

# BRAIN INJURY

vol. 18 issue 1

professional

Acquired  
Brain Injury Family  
**Interventions**



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ISSN 2375-5210

Brain Injury Professional is a membership benefit of the North American Brain Injury Society and the International Brain Injury Association



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Dr. Juan Carlos Arango-Lasprilla

## Editor Bio

**Dr. Juan Carlos Arango-Lasprilla** is currently an Ikerbasque Research Professor at BioCruces Vizcaya Health Research Institute affiliated with Cruces University Hospital in Bilbao, Spain. A neuropsychologist by training, his areas of expertise are neuropsychology, traumatic brain injury (TBI), and rehabilitation. Dr. Arango has received over 20 awards for his accomplishments in the area of brain injury and rehabilitation, including early career/emerging professional awards from the National Academy of Neuropsychology, the American Psychological Association's Division 22 Rehabilitation Psychology and Division 45 (Society for the Psychological Study of Ethnic Minority Issues), the International Brain Injury Association Young Investigator Award and Mid-Career awards such as the Arthur Benton Mid-Career award from the International Neuropsychological Society and The Mitchell Rosenthal Mid-Career award from the American Congress of Rehabilitation Medicine. He has published more than 300 articles and book chapters and edited 10 books.

## *from the* editor in chief

It is with great pleasure that I introduce this issue of *Brain Professional* focused on acquired brain injury family (ABI) interventions edited by my colleague, Dr. Kristine Kingsley. Since 2002, Dr. Kingsley has been involved in the delivery of clinical services (assessment and intervention) to adults with an acquired neurological disorder. She has been active in designing clinical protocols for individuals and families of individuals with diagnoses of traumatic brain injury (TBI), stroke, epilepsy, and mild cognitive impairment, Post-Concussion Syndrome, Parkinson's disease, Brain Neoplasms and Multiple Sclerosis. This issue brings together perspectives on acquired brain injury family interventions from Europe, US, and Latin America.

First, guest editor Kristine Kingsley describes the importance of describing family challenges and family members' reactions after a TBI and how, in holistic neuro-rehabilitation models, clinicians should understand early on the value of actively engaging family members in the "trainee's" recovery journey.

The feature article entitled, "Acquired Brain Injury - A Psychodynamic Approach to Family Systems" by Kristine Kingsley discusses how a family systems approach can play an important role in treating families of individuals with ABI. In the article, four case studies are presented. The second article entitled "The forgotten children - The aftermath of an acquired brain injury in the family" by Mia Moth and Anne Norup. In this article, the authors discuss the emotional consequences children living with a sibling or a parent with an acquired brain injury may experience, and the importance of incorporating their needs in the rehabilitation process.

In the third article entitled "Family problem-solving treatment: From research to clinical implementation" by Jamie Patronick, Sandra Glazer, and Shari L. Wade. This article offers an overview of Family Problem-Solving Therapy (FPST) and shows how online implementation of FPST has the potential to decrease barriers to care, particularly in populations that are traditionally underserved by behavioral healthcare.

The fourth article entitled "Traumatic Brain Injury in Latin America: Developing a Theoretical Model of Family-Based Care" by Juan Carlos Arango Lasprilla and Paul Perrin review research on the psychosocial impact of family caregiving for an individual with TBI in Latin America and propose a model in which an individual copes with and manages TBI symptoms in the context of his/her family system.

The fifth article entitled "Treatment Note: Collaboratively creating a values heat map online" by Andrew Bateman. The article highlights The Miller Values Card Sort task as a widely used and useful tool for evoking conversation about personal values. This sorting task can be used with family members to talk about 'shared values' and can help build a shared rehabilitation narrative.

The last article entitled "Encouraging Individuals with ABI and their Families of Diverse Background to Engage in the Rehabilitation Process: The value of Motivational Interviewing" by Kristine Kingsley presents a case study illustrating the importance of motivational interviewing techniques to encouraging the participation of family members in rehabilitation. This technique may increase family member attendance and rehabilitation adherence of the individual with ABI.

Our interview piece for this issue is with Angele M. Sander, a tenured associate professor in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine. The interview describes the research conducted using The Traumatic Brain Injury Model Systems (TBIMS) in the area of family members and family interventions. It concludes with recommendation for further research with area.

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**Kristine T. Kingsley, PsyD, ABP**

## *from the* **guest editor**

After a life changing brain injury or illness, it has been widely accepted that family members are directly and significantly affected by their loved ones' limitations. For many years and to a great extent, research on families after brain injury focused on describing family challenges and family members' reactions. On the other hand, in holistic neuro-rehabilitation models, clinicians understood early on the value of actively engaging family members in the "trainee's" recovery journey, so as to optimize the rehabilitation outcomes (Ben Yishay, 1974). Rosenthal and Young (1988) were among the first to publish an article on family intervention. In the article they described six types of intervention such as education, marital counseling or family therapy, sexual intimacy, family support groups, family networking and advocacy. The authors noted the importance of understanding and applying family system principles. The principles emphasize the need to understand the family as a system with individuals connected to and influenced by one another.

In this special edition, we have managed to attract a number of diverse topics on family and interventions. We hope you will enjoy reading a series of case conceptualizations using a psychodynamic approach based on some of the earlier works by researchers such as Laroi (2003), as much as you will savor a problem solving oriented intervention designed primarily with young adults in mind (J. Patronick, S. Glazer, S & Shari L. Wade).

Furthermore we are presenting an intriguing interview with Dr. Angelle M. Sander, who answers questions about the Traumatic Brain Injury Models System, and the work conducted specifically with families. This special edition also showcases the work of our international colleagues (Anne Norup & Mia Moth Woldffbrandt) for example, on the challenges siblings encounter while growing up in a family where a member is struggling with the sequelae of an injury; you can also read about an interesting intervention by Dr. Andrew Bateman based on the Miller et al. Values Card Sort task, a widely used and useful tool for evoking conversation about personal values. Traumatic brain injury (TBI) is a leading cause of death and disability around the world. In particular, Latin America has the highest incidence of TBI due to road traffic injuries and violence, and the second highest rates for short-term intracranial injury due to violence. An article written by Drs. Juan Carlos Arango Lasprilla and Paul Perrin on a theoretical based model on family care, speaks about engaging Latino families into treatment.

We end this special edition with yet another perspective on how to engage families; this time we develop how motivational interviewing can be introduced into a family system to address ambivalence and increase adherence to suggestions in a collaborative manner.

At this point I would like to express my sincerest gratitude for my colleagues who made this edition possible, as well as those of you who taught me so much over the years on the resilience of families in the face of adversity. I would also like to pay my respects to the tens of hundreds of families I met over the years, and to remember their love and resilience for one another.

### Editor Bio

Kristine Kingsley, PsyD, is a former Clinical Assistant Professor of Rehabilitation Medicine and Associate Coordinator of Internship Training at NYU Langone Health. She is currently in private practice and serves a clinical supervisor at Ferkauf Graduate School of Psychology. She is board certified in Rehabilitation Psychology.

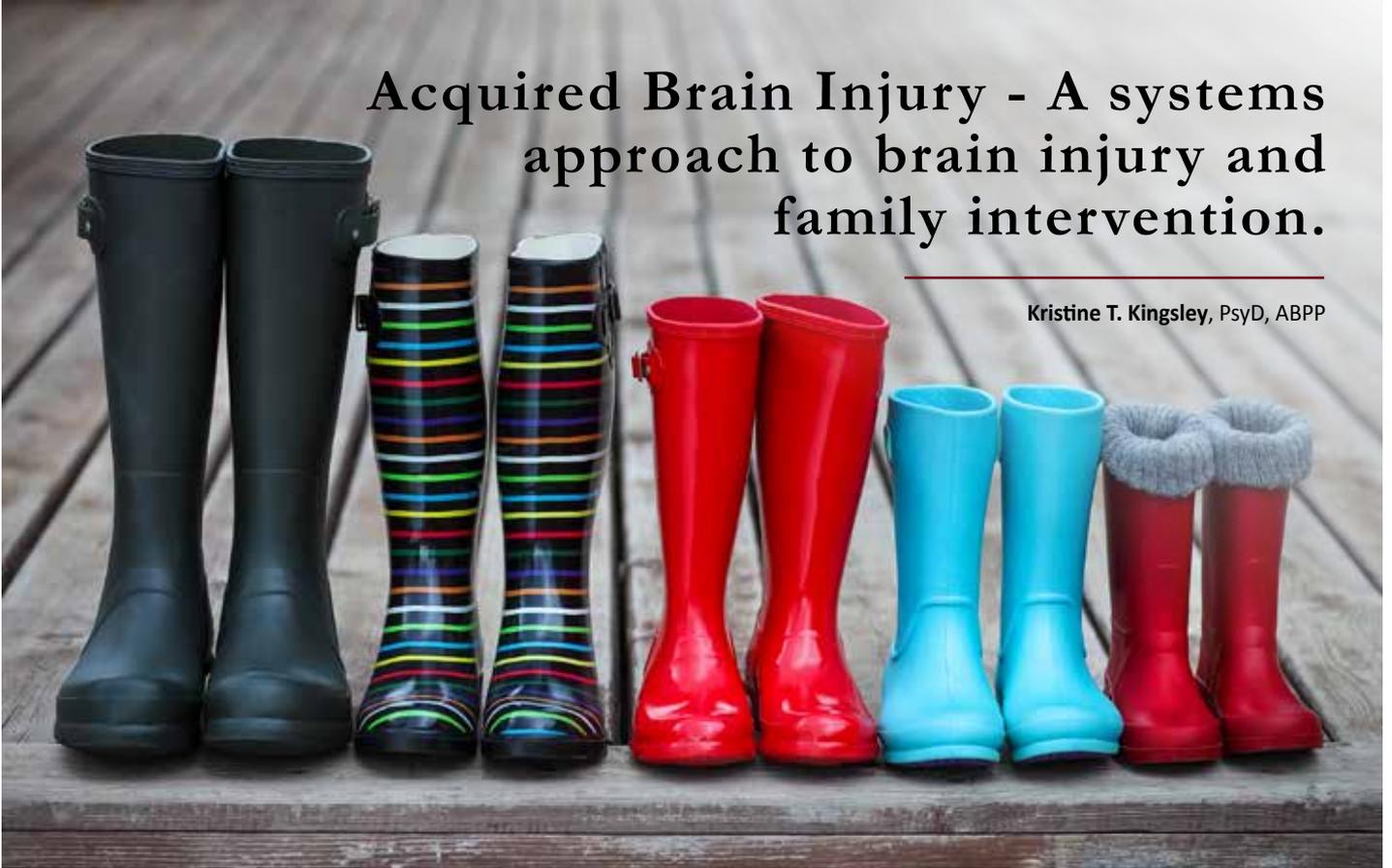
Since 2002, Dr. Kingsley has been involved in designing and delivering clinical services (assessment, intervention) to individuals with acquired neurological disorders. Her clients involve individuals with diagnoses of traumatic brain injury, stroke, epilepsy, and mild cognitive impairment, Post-Concussion Syndrome, Parkinson's disease, Brain Neoplasms and Multiple Sclerosis. Dr. Kingsley has presented and published both nationally and internationally on how to provide holistic neuro-rehabilitation services, emphasizing family engagement and intervention using culturally competent models and practices. Additionally, she has taught and supervised hundreds of psychology residents on the intricacies of family assessment and treatment.

Dr. Kingsley is a faculty member of Cognitive Rehabilitation at the American Congress of Rehabilitation Medicine (ACRM's) and a co-author to their most recent systematic review (2009-2015), as well as one currently in progress. She recently contributed in the writing of ACRM's 2nd Edition "Cognitive Rehabilitation Manual and Textbook: Translating Evidence-Based Recommendations into Practice.

Dr. Kingsley is the Chair- Elect (2019-2021) of ACRMs International Interdisciplinary Special Interest Group, and is serving a four year term as the Editor and Communications Chair for the American Board of Professional Psychology.

# Acquired Brain Injury - A systems approach to brain injury and family intervention.

Kristine T. Kingsley, PsyD, ABPP



An (ABI) is an injury or illness of the brain may often cause changes in the cognitive and emotional functioning of the person who has sustained it, which in turn can generate significant distress among caregiver and other family members. The etiology of the ABI- be it a blow to the head, bleeding related to a vascular occurrence or tumor, reduced presence of oxygen and or a viral attack can cause may well destroy vital brain tissue. Common cognitive and emotional changes post ABI such as memory / attention deficits and reduced executive functions within the realm of emotional control, quality of interpersonal interactions as well as adjustment to disability issues may prohibit the individual from returning to previous levels of independence. Symptoms, which may vary depending on location and severity of the injury, have often been mistaken by family and friends as manifestations of willfulness or other personality traits on the part of the individual. Caregivers have reported disruption of normal family functioning following ABI including decreased communication, blurring of family roles, and decreased sharing or warmth and affection. These changes may be partially related to cognitive and behavioral impairments in the persons with ABI, but can also be related to changes in the family's schedules, income and lifestyle. This can result in family members working longer hours therefore having less time to interact with others. The distress can come from a change in dynamics of the members such as a primary breadwinner becoming dependent on his or her spouse for financial support (Wiat et al., 2016).

