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Brain Injury Rehabilitation for the Life Care Planner: A Look Through the Family Kaleidoscope

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Abstract. *The enormous burden and stress experienced by families with a family member with a brain injury has recently been addressed in the rehabilitation literature. The literature would suggest a positive relationship between the functioning of the family and rehabilitation outcomes. Using a family systems perspective, this article describes various interventions aimed at strengthening the family support system. In developing life care plans for individuals with brain injuries, it is essential that life care planners take into account the need for interventions that support and strengthen the family.*

Introduction

In recent years, there has been a growing understanding of the relationship between injury and illness recovery and the ability of families to cope. When dealing with serious injuries or illnesses, it is of paramount importance to consider and strengthen the family support system. Nowhere is this more evident than in the field of brain injury recovery. This article will examine marital and family issues that rehabilitation practitioners encounter when working with clients with brain injuries, as well as provide some useful strategies and interventions.

When a traumatic brain injury occurs, the client with a brain injury typically goes from being a fully functioning and contributing member of the family to one who is now dependant on others for all or most of his/her needs. The brain injury may manifest itself in terms of physical, cognitive, and personality difficulties. Research findings suggest that personality changes are perceived by family members to be far more difficult to cope with than physical or cognitive changes stemming from brain injuries (Brooks & McKinley, 1983; Jacobs, 1988). According to Lezak (1978), personality alterations of persons with brain injuries can roughly be conceptualized in five broad and overlapping categories (p. 592):

1. Impaired capacity for social perceptiveness, resulting in self-centered behavior and diminished ability to be empathetic and self-reflective,
2. Impaired capacity for social control giving rise to impulsivity, random restlessness, and impatience,
3. Stimulus-bound behavior resulting in difficulty in organizing, and decreased or absent behavioral initiative,
4. Emotional alterations such as apathy, silliness, lability, and either a greatly increased

sexual interest, or a virtual loss of sex drive,
5. Inability to profit from experience, even though the ability to absorb new information may be intact.

In studies involving clients with brain injuries, research findings reveal high levels of burden placed on families, and especially the family member who is the designated caregiver (Marsh, Kersal, Havill, & Sleigh, 1998; Brooks, Campsie, Symington, Beatty, & McKinley, 1986; Livingston, 1986). Sadly, longitudinal studies suggest that this burden becomes worse over time (Hoofien, Gilboa, Vakil, & Donovick, 2001; Brooks, et al, 1986 & 1987; Livingston, 1986). Other studies have demonstrated high levels of caregiver psychological distress including depression and anxiety (Marsh, et al. 1998; Kreutzer, Gervasio, & Camplair, 1994; Rosenbaum & Najenson, 1976). In couples where one spouse has suffered a brain injury, many studies have found alarmingly high incidence of marital breakdown. One such study, undertaken by Wood and Yurdakul (1996) utilizing a sample of 131 brain injured subjects, found that only 42% of couples were able to sustain their relationship longer than five years post injury.

Apart from the direct stresses on families when dealing with the physical, emotional, and personality changes of the client, there also are secondary stresses such as reduction of family income, alteration of interpersonal relations, work patterns and social activities. Oftentimes, children, who are bewildered by the profound changes and disruptions to their own lives within the family, will start "acting out" their feelings of confusion and despair in aggressive acts, or perhaps by becoming withdrawn. These secondary stresses compound the already fragile situation, with the added stresses serving only to inhibit the recovery of the family member with a brain injury.

Recent studies have demonstrated a positive relationship between functional and psychosocial outcome of clients with a brain injury and family functioning (Watts & Perlesz, 1999; Douglas & Spellacy, 1996; Rivara, Jaffe, Polissar, Fay, Liao, & Martin, 1996). In families where there was good social support, good communication, good problem solving abilities, and flexibility, there was better patient outcome (Rivara, et al. 1996; Douglas & Spellacy, 1996).

From a rehabilitation perspective, there can be little doubt as to the need to provide support services aimed at strengthening the functioning of the family as part of client/patient planning. The next section of this article will address different forms of family support and interventions for families who have a family member with brain injury.

