




Concussion, Mild, Moderate and Severe Brain Injury.
Complex Cases. Outcomes that Work.



BRAIN INJURY ASSOCIATION OF MICHIGAN



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Date



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Communicating About Prognosis After TBI Results of a National Survey



Conflict of Interest Statement

I am an employee of ReMed Recovery Care Centers, a Community Based Rehabilitation program that serves people who have rehabilitation needs associated with brain injury. I have no other affiliations with or involvement in any entity with any financial interest in this research.


Objectives

- Increase understanding of research on communication of information by healthcare providers after traumatic brain injury
- Discuss findings from a national survey study of TBI survivors and their families
- Identify strategies/recommendations for improving communication about outcome to families and individuals after traumatic brain injury




ACRM AMERICAN CONGRESS OF REHABILITATION MEDICINE
Improving lives through interdisciplinary rehabilitation research

- Results of a national study and implications for practitioners
- Project was initiated and completed by
 - The Prognosis After Traumatic Brain Injury - Interdisciplinary Task Force (BI-ISIG) of the American Congress of Rehabilitation Medicine (ACRM)
 - Approved by an independent Institutional Review Board (IRB) with funding granted by the Council on Brain Injury a 501 c3
 - Vetted by the Board of the Council on Brain Injury
 - Vetted by the Editorial review Board of the ACRM
 - Co-Chairs of Task Force at the time of the project:
 - David Krych, MS, CCCSLP; ReMed Recovery Care Centers
 - Rosette C. Biester, Ph.D.; Hospital of the University of Pennsylvania and the Veterans Administration Polytrauma Hospital; Philadelphia

Rationale for Project

- Research regarding persons with neurological conditions (e.g., stroke and traumatic brain injury) and their significant others, indicates:
 - There is poor understanding of long-term consequences of these neurological conditions
 - There are unmet needs associated with these conditions;
 - There is need for more complete diagnostic and prognostic information
 - There is a need for continued professional support including ongoing communication.

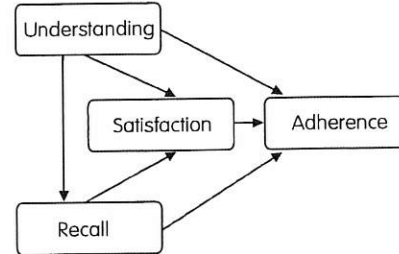



Why Study Communication Regarding TBI per se?

- Task Force members identified **communication** by health providers as an important area of study especially regarding:
 - Importance of potential symptoms of TBI
 - Potential prognosis after TBI
 - Apparent difference between health care professionals and those they serve regarding communication
- Compliance with treatment, expectations about recovery, planning for the future, and better decision-making are all related to effective communication.
- Effective communication involves how and when information regarding a traumatic brain injury is relayed. (Kessels, 2013 JRSJM)
- **Satisfaction** with various aspects of treatment and how information was communicated, was also identified as an important component related to communication.



Ley's Model on the Interactions Between Patient-Related Factors and Therapy Adherence; Kessels, 2013 Journal of the Royal Society of Medicine



Literature on Communication About Prognosis by Health Care Providers

- Literature on **communication** specific to TBI is limited.
- Some research has addressed the unmet and ongoing needs of individuals with TBI and their families, their perceptions of needs, and related stress regarding unmet needs. E. Pickelsimer et.al. 2007 JHTR
- Most studies have focused on communication with **families** rather than **individuals with brain injury** likely due to access.
- Examined literature on disability, end-of-life issues, and pediatric medical conditions



Literature Review Continued

- Close relatives of individuals with TBI have consistently identified information as one of their greatest needs (Bond et al., 2003; Kowakowsky-Hayner, Miner, & Kreutzer, 2001; Perlesz, Kinsella, & Crowe, 2000)
- Families repeatedly indicate that they were not satisfied with the information they received from care providers (Lefebvre et al., 2005; Sinnakaruppan & Williams, 2001)
 - they specifically identify having access to information about their loved one's condition and prognosis
 - having their answers to questions answered honestly and directly as primary family needs (Serio, Kreutzer, & Witol, 1997; Testani-Dufour, Chappel-Aiken, & Guedner, 1992).