Regardless of the attribution made by families, financial stress due to limited income, increased medical and other expenses as well as changes in family roles and dynamics often ensue. Additionally, caregivers or family members (parent, spouse, and child) may experience feelings such as guilt, shame or even anger over a) the circumstances leading up to and surrounding a brain injury, b) stress related to cognitive and communication deficits individuals may present with. It is not uncommon for families to experience symptoms consistent with bereavement (Laroi, F, 2003).

Over three decades of empirical work leaves no doubt that families and caregivers experience significant distress after a loved one sustains a traumatic brain injury. Emotional distress, including depression and anxiety has been documented during the first year following injury, and as long as seven years post injury. While injury related impairments in the person with TBI often improve over time, caregivers are shown to sustain significant distress over time. This distress is manifested in several ways, as in seeking mental health services and or increasing use of alcohol, sedatives. One third of caregivers endorse elevated levels of distress pre-injury, which may make them especially vulnerable to poor adjustment following injury.

Undoubtedly, the need for education about injury related changes and how to manage them is critical; as is the need for caregivers to manage their own reactivity and emotional distress, with feelings of grief and loss. Involvement of family caregivers in the rehabilitation process can maximize the person with injury's benefit from rehabilitation and can help to ensure generalizability of what is learned in the rehabilitation setting to the everyday environment. Adequately meeting family caregivers' needs can also improve their own mental and physical health.

Many available interventions, tend to be education focused or supportive in nature, and tend to overlook a more "dynamic" approach to the issues at hand. In response to a psychotherapy based on the idea that the whole is greater than the sum of the parts, there has been a range of developments in cybernetics, communications, and psychodynamic psychotherapy which have formed the foundation and prompted the evolution of systemic theory and therapy. Cybernetics (Bateson, 1952) is the study of systems, be it electrical, social, physical, mechanical, biological or even psychological. A system is an entity composed of discrete parts which are connected in such a way that change in one part results in changes in other parts. A system is guided by circularity, equilibrium and homeostasis.

Families similarly can be seen as a system trying to maintain a homeostasis. The change in one family member as the result of an injury or illness will force the rest of the members to adapt and change also. Families are characterized by structures and rules – some of which are overt while others are covert. Families also have boundaries and present behavioral patterns which are repeated over and over again. In order for a clinician to better conceptualize the needs of a family- a needs assessment is only a first step. A family therapist will begin to appreciate the alliances and the coalitions (e.g., those between parents and children, spouses, or even siblings). Clinicians must understand the roles each member has – who is the breadwinner, the mediator, the healer, the matriarch, even the scapegoat. How firm are the boundaries formulating between members of the unit and even outside of the unit (Maitz, EA, Sachs, PR, 1995).

In the cases introduced below, we aspire to illustrate how family systems approach can play an important role in treating families of individuals with brain injury. In the "narratives" reviewed, we will not only demonstrate the permeability of family structures and problem orientation of its members to alleviate the impact of an ABI, but also the importance of re-establishing or re-distributing these roles in a flexible and adaptable manner. The purpose of the paper is to try and illustrate the pivotal role a systemic approach to family intervention can have, when treating individuals after ABI and their families. More specifically, clinical examples taken from rehabilitation practice (inpatient and outpatient), have been selected to showcase how family roles and responsibilities change after ABI and to present how these modified relations as a consequence of brain injury, can be re-established and redistributed anew. Lastly, a close collaboration between family therapy and brain injury specialist may be essential and the ideal interdisciplinary professional team of clinicians well versed in both brain injury rehabilitation and family therapy is emphasized.

## CASE I

**Description:** *Jack is a 63 year old man who sustained a stroke 18 months ago, with residual hemiparesis and expressive aphasia. Prior to his stroke, he was active, athletic (played tennis twice a week). He is the owner and managing director of a law firm and before his illness worked 60+ hours per week. Initially, he was very involved in his therapies, attended all his rehabilitation appointments and followed the home exercises assigned to him each time. However, as his progress began to slow down, he became more and more withdrawn and disengaged. He would barely leave his home and watched TV for hours. His eldest son, an attorney, is trying to keep the law firm afloat. However, the son's actions are often interpreted by Jack as meddling and his son really "trying to take over the business"; this in turn leads to tense exchanges between father and son. Jack's spouse is caught between showing support and encouragement toward her husband, while at the same time, wanting to recognize her son's efforts and dedication.*

**Intervention:** The therapist met with the family in order to help them redefine the father's role in the family. Jack was recommended and underwent a neuropsychological work-up, which showed mildly decreased memory function (verbal and visual), variable attention, and deficits in executive functioning (i.e., abstract reasoning, perseverations). These findings were consistent with some of the reports given to the neuropsychologist by both spouse and son, and it involved changes noticeable since the stroke. The therapist was able to provide a thorough feedback session with ample examples for the client and his loved ones to appreciate the changes in his current cognitive and emotional status.

Therapist also supported the notion of showing what were the current strengths and areas of challenge for the client (what he could still do post ABI). In this case, the therapist's role was to help Jack recognize that he had not made sufficient post-stroke changes in his expectations, especially regarding his practice. In this context, the therapist encouraged Jack to develop a written list of all of his roles and the associated responsibilities at the practice. When clearly written down and discussed with the therapist, the patient recognized the magnitude of his combined roles and the difficulty of trying to fulfil all of them while still in the process of recovery.

The therapist also met with Jack's son and wife and explained that their loved one had sustained a very significant injury and could no longer independently manage his practice. Following this, the therapist and the rest of the family went to work to redefine family roles and responsibilities. Efforts to discuss "enmeshment" and its impact among family members, and how it could prevent Jack from optimizing his actual potential in rehabilitation injury was essential – especially in view of Jack's reduced awareness.

**Outcome:** Jack agreed to have his practice sold and he retired from practicing law full time, although he remained active as a consultant on various local non-profit organizations. He felt more supported by his family and less intruded upon by their showing of care.

## CASE II

There is some evidence that parents adjust better than spouses however this finding is not consistent across the board. For example elderly parents with limited financial and energy resources may experience hardship in providing care to their adult children survivors of a traumatic brain injury. Similarly adult children may experience bitterness and resentment for finding themselves dependent once more to their parents. Conflicts between independence and dependence may be particularly stressful in these circumstances, as parents find themselves limiting their child's freedom and restrict their activities due to cognitive or behavioral impairments, e.g., "prohibiting" an adult child from driving, while they are still experiencing seizures.

**Description:** *Ann is a 27- year-old professional, who sustained a brain injury two years ago when she was hit by a car as a cyclist. She was hospitalized for several weeks due to her injuries (fractures) and was in an induced coma to address the brain swelling. Since her discharge from inpatient, Ann's journey and progress in rehabilitation have been "bumpy". She often starts therapies, eager to please her doctors and pacify her mother and step-father, only to quickly lose interest and show up sporadically to her appointments. She spends instead countless hours posting on social media, is currently unemployed, and has not dated since her TBI. At the onset of her recovery, friends were very supportive, but more recently contacts have become sporadic. A few months after her injury, Ann was "fired" from her job as an engineer due to "forgetfulness" and variable attention to detail, which caused a number of on the job serious errors. She was forced to move in with her parents due to financial but other "instrumental" needs as well. She engages in frequent arguments with them about boundaries, roles, and responsibilities. She states that both mom and stepdad never stopped seeing her as an immature person and take pleasure in treating her like a child. On the other hand, Ann's parents are exasperated with their daughter's anger, acting out behavior, and lack of accountability for not following up with medical recommendations and appointments. Ann's mom is feeling resentful that her daughter's behavior is causing her own marital strife.*

**Intervention:** When meeting with Ann, mother, and step-father, the therapist observed that the mother was the most active of the three participants. Ann would be withdrawn.

When asked a question by the therapist, she spoke in short statements, and seemed to be easily intimidated by mom's commentary. Furthermore, when step-dad attempted to say something, it would always be in support of his wife. Hence, the therapist observed that some of the problems Ann faced, had to do with previously established roles and patterns of alliances. In addition, Ann's cognitive difficulties (reduced concentration and verbal fluency) rendered her communication skills less effective. Therapist encouraged Ann's parents to be more aware of those difficulties and thus, to allow more time for their daughter to answer and or to comment on something. Mom was also encouraged to be less "involved" with her daughter's behaviors and allow more space for Ann's step-father to step in and be helpful. This ultimately helped to establish a stronger relationship between Ann and step-dad. The therapist at times allied with Ann, by listening carefully to what she had to say- allowing her an opportunity to be heard by others. This gave Ann the necessary confidence and support, which in turn provided the foundation for her increased sense of empowerment.

**Outcome:** Ann was able to find part-time work as an interior decorator and architect at a small, modest company. She was able to move out in with roommates, and is much more organized and attentive with her medical follow-ups.

### CASE III

Children of a parent who has sustained a brain injury, may also be negatively affected in a very direct way. They may experience sadness, anger or resentment for having one or both parents less "present" in their lives than before; anxious about the parent's and family's well-being; fear for their own safety and that of their parents and uncertainty about their future.

**Description:** *Sally and Harry, both in their 40s, have been married for 15 years and have an 11 year old son. Sally works as a paralegal. Harry was diagnosed with a brain neoplasm in 2010. He underwent surgery, but has had residual fatigue, reduced attention and weakness. Prior to his illness, he was working as an engineer for the metropolitan transit authority. Given his condition, he was forced to go on disability. He spends most of his time in the park, playing or coaching sports. He's an excellent coach to his son; the two spend hours together, frequently to the detriment of the child's homework. Harry almost never sets limits with his son, a point of contention between him and Sally. Their son's behavior has lately become problematic in school; he was suspended last month, for getting into a fist fight with another classmate. Sally is at her wits end. She feels she can no longer juggle it all: work, house, parenting etc. The couple has been having fights on a daily basis, which in turn lead to screaming matches.*

**Intervention:** During family sessions, it became quickly apparent that Harry (once medically stable), realized he could no longer provide for his son's material needs; instead he would become a "buddy" a "peer" to over-compensate. In addition, his wife contributed to the problem by failing to support him when he attempted to correct their son. Treatment intervention focused on strengthening the parental subsystem. Sessions were structured so that the parents were the principal discussants regarding disciplinary issues. The couple was encouraged to discuss their differences away from their son, and always support each other in front of the child-even when they disagreed.

By supporting generational boundaries, the therapist re-established the boundaries between parents and child in such a way as to allow parents to have a relationship together, to allow the survivor to relate to his child as a parent, and to allow the parents to make decisions about child-care together. Harry was recommended individual psychotherapy to address some of his own feelings of inadequacy and adjustment to disability issues.

**Outcome:** With more explicit and consistently implemented ground rules and other supports in place, Harry's son improved both academically and behaviorally (no more incidents in school).

### CASE IV

A clinician is not only asked to observe the current roles and behaviors, but may often have to delve into the past - in order to fully recognize and appreciate the context in which s/he will define and implement an intervention. Families are complex social systems that can only be understood through their relationships across many generations. In order to analyze these dynamics, Murray Bowen would often have families treated, construct a genogram. A genogram is nothing less than a mapping technique or family tree of pedigree chart which shows relationships between members of a family. Understanding the intergenerational dynamics, which pre-exist the brain injury, as well as history of trauma may provide a familial context in which current relations and stress may further impact the individual and his family.

In effect, family therapy may be comprised by a psycho-educationally oriented, and then a psychodynamic model capturing the following: a) share ideas and experiences regarding an acquired brain injury- with a mission to improve the understanding for each family member regarding the chronic nature of the condition, overcome misconceptions about the nature of the condition, and eventually build a family consensus; b) find the silver lining in the situation: shift focus from the negative to the positive aspects of the situation.; c) recognize the impact of thoughts on feelings; d) identify the "warning signs" which may indicate emotional escalation and then manage the emotions; e) increase the levels of effective communication; and f) understand the value and purpose of family boundaries and learn how to clarify them.

**Description:** *William is a 76 year old retired physician and married to Sandra for over 50 years. A year ago, he fell while cutting a tree on his property, and sustained a subdural hematoma. He is currently experiencing significant balance issues and forgetfulness. This family session is attended by his wife and two sons John (the mediator) and Barry (the scapegoat). "Absent" in this session is an eldest son, Larry; he died tragically in a drowning accident over thirty years ago. William was initially seen with his spouse for marital counseling. Sandra reports feeling overwhelmed by William's changes in his cognitive and behavioral status. She expresses concern over his forgetfulness as well as low initiation. She feels he is becoming depressed, and was recently alarmed by William's statement "I feel I would be better off dead". Initial treatment focuses on identifying the couple's needs, offering education to both parties about what to expect, and to help shift focus from negative to positive aspects of the situation. William's mood difficulties decrease and Sandra is reportedly feeling less resentful; they decide they would like to involve their two sons in the process so they request a number of family sessions. Sandra feels that their sons are also struggling with their own feelings about what happened, in addition to experiencing personal issues of their own.*

**Intervention:** Sandra begins the session by describing an argument that transpired on Mother's Day. Both sons are expected to join their parents for lunch. John, recently fractured a tibia, and walks with crutches.

