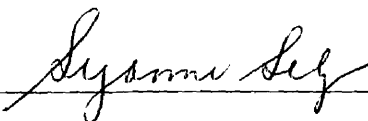


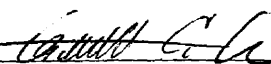
**Application of the Theory of Planned Behavior  
to health education programming  
for traumatic brain injury**

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## Abstract

The focus of this paper is to demonstrate how the use of health education models, specifically of the Theory of Planned Behavior (TPB), an expanded version of the Theory of Reasoned Action (TRA), can enhance and strengthen family/caregiver programming and the individual experiences of participants.

To this end, this paper explores the value of theory to health education practice and looks at the impact of traumatic brain injury (TBI) on the well-being of family members and caregivers. Secondly, it applies the TPB to the Holland and Shigaki three-phase family/caregiver education program for TBI. And, finally, the potential merits of this exercise are examined.

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## **Paper objective**

This thesis will apply the Theory of Planned Behavior (TPB), an expanded version of the Theory of Reasoned Action (TRA), to family/caregiver educational programming for traumatic brain injury (TBI). It will review the Holland and Shigaki three-phase family education program and examine how the TPB could strengthen the Holland and Shigaki program, enhance participation and increase knowledge and awareness about various aspects of brain injury for program participants. The objective of this thesis is to use the TPB to understand and strengthen health education programming and, in particular, to intervene in family/caregiver education programs for traumatic brain injury.

## **Methodology**

To accomplish this objective, I will examine areas of practice which can be strengthened via application of the TPB. These areas of practice include management of program materials, establishment of appropriately targeted program venues, standardization and accessibility of program materials, and the provision of select specifications for program design and implementation. Application of the TPB and its earlier version, the TRA, to health education practice has strengthened health programming in other fields and, by extension of the benefits derived by those programs, will be demonstrated to be equally beneficial in application to family/caregiver educational programming for traumatic brain injury in the above outlined areas.

To demonstrate those benefits, I will first investigate the value of theory to health education and health promotion. I will then examine elements of the TRB specifically and of its predecessor, the TRA. I will look at the Holland and Shigaki model of family/caregiver education for TBI and ways in which the application of the TPB might strengthen and enhance it. I will then parallel the benefits derived from application of the TPB and the TRA

to other health education programming with TBI family education programming. Health education, brain injury, psychological, physical medicine and rehabilitation journals, as well as Brain Injury Association documents will be extensively used as resource materials. The information was obtained primarily via a review of the literature conducted using Medline and Wilson Select searches of journals and periodicals chronicling existing health education programming, and through utilization of a Brain Injury Association bibliography of articles published on the role of family in brain injury, from which the data on brain injury incidence and severity were obtained.

### **The essence of theory**

“Theory” has been defined as, “systematically organized knowledge applicable in a relatively wide variety of circumstances...devised to analyze, predict, or otherwise explain the nature or behavior of a specified set of phenomena” (Webster, 1984). Theories are tools to help identify and understand elements of diverse phenomena or behaviors. Theories provide information about the purpose of these elements and give insight into their function. Theories also may suggest ways in which various elements can be influenced under a number of different circumstances (Hochbaum, et. al., 298).

Theories, whether partially developed (informal) and formulated on the basis of personal experience, or completely developed (formal) and formulated on the basis of scientific principles, provide an individual or group with a basis for action. Van Ryn and Heaney (318) point out that there are significant distinctions between partially developed and completely developed theories. Understanding these distinctions can help increase the value for practitioners applying well-developed theories to health education programming. Van Ryn and Heaney assert that a completely developed theory must incorporate three major elements:

1. The major explanatory factors that influence the phenomena of interest (e.g., a well-developed theory of individual behavior in crowds will specify the factors that affect the way a person behaves in a crowd).
2. The relationship among these factors.
3. The conditions under which these relationships do or do not occur (Van Ryn & Heaney, 317-318).

A well-developed theory can be generalized across diverse populations and environments.

In addition to generalizability, a well-developed theory suggests that relationships between factors indicated by the theory will hold true in most cases, with any exceptions generally specified within its context. A well-developed theory is also completely testable and differs from an informal partially developed theory or belief system in that it can be applied to relatively diverse practice situations with reasonable confidence and assurance of success (Van Ryn & Heaney, 318-319). Therefore, application of well-developed, tested theories, if carefully adapted, could significantly enhance health education practice. Well-developed and competently adapted theories can substantially aid practitioners in predicting

“what consequences various interventions are likely to have even in situations we have never before encountered. Certain social and behavioral science theories, and theories from a number of other fields, represent our best understanding of human health-relevant behaviors and of other factors of concern to the profession. They can, therefore, be invaluable at times as guides for selecting or developing and applying the most promising strategies and methods in any given situation” (Hochbaum, et. al., 296).

### **The value of theory to health education practice**

In examining the value of theory to health education practice, an understanding of the definition and scope of health education is needed. The Society of Professional Health Educators (SOPHE, 1976) proposed the following working definition of health education:

Health education is concerned with the health-related behaviors of individuals. . . ., it must take into account the forces that affect those behaviors, and the role of human behavior in the promotion of health and the prevention of disease. As a profession, health education utilizes educational processes to effect change or to reinforce health practices of individuals, families, groups, organizations, communities, and larger social systems. Its intent is the generation of health

knowledge, the exploration of options for behavior and change and their consequences, and the choices of the action courses open and acceptable to those affected (Simons-Morton, et. al, 370).

Within health education practice, health educators attempt to improve the health of the general public through theory-driven educational programming. As D'Onofrio (1992) describes the complexity of the practitioner's role in this effort in explaining that , "determining how this can be accomplished is the practitioner's responsibility. Theory is not a substitute for professional judgement, but it can assist health educators in professional decision-making. Insofar as the application of theory to practice strengthens program justification, promotes the effective and efficient use of resources, and improves accountability, it also assists in establishing professional credibility" (D'Onfrio, 394).

The efficacy of formal theories in predicting outcomes in a variety of diverse situations and populations makes the application of formal theory a valuable tool for health education practice. One specific area of health education practice in which the predictive aspect of theory can be invaluable is in problem analysis. Effective problem analysis is an essential component to high-quality programming. A complete understanding of theory and its potential applications can go a long way toward providing practitioners with that skill. D'Onfrio explains that a theory, in effect, consists of a series of abstract statements and principles that attempts to represent reality. Each theory attempts to explain a different dimension of reality. Therefore, each theory acts as a dedicated lens through which practitioners can view individual problems. D'Onfrio outlines five fundamental ways in which theories can aid practitioners in simplifying and understanding complex problems in health education practice:

1. predicting how variables or elements in a situation relate to each other;
2. integrating many observations that, on the face of it, may appear to be dissimilar;
3. separating out irrelevant factors and providing a way of organizing relevant ones;
4. allowing predictions that one would not make on the basis of intuition; and
5. explaining why variables function as they do, often by postulating hypotheses about processes (D'Onofrio, 394).

The usefulness of theory in predicting outcomes makes it key to planning for time and resources available for specific health education interventions. Health education practice generally does not have a direct impact on personal behavior. Health education interventions, rather than affecting immediate behavior changes, generally affect behavior indirectly through other processes and systems. Therefore, comprehensive planning of interventions is critical to successful health education programming. Theory can provide an effective blueprint for the planning process. A good theoretical model, D'Onofrio explains, identifies, "leverage points for change", by outlining the ways in which distinct variables within individual health interventions relate to specific behaviors (D'Onofrio, 395).

Program evaluation is another area of health education practice in which the prognostic and illustrative faculties of formal theory can aid practitioners. "When an educational program is based on an explicit theoretical model, formative evaluation can assess whether the program is changing variables (such as beliefs) that, theoretically, should lead to behavior change. If early evidence indicates a program is not working as intended, a program evaluation based on theory helps pinpoint areas of breakdown" (D'Onofrio, 395). Theory applied to evaluation following program completion can also help to explain reasons for the success or failure of specific programs, thereby providing a basis for improvement or replication, or for adaptation of programs to other populations or environments.



The indispensable value of the application of theory to health education practice was demonstrated by Van Ryn and Heaney, utilizing the well-tested and developed Social Learning Theory to help guide a health education intervention.

1. We had a clear sense of what the targets of our intervention should be (the explanatory factors of the theory: behavioral capacity, outcome expectations, and efficacy expectations) in order to maximize the likelihood of achieving our desired outcomes (the use of theory by health educators in the program development process).
2. The theory would have guided a needs assessment by specifying the type of information that would be most helpful in planning our program.
3. The theory provided us with specific ideas about the methodologies or learning activities that would be most effective in modifying the important influences on behavior.

Because theories must be coherent and their parts consistent with each other, basing our program on theory made it more likely that the components of our intervention would be consistent with each other, as well as being comprehensive.

4. We had a clear understanding of how to evaluate and improve on our program, linking specific activities with important intermediate outcomes that eventually result in the ultimate goal of the program.
5. ...We were more optimistic that our program would lead to behavior change than we would have been without a theory-based intervention. This confidence stems from knowledge of the success of other SLT interventions in the past (Van Ryn & Heaney, 327).

A further benefit of theory, seldom identified, also can benefit health education practitioners. The benefit comes via the every-day, informal consideration of well-developed social and behavioral science theories within the context of daily practice. Such informal consideration can help to broaden practitioners' awareness of issues that could diminish or intensify the effectiveness of health education interventions. And lastly, practitioners who are knowledgeable about theories often can draw inferences from them simply by consideration under specific circumstances, without ever actually applying one or another theory more formally (Hochbaum, et al., 301).

The application of theory has been shown to be an invaluable tool for effective health education practice. Theories also can provide answers to *why* individuals are not behaving in certain ways, *how* practitioners can attempt to change their behaviors, and *what* elements should be examined in a thorough evaluation of a health education program.

The purpose of this paper, as previously stated, is to examine the application of a specific theory, the Theory of Planned Behavior, to a specific intervention, a three-phase family education program for TBI. Before addressing whether the application of the TPB can strengthen and enhance family/caregiver education programs for traumatic brain injury, it is necessary to gain a better understanding of traumatic brain injury itself and of health education practice with regard to it. The following sections examine TBI, its impact on family members and caregivers, and the necessity of family education programs to family health and survival.

### **Traumatic brain injury and acquired brain injury defined**

Traumatic brain injury (TBI) is defined as an insult to the brain caused by an external physical force to the head, and not of a degenerative or congenital nature. The injury may produce a diminished or altered state of consciousness that results in impairment of cognitive abilities or physical functioning. The injury can also result in the temporary or permanent disturbance of behavioral or emotional functioning, and cause partial or total functional disability or psychosocial maladjustment (Brain Injury Association [BIA], 1986).

