

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

## *Analysis of a National Survey*

Rosette C. Biester, PhD, Dave Krych, MS-CCC-SLP, CBIS, M. J. Schmidt, MA, CBIS, Devan Parrott, MS, Douglas I. Katz, MD, Melissa Abate, LMSW, CCM, and Chari I. Hirshson, PhD

### ABSTRACT

**Purpose of the Study:** An online survey was developed to assess how well individuals with brain injuries and family/friends of those with traumatic brain injury (TBI) (significant others) felt they were informed about the nature and consequences of brain injury.

**Participants:** A total of 117 significant others completed the survey. They were primarily female (84.6%), white (94.9%), and well educated (81.2%). A total of 149 individuals with brain injuries completed the survey and again were primarily female (63.8%), white (88.2%), and well educated (82.9%).

**Results:** More than half of the significant other respondents indicated that they were not provided enough information about TBI (53.5%). Up to 53.8% of the respondents with TBI felt that they were not provided enough information, with 43% reporting dissatisfaction with services. Female survivors and those with mild brain injuries were significantly more likely to feel that they were not provided sufficient rehabilitation or information. Increased satisfaction with services was correlated with decreased time since injury ( $r = -0.165$ ,  $p = .049$ ). Qualitative analysis revealed key themes about prognostic information and the adequacy of discharge planning and resources.

**Implications for Case Management Practice:** Given that more than half of all surveyed indicated that they were not well-informed about brain injury and its possible effects, it is evident that case managers and their teams need to be aware of and invested in their efforts to educate both individuals with brain injuries and their significant others (family and friends) about both the nature and consequences of brain injury. Specific recommendations for practice are included.

**Key words:** family education, knowledge translation, patient education, prognosis, satisfaction, traumatic brain injury

It is well established that the quality, quantity, and timing of information delivered to individuals and families after brain injury are important as they set the stage for future information, encourage realistic expectations, and promote effective coping (Larson, Nelson, Gustafson, & Batalden, 1996; Lezak, 1986). Although some research has addressed the unmet and ongoing informational needs of individuals with traumatic brain injury (TBI) and their families and the stress associated with such needs, relatively little is known about the specific ways individuals and their families perceive the information provided to

them about brain injury and prognosis. This study addressed the topic using an online survey for families and individuals with TBI that specifically asked about their perceptions of the information provided to them about brain injury and prognosis within the

Address correspondence to M. J. Schmidt, MA, CBIS, Research Assistant, ReMed, 16 Industrial Blvd, Ste. 203, Paoli, PA 19301 (mschmidt@remed.com).

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first 6 months after injury. This article describes relevant literature, the surveys for both individuals with TBI and their significant others (families, spouses, or friends), and presents the quantitative and qualitative analyses of the data gathered from those surveys. Recommendations for practice, implications for case managers, and recommendations for further research are also provided.

## REVIEW OF PRIOR RESEARCH

Specific research on the timing, quality, and type of communication about disability to family members is rare. Much of the research about information communicated to individuals with brain injuries and their families comes indirectly from studies investigating similar topics including caregiver stress, satisfaction with services, or ongoing and unmet needs. Close relatives of individuals with TBI have consistently identified information as one of their needs (Bond, Draeger, Mandleco, & Donnelly, 2003; Kowakowsky-Hayner, Miner, & Kreutzer, 2001; Perlesz, Kinsella, & Crowe, 2000). They repeatedly indicate that they were not satisfied with the information they received from care providers (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005; Merritt & Evans, 1990; Oddy, Humphrey, & Uttley, 1978; Sinnakaruppan & Williams, 2001), and they specifically identify having access to information about their loved one's condition and prognosis and having their questions answered honestly and directly as primary family needs (Engli & Kirisivali-Farmer, 1993; Mathis, 1984; Serio, Kreutzer, & Witol, 1997; Testani-Dufour, Chappel-Aiken, & Gueldner, 1992). Similarly, inadequate communication between families and professionals before discharge from the hospital has been identified as a recurrent problem across populations (Guerin, Grimmer-Somers, Kumar, & Dolejs, 2012).

Research on information provided to specific subgroups of the population and at various points in the rehabilitation process further informs our knowledge on this topic. Parents of pediatric patients with TBI have been the focus of two reports. In two studies, between 66% and 70% of parents of children with TBI reported that their informational needs were unmet (Hawley, Ward, Magnay, & Long, 2003; Hermans, Winkens, Winkel-Witlox, & van Iperen, 2012), with 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 (Rosignano, Savage, Grant, & Philipsen, 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; and parents' perceived

limited involvement in decision making. Both vague and complicated languages (jargon) were identified as barriers to parents' ability to understand the implications of their 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 (Rosignano et al., 2013). Another subgroup is the families/surrogates of individuals with disorders of consciousness. The information provided to those families is often problematic, not based on evidence, filled with terms that may be confused (e.g., coma, vegetative, or minimally conscious state), and can include statements that color family expectations going forward (Fins, 2013; Wijdicks & Rabinstein, 2007).

