>.91</td>
</tr>
<tr>
<td>12. This is the saddest time of my life.</td>
<td>.61</td>
<td>.90</td>
</tr>
<tr>
<td>13. I feel devastated at the thought of losing my loved one.</td>
<td>.47</td>
<td>.90</td>
</tr>
<tr>
<td>14. I feel there is no hope in the future for me.</td>
<td>.49</td>
<td>.90</td>
</tr>
<tr>
<td>15. I feel tired and listless since the trauma.</td>
<td>.43</td>
<td>.90</td>
</tr>
<tr>
<td>16. I cannot stop crying when I think of the incident.</td>
<td>.46</td>
<td>.90</td>
</tr>
<tr>
<td>17. I regret wrong decisions made regarding family members treatment.</td>
<td>.53</td>
<td>.90</td>
</tr>
<tr>
<td>18. I have made plans for the immediate future adequately.</td>
<td>.55</td>
<td>.91</td>
</tr>
<tr>
<td>19. I get dissatisfied, often thinking about the trauma.</td>
<td>.51</td>
<td>.90</td>
</tr>
<tr>
<td>20. I am in a better position than other caregivers.</td>
<td>.35</td>
<td>.88</td>
</tr>
<tr>
<td>21. This situation could have been worse.</td>
<td>.45</td>
<td>.90</td>
</tr>
<tr>
<td>22. I expect things to change for the better in the future.</td>
<td>.43</td>
<td>.90</td>
</tr>
<tr>
<td>23. The things I used to do before this traumatic event still interest me.</td>
<td>.43</td>
<td>.90</td>
</tr>
<tr>
<td>24. I am satisfied with the treatment regimen and patient care.</td>
<td>.42</td>
<td>.90</td>
</tr>
<tr>
<td><strong>TOTAL ALPHA</strong></td>
<td></td>
<td><strong>.90</strong></td>
</tr>
</tbody>
</table>

**Final Reliability Analysis of RBTS**

After final Confirmatory Factor Analysis (CFA) an additional reliability analysis was
conducted on each domain with the remaining items. This was done to determine whether each domain was still internally consistent. This analysis helped in computing the exact alpha level for each domain within the revised item pool. Table 24 shows that alpha level for each domain and global scale. Final version of the RBTS scale had 19 items. Anxiety, depression and life satisfaction domains had 5, 7 and 7 items respectively.

| Table 24. Final Cronbach’s Alphas for the Domains and Global Scale (RBTS) |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|
| Anxiety                | Depression    | Life Satisfaction | Global        |
| .73                         | .87            | .81              | .91            |

The anxiety domain was constructed at the outset with items 1 through 8. After the initial reliability analysis for this domain, items numbered 1 and 8 were deleted based upon their low ‘item-total scale correlations’ and the figures in the ‘alpha if item deleted’ column (see Table 17). Item 2 was initially deleted but it was seen that when added to the depression subscale, this item actually increased the depression subscale alpha. Decrease in the anxiety subscale alpha (due to the deletion of item 2) was minimal. This decrease should be seen in relation to the increase in the depression subscale alpha (after item 2 is added). This can be done if needed at some later date. It should be noted that these items were identified earlier as potential items for deletion based upon their poor performance on the item-to-item correlation matrix.

| Table 25. Standard Deviation and Means for the Domains and Global Scale (RBTS) |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|
|                                | RBTS | Anxiety | Depression | Life Satisfaction |
| Mean                            | 30.3 | 10.13   | 9.95        | 10.22           |
| Standard Deviation              | 5.54 | 1.86    | 2.17        | 2.24            |

Table 25 shows the mean and standard deviation scores for the global scale and the subdomains. These are the standard deviations used in the calculation of the standard error of measurement that is given below.

**Standard Error of Measurement (SEM)**

110
Apart from computing alpha levels to determine the reliability for each domain of the RBTS, the standard error of measurement (SEM) was also computed for each domain (see Table 26). A detailed discussion of SEM is given on page 65. In the present analysis, each domain had a low SEM indicating that change in scores was not likely due to error in the instrument. Springer, et al. (2002), suggest a five per cent or less of the range of all possible scale scores as adequate. The range is the maximum possible score after the minimum is taken away from it (Global: 120 – 24 = 96; Sub scale: 40 – 8 = 32). Five percent of the range is 4.8 for global and 1.6 for the sub scales. The SEM shown below in Table 26 indicates that they are well below the five percent margin.

| Table 26. Standard Error of Measurement (SEM) for the Domains and Global Scale (RBTS) |
|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Anxiety | Depression | Life Satisfaction | Global |
| 1.02    | .93        | 1.03               | 1.77               |

Validation Analysis of the ABTPRR

**Construct Validity**

Convergent construct validity was established by examining correlations using Pearson Product Moment Correlation (commonly referred to as Pearson’s r) between global scale (that is defined as all items on the final version of the RBTS) and specific demographic characteristics discussed below. Convergent construct validity was also established by examining correlations between the RBTS and three external instruments included in this study for this purpose. Correlations between the RBTS and three single-item indicators (Items 25, 26 and 27) also helped to establish convergent construct validity.

Nurius and Hudson (1993) state that validity coefficients tend to be much smaller than reliability coefficients, with a range between .40 and .60, and a median of about .50. Therefore, any measurement instrument with a validity coefficient greater than .50 can be viewed as among the best 50 percent of all instruments in terms of its validity. This criterion for validity standards of .50 is generally regarded as acceptable, however, for the purpose of this current study, a
coefficient of .60 or better is the stated goal. This standard was easily achieved in the pilot study and the researcher was confident it could be achieved in the final study. For this study, $R^2$ value was also calculated. The $R^2$ value represents the proportion of variance in the dependent variable (global domain) that is explained by the independent variable (demographic indicators).

Demographic characteristics were acquired through items (1 to 13) on the last section of the questionnaire (see Table 27 and Appendix E). Demographic variables used for determining convergent construct validity include age of respondent, his or her relationship to TBI patient, help received (from primary, secondary or tertiary sources) and respondents’ status of being a breadwinner or not. Additionally, TBI patients’ variables included for convergent construct validity was the Glasgow Coma Scale and duration of time that had elapsed since TBI.

<table>
<thead>
<tr>
<th>Demographic Indicator</th>
<th>Global Domain - Reaction of TBI Patients’ Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$R$</td>
</tr>
<tr>
<td>Age of the respondent</td>
<td>.61</td>
</tr>
<tr>
<td>Relationship of respondent with patient</td>
<td>.74</td>
</tr>
<tr>
<td>Time since TBI injury</td>
<td>.85</td>
</tr>
<tr>
<td><strong>MEAN CORRELATION</strong></td>
<td><strong>.70</strong></td>
</tr>
</tbody>
</table>

The global scale was theorized to correlate with demographic variables of age, relationship and time since injury. It seemed that older the subjects were, higher was their reaction as noted by the RBTS. Subjects who were breadwinners in the family also reacted higher on the RBTS. Relatives of patients with severe TBI as recorded by the Glasgow Coma Scale reacted higher on the RBTS. As shown in Table 27, demographic variables had a correlation with the global scale (RBTS) of over .60 as anticipated. This provided evidence for convergent construct validity. Correlations between the RBTS and three single item indicators were used in this study to establish convergent construct validity. Single-item indicators were items numbered 25, 26 and 27. Items 25, 26 and 27 revealed respondents’ report of anxiety, depression and life satisfaction respectively. It was theorized that the RBTS would correlate with three single item indicators.
Table 28. Correlations Between Subdomains of RBTS and the Single-item Indicators

<table>
<thead>
<tr>
<th>Subdomains</th>
<th>Single-item Indicators - G25, G26 &amp; G27</th>
<th>R</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>anxsub</td>
<td></td>
<td>.67</td>
<td>.45</td>
</tr>
<tr>
<td>depsub</td>
<td></td>
<td>.71</td>
<td>.50</td>
</tr>
<tr>
<td>lsub</td>
<td></td>
<td>.71</td>
<td>.50</td>
</tr>
</tbody>
</table>

These results also turned out as hypothesized. As anticipated all correlations (of single item indicators with RBTS) as shown in Table 28 fell above .60. This provided evidence for convergent construct validity. The reliabilities of the external scales are obtained from the current sample are given below in Table 29. This is necessary to ensure that the external scales are adequate for use as correlates for convergent construct validity, based on the sample chosen.

Table 29. Cronbach’s Alphas and SEM for the External Measures

<table>
<thead>
<tr>
<th>External Measures</th>
<th>CAS</th>
<th>BDI</th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cronbach’s Alpha</td>
<td>.79</td>
<td>.88</td>
<td>.81</td>
</tr>
<tr>
<td>SEM</td>
<td>.11</td>
<td>.09</td>
<td>.33</td>
</tr>
</tbody>
</table>

The above Table 29 shows that the BDI and SWLS both have acceptable rates of reliability (see discussion on p. 64). The CAS fall short by .01 and is corrected for this study. The SEM falls well within the standard of 5% of the range of all possible scores.