An estimated 2 million brain injuries occur each year (Dept. of Health and Human Services, 1989). TBI accounted for 34% of all injury deaths in the United States in 1992 (Sosin, Sniezek & Waxweiller, 1779). Approximately 370,000 Americans are hospitalized for brain injury each year, with an estimated 99,000 sustaining moderate to severe injuries resulting in lifelong disabilities (Kraus & Sorenson, et. al., 1994). Susceptibility to incurring TBI injury is determined to a great

extent by age and gender variables. Males between the ages of 15 and 24 and individuals over age 75 were shown in a study conducted between 1990 and 1993 to have the highest incidence of TBI (CDC, 1997, 9-10).

In 1997, the Board of Directors of the Brain Injury Association adopted a definition for acquired brain injury to encompass injuries beyond those only caused by external trauma. Acquired brain injury (ABI) is defined as an insult to the brain occurring since birth including, but not exclusive to, traumatic brain injury. An acquired brain injury commonly results in neuronal activity changes that can affect the metabolic activity, physical integrity or function of neurons (BIA, 1997). Causes of acquired brain injury include external forces applied to the head and/or neck (e.g., TBI with or without skull fracture), anoxic (lack of oxygen to the brain)/hypoxic (lack of oxygen to body tissues) injury, vascular, infectious disease, intracranial surgery, metabolic disorders, intracranial neoplasms, seizure disorders and toxic exposure (e.g., substance abuse, volatile agent inhalation, etc.) (BIA, 1997).

### **Health education practice with respect to traumatic brain injury**

The literature regarding health education programming for traumatic brain injury indicates that brain injury rehabilitation teams at hospitals and treatment centers, both traditionally and currently do not include professional health educators (Serio, et. al., 1995, 35). Educational programming is an integral part of the rehabilitation plan, but the educational aspects of treatment plans are often the responsibility of the team Social Worker or the Speech, Occupational, or Physical therapists. As DePompei & Zarski (1989) and Serio and colleagues (1995) indicate, educational programs in rehabilitation settings for brain injury patients and their family members are offered most often during initial hospitalization and revolve

primarily around crisis intervention and family distress surrounding the initial stages following severe brain injury (DePompei & Zarski, 82-83).

Drotar and colleagues (1996) demonstrated that surveys of family members of brain injured individuals reported a desire for educational interventions at later stages in the rehabilitation process. Family members specified that they would find additional information about the consequences of brain injury and available resources extremely helpful in learning to more effectively manage the social, financial and behavioral ramifications of TBI. Other studies, (Brooks, et. al., 1986, Kreutzer et. al., 1994 and Blosser, et al., 1995) have also indicated that additional education about what to expect at various recovery stages and tools to help manage behavioral outbursts ranked at the top of lists of needs expressed by family members/caregivers as “unmet” (Drotar, et. al., 1996).

### **The impact of brain injury on family members and caretakers**

Following brain injury, the changes families experience range from relatively mild to complete compromise of family system functioning. Individual roles and expectations are often at the very least blurred, but more often altered or even reversed (Muir, et. al, 45). The person who has suffered traumatic brain injury often exhibits difficulties with thinking in areas which include attention, motivation and arousal, communication and language, vision and hearing, learning and comprehension. Personality, mood and emotional responses are very often altered. The injured individual may experience difficulty initiating and carrying out simple to complex behaviors and routines which previously caused them no difficulty. They may be unable or less able to control their impulses and emotions and may act out aggressively or lash out emotionally, most often at family members and caretakers with whom they have the greatest interaction. Physical manifestations including deficits in mobility,

coordination, endurance, energy, dexterity and sensation are also often present to varying degrees (Braunling-McMorrow, et al., 3-1 to 3-3).

Education of families, friends and caregivers of brain injured individuals as to what to expect and where to find help are especially important because of the wide variety of deficits experienced by brain injured individuals. They often manifest life-long physical, emotional and behavioral issues that impact every aspect of their lives and relationships. The ways in which the individual acts, feels, thinks and relates to other people in his or her life all change. The changes range from subtle to so drastic that the individual can become nearly unrecognizable as the same person they were, to themselves and to their family and friends. (Braunling-McMorrow, et. al., 3-3).

The impact of brain injury on family/caregiver dynamics and functioning has been the subject of a considerable body of research over the past 20 years. Coping with the impact of brain injury and the changes it makes in the dynamics of personal interaction and relationships has been shown to be one of the most difficult tasks that can confront a family post-injury (Florian, Katz, & Lahav, 223-224). Research has been conducted which demonstrates the impact on families immediately post-injury to as long as 10 years post-injury. For example, (Brooks, 1984, 131-135) showed that relatives of the injured individual showed that relatives reported being under significantly greater stress at 5 years post-injury than at 1 year. At 5 years post-injury, study participants reported experiencing increases in the incidence of disturbing/ challenging behaviors (violence, verbal aggression, inappropriate social behaviors, dependency etc.) and a reduced ability to cope with the brain injured family member compared with their experience at 1 year post-injury.

Brooks (1984) suggests that family members' needs and the degree to which they are met also change over time (133-36). To prevent family breakdown and caregiver burnout, assure timely service provision and utilize limited resources effectively, the needs of families coping with brain injury should be identified at various stages of the recovery process and appropriate interventions be applied.

### **Justification for TBI health education programs for families/caregivers**

Interventions focusing on the empowerment of families and on providing them with sequenced condition information and strategies to manage behavioral issues were shown to result in significant increases in levels of needs met (Blosser & DePompei, 48-50). Because traumatic brain injury assaults not only the injured individual, but also his or her entire personal system, it results in tremendous changes within what is referred to as the "family system". The term family system is derived from the "family systems theory" of therapeutic intervention (Maltz & Sachs, 8-10). Within the parameters of this theory, the family is perceived as a dynamic group, or system, with a distinct structure, operational rules and patterns of communications. The family system operates as a cohesive unit to enable the accomplishment of tasks that meet the needs of each member as well as of the family as a whole. The members of the family system are linked both psychologically and behaviorally to each other through complex connections which develop over the life cycle of the group. As such, any significant changes in the life patterns or behaviors of any one family system member produce changes for all other members. The dynamic nature of the family system, as articulated by the theory, allows the system to continually change in response to the behavior of individual members and to events happening within and around them (Maltz & Sachs, 2-4). Based on this understanding of the dynamics of family structure, and on knowledge of the

extensive impact TBI/ABI has on family system dynamics, effective educational interventions with brain injured individuals should include the entire family system.

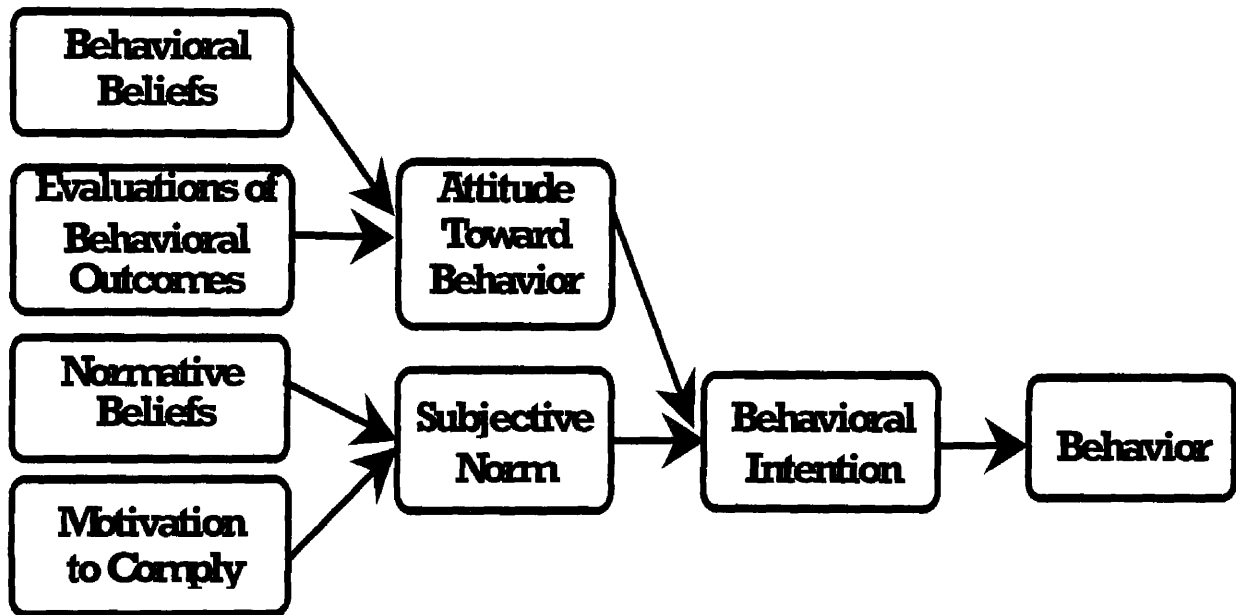
In light of the fact that the majority of current programming for families and caregivers of TBI patients is made available during initial hospitalization and primarily stresses crisis intervention and family distress in the initial stages following severe brain injury (DePompei & Zarski, 82-83), I wanted to explore a comprehensive program centered around providing information to family members and caregivers based on their unique needs at various stages throughout the TBI recovery process. Therefore, I chose to examine the Holland and Shigaki three-phase model of family education for TBI because it is based upon providing information at various stages, from acute inpatient rehabilitation to community re-entry. It is based upon the development of a literary resource of TBI condition and resource information which is staged from initial injury through later stages of the recovery process. I then chose to examine ways in which application of the Theory of Planned Behavior to the Holland and Shigaki model might strengthen and improve specific areas, based upon comparison of ways in which other health education programming was strengthened and enhanced by application of the TPB and its earlier version, the TRA (due to the scarcity of TPB and TRA application to actual TBI programming).

### **The Theory of Planned Behavior and Theory of Reasoned Action outlined**

The Theory of Reasoned Action was the first theory model proposed by Ajzen & Fishbein, and it is based on the supposition that a relatively small number of concepts can be used to predict, explain, and influence the behavior of individuals (*Figure 1 – TRA Schematic Representation*). Specifically, the TRA proposed that an individual's intention to perform any given behavior is, in itself, the immediate determinant of the behavior. *Behavioral intention* is,

according to the theory, a weighted sum of two primary determinants: 1) *personal attitude* toward performing the behavior, and 2) *subjective norms* regarding the behavior. Personal attitude toward a behavior refers to the degree to which a person favorably or unfavorably evaluates any given behavior. Attitude toward behavior is asserted to be a function of an individual's belief that performing a behavior will lead to certain consequences, and his or her evaluation and weighting of those consequences (Ajzen & Fishbein, 1980).

