
*“MEN’S” ILLNESS OVERLOOKED
IN WOMEN AND “WOMEN’S” ILLNESS
MISDIAGNOSED OR DISMISSED*

**Women Living with Traumatic Brain Injury:
Social Isolation, Emotional Functioning
and Implications for Psychotherapy**

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SUMMARY. Women living with Traumatic Brain Injury (TBI) typically experience social and emotional sequelae that can be effectively addressed in the context of a psychotherapeutic relationship. Traumatic Brain Injuries can affect the full range of human functioning, from activities of daily living to experiencing a coherent sense of self. In this article, we focus on two issues, social isolation and emotional functioning, that encompass a number of key challenges facing women with TBI and are common and fruitful foci of psychotherapy. Social isolation includes marginalization in multiple communities, the invisibility of cognitive disabilities, difficulties in interpersonal relationships, and difficulties in employment and access to transportation. Emotional functioning includes posttraumatic stress symptoms, loss of self-esteem, anxiety, depression, anger, and shame. Two exemplary cases are used to illustrate the themes and underscore the complexities and realities of adjusting to TBI. Recommendations for therapists and consumers are woven throughout the paper. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

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Traumatic Brain Injury (TBI) has become a major public health problem in the United States. It is estimated that a little more than 2% of the U.S. population currently lives with disabilities resulting from TBI, and recent legislation (Traumatic Brain Injury Act), as well as governmental reports, have acknowledged the magnitude of the problem (e.g., U.S. General Accounting Office, 1998; National Institutes of Health (NIH) Consensus Statement, 1998). The value, complexity, and various theoretical frameworks for conducting psychotherapy with individuals with TBI have been discussed elsewhere (e.g., Cicerone, 1989; Langer, 1992; Pollack, 1994; Prigatano, 1994, 1999), although issues particular to women have not, to our knowledge, been published in the literature. In this article, we will be focusing on the experiences of the three authors as contextualized exemplars of the process of conducting psychotherapy with women with brain injury.

The goals of this paper are not to represent the enormous range of issues faced by women with TBI, but to focus on the particulars of three

perspectives in order to illustrate broader themes. Judy Panko Reis (JPR), the Director of the Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago, sustained a TBI in 1980. She will discuss her experiences as a woman living with TBI. Wendy Heller (WH), a Full Professor, the Director of Clinical Training, and a licensed Clinical Psychologist at the University of Illinois at Urbana-Champaign, has been JPR's therapist since 1984 and has trained graduate students in neuropsychological assessment and intervention. Debjani Mukherjee (DM), a postdoctoral Ethics Fellow at the University of Chicago and a graduate of the Clinical/Community Psychology program at the University of Illinois, will focus on her psychotherapy with an Asian American university student whose needs were not being met by traditional models of rehabilitation.

In the United States, more men than women sustain TBIs (NIH Consensus Statement, 1998). Because of this fact, because rehabilitation medicine was conceptualized primarily to treat male war victims, and because medicine has more generally ignored gender-specific health concerns, the physical and psychosocial concerns of women with TBI have been neglected by service providers (e.g., Gill, Kirschner, & Reis, 1994). Furthermore, the nature of TBI and the "invisibility" of cognitive disabilities has typically led to marginalization within both the women's and disability communities.

Although traumatic brain injuries can affect various brain structures and the insults are not uniform, common areas of difficulty have been identified by clinicians and researchers. The areas include:

1. activities of daily living, such as problems with grooming, eating, using public transportation or managing finances;
2. cognitive functioning, such as memory, language, and communication problems, and limited compensatory strategies;
3. emotional functioning, such as anger, anxiety, apathy, depression or disinhibition;
4. physical health issues, such as pain or fatigue;
5. preinjury factors, such as cultural and class barriers, substance abuse, or family dysfunction;
6. impaired sense of self, such as unawareness of deficits or inappropriate expectations for self and others; and
7. social functioning, such as lack of social support, loss of power and control, lack of access to services or funding, or social devaluation of persons with brain injury.

(e.g., Bergquist et al., 1994; Corrigan, Smith-Knapp & Granger, 1998; Heller, 1997; Lezak, 1995; Malec & Basford, 1996; Mukherjee, Heller, & Alper, 2001; Ponsford, Sloan & Snow, 1995; Prigatano, 1994; Rosenthal & Ricker, 2000). These areas of functioning overlap and are sometimes artificially separated for clinical and research purposes but generally, after a TBI, multiple areas of functioning are affected. Moreover, the adjustment and accommodation process is complex and dynamic and women can experience difficulties in various areas as they adjust to the TBI.