Ambiguous language can also be problematic in communicating information about disability. Previous research has shown that nebulous words like "sick" are used differently by physicians and families (deWit, Donohue, Shepard, & Boss, 2012). Although substitutions for words like "disability" or "problem" (now challenge or difference) have become common in today's rehabilitation and education cultures, families often require more specific and direct wording. Most family members want and need information that is truthful and understandable, uncomplicated by medical terminology, and that explains even the most basic conditions (deWit et al., 2012). Repeatedly, families of individuals with brain injuries, spinal cord injuries, and developmental disabilities have reported a need for direct, honest, and understandable information about their loved one's diagnosis, treatment, and prognosis (Meade, Taylor, Kreutzer, Marwitz, & Thomas, 2004; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007).

Information needs were also found to persist or change over the length of an individual's life after injury, with families reporting a change in what types of information they desired from acute hospitalization through community re-entry (Pickelsimer et al., 2007; Rotondi et al., 2007). Of all identified needs, information (understanding the injury, treatment, and its consequences) was the only need that occurred throughout all phases of treatment (acute, inpatient rehabilitation, return to home, and living in the community) (Wijdicks & Rabinstein, 2007). Family members of individuals with TBI consistently felt that the explanations provided by health care providers were "not understandable," with some families going as far as to say that information was inaccurate or misleading. Furthermore, physician-provided information about prognosis is often misinterpreted by family members. This may be an artifact of the shortcomings of the interaction including the nature of the language used by the physician, biases based on family expectations, or both. In one study, family members/surrogate decision makers were able to accurately

*...physician-provided information about prognosis is often misinterpreted by family members. This may be an artifact of the shortcomings of the interaction including the nature of the language used by the physician, biases based on family expectations, or both. In one study, family members/surrogate decision makers were able to accurately interpret optimistic probabilistic statements (such as 90% chance of survival), yet they misunderstood more pessimistic statements such as 5% chance of surviving.*

interpret *optimistic* probabilistic statements (such as 90% chance of survival), yet they misunderstood more pessimistic statements such as 5% chance of surviving (Zier, Sottile, Hong, & White, 2012).

Perception of the adequacy of information provided also seems to change over time. One study found that 62% of families initially reported that they had adequate information on their loved ones' physical problems, with reports of adequacy for that information dropping to 59% at follow-up. Similarly, fewer families (49%–43%) reported having adequate information about cognitive problems at follow-up (Winstanley, Simpson, Tate, & Myles, 2006).

Although individuals with TBI and their families report that they need practical support and teaching during their recovery, how often they get it is varied. For example, in one study nurses taught daily activities most often (38.8%), whereas they provided less teaching about mood swings and other emotional symptoms of TBI (7.0%) (Coco, Tossavainen, Jaaskelainen, & Turunen, 2013). Similarly, families reported that the information provided to them about the long-term effects of TBI such as cognitive and personality change was inadequate (McMordie, Rogers, & Barker, 1991).

Repeatedly, the importance of well-communicated information about diagnosis, treatment, and prognosis has been associated with better family understanding, satisfaction, and improved outcomes. Still, little is known specifically about how individuals with TBI and their significant others perceive the information provided to them about their brain injury and its potential impact. The aims of this study were to examine the perceptions of individuals with TBI and significant others (family and friends) as well as their satisfaction with regard to the type, quality, and quantity of information they were provided about TBI within the first 6 months after injury.

## **METHODS**

### **Instrument Development**

Two online surveys were developed to assess how well both individuals with TBI and their significant others (family members, spouses or partners, friends, etc.) felt they were informed about the possible

consequences of their injuries. The surveys were constructed by members of the American Congress on Rehabilitation Medicine's Brain Injury Special Interest Group's Prognosis Task Force on the basis of prior work of researchers (Morris et al., 2005; Pickelsimer et al., 2007). The surveys were then piloted with an advisory panel composed of both adults with TBI and family members, and reviewed and approved by an Institutional Review Board. Each survey was 42 items in length, with one final open question for comments. The first 20 questions were demographic including one question about severity of injury, determination of which was made on the basis of self-report and adapted from the Severity Classification Model (Breed et al., 2008). The second half of the survey focused on perception of and satisfaction with information provided about brain injury and recovery to the participant. Questions were clustered around three primary areas: medical and rehabilitation, cognitive, and emotional and personality. Responses in this section utilized a five-point Likert scale rating of "strongly agree," "agree," "neutral," "disagree," "strongly disagree," and included an "N/A" response option. The instrument was administered online, with links to the survey being provided through state brain injury associations, rehabilitation facilities, support groups, and professionals. There was no matching component to the survey; that is, an individual or a significant other took the survey without its being paired with either their significant other or injured loved one. Anonymity was ensured through privacy protection features of the online survey host.