### Theory of Reasoned Action

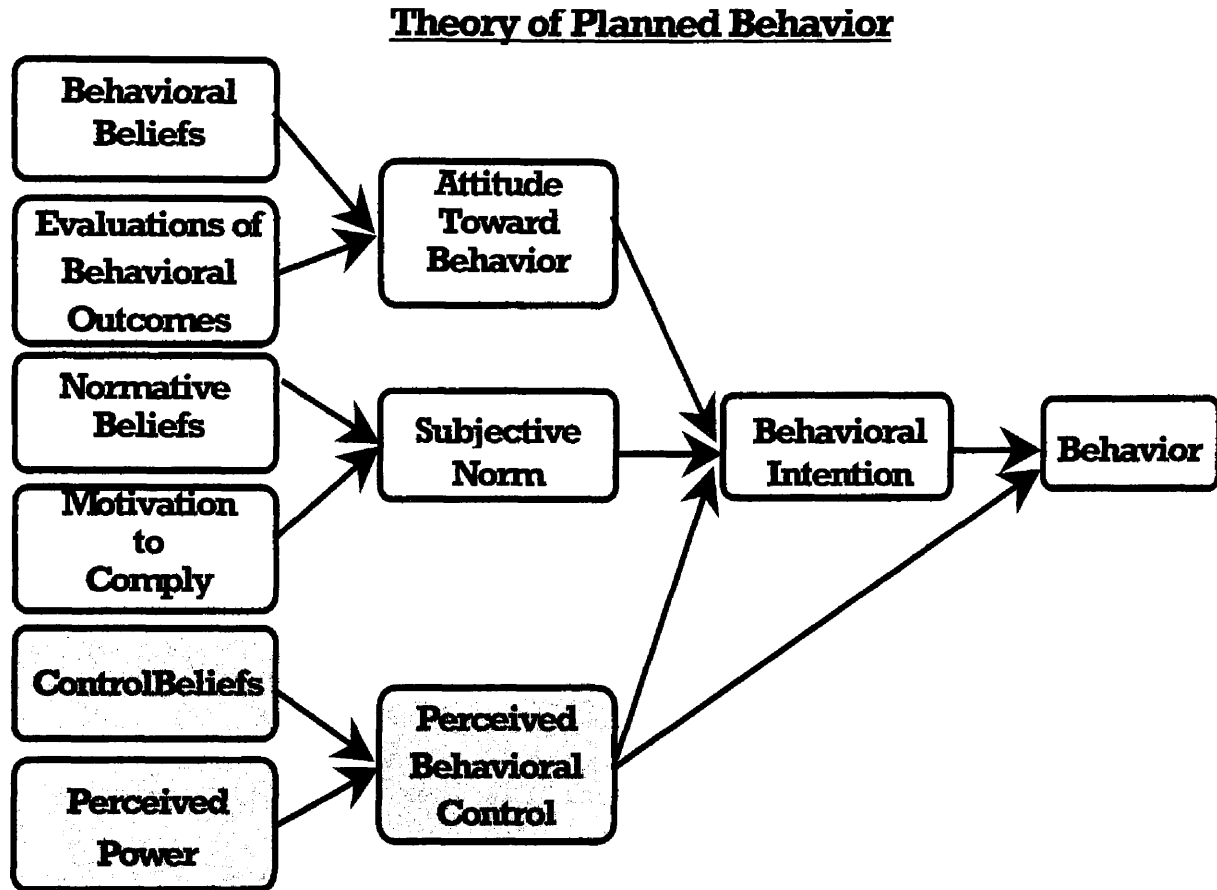


(Hausenblaus, et. al., 1997).

The social component of Ajzen and Fishbein's Theory of Reasoned Action, *subjective norms*, reflects perceived social pressure on an individual to engage in or not to engage in a given behavior. Subjective norms are a function of the individual's beliefs about whether significant others think he or she should engage in a behavior, and further weighted by his or her own motivation to comply with the desires of those significant others (Becker, T., et. al., 620 ). As the TRA was tested in application to diverse arenas, other strong motivational factors toward



behavior were observed as instrumental in determining behavior. Ajzen subsequently expanded the TRA to include these factors and the expanded model is the **Theory of Planned Behavior** (Figure 2 – TPB Schematic Representation – with added concepts shaded).



(Hausenblaus, et. al.. 1997) \*Shaded areas indicate concepts added to the TRA

The additional motivating factors, *control beliefs*, representing an individual’s beliefs regarding available resources for and blockades against action, and *perceived power*, the impact on an individual of each resource or blockade to facilitate or inhibit a behavior, were added to the TRA as the factors contributing to the element, *perceived behavioral control*. This added element is manifested when an individual with strong control beliefs about the existence of resources to facilitate a behavior will also show high perceived control over the behavior, and

an individual with strong control beliefs about the existence of blockades which inhibit a behavior will show low perceived control over the behavior.

According to both theories, however, performance or nonperformance of any given behavior is principally determined by the strength of an individual's intention to perform (or not perform) that behavior; where "intention" is defined as the subjective likelihood that an individual will perform (or try to perform) the behavior in question. Both theories propose, generally, that the more an individual believes that performing a behavior will lead to positive outcomes or prevent negative outcomes, the more favorable that individual's attitude toward performing the behavior will be. Similarly, the more an individual believes that specific referents (individuals or groups) think that he or she should (or should not) perform a behavior, and the more that individual is motivated to comply with those referents, the stronger will be the perceived pressure (the subjective norm) to perform (or to not perform) that behavior (Fishbein & Guinan, 6). And, finally, as the added element *perceived behavioral control* indicates, the more an individual believes that he or she has control over available resources toward and blockades against a specific behavior, the stronger will be that individual's perception of control over the decision to perform (or to not perform) and the actual performance (or non-performance) of that behavior.

### **A three-phase model for educating families/caretakers about TBI**

In 1998, Daniel Holland and Cheryl Shigaki proposed a three phase model for educating families and caretakers of traumatically brain injured patients based on the assumption that shorter inpatient stays for brain injury dictated by the current health care environment allow less time for family and caregiver education about brain injury and its implications for interaction with the injured individual. The proposal charges that, in light of the shorter-

duration brain injury rehabilitation programs, what is required is an education program that meets family/caregivers needs for information as they arise and delivers standardized information about traumatic brain injury, to ensure that each family group receive core knowledge upon which more individualized education can be built.

Holland and Shigaki assert that, because brain injury patients are now discharged from inpatient care at earlier stages in recovery, the education process for both patient and family/caregivers is often severely disrupted. Compounding the problem during this phase of the process, is often that both the patient and their family and caregivers have difficulty at this stage perceiving information that deals with anything other than the injured individual's immediate survival and future. The program model suggests that it is necessary to provide a comprehensive educational program for families and caregivers which can be delivered throughout the entire course of the recovery process, and which delivers information at appropriate points in the process. The model is divided into three phases in order to address family and caregiver information needs in a step-wise fashion. The emphasis is on, according to Holland & Shigaki, "attempting to match the educational content with the TBI family's acute need for it. ...The three phases of the model correspond to the brain injured family's progression through the continuum of care" (994).

The structure and purpose for the model, as explained by Holland and Shigaki, are as follows:

- Phase I:** Intensive Care Unit (ICU) through medical stabilization and acute hospitalization.
- Phase II:** End of acute hospitalization through acute inpatient rehabilitation.

**Phase III:** End of inpatient rehabilitation through outpatient rehabilitation and community re-entry.

The information used for educating patients and families ... has been gathered from published sources. It has been scheduled ... according to that phase for which it is most appropriate (Holland & Shigaki, 994).

The authors explain that their proposal intends that the educational materials be presented under the supervision of a rehabilitation psychologist or social worker who can discuss the materials with the family and caregivers and answer any questions. The Appendix to their report lists a bibliography (see *Appendix - Sample Resource Bibliography*) of resources (999-1009), but they caution that, rather than being a comprehensive resource list, the bibliography is meant to provide an example of how educational materials can be staggered to be more time-relevant to specific phases of recovery (995).

The information provided during the three phases would be tailored to meet specific needs:

**Phase I– ICU through medical stabilization and acute hospitalization:**

The family is often confused and unaware of rehabilitation procedures and terminology and has no understanding of what is involved in the recovery process. The educational program at this phase would address the need for information, and be conducted or overseen by the rehabilitation psychologist or social worker to provide continuity. The authors explain that the objectives of this stage are: 1) to provide face-to-face support for the family, 2) to present basic brain injury information so that family can better comprehend what is occurring and, 3) to clarify terms and procedures and answer questions that arise regarding trauma care and traumatic brain injury recovery (995).

**Phase II – end of acute hospitalization through inpatient rehabilitation:**

The family and caregivers are preparing for the next stage of the rehabilitation process. They often do not have a clear picture of the nature and purpose of rehabilitation medicine, the make-up of the treatment team and the goal-directed structure of the process. During this phase, family members are often faced with complex decisions regarding the length and type of care the injured individual will receive and the extent of the family's involvement in the process. The objectives of this phase, therefore are: 1) to orient the family and caregivers to TBI rehabilitation and the goals of treatment and care, 2) to provide comprehensive information regarding the full spectrum of potential outcomes of brain injury so that family expectations can be based on realistic possibilities, 3) to emphasize the significance and psychology behind family systems and family/partner dynamics and discuss potential disruptions to them, 4) to introduce considerations regarding primary caretaker responsibilities and discuss difficulties that might arise, and 5) to prepare the family and caregivers for what to expect throughout the various stages of the outpatient rehabilitation process.

**Phase III – end of inpatient rehabilitation through community re-entry:**

The family is preparing for the injured individual's return home and for outpatient rehabilitation. The emphasis is on information regarding the importance of continued rehabilitation in outpatient programs and on the management of emotional or behavioral changes which may arise. The objectives of this phase, therefore, are 1) to educate the family regarding the protracted nature of the brain injury recovery process, 2) to emphasize strategies to manage behavioral and personality changes in the injured individual, 3) to address sexuality and relationship issues, 4) to familiarize the family and caregivers with support services and community resources available to them, 5) to

provide a broad understanding of adaptations that may be necessary in the home environment, 6) to discuss issues regarding school or vocational re-entry, and 7), to provide insights for the family and caregivers of traumatic brain injury recovery from patients' perspectives.

Holland and Shigaki emphasize that the intention of their model is to provide a “cost-effective, standardized process of enhancing family education. ... The intent is to improve TBI family education, ... during a time of change in rehabilitation settings in which there is increased risk of a diminution of the family education process if innovative measures are not taken” (1997).