Typically, a woman who sustains a brain injury receives acute hospital services (possibly including time in a critical care or intensive care unit), post acute services, inpatient rehabilitation, and outpatient rehabilitation. The extent of services received depends on many factors such as the severity of the injury, services available at the hospital where the woman is being served, and in today's health care climate, the ability to pay for services. In the hierarchy of "required" services, psychotherapy might fall lower than other forms of therapy such as physical, speech and language, and occupational therapies, but at some point during the adjustment process, usually while experiencing extreme emotional distress, women might enter into psychotherapeutic relationships. It should also be noted that given the high estimates of brain injury, including undiagnosed cases or mild brain injuries, it is likely that a therapist practicing in the United States will encounter clients who have sustained brain injuries. To the degree that psychotherapists become more cognizant of the impact brain injuries can have on cognitive, emotional, and adaptive function, the more they will be able to identify the role a TBI might play in a particular client's life. Then, the primary task for the psychotherapist becomes one of determining how best to intervene given the woman's relative cognitive and emotional strengths and weaknesses, and understanding that the social and cultural context of the injury affects the way that it is experienced, talked about and (de)valued.

According to a National Institutes of Health (NIH) Consensus Statement on Rehabilitation of Persons with Traumatic Brain Injury (1998),

Psychotherapy, an important component of a comprehensive rehabilitation program, is used to treat depression and loss of self-esteem associated with cognitive dysfunction. Specific goals for this therapy emphasize emotional support, providing explanations of the injury and its effects, helping to achieve self-esteem in the context of realistic self-assessment, reducing denial, and increasing ability to relate to family and society.

For women with TBI, therapeutic goals have to acknowledge societal and cultural expectations of women, individual differences in negotiating role changes and disability status, and longstanding patterns of interacting in families and society. Teasing apart the organic and non-organic sequelae of a TBI often becomes a complicated and lengthy process. For example, the denial which is mentioned in the NIH report can be on many levels. Damage to specific areas of the brain can result in anosognosia (literally not knowing that you do not know) or unawareness of deficits (Prigatano & Schacter, 1991). Psychological denial, of the type with which therapists are familiar can look behaviorally similar to the denial due to brain damage (Lewis, 1991). There are some differences, however. The time course is different in that psychological denial is more persistent. Furthermore, denial that reflects neural damage does not occur in isolation but is part of a pattern of functional deficits. Clinically, the individual who is employing psychological denial is more likely to become distressed when confronted with reality than the person with denial caused by TBI. This example underscores the ways in which traditional views of psychological mechanisms, such as denial, are complicated by damage to the brain.

Prigatano (1994, p. 175) reported that, in working with individuals with brain injury, “one repeatedly encounters them [sic] asking three questions: 1. Why did this happen to me?, 2. Will I be normal again?, and 3. Is life worth living after brain injury?” We would like to expand upon this conceptualization. Many women who enter into a psychotherapeutic relationship are struggling with issues of how to negotiate and incorporate new identities (e.g., woman with disability, person who has “survived” traumatic experience, mother with disability), how to overcome institutional obstacles (e.g., applying for and receiving governmental benefits, using the public transportation system), adjustment to brain injury, and dealing with the emotional sequelae (e.g., depression due to site of injury, loss, social isolation) associated with TBI. In this article, we focus on two issues, social isolation and emotional functioning, that encompass a number of key challenges facing women with TBI and are common and fruitful foci of psychotherapy. We will also use JPR’s narrative of becoming a mother as an exemplar of the new roles and developmental life-experiences that are affected by the social and emotional sequelae of TBI.

Social isolation is a broad area including marginalization in multiple communities, the invisibility of cognitive disabilities, difficulties in interpersonal relationships, and challenges in employment and transportation. After a TBI, specific brain structures might be affected that

influence the social repertoire of individuals. For example, damage to the right hemisphere can affect the ability to understand nonverbal communication that involves processing facial expression, voice intonation, and gestures. Right hemisphere damage can also affect the ability to take another's perspective, respond appropriately in an emotional situation, and show appropriate affect. Damage to the left hemisphere can cause expressive speech problems, which lead to difficulties in communication, and damage to anterior brain regions can cause problems with social judgment and behavior (for review, see Heller, 1997; Lezak, 1995). TBI-related problems in social functioning can be further compounded by the social and institutional factors that impede adjustment, such as difficulty receiving appropriate services without an effective advocate and cultural assumptions about disability and dependence (Mukherjee et al., 2001).

Emotional functioning is another broad area and would include post-traumatic stress symptoms, loss of self-esteem, anxiety, depression, anger, and shame. Langer (1992) discussed postmorbidity emotional themes that arise after brain injury regardless of age, gender, or cultural background. She viewed them as universal themes that are expressed to a different extent depending on the individual's circumstances. The themes she outlined include: humiliation, fear of failure, helplessness, powerlessness, loss of dignity, love, competence, identity and control, issues of manhood/womanhood, sexual feelings, fear of the future, sense of mortality and financial concerns. Obviously a unique configuration of some or all of these themes can be present in any individual. A systematic exploration of at least some of these themes might have great therapeutic value and may not be formally addressed in rehabilitation. For example, an exploration of the sense of loss is typically an important part of the therapy process. The possibilities of loss are myriad and can include loss of physical abilities, loss of cognitive abilities such as processing of information or memory, loss of time from valued activities, loss of memory for events surrounding the injury, loss of previous relationships, and perhaps especially, a loss of the previously-defined self.