Patient-Family Educational Support

During the acute stages of recovery, clients with brain injury often are unable to participate directly in rehabilitation planning due to the effects of their injuries. They may be in a coma, confused, agitated, or aphasic. Often by default, spouses and family members are placed in the position of having to make important decisions on behalf of the client, and oftentimes take over financial and other responsibilities. Yet, these same family members are in a very vulnerable position when they are faced with these extra demands. Family members close to the client often find themselves in a state of shock and disbelief (Mathis, 1984). It is a time of confusion and crisis for family members. This is the time when early family support services are necessary.

Patient-family education programs have now become an integral part of many in-patient and out-patient rehabilitation programs. During the early stages of traumatic brain injury, hospital and rehabilitation staff will often provide useful information to family members in the

form of booklets or other publications on the effects of brain injuries. This may be accompanied by educational information sessions. While this type of intervention is useful, it is equally important not to overload families with information as this might add to their already heightened sense of feeling overwhelmed. One of the difficulties with providing this sort of information early on is that it is nearly impossible to make predictions regarding eventual outcomes. In providing educational material describing various deficits associated with brain injuries, there is the risk of causing needless anxiety and alarm in family members. Although it is also tempting to provide reassurances that "everything will be fine" by professionals during the acute stages, this could engender feelings of anger and disillusion when the client does not make a full recovery.

Before providing any sort of information on the effects of brain injuries, it is important to gauge the readiness of family members to receive it. During the early stages following an injury, families first need a sense of hope, balanced by a sense of reality. Educational material and information about the effects should initially be relatively simple and offered on a "need to know" basis. During the initial stages following traumatic brain injury, it is common for family members to be in a state of denial. At this point in time, they may not be receptive to detailed or specific educational information. As the extent of deficits from the injury become clearer, and the family becomes more amenable, more specific information can be offered to them.

Once the client has moved from the initial or acute stages of the injury and into a rehabilitation setting, patient-family educational programs can be geared to the specific requirements of the client and family. According to Diehl (1983), in this context, patient-family educational programs help to "assist the patient and family to acquire new information, to develop skills, achieve confidence, assume behavior that aids in the coping process, and adapt to future situations (p. 395)." At this stage, family members involved in patient-family educational programs should be assuming an active role in terms of learning and applying specific skills. Integrating family members at this stage as partners in the rehabilitation process can be seen as a way to bridge the gap between the client's stay at the rehabilitation setting and when he or she is discharged home.

Stress Management

Family members typically are ill-equipped with the necessary skills of providing care for someone with a brain injury. It is crucial for caregivers to understand the value of taking care of themselves first, before the needs of the client. This notion may be counter-intuitive, in that it seems to be encouraging selfish behavior. However, the need for caregivers to maintain their own health, energy, and morale cannot be over stated. The well-being of the family member with a brain injury very much depends on the well-being of the caregiver. Therefore, any life care plan must include built-in allowances for the caregiver to have proper rest, to visit friends, engage in regular exercise, and opportunities for at least occasional self indulgences.

Respite

In order to provide caregivers with the opportunity to look after themselves and to maintain their own health, the provision of respite care is crucial. Respite care can take many shapes and forms. Respite can be family members, friends, or paid home support workers coming in to the home for a few hours at a time, or it could mean the family member of the client being placed at a respite facility for a week at a time. An effective life care plan will

include provisions for both short periods and longer terms of respite. Short periods of respite should be sufficient to allow for daily opportunities for the principle caregivers to look after their own needs, be it for a rest, to go shopping, visit with a friend, or perhaps take a class or a fitness break. This should not be confused with providing time to go out to attend meetings and appointments, or shopping for medical supplies on behalf of the patient. It is simply a time to themselves. This form of respite needs to conform to the lifestyle and needs of the caregiver. The caregiver should not feel that they have to leave the house when a respite care provider comes to the home, particularly when they do not want to do so. In some cases, it may be beneficial for the respite provider to take the patient out of the house, perhaps on an outing. There may be opportunities for inherent respite when rehabilitation professionals such as occupational therapists, speech therapists, or rehabilitation assistants work with the client, especially if the therapy sessions are in the client's own home. As part of developing the life care plan, it needs to be determined whether the caregiver needs to be at home when the various rehabilitation personnel are working with the client.