Implementation of comprehensive family education programs for TBI such as the Holland and Shigaki model can be difficult under current health care cost-saving regulations. The fact that their proposed model was not implemented (according to Holland) reflects a growing problem in the health care industry<sup>1</sup>. It has been both his and Shigaki's experience<sup>2</sup> that in managed care settings, the primary objective is to save money. If health care institutions operating under managed care guidelines are going to save health care dollars over the long term, however, he contends they must be willing to invest in health education and prevention up front. Without this initial investment, the cost-offsets created by long term savings will not be gained. For example, not implementing the Holland and Shigaki model may have realized cost savings that particular year, but the long-term costs of having families who are unprepared to be effective caretakers will result in far more expense in the future, including

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<sup>1</sup> The model was not formally implemented due to a change in mission and priorities of the University of Missouri inpatient rehabilitation hospital under a change in hospital ownership.

<sup>2</sup> E-mail correspondence with C. Shigaki of 11/20/99 and D. Holland of 12/02/99.

second accidents, behavioral management problems, and the manifestations of caregiver burnout.

### **Enhancements based on TPB application to the Holland & Shigaki model**

The Holland and Shigaki three-phase model of family education about brain injury depends on one basic assumption. To ensure the greatest level of family function post-injury, it is essential to provide families/caregivers of brain injured individuals with a comprehensive educational program which can be communicated to them at appropriate intervals throughout the recovery process (1998, 994). The assumption is that families and caregivers will experience and exhibit a continuous need throughout the recovery process to acquire medical and resource information, and will actively participate in programs designed to meet that need.

This model was chosen to analyze due to the scope of its educational offerings. Family needs for information and resource access are strong throughout the recovery process. This model exemplifies a program which can help to meet those needs even in the face of shorter inpatient rehabilitation within managed care settings. If a program such as the Holland and Shigaki model is to fulfill these requirements, the materials available to families and caregivers need to have the greatest impact on those individuals most likely to participate, and at times within the recovery process when they are most likely to seek information.

Application of the TPB to the Holland and Shigaki model can help administrators strengthen it in a number of ways. First, by enabling more effective management and review of program materials and by helping health programmers establish, via results obtained from theory application analysis data, appropriate venues for access to the materials suggested in the program bibliography. For example, analysis of theory application data which showed those most likely to participate and which factors motivate them might suggest that an

internet library accessible by family members and caregivers nation-wide would be an effective way to draw participation. Data showing likely participants, the specific motivating factors which lead to their participation and the needs they feel the strongest need to have met by educational programming might also provide programmers with select specifications for appropriate materials most likely to have the greatest impact during specific recovery stages. Similar data could aid practitioners in ensuring the standardization and availability of materials to program participants by indicating which materials were likely to have the greatest impact on those most likely to participate. Information derived from theory application could also give health education programmers insight into locations most likely to serve the greatest numbers of family members/caregivers in specific areas and help them to recruit various organizations, such as Brain Injury Association chapters to provide those venues.

### **Paralleling other TPB and TRA health programming applications to TBI education**

Until recently, though brain injury programming was widely studied within physical and occupational medicine and rehabilitation journals, health education programming with the field of brain injury rehabilitation has been limited. The TPB and TRA have, however, been applied within the past decade to a number of other diverse health programs, and the benefits derived by those programs can be extended to apply to TBI educational programming. The TPB and TRA have been employed to help practitioners understand and predict participation in various programs, as well as to design effective programming most likely to reach targeted populations. One example is the Baker and colleagues (1996) study of condom use among STD clinic participants. The authors applied the TRA to try to understand what factors were significant to the decision of 830 patients registered for services at a large, urban, health department STD clinic. The survey instrument included questions identifying demographics, self-reported sexual activity and use of condoms over the previous month, visit purpose and



TRA model variables. These variables included condom use intention, attitudes toward condom use, the perceived likelihood of nine outcomes of using condoms and perceived norms and motivations to comply (Baker, et. al, 531).

The results of this study indicated that application of the TRA can be beneficial in helping practitioners understand what factors account for the differences in intention to comply among different populations. Attitude and social norms were statistically determined to have accounted for a large proportion of the variance in intention to use condoms for both men and women (Baker, et. al, 537). These benefits could also be realized in application of the TPB and TRA to TBI family programming. Understanding the factors which most significantly contribute to the variance in family members and caregivers intentions to participate in educational programming could help TBI educational programmers design programs more likely to reach greater numbers of impacted individuals.

Another area of health programming to which the TPB and TRA have been applied is the area of sports and exercise physiology. The Hausenblaus, Carron and Mack (1997) study employed a meta-analysis of studies conducted to analyze the utility of the TRA and TPB in predicting and explaining exercise behavior (Hausenblaus, et. al, 39). A total of 31 studies was used, many of which contained repeated measurements of specific constructs at various points in time, generating 162 effect sizes (based on N=10,621 participants).

The results of the meta-analysis provided strong general support for the validity of the TRA in this application. The results showed that intention has a large effect (ES=1.09) on exercise behavior, and implied strongly that subsequent to individuals forming the *intention* to exercise, exercise behavior follows closely (Hausenblaus, et. al., 44). By extension, in application to TBI family programming, the results of such an analysis can enable

administrators and programmers to determine the factors leading to educational program participation behavior. Determination of the factors leading to the intentions behind individuals' active participation in educational programming can aid in the design of outreach strategies/techniques which can provide family members/caregivers with access to materials and activities when they are most in need of them.

A third area of TPB and TRA application to health programming is the area of education psychology. The Norwich and Duncan study, which investigated the impact of learner attitudes, beliefs and interests on participation and achievement in school activities, clearly illustrates how specific values, beliefs and intentions relate to actual classroom behaviors (Norwich & Duncan, 319-320). The authors expanded upon the TRA by adding the variable, "perceived preventive factors", to the theory. This addition was based upon their finding that perceived pressures to take part in school learning (i.e., subjective norm) did not significantly relate to learning intentions or classroom behavior (313). The authors described this variable as, "those specific obstacles which a person perceives as making it difficult to carry out the behavior in question. In the context of school learning these obstacles could include ...perceived lack of capability or confidence, poor teaching and resources for learning, competing interests and/or negative influences of others" (314).

One implication of this modification to the TRA as it relates to TBI family education programming is that it illustrates that it is possible to elaborate on the Theory of Reasoned Action to better account for factors which might impact specific skill-based behaviors within challenging learning settings. Therefore, such adaptations, once tested for their utility in TBI educational settings, could help to provide health education practitioners with an enhanced understanding of the influence of personal interests and social pressures on the learning

behavior and intentions of TBI educational programming participants (Norwich & Duncan, 320). TBI family education programs are not necessarily as “formal” as school settings or regularly conducted in classroom settings, but similar dynamics of attitudes, beliefs and intentions to comply to those for formal classroom situations also apply to these programs. Gaining an understanding of how and why specific values, beliefs and intentions influence individual’s behavior in actual educational settings, such as occurred as a result of this application, could help facilitate more effective, more precisely targeted programming for TBI family education.

These diverse applications illustrate the flexibility and utility of the TPB and TRA in designing, evaluating and revising health education programs. By extension, and in the absence of studies applying the TPB or the TRA specifically to health education programming for TBI, family/caregiver educational programming for brain injury would also be strengthened and enhanced by the application of these theories.

### **Specific motivating factors illustrated via models of TPB application**

One of the key benefits derived from application of the TPB to the Holland and Shigaki model, as outlined in item #2 above, is the delineation of motivating factors which are likely to influence the intention to participate of family members and caregivers. Application of the TPB can help delineate what attitudes and beliefs are motivating factors influencing family/caregivers to participate or to decline to participate, and allow them to effectively intervene to attempt to change those attitudes and beliefs. Figure 3 below, *TPB applied to Phases I and II of the Holland & Shigaki family education model*, illustrates family/caregiver beliefs and attitudes that participation in phases I and II of the TBI education/support program might increase their already high levels of stress and will not address issues specific to their

personal circumstances. These attitudes and beliefs in turn lead to family/caregivers deciding not to participate.

From the belief held by family/caregivers that their current situation of dealing with the brain injury of a loved one is very stressful, creating immediate concerns about the long-term survival, return to normalcy and ability to be independent of the affected individual stems their attitudes toward participation. Their belief that participation in phases I and II of the family education/support program will not help to alleviate their stress or help them cope with impending lifestyle changes, coupled with the evaluation that these are undesirable outcomes, leads to their attitude that participation in phases I and II of the program will increase stress and would not help them cope with issues specific to their personal circumstances. These elements then lead to family/caregiver intentions not to participate and, finally, to not participating.

Also contributing to the decision not to participate in phases I and II of the education/support program is the belief of family/caregivers that their siblings, parents, spouses and friends do not want them to participate, coupled with their desire to comply with the wishes of these significant others, leading to the formation of the “subjective norm” that they are under pressure not to participate. This norm contributes to their intention not to participate, as does their belief that significant obstacles exist against their participation, reinforced by a perception that they have little personal control over the obstacles they believe to exist.

Application of the TPB to the final stage of the three-phase model, as illustrated in Figure 4 below, *TPB applied to Phase III of the Holland & Shigaki family education model*, demonstrates that the norms, intention and behavior aspects of the theory are identical in this phase to phases I and II, while family/caregiver beliefs and attitudes about phase III participation differ. Family/caregiver

attitudes and beliefs at this stage in the recovery process reflect that a primary consideration for them at this point is preparing for full responsibility for the affected individual's care.

The beliefs of family/caregivers, who for the first time face full responsibility for the TBI patient's care, that participation in phase III of the program will be an additional burden on their already limited resources are coupled with their evaluation that they are overwhelmed by new responsibilities and unable to handle any additional burdens. This combined belief/evaluation lead to the attitude that program participation ranks low on their list of immediate priorities. As in the illustration of the TPB applied to phases I and II, these attitudes and beliefs, along with the control beliefs, perception of power and their perceived control over participation, then lead to family/caregiver intentions not to participate in phase III of the education/support program, and ultimately to their not participating.