In sum, TBIs can affect the full range of human functioning from activities of daily living to experiencing a coherent sense of self. We begin with brief case histories of two women who experienced brain injury and describe some initial reactions. Throughout the rest of the paper, we will be using their experiences to illustrate the kinds of issues that are commonly faced by women with TBI. JPR has written her own narrative and Jessica's (pseudonym) narrative has been (re)created by her therapist (DM).

CLIENT EXAMPLES

(JPR) The winter I was twenty-eight, life was lush with promise and I loved it. I lived independently, traveled frequently for business and pleasure and when I became torn between lucrative job offers from competitors on both coasts, I rejoiced in the knowledge that I had exceeded my career goals as a research manager for a top actuarial firm in Chicago. Blessed with good health and a loving family, I looked forward to taking a leave from my job to join my fiancé in Hawaii where he was finishing his medical residency. Shortly before our planned marriage, while tent camping in a Hawaiian state park, assailants bludgeoned the right hemisphere of my brain into raw meat and left me for dead in an assault that murdered my fiancé. Days after authorities slipped his corpse into a rubber bag and sent him home to his family in New York, a flight nurse transferred me onto a stretcher that occupied two rows of seating, and my parents accompanied me home to Chicago. My parents told me that once back home, living with them, I would need to learn how to live life anew. Like a limp marionette I went along with the program.

Three years after my brain injury, laurels of victory were lavished upon me by family, friends, and physicians. Enduring an Everest of intensive rehabilitation therapies, I conquered the wheelchair, and learned scores of compensatory strategies for so-called irrecoverable losses. Most critically, I managed to resume a physical and emotional quality of life that again held the promise of marriage and graduate school. But problems prevailed. Although I had achieved more in three years than countless numbers of individuals with TBI would accomplish through a lifetime of therapies, the victory was hollow. I felt isolated and mutilated. The assault claimed function of my left leg, resulting in the use of a leg brace and cane and decimated use of my left hand and arm. With impairments in the left visual field of both eyes, I was unable to resume driving. Less apparent but equally humiliating was the devastation wreaked by a host of cognitive and perceptual deficits that were yet to reveal their full ravages.

I figured that my malaise would vanish once I left my parents' home to marry my husband. After all, I had worked diligently to set myself up for success by taking things slowly. My husband and I knew one another before the injury and he had vigilantly remained by my side throughout the three years of rehab.

Heeding my vocational counselor I started grad school sensibly, carrying only two classes; surely the worst was behind me. Things were bound to improve!

(WH) I met JPR for the first time after she was married and had become a graduate student at the University of Chicago. Before I started working with her as a therapist, my graduate advisor in the Biopsychology program, Dr. Jerre Levy, had suggested I interview her as a potential case study of a person with a right hemisphere injury. In the course of that interview process, JPR shared with me some of her journals and I had an opportunity to evaluate her psychological status pre-injury. This assessment made it clear that JPR had some enormous strengths that would prove to contribute in important ways to her unique adjustment to brain injury. JPR is an exceptionally intelligent and motivated person who has personality characteristics that are typical of people who approach challenges head-on, as opposed to avoiding them. She combines this trait with a contemplative side and is able to reflect upon her self and her behavior in a non-defensive way. She is also capable of engagement, trust, and attachment to others, a characteristic that helped her to cope with the remarkable post-traumatic sequelae of having been the victim of a murderous attack.

Despite her intellectual and emotional strengths, JPR had quite a few issues that needed attention. She experienced changes in her cognitive and physical abilities that interfered with her ability to function in the same ways and with the same efficiency and ease that she had in the past. She was finding herself forced to deal with losses in status and sense of self on many levels, including changes in her appearance that she viewed as negative and inability to drive an automobile. The impact of these losses became more, not less, obvious as she progressed in her adjustment to the brain injury and as the most pressing demands of survival diminished. This is a common pattern among people with brain injuries and their families, who often face, at some point, the painful reality that recovery is not a simple, straightforward process. (Mukherjee, 2000)

(DM) Jessica emigrated from Taiwan to the United States when she was in her early twenties. She had spent the first few years working in her family's business and then saved up enough money to attend university. Jessica was about to start her second year

when she sustained a traumatic brain injury. She was crossing the street to go to the grocery store in her neighborhood and was standing on the median of the busy road when a truck jumped over the median and hit her. The next moment she recalled was waking up in the hospital with a really bad headache. No one would answer her questions about why she was there. She knew her parents were very worried and that her “face had been smashed in.” She had no idea that the accident might have affected the way that she was thinking, remembering, concentrating or experiencing emotion.

After the accident, she was in the hospital for about 10 days, received some outpatient rehabilitation and then left to start her sophomore year of college. Within a month, she was back at home. She was unable to stay awake, had unbearable headaches, and could not concentrate or focus on her schoolwork. She tried to go back to college the next semester and ended up dropping to below half-time status. It was at this point that she first found out about the office for students with disabilities and decided to learn more about receiving services.