Barry is asked to arrive at the parents' apartment earlier so as to help his brother with packages upstairs, but he is delayed. Sandra becomes upset and calls her youngest son, unreliable. In an attempt to explain things, the conflict worsens between mother and son, triggering William's mood. In turn, William wanting to show loyalty toward his wife, begins to berate Barry for his thoughtlessness. At this point, John pipes into the animated discussion and tells his mother to stop thinking negatively about everything and everyone. He adds that she would benefit from working through her negative outlook on life in her own individual therapy. At which, Sandra breaks down sobbing and states: "How could you expect me not to have a negative outlook in life; "look at how many losses (parent, child, and sibling) I have encountered in life." William becomes overwhelmed by Sandra's affective expression. He wants to console her, but his words are ineffective. The three of them (Sandra, John & Barry) are all eager to discuss the effect of the child's / brother's untimely death had on their lives. Having gained the preliminary understanding of the situation, the therapist carefully and sequentially takes the side of each member (while seeking to maintain the overall balance); the aim is to begin a genuine dialogue of mutual accountability to review the reliance on dysfunctional acting-out and to find the strengths and resources of this family. However, the therapist also makes a connection to a common thread of unresolved grief: the grief for the lost son / sibling more than forty years, but also the vulnerability and grief felt with respect to the elderly spouse / parent. Members of this family were all encouraged to verbalize how they feel about William's changes and challenges- even the fragmentation occurring vis a vis the old Self. The family is reminded of Virginia Satir's adage that all families have healthy intentions which get lost in unhealthy encounters (Nichols, MP, & Schwartz, RC, 2006). The therapist then subsequently works during the remainder of the visit with each family member to help each member convey their needs and desires in appropriate ways.

**Outcome:** Members of the family begin to verbalize feelings of vulnerability and loss Vis a Vis previous traumatic situations and current changes in William's level of independence. They begin to talk about their own existential anxiety and mortality. Both sons discuss ways they can be more supportive toward their mother Sandra, with caregiving responsibilities (instrumental and emotional).

**Epilogue:** When a person survives brain injury, there is a tremendous ensuing ripple effect on him or her and loved ones. One needs to appreciate that a family's situation may be not only difficult due to current circumstances alone: members worried about the future, heartbroken about the "loss" incurred by their beloved, and at the same time frustrated by the daily management of their well-being. Families however have a pre-morbid history and those problems reflect deeper issues within the entire family system across and top down. Understanding the intergenerational patterns may be essential in conceptualizing an effective treatment, as families respond to a crisis with both primary and secondary reactions. (Fowers, BJ & Richardson, FC, 1996). Overall, there are many benefits to the potential of a family systems approach when working with families of individuals with an acquired brain injury; therefore the need for a close collaboration between a neuropsychologist and a family systems trained professional may be essential. In fact moving forward, the value of a close collaboration between a neuropsychologist and a family therapist on a theoretical and a practical basis may be warranted.

In general, this paper has pointed to the potential of a family systems approach, but also to the clinical and therapeutic challenges that working with families of individuals with brain injury may present. The importance of a close collaboration between the family therapist and the brain injury professional is stressed. Furthermore, although there seems to be a lack of interface between neuropsychology and family therapy on a theoretical level, on a practical and clinical level there is room for collaboration between the two disciplines. Families of persons with brain injury provide both brain injury professionals and family therapists alike with an interesting, yet highly challenging client-group. Family therapists do not believe in isolated problems. The nature of work involved in brain injury rehabilitation makes for a perfect match within the realm of a systemic approach.

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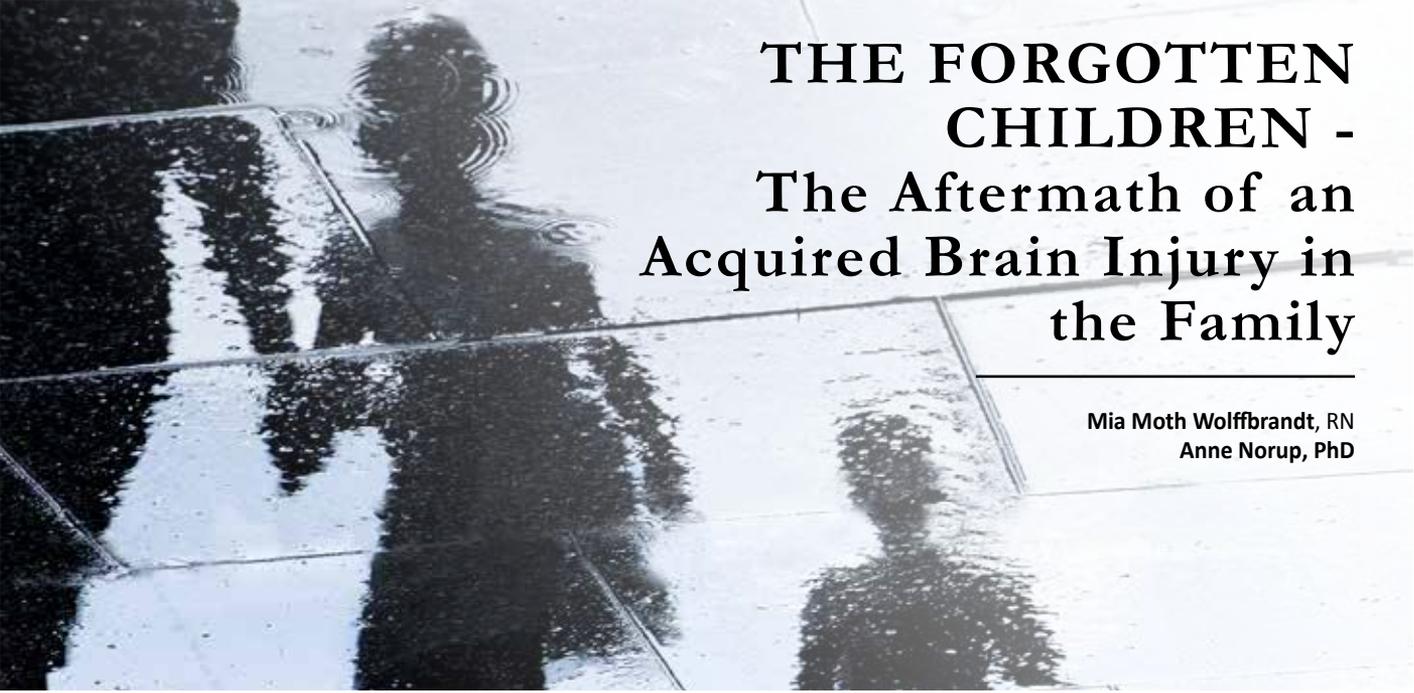
## Author Bio

**Kristine Kingsley, PsyD**, is a former Clinical Assistant Professor of Rehabilitation Medicine and Associate Coordinator of Internship Training at NYU Langone Health. She is currently in private practice and serves a clinical supervisor at Ferkauf Graduate School of Psychology. She is board certified in Rehabilitation Psychology.

Since 2002, Dr. Kingsley has been involved in designing and delivering clinical services (assessment, intervention) to individuals with acquired neurological disorders. Her clients involve individuals with diagnoses of traumatic brain injury, stroke, epilepsy, and mild cognitive impairment, Post-Concussion Syndrome, Parkinson's disease, Brain Neoplasms and Multiple Sclerosis. Dr. Kingsley has presented and published both nationally and internationally on how to provide holistic neuro-rehabilitation services, emphasizing family engagement and intervention using culturally competent models and practices. Additionally, she has taught and supervised hundreds of psychology residents on the intricacies of family assessment and treatment.

Dr. Kingsley is a faculty member of Cognitive Rehabilitation at the American Congress of Rehabilitation Medicine (ACRM's) and a co-author to their most recent systematic review (2009-2015), as well as one currently in progress. She recently contributed in the writing of ACRM's 2nd Edition "Cognitive Rehabilitation Manual and Textbook: Translating Evidence-Based Recommendations into Practice.

Dr. Kingsley is the Chair- Elect (2019-2021) of ACRMs International Interdisciplinary Special Interest Group, and is serving a four year term as the Editor and Communications Chair for the American Board of Professional Psychology.



# THE FORGOTTEN CHILDREN - The Aftermath of an Acquired Brain Injury in the Family

Mia Moth Wolffbrandt, RN  
Anne Norup, PhD

## An acquired brain injury (ABI) affects the entire family

An ABI can be caused by a trauma, stroke, infection or other diffuse brain injuries, all of which occur unexpectedly and without any warning. After a period of inpatient treatment, the survivor will frequently continue onto a long-term rehabilitation process. While during this time, the survivor may experience a gradual improvement, the injury will often have long-term sequelae combining physical, cognitive, emotional / behavioural, and social difficulties<sup>1</sup>. Additionally, an ABI does not only have an impact on the survivor, but will also affect his/ her family; members of that unit will have to adapt to a novel life situation in which family dynamics involving roles, boundaries and communication, often will be changed<sup>2</sup>. The impact an ABI has on the entire family, has been explored in several studies in which families living with brain injury report high levels of distress, significant symptoms of depression and anxiety, decreased quality of life as well as reduced family functioning up to five years post-injury<sup>3-5</sup>. Furthermore, a recent register-based study investigated the socioeconomic consequences after a traumatic brain injury and found significantly increased healthcare costs, higher risk of job loss as well as a significant increased risk of divorce during the first three years post-injury<sup>6</sup>. Thus, it is now well-established that the injury affects not only the survivor but the family, hence it is of utmost importance that approaches in the rehabilitation process include the entire family.

## Children facing the effects of a family member surviving brain injury

When working with the entire family in neurorehabilitation, particular attention towards children is needed. Children at any age are vulnerable, and are dependent on their family of origin to thrive and develop. Furthermore, children are still undergoing crucial biological, emotional and psychological changes which occur during child development, rendering them more vulnerable and dependent on a functional care system, in order to actualize their potential and attain independence.

Thus, when a close family member, such as a parent or a sibling sustains an ABI, the whole family system changes within minutes; this creates a very stressful situation, and the children immediately become at risk of emotional distress. A child is not prepared for, nor does he or she have any prior experiences dealing with such a "crisis". In the long run the child may present a high risk for failure to thrive, unable to achieve certain development milestones<sup>7</sup>. In some cases, the children may even have witnessed the injury or onset<sup>7,8</sup>. In the research literature, as well as in clinical practice, these children have been identified as a neglected group that we as professionals need to be concerned about.

This short clinical paper will outline research concerning the consequences and emotional effects on these "forgotten children", while offering tips for clinical practice.

## Detected effects on the forgotten children

Research has revealed how children living with a sibling or a parent with an acquired brain injury have symptoms of post-traumatic distress<sup>9</sup>, deal with significantly reduced self-esteem<sup>10</sup> and report internalizing symptoms such as sadness and worry<sup>11,12</sup>. The importance of helping and supporting this vulnerable group was emphasized by a Finnish registry-based birth cohort, where children of a parent presenting with at least a mild to moderate brain injury diagnosis, were found to be at significantly more risk of: a) having contact with psychiatric services during childhood and adolescence<sup>13</sup>, and b) showing an increased risk of being diagnosed with a psychiatric illness themselves<sup>14</sup>. The study suggests that the children's mental health of ABI survivors is highly at stake, and that their well-being relies heavily on adult support to minimize the risk of such serious consequences from becoming their reality.

In addition, within qualitative research, children's experiences of adult ABI survivors have been examined, in which the focus was the relational / interpersonal changes that occur when a sibling or a parent sustains a brain injury.

Tyerman et al. has described how *children of a sibling* with an acquired brain injury struggle with the feeling of “living their worst nightmare”, experiences of disconnectedness in family relationships, and that the togetherness with their brother or sister has been affected<sup>15</sup>. In other studies, it has been described how the fear of losing the close sibling relationship is in marked contrast with the possibility of building a new and even closer relationship<sup>16</sup>.<sup>17</sup>. The process which siblings go through has been well illustrated by Bursnal et al. in which the theme “regaining balance” describes how siblings struggle in the emotional turmoil of change with a sense that security, predictability and control are threatened<sup>18</sup>. In the hospital setting, the healthy sibling often feels ignored by health care professionals, and at the same time they may feel overlooked by the parents, from whom they seek recognition and validation of their identity and worth<sup>17</sup>.

Kieffer-Kristensen & Johansen<sup>8</sup> have focused on *children living with a parent* and have described how children often suffer a “hidden loss” as the parent is physically present, but psychologically absent. This can be difficult for the individual child to talk about, as children tend to suppress or hide their feelings to protect their parents. Nevertheless, the child is daily confronted with the parents’ dysfunctions, where outbursts of anger, memory difficulties, fatigue and apathy can be symptoms that children have the most difficult time coping with<sup>8,19</sup>. The change in the relationship to the injured parent means that children often assume an increased responsibility and must act more adult and grown-up than what they feel they are capable of. Consequently, there is a role reversal, where the child assists the parent even though the child feels that it should be the other way around<sup>8</sup>.

In addition, the child often seeks attention from the other “healthy” parent, who may “dismiss” them, as they themselves are overwhelmed, stressed and busy taking care of the injured. Overall, these children experience a double loss when the relationship with the healthy parent changes<sup>8,19,20</sup>.

