

FAMILIES WITH BRAIN INJURY: A MODEL FOR INTERVENTION

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“When a person experiences a brain injury, it has a profound effect on the family system, as well as the individual roles of family members. This presentation will focus on the fixed, transitional and reconstituted roles within the family system. It will address the implications for the patient’s historical family system and how that system is reconstituted through challenge, transition and transformation during the rehabilitation process. “

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Introduction:

When a person sustains a brain injury family life is severely disrupted. The individual, the individual family members and the family are all traumatized.

In response to the initial crisis:

1. Family life is reorganized around the injury.
2. Individual family members mobilize to meet the emergency.
3. Individual and family needs are “temporarily” put aside so that the needs of the injury can be addressed.

The family represents a treatment unit that is often not adequately considered in medical and rehabilitation settings.

We would like to present the case for recognizing the family system in the treatment and rehabilitation of traumatic brain injury and to present a model being developed at RIRM.

For the purposes of this presentation we will define the family as all those living with the injured person and those individuals who may not be living with the injured person but who assume regular care taking or case management responsibilities. While we recognize that this does not include all the forms “family” can take, it provides for a manageable working definition. It also focuses this discussion on the day to day changes and tasks to be confronted when a family member sustains a traumatic brain injury and the challenges faced in balancing injury and non-injury family needs.

To understand the role of the family in the treatment and rehabilitation of the individual with a traumatic brain injury it is necessary to:

1. Look at the interaction of injury, individual, family and treatment variables.
2. Look at the changing challenges for treatment.
3. Look at what skills are most adaptive at each stage of an injury.

Injury Variables:

1. Onset
 - a. Acute Onset
 - b. Gradual Onset

Life Cycle of the Injury:

Each stage of an injury requires varying tasks and adaptive skills. Initial relief that the family member is alive and hope quickly followed by enormous stress on the family and individual family members. The combination of the injury itself, the fears and concerns about the effects of

the injury on both the individual and the family, the need to navigate the medical system and to make judgments and decisions one may feel ill prepared to make.

We would like to present family variables and social/emotional issues within the context of the demands of a traumatic brain injury.

1. What is it like for the family to have a member with a traumatic brain injury?
 - a. Systems theory: Any change in one part of a system affects the system.
 - b. Find clues in learning how families of origin have made sense of loss.
 - c. The structure of the family changes. Roles change.
 - d. The family has to find a new identity.
 - e. The family has to learn how to incorporate ambiguous loss and unresolved grief.

Acute or Initial Phase: Includes onset of symptoms, occurrence of the injury and in-patient care.

1. The family may find itself in a strange and confusing world. Family members play a major role in communicating information, and must learn how to negotiate the medical system and access care. They may also take on a case management role.
2. Good problem solving skills.
3. Quick mobilization which requires maximum flexibility. Changes in time allocation and designated roles.
4. Family caretaker, breadwinner or child may be injured. May shift the balance of nurturing.
5. Family members may need to take time off from work or school.
6. New child care arrangement may have to be made.
7. Family routines are disrupted.
8. Family rituals are suspended.
9. Family life is put on hold. Family is reorganized around the illness.
10. Shopping, cooking, household chores, homework and bedtime routines are changed or neglected.
11. These changes may be easier at the beginning if families are flexible, adaptable and have a support network, but can become problematic over time.
12. Family may find that longstanding habits may be difficult to break and role changes resisted.

13. Guilt about meeting household responsibilities and neglecting needs of those at home versus need to be at the hospital to oversee care, keep the injured person company and meet with doctors.
14. Experience separation and loss.
15. Children may be separated from parents, familiar caretakers or siblings.
16. Emotional supports may be withdrawn at a time when they are most needed.
17. Tasks are illness focused.
18. Keeping up with illness needs and hospital vigils can be exhausting and leave little energy for other family needs.

Medical Care Issues:

Providing information to health care personnel (who and what) family members are often the main source of information in the face of TBI.

1. Uncovering the information.
2. "It's news to me."
3. What family member has what information?
4. Pieces of a puzzle: The Dead Sea Scrolls.
5. Who and what comes out of the woodwork.
6. How does the family arrive at a consensus about care?
7. Selection of institution and health care specialists. Do they have access to state of the art and equipment?
8. Adapting to health care environment. Learning the culture of a health care facility. What is the hierarchy of the medical center? Who has what role?
9. A balance between being an advocate for one's family member and trusting the judgment of the medical community.
10. Learning medical language. A new language must be learned.
11. Learning how to access information. Did we speak to the right person? Do we need a second opinion?
12. Comparing notes with other families is a common source of helpful information but it may also cause doubt about the chosen course of treatment.
13. Learning how to evaluate the information. Are we making the right decision?