### **Participants**

Surveys were completed by 156 individuals with TBI and 120 significant others (family, spouses/partners, friends) although 10 duplicate surveys (identified by both matching date of birth and matching IP addresses) were removed from the data pool, leaving 149 individual and 117 significant other surveys. Respondents were solicited independently, and individuals and their significant others were considered separately and not in matched pairs. Participants in both groups were overwhelmingly female, white, and well educated. Of the individuals with TBI, 33.3%

had no loss of consciousness (LOC) or an LOC of less than 20 minutes. An additional 8.3% had an LOC of less than 24 hours (41.6% mTBI). Significant others tended to be parents (50.9%) or spouses/partners (23.6%) although children, siblings, and friends/others were also represented. Demographic information for participants is presented in Tables 1 and 2.

### Data Analysis

Data were statistically analyzed using SPSS version 20 software. Descriptive statistics were calculated and examined first. Further analyses examining the participants' responses were investigated using frequencies and Spearman correlations. Sixty-five of the 117 significant others and 96 of the 156 individuals provided comments in this area. Comments were analyzed using conventional content analysis methods by three reviewers. First, all comments were read so that categories/themes of comments could be developed (Hsieh & Shannon, 2005; Mayring, 2000; Zhang & Wildemuth, 2009). Next, a coding system was developed to correspond to the themes identified. Reviewers then coded a sample of comments and revised codes as a group in order to establish appropriate interrater reliability, which during piloting reached

89% agreement. All comments were coded by the three reviewers.

## RESULTS

Overall, 41.6% and 38.5% of individuals and significant others, respectively, indicated satisfaction with the rehabilitation services received. Each survey was broken down into three subgroups: medical and rehabilitation information, cognitive information, and emotional information. All subscales strongly correlated with each other, showing similar satisfaction across the three domains. The medical and rehabilitation information domain significantly correlated with the cognitive information domain ( $\rho = 0.89, p < .0001$ ) and the emotional information domain ( $\rho = 0.703, p < .0001$ ). The emotional information domain correlated with cognitive information domain as well ( $\rho = 0.796, p < .0001$ ).

Generally, individuals and significant others 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 services and satisfaction, with those who felt they received services and information also indicating higher satisfaction scores. Table 3 (or a link to digital content) illustrates responses to each question by both individuals and significant others.

**TABLE 1**  
Demographics

	Individuals With TBI (n = 149)	Significant Others (n = 117)
Age (year)	37.67 (12.36)	46.40 (13.71)
Age at injury (year)	27.67 (13.21)	36.03 (12.43)
Time since injury (year)	10.31 (8.80)	10.37 (8.80)
Race (%)		
White	88.2	94.9
African American	2.0	2.6
Hispanic	1.3	0.9
Native American	0.7	0.9
Other/unknown		0.9
Sex—female (%)	62.1	84.6
Education (%)		
Some high school	3.3	2.6
High school/GED	11.1	16.2
Some college/AA	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	9.8	18.0
Severe	52.3	48.7

Note. AA = Associate of Arts; GED = General Educational Development; TBI = traumatic brain injury.

### Survey for Individuals With TBI

Of individuals with TBI completing the survey, most did report having had some rehabilitation services: 55.8% reported an inpatient acute rehabilitation stay and 78.2% stated that outpatient services were provided. An additional 17.9% reported a stay in a skilled nursing facility. More than half (50.3%) reported that they were not given enough information about brain injury by health care providers, with 30.1% reporting

**TABLE 2**  
Type of Rehabilitation Received by Respondents by Injury Severity

Severity	Acute Rehabilitation (%)	SNF (%)	Outpatient Rehabilitation (%)
Mild (n = 50)	28	12	72
Moderate (n = 12)	50	8.3	67
Severe (n = 68)	82	26	82

Note. SNF = Skilled nursing facility.