Table 30. Correlations Between the RBTS and the External Measures

<table>
<thead>
<tr>
<th>External Measures</th>
<th>r</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAS</td>
<td>.70</td>
<td>.49</td>
</tr>
<tr>
<td>BDI</td>
<td>.59</td>
<td>.35</td>
</tr>
<tr>
<td>SWLS</td>
<td>.79</td>
<td>.62</td>
</tr>
</tbody>
</table>

RBTS and three external measures were theorized to correlate to establish convergent construct validity. Three measures used for this purpose were Clinical Anxiety Scale (CAS),
Beck Depression Inventory (BDI) and Satisfaction with Life Scale (SWLS). RBTS correlated with three external measures that were administered along with the RBTS as theorized at the outset. As shown in Table 30 all the external measures had a correlation with the RBTS that was over .60 as theorized. This provided evidence for establishment of convergent construct validity.

**Discriminant Construct Validity.**

It was expected that some demographic indicators would not correlate with the global domain of the RBTS (see Table 31). These specific demographic indicators were used to establish discriminant construct validity. Demographic indicators selected for this purpose, were all related to the respondent, including relatives’ gender, education and income. These indicators were specifically chosen after consultation with the focus group of professionals and literature review.

| Table 31. Correlations Between Discriminant Demographic Indicators and Global Domain |
|-----------------------------------------------|-----------------------------------------------|
| **Demographic Indicator** | **Global Domain - Reaction of TBI Patients’ Relatives** |
| | **R** | **R²** |
| Gender of the respondent | .51 | .26 |
| Education of the respondent | .34 | .11 |
| Income of the respondent | .09 | .01 |
| **MEAN CORRELATION** | **.34** | **.14** |

As shown in Table 31 these demographic indicators had low correlations with the global domain. Gender had the strongest correlation of $r = .51$. This result is possible because gender may play some role in the way the respondent reacted to TBI of relative. The global scale had weak correlations with education ($r = .34$) and care giver status ($r = .39$). Weakest correlations of the global scale were with income ($r = .09$) and religion ($r = .08$). Above correlation scores support the existence of discriminant construct validity. This is because demographic variables did not correlate with global domain of the RBTS. There is a difference between mean correlations of convergent and discriminant demographic indicators (convergent mean $r = .70$, $R^2 = .50$, discriminant mean $r = .34$, $R^2 = .14$). When examining mean correlation for convergent
validity items, approximately 50 percent of explained proportion of variance is accounted for, compared to only 14 percent of proportion of variance accounted for by discriminant validity items. Therefore, the difference between mean convergent r value and the mean discriminant r value was .36, while difference between mean convergent R² value and mean discriminant R² value was .46.

The preliminary evidence of construct validity was also found in the final factor analysis that was presented earlier. Items correlated more strongly with their domains and less strongly with other domains, indicating that items converged with domains with which they were hypothesized to correlate. These findings provide evidence of good construct validity for each domain of the RBTS.
CHAPTER VI
DISCUSSION AND CONCLUSIONS

Introduction

Initial validation study has generated required information related to reliability and validity of the RBTS addressing the preliminary utility of this measurement device. In other words, the RBTS’s capacity to distinguish between TBI patients’ relatives who have excessive amounts of anxiety, depression and low satisfaction with their lives and those relatives who do not react in such a manner still remains to be studied. Initial analysis of this can be done with the data currently generated. Results of this initial study show that the RBTS possesses potential to measure what it purports to measure. At the outset of this chapter, issues related with validation process will be addressed. This chapter also addresses implications for social work practice, social research, limitations of this study and suggestions for future research plans. Finally, utility of the instrument, which is directly related to reliability and validity of the measurement device, will be discussed.

Sample Characteristics

It is important to discuss salient features of the sample to comprehend the results. The total sample size \( n = 279 \) was considered large enough to conduct the required data analysis. To be specific, sample size was adequate to conduct reliability validity analysis. Subjects came from a background (Indian nationality) that was comprised of some common culture and social characteristics despite many differences. This provided for a relatively homogenous sample. India, where this data collection was conducted, is a land of varied languages, income, religions, education and caste. It is important to point out subtle differences in geographical areas and backgrounds of subjects to determine if these factors could have significant impact on the results.

Although respondents came from specific states around the National Institute of Mental Health and Neuroscience (NIMHANS), they all belonged to the same country with similar
geographic conditions. India has an official national language that is not accepted by many southern states that have their own state language. There are more than 15 official languages and about 80 dialects. It has been noted, in general that despite language differences people communicated adequately with each other. However, in this study precaution was taken in advance to translate the questionnaires into three major languages (Hindi, Tamil and Kannada). The resource persons (who translated the languages and the neurosurgical personnel) suggested that translations in these three languages would be most beneficial and adequate. Only subjects whose native languages were among the three mentioned were included in this study. These three major languages were the native languages of most of the subjects. The interviewer communicated well in all three languages and, hence, there was no problem with language barriers affecting the outcome of the validation process. Interviewer was trained to interview in the languages translated. During the survey the interviewer repeated the questions on the Likert scale when requested by the respondent. The interviewer made it a point not to change statements or questions in any way or to explain using examples.

Over half of the respondents (225) came from a family with an annual income below 10,000 rupees (the currency of India approximately equal to $200). Fifty-two subjects had an annual income of 10,000 to 30,000 rupees and 42 subjects had an annual income of rupees 30,000 to 50,000 rupees. The researcher was cautioned by an officer in the Records Department (NIMHANS) not to put too much faith in income reported by respondents because many previously reported income figures were false. This was likely due to the fact that the hospital charges were based on income level given by respondents. Those subjects who fell below the low-income bracket were allowed a significant reduction in their hospital charges. Furthermore, it was difficult to get an accurate assessment of income of subjects because income in rural areas (where most of the respondents resided) is comprised of wages, land produce and other income generated in kind. It is also well known that more affluent people usually conceal major sources of income from authorities. There has not been any administrative action taken in this regard because the poor would get penalized and the rich would probably keep their prosperous position. Therefore, too much emphasis cannot be placed on this demographic indicator. If an
accurate assessment of income for respondents were possible, it may well have changed relatives’ reactions. Future research could determine whether respondents with more income have less anxiety, depression and more life satisfaction.

Majority of respondents, (267) were Hindus. There were 8 and 4 subjects who practiced Islam and Christianity, respectively. This emphasizes the homogenous character of the sample group. It is to be noted that India as a whole (regardless of different religious factions) has withstood foreign intrusion. Thus, religion has historically been an issue only when it came to upholding principles and values of each religious group. The small group who were non-Hindus in this study share the country’s heritage and general character with majority of sample, which only adds to the homogenous nature of sample. This has added to the credibility of study findings. It should also be noted that religion and traditional faith healing used to play a very important role in the health of an individual (Bhattacharya, 1983; Weiss et al. 1986). A later study (Chadda et al., 2001) does show that this emphasis on religion and faith healing may be changing due to changes in attitude, public education and availability of hospitals. However, importance of spiritual aspects in quality of patients’ lives was emphasized at a symposium and workshop (Vasudevan, 2000). Emphasis of religion is also seen in numerous temples that are built on hospital campuses to cater to needs of patients and staff alike (Gopalkrishna, 2000).

There were 131 (47%) respondents who had no education at a formal school of any kind. Seventy-five (27%) of subjects had an education of tenth grade or less. There were 47 (17%) and 25 (9%) subjects who had either preuniversity certificate or graduate degree, respectively. This is a little higher than the 40-percent literacy rate in the entire nation. Literacy did not have a direct affect on comprehension of the questionnaire because the researcher interviewed respondents using survey technique. It was noted that there were two relatives one of whom had a master’s degree and another who was teaching had decided not to participate in the study. One cannot infer much about these subjects due to the small number and the nonparticipation by these more educated persons could be due to chance.

It should be noted that caste system might be of some importance in this study. It was difficult to include this indicator in the questionnaire due to deep attitudinal prejudices that still
exist. People generally do not disclose caste to which they belong. The caste to which a person
belongs may have had a bearing on results of this study, as caste molds a person’s attitude
towards life. For example, a person from Sudra caste is generally known to possess a fatalistic
attitude. To be specific, one would accept hardships easily (consequently have lower adverse
reaction or lower rate of anxiety or depression) believing them to be fruits of one’s past life. The
following discussion explains concept of caste as prevalent in India.