Approximately 16 months after her accident, Jessica was referred to me for psychotherapy by the Counseling Center at the University. I had over seven years of experience working with women (and men) with brain injury in the context of neuropsychological assessment, but was relatively new to the enterprise of doing therapy with individuals with cognitive disabilities. Like many women with a brain injury, Jessica’s difficulties were not visibly apparent. If you looked closely, you could see some scars on her face (which she later reported were from her face “being smashed by the truck driven by a drunk driver”), but she did not have any other physical signs of her brain injury. Jessica cried during most of the intake interview. She had been from office to office on campus seeking services that were appropriate for her problems. She told me that I was her “last hope.” She kept referring to me as a neuropsychologist who would be able to help her figure out what was going on.

Jessica had many strengths when she entered the psychotherapeutic relationship but because she sought therapy when she was in acute distress, she felt as if she had lost all control over her life and felt helpless and hopeless. Before the accident, she had been the sort of person who worked consistently towards long-term goals, such as immigrating to the United States or completing a university degree. She had overcome personal losses and

disappointments, always with the hope of a better future. The brain injury (temporarily) undermined her sense of hope and her spiritual belief that if she worked hard and lived a “good life,” then she would be at peace. And although she was from a tight-knit family and identified with the Asian American community, she preferred to keep to herself and only open up to those that she knew very well. Her need for services and support subsequent to the accident was counter to the way in which she had coped and succeeded before. The brain injury not only affected her attention, concentration and language skills, but also forced Jessica to alter deeply ingrained ways of interacting with her environment and question her fundamental beliefs and worldview.

PSYCHOTHERAPY ISSUES

Social Isolation

Often unemployed, living alone, and having few if any friends, women with TBI are isolated from mainstream women’s support networks and social activities as well as from dating opportunities. Social stigma and the common problem of transportation, if the TBI results in a visual or mobility impairment, are significant isolating factors. Women who are married at the time of injury commonly express concerns about marriage problems. Many women report that their slow cognitive processing, memory and communication deficits add to their frustrations and can cause them to feel sad or depressed. Frequently living with invisible disabilities, women with TBI can be shunned by other individuals with disabilities, leaving them on the sidelines within the disability and disabled women’s communities, denied the supports these groups can offer. Getting the right emotional and psychological support is critical to dismantling the barriers of social alienation that accompanies TBI.

(JPR) Soon after I entered therapy it became clear that I was struggling with deep remorse over the loss of my identity as a successful able-bodied businesswoman. No longer employed or able to drive, I lost access to pre-injury friends and was too self-conscious about my TBI to make new friends. My life was so different . . . strangers in parks and students on campus stopping to ask if I needed help or “whether I was born this way?” I spent countless moments filling empty days desperately yearning for the professional respect, collegiality, and socializing that had once come to

me so easily. It horrified me that the reactions of my one-time colleagues and new acquaintances seemed to rob me of the social cachet of “being one of the crowd.” How would I ever recover a sense of belonging to the world, any world?

The answer came very unexpectedly when I found myself randomly deemed ineligible for the accessible public transportation service that had been transporting me to therapy. Outraged that neither transportation bureaucrats or my state senators were willing to help me counter this grave injustice, I reluctantly allowed myself to connect with the local independent living center for people with disabilities that advocated to increase transit options. In order to make this contact I was forced to swallow my pride and acknowledge that I was a disenfranchised person with a disability, sorely in need of help. In therapy we addressed my initial discomfort in making the contact and how frightening it was for me to identify with the people working at the center. For a long time I kept saying that these people were not like me because I was a business-woman.

But with support in therapy I permitted myself to work with other professional women with disabilities from the suburbs and watched my consciousness slowly begin to shift. Then when we confronted board members of the transit agency who angrily referred to us as “you people, making unreasonable demands,” I realized that my business persona was quickly yielding to the truth that I was more like the women with disabilities at my side standing up for what we believed to be just than the suited businessmen from the transit agency taking great pleasure in denouncing our entitlements as taxpayers.

It was at that moment that a new community and sense of pride emerged for me. For years to come, in therapy we used that experience as a platform to launch an empowering range of breakthroughs in my consciousness that included lifetime firsts such as publishing a magazine, participating in school parenting activities and becoming gainfully employed as the director of a women’s health center.

(WH) JPR’s story illustrates the difficulties women face in coping with real and perceived losses in status and identity, and the challenges inherent in re-authoring their life stories in a positive way (Stewart, 2000). JPR’s first challenge was to regain her self-esteem after losing the identity she had worked so hard to foster and in which she had taken so much pride. Accepting a new identity depended a great deal upon her ability to see that such a change

was not a compromise, although at first it was impossible to see it any other way. As a therapist, it was necessary for me to resist being drawn into the despair she felt and to tolerate my own horror as she relived and re-experienced the initial trauma as well as a series of subsequent blows to her prior sense of self (e.g., the development of rheumatoid arthritis). Then, it was important to reframe her experience of her current condition in terms that allowed her to perceive possibilities for herself and her future that she found difficult to envision. Note that reframing does not mean denying the magnitude of distress, injustice, or pain: The feelings must be acknowledged and honored. Reframing means introducing or fostering narratives or perspectives that provide an alternative to the limiting, self-defeating, or self-denigrating ones within which the woman with TBI may find herself locked. To the degree that such reframing can be accompanied by concrete opportunities to experience mastery, social connectedness, and self-fulfillment, it will contribute to the (re)construction of a transformed, but rewarding, identity.