# Theory of Planned Behavior as Applied to Phases I and II of the Holland & Shigaki Family Education model for Traumatic Brain Injury

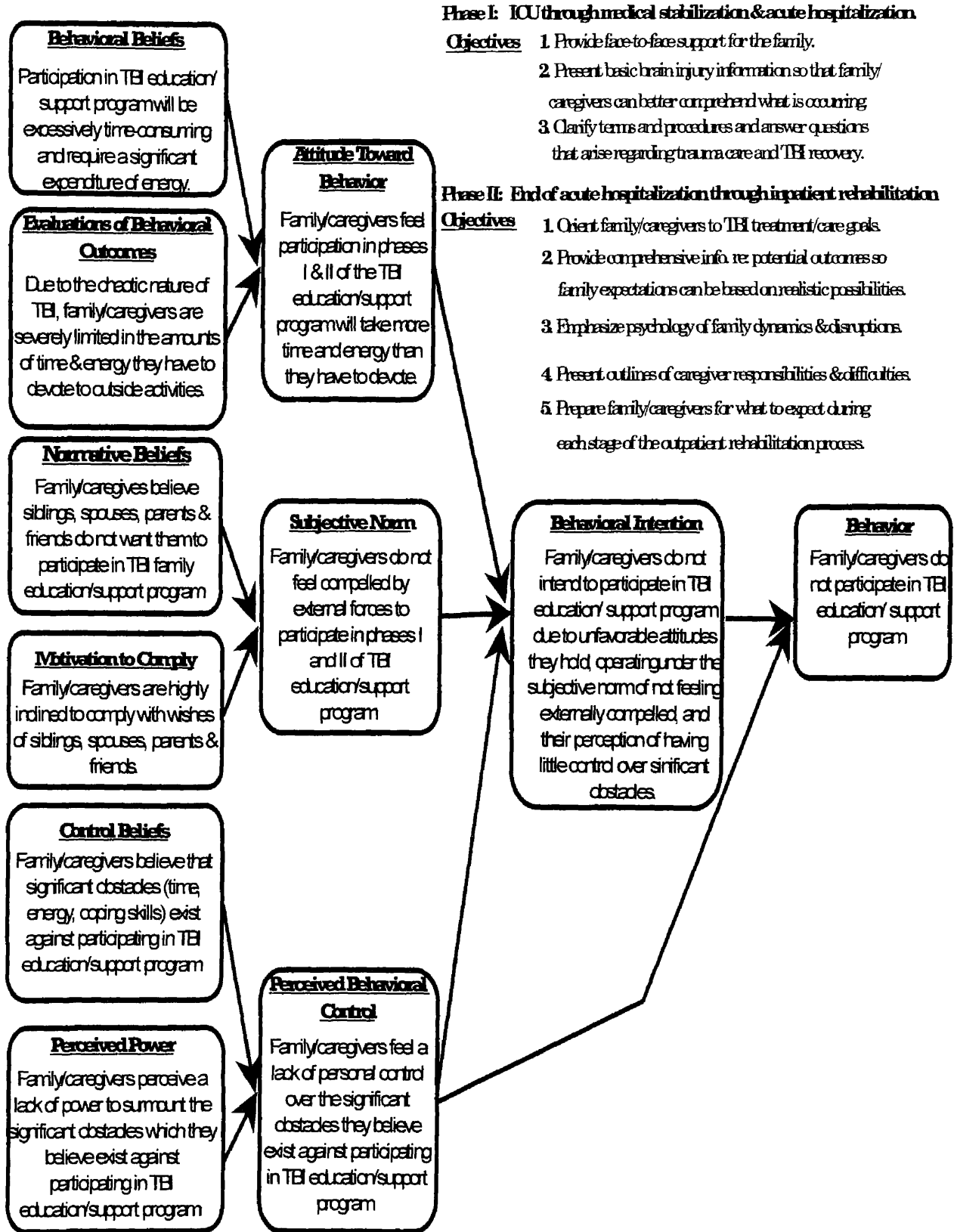


Figure 3 – TPB applied to Phases I & II of the Holland & Shigaki TBI family education model

# Theory of Planned Behavior as Applied to Phase III of the Holland & Shigaki Family Education model for Traumatic Brain Injury

Phase III: End of inpatient rehabilitation through community re-entry.

### Objectives

1. Educate the family regarding the protracted nature of the TBI recovery process.
2. Emphasize strategies to manage behavioral & personality changes in the brain-injured individual.
3. Address sexuality and relationship issues.
4. Familiarize family/caregivers with support services and community resources available to them.
5. Provide a broad understanding of adaptations that may be necessary in the home environment.
6. Discuss issues regarding school or vocational re-entry.
7. Provide insights for the family/caregivers of brain injury recovery from the patient's perspective.

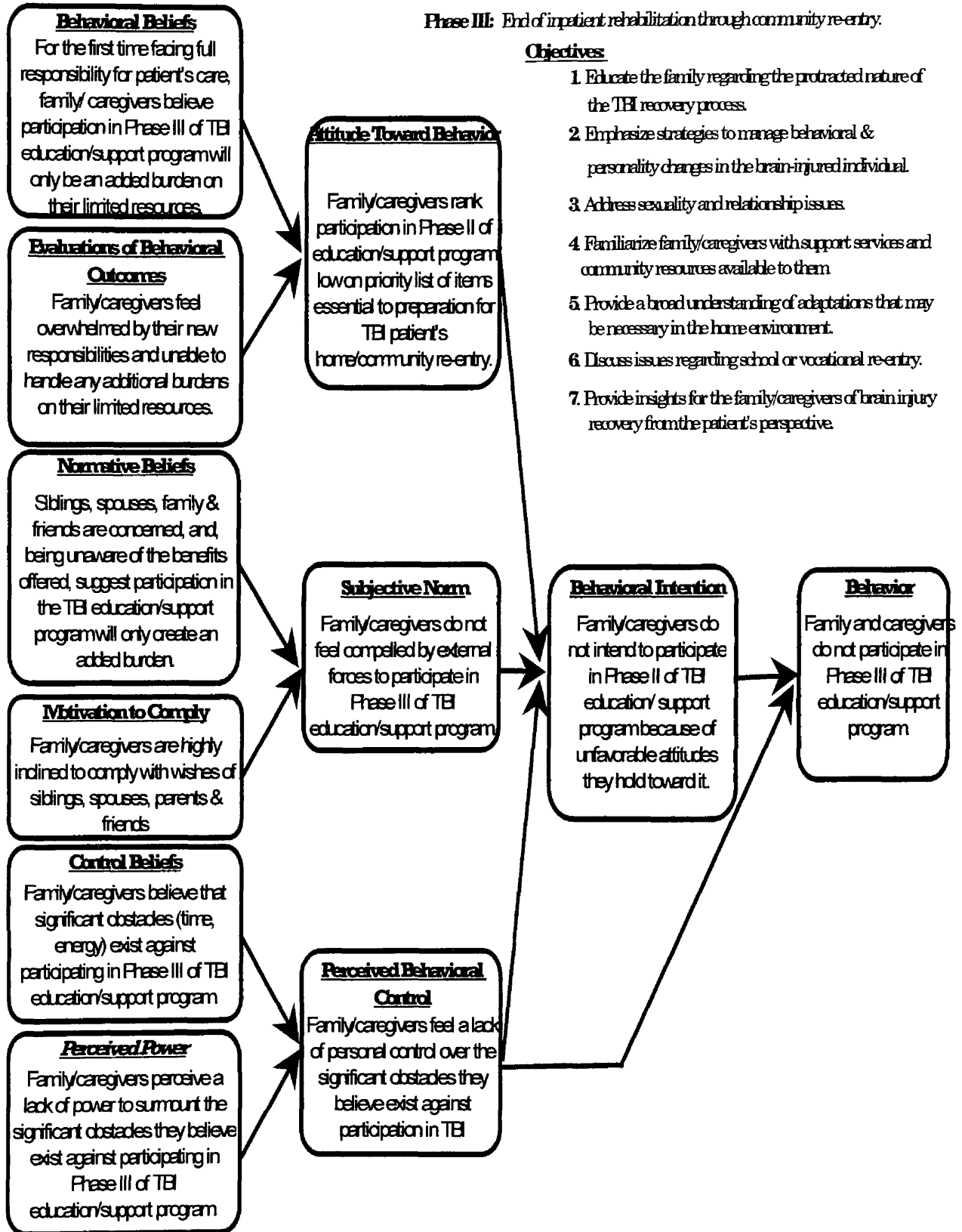


Figure 4 – TPB applied to Phase III of the Holland & Shigaki TBI family education model

### **Attitudes, beliefs, intentions and behavior interventions via TPB application**

Once application of the TPB to the Holland and Shigaki 3-phase education program has demonstrated certain beliefs and attitudes which are influencing family members and caregivers intentions to participate in the program, health educators can then intervene to attempt to change those beliefs and attitudes. Identification of specific factors motivating program participation decisions can also help program administrators to design program materials to address issues demonstrated as important at various stages in the recovery process.

For example, an intervention based on the attitudes and beliefs, as illustrated in Figure 3, which influence family/caregiver participation in phases I and II of the program might impact the various elements depicted in the following ways:

1. **Behavioral belief:** Family/caregivers believe that participation in phases I & II of the TBI education/support program will consume a great deal of time and require them to expend a significant amount of energy.
2. **Intervention:** Health educators could intervene in these beliefs by explaining that the amount of time required for program participation is no more than 1 to 2 hours per week to obtain optimum benefits and that, since the bulk of the program is self-administered, energy expenditure can be primarily determined by the participant.
3. **Evaluation:** Family/caregivers evaluation of the belief that program participation will consume a great deal of time and significant energy expenditure is that, due to the chaotic nature of TBI, they are severely limited in the amounts of time and energy they have to devote to outside activities.

**Intervention:** Health educators could help family members/caregivers to evaluate themselves as being less limited in amounts of time and energy to devote to



participation by emphasizing aspects of phases I and II of the TBI education/support program which provide resources toward more effective time management and help participants get better results from the energy they are already expending toward coping with the effects of TBI.

4. **Attitude:** From their evaluation that they are severely limited in the amounts of time and energy they have to devote to outside activities due to the chaotic nature of TBI, family/caregivers form the attitude that participation in phases I & II of the education/support program will require more time and energy than they have to devote.

**Intervention:** Changing the beliefs and evaluations of the beliefs of family/caregivers regarding participation in phases I and II of the TBI education/support program will help promote a positive attitude among them toward program participation.

5. **Normative Beliefs:** Siblings, spouses, family & friends are concerned by the effects on their loved ones of coping with TBI and, being unaware of the benefits offered, feel that participation in phases I and II of the TBI education/support program will only create an additional burden.

**Intervention:** Health educators could intervene in this belief by implementing an information session or sessions for those close to family members or caregivers. This session or sessions could explain the nature of TBI and ways in which it effects both the affected individual and families. The session could also emphasize that the TBI education/support program includes stress-relief techniques, time management and task organization planning, and resource availability information which can help

family members and caregivers cope with the lifestyle changes and added responsibilities brought about by TBI, as well as providing a support network.

6. **Motivation to comply:** Family/caregivers are highly motivated to comply with their perceptions of the wishes of the siblings, spouses, parents and friends.

