

Strengthening Families after Brain Injury



Dr. Jeff Kreutzer

Virginia Commonwealth University
Medical Center

Brain Injury and The Family

Mauss-Clum & Ryan
Journal of Neurosurgical Nursing

Changes in the Patient

| | |
|--------------------|-----|
| Decreased memory | 87% |
| Dependency | 73% |
| Depression | 57% |
| Impatience | 57% |
| Decreased ambition | 53% |
| Irritability | 53% |
| Temper outbursts | 50% |



from Mauss-Clum & Ryan

Changes in the Patient

| | |
|----------------------------------|-----|
| Less learning from experience | 47% |
| Decreased self-control | 47% |
| Sexual disinterest/preoccupation | 47% |
| Self-centered | 43% |
| Inappropriate behavior in public | 40% |
| Inflexibility | 20% |

from Mauss-Clum & Ryan

Family Reactions

| | <u>Mothers</u> | <u>Wives</u> |
|------------------|----------------|--------------|
| Frustration | 100% | 84% |
| Irritability | 55% | 74% |
| Annoyance | 55% | 68% |
| Depression | 45% | 79% |
| Social isolation | 27% | 74% |

from Mauss-Clum & Ryan

Family Reactions

| | <u>Mothers</u> | <u>Wives</u> |
|----------------------|----------------|--------------|
| Less time for self | 36% | 58% |
| Financial insecurity | 18% | 58% |
| Guilt | 18% | 47% |
| Feeling trapped | 45% | 42% |
| Little respite | 9% | 32% |

from Mauss-Clum & Ryan

Family Reactions



| | <u>Mothers</u> | <u>Wives</u> |
|-----------------------|----------------|--------------|
| Anger | 45% | 63% |
| Verbal abuse | 36% | 26% |
| Physically threatened | 18% | 21% |
| Criticism of care | 0% | 21% |

from Mauss-Clum & Ryan

Unique Reactions of Wives

- ▶ No sexual outlet 42%
- ▶ I'm married but don't have a husband 42%
- ▶ I'm married to a stranger 32%



from Mauss-Clum & Ryan

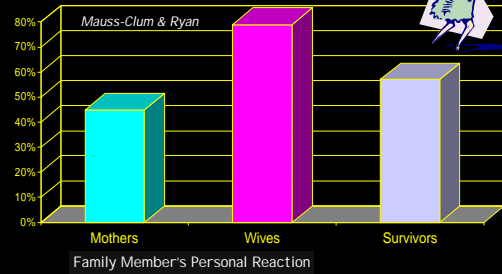
Common Emotional Reactions



| | <u>Mothers</u> | <u>Wives</u> | <u>Patients</u> |
|-----------------|----------------|--------------|-----------------|
| Depression | 45% | 79% | 57% |
| Irritability | 55% | 74% | 53% |
| Angry/Outbursts | 45% | 63% | 50% |

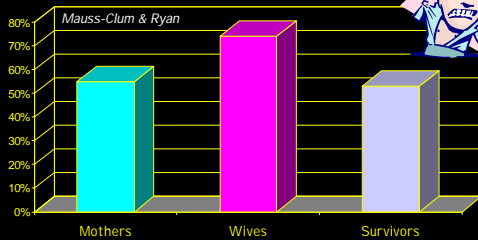
from Mauss-Clum & Ryan

Depression After Brain Injury



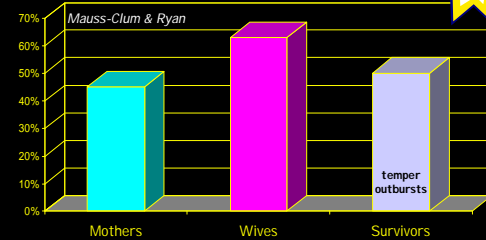
Family Member's Personal Reaction

Irritability After Brain Injury



Family Member's Personal Reaction

Anger After Brain Injury



Family Member's Personal Reaction



**a family member's
point of view ...**

**"Survivors don't get well
and they still need services
10 or 15 years later."**

from the VA statewide community based needs assessment



**a family member's
point of view ...**

**"Doctors have no clue about what happens
after someone gets out of the hospital,
and we've got to let them know."**

from the VA statewide community based needs assessment



**a family member's
point of view ...**

**"Although my son is only six now, I won't
be here forever. What will happen
to him when my husband and I are gone?"**

from the VA statewide community based needs assessment



**a family member's
point of view ...**

**"I don't remember the last
time I had a medical check-up."**

from the VA statewide community based needs assessment



**a family member's
point of view ...**

**"If I go to a counselor and tell him that my husband is irate,
they might tell me to leave him because they
don't understand it's because of the brain injury."**

from the VA statewide community based needs assessment



**an injured person's
point of view ...**

**"If someone had told me what the next
four years would be like,
I would have laid down and died."**

from the VA statewide community based needs assessment



an injured person's point of view ...