(DM) Jessica's isolation was on many levels. Her friends and family did not understand what it was like for her to have had a brain injury. Even before her accident, she had experienced some feelings of being an "outsider" because English was not her first language and she was a "mature" student. She had coped by immersing herself in her academic work and focusing on the fact that her tenure at the university was temporary. After the injury, she was unable to concentrate, focus, and work "as hard" as she used to. She had "lost" time and had to drop numerous courses. She reported that she felt ashamed and angry at herself. While one of my supervisors wanted me to focus on the issues of shame that are stereotypically associated with Asian American women, I knew that the feelings of hopelessness, self-blame and regret were intertwined with Jessica's brain injury. Her cultural upbringing and pride were being shaken by having to access services and "fail" at tasks at which she had easily excelled before the accident. But the injury itself had resulted in more concrete and literal thinking about her situation as well as perseverance; she perseverated on being unable to accomplish her goals and therefore felt more ashamed than she would have had she not been perseverating on her difficulties.

Jessica's religious beliefs had always been a source of comfort for her. But now, after her injury, she felt distant from God. She also did not want to "waste time" going to church, an activity she had engaged in regularly since her childhood, because her schoolwork was taking exponentially longer to complete than it did before her injury. She felt very alone.

Jessica's acceptance of her cognitive disability was the key to alleviation of some of her difficulties. Like JPR, Jessica did not initially feel comfortable identifying as someone with a disability. She reported that the only reason she used the office of rehabilitative services was because she had no other choice. She worried that someone would see her enter the office or ask her why she was able to receive extended time on her exams. She reported that she did not want others to think that she was trying to get away with doing less work or having it easier. She did not identify with the students in wheelchairs or with more obvious disabilities who were typically in the office of rehabilitative services.

Jessica did not enter psychotherapy until she "couldn't take it on her own." She was seen by the counseling center on campus after her Resident Advisor expressed concern about suicidality and only agreed to see me for therapy because she had heard that I was a "specialist in Neuropsychology" and could help her with her "brain problems." The fact that I was a South Asian American woman also helped the process. Jessica agreed that Taiwanese and Indians in Asia might not have a lot in common, but in the Midwestern American context, she felt that I understood her cultural, family, social and interpersonal issues more than a non-Asian woman would have understood. Jessica's multiple identities (Asian American, Woman, Person with Cognitive Disability, University Student, Therapy Client) played out in various ways to simultaneously isolate her and offer opportunities for making connection with a variety of support services. In therapy, we explored the diverse communities with which she identified and brainstormed about how best to connect with various parts of herself and her experiences to help her cope with the difficulties that she was experiencing. I underscored that identifying with one community did not mean disowning another community and that the process was dynamic and continuously open to reconfiguration.

Emotional Functioning

Women with TBI often enter a psychotherapeutic relationship when they are in emotional distress. The distress can take the form of a range of clinical and subsyndromal mood and anxiety disorders including depression, anxiety, and post-traumatic stress reactions such as emotional numbness. Some of the symptoms are directly related to the brain injury itself (e.g., specific sites of damage are associated with depression), while others are related to the cultural experience of living life after brain injury (e.g., adjusting to living in the United States as a woman with a disability) and still others to an individual's reactions to acquiring a brain injury and the associated losses mentioned above. Often through the therapeutic process the conceptualizations of loss turn into conceptualizations of new opportunities or new challenges, but working through and alleviating emotional distress is typically a major focus of therapy.

(JPR) Two months after marriage and into grad school, my successes withered into a thicket of miseries. Increasingly, my husband was coming home from work to find me crumpled on the floor weeping uncontrollably. Nights offered little respite and were punctured by torrents of terrors and nightmares that hijacked me underneath a shield of blankets that I clutched tightly over my head until I felt safe enough to fall asleep. That I was "coming undone" came as a big disappointment and shock to my parents, who urged me to shape up before my husband got fed up and left. The injury had been trying for them too; always hoping for the best as they watched and cheered me to inch my way back to sit up, walk in the parallel bars, dress one-handedly, toilet, bathe and feed myself independently. To my parents, my rehabilitation was short of miraculous. When I walked down the aisle with my husband they were convinced that their "old vibrant" daughter was back. And so was I until my emotional state began to disintegrate. With my husband's support I soon sought help.

While I was always privy to therapists and counselors, locking into the right fit would prove arduous. At the rehab hospital I was assigned a competent male psychologist who worked effectively with me in the bubble world of an in-patient. But upon discharge my discomfort in discussing matters of sexuality with a man and his disconnection from my pre-injured life drove me to re-connect with my female pre-injury counselor. Resuming ther-

apy with her was comforting and familiar but short-lived. By the fourth session it was clear that something was missing. For the first time in our five-year relationship, she was coming up short on guidance—ending every session suggesting that perhaps I ought to consult with my neurologist on this fear or that anxiety. I welcomed her honesty but found her frequent urgings to consult with my neurologist untenable. Living on a fixed income I was strapped financially, in no position to pay for ongoing sessions with both my counselor and my neurologist simply to save my marriage. Relentless in my quest I tried another venue, investigating support groups for TBI and those for violence, only to reaffirm my need for individual therapy.