**TABLE 3**  
Survey Questions and Responses

	<b>Strongly Disagree (%)</b>	<b>Disagree (%)</b>	<b>Neither (%)</b>	<b>Agree (%)</b>	<b>Strongly Agree (%)</b>	<b>N/A (%)</b>
I was given enough information about my brain injury						
Individual with TBI	34.6	15.7	13.1	20.9	9.2	6.5
Significant other	24.8	27.4	16.2	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)						
Individual with TBI	25.5	17.0	12.4	27.5	10.5	7.2
Significant other	14.5	20.5	11.1	35.9	11.1	6.8
I was told what to expect about my recovery						
Individual with TBI	31.4	20.9	17.0	19.6	4.6	6.5
Significant other	20.5	24.8	17.1	28.2	6.8	2.6
I helped to identify my treatment goals						
Individual with TBI	22.2	15.7	14.4	28.1	8.5	11.1
Significant other	9.4	14.5	12.8	31.6	23.1	8.5
My progress was reviewed with me regularly						
Individual with TBI	19.0	17.6	13.1	30.7	11.8	7.8
Significant other	12.8	17.1	13.7	33.3	17.1	6.0
I received the medical and rehabilitation services that I needed						
Individual with TBI	26.1	15.0	11.1	28.1	15.7	3.9
Significant other	14.5	23.1	16.2	29.1	17.1	0.0
I was satisfied with the educational resources I received about my brain injury						
Individual with TBI	37.9	14.4	13.7	19.0	8.5	6.5
Significant other	24.8	29.1	16.2	20.5	6.0	3.4
I was told about the possible effects of my brain injury on my thinking abilities (e.g., memory, problem-solving, and language)						
Individual with TBI	26.1	15.0	11.1	26.1	15.0	6.5
Significant other	10.3	13.7	10.3	47.9	11.1	6.8
My thinking abilities were tested by a neuropsychologist, a speech therapist, and/or an occupational therapist						
Individual with TBI	9.8	4.6	5.9	34.0	37.9	7.8
Significant other	6.0	1.7	2.6	52.1	30.8	6.8
The therapists tried their best to explain the results of these tests						
Individual with TBI	10.5	15.0	13.7	28.1	20.3	12.4
Significant other	5.1	11.1	17.1	40.2	12.0	14.5
I understood what I was told about these tests						
Individual with TBI	14.4	13.1	20.3	29.4	7.8	15.0
Significant other	3.4	12.8	16.2	42.7	9.4	15.4
Therapy was provided to help me with my thinking problems						
Individual with TBI	24.8	8.5	8.5	32.0	18.3	7.8
Significant other	7.7	15.4	16.2	35.0	15.4	10.2
I was told that changes in my thinking abilities (including memory, problem solving, and language) might be a problem in areas such as work, school, and child care						
Individual with TBI	25.5	9.8	7.8	30.7	21.6	4.6
Significant other	4.3	11.1	14.5	45.5	15.4	9.4
I was given recommendations on how to participate in activities such as work, school, and child care						
Individual with TBI	30.7	17.6	11.1	23.5	10.5	6.5
Significant other	16.2	24.8	18.8	23.9	3.4	12.8
I was satisfied with the information I received about the cognitive issues associated with my brain injury						
Individual with TBI	32.7	13.7	17.6	19.0	9.8	7.2
Significant other	17.9	25.6	20.5	22.2	5.1	8.5

(continues)

**TABLE 3**  
**(Continued)**

	<b>Strongly Disagree (%)</b>	<b>Disagree (%)</b>	<b>Neither (%)</b>	<b>Agree (%)</b>	<b>Strongly Agree (%)</b>	<b>N/A (%)</b>
I was told that emotional or personality changes sometimes occur after brain injury						
Individual with TBI	23.5	13.1	7.8	34.6	15.0	5.9
Significant other	9.4	12.8	10.3	47.9	12.0	7.7
I was told that irritability, poor frustration tolerance, and/or loss of temper are sometimes symptoms of brain injury						
Individual with TBI	22.9	16.3	8.5	34.0	11.8	6.5
Significant other	10.3	16.2	9.4	43.6	13.7	6.9
Treatment was recommended for my emotional and/or personality changes						
Individual with TBI	23.5	19.6	13.1	21.6	11.8	10.5
Significant other	11.1	29.1	12.0	26.5	7.7	13.7
I was told that depression and/or anxiety could occur after my brain injury						
Individual with TBI	22.9	16.3	7.2	32.7	15.0	5.9
Significant other	8.5	15.4	8.5	47.9	12.0	7.7
I was satisfied with the emotional/personality information I received about my brain injury						
Individual with TBI	29.4	21.6	11.8	19.0	9.8	8.5
Significant other	21.4	21.4	17.1	26.5	6.0	7.7
Overall, I am satisfied with the rehabilitation that was received or is being received for the traumatic brain injury						
Individual with TBI	15.7	22.9	18.3	13.1	27.5	2.6
Significant other	19.7	17.9	17.1	28.2	10.3	6.9

Note. TBI = traumatic brain injury.

that they felt the information provided was adequate. Regarding satisfaction with rehabilitation services provided/being provided, 41.6% of individuals reported satisfaction and 38.6% indicated dissatisfaction.