"In my accident three things were damaged:
the utility pole, the car, and me.
They knew what to do with the utility pole and the car.
They didn't know what to do with me, and they still don't"

from the VA statewide community based needs assessment



an injured person's point of view ...

"I lost my friends because they didn't
know how to deal with my injury.
Neither did I."

from the VA statewide community based needs assessment



an injured person's point of view ...

"My life issues don't necessarily happen
Monday-to-Friday, nine-to-five."

from the VA statewide community based needs assessment

Family Support Principles

- ▶ Brain injury causes drastic life changes for everyone in the family
- ▶ Most people want their old life back
- ▶ Well informed people do better
- ▶ Every person deserves respect
- ▶ Every person in the family is important



Family Support Principles

- ▶ Each adult family member has the right to make choices, good or bad
- ▶ In the long-term, the family ends up taking the most responsibility for helping the patient
- ▶ You have to take care of yourself to effectively help other people



Major Challenges Faced by Families after Brain Injury

- ⇒ Appreciating and coping with change
- ⇒ Appreciating normal recovery patterns and mastering the art of patience
- ⇒ Recognizing and coping with stresses and crises
- ⇒ Managing intense emotions
- ⇒ Avoiding guilt and blame
- ⇒ Taking care of one's self as well as the survivor





Physical Concerns

Brain Injury Problem Checklist

- tired
- moves slowly
- loses balance
- headaches
- drops things
- weak
- trouble sleeping
- dizziness
- muscles tingle or twitch
- other



Cognitive Concerns

Brain Injury Problem Checklist

- confused
- misplaces things
- loses train of thought
- thinks slowly
- trouble making decisions
- poor concentration
- forgets if he has done things
- forgets what he or she reads
- forgets names
- easily distracted
- other.....

Behavioral and Emotional Concerns

Brain Injury Problem Checklist

- frustrated
- bored
- restless
- impatient
- sad, blue
- lonely
- complains
- difficulty getting things started
- misunderstood by others
- jumpy, irritable
- other



Communication and Social Concerns

Brain Injury Problem Checklist

- difficulty thinking of the right word
- argues
- makes spelling mistakes
- thinks only of self
- uncomfortable around others
- writes slowly
- trouble making conversation
- writing is hard to read
- other.....



The Family Change Questionnaire

1. How did you feel when you first learned that your injured family member was hurt?
2. How did you feel when you realized that your injured family member was going to live.



The Family Change Questionnaire

3. How did you feel when you began to recognize that the brain injury might have long-term effects?
4. How have other family members reacted to the injury and the injured person?



The Family Change Questionnaire

5. Have you made yourself available to provide more emotional support to your injured family member and other family members? If yes, how so?
6. Before the brain injury, what were the most important plans for your future and the family's future.



Coping with Losses and Changing Demands and Roles

- ❑ Realize that your feelings are a common, normal response to your experience.
- ❑ Recognize there is a natural human tendency to worry and focus on the negative.
- ❑ Learn to focus on your accomplishments, strengths, and resources.
- ❑ Think about the future you want and the best ways to get there.



Coping with Losses and Changing Demands and Roles

- ❑ Be kind to yourself and allow yourself and others time to adjust.
- ❑ Remain active, try to do things you enjoy.
- ❑ Build new relationships and improve old relationships.
- ❑ Try to give up some old responsibilities when you take on new responsibilities.



Remaining Patient and Learning to Live with the Idea that Recovery Takes Time

- ❑ Realize that recovery is a long process and solving big problems takes time.
- ❑ Try to view recovery on a daily basis.
- ❑ Avoid comparing things to how they were before the injury.
- ❑ Remember that taking on too much too soon can easily lead to failure.




Remaining Patient and Learning to Live with the Idea that Recovery Takes Time

- ❑ Focus on accomplishments and progress instead of failures.
- ❑ Remember that no one is perfect and everyone makes mistakes. Try to learn from your mistakes to make the future better.
- ❑ Avoid pushing yourself too hard or putting yourself down.