Alone, once again I found myself isolated and terrified. That I had lost most of my close business friends post-injury and the fact that my former employer was unwilling to re-hire me at a wage comparable to my pre-injury salary just added to my terror. On the verge of losing my new husband and quitting grad school, my life was quickly spiraling downward when something extraordinary happened. Studying at the University of Chicago, I immersed myself in the philosophy of science focusing on the mind/brain relationship and soon stumbled upon Professor Jerre Levy, a woman brain researcher on campus. I absorbed her comments about my “smart” brain putting me in good stead for additional recovery like a wilted rose bush soaks up drops of rain after a drought. But when it came to my request for help in finding a therapist, she was hard-pressed. Upon further reflection, she referred me to WH.

When WH and I began our relationship in 1984, I was struggling with meaning. I told her that I had lost touch with what it “meant” to engage in everyday activities like ordering meat from a butcher, going to hear a concert, or reading a book. Everything, I complained, “felt like cardboard.” Like someone who had forgotten the knack of riding a bicycle, I had lost the feel for life, didn’t know how to get it back. What was worse was the fear. . . . Everything terrified me; the terror itself petrified me. I became obsessed with the idea that bugs were breeding and living all over my body.

Within the first year of therapy I devoted much of my therapy time to describing my fears and anxieties and to the hallucinogenic-like quality of my new reality. We uncovered problems with first time phobias and perseveration, and then created our own

strategies for managing them. Meeting steadily two to three times a week, and paying for my sessions with Medicare, I gradually began to trust WH's understanding of the complexities of the damage to the right hemisphere of my brain. As we sleuthed back and forth through issues of my childhood and current day dilemmas that included an array of issues ranging from my risk for and terror of seizures to my frustrations trying to get into the physically inaccessible campus library, developmental questions concerning my biological clock pressed forward.

(WH) My work with JPR illustrates that psychotherapy with women who have experienced brain injuries is best viewed as an ongoing process. Short-term interventions may be helpful, but the complexity of the problems generally benefits from a lengthier intervention. In JPR's case it was necessary to unravel the threads that originated in her family of origin from those that stemmed from her traumatic experience. In turn, these had to be differentiated from the cognitive and physical sequelae of damage to the particular parts of her brain that had been injured.

Furthermore, the intensity of the trauma had far-reaching psychological consequences. Issues from JPR's childhood re-emerged and anything not fully resolved in the past was re-cycled with a vengeance. Her defense mechanisms and psychological buffers were eroded by the intensity of her pain and loss. Like anyone in the throes of extreme grief, her emotional resources were stretched to the limit. However, the circumstances made it difficult for her support network to perceive and respond to that grief.

Typically, parents, friends, and rehabilitation therapists (physical, speech and language, etc.) are focused on encouraging the person with a brain injury to "buck up," to tackle the task, to have a "stiff upper lip," to tough it out. This type of coaching is very positive with regard to getting a person to the point where they can experience a success in a particular domain (e.g., walking a certain distance). However, that domain is generally limited to a specific activity or behavior. Few individuals in the grieving person's world have the opportunity or time to acknowledge and explore the pain that she is experiencing. The data, however, are incontrovertible in showing that the degree to which a person is able to express and process the emotions surrounding a traumatic event is directly related to the degree to which that event has an impact on one's subsequent physical and mental health (e.g., Pennebaker, 1995). Psychother-

apy has a unique contribution to make in this process and hence in the emotional, physical, and social adjustment to trauma.

Frequently compounding the grieving process in cases of brain injury, as exemplified in JPR's case, are the sequelae of post-traumatic stress symptoms. These can interfere with the emotional process of confronting the feelings and experiences in the context of a safe and supportive environment. Emotional numbing is a core characteristic of post-traumatic stress, as is a tendency to over-react to a variety of stimuli with catastrophic fear and anxiety. JPR struggled with this sense of numbness, experienced as a lack of "meaning" and emotional connection. She was also overcome by a host of fears that interfered with her daily activities and well-being in a variety of ways.

JPR's sense of numbness and her catastrophic anxiety were resolved in therapy through a patient but persistent process of acknowledging her feelings in all of their intensity and by providing a "holding environment" in which JPR could experience them. These experiences were bounded by feedback and discussion that put things gradually in perspective by reflecting upon and understanding the causes of the feelings, which diminished the tendency to generalize them to other situations.