**Intervention:** Providing evidence to siblings, spouses, family & friends that participation in phases I and II of the TBI education/support program is worthwhile will help to motivate family/caregivers to comply with their wishes and participate.

7. **Subjective Norm:** Holding the normative belief that their siblings, spouses, family and friend do not want them to participate in phases I and II of the TBI education/support program, family/caregivers therefore do not feel externally compelled to participate.

**Intervention:** Changing family/caregiver normative beliefs and motivation to comply with those beliefs regarding participation in phases I and II of the TBI education/support program, will produce subjective norm of feeling externally compelled to participate.

8. **Control Beliefs:** Family/caregivers believe significant obstacles (i.e., having sufficient time/energy to devote) exist that keep them from participating in phases I and II of the TBI education/support program.

**Intervention:** Health educators/program administrators could intervene in these beliefs by presenting scheduling flexibility options and explaining to family/caregivers that the program can aid in organizing responsibilities, thus increasing energy levels.

9. **Perceived Power:** Family/caregivers perceive a lack of power to surmount the significant obstacles they believe exist against their participation in phases I and II of the TBI education/support program.

**Intervention:** Since family/caregivers perceive a major obstacle against participation in phases I and II of the TBI education/support program to be the lack of sufficient time or energy to devote, health educators could provide them with program scheduling information, availability of program materials on-line for at-home perusal, time-management and task organization techniques which could help them begin to perceive themselves as having the power to surmount these perceived obstacles.

10. **Perceived Behavioral Control:** Family/caregivers feel a lack of personal control over the significant obstacles they believe exist against their participation in phases I and II of the TBI education/support program.

**Intervention:** Changing family/caregiver control beliefs and their perceived power over those beliefs regarding obstacles they believe exist against participation in phases I and II of the TBI education/support program, will generate the perception among them of behavioral control over those obstacles.

11. **Behavioral Intention:** Family/caregivers do not intend to participate in phases I and II of the TBI education/support program because of unfavorable attitudes they hold toward the program.

**Intervention:** Changing unfavorable attitudes of family/caregivers to favorable, their subjective norm of not feeling externally compelled to participate to feeling externally compelled, and their perception of having a low level of behavioral control over existing obstacles to a perception of having a high level of behavioral control,

will help to create the intention among them to participate in phases I and II of the TBI education/support program.

12. **Behavior:** Family/caregivers do not participate in phases I and II of the TBI education/support program.

***Intervention:*** Changing family/caregivers intentions regarding participation in phases I and II of the TBI education/support program could result in their participation.

Utilizing application of the TPB in this way, health educators could change negative attitudes among family members and caregivers toward program participation into positive ones. The TPB and the TRA, in many diverse applications have been shown to be beneficial in predicting how individuals will behave based on their attitudes toward specific behaviors. The three studies cited earlier in this paper are examples of the predictive capacities of these theories.

There are some areas where application of the TPB to the Holland and Shigaki model, while useful in predicting factors influencing participation, and therefore allowing health educators and administrators to intervene, falls short in consideration of other factors which could exert strong influences over family/caregiver decisions to participate. The TPB does not take into consideration other reasons family and caregivers might choose not to participate, such as financial and emotional issues, i.e., program materials or transportation costs are too expensive, or that dealing with the accident alone is emotionally overwhelming and leaves little room for other considerations.

The TPB also makes the assumption that the behavior of all family members or caregivers can be predicted by its application and therefore interventions will impact all members of the group, when in reality, each person reacts to a crisis uniquely. Therefore, health education interventions undertaken to change beliefs, belief evaluations and attitudes may impact each individual differently at different points in the recovery process and not influence all family members and caregivers to participate at any given time. These weaknesses of the TPB in this application could potentially render it less effective in its predictive value, but based on the benefits reported via application of the TPB and TRA to the other health programming applications referenced previously, the evidence suggests that overall the applications of the TPB to family educational programming for TBI should be beneficial in providing health educators with an effective tool to influence family/caregiver participation and help to fulfill a well-documented need for education and support following traumatic brain injury.

## **Discussion**

The value of theory to health education practice lies in the strengths it imparts to practitioners. Theory provides individuals and, by extension, groups, with insights into the function of elements of diverse phenomena and human behaviors, and suggests how these elements might be influenced under diverse circumstances. Theory, therefore, is vital to decision-making health issues. As previously established, a well-developed theory is one that is completely testable, can be applied in a wide variety of circumstances, and generalized across diverse populations and environments. Theory is an essential tool to the enhancement and fortification of health education practice. Well-developed and validated theories enable health educators to predict health outcomes, and provide them with the means to effectively

select, develop and apply strategies and methods to diverse practice situations, and to more easily evaluate program outcomes and performance.

This paper has discussed educational programming for family and caregivers of individuals suffering from traumatic brain injury throughout the rehabilitation process. It has shown that education of families, friends and caregivers of brain injured individuals as to what to expect at various stages, and where to find help is especially important due to the wide array of deficits impacting their lives and relationships (Braunling-McMorrow, 3-3).

To address this need, the three-phase model designed by Holland and Shigaki presents a basis for TBI educational programming. The model was developed on the assumption that currently mandated shorter inpatient stays for TBI allow less time for the presentation of family/caregiver education. The authors propose that, in light of shorter-duration rehabilitation programs, educational programming which meets family/caregivers' ever-changing needs for standardized information about TBI will ensure that each family group receives a core of knowledge upon which more individualized education can be built<sup>3</sup>.

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<sup>3</sup> The model, never formally implemented, was developed while Holland and Shigaki worked at the University of Missouri, within the inpatient and outpatient rehabilitation programs. They were attempting to develop a lending library and educational model, and hoped to develop models which could help to fulfill the needs for information they had witnessed families and caregivers begin to exhibit very early on in the rehabilitation process. Their effort was interrupted when a large for-profit rehabilitation hospital bought the academic inpatient rehabilitation hospital and changed its mission and priorities. The outpatient rehabilitation clinic was later closed. This, according to Ms. Shigaki, created an immediate disconnection between the acute care setting and the inpatient rehabilitation setting, and shifted responsibility for educational programming to the new owners who had a different approach to education. Front line staff including nurses, case managers, psychologists and physicians were very supportive of the project and were taken by surprise when it was tabled by the new management. The need for comprehensive family education has been established, the challenge for health educators in implementing such programs in managed care settings will be to convince administrators of the long-term cost savings of effective family education throughout the rehabilitation process, and the corresponding reduction in second accidents, psychological adjustment difficulties and countless other long-term costs of failing to provide family members and caregivers with the information and resources they need to make the rehabilitation process successful.

Application of the TPB and the TRA to other health education programming has enabled programmers to improve such programs. By extension, in light of the limited literature documenting application of the TPB or TRA specifically to TBI family education programming, I explored a number of ways in which application of the TPB to the Holland and Shigaki model for TBI family/caregiver education might aid practitioners and administrators. Application of the TPB to the three-phase model could enable programming to be specifically targeted and help to determine significant factors and circumstances influencing program participation behavior in order to enable development of effective outreach strategies and venue selection. TPB application to the Holland and Shigaki model could also enable administrators/practitioners to better design program materials to fulfill specific needs of participants at various stages in the recovery process and to formulate program evaluation strategies and techniques to enhance existing programming.

## **Conclusion**

This paper argued that the joint application of the Holland and Shigaki model and the TPB offers aids in the understanding of and interventions into family-based educational programming for TBI. The primary merits profiled were that application of the TPB can enable health educators to 1) determine which family members/caregivers are most likely to participate in educational programming and their motivation; 2) enable health educators and administrators to better determine specific motivation factors for family members and caregivers at different stages in the recovery process, and to develop a profile of individuals most likely to participate; 3) choose the most effective program materials, categorized by appropriate stage of recovery; 4) provide an effective tool to aid in program design and enhancement decisions, and 5) develop effective, targeted outcome evaluation designs and methods.

**Appendix: a resource bibliography for families and professionals****(Note: prices and availability may vary)**

<u>Format</u>	<u>Title/Individual Authority</u>	<u>Publisher/source</u>	<u>Notes</u>
<b>Phase I</b>			
<b>ICU Through Acute Hospitalization</b>			
Article	Information General Sobre: Lesion Cerebral (General Information Sheet: Brain Injury, by NIC HCY)	Brain Injury Association, Inc. (See below)	One of few materials available in Spanish (FREE)
Book	Traumatic Head Injury: Cause, Consequence and Challenge	Head Injury Association of KS & Greater Kansas City, Inc., 1100 Pennsylvania, Suite 305, Kansas City, MO 64105, USA (816) 842-8607; 1-800-783-1356	Contains glossary and description of Healthcare providers.
Book	Brain Injury Glossary (Lehmkuhl, ed.)	HDI Publishers (See below)	(\$9.50) for printed format. Also available for Windows '95, Windows 3.1 or IBM-formats. 850 entries.
Booklet	Preguntas sobre lesion traumatica del cerebro (Basic Questions About Head Injury and Disability, a "Tailored Information Packet")	Brain Injury Association, Inc. (See below)	One of few materials available in Spanish
Booklet	Dano cerebral: Guia para familiares y cuicadores (Jose' Leon-Carrion)	Brain Injury Association, Inc. (See below)	One of few materials available in Spanish (\$12.050)
Booklet	What is Anoxic Brain Injury? (David F. Long, 1990)	Brain Injury Association, Inc. (See below)	(\$2.00)
Booklet	About Head Injuries	Channing L. Bete Co., Inc., 200 State Rd., South Deerfield, MA 01373, USA 1-800-628-7733	Covers basic information including Identifying the members of the treatment team and how to take stock of yourself as a caregiver. For physicians' and psychologists' office/clinic distribution.
Misc.	Introductory Information for Families	Brain Injury Association, Inc. (See below)	A collection of readings. Basic Information about TBI, guide for selecting a rehabilitation facility, and information about the Brain Injury Association (\$7.00).
<b>Phase II</b>			
<b>End of Acute Hospitalization Through Acute Inpatient Rehabilitation</b>			
Article	A survey of accredited and other rehabilitation facilities: education, training, and cognitive rehabilitation in brain injury programs.	<i>Brain Injury</i> , 7, 319-331. Also available through: National Info. Clearinghouse	
Article	Severe Brain Injury (Adapted from 'Coma, Its Treatment and Consequences')	Brain Injury Association, Inc. (See below)	This article is in hand-out format and would be appropriate for use in a clinic or hospital setting.
Article	<i>Fact Sheets:</i> Head Injury Finding an Attorney Conservatorships Legal Planning for Incapacity Coping with Behavior Problems After Head Injury - plus others	Family Caregiver Alliance, 425 Bush Street, Suite 500, San Francisco, CA 94108, USA (415)434-3388 FAX: (415) 434-3508 e-mail: <a href="mailto:info@caregiver.org">info@caregiver.org</a> . Web: <a href="http://www.caregiver.org">http://www.caregiver.org</a>	Good information w/resources and hotlines on the back. May be somewhat more relevant for people who live in California. Families may want to order separately: Up to 5 titles: \$1.00; Up to 6 titles: \$2.00; Professionals may want to order complete set with binder: \$15.00. Many are available in Chinese and/or Spanish
Article	Know Your Brain	National Institute of Neurological Disorders and Stroke, National Institute of Health, P.O. Box 5801, Bethesda, MD 20824; 1-800-352-9424 FAX: (301) 402-2186	Basic information about the brain with simple drawings.
Article	Subarachnoid Hemorrhage and Aneurysm ('Learning' series, 1993)	University Hospital & Clinics, One Hospital Drive, Columbia, MO 65212, USA (314) 882-4141	Includes easy to read, general info. plus a glossary and schematic diagrams. It would be most appropriate for use with recently head injured patients.
Audio	Neuropsychological Assessment: What it does and does not do. (Kay & Mateer)	Brain Injury Association, Inc. (See below)	(\$10.00)
Book	Head Injury: A Family Matter, (J. Williams and T. K., 1991)	Paul H. Brooks Publishers	Can be ordered through a Bookstore (\$30.00)
Book	Coming Home: A Discharge Manual for Families of Persons with a Brain Injury	HDI Publishers (See below)	(\$12.50)



