Interpreting Responsiveness in Persons with Severe Traumatic Brain Injury: Beliefs in Families and Quantitative Evaluations

Objective: To describe beliefs in families of minimally conscious or vegetative patients about the functional abilities of their family member (the patient) and to better understand the relationship between family beliefs and the patient's objectively measured functional status. **Design:** Qualitative pilot study using audiotaped, semistructured interviews with family members at the beginning of the patient's admission to a brain injury rehabilitation unit (T1) and prior to discharge (T2). **Setting:** An inpatient brain injury rehabilitation unit at a community-based rehabilitation hospital. **Participants:** Five families of patients believed to be vegetative or minimally conscious admitted for evaluation between July 1993 and June 1996. **Methods:** The content of interviews was analyzed with qualitative techniques. Beliefs and evidence cited by the family were recorded and compared with medical injury data and results from single-subject evaluation of sensory and cognitive capacities. Relevant social and demographic data and observations of clinical team discussions about the patients were also used in the analysis of each case. **Results:** Most observed behaviors, movements, or other cues were given meaning by family members, regardless of the results of objective assessment. Recurrent themes at T1 were: 1) relief that the patient was alive, 2) hope for a full recovery, 3) confusion about the nature and impact of the brain injury, 4) belief that the patient was more functional than he or she appeared to be, and 5) failures to respond were due to functions other than basic limitations of consciousness. Recurrent themes at T2 were: 1) anxiety about the future and impact on the caregiver, 2) continued hope for full recovery, 3) fear about the plateauing of the patient's performance, and 4) coexistence of hope and worry. **Conclusions:** Beliefs of family members about the functional capacities of persons who are vegetative or minimally conscious are ever present in the evaluation process of these patients. It is important that beliefs be identified and respectfully addressed through education and counseling and that the interpretation of behaviors observed by family members be incorporated into the objective assessment of the patient.

Etienne J. Phipps, PhD
Director
Behavioral Sciences and Medical Ethics
Associate Professor
Department of Medicine[*]

Madeline Di Pasquale, PhD
Neurobehavioral Specialist[†,§]

Cynthia L. Blitz, MA
Doctoral Student[‡]

John Whyte, MD, PhD
Director[§]
Attending Physician[†]
Associate Professor
Department of Physical Medicine and Rehabilitation[*]

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[*] *Temple University School of Medicine, Philadelphia, Pennsylvania.*

[†] *MossRehab, Drucker Brain Injury Center, Philadelphia, Pennsylvania.*

[‡] *University of Pennsylvania, Philadelphia, Pennsylvania.*

[§] *Moss Rehabilitation Research Institute, Philadelphia, Pennsylvania.*

Address correspondence to E.J. Phipps, Department of Medicine, Albert Einstein Medical Center, 5501 Old York Road, Philadelphia, PA 19141.

SEVERE traumatic brain injury (TBI) may result in prolonged periods of unconsciousness lasting from hours to weeks, and sometimes indefinitely. Patients with severe brain injury begin in *coma*, a state of unconsciousness in which the eyes are closed, there is little movement, and there is absence of any psychologically understandable response to external stimulation or internal need.[1] Coma is a time-limited state. Some patients have clear recovery of consciousness directly from coma, while others evolve over a period of 2 to 4 weeks into the *vegetative state*. The veg-

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etative state is similar to coma in terms of absence of meaningful response, but unlike coma, the eyes are open and there may be significant amounts of spontaneous movement and posturing. Vegetative patients may still recover consciousness, but many do so gradually, spending prolonged periods in a *minimally conscious state*. This state is difficult to distinguish from the vegetative state by simple observation but is characterized by inconsistent but verifiable evidence of conscious processing.

For a number of years, we have noted that family members and clinicians working with vegetative and minimally conscious patients often have difficulty determining with certainty what level of sensory and cognitive processing is present in a given patient at a given time. The presence of roving eye movements, spontaneous limb movements, and facial grimacing may all lead family or staff to believe that conscious processing is present when that may not, in fact, be the case. The uncertainty about a patient's cognitive abilities in turn may lead to conflict about what services are appropriate, whether the patient is making progress, and whether the patient merits a trial of active rehabilitation.

In 1992, two of the authors (JW and MDP) began a project intended to provide objective quantitative assessments of vegetative and minimally conscious patients. In this project, we applied the techniques of single-subject experimental design to answer clinical questions about sensory and cognitive function in such patients.[2,3] The methodology, which controls for the occurrence of spontaneous, reflexive, and coincidental behaviors, is able to identify subtle evidence of conscious processing that is not otherwise apparent, and also can sometimes determine that patients who are believed to be responding to their environments are, in fact, vegetative. Although several standardized assessment scales now exist for minimally conscious patients,[4-6] the individualized methodology developed by Whyte and Di Pasquale is capable of directly evaluating specific behaviors that are believed by staff or family members to be of functional significance.[2]

Quantitative, objective assessment of severely impaired patients proved to be a valuable tool in the hands of brain injury clinicians, resolving the clinical uncertainty in a majority of cases regarding patients' visual status, ability to follow commands, ability to use a yes/no communication system, improvement over time, and response to pharmacologic and other treatments. However, although family members were generally involved in identifying the clinical questions to be addressed—suggesting behaviors to be evaluated for command following, providing biographical facts for use in yes/no communication protocols, etc—it appeared that their participation did not preclude the types of conflict that had often been present prior to the initiation of the quantitative assessment method. That is, family members often disagreed with the conclusions suggested by the controlled scientifically oriented evaluations, particularly when the results were discouraging. It became clear that family beliefs about these patients' level of function were not related in a straightforward way to the results of scientifically designed evaluation protocols. Where, then, do beliefs in families come from?