### Medical and Rehabilitation Information

In this section, individuals were asked questions about the information provided to them about the medical and physical consequences of brain injury as well as about the services specific to those needs. The Medical and Rehabilitation subscale showed moderate satisfaction overall, with only 30.1% indicating they were given enough information about brain injury. Thirty-eight percent felt they were informed about brain injury symptoms they may experience, whereas 24% indicated they were told what to expect during recovery. Thirty-seven percent indicated they helped to identify treatment goals, and 42.5% felt their progress was reviewed with them regularly. Forty-four percent felt they received the medical and rehabilitation services they needed, whereas only 28% felt satisfied with the brain injury educational resources they received.

### Cognitive Information

Mild to moderate satisfaction ratings were present on the cognitive information domain items, with only 28.8% of patients reporting satisfaction with

information received about the possible cognitive issues associated with brain injury. Only 41.1% of individuals reported they were told about the possible effects of brain injury on thinking abilities, but 71.9% reported their thinking abilities were tested by a neuropsychologist, speech therapist, or occupational therapist. Of the patients who reported testing, only 55.2% reported that the results were explained to them and only 43.8% reported that they understood what they were told about the tests. Fifty percent reported that therapy was provided to help with thinking problems. Fifty-two percent of the individuals with TBI reported that they were told the changes in their thinking abilities might impact areas such as work, school, and child care, and only 34% indicated they were given recommendations on how to participate in these activities.

### Emotional and Personality Information

Only 28.8% of respondents expressed satisfaction with the emotional and personality information they received about their brain injury, although 49.6% reported they were told that emotional or personality changes sometimes occur after brain injury. Forty-six percent reported they were told that irritability, poor frustration tolerance, and loss of temper are symptoms of brain injury, and forty-eight percent reported they were told about depression and anxiety. Only

33.4% reported that treatment was recommended for their emotional/personality changes.

### Significant Other Survey

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%). Significant others indicated that their loved ones had, by and large, received some rehabilitation, with 74.6% reporting an inpatient acute rehabilitation stay and 79.2% reporting that outpatient services were provided. An additional 31.5% reported a stay in a skilled nursing facility. More than half (52.3%) of the significant others reported that they were not given enough information about brain injury by health care providers, with 30% reporting that they felt the information provided was adequate. Regarding satisfaction with rehabilitation services provided/being provided, 39.6% of significant others reported satisfaction, with 40.5% indicating dissatisfaction.

The Medical and Rehabilitation subscale showed moderate satisfaction overall, with only 29.6% indicating they were given enough information about their loved one's brain injury. Forty-seven percent felt they were informed about brain injury symptoms such as headaches and dizziness, whereas only 35% indicated they were told what to expect during recovery. More than half of the respondents (54.7%) indicated they helped to identify treatment goals, whereas 50% felt their progress was reviewed with them regularly. Forty-six percent felt they received the medical and rehabilitation services they needed, whereas only 26.5% felt satisfied with the brain injury educational resources they received.

Within the questions on the cognitive information domain, 27.3% of significant others reporting satisfaction with information received about the possible cognitive issues associated with brain injury. Although more than 80% reported their thinking abilities were tested by a neuropsychologist, speech therapist, or occupational therapist, only 59% of significant others reported they were told about the possible effects of brain injury on thinking abilities. Of those reporting testing, 52% reported both that the results were explained to them and that they understood what they were told about the tests. Fifty percent reported that therapy was provided to help with thinking problems. Nearly 61% percent of significant others reported they were told the changes in their thinking abilities might impact areas such as work, school, and child care and only 27.3% indicated they were given recommendations on how to participate in these activities.

Only 32.5% of significant others expressed satisfaction with the emotional and personality information

**TABLE 4**  
Comments by Significant Others of Individuals With Brain Injury

Comment Theme	Frequency (n)	Comments Made (%)
Telling story	35	41.9
Information was adequate	1	0.5
Information was inadequate	14	17.36
Rehabilitation was adequate	4	4.79
Rehabilitation was inadequate	17	20.96
Discharge planning/resources inadequate	10	11.98
Alternate therapy	1	1.19
Survey itself	1	1.19

they received about brain injury, though nearly 60% reported they were told that emotional or personality changes sometimes occur after brain injury. Up to 57.3% reported they were told that irritability, poor frustration tolerance, and loss of temper are symptoms of brain injury, and nearly 60% reported they were told about depression and anxiety. Only 34.2% reported that treatment was recommended for their loved one's emotional/personality changes.