**Appendix (Continued)**

Book	Head Injury and the Family: A Life and Living Perspective; Arthur E. Dell Orto & Paul W. Power, 1994)	PMD Publishers Group, Inc., P.O. Box 4116, Winter Park, FL 32793, USA; Also available through: St. Lucie Press, 100 E. Linton Blvd., Suite 403B, Delray Beach, FL 33483 USA (407) 274-9906 FAX: (407) 274-9927	One of the best books written in this area. Easy to read, written with family, caregivers and patients in mind. Includes exercises and vignettes. Winner of an award for Excellence in Medical Communication.
Book	Traumatic Brain Injury Rehabilitation Training Consortium Monograph Series. Volume 2: Assistive Technology in Traumatic Brain Injury Vocational Rehabilitation.	St. Lucie Press, 100 E. Linton Blvd., Suite 403B, Delray Beach, FL 33483 USA (407) 274-9906 FAX: (407) 274-9927	Assistive technology, under the ADA, is that designed for/used by individuals with the intent of eliminating, ameliorating, or compensating for functional limitations. Coverage includes impaired functions that limit vocational outcome, behavior concerns in the workplace, maximizing a client's residual knowledge, skills, use of computers and adapting work environments (\$19.95).
Book	The Patient Guide to the Human Brain (1990)	Tim Peters and Company, Inc., Gladstone, NJ 07934 (Distributed by Gerigy)	
Booklet	Substance Abuse Task Force White Paper (1988)	Brain Injury Association, Inc. (See below)	Review of the literature on substance abuse & head injury. Incl. statistics, and treatment options, strategies and extensive bibliography (\$7.50)
Booklet	Individual Psychotherapy with the Brain Injured Adult; (H. Carberry & B. Bund, 1986)	Brain Injury Association, Inc. (See below)	(\$1.00)
Booklet	Catastrophic Injury Cases: The Relationship of Traumatic Brain Injury and Spinal Cord Injury (J. A. Harp, J. S. Taylor & T. Elliot, 1989)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Behavioral and Psychosocial Sequelae of Pediatric Head Injury (T. McGuire & M. Rothenberg, 1986)	Brain Injury Association, Inc. (See below)	(\$3.50)
Booklet	Application of Neuropsychological Test Results to Interdisciplinary Cognitive Rehabilitation with Head Injured Adults (R. Tankle, 1988)	Brain Injury Association, Inc. (See below)	(\$2.00)
Booklet	Recovery and Cognitive Retraining after Craniocerebral Trauma (Pregatano, 1987)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Mild Brain Injury: Damage & Outcome (Wayne Alves, John Jane, 1985)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Adolescents with Closed Head Injuries: A Report of Initial Cognitive Deficits (Elisa Slater & Susan Bassett, 1988)	Brain Injury Association, Inc. (See below)	(\$2.50)
Booklet	Spouses of Persons Who Are Brain Injured: Overlooked Victims (E. Ziegler, 1987)	Brain Injury Association, Inc. (See below)	(\$1.00)
Booklet	Guide to Selecting and Monitoring Head Injury Rehabilitation Services (M. S. Reitter, 1992)	Brain Injury Association, Inc. (See below)	(\$2.00)
Booklet	Introduccion para los pacientes y sus familias, Los lesion oculta: Un trauma menor del la cabeza (The Unseen Injury: Minor Head Injury) (Thomas Kay, PhD)	Brain Injury Association, Inc. (See below)	One of few materials available in Spanish (\$1.00)
Booklet	Trauma Cerebral Un folleto para familias (Head Injury: A Booklet for Families) (Ruth & Terry Hutchinson and the Texas Head Injury Association)	Brain Injury Association, Inc. (See below)	One of few materials available in Spanish (\$1.00)

## Appendix (Continued)

Booklet	Questions to Ask at a Post-Acute Rehabilitation Program	Family Caregiver Alliance, 425 Bush Street, Suite 500, San Francisco, CA 94108, USA (415)434-3388; FAX: (415) 434-3508 e-mail: <a href="mailto:info@caregiver.org">info@caregiver.org</a> . Web: <a href="http://www.caregiver.org">http://www.caregiver.org</a>	
Booklet	Head Injury: A Guide for Families	HDI Publishers	Structured by problem w/ examples & Practical coping strategies (\$9.50 each).
Booklet	Family and brain injury: a selected Bibliography, (Kreutzer, 1990)	Natl. Information Clearinghouse (See below)	(\$4.00)
Booklet	Brain Injury and Alcohol (Robert L. Karol & Dorothy Halla-Poc, 1987)	Thomas & Company, Inc. Minneapolis, MN	Workbook designed to be used with a healthcare professional.
Manual	Brain Injury: Survivor and Caregiver Education Manual	Aspen Publishers, Inc., 200 Orchard Ridge Drive, Gaithersburg, MD 20878, USA 1-800-638-8437; (8:30-5:00 ET)	Loose pages designed to be copied for handouts. Has 30-day free review. <i>Supplements will be automatically sent unless you notify Aspen in writing</i> (\$169.00)
Manual	Family Articles about Traumatic Brain Injury	Therapy Skill Builders, Psychological Corporation, 1-800-228-0752 (FAX: 1-800-232-1223)	Includes handouts and resource information, 79 articles, 90 day money-back guarantee (\$89.00)
Misc.	Legal and Financial Issues for Families	Brain Injury Association, Inc. (See below)	Packet designed for families, that explores some of the legal and financial issues faced after TBI (\$10.00).
Pamphlet	Head Injury: 'What do we do now?'	MO Dept. of Health, Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services, Traumatic Head Injury Program, P.O. Box 570, Jefferson City, MO 65102-0570, USA 1-800451-0069	Head injury pilot project, contact information for a service coordinator.
Video	The Unseen Injury: Minor Head Injury (1986)	Brain Injury Association, Inc. (See below)	Designed specifically for viewing by family members. Single copies of the professional and family brochures accompany the tape. More brochures available (\$70.00 set).
Video	Surviving coma: The Journey Back (1987)	Brain Injury Association, Inc. (See below)	Documentary PBS originally aired. This is a short version with less emphasis on euthanasia (\$95.00)
Video	The Effect of Head Injury on The Family	Natl. Information Clearinghouse (See below)	19 minutes (\$35.00)
Video	Family Perspectives on Head Injuries	Natl. Information Clearinghouse (See below)	19 minutes (\$35.00)
Video	The Impact of Brain Injury on Relationships: Three Personal Stories	Natl. Information Clearinghouse (See below)	20 minutes (\$35.00)
Video	The Brain and Behavior	The Transitional Learning Community, 1528 Postoffice Street, Galveston, TX 77550, USA 1-800-TLC-GROW	Understanding the brain. Effects of head injury Are discussed in terms of behavior. (\$75-each, \$200-set of 3). Extra workbooks are available for \$5.00 each. Series sample tape-available for \$5.00
Video	The Maze	The Transitional Learning Community, 1528 Postoffice Street, Galveston, TX 77550, USA 1-800-TLC-GROW	Life after brain injury. Techniques for finding solutions to problems. (\$75-each, \$200-set of 3). Extra workbooks are available for \$5.00 each. Series sample tape-available for \$5.00
Video	Rehabilitation and you	The Transitional Learning Community, 1528 Postoffice Street, Galveston, TX 77550, USA 1-800-TLC-GROW	How to make rehabilitation work best for you. (\$75 each, \$200 for set of 3). Extra workbooks are available for \$5.00 each. Series sample tape is available for \$5.00
<b>Phase III</b>			
<b>End of Inpatient Hospitalization Through Community Re-entry</b>			
Article	Living With a Head Injury (Belinda Talbert, 1991)	<i>Cognitive Rehabilitation</i> (January, 1991), special issue, pp. 2-17.	A well-written, detailed story by a TBI survivor. The author discusses her surprise regarding how much her head injury impacted her life and the work and time required to readjust.