In ancient India, people were broken into four groups based on economic division of
labor. People in charge of religious ceremonies and their families belonged to the purest group
called Brahmins. The second highest in this hierarchy, Kshatriyas and their families defended
people from external invasion. Vaisyas were merchants and business people who engaged in
trade and commerce. The lowest sect was called Sudras or Untouchables (in the literal meaning
of this word). The continuation of this system and its exploitation (by those in the higher
hierarchy) of the Sudras, lowest on the ladder of caste system, led to what is currently regarded as
negative effects of caste system. Even though caste system has officially been abolished since
India attained its independence, practice and exploitation of caste system is prevalent today. This
is included in the discussion because researcher believes it to be an important variable and, thus,
results could be affected by this variable. However, this discriminant indicator could not be
included in this study because of prejudice prevalent in society. In other words, lower caste
persons are looked down upon and ridiculed and, consequently, such people do not volunteer the
caste to which they belong.

Findings on these demographic variables indicate that data collected from subjects
coming from different religions, incomes, education, gender or who spoke different languages
was defensible only to a limited degree. This is because it is likely that these characteristics
influenced scores on various measurement instruments. Collection of data that respondents
would not voluntarily reveal is an obstacle in this research study. Caste as an indicator needs to
be studied further to see if it might have an impact on this study.

**Importance of Study Findings and Generalizability**

One of the requirements for generalizing the findings of any study is collection of a
random sample. Under perfect or ideal circumstances a random sample would be an asset. However this is not always possible in research studies. Instrument development studies often employ nonprobability sampling methods. It is acceptable to use nonprobability sampling, especially if coupled with a large sample size. Large sample size is required for data analysis methods employed in this study, such as reliability estimates and factor analysis. Random sampling is a major assumption made for parametric statistics.

Mean duration of hospitalization for relatives’ family member with TBI was 4.03 days. All relatives’ had family members with severe or moderate TBI. Length of hospital stay for TBI patients and degree of severity, as recorded by the Glasgow Coma Scale, was not taken into account. Therefore, generalizability of these findings to relatives with mild TBI patients or patients with longer hospital stay is limited. Given that subjects came from India, generalization of findings to populations outside India should be done with caution.

Subjects were interviewed in the casualty department (emergency room), short stay wards, surgical wards, intensive care unit, pre and postoperative wards. Though, this study did not discern degrees of relatives’ reaction in these different settings, further studies examining the reliability and validity of the RBTS will accurately ascertain how sensitive the RBTS is, to different settings.

The interviewer included all subjects (who met the required criteria) referred by the neurosurgeons, the medical officer, researchers in the epidemiological study of patients and their families. Generalizability is limited by the purposive sampling technique used. The relatively large sample size obtained helps to offset some limitations of the purposive sampling technique.

**Reliability Analysis**

The standards for reliability are discussed in detail on page 64. This study chose an alpha coefficient of .80 to .84 as the standard of reliability. This range is considered to be acceptable for use with individual clients (Springer, Abell & Nugent, 2002). Global scale, depression and life satisfaction subdomains had final Cronbach’s alphas ranging from .81 to .91. These values reached acceptable alpha values for use with individual clients. Anxiety subdomain had a Cronbach’s alpha of .76 (not acceptable range for use with individual client). Further
modification of items may increase the reliability of the anxiety domain.

It could be argued that the anxiety domain could still be regarded as acceptable because the purpose of the scale is not to determine whether the respondent gets treatment. On the other hand, this scale was designed to help social workers direct treatment towards alleviating anxiety, depression or enhancing the life satisfaction of the respondent. Nunnally and Bernstein, in 1994, stated that a reliability of .70 could be regarded as modest. They caution the importance of test scores when scores determine important outcome for the client that is based on scores (placement of a subject in a particular situation or receipt of a service). Even if the anxiety domain is retained based on this argument, further testing is required before it could be used with confidence. The coefficient values however, indicate good internal consistency of the depression and life satisfaction domains of the RBTS. Values for reliability coefficient of the RBTS reported here are based on one sample and cannot be considered stable until replication is done. In other words, we cannot say that reliability coefficients are stable, as these are results of an initial study. Use of RBTS in relation to its reliability should be done with caution. The reliability scores were not as high as expected. This could be due to inadequate conceptualization process. There could be a possibility that the items are not tapping the constructs as expected. However considering the setting and context of the study, the reliability scores are acceptable (N. Abell, personal communication, June, 16, 2002).

Scores obtained for standard error of measurement (SEM) are good indicating that measurement error in the RBTS was very low and that changes in scores were not likely due to measurement error. SEM for the global scale was 1.77, while SEM for subdomains were as follows: anxiety subdomain had a low SEM of 1.02, depression sub domain had a SEM of .93 and life satisfaction subdomain had a SEM of 1.03.

Information about reliability of the RBTS established in this study could provide an impression of how consistently the scale performs. One, however, cannot make specific judgments about its reliability without further replication studies. Reliability coefficient of the RBTS that is reported in this study is a special case of split-halves reliability. Cronbach’s alpha is associated with “generalizability across the universe of test items and not across time, examiners,
situations, and so on” (Sechrest, 1984, p. 30).

This leads one to state that reliability scores of the RBTS reported in this study deal with representativeness of the instrument. Representativeness is related to other possible items related with the construct (reactions of TBI patients’ relatives) that the instrument has set out to measure. In other words, the scores do not tell us how reliable the RBTS may be with different types of people administering it or how reliable it is in different situations or over time. Therefore, information given by reliability scores is extremely useful but limited. There is need for future research to address how reliable the RBTS is across time and in different situations when it is used for the purpose for which it was constructed. That is, to determine degree to which TBI patients’ relatives react with regard to anxiety, depression and life satisfaction.

Validity Analysis

Face and Content Validity

It is stated that if an instrument has content validity then it must also have face validity (Sechrest, 1984). Face and content validity are conceptually different. At the outset of this study, a major factor in the development of the RBTS included the process aimed at maximizing its content validity. This not only laid a good foundation for the remainder of instrument development but also provided an instrument that is more relevant and appealing to practitioners. It was imperative that practitioners find the instrument useful and easy to administer. This (making the instrument more useful and easy) was an important task in development of the RBTS. A goal of instrument construction is for the RBTS to be clear to practitioners and clients. This clarity of goal was achieved by the focus groups input, which led to enhanced content and face validity.

Factorial Validity

Another important validity analysis is confirmatory factor analysis (CFA). This was done using Multiple Groups or Group Centroid Method (Nunnally & Bernstein, 1994). CFA was conducted to reveal whether items load strongly onto the domains with which they were intended to load. Items, which had weak or misplaced loading with their respective domains, were deleted from the instrument. Final (second) CFA was done after items (three items from anxiety domain,
one each from depression and life satisfaction domains) were removed. There were 19 items remaining after final CFA was conducted.

Factorial validity indicates that an instrument is properly classified. This does not mean that it is good or useful for any purpose. According to Nunnally (1978), even if a test has a high factorial validity, it may be invalid as a predictor of particular criteria. To be confident of factorial validity results, it is recommended that 5 to 10 research subjects per instrument item are collected in the sample. This criterion was applied in this research study and the total sample consisted of 279 subjects. There were 27 items in total, thus, there were slightly more than the suggested number of subjects in the sample. DeVellis (1991) states that factor analysis is often undertaken with less than ideal sample size and recommends that the factor structure should be confirmed with independent samples. This can be done in a replication of current findings in the study of the RBTS. Future studies should include large and varied samples.

**Construct Validity**

Construct validity is established over a length of time and is not an easy process. It is established based on judgments from information accrued over time (Carmines & Zeller, 1979). Construct validity was established by testing both convergent and discriminant construct validity. Convergent and discriminant construct validity was established by examining correlations using Pearson’s r and $R^2$. Nurius and Hudson (1993) state that validity coefficients tend to be much smaller than reliability coefficients and fall between .40 and .60 with a median of about .50. In this present research, a correlation coefficient of .60 or better was achieved. The RBTS and specific demographic indicators correlated as theorized at the outset, testing convergent construct validity. Convergent construct validity was also established by examining correlations between the RBTS and three external instruments included in this study for this very purpose. Correlations between the RBTS and three single-item indicators (Items 25, 26 and 27) also helped to establish convergent construct validity. Discriminant construct validity was established by examining correlations between the global scale and specific demographic indicators that were not hypothesized to correlate. There was a difference between mean correlations of convergent demographic indicators and discriminant demographic indicators (convergent mean $r$
Mean correlation for convergent construct validity items accounts for approximately 50 percent of proportion of variance in the global domain, while only 14 percent of the proportion of variance is accounted for by the discriminant validity items. This indicates that demographic indicators that were expected to associate with strong reactions (high anxiety, high depression and low life-satisfaction) of TBI patients’ relatives explained 36 percent more of proportion of variance. This was more than the proportion of variance explained by demographic indicators that were not expected to be associated with the strong reaction (high anxiety, high depression and low life-satisfaction) to TBI.