(DM) Like JPR, Jessica also had to search for the appropriate therapeutic service provider. She wanted someone who understood the ways in which her brain injury could have affected her functioning. A male counselor at the University counseling center had worked with her for a few sessions and "it wasn't working out." He simultaneously referred her to the neuropsychological assessment practicum (a course which provides clinical training by combining didactic instruction with hands-on experience) and to me for psychotherapy. She was in the process of undergoing a neuropsychological assessment when she was referred to me and searching for answers to questions that she felt would clear up her problems. The neuropsychological test results did not prove to be as helpful as she and I had hoped they would be. For example, on tests of cognitive functioning, Jessica consistently scored in the average to low-average range with relative weaknesses in language and concentration. *The evaluator was unsure whether Jessica's difficulties were due to English being her second language or to changes due to her brain injury. There was no baseline information for comparison and furthermore, neuropsychological assessment measures are typically not normed on Asian American populations.* Experientially, Jessica felt "like a different person" after the injury and she expected to hear

clear-cut findings that documented her difficulties and justified a biological basis for her problems. In therapy we examined what it meant for her to have a brain injury and how best to work with her strengths. We focused on alleviating her symptoms independent of the etiology of the difficulties.

Jessica was depressed and anxious. Sometimes she could not get out of bed. She had trouble concentrating, had lost interest in friends, and did not enjoy anything. My supervisor felt strongly that she should be on antidepressants but Jessica refused. Jessica was also anxious, especially around academic issues. She reported at least one panic attack during an exam, and often “went blank” when she was under pressure. She cried through sessions and cancelled others because she was too stressed. She reported that her symptomatology was new to her. She had been sad before and had experienced and overcome difficulties, but the TBI and her subsequent problems were of a magnitude that she had no measure for nor words to express. How would she earn her living, who would accept her and love her with her new difficulties, how would she pass her exams and graduate with the degree for which she had been working for so many years? She was overwhelmed with worries and could not sleep, further exacerbating her inability to concentrate and overwhelming feeling of fatigue.

In therapy, cognitive-behavioral techniques were used to help Jessica reduce her levels of anxiety and manage the stress she was experiencing. Relaxation techniques such as guided relaxation and breathing were also used. I encouraged her to meditate and go to church (sources of relaxation for her before her injury). We sat on the floor during therapy sessions and turned off the lights because the chairs made it difficult for her to relax and the fluorescent lights exacerbated her headaches. In addition, we explored her emotional reactions in the context of her current abilities and experiences and supportive psychotherapy was provided to encourage her to re-frame her distress in a more positive way, while at the same time acknowledging the losses and difficulties she was facing. She reported that the therapy session was the one hour a week that she could focus on herself and “be free to be herself.”

Parenting

For JPR, the decision to become pregnant was a pivotal point in the therapeutic process. We end our discussion of social and emotional

functioning in women with brain injury with JPR's narrative about deciding to and becoming a mother.

(JPR) Two years into therapy I felt more secure in my marriage and expressed an interest in becoming pregnant. The subject was a loaded one for me because it seemed as though I was still struggling to learn how to dress, transport and bathe myself. How could I accept responsibility for mothering a helpless infant when I hadn't yet fully learned to manage my own personal care? The issue became even more daunting when my search for resources and supports for mothers with disabilities came up empty. Once again WH and I negotiated new ground by discovering methods and frameworks for me to embrace that could help me shift the activity of mothering with the effects of TBI from the pathological realm, as something I shouldn't or couldn't do, to a framework of wholeness and normality; something at which I could thrive and succeed.

When I did get pregnant with my son, my neurologist assured me that carrying the baby during pregnancy and delivering safely would be no problem. In therapy we confronted the delicate issue of what it meant to be a mother when one was physically incapable of independently performing most parenting tasks such as bathing, dressing and diapering. This discussion of parenting competence, given my limitations due to the brain injury, was to be an ongoing one, starting with addressing how to meet the basic needs of the infant and evolving into a focus on my physical constraints at keeping up with a robust toddler and my anxieties as my son moved into school life. Irritating inconveniences like inaccessible preschools, disability unfriendly pediatricians and my loneliness as a mom with unique concerns were topics addressed and usually resolved positively in therapy. However, there never seemed to be enough time to adequately quell the lack of confidence I felt in my new role as mom when it came to my perceived reactions of his teachers, his friends and their mothers to my disabilities. My sense of entitlement as a mother was yet a long time to come.

As my son grew, so did I. Like any other parent I faced uncertainties in his development, but as time progressed it was becoming abundantly clear that underlying the secret fears I shared in therapy as a woman with a brain injury, there were two recurring themes in particular that like shifting tectonic plates, reconfiguring seaboard communities, these forces had the power to create new

worlds as well as shatter current ones. For me were the nagging problems of “transportation/my mobility” and the residue of emotions I carried inside me regarding the “violence/my former fiancé’s murder/my survival.”

Living with serious mobility impairments due to paralysis on the left side of my body, coupled with my inability to resume driving, I experienced a wave of insecurities that often seemed to swamp the healing potential of therapy. It wasn’t uncommon for me to be without reliable transportation to get to and from my home and the university. Unable to take the inaccessible public transit I relied on a form of special transit for the disabled that was limited in its scope of service and its reliability. Sometimes it seemed that all I was addressing in therapy was my frustration in attempting to get my baby around town or my ability to even get to and from therapy.