Stress Overload Signs

Disorganization

- ❑ forgetting keys 
- ❑ losing things
- ❑ making dumb mistakes

Dependency Fantasies

- ❑ daydreaming about spending a few days somewhere, even in the hospital - to sleep, read, be taken care of





Stress Overload Signs

Difficulty with Small Decisions

- ❑ can't decide what to wear
- ❑ stumped about what to have for lunch

Depression

- ❑ desire to curl up on bed, pull covers up over head, sleep for a week

Witkin 1991



Social Readjustment Rating Scale

| Life Event | Value |
|------------------------------|-------|
| death of spouse | 99 |
| divorce | 91 |
| marriage | 85 |
| death of close family member | 84 |
| fired at work | 83 |
| marital separation | 78 |
| jail term | 72 |



Holmes and Raye 1967

Social Readjustment Rating Scale

| Life Event | Value |
|---------------------------------|-------|
| personal injury or illness | 68 |
| death of close friend | 68 |
| retirement | 68 |
| change in financial state | 61 |
| spouse begins or stops work | 58 |
| change - family member's health | 56 |



Holmes and Raye 1967

Social Readjustment Rating Scale

| Life Event | Value |
|---------------------------------|-------|
| change line of work | 51 |
| residence change | 47 |
| increased arguments w/spouse | 46 |
| change in work responsibilities | 46 |
| trouble with boss | 45 |
| revision of personal habits | 44 |

Holmes and Raye 1967

Social Readjustment Rating Scale

| Life Event | Value |
|---------------------------------|-------|
| trouble with in-laws | 43 |
| change in living conditions | 42 |
| change in work hours/conditions | 36 |
| minor violations of law | 30 |
| change in sleeping habits | 27 |
| change in recreation | 26 |

Holmes and Raye 1967

Managing Crises and Stress

- ❑ Check your "pressure gauge" often.
- ❑ Practice effective problem solving. Brainstorm ways to solve problems and try out different solutions.
- ❑ Have a back up plan.
- ❑ Take time for yourself, do things you enjoy.

Take Your Temperature Often

- ? How am I feeling
- ? Am I upset
- ? What am I worrying about



Getting Better and Better

The 13 Item Stress Test

True or False?



- ▶ I have a lot to do.
- ▶ I have more to do than I can handle.
- ▶ I'm not being productive.
- ▶ I'm trying really hard but getting nothing done.
- ▶ I'm feeling unhealthy.
- ▶ I can't afford to take breaks for time off.
- ▶ I'm pushing myself too hard.

The 13 Item Stress Test

True or False?



- ▶ I don't sleep very well.
- ▶ Too many people are telling me what to do.
- ▶ I am not treating people well.
- ▶ I feel totally exhausted.
- ▶ Nobody is happy with what I do.
- ▶ I can't stand living like this.

Stress Management Worksheet



- What are the main sources of stress in my life?
- What do I do now that helps me manage stress more effectively?
- What do I do that makes it harder to manage stress?
- What can I do to better manage stress?
- Where should I start to make things better?

Managing Crises and Stress

- Tell yourself to relax, breathe slowly and deeply.
- Close your eyes, imagine yourself in a pleasant situation or place.
- Keep up a healthy lifestyle - exercise, eat right, avoid caffeine, alcohol, drugs, and tobacco.
- Seek support from trusted friends and family.
- Talk to others about how they cope successfully.

To successfully manage the multitude of problems - remember ...

- You have more responsibilities now than before the injury
- You have lots of new sources of stress in your life
- Everyone has limits
- You will be less effective doing anything if you do too much
- Your emotional well being may be the greatest casualty of over-commitment



The Feelings Checklist

Directions

- Take a moment to think about how you feel.
- Check off the boxes next to the sentences that describe you.



The Feelings Checklist

- I often feel frustrated.
- I get angry easily.
- I don't like much about myself.
- I worry a lot.
- I have made many mistakes.
- I worry about the future.



The Feelings Checklist

- I am lonely.
- I believe that I am at fault for many of our problems.
- I feel sad.
- People don't understand me.
- I feel overwhelmed.
- My feelings change from minute to minute



The Feelings Checklist

- I get upset easily.
- Very few people care about me.
- I have many fears.
- I feel like I should be doing more.
- I'm disappointed in myself.
- I wish my life could be the way it was before.
- I am often grouchy.



The Feelings Checklist

- Review the items you've checked and the ones you haven't to better understand your feelings.
- The more items you've checked, the more likely it is that you are experiencing many different strong emotions.
- Is there a pattern to the items you've checked?
- Show your checklist to someone you know and trust. Do you agree on the items that should be checked.



Managing Intense Emotions that You and Other Family Members Have

- As a first step, recognize your intense emotions. Keep a diary of your feelings.
- Recognize your power to control your emotions.
- Remember that having bad feelings will only make things worse. Instead, focus on solving problems one at a time.
- Under-react. Ask yourself if a problem is worth getting upset about. If not, then try to let it go.