Throughout history, people have used a variety of interpretive frames to explain events, tragedies, and other unexpected occurrences. Individuals' framing of an experience is derived from how they construct reality; what evidence is considered important, and how that evidence is interpreted.[7] Beliefs about responsiveness in TBI and the framework for understanding its impact on the person involved draw on established belief and religious systems, idiosyncratic beliefs, and life experiences[8] in order to provide explanation, guide decision making, and provide hope.

Initial responses of family members to a severe TBI often involve relief that the individual has survived and a profound hope for a full recovery. Expectations for recovery may be shaped by information from a variety of sources. Television and the popular press provide stories about the exception-to-the-rule patient who "wakes up" after 10 years in coma with no apparent deficits. Fictional portrayals of coma often suggest that return of consciousness is abrupt and complete. Faith, including a belief in miracles, sometimes provides families with hope that divine intervention is imminent. A belief in the nearly miraculous powers of medicine may also contribute to optimism, suggesting that with enough treatment, anything is possible. In addition, incomplete or confusing information imparted during the acute phase of treatment may contribute to family members' optimistic projections. Finally, the inconsistency and variability of the patient's behavior itself may predispose family members to remember instances of behavior that appear volitional, while forgetting behavioral failures.

Beliefs in families about the responsiveness of the person who is traumatically brain injured have been reported by a number of investigators. Jacobs et al[9] noted that in cases where the patient showed little or no improvement, family members intensified "their interpretation of random patient motions as evidence of change, even when these movements could not be verified by staff." Tresch et al,[10] in a study of 36 families of patients in the persistent vegetative state, found that 90% of patients were considered by family members to have some awareness of pain, light or darkness, environment, taste, verbal conversation, or family members' presence. Further, Romano,[11] in following families of 13 patients with TBI who had been transferred to rehabilitation, commented on the persistent denial observed in these families about the limited functioning and responsiveness of the injured family member. The lack of psychological movement on the part of family members through stages of a grieving process was considered by the investigator to be a major barrier to family recovery from this tragic event.

In this complex context, we became interested in trying to understand more about what families believe about the sensory and cognitive abilities of their vegetative or minimally conscious family member, how these beliefs develop, and how they do or do not change over time in relation to the evolution of the patient's status. A better understanding of the development of family beliefs could improve the ability of clinicians involved in brain injury to work effectively with families and could have an important impact on rehabilitation outcomes such as discharge destination, resource utilization, functional status, and family (consumer) satisfaction. In this article, we discuss five patients with TBI who entered our unit in a minimally conscious or vegetative state. We present the results of the objectively based quantitative assessment in parallel to the beliefs of family members at two different points in time; we discuss the impact that the beliefs had on the clinical care of the patients; and we discuss recommendations for working with families in this challenging area.

METHODS

Study sample

Families of patients believed to be vegetative or minimally conscious (based on clinical evaluation and/or family report) and who were hospitalized at the Drucker Brain Injury Center of MossRehab, in Philadelphia, Pennsylvania, were eligible to participate in this study. The patient had to have been admitted to the brain injury unit between July 1993 and June 1996 because questions existed about the patient's ability to meaningfully and consistently respond to external stimulation.

Eleven families were approached about participation in the study; four refused participation. One family refused because they felt that their family member (the patient) was a "private person" who would not want to be involved in research. In addition, the family felt that because the patient was so medically unstable, they needed to focus their attention on "getting him well" and did not feel they could shift their focus away from the patient to participate in a study. Two families refused because their visiting schedule was already complicated enough, and they did not want to commit to another required meeting. The fourth family stated only that they were "not interested" in participating. After enrollment and initial evaluation, two of the seven patients whose families chose to participate were clearly responding at a higher level than anticipated from their referral information and were deemed not to be minimally conscious. Therefore, little subsequent quantitative data were gathered, and their cases are not included in this report. The remaining five patients and their families are discussed below.

Procedure and protocol development

Using a qualitative research paradigm that emphasizes the importance of describing the subjective perceptions of participants, we began to develop an interview guide that would be used to collect our data. Using the literature on and clinician experience with family response to TBI, we identified areas where beliefs about patient functioning and awareness were typically expressed, as well as a set of factors thought to be associated with the development of these beliefs. These elements involved the following domains: family understanding of the reason for transfer from the acute care hospital to rehabilitation hospital, initial understanding and sources of information about the patient's injury, current understanding about the patient's functioning and awareness, interpretations of patient behaviors with family and others, family perception of the clinical team's understanding of the patient, and family perception of how well the team appreciated their views. We then constructed a semistructured interview guide that asked families about these domains. The questions related to this report are listed in Appendices A and B.

Data collection and analysis

Because of a concern that families of patients on the brain injury unit might not be forthcoming about their beliefs with clinicians involved in the care of the patient, we did not involve clinician members of the research team in the collection or analysis of the qualitative data. Thus, until the final stages of this project, the research team was divided into a family research team and a patient evaluation team.