There is sufficient evidence of construct validity. Construct validity hopes to establish that the RBTS the external instruments are tapping similar underlying constructs. There is one important possible explanation for high correlations observed in convergent construct validity analysis. The explanation could be that the various instruments are tapping the same construct. Strong correlations between the RBTS and the external instruments, between the RBTS and the three single-item indicators and between the RBTS and specific demographic indicators, provide initial evidence of construct validity. There is, however, need for additional future replication research.

**Scoring of the RBTS**

Averaging the rating for the three domains consisting of seven items each and the global scale, scores the RBTS. Each item is rated on a five-point likert scale ranging from one to five. In this study in 14 instances the subjects initially reported indecision between two ratings. The researcher would repeat the question and request only one choice. Special attention is paid to the correct scoring of the reverse items. These items are item 1, item 8, item 18, item 20, item 21, item 22, item 23 and item 24. These items were reverse coded before analysis. Higher the score obtained on each of the subdomains, higher the level of respective reaction in the subject.

**Limitations of the Study**

Although limitations of this study have been discussed throughout this chapter, additional summary of limitations will be provided here. The most crucial aspect of this study is the sample. Even though sample size was regarded to be adequate, manner in which it was selected is a major
limitation of this study. Nonprobability, purposive sample makes the sample less representative of the population from which it was selected. Results should be viewed with caution due to this limitation. It is difficult to gauge how respondents who chose not to participate in this study would have responded differently from those respondents who did volunteer to participate in this study. The sample was drawn from population of patients who were admitted to the National Institute of Mental Health and Neuro Sciences (NIMHANS), in Bangalore, India. Respondents came from different parts of India. Therefore, it is only possible to generalize the findings to the larger Indian subcontinent, but not outside of India.

Not much is known about the performance of Western measures in India. In making this cultural leap, there is concern regarding the impact of results. For example, the Western instruments are developed for use with the Western population. These measures have to be modified and normed for use with the Indian population to make sure it is relevant and measures the construct the way it was intended to measure.

A comparative sample using a group of relatives with a family member who has spinal cord injury or mental illness might have provided more insight. More important, a comparative study of groups consisting of subjects speaking different languages would be beneficial. Different versions of the instrument (translated in different languages) could be compared. This was not possible due to time and financial constraints.

It was not possible to conduct known-instruments criterion validity (see p. 91 for discussion). It was noted that performance of external scales in India is not well established. If results show a poor correlation between the current measure and well established, external measures then the outcome is attributed to the likely poor performance of the new measure (and not the measures that are used as criterion).

The findings of this study are based totally on the responses given by a sample that has little formal education. The responses may be different from that obtained from a sample that is largely educated. It is also important to note that the questionnaire was read to the respondents and the responses noted down by the researcher. Again, the results may be different if the questionnaire was used as a self-report instrument. This is potentially a strong point, when one
considers the consistent responses recorded by the researcher.

**Recommendations for Future Research**

Emphasizing points discussed previously in this chapter, a more complete summary of recommendations for future research will be presented here. Initial studies of validation of an instrument do not definitively establish reliability and validity. Definite establishment of psychometrics is done over time with replication studies. Internal consistency or reliability has to be established through further studies. Factorial validity needs to be established on other (maybe even larger) samples. Construct validity cannot be established accurately in one initial study. This can be endeavored through many validation studies. Future research studies need to be done in countries other than India, especially in the United States of America. This would increase generalizability of the findings.

Known groups’ criterion validity using a group with a similar condition or trauma needs to be conducted. It could even be a control group of normative subjects. A prospective study would be interesting. It would be worthwhile to observe if relatives who scored high of anxiety and depression and low on life satisfaction succumbed to mental illness.

It was not the purpose of this initial study to determine a cutoff point for determining relatives of TBI patient who seem to have a high rating of anxiety, depression or low life satisfaction. Attempting to do this in this study would have been premature and a waste of time because practitioners with inadequate training and experience would interpret a clinical cutting score at face value based solely on the findings of this initial study. Such a cutoff point should be determined only in replication studies when the psychometrics can be more accurately established than could be done in this initial study. In this study it is argued that all three constructs are the result of TBI relative. It should be noted that care should be taken to make sure that life satisfaction is not a result of high anxiety and depression. This would be a challenge for future research. Future research should try to use a probability sample to make the findings more generalizable. Additional studies would show how sensitive the RBTS is to change over time and situation. This would be especially useful because stages of adverse reaction (high anxiety, depression and low life satisfaction) that most relatives of TBI patients go through differ in
degree. This difference depends on various factors, including personality of relative, severity of patients’ TBI, rate of recovery of TBI patient and duration of injury. Studies taking into consideration such varying factors would be beneficial to practitioners and researchers alike. Future studies including similar samples (groups with similar disabilities or groups speaking different languages in India) for comparison would be productive.

Current research has generated valuable data regarding patients and relatives (sociodemographic data). Known groups analysis is possible with the when the mean and standard deviation scores are reported on all the demographic variables. It would be a separate study by itself to analyze relationship between various demographic indicators and emotional reaction. Demographic indicators are severity of TBI, duration of hospital stay of TBI patient, age, gender, education, income, religion, the importance to respondent, relationship to patient, help received from various sources, stress of responsibility, caregiver and breadwinner status. It would be valuable to study the difference in reactions of parents in comparison to siblings, children and spouses.

Research needs to be conducted on educated samples to see how the RBTS performs as a self-report measure. It would be helpful to ascertain readability of the measures translated in Kannada, Tamil and Hindi. An equivalent of the Flesh-Kincaid grade level is needed in the Indian languages. In addition, this research study has paved way for indepth study to use this device for intervention with families of TBI patients. Future psychometric studies in this field in India can use this study as a foundation. It would be beneficial to compare groups using external scales to divide sample into groups scoring high on anxiety, depression and low life satisfaction. It would be useful to see how the RBTS does on these three groups.

Implications for Social Work Practice and Research

Relatives of TBI patients are known to need social work intervention for quite some time. A measuring instrument that includes the relatives of TBI patients has been developed (Symptom Check-List SCL 90 R) only recently. This instrument, however, includes the relative in so far as it concerns the TBI patient. Most questions pertain to relatives’ perception of TBI patient. There are no instruments that can easily look for adverse reactions of relatives so that early and relevant
social work intervention can prevent future maladjustments.

The current 19-item measurement device in this study was developed with help of practitioners in the field of TBI, especially neurological and neurosurgical social workers (comprising the focus group that helped in the important instrument development phase). The small number of items, multidimensional nature of the measure, as well as its ease in administering, is likely to be attractive to practitioners. Clients will probably find the short, easy to read and comprehend instrument less of an ordeal to endure than a lengthy interview. Relatives of TBI patients will find such a measure easier to deal with, particularly more so than a multitude of questions repeatedly asked by different persons, immediately after trauma. Results of this questionnaire (RBTS) would be useful to other professionals that would aid in social workers’ interdisciplinary cooperation and teamwork. Literature on reactions of relatives to TBI of their family member places heavy emphasis on high anxiety, depression and low life satisfaction. Practitioners have remarked that follow-up over years, reveals that a large number of relatives have resorted to professional help for mental health problems. TBI and its sequelae deplete relatives of their repertoire of skills to adjust in a healthy manner to adverse reaction to TBI. The RBTS was developed taking into consideration existing literature and practitioners’ input.

The RBTS is the only instrument known to address adverse reactions to TBI (high anxiety, depression and low life satisfaction). The RBTS can discern from individual clients’ responses, the areas (anxiety, depression or life satisfaction) that need to be addressed in treatment. Thus, the RBTS has heuristic value for social work practitioners. Additionally, good reliability and validity estimates possessed by the RBTS increase its viability and worth.

Ability of the RBTS as an instrument to detect heightened reactions and three common, specific types of reactions can lead to an increased efficacy of preventive programs for relatives of TBI patients. With this instrument, social workers can offer different counseling packages to clients depending on type of reactions portrayed by the client. Detailed follow-up work to initial counseling can help in prevention of major disorders of mind and body.

Even though this scale is important, it is not sufficient for social workers working in the field of TBI. Although diagnosis, treatment and prevention are important aspects of social work,
literature in social work has demonstrated that interventions need to be empirically demonstrated as effective (Fischer, 1973; Harrison & Thyer, 1988; Rubin, 1985). Evaluation of practice effectiveness needs valid and reliable measures. Diagnostic measures like the RBTS are invaluable in showing clients areas in which they need help as they come in for treatment. This would make evaluation more meaningful. Until replications are done the RBTS serves more as a research instrument than as a tool of assessment and treatment. As a beginning, it forms a foundation for further replication studies. Since it is the only measurement of its kind catering to relatives of TBI patients, the RBTS is an inspiration for other measuring devices in this and related fields.