➔ Managing Intense Emotions that You and Other Family Members Have

- ❑ Talk to trusted others about your feelings and positive ways to cope.
- ❑ Recognize the difference between what you think and how you feel.
- ❑ Strong emotions can undermine your best problem solving efforts.
- ❑ Avoid making decisions when you have strong emotions.

Guilt is anger directed toward ourselves -- for what we did or did not do.

Peter McWilliams



Guilty or Not Guilty?

- ❑ Sometimes I wish I was the one who was hurt instead.
- ❑ I should be doing more to help.
- ❑ I wish I would have done something to prevent the accident.
- ❑ What happened is my fault.



Guilty or Not Guilty?

- ❑ I can't let this happen again.
- ❑ I have made many mistakes.
- ❑ Everyone else blames me for what happened.
- ❑ I get blamed for everything that goes wrong.

➔ Avoiding Guilt and Blame

- ❑ Recognize the dangers and sources of guilt and blame.
- ❑ Try to realize when you are blaming others or feeling guilty.
- ❑ Recognize that getting help from others may depend on the feelings you convey.
- ❑ Remember that people respond better to a positive attitude, and a positive attitude is critical for success.

➔ Avoiding Guilt and Blame

- ❑ Make a commitment to strengthen your family and fight the temptation to blame others.
- ❑ Be careful not to become preoccupied with other people's faults and problems. Instead focus on what you can do to make things better now.
- ❑ Focus on positive, constructive approaches to problem solving.

➔ Taking Care of One's Self as Well as the Survivor

- ❑ Realize that TBI impacts your whole family.
- ❑ Think about what you need to be healthy and strong.
- ❑ Remember, you must take care of yourself so that you can better take care of the survivor and other family members.
- ❑ Give yourself breaks and learn when and how to ask for help.

Fundamentals for Success



- recognize the benefits of hope and a positive attitude
- be patient and persistent
- get better by learning and trying

Fundamentals for Success



- create or find a supportive environment
- live according to your good values
- define success in your own terms

"Readiness" as a Concept

Sometimes family members just aren't ready for help -

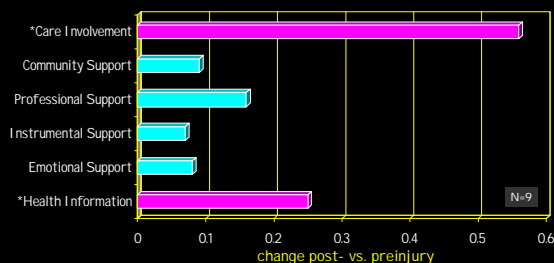
- ⊘ No doubt, he'll get better once we get him home.
- ⊘ These people are too negative. I know that he'll be just fine.
- ⊘ I just can't deal with one more thing.
- ⊘ These doctors just want to make money. We need to get her home.



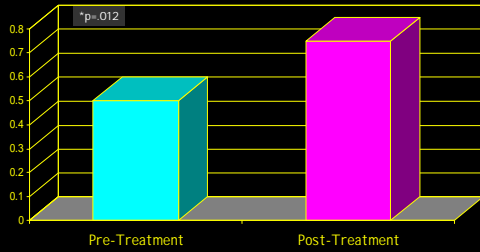
Brain Injury Family Intervention Program Preliminary Findings

Jeffrey S. Kreutzer, Ph.D.,
and Laura A. Taylor, Ph.D.
Virginia Commonwealth University
School of Medicine

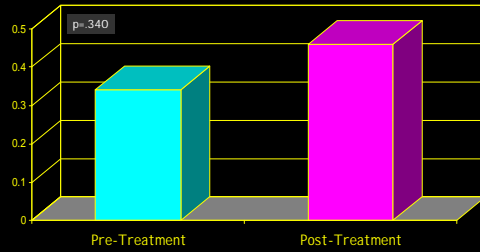
FNQ Subscale Score Postinjury Changes proportion of needs rated as "met"



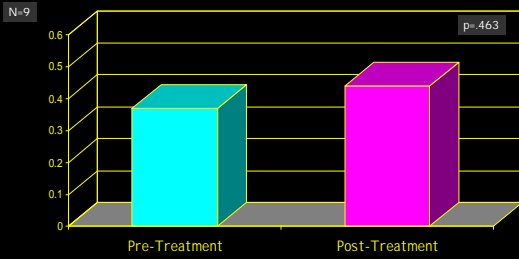
FNQ Health Information Needs proportion of needs rated as "met"