In sum, existing research literature clearly highlights the children’s vulnerability and the serious consequences they encounter, when a sibling or a parent sustains an acquired brain injury. The findings emphasize the necessity of paying attention to the needs of these children, and that it is of utmost importance to support them throughout the hospitalization period, the outpatient rehabilitation, as well as the years to come. However, to our knowledge, no evidence-based initiatives or interventions specifically directed towards these forgotten children exists or have been tested so far.

## Moving forward

Research is required to gain a greater understanding of the children’s needs and to incorporate their needs in the rehabilitation process. Optimally, this knowledge must be gained from the children themselves and from their close family. Therefore, qualitative studies are needed aiming to explore the forgotten children’s needs and to explore how they could be supported throughout different phases of the rehabilitation period, i.e. in the hospitalization, the following rehabilitation and years to come. Consequently, initiatives or interventions towards these forgotten children needs to be developed systematically. Meanwhile, health care professionals must be aware of the forgotten children keeping in mind the seriousness of the matter.

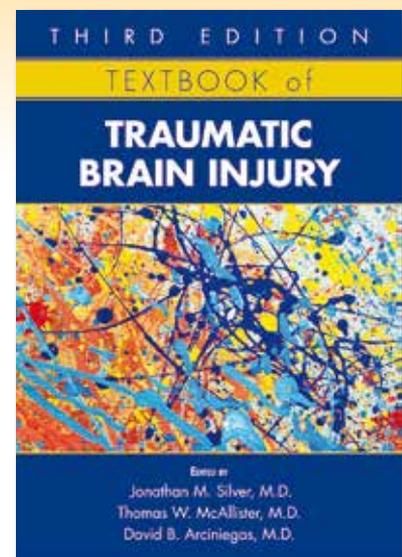
## Textbook of Traumatic Brain Injury, Third Edition

*Edited by Jonathan M. Silver, M.D.,  
Thomas W. McAllister, M.D., and David B. Arciniegas, M.D.*

Despite the increased public awareness of traumatic brain injury (TBI), the complexities of the neuropsychiatric, neuropsychological, neurological, and other physical consequences of TBI of all severities across the lifespan remain incompletely understood by patients, their families, healthcare providers, and the media.

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## A few take-home messages for both professionals and families

**Accept the need for help** – all families living with the consequences of brain injury will experience distress, and help is needed and required in many cases; but families may often be reluctant in seeking help. Unfortunately, persistent distress will affect the children in the family.

**Talking to a professional** – many children have questions and are intellectually curious but are afraid to approach the healthy parent. In many situations talking to a health professional who is knowledgeable of brain injury and its aftermath consequences can be helpful – information in age-adjusted language with specific examples from everyday life with a brain injury survivor.

**Talking to other adults** – it is very important that the child has an adult outside the immediate family (teacher, family member etc.), who knows about the situation and can talk freely to them. This gives permission to children to broach “forbidden” or “taboo” questions, while at the same time allow them to show feelings of sadness or distress that the child might try to hide in front of the healthy parent.

**Recharging batteries** – the child needs to be able to do ‘normal’ and regular childhood things which are not associated with the home situation, and be allowed to engage in playing and other leisure activities.

**Attention and affection** – children need love and affection in order to develop and thrive. It is important that parents keep providing it despite the distressing situation. Acknowledging and caring for the need of the individual child is key.

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## Author Bios

**Mia Moth Wolffbrandt**, RN, Master of Health Science, has more than 20-years of experience as a clinical nurse within hospital-based neurorehabilitation of patients with severe acquired brain injuries. In this field, she has been working with both injured children, adolescents and adults. As an active professional in the interdisciplinary teamwork, she finds a strong collaboration as a critical key for the patients and their relative's rehabilitation. One of her focus areas in both the mono- and interdisciplinary teamwork, has been to optimize the treatment and rehabilitation of patients, who displays agitated behavior. As the patient's closest relatives also are critical collaboration partners, one of her highly prioritized areas in clinical practice has been focusing on the needs of the entire family in the rehabilitation process. In 2017, she completed her Master of Health Science from Copenhagen University with her thesis “Nursing opportunities and potentials in the highly specialized neurorehabilitation of patients with severe acquired brain injuries - from the perspective of nurses and patient's relatives”.

Currently, Mia is working as a research nurse on an ongoing randomized controlled trial investigating the effects of a manualized intervention program to families living with the consequences of TBI or spinal cord injury, with Anne Norup as principle investigator. Through this position her primary tasks consist of eligibility review, recruitment of families to the project and data handling.

**Anne Norup**, PhD, is an associate professor at the University of Southern Denmark and is head of Neurorehabilitation Research and Knowledge Centre, Rigshospitalet, Copenhagen. Anne Norup has worked as a clinician and researcher within neurorehabilitation for many years. Most of her published research has examined the impact of traumatic brain injury on the family, needs and burdens in the family after brain injury, psychosocial effects of TBI in adolescents and current and ongoing research interest is fatigue after brain injury and exploring possible interventions. Currently, Anne is the principle investigator of a research study investigating the effects of a manualized intervention program to families living with the consequences of TBI or spinal cord injury. Recently, Anne Norup has been appointed as the head of a newly founded Neurorehabilitation Research and Knowledge Centre, Rigshospitalet, where she will be working dedicated to improving the cross-sectoral neurorehabilitation for patients with injury to the brain or spinal cord.

# events

## 2021

### September

16: *EBIS Conference*, September 16, Brussels, Belgium. For more information, visit [ebissociety.org](http://ebissociety.org).

26 – 29: *ACRM 98th Conference*, September 26 – 29, Virtual. For more information, visit [www.acrm.org](http://www.acrm.org).

### November

11 – 14: *AAPM&R 2021 Annual Assembly*, November 11 – 14, Nashville and online. For more information, visit [www.aapmr.org](http://www.aapmr.org).

### December

9 -10: *Inaugural Virtual Conference on Disorders of Consciousness*, December 9-10, Virtual format. For more information, visit [www.internationalbrain.org](http://www.internationalbrain.org).

## 2022

### March

31 – 3: *AOTA Annual Conference & Expo 2022*, March 31 – April 2, 2022, San Antonio, Texas. For more information, visit [www.aota.org](http://www.aota.org).

### September

21-24: *Fourth International Conference on Paediatric Brain Injury*, September 21 – 24, New York, New York. For more information, visit [www.internationalbrain.org](http://www.internationalbrain.org).

21-24: *2022 NABIS Conference on Brain Injury*, September 21 – 24, New York, New York. For more information, visit [www.internationalbrain.org](http://www.internationalbrain.org).

21-24: *2022 Conference on Medical & Legal Issues in Brain Injury*, September 21 – 24, New York, New York. For more information, visit [www.internationalbrain.org](http://www.internationalbrain.org).

## 2023

### March

29 – 1: *14th IBIA World Congress on Brain Injury*, March 29 – April 1, 2023, Convention Centre in Dublin, Ireland. For more information, visit [www.internationalbrain.org](http://www.internationalbrain.org).

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# Family Problem-Solving Treatment: From Research to Clinical Implementation

Jamie Patronick, BS • Sandra Glazer, BA • Shari L. Wade, PhD

## The Importance of the Family

The family environment plays a vital role in a child's recovery from acquired brain injury (ABI). Childhood ABI is associated with increased family burden, parental distress, and conflict and dysfunction.<sup>1,2</sup> Caregivers commonly experience burden associated with stressors such as managing their child's medical needs and behavioral changes, and between 17-40 percent of parents report clinically significant distress and depressive symptoms.<sup>3</sup> Additionally, as the family unit adapts to home life post-ABI, family members must shift roles and accommodate new demands. Differences in how parents cope with their child's injury may lead to marital strain, conflicting parenting styles, and differing perceptions of the child's abilities.<sup>4,5</sup> Siblings are also impacted greatly, as parents spend more time attending to the injured child's needs and the relationship dynamic between children changes.<sup>6</sup> These effects have been observed to persist for years post-injury and tend to worsen during times of increased stress, particularly during transitional periods of life such as adolescence and young adulthood.<sup>2</sup>

Developmental psychology research has established a reciprocal relationship between parenting behaviors and childhood functioning, and this association is amplified in the context of ABI recovery. A child's behavior and functioning following their ABI influences parenting behaviors, parental distress, and overall family functioning, and these parent and family factors, in turn, influence the child's recovery and long-term functioning.<sup>7,8</sup> Therefore, interventions involving parents or the whole family offer numerous avenues for improving the child's psychosocial functioning. Targeting parent-child interactions, problem solving, communication skills, and positive discipline in a family context can improve parent and child functioning and the quality of the interaction between them.

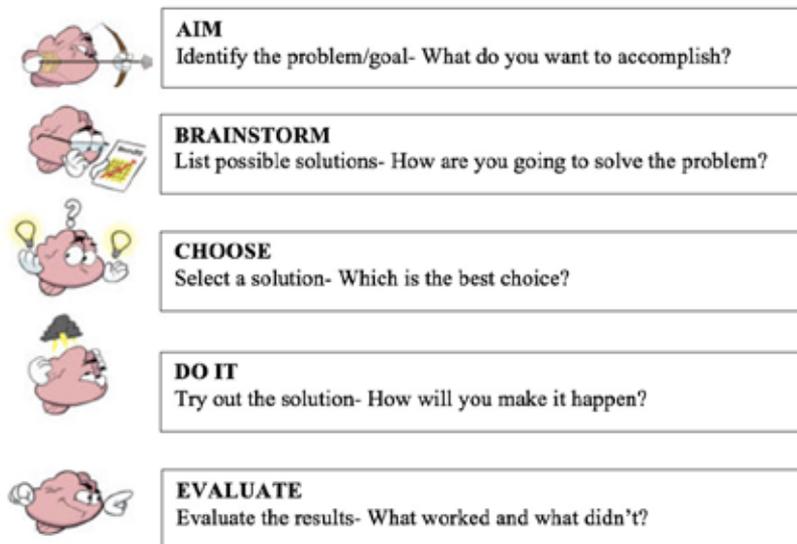
## What is Family Problem-Solving Therapy?

Given the critical influence of the family environment on outcomes following ABI, family-centered intervention models, such as Family Problem-Solving Therapy (FPST), have become increasingly popular, particularly for adolescent and young adult survivors. FPST combines components of problem-solving training and family therapy to support collaborative problem-solving around real-world issues. FPST has been implemented both face-to-face and online, with online delivery consisting of self-guided modules, usually combined with synchronous videoconferencing sessions with a trained therapist. This telehealth format was implemented after initial face-to-face trials were limited by low participation rates and nonadherence,<sup>9</sup> but as discussed later in this article, recent trials have compared treatment effectiveness across face-to-face and online modalities.

Telehealth interventions mediate practical barriers to care such as transportation, time, and limited provider access in rural areas, and can also reduce the stigma associated with mental health treatment. As telehealth has become ubiquitous in recent months due to the COVID-19 pandemic, streamlining and implementing family interventions in this format is even more relevant. COVID-19 has also highlighted disparities in access to reliable devices and internet connectivity, which are important considerations for the widespread implementation of telehealth interventions.

The initial sessions of FPST involve cognitive reframing, wherein the child and family are encouraged to view their problems as challenges that can be conquered with the proper problem-solving skills. Next, families are trained in the five-step problem-solving framework, model by Nezu and colleagues (FIGURE 1).<sup>10</sup>

FIGURE 1: Sample images from the online FPST module introducing the 5-step problem solving framework.



Based on the model by Nezu and colleagues.<sup>10</sup>

Once the family has begun applying the problem-solving framework to problems or “Aims” in their own lives, additional psychoeducation modules address other challenges related to brain injury recovery, including difficulties that the adolescent may face with executive functioning, emotion regulation, communication, and social relationships. Further supplemental modules are provided to families as needed, including information about seizure management, sibling concerns, marital communication, and family coping. There is also a supplemental module exclusively for siblings that addresses coping with common feelings of guilt, embarrassment, loneliness, and anger. See Table 1 for a summary of typical FPST session content, adapted from an intervention for teens with TBI, called Teen Online Problem-Solving (TOPS). Overall, the treatment focuses on applying skills to the adolescent’s and family’s real-world problems and emphasizes continual practice of these skills. Clinical trials of online FPST thus far have shown promise in improving social competence, decreasing internalizing and externalizing behavior problems, improving family functioning, and decreasing family distress.<sup>11</sup>

TABLE 1: TOPS Sessions

Session	Title	
Session 1	Getting started	
Session 2	Staying positive	
Session 3	Problem solving	
Session 4	Cognitive deficits	
Session 5-6	Behavioral effects	
Session 7	Communication	
Session 8	Social problem solving	
Session 9	Handling crises	
Supplementary sessions (up to 6)	Stress management	Taking care of yourself
	Marital communication	Memory difficulties
	Sibling concerns	Planning for after high school
	Pain management	Talking with your adolescent
	Session 14	Planning for the future and review

Adapted from Wade SL, LeBlond EI, Shultz EL. Family-based Interventions. In: Locascio G, Slomine BS, eds. Cognitive Rehabilitation for Pediatric Neurological Disorders. Cambridge: Cambridge University Press; 2018:100-121. doi:10.1017/9781316855683.007

## Effectiveness and Evidence-based Guidelines

Recent evidence exploring the comparative effectiveness of face-to-face vs. online FPST suggests that delivery matters. In trials comparing face-to-face with both self-guided and therapist-guided online FPST, families assigned to therapist-guided treatment displayed significant reductions in parental depression immediately following treatment, while parents in the self-guided online group did not decline in depressive symptoms.<sup>12</sup> Additionally, both online groups demonstrated improvements in parent-reported adolescent quality of life and cognitive symptoms.<sup>13</sup> These findings suggest that not all treatment modalities are created equal. Examination of the previous online FPST studies together underscores the importance of having a therapist who can engage families with fewer resources. Specifically, families with lower SES reported the greatest improvements in their child’s social competence and behavior.<sup>14</sup>

Additionally, differences in parental depression favoring therapist-guided treatment were more pronounced in families of lower SES.<sup>12</sup> Further analyses revealed that therapist-guided online treatment is superior to face-to-face treatment in improving cognitive symptoms specifically in single-parent families. Lower SES families with fewer resources and more complex challenges may require the skill-based training and support that the therapist-guided intervention provides, over and above access to online information.