Utility

Gottman and Leiblum (1974) referred to utility as degree to which one gets practical advantage from an instrument. The validation process described above established the validity and reliability of the instrument that is useful, to both practitioners and researchers. Social workers will be able to identify TBI patients’ relatives with a high degree of anxiety, depression and low life satisfaction in order to target treatment process. Researchers can norm this instrument on other similar populations after in depth replication studies. To date there has not been an instrument developed for assessing anxiety and depression of relatives of TBI patients in particular. In addition, RBTS is unique with its combined features of brevity and multidimensionality.

In specific, this study is the first of its kind in India in the field of relatives’ reactions to TBI. This study is invaluable with regard to the detail regarding emotions of relatives and lays a strong foundation for future research in India. The main advantage of this study to Indian social workers would be the availability of the brief, multidimensional measure for use with relatives of TBI patients. The RBTS would make social work intervention quick and efficient.

Developing social work practice knowledge in non-Western world using non-Western literature is difficult because of the absence of developed knowledge. Western models are still used and indigenized. Kendall, in 2000, remarked that in planning the curriculum for Indian social work students, the faculty looked at the experience of the British and American program
and settled on a combination of British background in social service with an American emphasis on professional courses and social work practice. Kulkarni (2000) states that an immediate concern is that of the heavy dependency of Indian social work on imported models, techniques, literature and so on. Pawar, in 1999, spoke of the American influence, dated curricula, and limited social work training that led to decreased social work development.

Medical and psychiatric social work reflects whole sale borrowing from the U.S. social work education model (Nagpaul, 1993). There is no basic text on Indian social work. India has found a readymade body of formulated concepts, principles, theories and techniques in U.S. social work literature. In this study, the theories have been transferred keeping in mind that even though the structure of the Indian joint family is different from the Western nuclear family, the reactions and stages of TBI patients’ relatives are similar. Social work in India has existed for more than 60 years (Pathak, 2000). There are several gaps in indigenous literature in the last five decades. The author specifies that there are no books on social group work, child welfare, psychiatric social work and correctional social work to name a few. He adds that students rely on books published in the U. K. or the U. S.

This calls for deepening the knowledge base of social work in India. Kulkarni (2000) specifies that research is needed in areas of resource utilization, impact of tangible indicators, feasibility of projects, success or failure or projects. There is a need for social workers in India to conduct research on evaluation of social work intervention. To assess problem areas and effectiveness of social work intervention instruments like the RBTS are indispensable.

There is little evidence to suggest that professional social work has responded to any critical social problem (Srivastava, 1999). The culture bound pattern of social work education and practice is yet to emerge. There is little recognition of social work as a full-blown profession in India. He added that the major shortcoming of social work education in India is the inability to indigenize its knowledge base. It is reiterated that social workers are giving a higher priority than done hitherto to social research. This study contributes to the sparse literature that exists in India. It is hoped that this study will be a foundation for future research in this area. Even though the RBTS was designed specifically for the Indian population, it is noticed that it seems to be
applicable to the Western clientele too. Referring to ensuring correct criterion validity of constructs being measured, Davar (1999, see p.16) stated that ‘medicalizing’ trauma and linking it to medical categories, may lead to misinterpreting contexts of human experiences facing trauma. The current study reiterates this issue in delineating and differentiating the constructs from the major psychiatric disorders. To make it applicable universally, there is a need to conduct replication studies to norm it to different cultures.
# APPENDIX A

## ARTICLE CATEGORIZATION (Five Categories Klien and Bloom’s, 1994)

<table>
<thead>
<tr>
<th>Category</th>
<th>Articles</th>
</tr>
</thead>
</table>
**APPENDIX B**

**CRITICAL REVIEW OF TECHNOLOGY ARTICLES**

<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theory:</strong></td>
</tr>
<tr>
<td>Implies Systems theory.</td>
</tr>
<tr>
<td><strong>Hypothesis/Purpose:</strong></td>
</tr>
<tr>
<td>Purpose was to describe the structure, contents, rationale, development, clinical utility and research potential.</td>
</tr>
<tr>
<td><strong>Research Design:</strong></td>
</tr>
<tr>
<td>Instrument validation study. Instrument was developed over a 10 year period. A pilot test was done on 60 families leading to a multicenter field test. There is no mention of training the interviewers.</td>
</tr>
<tr>
<td><strong>Sample:</strong></td>
</tr>
<tr>
<td>The multicenter study included 11 programs contributing 190 interviews.</td>
</tr>
<tr>
<td><strong>Measurement:</strong></td>
</tr>
<tr>
<td>The Head Injury Family Interview, a five part structured interview designed to gather clinical and research data on outcome of persons with head injury and their family members.</td>
</tr>
<tr>
<td><strong>Data Analysis:</strong></td>
</tr>
<tr>
<td>Reliability analysis (using Cronbachs alpha), Multiple correlation for validity (convergent and discriminant construct validity, confirmatory factorial validity and concurrent, criterion validity.</td>
</tr>
</tbody>
</table>

**Theory:**
No mention of theory. Rationale for study implies psychodynamic perspective.

**Hypothesis\Purpose:**
The study aims to identify the amount of time and therapy relatives are able to provide and the factors associated with variations in their input.

**Research Design:**
Descriptive study; Observations were obtained from the treatment staff. To validate this, data was also obtained from the patients. Corroborative information was obtained from reports by other staff members in weekly team meetings and medical records. Only trained social workers did the in depth interviewing and recording.

**Sample:**
37 patients and relatives were studied. Patients in coma, admitted to the hospital between 1984(January) 1985 (September), who were able to obey a command 2 weeks after hospitalization.

**Measurement:**
Time spent by relatives with the patients, number of relatives available, their characteristics, motivation, cost and patients condition were the variables systematically studied using trained observation and structured recording.

**Data Analysis:**
Descriptive statistics. Data on the above variables were analyzed using percentages, measures of central tendency and measures of variance.

<table>
<thead>
<tr>
<th><strong>Theory:</strong></th>
<th>No theory mentioned. Need for the study refers to Organizational theory.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hypothesis/Purpose:</strong></td>
<td>Nondirectional. There is a difference in scores on GHQ between relatives of patients with severe and mild head injury.</td>
</tr>
<tr>
<td><strong>Research Design:</strong></td>
<td>The relatives of mild head injured patients comprised of the comparison group. The experimental group had relatives of patients with severe head injury.</td>
</tr>
<tr>
<td><strong>Sample:</strong></td>
<td>Relatives of 83 male patients with severe (42) and mild (41) head injuries. (Criteria for severity was a post traumatic amnesia (PTA) of duration greater than 48 hours and a Glasgow Coma score of less than eight. Patients with only soft tissue damage and PTA of less than 48 were classified as minor). Relatives were assessed three months after the injury.</td>
</tr>
<tr>
<td><strong>Measurement:</strong></td>
<td>GHQ (General Health Questionnaire) assessing the psychological functioning of the relatives. Glasgow assessment schedule designed to provide a comprehensive rating of the patient’s needs for rehabilitation.</td>
</tr>
<tr>
<td><strong>Data Analysis:</strong></td>
<td>Parametric statistical analysis. Independent groups t test.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theory:</th>
<th>No theory overtly mentioned. Reference is made to Crisis Theory.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesis/Purpose:</td>
<td>Purpose is to assess the needs of relatives living with severe deficit headinjured persons and to determine their need for additional support.</td>
</tr>
<tr>
<td>Research Design:</td>
<td>Descriptive research design.</td>
</tr>
<tr>
<td>Sample:</td>
<td>Convenience sample of individuals participating in support groups for relatives of headinjured persons. Subjects’ relatives had to be at least 15 years of age, with residual deficits as a result of head injury and who live at home, needing assistance with or supervision of activities of daily living.</td>
</tr>
<tr>
<td>Measurement:</td>
<td>Questionnaire on comprising structured and open ended questions (based on review of literature). Reliability was not tested. Face and content validity was tested by clinicians, minister and families all of whom had close interactions with head injured patients.</td>
</tr>
<tr>
<td>Data Analysis:</td>
<td>Item analysis employing descriptive statistics.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theory:</th>
<th>None mentioned. Implies use of systems theory.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesis/Purpose:</td>
<td>Purpose was to identify predictors of families at risk for having unmet needs and to develop preliminary intervention strategies. Injury, patient and family characteristics predict family needs.</td>
</tr>
<tr>
<td>Research Design:</td>
<td>No mention was made regarding the actual study or data collection. Data was collected from relatives after two years post-injury.</td>
</tr>
<tr>
<td>Sample:</td>
<td>180 survivors of brain injury (older than 16, sustained closed head injury and no prior psychiatric or neurological problems) and heir relatives (who completed at least 75% of the items on the relatives’ questionnaires). Traumatic brain injury survivors were referred as outpatients through either a federally sponsored research project or through physicians, attorneys or social service agencies.</td>
</tr>
<tr>
<td>Measurement:</td>
<td>Neuropsychological test results, relatives’ questionnaires and medical records. The Family Needs Questionnaire has good internal consistency (Cronbach’s alpha = .78 to .88). It also claims to have content validity, factorial validity and construct validity (scores not mentioned).</td>
</tr>
<tr>
<td>Data Analysis:</td>
<td>Univariate, bivariate and multivariate statistics were used. Wilcoxon rank-sums tests, Multiple regression</td>
</tr>
</tbody>
</table>

**Theory:**
No theory mentioned. It can be traced to an ecosystemic perspective.

**Hypothesis/Purpose:**
To study the affective symptoms of brain injured individuals and their spouses during the chronic as opposed to the acute stages following TBI.