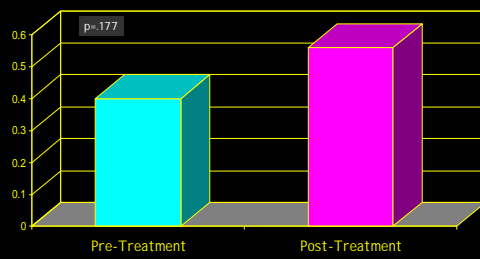
FNQ Emotional Support Needs proportion of needs rated as "met"



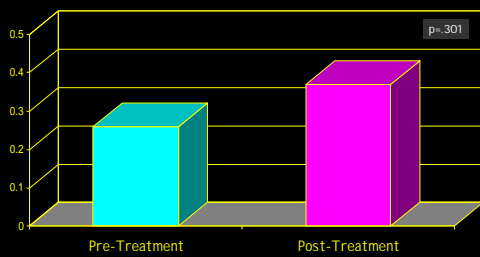
FNQ Instrumental Support Needs proportion of needs rated as "met"



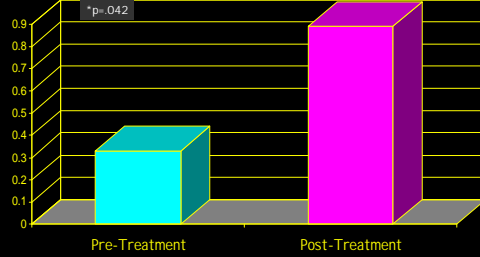
FNQ Professional Support Needs proportion of needs rated as "met"



FNQ Community Support Needs proportion of needs rated as "met"

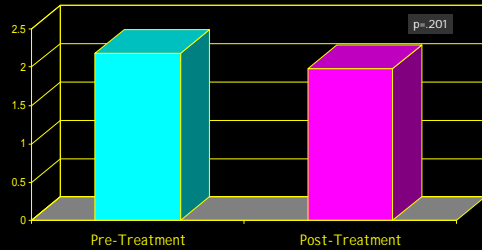


FNQ Involvement with Care Needs proportion of needs rated as "met"



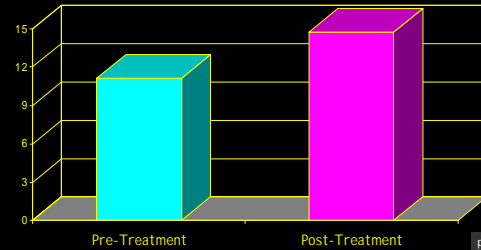
General Functioning Scale Family Assessment Device

*lower scores denote better functioning



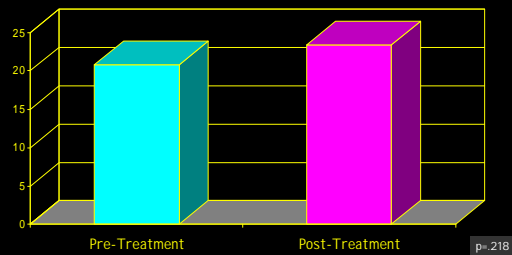
Satisfaction with Treatment Subscale Service Obstacles Scale

*higher scores denote higher satisfaction levels



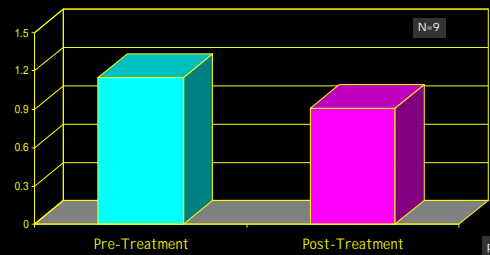
Satisfaction with Life Scale

*higher scores denote higher satisfaction levels



Depression Subscale Brief Symptom Inventory

*lower scores denote lower levels of emotional distress



Fundamentals for Successfully Working with Families

- ▶ Recognize the critical long-term role played by family members
- ▶ Appreciate that reactions to TBI are part of a long-term adjustment process
- ▶ Create a supportive environment
- ▶ Be patient, remember that TBI is a new experience for the family



Fundamentals for Successfully Working with Families

- ▶ Be sensitive to the likelihood that people are overwhelmed
- ▶ Practice good listening skills
- ▶ Ask if they have questions and answer honestly
- ▶ Only provide as much information as each person can handle
- ▶ Focus on the positive to convey hope



**The National Resource Center
for Traumatic Brain Injury**

www.neuro.pmr.vcu.edu



Jeff Kreutzer

jskreutz@vcu.edu

Virginia Commonwealth University
Medical Center

**Box 980542, Richmond, VA 23298-0542
USA PH 804 828-9055**