Chapter 13
Acquired Brain Injury and the Family: Challenges and Interventions

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Introduction

In clinical practice, the neurorehabilitation team encounters families that have experienced trauma, turmoil, and significant losses. Injuries are generally ill-timed and families are frequently ill-prepared for the length, uncertainty, and challenges of the post-injury process. In the literature, much has been written about "caregiver burden" and the stressful impact an acquired brain injury (ABI) can have on family systems. There is increasing awareness of the importance of identifying family needs and establishing effective and comprehensive interventions.

In some ways, families may actually experience more distress than the actual survivors of ABI. Crimmins (2000) described how accidents divide life into "the great Before and After." Survivors tend to have amnesia for the very time period that was most traumatic, whereas loved ones are clearly able to remember those unfortunate events. In the early months post-ABI, the entire family system tends to focus, almost exclusively, on the needs of the person who was injured. The amount of distress that a particular significant other will experience depends on a variety of variables, such as the quality of the relationship prior to the injury, the specific commitment to the injured loved one, the amount of time and extra responsibilities involved, other simultaneous life stressors, and the adaptiveness of coping skills. Each family subsystem confronts unique challenges, and each unit requires knowledge, partnership, and understanding from the team. In the best situations, the survivor has good awareness, is hardworking, has a constructive attitude, makes very active gains, and can reintegrate to productive roles at home and in society. In the most challenging situations, the survivor has poor awareness, severe impairments, requires long-term care, and will not be able to integrate successfully to home or community settings.

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Dell Orto and Power (2000) summarized various frustrations of primary caregivers, such as trying to balance multiple roles, feeling overwhelmed due to the lack of assistance by other significant others, feeling restricted socially, and dealing with the reality that their pre-morbid loved one may be permanently different.

Family Needs

There are commonalities in caregiver needs that we see clinically each day. Despite the type of acquired brain injury and regardless of age, gender, background, and other differences, caregivers need education, coping tools, and hope. They need to feel respected and empowered by the clinical team because their situation has led them to feel powerless and deeply concerned about how the future will unfold.

Powell et al. (2017) looked at the primary concerns of caregivers of adults with traumatic brain injury (TBI) during the initial months following discharge to home. Caregivers were most concerned about managing the client's emotional and behavioral changes as well as balancing their time properly to make sure their own needs were met. In the clinical world, families report initial concerns upon client's discharge home to be safety related, assuring that medical and rehabilitation needs are properly met, and learning to cope with role changes. Carlozzi et al. (2015) describe how caregivers have most difficulty meeting their needs for social and emotional health. Powell et al. (2017) describe how caregivers gradually return to increased participation in everyday activities over time, similar to what is seen in the literature regarding caregivers of stroke survivors (Cameron & Gignac, 2008).

Hart et al. (2018) reconceptualize moderate and severe TBI as a chronic condition and do a scoping review of the literature. They describe the variability in educational materials used across sites and lack of uniformity in training of caregivers. They highlight the importance of developing evidence-based educational interventions and recommend the use of a Self-Management Training model which has been effective for other chronic conditions (Lorig & Holman, 2003) due to inclusion of problem-solving strategies and goal setting in addition to provision of education.

Research, going back 40 years, highlighted that caregivers of individuals post-ABI are at increased risk for depression, anxiety, and physical illness (Oddy, Humphrey, & Uttley, 1978) which we still see clinically today. The Family Needs Questionnaire (FNQ; Kreutzer, Serio, & Bergquist, 1994) is a classic tool that was developed to quantify the multiple needs of family members in order to identify families at high risk and target interventions appropriately. The six categories identified were needs for health information, emotional support, instrumental support (refers to the need for respite and practical everyday assistance), professional support, community support, and involvement in care. The scale was developed based on extensive family interviewing and a comprehensive literature review (Serio, Kreutzer, & Witol, 1997). Research has shown that medical needs are perceived to be most important as well as most frequently met. In contrast, emotional needs were most often perceived as unmet (Serio, Kreutzer, & Gervasio, 1995).