A working group affiliated with the American Congress of Rehabilitation Medicine systematically reviewed various cognitive rehabilitation, emotional, and family treatment studies for children with ABI and created evidence-based guidelines for clinical practice.<sup>15</sup> Laatsch and colleagues compared effectiveness across domains such as executive functioning, emotional control, family/caregiver functioning, and use of technology. The meta-analysis suggests that FPST should be a practice standard in emotional control for older adolescents following TBI. FPST was also determined to be a practice standard for improving executive functioning strategies in older children, including problem-solving, communication, and self-regulation. Lastly, FPST is considered to be a practice standard for family-centered interventions for both children and adolescents following ABI. Within the authors' review of technological standards for online self-guided interventions, FPST was also identified as a practice guideline for children and adolescents following TBI.

## Who benefits?

Although FPST has been previously studied in TBI samples, it is well-suited to support behavioral recovery from acquired brain injuries that occur from a variety of sources, such as infection, brain tumor, or stroke.<sup>16,17</sup> The neurocognitive sequelae that result from ABIs from various causes share deficits of memory, attention, executive functioning, self-regulation, and social competence.<sup>18</sup> These are all consequences that are addressed in the FPST program and the problem-solving heuristic itself can be flexibly employed to address a range of challenges. Online FPST is currently being adapted to address ABI more broadly with other neurological conditions using a transdiagnostic, rather than diagnosis-specific, approach. This adapted program will address common components of neurological insult across diagnoses (such as cognitive functioning, social competence, and family impact) as well as provide supplementary modules tailored to problems experienced by the specific diagnoses (such as medication adherence for adolescents with epilepsy).

Though FPST has been deemed a standard of care for adolescents, the evidence base for children younger than 11 recovering from ABI suggests that problem-solving and other cognitive behavioral approaches are not effective in addressing their behavioral problems.<sup>19-21</sup> Instead, recent approaches have focused on modifying parenting skills based on evidence that harsh or permissive parenting directly contributes to behavioral problems post-ABI.<sup>22</sup> This framework has shown significant increases in positive parenting behaviors (such as giving praise) and decreases in negative parenting behaviors (such as asking questions during child-directed interactions).<sup>23</sup> One of these parent-training programs, the Internet-based Interacting Together Everyday: Recovery After Childhood TBI, or I-INterACT, intervention shares common features of bolstering warm, responsive parent-child relationships and delivering consistent, nonpunitive discipline.<sup>24-26</sup> Another intervention that has seen similar success with reducing dysfunctional parenting practices is the Signposts intervention.<sup>27</sup> This cognitive behavioral approach teaches strategies such as labeled praise, effective instructions, behavior support plans, and problem-solving within the family and

has found significant treatment effects in dysfunctional parenting practices, frequency of disruptive behavior at home, and cognitive and emotional regulation.<sup>28,29</sup>

In the clinical implementation of FPST, patient and family comfort with online treatment modalities should also be taken into consideration. In earlier FPST trials, some parent participants expressed discomfort with telehealth due to an unfamiliarity with technology, privacy concerns, and a perception of loss of connectedness and rapport with the therapist.<sup>20</sup> A recent exploration into preferences for treatment delivery found that both parents and adolescents reported pre-treatment that self-guided online therapy would be the most convenient, and parents were less likely than adolescents to think face-to-face treatment would be most beneficial. Importantly, adolescent preferences were significantly related to attrition, such that adolescents assigned to a non-preferred treatment delivery had higher dropout rates. However, overall, online treatments were perceived favorably by both parents and adolescents, and the family's pre-treatment preferences did not correspond with post-treatment satisfaction or benefit.<sup>30</sup> This suggests that a positive experience in therapy influences a family's ultimate satisfaction with the treatment, and that even in cases when providing families with their preferred delivery is not feasible, families can still benefit and feel satisfied with the care received. This consideration may be especially important for families with lower resources, who likely experience the most benefit from therapist-guided treatment but have the fewest options for delivery type due to inequities in quality of insurance coverage and access to care.

Further work has begun to characterize barriers to care following ABI specifically in the Appalachian community, as well as differences in barriers faced by rural and urban families. Identifying how to best facilitate and distribute FPST to the families that will benefit most and mitigating impediments to successful treatment will be vital for the implementation phase.

## Clinical Implementation

At present, FPST continues to be evaluated in clinical populations through an implementation award from the Patient-Centered Outcomes Research Institute (PCORI). Currently there are fifteen partnering children's hospitals across North America (see FIGURE 2). In addition to staff psychologists and psychology trainees, speech language pathologists (SLPs) and clinical social workers have been trained to deliver the intervention and the manual has been modified to address differences in expertise and scope of practice between different types of professionals (e.g., SLPs versus psychologists).

We will implement FPST as part of regular clinical care for ABI and evaluate its effectiveness in reducing behavioral concerns and improving quality of life. Our overarching goal is to make sure that all children with ABI are screened for behavioral health concerns and referred for treatment when needed. Toward this end, we will work to increase the uptake and capacity to deliver FPST across our 15 partnering sites. In addition, Spanish translations of FPST are being developed to provide care to a broader demographic of patients and families both in North America and worldwide. The implementation of online FPST has the potential to decrease barriers to care, particularly in populations that are traditionally underserved by behavioral healthcare. Since families can also benefit from completing the program independently, without therapist involvement, it is possible to provide the FPST program to patients who might not otherwise be able to access care due to lack of providers in their area or lack of insurance coverage.



FIGURE 2: Map of partnering children’s hospitals: University of California-San Francisco Medical Center (San Francisco, CA); Children’s Hospital of Colorado (Aurora, CO); St. Luke’s Hospital (Boise, ID); Kennedy Krieger Institute (Baltimore, MD); Mott Children’s Hospital-University of Michigan (Ann Arbor, MI); Cincinnati Children’s Hospital Medical Center (Cincinnati, OH); Nationwide Children’s Hospital (Columbus, OH); Holland Bloorview Kids Rehabilitation Hospital (East York, ON, Canada); Children’s Hospital of Philadelphia (Philadelphia, PA); UPMC Children’s Hospital of Pittsburgh (Pittsburgh, PA); Dell Children’s Medical Center of Central Texas (Austin, TX); Texas Children’s Hospital (Houston, TX); TIRR Memorial Hermann (Houston, TX); Primary Children’s Hospital (Salt Lake City, UT); Seattle Children’s Hospital (Seattle, WA)



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The family environment plays a vital role in a child's recovery from acquired brain injury (ABI). Caregivers commonly experience burden associated with stressors such as managing their child's medical needs and behavioral changes, and between 17-40 percent of parents report clinically significant distress and depressive symptoms.

## Acknowledgements

We would like to thank the patients and families who participated in all trials of FPST. Research reported in this article was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (PCS-1409-24099). The statements in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

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## Author Bios

**Jamie Patronick, BS**, is a graduate student in the Clinical Psychology doctoral program at the University of Cincinnati. She previously served as coordinator for a grant-funded study investigating the biological, environmental, and therapeutic factors influencing neurobehavioral recovery from TBI. Her current research interests include developing evidence-based family interventions for TBI and acquired brain injury, with an emphasis on identifying and mediating barriers to receiving mental health care.

**Sandra Glazer, BA**, is a graduate student at the University of Cincinnati in the Clinical Psychology doctoral program. She has worked on grant-funded studies in the area of traumatic brain injury for almost four years, ranging from mouse models of TBI to neuroimaging correlates of brain injury with psychosocial impact in children and adolescents. Her research interests are in acute recovery from pediatric TBI, and evidence-based interventions targeting executive functioning skills such as problem-solving.

**Shari L. Wade, PhD**, is a pediatric rehabilitation psychologist who has conducted federally-funded research examining outcomes of pediatric traumatic brain injury and factors that influence outcomes since 1991. This widely-cited research has shaped how the field understands the role of social environmental factors on recovery and the effects of TBI on child and family functioning over time. For the past 21 years, she has conducted single site and multicenter randomized clinical trials of interventions to reduce morbidity following pediatric traumatic brain injury, including some of the first Class 1 clinical trials for pediatric TBI. She has developed and tested technology-based interventions to reduce behavioral morbidity and family consequences of pediatric TBI for nearly two decades, beginning with an R21 award from NICHD in 2001. Dr. Wade is also leader in multi-center clinical trials for pediatric TBI and served as the principal investigator (PI) and director of the Rehabilitation Research and Training Center (RRTC) for Pediatric Brain Injury Interventions, the only federally-funded center for pediatric TBI.



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# Traumatic Brain Injury in Latin America: Developing a Theoretical Model of Family-Based Care

Juan Carlos Arango Lasprilla, PhD • Paul B. Perrin, PhD

Traumatic brain injury (TBI) is a leading cause of death and disability around the world.<sup>1</sup> In particular, Latin America has the highest incidence of TBI due to road traffic injuries and violence, and the second highest rates for short-term intracranial injury due to violence.<sup>2,3</sup> In many Latin American countries, violence is a leading cause of death.<sup>4</sup> In Colombia, TBI prevalence is 6.4 (95% CI: 5.0 to 7.8) per 1,000 people,<sup>5</sup> due heavily to intentional injuries from hostile guerillas and landmine explosions.<sup>6</sup> In Mexico, TBI is the third leading cause of death, and injuries are caused predominantly by motor vehicle accidents.<sup>7</sup> Estimates suggest there are approximately 909 new TBI cases per 100,000 people in Latin American countries.<sup>8</sup> The TBI mortality rate in Latin America overall is 75.5 per 100,000 inhabitants, as compared to 56.8 per 100,000 in the United States.<sup>9,10</sup> The burden of TBI disproportionately affects low- and middle-income (LMIC) countries that have a higher prevalence of risk factors but also less developed health and rehabilitation systems to deal with associated outcomes. More than 90% of deaths caused by TBI occur in LMICs are due to risk factors such as living below the poverty line, residing in a conflict zone,<sup>11</sup> lack of prevention measures, and under-resourced health systems.<sup>12</sup>

## Family Needs After TBI

Despite the high death rates after TBI in Latin America, TBI is increasingly considered a chronic health condition<sup>13</sup>. People with TBI experience long-term symptoms across cognitive, somatic, affective, behavioral, and motor domains<sup>13</sup>. Recovery time is extremely variable, and often symptoms remain many years after injury<sup>14</sup>. Only 40% of people with TBI return to work within two years post-injury<sup>15</sup>, and more severe symptoms are associated with reduced employment<sup>16</sup>. The responsibility for TBI symptom management often falls on family members who become caregivers, and a large proportion of family caregivers devote over 40-50 hours a week to TBI symptom management<sup>17</sup>. Families affected by TBI experience myriad unmet emotional, instrumental, and professional support needs regarding symptom management<sup>18</sup>, and research in Latin America has shown these high rates of unmet needs are closely associated with caregiver mental health problems<sup>19</sup>. Family members are often inexperienced in caregiving and symptom management, and physical symptoms in individuals with TBI in Latin America are associated with greater family household needs, and emotional symptoms with greater family informational needs<sup>20</sup>. It is not surprising then, that this transition and a lack of services or family-based coping strategies can lead to stress on the family system<sup>21</sup>.