Shortly after my son was born we discovered in therapy that I was struggling to disassociate him from my dead former fiancé. For example, I kept calling my son by my late fiancé’s name. Slowly, after some years in therapy, WH began to guide me back to Hawaii, occasionally referring to the night in the tent. But another few years would pass before we were able to relocate me back inside the tent. The process would be long, tender, and confusing, but in the end enormously rewarding—once we were able to clearly identify and understand the tenuous connections between the normal emotional baggage I carried pre-injury together with the fears I had resulting from the organic nature of the brain injury itself and those triggered by the post-traumatic stress from my assault and my fiancé’s murder.

CONCLUSION AND RECOMMENDATIONS

We have used two exemplary cases of women who sustained a brain injury to illustrate the social and emotional sequelae of TBI and the issues that may be addressed in the context of psychotherapy. While JPR and Jessica had different histories and experiences, common themes emerged in their adjustment process. Social isolation included relating differently to friends and family, struggling with gaining access to services such as transportation or academic supports, and having difficulty finding appropriate therapeutic services. Emotional functioning included fear, anxiety, shame, hopelessness, helplessness, and posttraumatic stress

symptoms. In working with both JPR and Jessica, their therapists had to try various strategies, be flexible in their approach and be open to novel ways of relating in a therapeutic relationship. We end with some suggestions that may help practitioners and women living with TBI facilitate the adjustment process.

Understanding the individual as belonging to multiple communities (e.g., based on class, gender, ethnicity, religion, sexual orientation, disability status) is one helpful way to increase access to support and services. The TBI might have changed the level of comfort and feelings of belonging within the various communities of which a woman is a member. Therefore, new alliances might need to be formed and explored. For some women, the disability community can be a source of empowerment. We recommend that therapists make themselves aware of the disability advocates and support groups in their geographic areas. The Brain Injury Association (www.biausa.org), a non-profit agency started by a woman with a child with TBI, has regional and state offices which can provide information on resources. The Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago can also be a good starting place. They regularly publish an educational newsletter, *Resourceful Woman*, which is free of charge and available by contacting hrcwd@rehabchicago.org. For women who do not identify as someone with a disability or who do not feel accepted by the disability community, alliance with other communities of support can be explored.

It is helpful for the therapist to have information from a neuropsychological evaluation. While it is best to have current data, historical information might also be helpful in understanding the dynamics of various areas of functioning. A neuropsychological examination will typically address motor, sensory-perceptual, visuo-spatial, intellectual, cognitive flexibility, memory, language, and academic functioning. For example, standardized information about verbal, nonverbal, short-term and long-term memory would be helpful in tailoring psychotherapeutic goals realistically. While performance on time-constrained, standardized measures can serve as guidelines for designing appropriate interventions, *the ecological validity of neuropsychological assessment measures is not as strong as the reliability and content and construct validity*. For example, a woman who shows impairment on a test of facial recognition may or may not have difficulties recognizing “real world” faces in which other contextual cues are present. But a neuropsychological evaluation will give the therapist a reasonable idea about which areas are relative strengths and weaknesses for the woman

with TBI. The neuropsychologist may also have creative ideas for intervention or have found out key social and historical information which will facilitate the psychotherapeutic process.

Exploring loss is often a fundamental task of psychotherapy with women with TBI and it is important to remember that there are individual differences in response to loss (e.g., Wortman & Silver, 1989). The therapist should be careful not to perpetuate assumptions about healthy or “normal” reactions to loss and to understand that the range of reactions may be much wider than is commonly assumed.

The specific context of the brain injury is also very important. For example, if the TBI is a result of violence, there might be posttraumatic stress responses such as emotional numbing. If the injury occurred in the context of interpersonal or domestic violence, then the woman might have had to deal with the police and medical professionals who do not investigate the context of the injury, and who are relatively insensitive to cultural norms about privacy and denial of violence. This can be particularly challenging if the individual is experiencing cognitive deficits and symptoms of post-traumatic stress.

The meaning of the injury to the individual is another issue that can affect responses. Awareness of compromised cognitive abilities that were fundamental to their previous lives (e.g., a teacher who has problems organizing verbal information) might not only pose obvious problems in returning to work, but can undermine the sense of self that the woman has created. Again, if these issues are not dealt with in a therapeutic setting, they can have a potent influence on an individual’s ability to function effectively.

The cultural context of the injury should also be addressed. If the person has an observable disability (e.g., one that leads to the use of a wheelchair) issues (both positive and negative) about acceptance and societal attitudes might need to be addressed. Cultural beliefs may be internalized and affect the individual’s self-concept. In addition, individuals from minority groups may have beliefs about health and competence that are not shared by the majority culture. In fact, given the diversity of experiences and worldviews regardless of ethnicity, systematically addressing beliefs about health, well-being, and competence will give the therapist a broader context for understanding the impact of the TBI.

In summary, the value of psychotherapy for women living with TBI is inestimable. This article has highlighted two of the most intractable problems women face, social isolation and emotional distress, that can be meaningfully addressed in psychotherapy, with important consequences for adjustment and well-being.

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