Witol, Sander, and Kreutzer (1996) reported that families are generally satisfied with the information and support provided by professionals at early and late post-injury intervals. However, family members have difficulty getting their emotional and instrumental support needs met, a situation worsening over time in the case of emotional support.

Unpublished data from 2006 involving comparison of FNQ results in three different settings reflected more unmet needs in families attending a long-term stroke support group than in families of survivors in outpatient or inpatient neurorehabilitation programs. The low percentage of needs being met in families of individuals in the long-term stroke support group may be due to a selection factor, as the stroke group participants are not representative of all people post-stroke. The stroke group is a social/recreational program that meets on a weekly basis for survivors and caregivers. The families studied had been caregiving for an average of 7 years.

Serio et al. (1995) reviewed the predictors of family outcome by studying injury, patient, and family characteristics. They concluded that time since injury influences family reactions as caregivers report more unmet needs over time, consistent with our unpublished data. These authors also reported that patients' emotional and behavioral problems correlated with increased caregiver stress. Family members' perceptions of patients' problems are more important predictors of needs than test results. In terms of family characteristics, they found that spouses had more difficulty adjusting to the injury of a loved one than parents, reporting more depression, anxiety, isolation, and distress.

The Brain Injury Family Intervention (BIFI) is an evidence-based intervention that was designed to mitigate family challenges by providing education and teaching effective coping tools. Using the FNQ, significant gains were found in the areas of health information, emotional support, professional support, and involvement in care following training with the BIFI (Kreutzer, Stejskal, Ketchum, & Marwitz, 2009). Meixner, O'Donoghue, and Hart (2017) demonstrated that use of the BIFI following a 3 day training protocol boosted providers' knowledge and confidence in working with clients with TBI and their caregivers.

Kitter and Sharman (2015) describe the financial strain that caregivers deal with due to the high costs of care and high caregiver demands limiting their ability to work. Sabella, Andrzejewski, and Wallgren (2018) come up with a brief scale of financial hardship for caregivers of clients with TBI. Their goal was to identify financial hardships in family and preliminary findings indicate it may be a useful scale.

Family Coping

Families are the neurorehabilitation team's primary partners in facilitating survivor progress, and they play a major role in client recovery. Consequently, meeting caregivers' needs and reinforcing positive coping skills is critical (Serio et al., 1997).

The literature on family coping post-ABI includes many references to Kubler-Ross's (1983) stages of denial, anger, depression, and adjustment following a major loss. Each member of the family as well as the entire family unit as a whole goes through an adjustment period following the ABI of a loved one. In clinical practice, many survivors and families have rebelled against the terms "adjustment" and "acceptance" of an injury, assuming that these words denote "giving in" to the injury instead of overcoming it. In reality, these terms refer to the ability of the client and family to go forward in a productive manner despite the sequelae of the injury.

Lezak's classic article (1978) "Living with the Characterologically Altered Brain Injured Patient" describes the qualitative challenges that families face in dealing with loved ones who have behavioral difficulties following an ABI. She discusses several categories of behavioral alterations that create the greatest adjustment challenges for families: reduced empathy and self-centered behavior, reduced self-regulation, increased impulsivity and silliness, reduced executive functioning abilities, such as difficulties with initiation and planning, increased or reduced sexual interest, and difficulty with social learning. Over time, there has been more emphasis on quantitative measures of family needs and coping styles.

Nabors, Seacat, and Rosenthal (2002) described various factors that are powerful predictors of family adjustment, such as pre-injury family functioning, level of financial stress, perceived level of burden, coping mechanisms used, and availability of social support systems. They highlighted the importance of ongoing assessments of family needs.

Man (2002) identified several types of adaptive coping strategies used by families of ABI survivors, inclusive of positive appraisal, resource requisition, family tension management, and acquisition of social support.

Although there are meaningful and rewarding aspects of being a primary caregiver, at times the role can be very overwhelming, lonely, and thankless. It is not uncommon for survivors to unfairly direct a significant amount of post-injury frustration and anger toward their loved ones, by verbal attacks or disrespectful behavior. Caregivers usually have to bear the brunt of their loved one's frustration. It is important for significant others to learn how to deescalate stressful encounters and how to cope constructively with a loved one's unreasonable behavior. Without proper training to handle these challenging situations, many caregivers can turn toward destructive coping strategies.