### Qualitative Analysis

Qualitative analyses of comments made revealed key themes including the telling of personal stories and specific comments about the care received; the giving of information diagnosis, prognosis, or brain injury; and the adequacy of discharge planning and available resources; alternative treatment(s); and suggestions about the survey itself. Tables 4 and 5 reflect the frequency of comments made on these themes by each group and the percentage of total number of comments made for each theme.

**TABLE 5**  
Comments by Individuals With Brain Injury

Comment Theme	Frequency (n)	Comments Made (%)
Telling story	58	44.96
Information was adequate	3	2.3
Information was inadequate	31	24.03
Rehabilitation was adequate	6	5.03
Rehabilitation was inadequate	20	15.5
Discharge planning/resources inadequate	7	5.03
Alternate therapy	1	0.7
Survey itself	1	0.7

*Females reported significantly lower scores than males on all subscales... Those with mild brain injuries were more likely to feel they were not provided enough information about their brain injuries ... and to state that they did not receive the medical and rehabilitative services that they needed.*

### Post Hoc Analyses

Further analysis of the data revealed a significant difference between male and female survivors' satisfaction. Females reported significantly lower scores than males on all subscales (medical:  $t = 4.07, p = .000$ ; cognitive:  $t = 3.08, p = .003$ ; and emotional:  $t = 3.39, p = .001$ ) and the total score ( $t = 3.01, p = .003$ ). Those with mild brain injuries were more likely to feel they were not provided enough information about their brain injuries ( $p = 0.313, p = .000$ ) and to state that they did not receive the medical and rehabilitative services that they needed ( $p = 0.344, p = .000$ ). These effects were not found among family respondents. Further investigation showed mildly injured females scoring significantly lower than mildly injured males ( $t = 3.46, p = .002$ ) but males and females with severe injuries scoring about the same ( $t = 0.373, p = .711$ ). The main effect was that of gender ( $F = 4.877, p = .03$ ), with no effect for severity ( $F = 0.097, p > .05$ ), and no interaction ( $F = 3.009, p = .055$ ). See Figure 1.

Across both survivors and significant others, increased satisfaction with services was found to be correlated with decreased time since injury ( $r = -0.165, p = .049$ ), showing that shorter time since injury was related to increased satisfaction ratings. Neither years of education, occupational status, or age nor age at injury correlated with satisfaction scores ( $p > .05$ ).

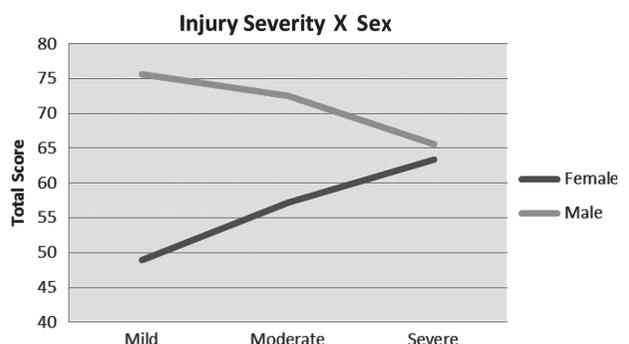
### DISCUSSION

To our knowledge, this is the first study to look specifically at individual and significant other perceptions of and satisfaction with information received within the first 6 months after brain injury across a national sample utilizing both quantitative and qualitative measures. Results of this survey indicate that both individuals who sustained TBI and their significant others report not having enough information about brain injury. Interesting questions emerge as to why females and especially females with mild brain injuries seem to be overrepresented in terms of survey completion. The findings, in many ways, are

similar to earlier findings. Prior researches involving close relatives of individuals with brain injuries and individuals themselves have indicated unmet informational needs and dissatisfaction with information provided (Lefebvre et al., 2005; Merritt & Evans, 1990; Oddy et al., 1978; Sinnakaruppan & Williams, 2001), yet have not specifically investigated the relationships between and characteristics of those who are most and least satisfied and their specific experience with rehabilitation. This study reveals some interesting effects involving sex, severity of injury, and time since injury.

Female individuals with mild brain injuries were the most likely to feel they were not provided enough information about their brain injuries and to state that they did not receive the medical and rehabilitative services that they needed. Again, this is a finding that has been echoed in other research and, in part, may be explained by the fact that a number of these individuals may not have been diagnosed or treated after injury. In sharp contrast, however, were the findings for males whose satisfaction was inversely correlated with severity of injury and whose level of satisfaction was greater than for *all* females, regardless of the severity of injury (see Figure 1). The literature addresses the case of persistent problems in women with mild brain injuries (Dischinger, Ryb, Kufera, & Auman, 2009; Meares et al., 2008; Sheedy, Harvey, Faux, Geffen, & Shores, 2009), which may explain, in part, the sex difference in satisfaction.