Interviews were conducted with consenting family members. While an attempt was made to encourage participation of all family members, family members presented for the interview in various constellations. We took a broad view of this dilemma, recognizing that the clinical reality on a brain injury unit often involves working with parts of family systems. Are the family members who participated speaking for their family? Are they the most responsible? The most guilt-ridden? Do they represent others or only their own experience? While we did not seek to answer these questions, we were confronted with the disparity of family participation from case to case. We addressed this in our later analysis of data by reviewing the clinical course of each case with the clinicians involved and confirming the presence or absence of family members during the course of the patient's evaluation. In the cases presented, family members who participated in the interviews were the family members with whom the clinical team had the most contact, and whose beliefs about the patient's responsiveness were most prominent in the evaluation and rehabilitation of the patients to be described.

Families were interviewed twice: once at the beginning of the patient's admission to the brain injury unit for evaluation (T1), and later on completion of the evaluation process prior to discharge (T2). There was one case where the T2 interview was not conducted because the patient died during the hospitalization.

The interviews were audiotaped and transcribed. Each transcription was read by each member of the family research team. Responses to questions were summarized and recorded using the interviewee's own words. Salient themes, beliefs, and other important issues from the interviews were identified individually by members of the research team. When agreement about how to characterize or label a belief or theme was not unanimous, the item was discussed by the research team until consensus was reached; if consensus was not obtained, the item was not included. Beliefs and evidence cited by family members in support of those beliefs were recorded.

Our operational definition of a theme was adapted from ethnographic research and referred to a tacit or explicit postulate or position that organized or interpreted experience.[13-15] In this study, general themes were often expressed through the form of beliefs, as either specific statements made by the interviewee that attributed meaning or intent to a behavioral or nonverbal response (eg, the theme, *the patient was more functional than he appeared to others*, may have been expressed by a statement such as, "I know that he hears, even if the clinicians don't think he can, because I see his eyes move towards me.") or as a more general statement connecting the patient's responses to his/her personality, will, or motivation (eg, a statement of "I don't care what they say, my daughter is a miracle child and will surpass everyone's expectations," likewise supports the theme, *the patient was more functional than she appeared to others*).

In sum, the family interview data reported here are those that were (1) identified independently by (different) members of the research team; and (2) agreed to be recurrent throughout an interview, consistent with reference to other responses, and important from the perspective of the interviewee. (Other areas covered in the interviews will be reported in subsequent publications.)

Medical injury data and results from the single-subject evaluation of responsiveness (described earlier) were used to better understand the relationship between family beliefs and the patient's objectively measured functional status. Relevant social and demographic data were also obtained from patient charts and from observations of clinical team discussions.

RESULTS

Each of the five cases reported here includes patient injury data; family data from interviews at T1 and T2, findings from quantitative evaluation conducted around the time periods of the T1 and T2 interviews, and case-specific commentary contrasting the qualitative interpretations with the quantitative results.

Demographic and injury data describing the patients whose families consented to be part of this study are presented in Table 1. Differences between the patients whose families consented and those patients whose families refused participation are described in Table 2. In "refuser" families, the patients tended to be older than those in the "consenting" families. The refusing family member was also more likely to be married to or living with the patient as a partner, rather than a

Table 1. Description of patients

Case No.	Age (y)	GCS score at injury	DRS at admission	DRS at discharge	Outcome/ destination
1	29	3	23	16	Deceased
2	20	5	22	12	Home
3	30	3	24	24	Home
4	19	3	24	9	Home
5	22	4-5	24	10	Nursing home

parent of the patient. As shown in Table 2, there were no differences between the consenting and refusing groups in terms of severity of the injury at admission, patient condition at discharge, or patient destination at discharge. Table 3 shows the relationship of the day of injury to the time of the T1 and T2 interviews.

Case 1

The patient was a 29-year-old male who was injured as a passenger in a motor vehicle accident. Initial computed tomography (CT) scan of the head identified blood in the right ventricle, intraparenchymal hemorrhages in the right frontal and left temporal and parietal lobes, and pontine hemorrhages within the gray-white junction consistent with shearing injuries. A small subarachnoid hemorrhage and subdural hematoma were also noted. Both parents of the patient presented for the T1 interview. A T2 interview was not conducted because the patient died during hospitalization.

The patient was admitted to acute rehabilitation approximately 3 months post injury. On initial evaluation, he was essentially unresponsive to command. No visual tracking was noted, although he did direct his gaze spontaneously in the right lateral direction. He demonstrated an apparently purposeful movement: he pulled at both his j-tube and collar of his hospital gown with his right hand.

At the time of the T1 interview, the team was addressing the clinical question of whether the patient could follow verbal commands, in this case to make specific gestures such as the "peace sign" and sticking out his tongue, things that the family and staff had seen him do inconsistently. He made a target gesture in response to commands on only 17% of trials, but when he did respond, he performed the correct gesture 100% of the time. Using a visual assessment protocol,[2] the team determined that the patient had vision in both visual fields, but there was a localized right

Table 2. Comparison of patients in consenting and nonconsenting families

	Consent obtained (n = 5)	Consent denied (n = 4)
Mean age (y)	24 (range, 19-30)	55 (range, 43-64)
Mean DRS at admission	23 (range, 22-24)	23 (range, 17-24)
Mean DRS at discharge	14 (range, 9-24)	18 (range, 7-21)
No. married/living with partner	1	4
No. discharge to home	3	4

Table 3. Patient injury and family interview dates (mo/y)

Case no.	Date of injury	T1 interview	T2 interview
1	9/93	2/94	Patient deceased
2	12/93	7/94	2/95
3	2/94	6/94	3/95
4	4/94	6/94	8/95
5	9/94	2/95	8/95

eye problem due to multiple right orbit fractures. The focus at the time of the T1 was to determine if a medication would increase his level of arousal and improve his response rate.