Cameron, Cheung, Streiner, Coyte, and Stewart (2006) found that caregivers experience more symptoms of depression when they care for survivors of stroke who exhibit memory and comprehension symptoms. Their study demonstrated that 45% of caregivers reported elevated levels of symptoms of depression. They emphasized the importance of addressing the needs of caregivers by providing needed information and resources on how to handle neurocognitive difficulties.

Family Subsystems

Spouses, parents, siblings, and children are frequently the caregivers who are involved in the recovery process as primary caregivers. Sady et al. (2010) report that most caregivers of clients with TBI are parents and spouses.

Individuals who are dealing with the ABI of a marital partner are often dealing with financial, social, and personal stressors in addition to adjusting to the particular physical, cognitive, and psychosocial changes in their spouse. A spouse whose loved one has been severely injured may lose a confidante, sexual partner, household comanager, and childrearing assistant all at once (Serio et al., 1995).

Kreutzer, Gervasio, and Camplair (1994) stated that caregiving spouses reported greater family dysfunction and increased likelihood of depression compared to parents who acted as primary caregivers. Spouses of individuals post-ABI face a loss of peer-based, reciprocal relationships when they take on caregiving roles, compared to parents who return to roles familiar from child-rearing years (Wood, Liossi, & Wood, 2005). The concept of social limbo experienced by spouses after the ABI of their partner refers to the fact that spouses may not only lose the equal partnership with their loved one but they also lose the ability to maintain friendships outside of the marriage. This is the case because of lack of time or rejection by peers due to the survivor's neurobehavioral changes (Lezak, 1978). Wood et al. (2005) found that unpredictable behavior on the part of the survivor imposed the greatest burden on marital relationships and contributed to relationship breakdown.

Blais and Boisvert (2005) examined the factors associated with marital adjustment following ABI. They found that frequent use of problem-solving skills and positive reinterpretation of problems encountered, in addition to low use of avoidant coping skills were associated with higher adjustment levels.

Katz, Kravetz, and Grynbaum (2005) researched the impact of wives' "coping flexibility" and duration of time since the husband's traumatic brain injury (TBI) on perceived burden. They focused on wives in particular because their literature review demonstrated that TBI creates more difficulties for wives than for other family members. These authors defined coping flexibility as the ability to modify an ineffective coping approach and to seek a more appropriate and adaptive coping strategy. They found that only in cases of wives who had reduced coping flexibility did perceive burden increase with time since injury.

Each survivor's particular combination of neurobehavioral, cognitive, and physical difficulties in addition to the effects of medications can pose unique challenges to intimacy. Problems with focused and sustained attention can interfere with both social and physical aspects of sexual activity. Frontal lobe disinhibition can lead to socially inappropriate sexual behavior. At the other extreme are survivors who are very withdrawn or passive following their ABI and who demonstrate a very decreased libido. Functional deficits, such as communication problems, mobility loss, perceptual problems, loss of sense of smell, reduced sensation and tremor, can all contribute to intimacy challenges. As survivors with ABI may no longer have the full capacity for empathy and interpersonal sensitivity, they may no longer be able to satisfy their partner's need for affection or intimacy (Lezak, 1978). Spouses may struggle with shifting from caregiver to sexual partner, especially in cases where the injured spouse has become very childlike.

Screening survivors and families for concerns regarding changes in intimacy should be part of the initial clinical interview, so that difficulties can be identified and addressed early on.

When parents are the primary caregivers, the role shift is different from that of a spouse. In cases where there are two parents, both can help each other assist their child. There is some familiarity in caring for a grown child as parents once did in the past, in contrast to a spouse who has always been an equal with his or her marital partner. Additionally, parents generally feel unconditional love and responsibility toward their child regardless of the level of challenge presented. In the case of a marriage partner, there is always the option of divorce. Testa, Malec, Moessner, and Brown (2006) reported that caregivers had more complaints at 2 years post-injury than at 6 months, which they speculate may underlie the high rate of divorce, up to two-thirds, at 2 years post-injury. Their study noted a strong relationship between neurobehavioral problems and impaired family functioning.