Literature Review Continued

- Parents of children with TBI have been the focus of two reports. In the two studies, between 66 and 70% of parents reported that their informational needs were unmet (Hermans et al., 2012; Hawley et al., 2013).
- 45% of parents reporting that they had inadequate information on their children's problems and what to expect in the future (Hermans et al., 2012).
- In a similar study (Rosigno et al., 2013), key issues for parents were
 - access to the child
 - lack of regular discussions with key health care staff
 - not having updates with adequate explanations; differing expectations regarding how often, when and how they should be "talked" to
 - perceived limited involvement in decision-making
 - Vague and complicated language (jargon) identified as barriers to ability to understand the child's medical condition
 - Interestingly, these issues were prominent in those parents whose children sustained severe TBIs and less so in those whose children had moderate injuries



What does good Communication get you?



- Quality of communication is related to **comprehension of and satisfaction with** the information provided.
- Diminished Psychological stress associated with traumatic injuries
- Family members having better interactions with treaters/ which yields;
 - More likelihood of carrying out treatment recommendations
 - (Francis et al, 1969; Larson et al, 1996 ; Korsch & Marcy,2000; Little et al 2001; Kessels 2013, (Azoulay et al, 2000).



Communication With Families; (Rotondi et al,2007) & (S. de Wit et al, 2013)

What Families Say They Want	What Families Say They Get
Information that is <ul style="list-style-type: none">• Truthful• Understandable• Uncomplicated by medical terminology• Which explains even the most basic conditions	Explanations that are <ul style="list-style-type: none">• “not understandable” mainly due to jargon• Subset of families reported that prognostic information was inaccurate or misleading• Questions are not answered directly and in a respectful manner



- The need for a survey for both individuals with TBI and their significant others was identified by the ACRM Prognosis Task Force.
- The survey was designed to assess how well people who had sustained a traumatic brain injury and their significant others were informed about the nature of brain injury and symptoms they might expect.
- The survey also determined how involved in treatment the person was and how satisfied they were with information and services received



Taskforce Members

- Task Force met in person twice per year at the ACRM annual conference and the midyear working meeting
- Monthly teleconference discussions were scheduled
- Members of Task Force were specialists in traumatic brain injury (neuropsychologists, therapists, program coordinators, researchers, neurologists, Physicians etc. and included about 25 members)
- One member on the Task Force had sustained a TBI and was invaluable in providing insights and recommendations regarding the survey development. (Ann Forrest; BIAA advocate)
- One member was a parent of a daughter who had sustained a TBI. (Marilyn Spevack NHIF Founder and TBI advocate)



Survey Process and Questions

- Task Force identified 3 main areas:
 - Medical/Rehabilitation
 - Cognitive
 - Emotional/Personality
- Task Force generated questions in all 3 groups, based on:
 - Clinical Experience of Task Force members
 - Prior Research (including Pickelsimer, et al, 2007 and Morris et al, 2005)
 - Input from an advisory panel of individuals who had sustained TBI and family members from a TBI support group in Fairfax, VA



Survey Development

- Initial length of survey: 50 Items across 3 domains (Medical/Rehabilitation, Cognitive, Emotional/Personality)
- Advisory group at Fairfax made a number of recommendations
 - Shorten the surveys
 - Include others besides family members (define significant others)
 - Include a does not apply option
 - Allow for an open ended comments section
- Two separate surveys were developed: 1) Individual with TBI; 2) Significant others



Survey Length and Format

- The first twenty questions were demographic including one question about severity of injury, which was on the basis of self report and adapted from the Severity Classification Model (Breed et al., 2008).
- The next 21 items of the survey were based on a 5-point Likert scale with a Not Applicable option
 - 7 Medical/Rehabilitation
 - 8 Cognitive/Thinking
 - 5 Emotional/Personality
 - 1 General Satisfaction
- Demographic information consisting of gender, race, age, marital status (pre- and post-injury), educational level, occupational status (pre and post), relationship to the injured (for SO survey), and severity of injury
- Open ended comments section



Inclusion Criteria

- Individuals who had sustained a TBI:
 - Age \geq 20
 - At least 6 months post-injury
 - No pre-existing neurological or cognitive conditions
- Sig Others:
 - 21 years of age or older
 - Someone who knows the injured person well, who preferably resides or resided with them, and who knew the person prior to the injury. The relationship may be familial, romantic, or platonic. The injured party they were referencing had to have sustained the TBI from age 20 on.