At this time, the parents of patient 1 thought that their son's level of awareness and responsiveness had improved since he was first hospitalized in acute care. Reflecting back on their acute care experience, they remarked that at that time, they thought he was unresponsive and described him as "walking in the distance somewhere." At T1, they both felt that his inconsistency in responding was due to a hearing problem. They gave as evidence that he usually responded if asked twice to do something. While they had decided that the hearing problem could be overcome by speaking loudly, they remained unsure if he understood what was being said. They relied on observations of facial expressions and other nonverbal responses to determine if he heard or understood. For example, they were certain that they saw his face change when they called his name.

Both mother and father said they had also noticed an overall improvement in this patient's ability to respond to a variety of cues. In terms of verbal communication, they believed that their son was trying to talk and cited his making a growling noise in his throat as evidence. They thought they had heard him asking to have his catheter taken out. They felt that their son had become more "like a child," and that he was communicating nonverbally and through touch. For example, they believed that he was using head movements to express anger and that he touched his father's face as an expression of happiness in seeing him.

Although the family attributed his lack of responding to a hearing problem, they allowed for error in their belief by acknowledging that they were unclear about how much he understood. They saw patient 1 in a developmental context, exploring his environment in a way that an infant does—through sensory experiences—and they interpreted his movements, gestures, and facial expressions as emotional indicators.

Approximately 9 months after his injury, patient 1 died unexpectedly. Prior to his death, he had demonstrated increased verbal utterances, some intelligible comments, and was participating in some self-feeding of pureéd foods, despite being severely impaired.

Case 2

The patient was a 19-year-old man who was injured as the driver in a motor vehicle accident. Initial CT scan of the head identified a right frontotemporal contusion. A right frontotemporal craniotomy was performed, with partial right temporal and frontal lobectomies. The patient's mother was interviewed at both T1 and T2.

Patient 2 was admitted to rehabilitation approximately 3 months post injury. At the time of the initial evaluation, he had spontaneous eye opening and appeared to visually fixate the examiner. Although he made some verbalizations, he did not appear to follow verbal or visual commands.

The mother of patient 2 was initially reluctant to consent to participate in this study because she did not see it contributing to the care of her son. However, she did consent 7 months post injury, by which time the patient had already shown considerable improvement. It was noted that although the patient was dependent for all aspects of activities of daily living, he was doing some self-feeding of purëed food for up to 10 minutes, with supervision for rate, amount, positioning, and swallowing safety. He required a wheelchair. He was able to verbally express some thoughts, but there was an abundance of obscene verbalizations. Self-injurious behaviors, such as biting his right hand, had decreased since admission. There had also been some decline in functioning, particularly noted by decreased level of arousal. It was suspected that the right frontal subdural hematoma, thought to be chronic based on previous CT films, was expanding.

At T1, the patient's mother expressed certainty that patient 2 would have a nearly complete recovery, based on what she said the family had heard from a neurosurgeon who operated on the patient. She reported being told that a "nonessential part" of her son's brain had been removed, and a "slight shaving" (in reality, a frontal lobectomy) had been performed. The surgeon reportedly told her that her son would go back to college in about 2 years and would have "slight impairments."

The patient's mother believed that her son was cognitively intact. ("He has it all together upstairs.") She was certain that he remembered what had happened to him because he asked about his car (which was involved in the accident). She believed he could read because she observed him looking at a book that was placed on his bed. She was concerned, and somewhat confused, about his use of obscene language, which she had not permitted at home. She believed, however, that this was one indication of the brain injury; her son could not control himself verbally and did not realize what he was saying. She was convinced that what her son needed was to have his brain "retrained," and in that way, he would relearn everything and recover all functions.

The patient was discharged from acute rehabilitation approximately 22 months post injury. At the time of discharge, the patient continued to require a wheelchair for mobility but had increased his ability to stand and transfer. He required structure and setup for all activities of daily living. Although physically able to participate in some tasks with minimal assistance, cognitive structure was required to identify when to perform the task, to persist in performing the task, and to maintain adequate performance. The patient demonstrated moderate to severe deficits in memory, reasoning, planning, organization, and problem solving. He continued to demonstrate impulsivity and behavioral discontrol. Although he was able to understand feedback about his performance and to remember "rules," he was unable to implement them.

At the time of discharge, the mother believed that her son's responsiveness had improved from T1. She was very optimistic about his recovery. She believed that his progress was hampered by his being "lazy" and sleeping too much and that he would do much better at home where she could work more closely "retraining" him. She viewed him as completely aware of his actions and in control of his language. She did acknowledge that he had some short-term memory problems that came from the "mildest of shearing" of his brain. In spite of her determinedly optimistic presentation, when probed beyond the surface, the mother of patient 2 did express anxiety at T2 about whether her son would ever "go back to the way he was before."