Benn and McColl (2004) stated that parents who viewed the ABI of their child as a manageable family challenge instead of a catastrophe were able to adapt more successfully. These researchers discussed the process of redefinition of stressful events to make them more meaningful. They emphasized that coping strategies that allowed parents to reframe stressors and to obtain social support helped to reduce stress.

MS sustained a severe TBI due to a fall at age 27. He had a substance abuse history and had preinjury challenges relating to self-esteem, anxiety, and depression. D, his mother, was his only significant other and primary caregiver. D was bright, highly educated, and very eager to help her son improve. She suffered post-traumatic stress disorder (PTSD), activated by the events that started when she received the frightening phone call from the police department on the night of her son's injury. Each time MS had a setback, D's PTSD was reactivated. MS's lack of insight, anger control problems, and poor attitude in addition to physical and cognitive difficulties were very upsetting to his mother, who was hopeful that the injury could bring about post-ABI growth (Chap. 12).

D attended counseling sessions aimed at reducing symptoms of post-traumatic stress disorder and teaching strategies to set limits with her son, communicate her thoughts in a constructive fashion, and improve her sense of control and use of adaptive outlets for frustration. Fortunately, MS gradually made remarkable gains in his insight, attitude, and functional status. D also recovered from the emotional trauma and was able to foster her son's continued growth and reintegration to school and work.

Parents of young children or adolescents post-ABI frequently report significant distress and fear regarding their child's altered skills and their recovery. The family unit can become more cohesive or more at risk for breakdown following a child's injury, depending on the family unit's preinjury closeness, and the amount of support and guidance they receive. Their primary challenges include making certain that their child receives the appropriate neurorehabilitation programming and that he or she is reintegrated successfully to school at the appropriate time. Preventing social isolation and boosting self-esteem are usually important goals for children post-ABI that the clinical team can help address. Parents of young children are usually very eager to help the team by carrying over goals to the home setting and reinforcing home exercise programs. It isn't uncommon for parents to be in conflict relating to how to discipline their child with ABI, and how lenient or strict to be in rule setting and expectations. It is helpful for the clinician to train both parents in providing the same message to their child so as to increase clarity about parental expectations. Family counseling with the emphasis on parents working together as a team for the benefit of the family unit is usually very productive.

Parents of grown, married children who sustain an ABI can be very helpful to the survivor's spouse, who is usually exhausted by the demands of caregiving in addition to his or her other usual responsibilities. It is in everyone's best interest when different family members come together to best meet the needs of an injured loved one. In families where there is much tension or lack of cohesiveness, the survivor will ultimately suffer. Frequently, competition arises between the parents of the injured individual and his or her spouse regarding decision-making and treatment planning. A counselor can be very helpful in assisting different family members in working together for the survivor's benefit despite different viewpoints.

Elderly parents who become the primary caregivers of an adult child status post an ABI are in a particularly difficult situation. They suddenly have increased pressures and responsibilities instead of fewer daily activities and the enjoyment of retirement. In cases where their child will need long-term programming, parents usually gain greater peace of mind if they are able to locate a long-term residential program or supported living during their life time, thereby reassured that their loved one is being taken care of properly. It is important that elderly parents be encouraged to secure the assistance of an aide or other support services to ensure some respite.

Young children of a parent with an ABI often deal with the challenge of receiving less attention than they did prior to their parent's injury, as one parent suddenly has increased needs and the other parent consequently has less time. The child may feel an internal void due to the lack of attention and parental support. Additionally, in cases where the survivor has become childlike or attention seeking after the injury, competition may arise between the child and the injured parent for the other parent's time. Also, the child may be saddened or embarrassed by the fact that the parent is acting silly or inappropriate. Young children whose parent was injured frequently express guilt relating to somehow contributing to their parent's injury, and often require reassurance that they were not responsible. Additionally, children tend to express fear that their uninjured parent will get hurt, as they tend to feel more vulnerable following their other parent's injury. It is important to alert the child's principal, teachers, and school psychologist about the parent's injury and the need for the child to be given extra support and attention. It is also important for the child to be educated, based on his or her age level, on ABI sequelae, for better understanding of the parent's injury. This type of training should be offered through the neurorehabilitation program that the parent attends.