This study also found that those who did *not* receive acute rehabilitation were less likely to report having received adequate information or satisfaction with services or information across nearly all survey items, and held true for both survivors and significant others. This raises questions particularly for those with mild brain injuries. Could it be that there was less satisfaction in those with mild injury because they were less likely to encounter specialists, making it less likely that they would receive information? Another finding of interest was that respondents who completed the survey closer to the time of



**FIGURE 1**  
Injury severity and sex satisfaction scores.

*This study also found that those who did not receive acute rehabilitation were less likely to report having received adequate information or satisfaction with services or information across nearly all survey items, and held true for both survivors and significant others.*

injury were more likely to report increased satisfaction with services, suggesting the possibility of either improved provider–consumer communication and/or the evolution of individuals and their significant others’ informational needs as the chronicity of TBI becomes apparent.

### **STUDY LIMITATIONS**

There are several methodological limitations of this study. Use of an online survey inherently creates limitation and bias. The obvious advantage of web-based surveys is their cost to administer and anonymity. Still, a large number of people do not have access and/or choose not to use the Internet. Another limitation is related to the recruitment process: participants needed to locate the survey on various websites, requiring skills that younger individuals, those with higher education and greater socioeconomic means, and those with more mild injuries may be more likely to have. Although the reliance on the both individual and significant others’ memories regarding treatment received and information communicated may have impacted the data’s reliability, the survey was developed for the purpose of establishing the *perceptions* of those receiving services and information about brain injury. Still, there are biases and other influences on patient’s and significant other’s reports of satisfaction. All sorts of biases can influence a person’s later perceptions and reports of an experience that may differ

substantially from what was communicated or even what they might have reported at an earlier time. General satisfaction with outcome, present mood, likability of treating professionals, and fading and distorted memory of events can influence this reporting.

There were also demographic anomalies in this study. Of the respondents who were survivors, a high percentage were female (63.8%), white, and highly educated, which does not align with the current epidemiology of TBI. In almost every age group, TBI rates are higher for men than for women (Faul, Xu, Wald, & Coronado, 2010). Furthermore, research has shown that more females than males use the Internet to complete surveys, as in the case of this research (Weis, 2000).

### **CONCLUSIONS AND IMPLICATIONS FOR PRACTICE**

Brain injury occurs without warning, leaving those who survive and their significant others uncertain about the future and what lies ahead. Providers of medical care and rehabilitation specialists are responsible for preparing those in their care for a changed future by providing relevant information regarding possible symptoms and the course of recovery. Health care providers often believe that they have communicated the necessary diagnostic, treatment, and prognostic information, but they often do not take the time to determine whether the listener—the individual with TBI and/or the family member—has processed the information or fully understood it. Our survey’s results strongly suggest that more attention and effort needs to be placed on what to communicate, how to communicate, and how often to communicate sensitive diagnostic and prognostic information. Effective early communication is the first step to increasing awareness of limitations, as it sets the stage for future information, encourages realistic expectations, and promotes effective coping. Furthermore, it may ensure the provision of more effective, personally relevant, and timely therapeutic services.

As part of their practice, case managers, social workers, and other rehabilitation professionals are charged with providing family members of individuals with disabilities clear, appropriate, and compassionate

*Health care providers often believe that they have communicated the necessary diagnostic, treatment, and prognostic information, but they often do not take the time to determine whether the listener—the individual with TBI and/or the family member—has processed the information or fully understood it. Our survey’s results strongly suggest that more attention and effort needs to be placed on what to communicate, how to communicate, and how often to communicate sensitive diagnostic and prognostic information.*

information about their loved ones' diagnoses, treatment, and prognoses. Well-communicated information reduces family distress and allows families to make effective and meaningful decisions, advocate for their loved ones' needs, and ultimately prepare for the "new" normal. Research clearly indicates that communication between care providers and family members needs considerable improvement.

## RECOMMENDATIONS FOR PRACTICE

Case managers and rehabilitation professionals should consider the following evidence-based recommendations:

1. Create an organizational culture that values timely, honest, and direct communication to families and individuals about their disabilities and set aside resources to make this possible.
2. Recognize the importance of direct communication. Plan for and schedule specific communication about disability.
3. Hold conferences in a private place, at a mutually convenient time, with a limited number of the "usual" care providers. Time allotted should allow for both processing and questions.
4. Encourage family members to ask questions and check their understanding of information presented by asking them to restate the information or by restating and questioning.
5. 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 and ability to walk). Remember, most families want honest and direct information and may miss salient points when information is "cloudy."
6. Demonstrate empathy. Acknowledge the difficulty of the family's situation as well as their particular presentation (e.g., sadness and anxiety, etc.).
7. Provide well-developed and relevant written materials. Do not provide large stacks of information that are likely to be tossed aside. Instead, when possible, limit content to the individual at hand or at least the specific diagnosis and treatment plan. In addition, spoken information should be supported with written and visual material (e.g., pictographs and graphs).
8. Include families in informal situations such as daily rounds, therapy sessions, and care provision (e.g., feeding and grooming) as appropriate. These events serve as great teaching opportunities and reinforce information provided in more formal settings.
9. Develop and implement training for communicators including small group sessions and role

playing with peers and standardized patients. Allow professionals to observe the most skilled communicators in action.