14. Decision making skills about treatment and care.
15. Developing relationships with healthcare team.
16. Adapting to healthcare settings and treatment regimens. Witnessing hospital procedures and seeing one's family member in the context of the hospital can be traumatic for family members and symptoms of traumatic stress may be evident.
17. Maintain a sense of competency and control.
18. What meaning does the illness and symptoms have for the family?
19. Maintain a sense of hope.
20. Family cooperation.

Treatment Phase:

1. Accessing services (nursing, homecare, hospice, etc.).
2. Includes out-patient care and rehabilitation.
3. This phase can offer differing challenges depending on the nature of the injury and many of the challenges overlap injuries.
4. Progressive Injury:
 - a. Little relief.
 - b. Increasing demands.
 - c. Keeps the family inward focused.
 - d. Promotes the loss of pre-illness identity.
 - e. Requires flexibility to meet increasing demands.
5. Static Injury:
 - a. Demands are more predictable.
 - b. Can anticipate needs and develop routines.
 - c. Allows family members the opportunity to maintain relationships and activities outside the family.
 - d. Exhausting: Prolonged treatment can increase exhaustion and stress and make it difficult to find a place for the illness so that family life can resume.
6. Relapsing or Episodic Injury:

- a. Family is always on alert for a crisis.
- b. Periods of normalcy.
- c. Constant shift between crisis and non-crisis mode.
- d. Tremendous strain on the family.
- e. Need for new medical intervention (shunt revision, change in meds) and new decisions.
- f. Facing new disappointments and losses. Hopes are raised during periods of normalcy. "Maybe this medication will work."

7. For all injuries:

- a. We see signs of traumatic stress in the family system.
- b. Assumptions have been shattered.
- c. Normal feelings of loss, sadness, loneliness, resentment and anger cannot be expressed by individual family members.
- d. Guilt about these feelings can result in family members becoming isolated from one another and from themselves.
- e. Families become isolated from friends and other family members who might be supportive.
- f. Families find it difficult to be with others because of a sense that no one understands what they are going through.
- g. Ambiguous Loss: Goodbye without leaving. The person is there physically but his or her mind is not. Anxiety about unpredictability and ambiguity and grief can remain unresolved.
- h. Anticipatory Loss: Anticipation of death, loss of intimacy, the need to let go may result in the injured person becoming isolated and separated from family life and responsibilities.
- i. Roles may be reversed. Children may take on adult roles and adults may need care taking.
- j. Families lose a sense of identity.
- k. Routines and habits developed during the acute phase of the injury remain after those behaviors are no longer necessary or adaptive in meeting the day to day demands of family life.
- l. The family remains defined by the injury unable to restore a sense of equilibrium.

- m. Efforts continue to focus on rehabilitation and restoration of function.
 - n. Invisible Injury: Family members do not understand.
8. Impact of cognitive deficits on family life:
- a. Lack of awareness.
 - b. Impulsivity.
 - c. Poor attention and concentration may be seen as passive aggressive behavior.
 - d. Memory impairment may be seen as laziness.
 - e. Inappropriate behavior.
 - f. Anger.

Chronic Phase and Return to Health:

1. Family must establish equilibrium and find a balance between illness and non-illness family needs.
2. Understand the illness in the context of the family belief system.
3. What is the family's ability to understand the injury and follow needed regimens?
4. Develop strategies to cope with changes in day to day living.
5. What strengths, emotional resources and adaptive styles are most effective?
6. Learn how to return to routines.
7. Come to terms with ambiguous loss.
8. Come to terms with life changes.
9. Need help in restoring a sense of identity and tap into adaptive abilities. Learn how to return to family rituals and activities while making necessary adjustments.
10. Give up behaviors and routines no longer adaptive.
11. Depression in spouses is common.

Family Variables:

1. Life Cycle of the Family:
 - a. Age/developmental stage of injured family member.

- b. Age/developmental stage of children and other family members.
 - c. Life cycle stage of each family member.
2. Family financial analysis and who does it.
- a. Disability insurance.
 - b. Long term and short term disability.
 - c. Company policies.
 - d. Who is allowed to access financial information?
 - e. Is this the best person to handle the analysis?
 - f. Family backup systems when the most informed or responsible family member is the injured person.
 - g. Reallocation of financial resources.
 - h. Short term versus long term implications.
 - i. Cultural understanding and expectations.
 - j. Spiritual belief systems (individual and family).
 - k. Illness in context of the family belief system.