The mother's perception of the nature and extent of her son's functional impairments was different from the clinical opinion of the team. Her understanding of the "slight shaving" was clearly inaccurate. The partial frontal lobectomy would have serious implications for the patient's ability to return to the level of functioning she anticipated. Her assignment of significant meaning to simple questions and behaviors (eg, inferring reading ability from observing her son glance at a book) further indicated problems with her understanding of her son's deficits. Clear, accurate information about the nature and extent of the injury was repeatedly presented to her over the course of the patient's admission. While no one actively challenged what the team considered her denial and misperception, team members did outline the level of supervision and care he would require. Training prior to discharge focused on concrete issues for care and management.

Case 3

The patient was a 30-year-old male who was injured as the passenger in a motor vehicle accident and suffered a prolonged period of hypotension. Initial CT scans identified multiple facial and orbital fractures and an intraventricular hemorrhage, as well as subarachnoid blood in the suprasellar cistern. He remained unresponsive during his acute care hospitalization. Family members present at T1 and T2 were his sister and brother-in-law; the patient's parents were deceased.

Patient 3 was admitted to acute rehabilitation for evaluation approximately 3½ months post injury. Upon admission, he was noted to be unresponsive. His eyes opened to noise, but left lid closure and opening were incomplete. Noxious stimuli to the head or trunk failed to produce either motor localization or withdrawal. While there was no evidence of responsiveness noted on the admission examination, family members had seen some thumb movement and possibly some visual tracking. These observations led to clinical questions for the evaluation protocol: whether the patient could follow verbal commands, and whether the patient could respond to visual stimuli. Initial findings identified that the patient did not follow commands to move his thumb. He responded in only 12% of the trials, and his responses were not significantly different between the command conditions to move his thumb (14%), or to hold still (10%), and during the periods of observation with no commands (11%). At the time of the T1, the visual protocol identified no evidence of visual functioning.

The sister and brother-in-law believed that at this time the patient could hear, see, and communicate. They cited as evidence his facial expressions and watching his eyes track objects and people. They thought his comprehension was good and improved when he was spoken to in a loud voice, or if the message was repeated several times. However, at T1 they were not confident about his understanding because they observed that his responses were inconsistent, but they did not see his responses as random.

At T1, the family members also believed that the patient was using thumb signals to communicate yes and no. When he did not respond to a command from the clinicians, the family felt that it was because the clinicians were using language with which he was not familiar.

At T2, 9 months after admission, the patient remained essentially unchanged from admission. The treatment team had carried out a series of quantitative trials of behaviors, including command following for both thumb and eye movements, that failed to show any volitional response. While there was evidence of vision on later evaluation, it was minimal, and the team was never able to incorporate this into any functional activity, such as an eye gaze system for yes and no.

At T2, the family members felt that patient 3 had become more aware of his surroundings and was better able to communicate, though they were not sure that there was any consistency in his responses. They were, however, more confident in their own abilities to read his responses by observing his facial expression, rather than relying on thumb signals or any specific communication system. They were worried that they did not have a way of interpreting some of the patient's responses and that they were, as a result, not understanding what he was trying to say. In a sense, the problem now was more theirs than his. The other main concerns prior to discharge revolved around the more global uncertainties about the future for themselves and for the patient and around whether patient 3 had reached a plateau in his recovery.

Case 4

The patient was a 19-year-old female who was injured as the driver of a motor vehicle that collided with a tow truck. Initial CT scan identified a right frontotemporal subdural hematoma, which was evacuated. Radiologic studies also identified left parietal and right temporal contusions and a left-to-right shift. She remained unresponsive for her entire acute hospitalization. The mother of the patient presented for both the T1 and T2 interview.

At the time of admission to acute rehabilitation 2 months post injury, the patient appeared to be vegetative. Medical concerns included hypertension and tachycardia due to central sympathetic storms, seizure prophylaxis, and contracture management. Evoked potential data at the time of admission identified an intact right auditory response but an absent left response. Visual evoked potentials showed preserved cortical responses. Somatosensory evoked potentials showed absent response to right median nerve stimulation and a very low amplitude response to left median nerve stimulation that may have been an artifact, indicating a poor prognosis.

There were several behaviors identified by the family at the time of admission—specifically, hand squeezing and arm movements—that they felt were inconsistent but possible indicators of command following. Initial quantitative evaluation, therefore, focused on assessment of vision and hand squeezing to command. The patient produced hand squeezes on 25% of the command trials, on 28% of trials when given an incorrect command, and on 22% when observed with no command (no significant difference). The visual assessment identified vision in the left field but right-sided extinction or a partial field cut.

The mother's reactions to the protocol process at T1 included disappointment and disbelief when there was no evidence of command following. She questioned whether the right behaviors had been assessed and whether new protocols for other behaviors (such as toe wiggling, which they had recently observed) could be developed.

At T1, the mother of patient 4 firmly believed that because of her daughter's personality and intelligence, her recovery was going to surpass everyone's expectations. She cited being told shortly after the accident that her daughter "had no brain activity," and poor prognosis for recovery, and that the best they could hope for was that her daughter might be able to feed herself. That the patient was allowed to survive at all was a fact with which the mother was struggling at this time, and about which she expressed ambivalence and guilt.