IRB Review

- The final instrument was reviewed and approved in 2011 by an independent Institutional Review Board (IRB); Quietmind Foundation.
 - Funding for the IRB was granted by the Council on Brain Injury.
 - The approval was based on the a proposal submitted by the Prognosis Task Force.
- IRB restrictions limited recruitment;
 - Since this was not institution based the IRB, as an independent entity determined that the surveys had to be anonymous (no specific identifying information could be collected)
 - This limited our ability to match pairs
 - No direct solicitation as this would compromise anonymity



The surveys were administered online through SurveyMonkey

Links to the surveys were provided through; State brain injury associations, Rehabilitation hospitals, Professional organizations (CARF, ACRM, BIAA), Providers across the United States;

Entities were encouraged to further distribute the survey links through their own contacts



20. I was given enough information about brain injury by health care providers.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- N/A

21. I was told about brain injury symptoms (e.g., headaches, sleep problems, dizziness, visual problems, etc.).

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- N/A

	Number n=143	Significant Other n=117
Age	27.67 (12.38)	46.40 (13.71)
Age at Injury	27.67 (13.21)	35.03 (12.43)
Time Since Injury	10.31 (8.80)	10.37 (8.80)
Race		
Caucasian	88.2%	94.9%
African American	2.0%	2.6%
Hispanic	1.3%	3%
Native American	0.7%	3%
Other/Unknown		3%
Gender	62.1% Female	84.6% Female
Education		
Some High School	3.3%	2.6%
High School/GED	11.3%	16.2%
Some College/JAA	35.9%	35.9%
Bachelor's	23.5%	24.8%
Beyond Bachelor's	23.5%	20.5%
Severity of Injured Person Mild	32.5%	33.4%
Moderate	6.8%	15%
Severe	32.3%	48.7%
Rehabilitation Setting		
Acute Rehabilitation	54.2%	73.5%
Skilled Nursing	18.3%	29.1%
Outpatient	27.2%	80.3%

Respondents

- 149 *individuals with brain injuries* completed the survey
 - Mean age was 37
 - Time since injury 10.31 yrs
 - Primarily female (62.1%), Caucasian (88.2%),
 - Well-educated (35.9% some college, 23.5% bachelor degrees, and 23.5% masters+).
 - More than half report severe injuries (52.3%)
 - Just under a third reported mild TBI.
- 117 *significant others* completed the survey
 - Similar to the individuals with brain injuries, they were primarily female (84.6%), Caucasian (94.9%), and well-educated (35.9% some college, 24.8% bachelor's, 20.5% masters+).
 - Time since injury 10.37 yrs
 - Nearly half reported that their loved one had sustained a severe TBI, while one third reported mild TBI
 - The largest group completing the survey as significant others were parents (46.3%), followed by spouses/partners (27.3%), siblings (12.4%), friends and others (both 5%), and children (4.1%).

Diagnosis and Severity Findings for Those who Sustained a TBI

- Time of TBI diagnosis:
 - 0-3 months after injury: 65 %
 - > 3 months after injury: 21 %
 - Uncertain about date/timing: 13 %
- Severity of Injury:
 - No LOC: 12 %
 - LOC 0 to 20 minutes: 20 %
 - LOC > 20 min to 24 hrs: 8 %
 - LOC > 1 day to 1 month: 44 %
 - Uncertain: 14 %

Those Who Sustained a TBI and SOs Responded Similarly

- Independent samples T-tests were run to compare the two groups on the three subscales and the total scores.
- No significant differences were observed on any subscale nor the total score ($p > .05$).
- One finding that ran across both groups was that those who received acute rehabilitation (as per their report) were significantly more satisfied with information and services provided.
- Similarly there were strong positive correlations between reporting receiving information and satisfaction with services.
- Those who felt they received services and information also indicating higher satisfaction scores.

How clear through information about my brain injury

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	34.6%	13.7%	13.1%	25.8%	8.2%	6.5%
Significant Other	24.8%	27.4%	18.2%	22.2%	6.8%	2.6%
	I was told about symptoms I may have from my brain injury (e.g., headaches, sleep problems, dizziness, visual problems, etc.)					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	23.5%	17.0%	12.4%	27.5%	13.5%	7.2%
Significant Other	14.5%	20.5%	11.1%	31.3%	12.1%	6.8%
	I was told what to expect about my recovery					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	21.4%	20.3%	27.0%	18.8%	6.8%	6.5%
Significant Other	20.1%	24.8%	17.1%	24.2%	6.8%	2.6%
	I helped to identify my treatment goals					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	22.2%	13.7%	14.4%	28.1%	8.3%	11.1%
Significant Other	8.4%	14.5%	22.8%	31.8%	23.1%	8.5%
	My progress was reviewed with me regularly					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	19.0%	17.6%	13.1%	30.7%	11.8%	7.8%
Significant Other	11.8%	17.1%	13.7%	31.3%	17.1%	6.4%
	I received the medical and rehabilitation services that I needed					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	26.1%	15.0%	11.1%	28.1%	13.7%	9.5%
Significant Other	14.5%	23.1%	18.2%	28.1%	17.1%	6.0%
	I was satisfied with the educational resources I received about my brain injury					
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	N/A
Individual w/ TBI	17.8%	14.4%	13.7%	19.0%	8.5%	6.5%
Significant Other	14.4%	19.1%	18.2%	20.5%	6.0%	3.4%