Treatment Variables:

1. Demographics of the treatment team.
2. Working relationship of the treatment team.
3. Care coordination within and across departments with the medical team and medical system hierarchies.
4. Psychologist as the care coordinator.
5. Relationship with family members.
6. Relationship with the patient.

Economic Issues:

1. Will insurance cover medical needs?
2. How to cope with forms and administrative issues.
3. Extra expenses and services not covered by insurance.

4. Financial impact when main breadwinner is injured or family is faced with a loss of income.
5. Reallocation of family resources including money, time and space.

Life Cycle Issues:

Intersection of family life cycle, individual life cycle and illness life cycle

1. Illness/Injury life cycle
 - a. Onset:
 - i. Acute onset: Requires quick mobilization, flexible problem solving and ability to quickly access resources. Hope for improvement.
 - ii. Gradual onset: Requires the ability to sustain an effort and anticipate loss. Provides the family with the opportunity to plan for changes and for the ill member to participate in planning. No hope for improvement.

Socio-Economic Factors:

1. Impact of illness on financial viability of the family. Financial analysis and who does it.
2. Access to insurance (primary and secondary).
3. Under-insured.
4. Loss of financial independence and of income when main source of income is injured party.
5. Reallocation of family resources (time, money and living space).
6. Extra expenses not covered by insurance.
7. Discrimination based on disability.
8. Loss of social status.
9. Demographics of access to healthcare and insurance.
10. Demographics of TBI.
11. Availability of family members to provide care.
12. Life cycle of an illness or injury. The healthcare system rarely provides support throughout the life cycle of an illness. Limitations on insurance, limitations of rehabilitation programs.
13. Cultural factors.

Illness, Individual and Family Life Cycles:

1. Carter and McGoldrick marker events.
2. When in the life cycle of the family and of the individual does an injury occur?
3. Child may need to delay leaving home and family may return to the child-rearing stage.
4. Injury during child rearing phase may cause a family to be stuck in this phase.
5. If a parent is injured during this period the family may function as a single parent family with an additional child. Family resources may be severely strained or inadequate.
6. With an injured parent role reversal may occur and important developmental phases for a child may be missed.
7. These may be problems in some families and not others where caretaking is normative.
8. Progressive diseases tend to keep a family inward focused.
9. Chronic diseases allow more opportunity for members to return to life outside the family. Chronic illness or injury may promote the loss of the family's pre-illness identity.
10. Whose life plans have been put on hold? How to continue with those plans and meet the demands of the injury?

Family Treatment Model

Two sources have helped to shape the model we are developing at Rusk: Peter Steinglass' work developing MFDG for families with chronic illness and his thoughts about "finding a place for the illness" and Pauline's work on Ambiguous Loss.

1. Pauline Boss: Allow family members to tell their stories about what ambiguous loss has meant to them. This will vary with culture, gender, race, ethnicity, sexual orientation and age. What is the meaning of the injury within the context of the family belief system?
 - a. How does one maintain hope and optimism in the face of an ambiguous loss?
 - b. What is most painful about the loss and what is most difficult to adapt to?
 - c. How have they managed loss in the past will help to understand what it is like for them now and what will help them to manage their trauma.
 - d. What are the family's adaptive skills and flexibility? Ability to accept an alternative perspective.
 - e. What are the family's support systems?
 - f. What is the family's ability to understand the injury and follow needed regimens?

- g. What are the emotional resources of the family?
 - h. Family interventions may be needed throughout the life cycle.
 - i. Psychoeducational groups: During the rehabilitation phase or the chronic/return to health phase.
 - j. Provide needed information.
 - k. Normalize the experience.
 - l. Provide coping strategies.
 - m. Allow sharing of information across families.
 - n. Can identify high risk families.
2. Multiple Family Discussion Group: Ackerman Institute for the Family.
- a. Time limited multifamily intervention with brain injured and non-injured members.
 - b. Families are a source of valuable information about what it is like to be in family where a member has a brain injury.
 - c. Allows for the sharing of information and coping strategies.
 - d. Can compare notes across analogous family members.
 - e. Promotes the idea that it is the illness that presents a problem for all family members. The person is not the problem. Externalizes the problem.

Goals:

1. Learn how to balance illness and non-illness family needs.
2. Find a place for the illness and put the illness in its place.
3. Help families restore a sense of identity that incorporates pre-illness values and adjust to reconstructed values.
4. Help families understand how they have made sense out of loss.
5. Help families return to important rituals.
6. Identification of strengths and resiliency.
7. Helps individuals to put a voice to abilities and empower their skills.
8. Cost effective treatment method.