The family was under considerable stress, as they had been given a time limit by the insurance company during which the patient had to show evidence of command following to stay in an acute rehabilitation program. Each day, the patient's mother would state how many days were left before they "ran into trouble." When the patient failed to respond to a command, her mother would become greatly distressed and would frequently comment that they were "running out of time." Although the mother did not disagree with the evaluation team that her daughter was in a vegetative state, she did express more optimism about the future than seemed to be warranted based on the objective data.

Fortunately, patient 4 did recover consciousness slowly over several months and made remarkable progress. An alphabet board was her primary communication system. The patient occasionally spelled out a statement or greeting spontaneously, but responded 100% of the time when asked a question. Her accuracy rate for biographical questions was approximately 80%. She also verbalized responses to questions but, due to decreased volume and dysarthria, was difficult to understand. She required moderate assistance for upper extremity dressing but was dependent for all other activities of daily living.

At the time of T2, 13 months after injury, the patient had gone on a therapeutic leave of absence for several hours to her family home. Her mother believed that patient 4's "mental ability" was "getting broader" and that her overall functioning was improving. She believed that her daughter's verbal communication was "perfect" but that her voice had "no volume." She saw the patient as developing "like a baby" and that, likewise, her daughter's learning was beginning as if she were emerging from a new place. By this time, the mother of patient 4 was beginning to view her daughter as a different person than she was before the accident, mostly because she felt her daughter had no memory of the accident and did not appear depressed.

The mother of patient 4 provided a unique insight into the struggle of many families of persons with TBI. At the time of T1 interview, the question raised about why her daughter was "allowed to recover" is one that is often on the minds of families but rarely expressed. Also, the acknowledgment of a new and "different" person at the time of the T2 brings with it both acknowledgment of loss and acceptance of new expectations for recovery.

Case 5

The patient was a 20-year-old woman injured as a passenger in a motor vehicle accident. Initial CT scan of the head identified a left subdural hematoma associated with localized mass effect and a left-to-right shift. There were also indications of subarachnoid hemorrhage with blood layering across the cerebellar tentorium, a probable small contusion involving the left temporal lobe, and findings suggestive of diffuse cerebral edema. Both parents were present for the T1 interview. The father came alone for T2.

The patient was admitted to acute rehabilitation approximately 5 months post injury. She was not noted to follow any verbal commands or to make any purposeful movements, although she did open her eyes to noxious stimuli and possibly tracked to the right.

At the time of the T1 interview, the treatment team was evaluating the patient's ability to see, using a visual protocol, and to follow verbal commands to look at YES and NO cards on command. The cards were marked in both English and in the patient's native language, and verbal commands were given in both languages. The visual protocol identified that the patient had vision in both the left and right visual fields, with extinction or a partial field cut on the left. For command following, she made an eye movement in 62% of trials and was accurate 70% of the time, which was significantly greater than chance.

At T1, the patient's family felt that their daughter was doing better in acute care before she was transferred to the brain injury unit. This was because they saw her sleeping through much of the day in the brain injury unit, whereas earlier they reported she was "awake." In terms of functioning, the family relied heavily on interpreting the patient's eye movements and eye blinks. In agreement with the visual assessment, they believed her vision was intact, because they observed her moving her eyes toward the television and sometimes toward people. They were convinced that she could respond to questions using her eyes (open meant yes; closed meant no). They observed that she sometimes opened the left eye more than the right and were confused about how to interpret this. In terms of hearing and comprehending, the patient's father thought she understood everything that was being said. He based this on observing her facial expressions. He believed she knew what had happened to her in the accident because he observed her becoming emotionally upset while being shown a video of her sister's wedding, which she had attended prior to the accident.

It appeared to the clinical team that the family was having difficulty integrating information about patient 5's level of functioning, as determined by the quantitative protocol, into their understanding and interpretation of her behaviors. The treatment team could not identify volitional eye blinks from the patient, even when the family demonstrated their communication system. Although there was disagreement between the family and team, an agreement was reached to continue to work on yes/no eye communication with an eye gaze protocol (using biographical questions) because it was the most functional system, and to track changes in her responses over time.

Patient 5 remained in rehabilitation for over a year due to medical complications and disposition issues. Over this time she made several significant gains. She developed the ability to use a yes/no communication system, and later an alphabet board, to respond to questions. Her accuracy in yes/no communication rose to 79%. Spontaneous comments were limited but, when made, they focused on going home. She was dependent for all areas of self-care and required a wheelchair.

At T2, while emotionally and physically devastated from this experience, the patient's father believed that his daughter's functioning had improved remarkably since T1. He believed she understood "100%" of what was said and communicated "perfectly" using either the yes/no communication system or the alphabet board. He felt she was frustrated because she could not talk or write and because she realized that she would not be able to pursue a career. He was less focused on the scientific validity of incremental improvements in her performance and looked more toward the future. Specifically, he believed that faith and prayer were most important now for her recovery, because medical care had done as much as could be done for her. It is possible that ethnic and cultural factors contributed to his faith as well as to his attitude toward medical care. More salient in this case, however, seemed to be that this family came to the United States as immigrants in search of a better life for their family, believing in the "American Dream," that in America, "anything is possible" This theme may also have lent support to the beliefs expressed.