- About half of both groups reported not being given enough information about Brain Injury
- Less than 40% of both groups felt they were given enough information about what to expect regarding recovery



Significant Other Subgroup Findings

- No Significant Difference in responses of Significant Others were found based on their relationship to the Injured Individual.
 - Parents, siblings, spouses, and children did not respond differently from each other on the subscales



Acute Rehab vs. SNF and OP Findings

Rehabilitation Settings:

Acute Rehabilitation	54.2%
Skilled Nursing Facility	18.3%
Outpatient	77.1%

Comparison of those who received acute rehabilitation versus those who did not receive acute rehab:

- Those who did not get acute rehab were significantly less informed and less satisfied than those who had a course of acute rehab
- Examples: Disagree and Strongly Disagree responses to:
 - “I was given enough information about my brain injury”; “I was satisfied with the information I received about the cognitive issues associated with my brain injury”;
 - “I was told that emotional or personality changes sometimes occur after brain injury.”



Medical/Rehabilitation Area

- Positive responses (i.e., “Agree” or “Strongly Agree”) were below 50% for all of the 7 items; this suggested mild satisfaction/perception of information given.
- **Lowest responses:**
 - “I was told what to expect about my recovery” (24%)
 - “I was satisfied with the educational resources I received about my brain injury” (28%)
- **Highest response:**
 - “I received the medical and rehabilitation services that I needed” (44%). But, still relatively low – below 50%.



Cognitive Area

- Positive responses (i.e., “Agree” or “Strongly Agree”) were below 50% for 5 of the 8 items (63%), suggesting mild to moderate satisfaction/perception of information given.
- Overall, satisfaction and perception of information received was better for **COGNITIVE** as compared to **MEDICAL/REHABILITATION** items
- **Lowest** response was the satisfaction item: “I was satisfied with the information I received about the cognitive issues associated with my brain injury” (only 29%)
- **Highest** response was treatment-related:
 - “My thinking abilities were tested by a neuropsychologist, speech therapist, and/or occupational therapist (72%)



Emotional/Personality Area

- Positive responses (i.e., “Agree” or “Strongly Agree”) were below 50% for all of the 5 items
- **Lowest** response was a satisfaction item:
 - “I was satisfied with the emotional/personality information I received about my brain injury” (29%)
- **Highest** response:
 - “I was told that emotional or personality changes sometimes occur after brain injury (49.6%). Still relatively low, right at 50%



Gender Effects

- 62.1% of those who had sustained a TBI = Female
- 84.6% of Significant Others = Female
 - Females may be more inclined to do online surveys. Online Survey Behavior (W.G. Smith, 2008 San Jose’ University)
 - Care of an ill or disabled family member or friend is disproportionately done by women
 - Pavalko and Artis, Journals of Gerontology 97
 - Participants in TBI support groups are more likely to be female? “men are less likely to join a support group” Krizek et al; Cancer Practice Vol 7, issue 2, pages 86–92, March/April 1999
 - Women may seek social network support more frequently than men which would bring them in to contact with the survey more frequently? Pew Research ; Demographics of social media users (2012)



Gender Results

- Significant differences between male and female survivors were found:
 - Females reported significantly lower scores than males on all subscales (Medical/Rehab $t=4.07$, $p=.000$; Cognitive $t=3.08$, $p=.003$; Emotional $t=3.39$, $p=.001$) and the total score ($t=3.01$, $p=.003$)
 - Finding indicates that females were less satisfied and perceived that they received less information about brain injury than males.