**Research Design:**
During the retreat weekend, individuals with brain injury completed one set of questionnaires and were asked to rate their own levels of disability and psychological distress. The spouses who rated their own level of psychological distress as well as rating their injured spouse’s degree of disability completed a similar set of questionnaires. Couples were interviewed one year post-injury, making the study of the chronic stage of patient’s course of the disorder than the acute stage. Post traumatic amnesia of patients was more than two weeks indicating the study to of severe TBI.

**Sample:**
Convenient sample of 60 brain injured persons and their spouses. Couples who volunteered were interviewed one year post-injury. They were not paid but provided meals and hotel accommodation for the weekend retreat.

**Measurement:**
Self rated measures of sensory, motor, cognitive and behavioral disability. SCL 90 R depression and anxiety subscales. Reliability and validity not mentioned.

**Data Analysis:**

### Theory
No theory mentioned. The writing alludes to the ecosystems perspective.

### Hypothesis/Purpose:
There would be a difference in the perception of families and patients with regard to cognitive, emotional and physical changes after head injury.

### Research Design:
Comparison and control group. Subjects in the head injured group were studied one year after the head injury. Head injured subjects completed a questionnaire to rate changes on 15 items for three areas of functioning, comparing changes before and after the injury. Controls compared their five years as past and compared with the present. Family members completed their rating independent of the patients’ ratings. No intra judge or interjudge reliability check was conducted on the questionnaire responses as study required family members’ perceptions to be independent of the perceptions.

### Sample:
A sample of 20 closed head injured adults with moderate to good recovery (GCOS), 20 controls and 13 family members. The controls were tested for substance abuse and psychiatric disorder. These subjects were comparable in age, years of education and estimated WAIS revised intelligence scale. The head injured group consisted of persons who sustained a closed head injury of the acceleration-deceleration type, had a coma duration greater than one week, no history of substance or alcohol addiction or uncontrolled seizures and no significant neurosurgery or premorbid psychiatric disturbance.

### Measurement:
Questionnaire developed using some interview questions that Levin’s group proposed. Items were grouped into physical, cognitive emotional and biographical. Reliability and validity were not mentioned.

### Data Analysis:

**Theory:** None mentioned. Systems perspective could be the basis for the study.

**Hypothesis\Purpose:**
Purpose was to document the experiences of individuals with TBI and their caregivers for a 2-year period postinjury.

**Research Design:**
Prospective study. Caregivers were initially interviewed at the time the individual with TBI was admitted to the rehabilitation center. The interview was conducted by a trained social worker. Families also had to complete a questionnaire. Families were again contacted by phone at 6, 12, and 24 months postinjury by one staff member.

**Sample:**
Initial sample of 71 with a loss of 20 families over the 2 year period. Families were accepted over a 3 year period. Exclusion criteria were that the patient was under 15 years, had a secondary diagnosis of a long-term condition, non English speaking, admission greater than 3 months and no informed consent.

**Measurement:**
The self report questionnaires included the Subjective Complaints Checklist, Disability Rating Scale, At Risk Psycho social History Assessment, Family Assessment Device, Support for Significant Other, Perceived Stress Scale and Social Readjustment Scale. The norms, reliability and validity or the scales are not mentioned.

**Data Analysis:**
Descriptive and Nonparametric statistics. Friedman Test, Mann-Whitney U and Wilcoxon Signed-Rank Test.

<table>
<thead>
<tr>
<th>Theory:</th>
<th>Implies the use of family functioning and family development.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hypothesis\Purpose:</strong></td>
<td>Patient variables (indices of injury severity, neuropsychological tests, neurobehavioral problems checklist scale and kinship of caregiver) are good predictors of Caregivers distress and family functioning and family functioning after traumatic brain injury.</td>
</tr>
<tr>
<td><strong>Research Design:</strong></td>
<td>As a matter of standard protocol, family members were invited to complete the Neurobehavioral Problem Checklist and the Long Range Evaluation Scale prior to the patients’ appointment for neuropsychological assessment. During the appointment family members were interviewed and asked to complete the Family Assessment Device and the Brief Symptom Inventory.</td>
</tr>
<tr>
<td><strong>Sample:</strong></td>
<td>A sample of 62 families of adult outpatients with brain injury.</td>
</tr>
<tr>
<td><strong>Measurement:</strong></td>
<td>Questionnaire included the indices of severity, neuropsychological tests, neurobehavioral problem checklist scales, kinship of Caregivers, Brief Symptom Inventory and Family Assessment Device. Reliability and validity of the instruments were not mentioned.</td>
</tr>
<tr>
<td><strong>Data Analysis:</strong></td>
<td>Regression analysis</td>
</tr>
</tbody>
</table>

**Theory:**
Family Systems theory is mentioned however a specific one is not named.

**Hypothesis\ Purpose:**
The purpose was to characterize subgroups of families on the basis of differing perceptions, within and between families of changes in the persons with head injuries and the correlates of such differences.

**Research Design:**
Exploratory design. During the course of interviewing and testing in the subject’s home, the questionnaire was administered to the subjects. Indepth interviews were also conducted to gather vocational and academic information about the patient. Subjects were between one and three years postinjury and did not have a history of substance abuse, psychiatric disorder or CNS involvement.

**Sample:**
34 persons with head injuries and a significant other between 1 and 3 years postinjury. The subjects included were those who sustained closed head injuries of sufficient severity to require hospitalization but had no prior history of CNS involvement, severe substance abuse or psychiatric history of psychotic proportions.

**Measurement:**
Problem Checklist of the NYU Head Injury Family Interview

**Data Analysis:**
Descriptive statistics.
|---|
| **Theory:**
No theory mentioned. |
| **Hypothesis:**
The purpose was to elucidate factors associated with adjustment in the parents of adult head trauma victims. |
| **Research Design:**
Parents in the sample were interviewed and asked to complete four measures. Participants ranged between 33 to 69 years and 85% were female. |
| **Sample:**
Parents of 48 craniocerebral trauma victims were recruited from three organizations in Western Pennsylvania. The mean time elapsed after the TBI was 47 months. |
| **Measurement:**
Sickness Impact Profile, Symptom Checklist 90 R, Hassles Scale and Ways of Coping (revised) measures were administered. |
| **Data Analysis:**
Parametric statistical analysis. Correlation and t test were used apart from descriptive statistics. |

Theory: None mentioned. Systems perspective could be the basis for the study.

Hypothesis: Caregivers would show high levels of distress, report unhealthy family functioning and spouses would report higher levels of psychological distress and impaired family functioning than parents.

Research Design:
Caregivers were initially interviewed at the time the individual with TBI was administered the neuropsychological assessment.

Sample: 62 families of adult outpatients suffering from brain injury were evaluated. They ranged from 16 to 65 years of age and 1.5 to 60 months postinjury. Majority of the sample were male, mild to moderately injured and injuries resulting from motor vehicle accidents. Caregivers were chosen based on the number of hours spent caring for the patient.

Measurement: The self report questionnaires included the Family Assessment Device, the Family Project Information Sheet and the Brief Symptom Inventory. The norms, reliability and validity or the scales are not mentioned.

Data Analysis: Parametric statistics was used: t - Test.

**Theory:** No theory mentioned. The writing alludes to the ecosystems perspective.

**Hypothesis:** The purpose of the study was to compare the coping strategies and perceived family functioning in a sample of persons with chronic head injury and with those of an orthopedic sample.

**Research Design:** Comparison and control group. Subjects in the head injured group were divided into two: first consisted of those who had not completed one year after the head injury, while the second group consisted of those who were injured for more than a year. Control group was composed of subjects who had sustained traumatic injury without brain injury.

**Sample:** Subjects were recruited from an inpatient rehabilitation hospital: n= 40. All subjects were administered a standardized test (Galveston Orientation Amnesia Test) to ensure post traumatic amnesia had resolved.