It is very difficult for a parent who sustained an ABI to reestablish his or her status at home after a lengthy post-injury absence due to hospitalization and acute rehabilitation. Oftentimes, the household developed new norms while the survivor was away and it's very common for children to have become accustomed to having all their needs met by the uninjured parent. The injured parent usually is frustrated by his or her loss of power and may feel unimportant or excluded from the rest of the family. He or she may have particular difficulty setting limits and demonstrating good frustration tolerance. Hypersensitivity to noise and motion may also negatively affect parent–child interactions. Confidence may be very reduced as the parent post-injury is dealing with the loss of status at home in addition to other post-ABI changes.

Adult children tend to become the significant other for their parent in cases where the other parent is deceased, disabled, or not involved. As grown children usually are in the process of developing their career and busy with their own family needs, time management usually becomes exceedingly difficult. These family members will require substantial support and training from the neurorehabilitation team to facilitate positive coping.

Siblings become the primary caregiver in cases where the injured brother or sister was single and their parents are either deceased, in another state, or don't speak English. Clinically, it has been noted that siblings tend to be very devoted significant others and usually stricter and less protective than parents. It is emotionally very draining for siblings to try to care for their injured loved one while trying to manage their own daily responsibilities, and they will require a lot of team support and guidance.

Young siblings whose brother or sister was injured have to deal with reduced attention by parents, increased tension at home, change in the quality of the relationship with the injured sibling, and embarrassment in cases where the injured brother or sister display neurobehavioral difficulties. It is important to alert the school about the challenges that the sibling is experiencing so increased attention and support can be offered.

Family Training

One of the significant benefits of educating families on the repercussions of ABI is the reduction in number of common errors or misunderstandings. For instance, families tend to confuse a survivor's reduced executive functioning skills with laziness. Also, families tend to misinterpret a survivor's emotional lability or pseudobulbar affect with depression, and they confuse organic lack of awareness with psychological denial.

Lezak (1988) found that families cope more effectively with a loved one's injury when they have knowledge about the nature of the emotional changes associated with ABI.

Reinforcement of adaptive coping skills and positive problem-solving abilities is very important during family training. Grant, Weaver, Elliot, Bartolucci, and Giger (2004) found that a negative orientation toward problem-solving and a lack of preparedness for the caregiver role were variables that were associated with a higher risk of depression in caregivers of stroke survivors.

Family-based psychosocial intervention after stroke has been shown to increase efficacy and control, optimize social support, improve family cohesion, and promote effective problem-solving (Glass et al., 2000).

Palmer, Glass, Palmer, Loo, and Wegener (2004) discussed the value of educating survivors and families about depression post-injury and reviewing ways to adaptively solve psychosocial challenges that can contribute to depression. They also reviewed ways to recognize, identify, and manage symptoms of depression.

Dell Orto and Power (2000) highlight the value of group counseling for families by describing it as a "counterforce to helplessness, isolation, and desperation." Group counseling provides a forum for families to learn from each other's successes and failures and obtain training regarding productive ways to respond to survivor's behaviors and needs. Families can also benefit from being paired with other families who are further along in the process, who can act as mentors based on their first-hand experience with similar challenges.

"Rehabilitation is an equalizing process. No one much cares what you did before; they're focused on what you can do now and how you can learn to live independently again" (Crimmins, 2000). In running family groups, the equalizing process that Crimmins refers to become very apparent. For example, an unexpectedly close kinship developed between two women who were members of a family educational/support group. One was a pediatrician and the other was a tollbooth operator. Prior to their husbands' injuries, the two would likely not have become friends due to differences in age as well as cultural and educational backgrounds. However, within the group they were equals and they shared strategies and resources in a supportive manner. Their husbands who also had little in common except their ABIs were also group equals in their attempts to regain their autonomy and proceed to the next step of the process.