Research on the psychosocial impact of family caregiving for an individual with TBI in Latin America has shown that family TBI caregivers in Mexico report poorer health-related quality of life than healthy controls across various domains of mental and general health.<sup>22</sup> In Colombia, the majority of family caregivers studied reported some level of depression, and about half reported being overwhelmed by their caretaking responsibilities.<sup>23</sup> Further, TBI caregivers in Colombia report multiple important needs, especially the needs for health information, professional support, and involvement with care.<sup>18</sup> Though these needs have been similarly rated as important by United States TBI caregivers, they are more likely to be unmet for caregivers in Latin America.<sup>18</sup> Caregivers with high burden tend to care for TBI patients with poorer objective neuropsychological functioning.<sup>24</sup> As these studies show, the incidence of TBI is extremely high in this region, yet there are few—if any—comprehensive TBI rehabilitation centers; the majority of patients are discharged directly home, and family members shoulder the burden of care.<sup>22</sup> Latin America is comprised of many LMICs, and about 36% of the region's population lives in poverty.<sup>25</sup> Despite these risk factors, rehabilitation services that include family caregivers may maximize cultural strengths, such as a strong sense of familism.<sup>24</sup>

## TBI Primary Caregiver Interventions

The dominant paradigm in TBI intervention research both in Latin America and globally lacks a theoretical foundation for the involvement of all family members and is based solely on providing services to the patient, or at best, the primary caregiver<sup>26-39</sup>. The assumption is that one individual provides the majority of care, and the rest of the family is ignored in intervention research. Caregiver interventions tend to provide psychoeducation<sup>30</sup>, stress management strategies<sup>31</sup>, techniques to manage cognitive or behavioral symptoms in the individual with TBI<sup>32</sup>, and problem-solving skills<sup>33</sup>. Some use a combination of these approaches<sup>34</sup>. In general, these interventions have been shown to increase caregiver problem-solving skills<sup>33</sup>, reduce burden<sup>31</sup>, and decrease anxiety<sup>30</sup> and depression<sup>33</sup>.

Psychoeducational programs alone are less effective for improving caregiver outcomes<sup>32</sup>. However, the impact of interventions on the family, on symptom management, or on TBI patient quality of life has not been rigorously studied.

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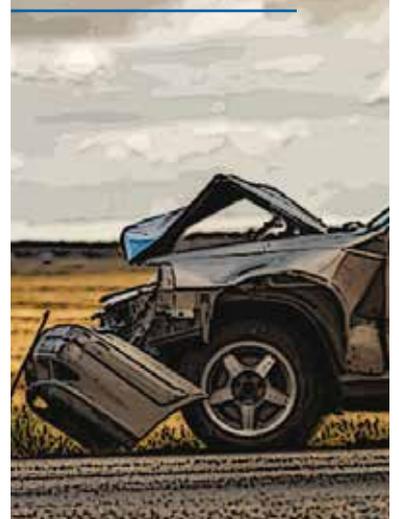
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## TBI Family Interventions

Because most interventions deal separately with individuals with TBI and their primary caregiver, the relationship between the two and a focus on the family environment are often lacking. Some research, however, has begun to use couples counseling in an attempt to reduce marital conflict and manage TBI symptoms<sup>35</sup>. To date, few published studies have intervened with the individual with TBI and at least two family members. Though many were case studies, some have included all family members and aimed to help families identify their own resources, cope with TBI, improve communication<sup>36,37</sup> and re-establish and redistribute family roles to restore cohesion<sup>37</sup>. Another was designed to meet family needs and reduce caregiver burden<sup>38</sup>. Family-systems and behavioral interventions were also used to improve family interactions and assist in behavioral change<sup>39</sup>, and family therapy has been adapted to repair non-cohesive relationships, as well as accept and adapt to the new roles for family members and the individual with TBI<sup>40</sup>. Two published longitudinal TBI family intervention studies have been conducted. In the first<sup>41</sup>, non-standardized family therapy was provided to 15 families of an individual with TBI, and families showed improved adjustment, cohesion, conflict, burden, and strain at a 24-month follow-up. In the second<sup>34</sup>, a manualized, five-session, psychoeducational intervention was given to 53 families addressing issues such as coping with change, problem-solving, dealing with emotions, goal-setting, and self-care. Participants reported a greater number of met needs and fewer obstacles to receiving services at the 3-month follow-up compared to baseline, although there was no change in family members' mental health or family functioning.

## TBI Family-Systems Intervention Model

Illness and disability are best understood as resulting from an interplay of genetic, developmental, psychological, and sociocultural factors; therefore, family interventions should be a significant part of any treatment<sup>42</sup>. Yet, many healthcare providers working with families after TBI are unsure how to intervene effectively to improve family functioning and the family system<sup>43</sup>. TBI is a family experience; it influences and is influenced by every member of the family. It changes family dynamics, including roles, boundaries, and communication, and families experience many significant needs during this time of crisis. Severe and chronic health conditions, such as TBI, can act as a magnifying glass for families, whereby family dynamics are exaggerated and normal family developmental processes can become pathological<sup>42</sup>. Given that family members and their caregiving play an integral role in the patient's symptom management, it is crucial to provide rehabilitation services within the context of the family system<sup>43</sup>.

Research has documented the importance of healthy family functioning after TBI in Latin America and the dramatically reduced mental health of TBI family caregivers in the region<sup>44</sup>. Family functioning, caregiver mental health, and patient TBI symptoms and disability are all interrelated<sup>45</sup>. Family factors likely have a reciprocal influence on the quality of symptom management that family members provide to individuals with TBI, and ultimately when family functioning is strengthened, it may be possible to improve patient TBI symptoms and disability.

Illness and disability are best understood as resulting from an interplay of genetic, developmental, psychological, and sociocultural factors; therefore, family interventions should be a significant part of any treatment.

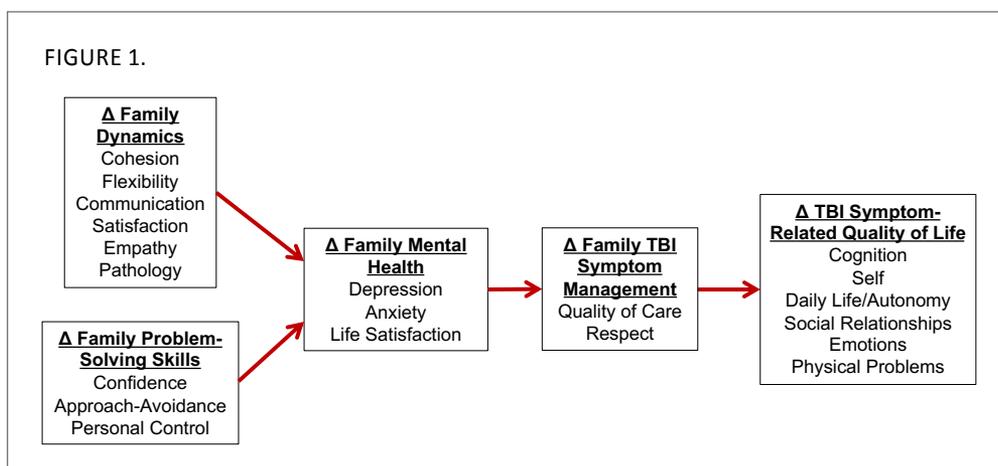
The current paradigm in TBI caregiver intervention research is limited by not fully including the entire family system. This is an especially important omission in Latin America, where familism values are paramount<sup>39</sup>, and therefore the family system needs to be a target of rehabilitation interventions. In the region, family members are often the primary—or only—resource that individuals with TBI have, particularly if they are living in poverty. It is extremely likely that evidence-based family-systems interventions would generate improvements in family dynamics and family problem-solving ability, strengthening the mental health of family members, which would improve family symptom management and patient TBI symptoms and disability (see FIGURE 1.).

The fundamental philosophy underlying this model is that an individual copes with and manages TBI symptoms in the context of his/her family system, particularly in Latin America. Although research has shown that these variables are individually associated with each other in the context of the family system, this model links them in a theoretical chain with a cascade of salubrious effects that evidence-based family-systems interventions could initiate. Although many—but not all—of the constructs in this model have been addressed in isolation in previous research, this model reflects a refinement and new application of theoretical concepts that provides specific targets for the development of TBI family-systems interventions. Future clinical research is critical in developing and testing family-systems interventions after TBI meant to target the model's central components.

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FIGURE 1.



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## Author Bios

**Juan Carlos Arango-Lasprilla**, PhD, is currently an Ikerbasque Research Professor at BioCruces Vizcaya Health Research Institute affiliated with Cruces University Hospital in Bilbao, Spain. A neuropsychologist by training, his areas of expertise are neuropsychology, traumatic brain injury (TBI), and rehabilitation. Dr. Arango has received over 20 awards for his accomplishments in the area of brain injury and rehabilitation, including early career/emerging professional awards from the National Academic of Neuropsychology, the American Psychological Association's Division 22 Rehabilitation Psychology and Division 45 (Society for the Psychological Study of Ethnic Minority Issues), the International Brain Injury Association Young Investigator Award and Mid-Career awards such the Arthur Benton Mid-Career award from the International Neuropsychological Society and The Mitchell Rosenthal Mid-Career award From the American Congress of Rehabilitation Medicine. He has published more than 300 articles and book chapters and edited 10 books. Dr. Arango is well-known both in the US and abroad and has been a guest editor of 12 special issues in prominent rehabilitation journals. He currently serves on the editorial boards of 30 publications and has been a reviewer for an additional 50 journals around the world. As a renowned expert in his field, he is often invited to national and international conferences to speak on brain injury, neuropsychology, and rehabilitation. He has lectured at Grand Rounds and at more than 95 different universities across the globe. Dr. Arango organized and chaired 4 international conferences on neuropsychology, cultural issues and Brain Injury Rehabilitation. In total, over 3,200 people from 5 continents attended the 4 conferences to hear 65 different international presenters present on these topics.

Dr. Arango is actively involved in a number of national and international organizations, including ACRM as co-chair of the Service Delivery Task Force. He is a founding member of the Colombian Neuropsychological Society, and he founded the IberoAmerican Journal of Neuropsychology (both in 2016). His research focuses on understanding and addressing the cognitive, psychological, and emotional needs of individuals with brain injury and their families. He is particularly interested in under-served populations, such as Spanish speakers, and carries out research in the US, Europe, and Latin America. He was PI of a large, multi-center norming study in which more than 14,000 adults and children from over 15 countries participated. Thanks to his leadership, normative data by country is now available for the 12 most commonly used neuropsychological tests in each respective population.

Dr. Arango is a pioneer in the field. Through hard work and dedication Dr. Arango has succeeded in ensuring that cultural issues remain at the forefront of rehabilitation research and the minds of rehabilitation professionals around the world.

**Paul B. Perrin**, PhD, is an Associate Professor of Psychology and Physical Medicine and Rehabilitation at Virginia Commonwealth University, as well as a Research Psychologist and the Co-Director of the Polytrauma Rehabilitation Center TBI Model Systems Program at the Central Virginia Veterans Affairs Health Care System. His research focuses on cultural, familial, and international approaches to disability rehabilitation and adjustment, particularly in underserved and minority populations with neurological conditions.



FIGURE 1

## Treatment Note: Collaboratively Creating a Values Heat-map Online

Andrew Bateman, PhD, MCSP

There is no limit to the number of categories you can create with a simple “drag and drop” the cards form into decks, and for illustration purposes here I have created three decks with two cards in each deck. Hovering over a card brings up the description of that word (in this case “Contribution – “to make a lasting contribution in the world” ... *shall I take this to my “important” or “very important pile”?*).

The Miller et al Values Card Sort task is a widely used and useful tool for evoking conversation about personal values. A deck of cards is used with a person who is asked to sort cards into piles of “very important”, “important” “not important”. We included a copy of the list of words as part of a chapter in our Brain Injury Rehabilitation Workbook (Winson, Wilson and Bateman, 2017) in a chapter about exploring identity, because it is helpful in encouraging conversations about motivation. I have used this alongside rehabilitation goal setting to help an individual talk about why they may want to do more of one kind of activity or another. Indeed the findings can also be taken into a “mindfulness meditation” that could take the form of compassionately wishing more of a given value or experience for yourself and others along the lines a “loving kindness meditation” as described by Irons and Beaumont (2017)

The COVID-19 pandemic has created the necessity to innovate in so many ways. This note is to illustrate that this exercise can still be done remotely, over web-conferencing, without the need to have a physical deck of cards, enabling this aspect of rehabilitation to proceed. Well-Sorted [<https://www.well-sorted.org/>] is a site originally built to support preparation for meetings by encouraging people to share ideas down and sort them, perhaps with an aim of creating discussion groups at the meeting. I found this a use-friendly app for this therapeutic card-sorting purpose.

There is a setting within the interface that can enable the sorting to be completed without choosing all of the 83 cards. FIGURE 1. Screenshot of “well-sorted” with a selection of the Miller Card-Sort words.

The next step in this procedure is handled by the clinician (in this software described as the “study” owner), if a minimum of two “sorts” are completed, the software generates a “heatmap” showing how the values are linked together. In this figure the client Joe, I was working with remotely (using a video conferencing platform, zoom) had identified 48 of the words listed as important. For his homework I set these 48 words into the well-sorted app and asked him to sort the words into as many decks as he saw fit. This was an activity that emerged in the course of a therapeutic encounter, where having chosen so many words as important, I had asked him to have a think about things that simply “went together for you”. Figure 2, kindly shared with permission, illustrates the results where for example “adventure, challenge, change fitness growth health and passion” were grouped. This enabled us to have a fruitful and motivating conversation about how he is planning his time to include “adventurous exercise”. It helped to make what was for him a rather abstract concept much more concrete. The sorting task can be sent to any number of friends and family members as talking about ‘shared values’ is likely to be a useful thing to do in building a shared rehabilitation narrative.