**Measurement:** Apart from measures specifically meant for the patient the FACES III was also administered.

**Data Analysis:** Multivariate analysis of variance for group differences across the measures.
# Critical Review of Measurement Devices

<table>
<thead>
<tr>
<th>Measures</th>
<th>Clarity</th>
<th>Definition</th>
<th>Psychometrics</th>
<th>Suitability</th>
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</thead>
<tbody>
<tr>
<td>SRAS</td>
<td>Items include all symptoms of anxiety disorder.</td>
<td>Clearly defined including physical and affective symptoms.</td>
<td>Norms: no data available. Reliability: split half reliability was .71. Correlation with CRS .74. Validity: concurrent criterion validity with known groups.</td>
<td>To assess anxiety as a clinical disorder and quantify symptoms.</td>
</tr>
<tr>
<td>IDD</td>
<td>Good, no ambiguity.</td>
<td>Covers the entire range of symptoms used in DSM 3 to diagnose MDD.</td>
<td>Norms: sample of psychiatric inpatients. Reliability: Cronbach’s alpha of .92, Spearman’s Brown Coefficient of .93. One day test retest correlation of .98. Validity correlated with other of depression (.80, .81, .87). Discriminant criterion validity discriminating levels of depression.</td>
<td>To diagnose major depressive disorder. Quantifies severity.</td>
</tr>
<tr>
<td>BDI</td>
<td>Very good.</td>
<td>No ambiguity in the definition.</td>
<td>Norms: sample of university students. Reliability: test retest reliability is above .90. Spearman Browns reliability was .93 using split half method. Validity: construct validity of .66 with psychiatric ratings. Coefficient of .79 in psychiatric patients and .54 in college students. With MMPI a .75 and Hamilton Rating scale.75 for psychiatric patients.</td>
<td>To detect depression in routine screening or research.</td>
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<tr>
<td>Measures</td>
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<td>Definition</td>
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<tr>
<td>FACE S -111</td>
<td>Good, based on Circumplex Model of Family Functioning and looks at family members perception</td>
<td>Fair, some ambiguity is evident in specific items</td>
<td>Norms: 2,453 adults across the life cycle and 412 adolescents; norms available on varying dimensions. Reliability: internal consistency is fair; overall alpha of .68. .77 for cohesion and .62 for adaptability. Validity: data not available.</td>
<td>Suitable for both adolescents and adults</td>
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<tr>
<td>GCS</td>
<td>Good, items clearly represent nonpsychotic depression</td>
<td>Good, straightforward</td>
<td>Norms: Actual norms not available. In part developed with high school students. Reliability: mean alpha of .92; SEM of 4.56. Two hour test retest correlation of .94. Validity: correlations .92 and .81. Excellent known groups’ validity and good construct validity.</td>
<td>Suitable to assess overall feeling of contentment with life, and sense of identity.</td>
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<tr>
<td>LSIZ</td>
<td>Fair, five items are easy to understand</td>
<td>Fair, compares life satisfaction to the respondent’s ideal.</td>
<td>Norms: A sample of undergraduate and a sample of male and female elderly citizens. Reliability: alpha of .87. Good test retest reliability with correlation of .82 for a 2 month period. Validity: construct validity with a measure of subjective well being scores ranging from .37 to .75.</td>
<td>Suitable for youths undergoing identity crisis or adults experiencing midlife crisis.</td>
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<tr>
<td>SDS</td>
<td>Fair, some items seem to be related to anxiety symptoms.</td>
<td>Defines depression specifically dividing it into 3 domains.</td>
<td>Norms: 56 patients with primary diagnosis of depression and 100 normal groups. 22 sample study for cutting score. Reliability: data not available. Validity: Concurrent criterion validity with known groups. Construct validity with known instruments was reported. Mean indices before and after were .74 and .39.</td>
<td>To assess depression as a clinical disorder.</td>
</tr>
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</table>
Dear Participant,

I am a doctoral student in Florida State University, conducting a research project on the reaction of caregivers to patients with traumatic brain injury. The research has long range potential usefulness in helping patients and their families receive services and attention. I greatly appreciate your participation in it. Your contribution would greatly help assessing families’ response to TBI. This study would require approximately 20 minutes of your time and is completely voluntarily. The information you provide would be kept absolutely confidential. By completing the attached scale, you are agreeing to be involved. While complete responses are most helpful, you may quit at any time without penalty.

If you have any questions regarding this project, you may phone me at 904-644-3235, or contact my Faculty advisor, Dr. Neil Abell, at 904-644-9753. My contact address is Florida State University, R-91, Room 245, Bellamy Building, Tallahassee, Florida. The Thagard student health center has a counseling center at 644-2003 if need arises. This study is in partial fulfillment of the course, I am enrolled in "Assessment methods in Social Work Practice Research" (SOW 6358).

Thank you for being a major contributor to this important research project.

Bhavani R. Hamann, MSW, M.Phil.

GENERAL RESPONSE OF CAREGIVERS OF TBI PATIENTS

Please read the case vignette carefully and then answer all questions that follow, as though you were the caregiver responding to the brain injury of a loved family member.

CASE VIGNETTE:

Last week, I was watching the television, when the telephone rang. I could not believe that my closest family member had been admitted to the Intensive Care Unit after an automobile accident. We had recently had breakfast together, laughing at the mundane oddities of life, just like any other day. Now the doctor says that the person dearest to me may not live or would not be able to walk, talk, remember, eat, or even recognize me! Would that not mean being brain dead? Those words sound awful, even as I think of the implications.

Who would listen to my woes, lend a helping hand or motivate me to excel in my work? Will I have to be the caregiver? If so what will that mean and how will it change me? The medical prognosis has conjured the worst images in my mind. I do not know how I will face all this. What is the impact of this event on my life?

Please read the following statements and indicate how strongly you feel about each statement, keeping in mind the above scenario rating each either by circling the
**appropriate number:**

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**Please enter the following responses in the space provided.**

1. Age: ____________________ 2. Sex: ____________________ 3. Total years of Education to date: ____________________

4. Race: __African American __Caucasian __Asian __Hispanic __Indian American __Other ______
APPENDIX E
REACTION TO TBI SCALE

Dear Participant,

I am a doctoral student at Florida State University in Tallahassee, Florida in the United States of America. I am conducting a research project on the reaction of caregivers to patients with traumatic brain injury. The research has long range potential usefulness in helping patients and their families receive services and attention. I greatly appreciate your participation in this study. Your contribution will greatly help in assessing families’ response to TBI. This study would require approximately 20 minutes of your time and is completely voluntarily. The information you provide would be kept anonymous. By completing the attached scale, you are agreeing to be involved. While complete responses are most helpful, you may quit at any time without penalty.

If you have any questions regarding this project, you may phone me at 3336491 (INDIA) or contact my Florida State University Faculty advisor, Dr. Tom Smith, at 850-644-9799. My contact address in India is Psychiatric Social Work Department, NIMHANS, Hosur Road, Bangalore-560029. The address and phone number of the nearest health center or counseling center will be provided if need arises by the interviewer. This study is in partial fulfillment of the doctoral program in Social Work.

Thank you for being a major contributor to this important research project.

Bhavani R. Hamann, MSW, M.Phil.

GENERAL RESPONSE OF CAREGIVERS OF TBI PATIENTS

Please read the following statements and indicate how strongly you feel about each statement, rating each by circling the appropriate number:

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am able to think clearly and make plans for the day.</td>
<td>1</td>
<td>2</td>
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<td>4</td>
<td>5</td>
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<tr>
<td>2. I feel shocked at the trauma of my close family member.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I feel nervous about the incident.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>4. I am unable to make plans to look after the patient.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
<tr>
<td>5. I am worried about the effect of the traumatic incident.</td>
<td>1</td>
<td>2</td>
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<td>5</td>
</tr>
<tr>
<td>6. I keep worrying about the treatment teams’ efficiency.</td>
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<tr>
<td>7. I am so preoccupied that I cannot carry on with routine as usual.</td>
<td>1</td>
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<td>3</td>
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</tr>
<tr>
<td>8. I feel calm and at peace.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>9. I feel alone in the world since the trauma.</td>
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<td>3</td>
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</tr>
<tr>
<td>Question</td>
<td>Score Distribution</td>
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<tr>
<td>10. My heart feels heavy and sad about the incident.</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>11. My appetite and sleep patterns have increased or decreased.</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>12. This is the saddest time of my life.</td>
<td>1 2 3 4 5</td>
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<tr>
<td>13. I feel devastated at the thought of losing my loved one.</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>14. I feel there is no hope in the future for me.</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>15. I feel tired and listless since the trauma.</td>
<td>1 2 3 4 5</td>
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<tr>
<td>16. I cannot stop crying when I think of the incident.</td>
<td>1 2 3 4 5</td>
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<tr>
<td>17. I regret wrong decisions made regarding family member’s treatment.</td>
<td>1 2 3 4 5</td>
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<tr>
<td>18. I have made plans for the immediate future adequately.</td>
<td>1 2 3 4 5</td>
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<td>19. I get dissatisfied, often thinking about the trauma.</td>
<td>1 2 3 4 5</td>
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<td>20. I am in a better position than other caregivers.</td>
<td>1 2 3 4 5</td>
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<td>21. This situation could have been worse.</td>
<td>1 2 3 4 5</td>
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<td>22. I expect things to change for the better in the future.</td>
<td>1 2 3 4 5</td>
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<tr>
<td>23. The things I used to do before this traumatic event still interest me.</td>
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<td>24. I am satisfied with the treatment regimen and patient care.</td>
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<td>25. I feel anxious in general.</td>
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<td>26. I feel depressed at this time.</td>
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<td>27. I am satisfied with help received from professionals.</td>
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Please enter the following responses in the space provided.