## Appendix (Continued)

Article	<i>Fact Sheets:</i> Hiring In-home Help How to Form a Support Group Caregiving Out-of-Home Care Options Advocacy Tips for Family Caregivers Work and Eldercare Assisted Living and Residential Care Facilities; --plus others	Family Caregiver Alliance, 425 Bush Street, Suite 500, San Francisco, CA 94108, USA (415)434-3388; FAX: (415) 434-3508 e-mail: <a href="mailto:info@caregiver.org">info@caregiver.org</a> . Web: <a href="http://www.caregiver.org">http://www.caregiver.org</a>	Good information with resources and hotlines on the back. May be somewhat more relevant for people who live in California. Families may want to order separately: Up to 5 titles: \$1.00; Up to 6 titles: \$2.00. Professionals may want to order complete set with binder: \$15.00. Many are available in Chinese and/or Spanish.
Article	Sex and the Brain-Injured Patient: Regaining Love, Pleasure, and Intimacy (L. Miller, 1994)	<i>The Journal of Cognitive Rehabilitation</i> May/June, 1994	This article is specific and covers many important areas. It is a good article for families and for therapists to read.
Book	Profiles in Caregiving: The Unexpected Career (Carol Aneshensel <i>et al.</i> , 1995)	Academic Press, 525 B Street, Suite 1900, San Diego, CA 92101-4495, USA 1-800-321-5068	A scholarly compendium of care giving with discussion of implications for public policy. My be less suitable & less interesting for lay audiences(\$39.95)
Book	Vocational Rehabilitation for Persons with Traumatic Brain Injury (Wehman and Kreutzer eds., 1990)	Aspen Publishers, Inc., 1900 Research Boulevard, Rockville, MD 20850, USA 1-800-321-5068	An edited book for health care professionals. (\$66.00)
Book	The 1997 Brain Injury Association National Directory of Brain Injury Rehabilitation Services	Brain Injury Association, Inc. (See below)	Desk reference for professionals listing brain Injury rehabilitation programs and individual Service providers nationwide, 393 pages (\$45.00).
Book	Planning for the Future: Providing a Meaningful Life for a Child with a Disability after Your Death.	Brain Injury Association, Inc. (See below)	(\$24.95).
Book	An Educational Challenge: Meeting the Needs of Students with Brain Injury (Dana S. DeBoskey, Ph.D.)	Brain Injury Association, Inc. (See below)	(\$14.50).
Book	Sexuality and the Person with Traumatic Brain Injury (E.R. Griffith, S. Lemberg, 1992)	Brain Injury Association, Inc. (See below)	(\$18.95).
Book	Living With Head Injury: A Guide for Families (R. Senelick & C. Ryan, 1991)	Brain Injury Association, Inc. (See below)	(\$8.95).
Book	National Directory of Head Injury Rehabilitation Services (1993)	Brain Injury Association, Inc. (See below)	(\$40.00).
Book	Why Did it Happen on a School Day? My Family's Experience with Brain Injury (1995).	Brain Injury Association, Inc. (See below)	(\$10.00).
Book	Integrating Community Resources	HDI Publishers (See below)	(\$16.50)
Book	The TBI Tool Kit	HDI Publishers (See below)	(\$24.95)
Book	Working After Brain Injury	HDI Publishers (See below)	(\$12.50)
Book	Respite Care: Principles, Programs and Policies (S. Cohen & R. Warren, 1989)	PRO-ED Publishers	This is out of print; may be available at a library.
Book	The Psychological and Social Aspects of Disability (R. P. Mannelli & A. E. Dell Orto, 1991)	Springer Co. Publishers	Publisher is out, may be available through library. May be reprinted in the future.
Book	Teaching the Head Injured What to Expect (1987)	Tampa General Rehabilitation Center, Tampa General Hospital, Tampa, Fl.	Outline format of information to review with Children and their teachers.
Book	The Head-Injured College Student (C. B. Holmes, 1988)	Charles C. Thomas Publishers, Springfield, IL. USA	This is out of print; may be available at a library.
Book	Parenting a Child with Traumatic Brain Injury (B/L/Jiges. 1990)	Charles C. Thomas Publishers, Springfield, IL. USA	Can be ordered through a book store; (\$29.95)
Booklet	Staying at Home: A Guide to Long-term Care and Housing (1996)	American Association of Retired Persons, 601 E. Street, NW, Washington, DC 20049, USA	Excellent publications with list of important issues to consider and state/national resources.

## Appendix (Continued)

Booklet	When Your Child Goes to School After an Injury (M. Lash, 1992)	Brain Injury Association, Inc. (See below)	(\$7.50)
Booklet	Susan's Dad: A Child's Story of Head Injury (L. E. Leaf, 1988)	Brain Injury Association, Inc. (See below)	
Booklet	Hearing Loss Following Head Injury (1984)	Brain Injury Association, Inc. (See below)	(\$1.00)
Booklet	Neuropsychology of Attention and Memory (M. J. Nissen, 1986)	Brain Injury Association, Inc. (See below)	(\$1.50)
Booklet	From One Family Member to Another (E. Burke, 1984)	Brain Injury Association, Inc. (See below)	A mother tells the story of her son's injury and recovery. Gives suggestions for structuring the home environment (\$1.00)
Booklet	Living with Chronic Pain (HDI Coping Series)	Brain Injury Association, Inc. (See below)	(\$9.50)
Booklet	When Your Child is Seriously Injured. The Emotional Impact on Families (M. Lash, 1990)	Brain Injury Association, Inc. (See below)	(\$4.50)
Booklet	Relationships Between Personality Disorders, Social Disturbances and Physical Disability Following TBI (Muriel Lezak, 1987)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Educational Concerns for the Traumatically Head Injured High School and College Student (R. Savage, 1987)	Brain Injury Association, Inc. (See below)	(\$4.00)
Booklet	Children with Disabilities: Understanding Sibling Issues (1988)	Brain Injury Association, Inc. (See below)	(\$2.50)
Booklet	Stress Management Following Head Injury: Strategies for Families and Caregivers (J. Falconer, 1984)	Brain Injury Association, Inc. (See below)	(\$1.00)
Booklet	Post-traumatic Headaches: Subtypes and Behavioral Treatments (Thomas Bennett, 1988)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Counseling Head Injured Patients: Guidelines for Community Mental Health Workers (M. Blanchard, 1984)	Brain Injury Association, Inc. (See below)	This is one of the few resources addressed to community mental health workers. (\$4.00)
Booklet	Brain Damage is a Family Affair (Lezak, 1988)	Brain Injury Association, Inc. (See below)	(\$3.00)
Booklet	Persisting Problems After Mild Head Injury: Review of the Post-Concussive Syndrome. L. Binder, 1986)	Brain Injury Association, Inc. (See below)	(\$5.00)
Booklet	The Head Injury Survivor on Campus: Issues and Resources (M. R. Ozer, HEATH Resource Center, 1988)	Brain Injury Association, Inc. (See below)	(\$42.00)
Booklet	Resource List of Organizations (C. Jensen for the NHIF, 1990)	Brain Injury Association, Inc. (See below)	List of organizations that assist persons with various special needs (\$4.00).
Booklet	Hiring Persons with A brain Injury: What to Expect	HDI Publishers (See below)	(\$9.50 each)
Booklet	Brain Injury: A Home Based Cognitive Rehabilitation Program	HDI Publishers (See below)	(\$9.50 each)
Booklet	Life After Brain Injury: Who Am I?	HDI Publishers (See below)	A well-structured book. Discusses specific problem areas. Includes good examples and gives list of practical coping strategies (\$9.50)
Booklet	Teaching Persons with a Brain Injury What to Expect	HDI Publishers (See below)	(\$9.50 each)
Booklet	Head Injury: Missouri Head Injury Guide for Survivors, Families and Caregivers	MO Health Dept., Injury Prevention Div, Head Injury Rehabilitation & Local Health Services, Traumatic Head Injury Program; P.O. Box 570, Jefferson City, MO 65102 USA; (573) 751-6246	This booklet is very good, particularly about legal issues and insurance. For people who live in Missouri.

## Appendix (Continued)

Booklet	Respite Resource Guide	National Council on the Aging, 409 3 <sup>rd</sup> St., SW, Suite 200, Washington, DC 20024, USA (202) 479-1200	Guide for professionals, includes information on the different types of programs available (\$8.00 plus \$2.00 shipping and handling).
Booklet	How to Hire Helpers: A Guide for Elders and Their Families	Task Force on Aging, Church Council Of Greater Seattle, 4759 15 <sup>th</sup> Street NW, Seattle, WA 98105, USA (206) 525-1213	How to advertise for, interview and hire home help. Requires prepay or P.O. 1-9 copies \$3.50 ea., 25-99 copies, \$2.50 ea., 100+ copies, \$1.50 ea.
annual	Controlling Your Frustration: A Class for Caregivers	Family Caregiver Alliance, 425 Bush Street, Suite 500, San Francisco, CA 94108, USA (415)434-3388 FAX: (415) 434-3508 e-mail: <a href="mailto:info@caregiver.org">info@caregiver.org</a> . Web: <a href="http://www.caregiver.org">http://www.caregiver.org</a>	Leader's manual (\$15.00), Participant's manual (\$10.00)
isc.	Life Care Planning forms	Brain Injury Association, Inc. (See below)	Come in sets of 17 forms to maintain records For all important issues in case-management and life care planning (1 set-\$5.00, 6 sets-\$20.00, 12 sets-\$35.00)
isc.	My Medical History and Medicine Record	University Physicians, Univ. Hospitals & Clinics, Rusk Rehabilitation Center (315) 882-4997	A pocket-sized, tri-fold card with medical record, Doctors' phone numbers & medication lists, for patients to carry with them. Similar record-keepers may be available through local hospitals and/or clinics.
mpHlet	Resources for Families and Caregivers of Brain-Impaired Adults	Family Caregiver Alliance, 425 Bush Street, Suite 500, San Francisco, CA 94108, USA (415)434-3388 FAX: (415) 434-3508 e-mail: <a href="mailto:info@caregiver.org">info@caregiver.org</a> . Web: <a href="http://www.caregiver.org">http://www.caregiver.org</a>	
mpHlet	How to Choose a Home Care Agency	The National Association for Home Care, 228 7 <sup>th</sup> St., SE., Suite 200, Washington, DC 20003-4306, USA (202) 547-7424	Gives a good short description of types of home care and questions to review when hiring home care help.
deo	A Fate Better Than Death (1981)	Brain Injury Association, Inc. (See below)	Features four young adults with traumatic brain injury. Focuses on support groups (\$70.00)
deo	'When Billy Broke his Head...and Other Tales of Wonder'	Independent Television Service, 190 E. 5 <sup>th</sup> St., St. Paul, MN 612/225-9035, Order from: Fanlight Productions, 47 Halifax, St., Boston, MA, 02130, USA 1-800-937-4113	From the perspective of an actual head-injured patient. Billy tells the story of rehabilitation & employment after MVA. 'Realistic' with a 'less than flattering view of Div. Of Vocational Rehabilitation' (\$245.00). Can be rented for \$50-\$100, depending on time-frame
deo	Returning to School Following TBI: A Guide for School Personnel	Natl. Information Clearinghouse (See below)	60 minutes (\$45.00)
deo	Ethical Issues for Families of TBI Persons	Natl. Information Clearinghouse (See below)	16 minutes(\$35.00)

Brain Injury Association, Inc., (formerly the National Head Injury Foundation), 1776 Massachusetts Ave., NW, Suite 100, Washington, DC 20036-1904, USA. Tel.: (202) 296-6443; FAX: (202)296-8850; or Family Help Line: 1-800444-6443

HDI Publishers, 10600 NW Freeway, Suite 202, P.O. Box 131401, Houston, TX 77219, USA.  
Tel.: 1-800-321-7037; FAX: (713) 956-2288.

National Information Clearinghouse, Rehabilitation Psychology and Neuropsychology Service, Department of Physical Medicine and Rehabilitation, P.O. Box 980542, Richmond, VA 23298-0542, USA.

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