I shared a draft of this treatment note with Joe and asked him about the exercise and how it impacted on him and his family. He wrote back very quickly to say:

*“I do remember doing the values exercise, as after doing it with you I explained it to my wife, and I spoke at length about what it meant to me and how it was part of my make up. I also felt that I was able to talk openly for the first time with her and other close family members about how and why things were affecting me and that moving forward I could use these values to help me.”*

As an ex-military man and engineer, the language of values was not really a familiar territory for him, but it clearly resonated and enabled great rehab progress.

FIGURE 2 a very simple “heat map” output, in this case with 1 ‘sort’ completed. The seven “decks” represent quite discrete aspects of identity and enable conversations, eg about “when I am doing things that align with tradition/justice/friendship” or “adventure/challenge/change”.

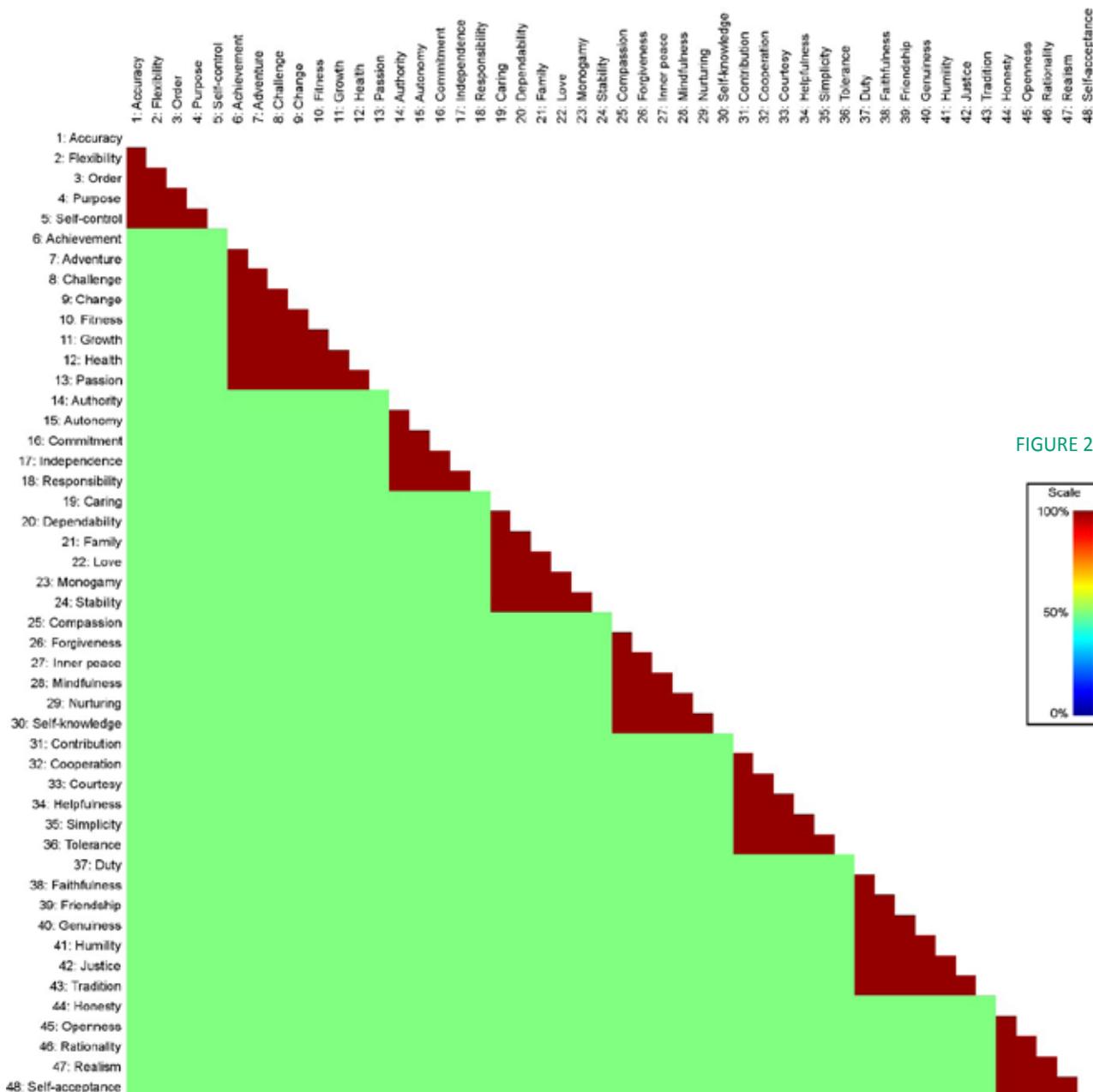
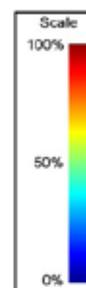


FIGURE 2



I will welcome any correspondence about this treatment note and am happy to share the resources to facilitate use of this. Andrew Bateman, December 2020; Email a.bateman@essex.ac.uk; Twitter/instagram @drandrewbateman.

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# Encouraging Individuals with ABI and their Families of Diverse Background, to Engage in the Rehabilitation Process: The Value of Motivational Interviewing

Kristine T. Kingsley, PsyD, ABPP

The United States is becoming increasingly diverse. Minority population growth has been steadily increasing in recent years such that clinicians are more frequently interacting with individuals from diverse backgrounds. Further, there is evidence to suggest that minorities are at greater risk for sustaining brain injuries, bringing an even greater number of minorities into rehabilitation facilities (Lequerica et al, 2014).

Individuals with acquired brain injuries often encounter difficulties seen among members of a lower socioeconomic status (SES). For those people of color whose insurance status do not prevent or limit their access to inpatient and outpatient rehabilitation services, other barriers may still be present. Health disparities remain in long term outcomes on account of institutional biases, mistrust in the healthcare system due to past experiences, limited available sources of information (e.g., secondary to language barriers), co-morbidities, additional psychosocial stressors (living in overcrowded, often crime-ridden areas), and lower levels of self-efficacy (Budnick et al. 2017). Patients from diverse racial and ethnic minority groups have been found to have shorter post spinal cord injury (SCI) hospitalization length of stay and higher readmission rates. They are also found to have higher levels of depression and more days in poor health, more difficulty with mobility, as well as greater difficulties returning back to work. Additionally, patients from diverse racial and ethnic minority groups have: lower self-reported well-being, poorer quality of life and life satisfaction, greater risk of marital breakdown. LatinX clients are less likely to receive rehabilitation after ED treatment for TBI symptoms with gender (women) also playing a factor.

In fact, LatinX patients with TBI receive different discharge dispositions than Whites, even in regions in which LatinX comprise the demographic majority, and even with comparable traumatic severity and insurance status. (Budnick et al., 2017; Owen, J. 2012). For those minorities who are fortunate enough to receive such services, studies show that health disparities remain in long term outcomes, even after accounting for socioeconomic status and insurance factors (Arango-Lasprilla & Kreutzer, 2010; Institute of Medicine, 2001; Rosenthal et al., 1996; Stewart & Napoles-Springer, 2000).

In terms of the provider's cultural competence the idea of cultural tailoring is developing slowly, but it is more supported. The emphasis has been support and education starting with families in ICU. The latest literature in cross cultural issues shows that family needs for information and professional support are met, but emotional support is still low and dependent on the culture. Early patient support focuses on pain management, behavioral management, anxiety about changes and depression. After discharge, services are more fragmented.

Collaborative approach to psychotherapy is associated with efficacy, such as with spiritual leaders (Spencer et al. 2019). Motivational interviewing and mindfulness often fit well with culturally and ethnically diverse groups since the consumer is often the expert on him/herself.



The concept of cultural humility refers to the practice of respecting folks from other backgrounds and identities on their own terms. A culturally humble approach seeks to understand others "in relation to aspects of cultural identity that are most important to the [person]" (Hook, 2013, p. 2). These most important aspects of one's identity may not be obvious to others, thus the process of being culturally humble requires the practitioner a non-judgmental curiosity, deep listening and self-awareness among other qualities.

Understanding and communicating with folks from other cultures, backgrounds and experiences sounds simple, just as the basic **OARS** skills (open ended questions, affirmations, reflection, and summarization) in motivational interviewing can seem deceptively simple. In fact, many of the qualities needed to practice cultural humility seem to overlap with the skills and methods taught in motivational interviewing (MI). It is said that an open minded and collaborative approach is at the foundation of cultural humility. Individuals with cognitive disabilities post a traumatic brain injury, present with unique challenges in terms of daily functioning. Engaging family in rehabilitation has been proven to be instrumental in optimizing rehabilitation outcomes. Encouraging the participation of a family member using a motivational interviewing may enhance attendance and adherence to treatment recommendations and suggestions.

## Case

Boris is a 36 year old Asian male, who sustained a traumatic brain injury when he fell from a ladder at work four years prior to onset of the treatment. Boris presents with minimal residual physical changes, but with impaired memory, and significantly reduced attention, executive function, and awareness of deficits. He does not use any personal device assistant equipment consistently. Pre-injury, Boris worked as a machine operator, and spent many hours practicing martial arts. He is married and has two school aged children. There is no known history of medical or mental health issues prior to his injury; no use of alcohol or other substances. Since his injury, he has been unable to return to work and spends his days at home watching TV; he seldom goes out on his own or initiates an activity- unless prompted by his wife.

A neuropsychological evaluation revealed deficient verbal and visual memory abilities, impaired problem solving skills and mental flexibility, and significantly reduced self-awareness of current cognitive difficulties. The therapist suggested the use of some form of memory notebook, which in turn implies training to external compensatory strategies (e.g., memory notebook training) and awareness training. Given the client's previously recorded difficulty with compliance to treatment recommendations, a motivational interviewing approach is recommended in his intervention. The treatment is expected to aim at an increased awareness of the discrepancy between Boris' desired and current states. (Boris' desire is to initiate and keep track of phone conversation with his wife and kids). He was the traditional patriarchal head of his family, and because his wife was not born in this country, he managed all of the family finances and took charge of any activities that involved interaction with the community. However, after severe brain injury, it was clear that he could not take on many of these responsibilities. As a result, the patient became despondent and ashamed that he could no longer 'take care of' his family.

Motivational interviewing is introduced with the hope of gaining the client's trust and slowly begin to peel the layers of an onion, to address his beliefs with respect to his role as a parent & a spouse, his role as a son, and finally his reasons for resisting the use of

any device or notebook as well as his low initiation in starting and following up with activities.

The intervention for the family on the other hand, is to provide psycho-education and to help each member accept the patient's needs; it is also to try and engage them in becoming more like co-trainers and cue the client for various events and plans.

The following dialogue is from the session immediately after testing is completed and results are being discussed.

**Therapist-** Thank you for coming in. As you know you just underwent a neuropsychological evaluation to assess how you are doing cognitively since the TBI. I have some of the results here, and I would like to discuss them with you. Would that be OK?

**Boris-** I guess it is OK

**Therapist-** Would it be OK for your wife to attend this meeting? Sometimes clients find it helpful to have an extra set of ears when they are receiving healthcare related information about themselves.

**Boris-** I guess it is fine.

**Therapist-** After reviewing your test scores from our recent assessment, I noted some areas that are kind of in sync with what you and your wife mainly reported to me the first day we met- mainly about your forgetfulness. Would you be interested in learning more about memory functioning and how it may affect activities of your daily life, as well as your quality of life?

**Boris-** I don't know, I don't feel like my memory issues are that huge. I just seem to have a lot of things on my mind lately.

**Spouse-** Are you saying Boris has dementia?

**Therapist-** It's true, some level of "forgetfulness" is common in all of us, especially when we are upset or moody. No, you do not have dementia, but you do have a memory impairment. What do you think about that?

**Boris-** I do forget some things like birthdays and anniversaries. But then again who doesn't after a brain injury. I don't want to have everything down in a notebook.

**Therapist-** You seem to have an appreciation of how the brain injury has affected your memory. I hear that you are not interested in keeping notes, I was wondering whether you would like us to talk about some strategies and some devices people use to bolster their memory and focus.

**Boris-** I guess.

**Therapist-** Now that we have identified some personal assistant devices, which would allow you to record important information and help you remember, how would you feel about selecting one of them.

**Boris-** I think I will go with the tablet.

**Therapist-** Great! Now on a scale of 1 to 10 with one being the lowest score and ten being the highest, how important is it to you to change your behavior and be more confident when asked to remember things?

Motivational interviewing is introduced with the hope of gaining the client's trust and slowly begin to peel the layers of an onion, to address his beliefs with respect to his role as a parent & a spouse, his role as a son, and finally his reasons for resisting the use of any device or notebook as well as his low initiation in starting and following up with activities.



**Therapist to Boris' family-** "This is so great that you have decided to cue Boris each time he needs to write down essential information. Therapist to Everyone- "Imagine how your life would be different, if you didn't struggle with memory?"

**Boris-** I would like to be able to see my children grow and continue with college. I want to be able to work again and help my family. Therapist- That sounds like a solid plan. "How might you see yourself in 5 or 10 years if memory is still a problem?" Do you see yourself using some strategy?