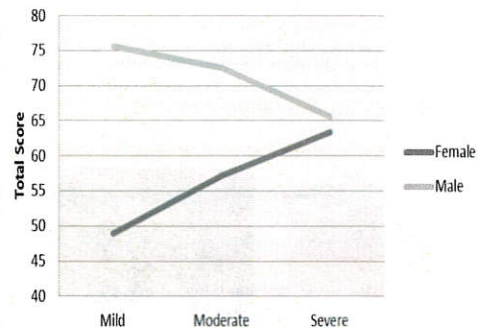


Gender Results

- Females who had sustained mild brain injuries scored significantly lower (i.e., less positive responses) than males with mild TBI ($t=3.46$, $p=.002$)
- Males and females with severe brain injuries did not show significant differences ($t=.373$, $p=.711$)



Injury Severity X Gender



Significant Other Subgroup Findings

- No significant difference in responses of Significant Others were found based on their relationship to the Injured Individual.
 - Parents, siblings, spouses, and children did not respond differently from each other on the subscales



Satisfaction/Perception of Information and Time Since Injury

- Increased satisfaction with services/perception of information received, was correlated with decreased time since injury ($r = -.165$, $p = .049$)
- Findings held for both Individuals with TBI and Significant Others regardless of severity
- Neither years of education, occupational status, age, nor age at injury correlated with satisfaction/perception of information scores ($p > .05$)



Qualitative Analysis of Comments

- 96 of the 149 (64%) individuals with Brain Injury made comments.
- 65 of 117 (56%) significant others provided comments.
- Key themes:
 - Need to tell personal stories
 - Adequacy of information provided
 - Adequacy of rehabilitation provided
 - Adequacy of discharge planning and available resources



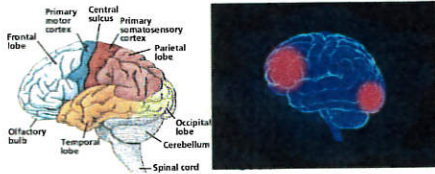
Recommendations

- Create an organizational culture that values timely, honest, and direct communication at all levels of service: Inpatient, outpatient, home and community.
- Develop and implement training for communicators and recognize that at some level all team members find themselves in situations where they are communicating critical information. Include small group sessions and role playing. Allow the team to observe the most skilled communicators in action.
 - How do we demonstrate empathy Acknowledge the difficulty of the family's situation as well as their particular presentation (e.g., sadness, anxiety, etc.)
 - Encourage questions and check understanding



Recommendations

- **USE ACCESSIBLE LANGUAGE AND AVOID JARGON.** When possible, include specific and numeric statements of probability. Describe expected outcomes in real life functional terms, (e.g., return to work, ability to walk, etc.). Remember, what families want most is honest and direct information and may miss salient points when information is "cloudy."
 - In addition, spoken information should be supported with written and visual material. (Kessels; pictographs) (graphs)



Recommendations

- From Kessels; *JRSM, May 2013 vol. 96 no.5 219-222*
 - 40-80% of medical information provided by healthcare practitioners is forgotten immediately. The greater the amount of information presented, the lower the proportion correctly recalled; furthermore, almost half of the information that is remembered is incorrect.
 - Age is a factor
 - Stress is a factor
 - People tend to focus more on diagnostic information and less on therapeutic instructions and treatment
 - Medical information can be remembered better by use of explicit categorization techniques (This makes sense cognitively; Clark and Clark)



A Standard Five-Category Set; Ley

1. Describe what is wrong
2. What tests will or have been performed
3. What is expected to happen- (where are we)
4. Which treatments will be needed
5. Finally: what can the person do to help in the process (This would apply to both the person who is the focus of treatment and important others)

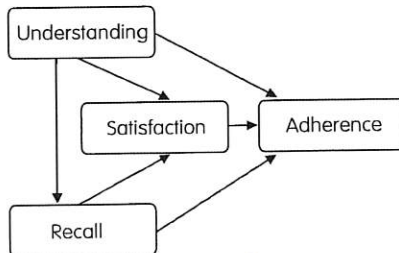


Find ways to Include Families in Planning and Therapeutic Sessions

- Daily rounds, therapy sessions, care provision (e.g., feeding, grooming, etc.) as appropriate. Find situations that can serve as teaching opportunities and reinforce information that may have previously been communicated. Repetition of information is a key to better understanding. Remember Ley's model



Ley's Model on the Interactions Between Patient-Related Factors and Therapy Adherence; Kessels, 2013 Journal of the Royal Society of Medicine



Individuals With Traumatic Brain Injury and Their Significant Others' Perceptions of Information Given About the Nature and Possible Consequences of Brain Injury

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