Periodic long-term respite breaks should also be provided to give the caregivers extended breaks. This can be for periods ranging anywhere from overnight to several weeks at a time. Depending on the demands of the client, these extended breaks need to be provided on a regular basis; normally several times a year. Depending on the situation, they can be provided in the home, to give the caregiver a chance to get away, or it may be more appropriate to arrange for the client to stay in a specialized respite facility.

Psychotherapy

For various reasons including poor insight, poor memory, or inability to profit from experience, clients with a brain injury often are not able to benefit from psychotherapy (Knight, Rutterford, Alderman, & Swan, 2002). Yet at the same time, these very difficulties make them extremely challenging for family members to deal with. Spouses or family members who are in the caregiver role can benefit from psychotherapy to ensure that they have the emotional strength to deal with these difficulties. Moreover, a psychotherapist well versed in behavior management techniques can act as a "coach" to the spouse by providing technical guidance and support. An example of this would be the implementation of a behavior management program to reduce the frequency of inappropriate behaviors such as swearing, yelling, or aggressive acts.

As indicated earlier, longitudinal studies involving family members of clients with brain injury demonstrate both the high level of burden placed on them and, in many cases, the development of psychopathology such as depression and anxiety disorders (Marsh, et al. 1998; Kreutzer, et al. 1994; Rosenbaum & Najenson, 1976). Yet, these same family members continue to be saddled with the ongoing responsibility for providing care to the family member with a brain injury. Therefore, it is imperative that life care planning takes into account the needs for family members to receive necessary psychotherapeutic support.

Family and Marital Therapy

As is the case for any major crisis, a brain injury can affect the overall functioning of the family. While some families are able to remain strong, other families become troubled or adopt maladaptive ways of coping. In many cases, family therapy or counseling intervention is necessary. Rosenthal and Young (1988) draw a distinction between the need for family

counseling versus family therapy approaches. They assert that family counseling is required when the family requires guidance managing within the basic structure of the family system, when the family is otherwise essentially normal. Family therapy, on the other hand, is useful when there is a pre-morbid history of dysfunction, or when the family reacts to the brain injury with maladaptive communication and interactional patterns.

Family counseling can take the form of psycho-educational sessions, with the counselor addressing family concerns by way of education and clarification regarding the effects of the brain injury. As an example, when a child is puzzled or upset over behavior changes exhibited by his or her father with a brain injury, psycho-educational sessions can help explain reasons why he exhibits certain behavior, provide reassurances that the behavior is not caused by something the child said or did, and provide ways of coping with the behavior. Psycho-educational sessions can be provided by a rehabilitation counselor, or be incorporated as an adjunct to psychotherapy services being provided to the client with a brain injury, assuming the therapist has a working knowledge of the effects of brain injuries. When using a psycho-educational family counseling approach, the initial duration of the intervention is usually brief (less than six sessions), and on an as-needed basis thereafter.

From time to time, rehabilitation professionals will encounter families who manifest dysfunctional ways of coping and interacting. Family members may demonstrate poor communication, lack of support to one another, excessive anger, hostility, or blaming. In some cases, children start "acting out," or family members may withdraw or rely on substance abuse as a way of coping (Kreutzer, Marwitz, & Kepler, 1992, Mauss-Clum & Ryan, 1981). It is important for rehabilitation counselors to have at least a fundamental understanding of family systems theory, to understand the nature of maladaptive communication and interactional patterns in some families.

In family systems theory, a family is viewed as an organism of interconnected members. Goldenberg and Goldenberg (1985) explain: "A family is a natural social system, with properties all it's own, one that has evolved a set of rules, roles, a power structure, forms of communication, and ways of negotiation and problem solving that allows various tasks to be performed effectively" (p. 3). When a catastrophic brain injury occurs in a family, the respective roles that family members assume are altered. The client is now *care dependant*, while the spouse (or other designated family member) now takes on the additional role as a *caregiver*. This can affect the power structure, rules of the family, and communication patterns. Marital and family therapy is a useful intervention that helps couples and families understand and cope with the changes in family dynamics and structure. A structural family therapy approach, as developed by Minuchin (1974) can help the family to "re-organize" the family structure, making it a healthier and stronger entity. It is instructive to note that studies have suggested that families which are more flexible and able to reorganize the structure of the family are better able to adjust to the effects that brain injury has on a family member (Kosciulek & Lustig, 1999; Zarski, Hall, & DePompei, 1987). Overall, research findings suggest that family adaptation to the profound changes from a brain injury very much depends on the strength and resilience of the family. Family therapy is one such way of strengthening the family.