**Boris-** Perhaps I can use a tablet to write down notes.

**Therapist-** How confident are you that you can accomplish this from a scale of 1 (min) and 10 (max).

**Boris-** I can see myself using a tablet with a 7 or 8 level of confidence.

After a moderate to severe acquired brain injury, it is widely recommended that persons and their family members actively engage in the rehabilitation process, because evidence suggests that this is associated with better outcome. Individuals with cognitive disabilities present with unique challenges, which may impact their well-being. Motivational Interviewing (M.I.) is a theoretical model of change, with a framework for conceptualizing a patient's / caregiver's current stage of change. M.I. is defined as a collaborative conversation, a conversation about change, usually behavioral, with an overall attempt to strengthen a person's or dyad's own motivation & commitment to change. (Rollnick, 2007). M.I. can therefore successfully explore and resolve ambivalence in individuals Vis a Vis their healthcare team, and the overall treatment recommendations.

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Since 2002, Dr. Kingsley has been involved in designing and delivering clinical services (assessment, intervention) to individuals with acquired neurological disorders. Her clients involve individuals with diagnoses of traumatic brain injury, stroke, epilepsy, and mild cognitive impairment, Post-Concussion Syndrome, Parkinson's disease, Brain Neoplasms and Multiple Sclerosis. Dr. Kingsley has presented and published both nationally and internationally on how to provide holistic neuro-rehabilitation services, emphasizing family engagement and intervention using culturally competent models and practices. Additionally, she has taught and supervised hundreds of psychology residents on the intricacies of family assessment and treatment.

Dr. Kingsley is a faculty member of Cognitive Rehabilitation at the American Congress of Rehabilitation Medicine (ACRM's) and a co-author to their most recent systematic review (2009-2015), as well as one currently in progress. She recently contributed in the writing of ACRM's 2nd Edition "Cognitive Rehabilitation Manual and Textbook: Translating Evidence-Based Recommendations into Practice."

Dr. Kingsley is the Chair- Elect (2019-2021) of ACRMs International Interdisciplinary Special Interest Group, and is serving a four year term as the Editor and Communications Chair for the American Board of Professional Psychology.



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# BIP expert interview



## The Traumatic Brain Injury Model Systems - Caregivers & Families An interview with **Dr. Angelle M. Sander, Ph.D., FACRM**

Angelle M. Sander is Professor in the H. Ben Taub Department of Physical Medicine and Rehabilitation at Baylor College of Medicine and is Director of the Brain Injury Research Center at TIRR Memorial Hermann. She has been PI on federally funded studies addressing prediction and treatment of cognitive, emotional, and psychosocial problems in persons with TBI, intimacy and sexuality after TBI, impact of TBI on caregivers, and cultural disparities in outcomes. She co-chairs the TBI Model System Special Interest Groups on Caregivers and Families and on Cultural Competency. She has won numerous awards, including the 2018 William Fields Caviness Award. Dr. Sander has over 100 peer-reviewed publications.

The Traumatic Brain Injury Model Systems (TBIMS) Program began in 1987 with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to improve care and outcomes for individuals who had sustained a TBI. In recent years, NIDRR had been renamed the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and has moved to the Administration on Community Living, in the Department of Health and Human Services. Originally there were four designated TBIMS centers that were able to provide emergency medical, acute medical and post-acute rehabilitation services. These centers were to foster clinical and research endeavors in the area of traumatic brain injury. Some initial TBIMS accomplishments included: a. the development of practice guidelines in medical care & rehabilitation, b. the creation of diagnostic procedures and objective measures, c. the description of how people recover in the first years, d. the identification of persistent problems that follow TBI, and d. the development of new assistive technologies to be used by survivors with cognitive difficulties in order to increase independent functioning. The three main components of the TBIMS Program are the Traumatic Brain Injury (TBI) National Data and Statistical Center, the Model Systems Knowledge Translation Center (MSKTC) and The Center for Outcome Measurement in Brain Injury (COMBI). Across the years, more than 500 peer reviewed publications have resulted from TBIMS research, including more than 6 special issues in leading journals in the field of rehabilitation. There is strong involvement in conferences and journals to increase knowledge and visibility of findings. Finally, dissemination of information through the website allows individuals interested in research to access the database after following a predetermined process. To ensure that research is translated into practice, NIDILRR separately funds a Model Systems Knowledge Translation Center, which promotes the adoption of research findings by stakeholders, rehabilitation professionals and consumers.

Dr. Sander is a professor with tenure in the department of Physical Medicine and Rehabilitation at H. Ben Taub Department of Physical Medicine and Rehabilitation at Baylor College of Medicine, where she is director of the division of Clinical Neuropsychology and Rehabilitation Psychology. She directs TIRR Memorial Hermann's Brain Injury Research Center and is a senior scientist on the TIRR Memorial Hermann Research Council. She has served as project director of two NIDILRR-funded Rehabilitation Research and Training Centers on Traumatic Brain Injury and has been the project co-director for the Texas Traumatic Brain Injury Model System at TIRR for the past three cycles.

Dr. Sander has been principal investigator or co-investigator of federally funded studies addressing prediction and treatment of cognitive, emotional and psychosocial problems in persons with TBI, intimacy and sexuality after TBI, impact of TBI on caregivers and cultural disparities in outcomes following TBI.

She co-chairs the TBI Model System Special Interest Group on Caregivers and Families, as well as the Cultural Competency Special Interest Group. She has more than 100 peer-reviewed publications, numerous book chapters and published abstracts, and multiple consumer-oriented dissemination products, including fact sheets, educational manuals, webcasts and videos. In November of 2020, she appeared in a special edition of *Rehabilitation Psychology* on families after TBI.

*Dr. Sander, please tell us what were some of the first areas of interest for TBIMS within the realm of family needs, assessment, and interventions following a TBI?*

During the early cycles of the TBIMS, efforts focused on documenting the impact of TBI on family caregivers. Impact on family functioning was documented by inclusion of the Family Assessment Device's General Functioning Scale in the TBIMS national database. Jeff Kreutzer and colleagues developed the Family Needs Questionnaire to document caregivers' needs and the extent to which they were met. They documented that emotional and instrumental support needs were unmet by a large number of family members at 1 and 2 years post-injury. From 2002-2007, Jeff Kreutzer led a multi-site module study documenting the emotional distress experienced by caregivers at 1, 2, and 5 years post-injury. Another area of research was the impact of caregivers' functioning on the outcomes of persons with TBI. Angelle Sander led a multi-site TBIMS Collaborative study in this area from 1998-2003, and publications from this study documented that family caregivers' emotional functioning and general family functioning contribute to outcomes in the person with TBI. As the TBIMS aged, the focus of family research moved to development and evaluation of interventions. In a series of TBIMS local studies, Jeff Kreutzer and colleagues developed and evaluated the Brain Injury Family Intervention (BIFI), focusing on education, skill-building, and psychological support. The BIFI has been shown to decrease caregiver burden, reduce unmet needs, and increase satisfaction with services.

*What have been some challenges/developments in TBIMS history since its inception?*

Lack of funding for family caregiver research has been a major obstacle to moving the field forward. While investigators can submit a caregiver study for many different funding mechanisms, there are few RFPs focused specifically on caregiving research. At the same time, there is limited information on caregiver issues in the TBIMS and other longitudinal TBI national databases.

While the Family Assessment Device was included in the TBIMS database for several years, there has not been a caregiver measure included since 2001. However, there are three module studies focused on caregivers during the current cycle- one on resilience in caregivers (led by Jeff Kreutzer at Virginia Commonwealth University); one on a problem-solving intervention (led by Shannon Juengst at UT Southwestern); and one on developing and piloting a structured telephone-based caregiver interview to assess needs of caregivers of persons with chronic severe cognitive disability (led by Joe Giacino at Spaulding-Harvard). We have also developed a Caregiver and Family Special Interest Group to find new ways to collaborate around the topic of family caregivers.

*What are some current areas of interest? What do you foresee being a future direction for TBIMS within the realm of family interventions?*

The TBIMS Caregiver and Family Special Interest Group is collaborating around two main areas of interest. The first is intimate relationships after TBI. Jeff Kreutzer and others have already led work showing the impact of TBI on marital relationships, and they have developed a couples intervention for people with TBI and their partners. Other TBIMS-related work in couples intervention is being conducted by Samantha Backhaus and colleagues at Indiana Medical School. Further development of this line of research is a focus of our group. Development of other interventions to assist caregivers is also active. Shannon Juengst is leading a module study on a problem-solving intervention for caregivers during inpatient rehabilitation. Her intervention leverages telehealth- a timely and exciting area of technology use with the potential to increase feasibility and access to interventions for caregivers.

*Have there been any TBIMS collaborations with other agencies within this area of research and or clinical practice? Any international collaborations?*

One of our most productive collaborations has been with the VA Polytrauma Rehabilitation Centers (PRCs), funded by the Department of Defense and led by Risa Nakase-Richardson. The five PRCs have developed a national TBI database that parallels that of the TBIMS, collecting longitudinal data on service members and veterans (SMVs) with TBI. They have included the Family Needs Questionnaire, which has allowed us (led by Jacob Finn) to collaborate on documenting unmet needs in family members of SMVs, which we hope to translate to service development. Lillian Stevens (formerly with the Richmond PRC) and Angelle Sander co-created the TBIMS Caregiver and Family SIG to collaborate on the topic of caregiving for persons with TBI, including SMVs. Based on her expertise with caregiver research conducted in the TBIMS, Angelle Sander has collaborated with NIH-funded researchers, led by Noelle Carozzi, to develop the CareQOL, which is the first measure in the NIH-sponsored Patient Reported Outcomes Measurement Information System, to assess outcomes of caregivers following TBI.

*Lastly, may there be any links I could include with the bibliography of articles published in this area?*

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## About the Interviewer

Kristine Kingsley, PsyD, is a former Clinical Assistant Professor of Rehabilitation Medicine and Associate Coordinator of Internship Training at NYU Langone Health. She is currently in private practice and serves a clinical supervisor at Ferkauf Graduate School of Psychology. She is board certified in Rehabilitation Psychology.

Since 2002, Dr. Kingsley has been involved in designing and delivering clinical services (assessment, intervention) to individuals with acquired neurological disorders. Her clients involve individuals with diagnoses of traumatic brain injury, stroke, epilepsy, and mild cognitive impairment, Post-Concussion Syndrome, Parkinson's disease, Brain Neoplasms and Multiple Sclerosis. Dr. Kingsley has presented and published both nationally and internationally on how to provide holistic neuro-rehabilitation services, emphasizing family engagement and intervention using culturally competent models and practices. Additionally, she has taught and supervised hundreds of psychology residents on the intricacies of family assessment and treatment.

Dr. Kingsley is a faculty member of Cognitive Rehabilitation at the American Congress of Rehabilitation Medicine (ACRM's) and a co-author to their most recent systematic review (2009-2015), as well as one currently in progress. She recently contributed in the writing of ACRM's 2nd Edition "Cognitive Rehabilitation Manual and Textbook: Translating Evidence-Based Recommendations into Practice." Dr. Kingsley is the Chair- Elect (2019-2021) of ACRMs International Interdisciplinary Special Interest Group, and is serving a four year term as the Editor and Communications Chair for the American Board of Professional Psychology.

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## SCARLETT LAW GROUP

Scarlett Law Group is a premier California personal injury law firm that in two decades has become one of the state's go-to practices for large-scale personal injury and wrongful death cases, particularly those involving traumatic brain injuries.

With his experienced team of attorneys and support staff, founder Randall Scarlett has built a highly selective plaintiffs' firm that is dedicated to improving the quality of life of its injured clients. "I live to assist people who have sustained traumatic brain injury or other catastrophic harms," Scarlett says. "There is simply no greater calling than being able to work in a field where you can help people obtain the treatment they so desperately need."

To that end, Scarlett and his firm strive to achieve maximum recovery for their clients, while also providing them with the best medical experts available. "As a firm, we ensure that our clients receive both

the litigation support they need and the cutting-edge medical treatments that can help them regain independence," Scarlett notes.

Scarlett's record-setting verdicts for clients with traumatic brain injuries include \$10.6 million for a 31-year-old man, \$49 million for a 23-year-old man, \$26 million for a 7-year-old, and \$22.8 million for a 52-year-old woman. In addition, his firm regularly obtains eight-figure verdicts for clients who have endured spinal cord injuries, automobile accidents, big rig trucking accidents, birth injuries, and wrongful death.

Most recently, Scarlett secured an \$18.6 million consolidated case jury verdict in February 2014 on behalf of the family of a woman who died as a result of the negligence of a trucking company and the dangerous condition of a roadway in Monterey, Calif. The jury awarded \$9.4 million to Scarlett's clients, which ranks as

one of the highest wrongful death verdicts rendered in recent years in the Monterey County Superior Court.

"Having successfully tried and resolved cases for decades, we're prepared and willing to take cases to trial when offers of settlement are inadequate, and I think that's ultimately what sets us apart from many other personal injury law firms," observes Scarlett, who is a Diplomat of the American Board of Professional Liability Attorneys.

In 2015, Mr. Scarlett obtained a \$13 million jury verdict for the family of a one year old baby who suffered permanent injuries when a North Carolina Hospital failed to diagnose and properly treat bacterial meningitis that left the child with severe neurological damage. Then, just a month later, Scarlett secured an \$11 million settlement for a 28-year-old Iraq War veteran who was struck by a vehicle in a crosswalk, rendering her brain damaged.

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