At T2, the family and team's observations had moved closer together, and there was agreement on the best communication system. As patient 5 made progress and the team could convey that progress to the family, family members began to use the yes/no communication system, and eventually the alphabet board, to replace the eye blink system.

In this case the family believed they had developed a method of communication that enabled them to reconnect with the minimally conscious family member. The drive to believe that the patient had the ability to communicate was critical for them, even if there was inconsistency in response. That need, combined with a lack of experience with and understanding about brain injury, led them to initially develop and believe in a system of communication for which there was no objective support.

DISCUSSION

Certain themes recurred across the interviews, reflecting a commonality of experience. Themes were both patient-focused and self-focused and shifted from the hopefulness seen at the time of the T1 interview to concerns about the reality facing the families seen closer to discharge at T2. Themes at T1, both explicit and implicit, can be summarized as follows:

- Relief that the patient was alive
- Hope that the patient would have a full recovery
- Confusion about the brain injury and how it resulted in the observed responses
- Belief that the patient was more functional/aware than he or she appeared to others
- Failures to respond were due to functions other than basic limitations of consciousness (eg, deafness, laziness, boredom, wrong behavior being assessed, and being better able to respond with family members).

The following were common themes at T2:

- Anxiety about the future and impact on self (the caregiver)
- Continued hope that the person would fully recover
- Fear about the plateauing of the patient's performance
- Coexistence of hope and worry.

Overall, the themes, implied or explicitly expressed, conveyed the strong position that any kind of response (from the patient) was a relief because it provided hope that the patient could recover and return to the way he or she was before the accident. Indeed, most observed behaviors, movements, or other cues were given meaning by all those family members interviewed at T1, with some uncertainty about those responses emerging by T2.

The preoccupation with "finding the person inside" was a crucial task for family members. They struggled to confirm that their family member was the same person they knew before the accident. It was almost as if what was observable on the surface to outsiders (ie, the limited, erratic response) was only a small part of what they believed to be there. In fact, the comments made by family members, through both beliefs and themes, conveyed a view that the patient, regardless of appearance and behavior, was essentially cognitively intact. This view is supported by several factors. First, popular media often portray persons in coma as "sleeping," and when they "wake up," they return to a normal level of functioning. This, combined with the fact that most families have no source of reference or experience for their current situation and no way to "construct" this reality, perpetuates the notion of normality. Comments about the patient's awareness such as "She knows what's on her mind," "She has it all together upstairs," and "He understands everything," offered evidence for this belief. Family members also relied on facial expressions as a window through which they interpreted how the patient felt (eg, "a knowing smile," a "twinkle in his eye"), as these were sometimes the only potentially meaningful behaviors available to them. The belief that the patient was aware of what was going on around him or her was consistent with being alive and supported the positive orientation families needed to sustain hope.

While T1 themes emphasized relief that the patient had survived, T2 themes additionally included the anxiety caregivers were feeling about the future. While all family members believed that the patient's functioning had improved since admission and voiced continued hope for a full recovery, the theme of hopefulness was not as prevalent at T2 as at T1. Most likely, the continued limited functioning of their family member was a disappointment to the wishes for full recovery expressed at T1.

The process by which family members of the minimally conscious or vegetative patient respond to the crisis of the injury is a complicated one. It is likely that the prognostic uncertainty at the time of the accident, coupled with a focus of efforts on keeping the patient alive, contribute to the family's hopefulness for recovery and to beliefs about awareness, understanding, and communication. Family members obviously have less ability than clinicians to distance themselves from the person. They look for ways to read the patient's responses, inconsistent and confusing as they may be, perhaps to forestall the loss, to provide a rationale for the patient's survival, and to maintain hope for the future. These are not small stakes.

Families and loved ones of the person who is vegetative or minimally conscious are faced with a profound tragedy that is not resolved or even softened through an objective evaluation of their family member. Whether a communication system can be found or established in no way diminishes the enormous loss of personhood for the patient and the subsequent impact of that loss on those who form the unit of care. It is no coincidence that the subjective views of family members support consciousness and, therefore, life. To know that there is "someone in there" implies that he or she can perhaps one day emerge. To suggest that there is "no one in there" carries with it significant medical, ethical, economic, and psychosocial implications that need to be sensitively yet honestly explored with family members of these patients.

Family members of persons who sustain a traumatic brain injury, especially those who remain severely impaired for long periods, must deal with an enormous amount of new information at a time when they have few emotional and cognitive resources available. In these cases, it is as critical to provide the family with emotional support and clear information about the patient's status and prognosis as it is to provide the patient with sound treatment. A conflict between family and staff is possible when a family feels a behavior has meaning and a team finds no evidence of this. Negotiating a time-limited evaluation and involving the family by using those behaviors they reportedly have seen in developing the responsiveness protocol can help address these issues.