10. When working with individuals from other cultures, be sure language is not a significant barrier. Focus on building trust instead of decision making and explore or acknowledge spirituality and religion and the role they play in family decision making.

## RECOMMENDATIONS FOR FUTURE RESEARCH

In addition, future research in this area is clearly recommended and should include an analysis of existing provider education protocols, follow-up on consumer comprehension of, and satisfaction with, available education, and further analysis of factors and biases that can affect understanding and reporting of critical information.

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**Rosette C. Biester, PhD**, is Clinical Associate Professor in Physical Medicine and Rehabilitation at the University of Pennsylvania School of Medicine and senior Polytrauma Neuropsychologist at the Michael Crescentz Veteran's Affairs Medical Center. Dr Biester's expertise and contributions to the field of brain injury rehabilitation are recognized nationally, with more than 28 years of experience in clinical care, research, and teaching/training areas. Her current clinical focus is on evaluation and specialized treatment of veterans with dual diagnoses of traumatic brain

injury (TBI) and posttraumatic stress disorder. Her research has focused on assessment of cognitive functioning in mild TBI, outcomes associated with blast-related injuries, challenges in communicating diagnostic and prognostic TBI information, and the association between neuroradiological and neurocognitive outcomes.

**David Krych, MS-CCC-SLP, CBIS**, is a speech and language pathologist who has served people with brain injuries for the past 35 years. Dave's contributions to the field of brain injury rehabilitation—particularly post-acute rehabilitation—are numerous, and his pioneering and ongoing accomplishments have been widely recognized by his alma mater and professional associations to which he has dedicated many years of service. Currently, Dave serves on the Executive Team at ReMed Recovery Care Centers. Dave has presented extensively in the United States and abroad and has published on a number of brain injury-related topics.

**M.J. Schmidt, MA, CBIS**, is both a family member of someone with a brain injury and a professional with more than 25 years of experience in the field. Schmidt has worked in acute and post-acute rehabilitation, as a researcher, and most recently with individuals who are incarcerated. Schmidt is a graduate of Southern Illinois University, with a master's degree in Rehabilitation Administration and Services. She is a certified brain injury specialist and chairs the Council on Brain Injury.

**Devan Parrott, MS**, holds a master's degree in biostatistics as well as a master's degree in clinical research management. She is currently working on a PhD in biomedical informatics and plans to graduate in 2016. She currently works as a biostatistician and research manager for the rehabilitation hospital of Indiana as well as teaching for the mathematics department at Indiana University–Purdue University Indianapolis.

**Douglas I. Katz, MD**, is Professor of Neurology at Boston University School of Medicine, a member of the academic neurology staff at Boston Medical Center, and Medical Director of the Brain Injury Program at Braintree Rehabilitation Hospital in Massachusetts. He is a recognized expert and leader in the field of traumatic brain injury rehabilitation with more than 29 years of experience in clinical care, clinical research, and program development. His research and publications have included studies of neuropathology, natural history, and outcome prediction in TBI, disorders of consciousness after brain injury, pharmacological treatment of cognitive problems after TBI, and structural and functional imaging in relation to recovery and rehabilitation after TBI. Dr Katz is President of the American Congress of Rehabilitation Medicine, 2015–2017.

**Melissa Abate, LMSW, CCM**, has been working with families and survivors of brain injury since 2002. Before relocating to Colorado, she worked at Mount Sinai Medical Center in New York City. She received her master's degree in social work from Yeshiva University and recently became licensed as a certified case manager. Melissa has also done extensive postgraduate studies in Family Systems. She has been an active member of the Brain Injury Alliance of Colorado's public policy collaborative. Her focus has been on expanding eligibility and services for survivors of brain injury. Over the last few years, Melissa has worked with the Colorado Health Care Policy and Finance on reestablishing transitional living programs for CO Medicaid participants, including testifying at the Senate and House in support of Senate Bill 160.

**Chari Hirschson holds a PhD** in Clinical Psychology from Ferkauf Graduate School, Yeshiva University. She completed a postdoctoral fellowship in Traumatic Brain Injury and Neuropsychology. She currently works as an instructor and Senior Clinical Psychologist at Mount Sinai School of Medicine in New York. She has published widely on topics pertaining to TBI.

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