1. Age: 
2. Sex: 
3. Total years of Education to date: ______
4. Annual income (in Rs.,): Below 1000 ____ 1000 - 3000 ____ 3000 - 5000 ____ Above 5000____
5. Relationship to patient: Parent ____ Spouse ____ Sibling ____ Child ____ Other______
6. Patients’ length of stay in hospital _______ days to date
7. Is respondent the main breadwinner? Yes _____ No ____
8. Is the respondent the main caregiver ______ or a secondary caregiver ______
9. Religion: Hindu ____ Muslim ____ Christian ____ Parsi ____ Jain ____ Buddhist____ Other____
10. How important is religion in the respondents’ life: a lot ___ moderate amount ___ not much___
11. TBI patients’ score on the Glasgow Coma Scale (rating severity of TBI) ___
12. Are additional responsibilities wearing you down? Yes ______ No ______
13. Other help received from: Family _____ Relatives _____ Friends _____ Institutions _____
APPENDIX F

CONSENT FORM

I HAVE BEEN READ THE DESCRIPTION OF THE STUDY AND MY ROLE IN IT. I AGREE TO PARTICIPATE IN THE STUDY VOLUNTARILY. I UNDERSTAND THAT THERE IS NO INCENTIVE AND THAT MY PARTICIPATION WILL IN NO WAY AFFECT THE TREATMENT OF MY FAMILY MEMBER WHO HAS TBI. I AM AWARE THAT I CAN AT ANY POINT OF THE INTERVIEW DECLINE TO CONTINUE. THE WITHDRAWAL OF PERMISSION WILL NOT HINDER MY TBI FAMILY MEMBER’S TREATMENT.

SIGNATURE/THUMB PRINT

DATE
APPENDIX G

INTERVIEW GUIDE

1. Please tell me about yourself (name, age, education, occupation, interests ……)

2. What kind of a person are you? (anxious, paranoid, obsessive, angry, patient or withdrawn ……)

3. Would you tell me more about the TBI to your family member? (when, where, how, type, seriousness, prognosis, treatment, or rehabilitation ……..)

4. Would you share your experiences after the trauma? (roles, occupation, family, physical and emotional impact ……..)
APPENDIX H

LIST OF RESOURCES FOR THE RESPONDENTS

1. Social work department, NIMHANS, Bangalore – 560056, Tph. 642121

2. Afcare counseling center, 281, 100 feet road, 7th block, 3rd stage, Banshankari, Bangalore – 580085. Tph. - 6693788

3. Dr. Usha Rao, Rehabilitation counselor, Tph. 6692888

4. Psychoclinic, 126, 7th main, 4th block, Jayanagar, Bangalore – 560011, Tph. 6345488

5. Shanti psychotherepeutic and diagnostic center for mental health care, 230. 1st cross, 8th main, Byrasandra, Jayanagar, Bangalore- 560011, Tph. 6631577

6. Zeitgiest, 878, 6th cross, 18th main, 6th block, Koramangala, Bangalore – 560095, Tph. 5534385

7. Center for psychological counseling, Social science block, Bangalore University, Jnanabharathi campus, Bangalore- 560056, Tph. 3211486

8. Sneha Vrinda, 37/D, Southend Road, Basavanagudi, Bangalore-560004, Tph. 6659731

9. Vishwa society for mental health, 10, 1st cross, 17th main, HAL 2nd stage, Indiranagar, Bangalore – 560038, Tph. 5272705

10. Sooouharda, 7th floor, BDA shopping complex, 4th block, Jayanagar, Bangalore- 560011, Tph. 6556555
APPENDIX I
PERMISSION TO CONDUCT THE RESEARCH (NIMHANS)

NATIONAL INSTITUTE OF MENTAL HEALTH AND NEURO SCIENCES
(DEEMED UNIVERSITY), BANGALORE - 560 029.


May 9, 2000

Dr. K. V. R. Sastry
Prof. & Head
Dept. of Neurosurgery
NIMHANS, BANGALORE - 560 029.

Sir,

Kindly refer to the project proposal submitted by Mrs. Bhavani Rajaram Hamann, Florida State University (USA) entitled: "Study of the General Response of Caregivers of Brain Trauma Patients", wherein the Ethics Committee has approved the Proposal for collecting data from the relatives of brain trauma patients who are admitted to NIMHANS, and to the Neurocenter in particular, in its meeting held on 28th April 2000 at 10.30 A.M. A separate intimation letter may be sent to the candidate accordingly.

Yours Sincerely,

V. KUMARAIAH
(Dean I/c & Member Secretary, Ethics Committee)
APPENDIX J
PERMISSION TO CONDUCT THE RESEARCH (FSU)

APPROVAL MEMORANDUM
November 7, 1996

TO: Bhavani Rajaram
(Social Work)

FROM: Betty Southard, Chair
Human Subjects Committee (IRB)

Re: Use of Human Subjects in Research
Project entitled: Study of the General Response of Caregivers of Brain Trauma Patients

The forms that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be exempt per 45 CFR § 46.101(b)(2) and has been approved by an accelerated review process. You are advised that any change in protocol in this project must be approved by resubmission of the project to the Committee for approval. Also, the principal investigator must promptly report, in writing, any unexpected problems causing risks to research subjects or others.

If the project has not been completed by November 7, 1997 you must request renewed approval for continuation of the project.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols of such investigations as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks. The Assurance Number is M1339.

BS/01
cc: N. Abell/2004
human/42wemths.app
APPLICATION NO. 96.353
APPROVAL MEMORANDUM
from the Human Subjects Committee

Date: May 5, 2000

From: David Quadeagno, Chair

To: Shevani Rajaram Hamann
1532 Palstone Lane
Crofton, MD 21114

Dept: Social Work

Re: Use of Human subjects in Research

Project entitled: Study of the General Response of Caregivers of Brain Trauma Patients

The forms that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be exempt per 45 CFR § 46.101(b)(2) and has been approved by an accelerated review process.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals which may be required.

If the project has not been completed by May 5, 2001 you must request renewed approval for continuation of the project.

You are advised that any change in protocol in this project must be approved by resubmission of the project to the Committee for approval. Also, the principal investigator must promptly report, in writing, any unexpected problems causing risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department and should review protocols of such investigations as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks. The Assurance Number is M1339.

cc: T. Smith
APPLICATION NO. 00.114
APPENDIX - K

STAGES IN CONSTRUCTION AND VALIDATION OF THE RBTS

LITERATURE REVIEW

MINI ETHNOGRAPHY

FOCUS GROUPS

Doctoral colleagues

TBI Relatives

Experts

Social Worker Neurosurgeon

PILOT STUDY USING 165 COLLEGE STUDENTS

LITERATURE REVIEW WITH FOCUS ON INDIA

FOCUS GROUPS

Relatives

Experts

Language specialist

Social Worker Neurosurgeon

FINAL STUDY CONDUCTED IN INDIA
References


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BIOGRAPHICAL SKETCH

Bhavani Rajaram Hamann was born in 1964, in Bangalore, India. She was the youngest of six daughters of parents who gave education the highest priority. Basic schooling, undergraduate and graduate degree in Business/Commerce, were all completed in Bangalore. A year of volunteering at the college dispensary revealed an aptitude and skill in counseling patients and relatives in 1986. This took her to Pune, India to complete the Masters in Medical and Psychiatric Social Work in. Back home in Bangalore, a year was spent working with a media consulting group that focused on enlightening women and children. A two year Master of Philosophy in Psychiatric Social Work was undertaken at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in 1990. The area of focus here was assessing reactions of families with traumatic brain injury patients. Upon completing in 1992, she worked as a research assistant in NIMHANS and as a psychiatric social worker in a substance abuse rehabilitation center. Following this, Bhavani worked with patients with Multiple Sclerosis and their families for two years. In 1994, as part of the group study exchange program of the Rotary International, she was sent to Wisconsin, USA to present information about India (with a team of four members) and to visit families, universities, hospitals and rehabilitation centers (learn about USA). Bhavani began the Ph.D Program at the Florida State University School of Social Work in fall, 1994. While working on her doctorate, she taught courses at the School of Social Work and worked as a computer lab assistant. She also worked as a coordinator for the NASW, Florida chapter. It was at this time Bhavani met her husband Tom. They moved to Alexandria, Virginia and then to Crofton, Maryland where Bhavani graduated with her Ph.D in Social Work from FSU in the summer of 2003. They have a daughter and a son.