Two additional topics warrant discussion. First, family members tend to mention "lack of interest" in the simple behaviors we are asking the patient to perform and "boredom" due to the repetition of the protocol over time. These issues tend to arise when their family member is making little progress and the team is having difficulty identifying clinical change. This can be interpreted as a defense; the family feels a need to explain the reason why their family member is not responding and, due to their lack of knowledge about brain injury and recovery, identify motivational factors that they feel are blocking progress. This issue requires that family education and support be provided on a consistent basis. Regular meetings allow a family to discuss their concerns and allow the team to provide information that will assist them in coming to understand brain injury and its consequences. Second, it is important that movement and behaviors made by the person with brain injury not be underinterpreted by the team; because of the inconsistent nature of these patients, it is possible that therapists could miss volitional behaviors if they are immediately labeled as reflexive or spontaneous. It is important to listen to the family and to incorporate the behaviors they observe into the objective assessment (eg, a mother's statement that "My son seems to lift his thumb when I ask him to" becomes: Can the patient follow a verbal command?). Responding to the family's observations with further evaluation validates their feelings and provides the team with a foundation for their initial assessment and their ongoing work.

Family members of patients who are minimally conscious or vegetative often refute attempts by clinicians to explain the reasons for their lack of responding and inconsistencies as related to the severe brain injury. Denial and anger are two common defense mechanisms used by families when they feel threatened by this type of information. Comments such as "if the therapists did more, my son would be better" and "He's bored by what it is you are asking him to do" are signals that the family is frustrated and defending against a different reality being presented by the clinicians. Sachs[16] identified that denial is something that should be acknowledged within the context of family sessions, with the understanding that it may not be penetrable. Denial becomes a clinical issue when it begins to interfere with clinical care and treatment planning for the patient. A family's belief that their family member will walk again, for example, despite a severe disability, becomes an issue when the family refuses to participate in family training to learn functional transfers or to modify their home to make it wheelchair accessible.

For the families of persons who are vegetative or minimally conscious, what clinicians label as failures to acknowledge the severity of the disability can be protective and supportive to them. Often labeled as "denial," the interpretative frames used by family members to make sense out of this tragic experience can help them adjust expectations for recovery. When a patient's responses are framed as indications of a new start, as if the patient were an infant, family members are more able to be accepting of small gains and perhaps better able to function themselves. Even at the level of specific beliefs, it is not difficult to understand that believing that a hand squeeze is a signal of the patient's understanding is clearly preferable to recognizing it as a meaningless reflex. Nonetheless, the treatment team has an obligation to be honest with the family and provide accurate clinical information regarding functional prognosis, with the understanding that acceptance of this information may occur gradually over time, or may not.

We have observed families *believing* in the patient in the deepest sense of the word. Specific movements, gestures, or expressions are evidence that confirm their belief. When objective evaluation provides data refuting that belief, it is not uncommon for family members to explain the discrepancy in a way that makes sense to them, or for them to drop their investment in the meaning of the specific response and find another one to replace it. This complex process suggests a number of important directions for research using both qualitative and quantitative methodologies. For example, prospective research is needed on how various factors predict both beliefs in families and the abilities of family members to alter those beliefs during the evaluation and rehabilitation process. Patient and family factors that could be examined include the role of the patient in the family system, faith and religion, cultural and ethnic differences, family functioning and communication styles, and differences between families who consent to research and those who refuse based on these identified domains.[17] Outcome research looking at the impact of beliefs on resource utilization, clinical outcome, discharge destination, and the family's own stress is another important direction for investigation. And last, intervention studies could test ways to improve family and staff collaboration, particularly when dealing with the multiple challenges related to differences between beliefs in families and objective evaluation data.

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Appendix A

Sample Questions: T1 Interview*

The following open-ended questions are followed by probes to obtain specific examples from the respondents.

Transfer from acute care to rehabilitation hospital

1. Can you tell me about the reason for the transfer?
2. What were you told about why [name of patient] was being transferred?
3. How did you feel about the transfer?

Initial understanding of injury

4. What were you told about [name of patient]'s injury?
5. Who told you that?

Current understanding

6. How long has [name of patient] been at Moss?
7. How would you describe [name of patient] at this point?
8. What do you think [name of patient] can do at this point?
9. What makes you think that he or she can do that?
10. Have you seen [name of patient] respond to something or someone else?
11. What have you observed?

Perception of treatment team's view of patient functioning and family beliefs

12. Do you think the team is aware of how you see [name of patient]'s abilities at this point?
13. What do you think they think about your views?
14. What makes you think that?

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*Questions presented here are questions related to the subject of this article. Other questions were also included.

Appendix B

Sample Questions: T2 Interview*

The following open-ended questions are followed by probes to obtain specific examples from the respondents. With all T2 responses, the respondent should be asked how his or her answers compare with those given at T1.

Current understanding

1. How would you describe how [name of patient] is doing now?
2. What do you think he or she can do?
3. How are these responses/behaviors different since admission?
4. What have you observed of [name of patient]'s behavior/responses with you?
5. What have you observed of [name of patient]'s behavior/responses with others?
6. What do you think [name of patient]'s understanding is of what has happened?
7. How aware do you think [name of patient] is of what he or she is doing/responding?

Treatment team's view of patient functioning and family beliefs

8. What did the treatment team tell you about what [name of patient] is able to do?
9. What do you think/feel about that?
10. Do you think the team knows about your views, how you see [name of patient]'s abilities, responses?
11. What do you think their attitude is toward your views?
12. What makes you think that?

Satisfaction with treatment team

13. How satisfied are you with the treatment team's evaluation of [name of patient]'s abilities/responsiveness?
14. How satisfied are you with the way they have dealt with your concerns and your views?

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*Questions presented here are questions related to the subject of this article. Other questions were also included.