Laroi (2003) stresses the importance of being able to distinguish the difference between primary and secondary reactions to brain injury. Primary reactions stem from physical and neuropsychological impairments directly related to the injury, whereas secondary reactions are rooted in normal reactions to a traumatic event. For example, angry outbursts by the client with brain injury may have an organic etiology that affects impulse control and self regulation. However, the anger might also be partly or entirely rooted in psychological issues or family

dynamics including feelings of inadequacy, competitiveness for attention of other family members, or unrealistic expectations of other family members (Laroi, 2003). A good understanding of the effects of brain injury combined with a theoretical grounding in family systems theory is helpful in determining an appropriate plan for clients with brain injuries and their families. Marital and family therapy should also be conducted by a skilled and professionally trained family therapist.

Social Support

Families with a family member with a brain injury often feel that they are unique or alone. Over time, there is a tendency for friends, former colleagues, and extended family to drop out of the picture and for many families, social isolation is the inevitable result. There are a number of interventions aimed at supporting and strengthening the family known as social support programs. Social support interventions would include self help groups, peer support programs, and family networks. Families who have already experienced the trauma of brain injury may be more effective than rehabilitation professionals in providing emotional support and information to other families undergoing similar experiences. Depending on the composition of the group, with peer support groups, there is the unfortunate possibility of degenerating to forums where participants vent and complain about lack of available services or other complaints. These forms of intervention are most effective when involving a counseling rehabilitation professional in a guidance or facilitative capacity, and structured to include both emotional support and educational components (Rosenthal & Young, 1988). Moreover, Rosenthal and Young (1988) recommend *family networking* as another form of social support. This intervention calls for linking a family in the more acute stages of brain injury with another family who has already experienced the stressful event. Social support interventions offer the possibility of replacing a sense of loneliness, isolation, and despair with a sense of hope and belonging.

Conclusion

There is a growing body of literature on the enormous burden placed on family with members who have experienced a brain injury. The literature also suggests alarmingly high incidence of marital breakdown in the years following a brain injury. Yet, there are encouraging research findings suggesting a positive relationship between the functioning of the family and rehabilitation outcomes. However, there also exists a notable lack of empirical research demonstrating the relationship between specific family interventions and outcome. Rehabilitation settings dealing with clients with a brain injury now generally accept the concept that family intervention is a necessary component of treatment. For life care planning professionals involved in brain injury rehabilitation, an understanding of the effects of a brain injury on the family, as well as at least a working knowledge of family systems theory is essential. This article has described several interventions and practical measures aimed at strengthening the family following a brain injury. Table 1 summarizes the relevant issues for the life care planner to consider when developing a life care plan for an individual with brain injury and his/her family. Consideration should be given to the timing of the intervention, paying close attention to the readiness of the family and client, and understanding what type of intervention(s) would best suit the client and family. It is imperative for life care planning professionals to take into account the need for interventions that strengthen the family as part of the long-term planning for clients with brain injuries.

Table 1. Considerations for the Development of Life Care Plans for Clients with Brain Injury and Their Families

Life care plans for clients with brain injury and their families should include the following:

√ Provision of ongoing information and educational materials on the subject of brain injury conveyed at times and level of readiness of family members.

√ Activities to promote integration of family members as partners in the rehabilitation process.

√ Opportunities for family caregiver to have proper rest, regular exercise, and social activities.

√ Regular respite breaks and periodic extended breaks for the family caregiver that conform to the lifestyle of the caregiver.

√ Psychotherapy support for family members, when indicated, to include:
* Family counseling using a psycho-educational approach.
* Family therapy when maladaptive communication or interactional patterns are present.
* Behavioral management coaching to assist family members in reducing inappropriate behaviors.

√ Inclusion of social support interventions.

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