No one can understand and relate to a family whose loved one was injured the way another family in a similar situation can. Group counseling can be a great source of peer and professional support.

SL sustained a stroke ending his career as a college professor. His primary difficulties included expressive aphasia and rigid thinking. He and his wife, J, were both in their sixties and were struggling to keep their relationship intact despite post-injury challenges.

In a stroke caregiver's group, J shared her plan to sell the family home of many years due to her own physical difficulties that made the upkeep of the house too cumbersome. Her husband was very against the move, due to his desire to remain in a familiar setting and exert some level of control over his life. He also was experiencing *post-injury rigidity of thinking and difficulty with change. Despite J's attempts to reason with her husband and have others, including professionals and family members, try to convince him of the merits of the move, he remained uncompromising and hostile. J was very emotionally distraught by her husband's lack of support of her needs since she had always been very dedicated and supportive of him. J benefited greatly from ventilating her mixed emotions to the group, who could relate to her challenging situation and provide reassurance, emotional support, understanding, and helpful advice. Over time, J felt empowered by the support and advice of the group to go forward with the sale of the house.*

How Families Can Help

Families need to know that it is a priority that they address their own physical and emotional health so that can successfully persist in caregiving. The following suggestions can optimize their effectiveness.

1. Reinforce carryover of learned strategies to the home setting to help survivors generalize progress to real life situations. If the client is resistant to doing same, speak to the therapy team and get ideas regarding how to address this obstacle.
2. Praise survivors on progress and provide only constructive criticism to help rebuild self-confidence. This is very vital as survivors tend to struggle with reduced sense of worth.
3. Help provide structure for survivors when they are not in rehabilitation so as to facilitate continued gains.
4. Keep survivors stimulated and active to help prevent regression but make certain they aren't overstimulated. Speak to the therapy team if you aren't sure how much stimulation is sufficient.
5. Be in regular contact with the neurorehabilitation team to exchange relevant information. Find out about available resources. Come to meetings prepared with questions.
6. Find an appropriate balance between over- and underprotectiveness to assure that the survivor is safe but also not prohibited from making gradual gains in self-reliance.
7. Encourage survivors to do home exercises. Assist the client in doing home exercises if they can't do alone.
8. Be flexible in creating a useful and realistic role for the survivor in the family. Families that identify meaningful roles for the survivor help clients rebuild a sense of purpose which boosts overall self-esteem.
9. Learn how to deescalate stressful situations so that the home is an environment of peace instead of chaos.
10. Participate in a family support group to obtain continued support and information.

11. Keep hopeful but realistic about continued progress.

The primary value of structured educational/support groups for families is that they provide knowledge about ABI and reinforce best practices for facilitating a loved one's recovery. It is comforting for families to meet others who can truly relate to the daily challenges they experience. Exchanging helpful ideas about how to handle difficult situations that arise can provide much support and reassurance to significant others. An agenda that is structured, facilitated by different team members, and that provides information about medical, physical, cognitive, and neurobehavioral sequelae of ABI best meets the needs of caregivers. A sample agenda includes:

1. Introduction—Review of the role of all team members and what to expect from rehabilitation.
2. Discussion regarding emotional and social changes post-ABI.
3. Discussion regarding neurocognitive changes post-ABI.
4. Discussion regarding the specialized roles of the physical therapist, speech/language pathologist, and occupational therapist.
5. Stress management training.
6. Problem solving how to adaptively handle challenging situations that arise.

Conclusion

A primary mission of the neurorehabilitation team is to alleviate family distress by providing information and support in a clear and sensitive manner. The team needs to aid and never impede a caregiver's attempts to cope constructively with the injury of a loved one. When the team is ineffective in meeting family needs, caregiver stress and frustration will be increased.

It is important for neurorehabilitation team members to be aware of the effects of prolonged caretaking on caregivers. The long-term implications of ABI can generate severe strain and tension on the survivor's family unit. Knowledge of the specific challenges that each family is dealing with and their particular strengths and vulnerabilities will help guide recommendations. All team members are responsible for prevention of caregiver breakdown and in providing families with skills, knowledge, support, and a sense of mastery.

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