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Parent perceptions of early prognostic encounters following children's severe traumatic brain injury: "Locked up in this cage of absolute horror"

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Abstract

Objective—Little guidance exists for discussing prognosis in early acute care with parents following children's severe traumatic brain injury (TBI). Providers' beliefs about truth-telling can shape what is said, how it is said, and how providers respond to parents.

Methods—This study was part of a large qualitative study conducted in the USA (42 parents/37 families) following children's moderate to severe TBI (2005 to 2007). Ethnography of speaking was used to analyse interviews describing early acute care following children's severe TBI (29 parents/25 families).

Results—Parents perceived that: a) parents were disadvantaged by provider delivery; b) negative outcome values dominated some provider's talk; c) truth-telling involves providers acknowledging all possibilities; d) framing the child's prognosis with negative medical certainty when there is some uncertainty could damage parent-provider relationships; e) parents needed to remain optimistic; and, f) children's outcomes could differ from providers' early acute care prognostications.

Conclusion—Parents blatantly and tacitly revealed their beliefs that providers play an important role in shaping parent reception of and synthesis of prognostic information, which constructs the family's ability to cope and participate in shared decision-making. Negative medical certainty created a fearful or threatening environment that kept parents from being fully informed.

Keywords

traumatic brain injury; prognostication or prognosis; communication; hope; disability; truth-telling; ethnography of speaking; speech codes theory

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Introduction

An important element in quality medical care is effective communication with parents [1-3]. Traumatic brain injury (TBI) continues to be the leading cause of morbidity and mortality amongst children in the USA [4]. The increased severity of the child's primary injuries places them at further risk for a series of maladaptive cellular, vascular, and systemic responses in early acute care (from emergency room admission to discharge to home or rehabilitation) [5-7]. Mortality following severe TBI is reported to range between 9 - 25% [7-10]. Differences in children's mortality rates, however, might also be explained by health care system disparities, such as differences in injured persons' access to rapid care or disparities in early acute care adherence to evidence based care [11]. The primary medical goal of early acute care following severe TBI is the multidisciplinary, coordinated, and evidence based prevention of secondary brain injury [12].

Most parents lack knowledge about the severity of children's primary injuries, or the preventative goals in early acute care. Parents require an understanding of the child's potential responses to his or her primary injuries, the subsequent treatments, and the heterogeneous range of potential outcome trajectories possible following children's severe TBI. Parents' lack of knowledge makes them strongly dependent on health care providers (subsequently referred to as providers) to act as credible authorities [13-17], so that parents can play an informed and active role in decision-making for their child [18].

Many providers lack any in-depth skills training in communication [19]. Yet, if a child's health condition, treatment, or prognosis is discussed ineffectively or without sensitivity, these communicative encounters may heighten a parent's distress [20-22], increase a parent's workload [23], and place a strain on subsequent provider-family interactions [3, 23-26]. While there is a wealth of evidence concerning communicating prognostic-laden information effectively in the pediatric palliative and cancer care literature, minimal guidance is available for providers who care for children following severe TBI [27]. Death and disability are statistically possible following severe TBI, however, a provider's ability to predict a child's long-term prognosis with accuracy and specificity is still limited so early after injury. Diagnosis, tests results, treatments, and provider daily assessments are likely to be discussed with parents during the early acute care period. Provider-parent discussions about the child's prognosis can be embedded in these topics or prognostic questions are likely to be asked by family members. Beliefs may differ between providers and parents about what information should be considered in shaping prognostic discussions [24, 28, 29].

This paper focuses on parents' metacommunications (parent talk about provider-parent talk) regarding provider-parent prognostic encounters in early acute care. These provider-parent encounters included formal meetings and unscheduled informal talk in the unit with the parent. Prognostic encounters were from a subgroup (29 parents from 25 families) across the USA during the early acute care period following children's severe TBI. This subgroup came from a larger qualitative investigation that recruited 42 parents of children following moderate to severe TBI between 2005 and 2007. The original study used descriptive phenomenology, an interpretive methodology, to gather parents' interview accounts as indices of parents' overall experiences managing children's moderate to severe TBI in the first 5 years [13]. In the original study, parent's entire interview accounts were used. Parents were able to describe key points across time when the family experienced cultural clashes with various community service-providers following the child's injury. Parents of children with severe TBI, for instance, reported that prognostic talk from early acute care providers could over emphasize the negative value of the family's life following children's severe TBI. In the original study, we were not able to explore in detail what specific early acute care interpretive factors surrounding provider-parent prognostic encounters seemed to shape a parent's sense of vulnerability versus empowerment. Subsequently applying ethnography of speaking, another interpretive methodology from the field of communication, allowed us to then treat this sub-group's descriptions of prognostic encounters as an index of parental attitudes, beliefs, notions, and expectations (parent culture) regarding provider delivery of prognostic information in early acute care.

Methods

Both the original study and this secondary analysis were conducted by the first author and done in accordance with established criteria for the ethical conduct of research on human subjects, with Institutional Review Board approval. Written informed consent was obtained from all parent participants during the original study. Transcript data were de-identified. Parents, for whom contact information was still current, were made aware of the secondary analysis and a copy of the resulting manuscript was shared with them prior to journal submission (n = 19 of 25 families).

This analysis began with transcript data from parents of children with moderate to severe TBI (n = 42 parents from 37 families) in which parents described their formal and informal prognostic encounters with various healthcare providers in the early acute care period. The provocative and detailed nature of accounts of prognostic encounters from parents of children with severe TBI (n = 29 parents from 25 families), when compared with the less provocative and detailed accounts (i. e., 'they were fine') from parents of children with moderate TBI, signaled to the first author that a deeper understanding of why parents of children with severe TBI were reacting so strongly (meanings, emotions, and behaviours) to the prognostic encounters they experienced in early acute care.

Participants

Because parents of children with moderate TBI had fewer details about provider-parent prognostic talk in early acute care and gave minimal examples of what was said to them in early acute care, they could not be used as a comparison group. Parents of children with severe TBI were included in this secondary analysis if they (a) discussed the prognostic encounters they experienced in the early acute care period; (b) gave specific examples of what was said; and (c) discussed the meaning they made of specific encounters (cognitively, emotionally, and/or behaviourally). After conducting a preliminary review of all 29 transcripts, the transcripts from 2 parents, from 2 separate families, were excluded because of a lack of sufficient detail in what was said to the parent and/or how the parent interpreted the encounter. While those two parents were not good informants for the aim of this analysis, both parents still expressed agreement with other parents' expectations of provider-parent prognostic encounters in early acute care.

Data collection and preparation

Prior to conducting this analysis, methodological considerations of conducting a secondary analysis on qualitative data were reviewed [30-32]. In the original study, all parents were interviewed in private by the same investigator (the first author). If two parents participated from the same family, they were interviewed together. Two interviews were conducted with parents to get a sense of family experiences over time and to conduct member checks. First interviews (n = 23 families) were done in person. Second interviews with parents were done primarily by phone (n = 19 families), and three parents were interviewed in person as their child needed to be interviewed in person, as a part of a separate study with the children. The parent from 1 family declined to participate in the second interview because of the revisiting of emotional feelings. Both interviews used open-ended questions in a semi-structured approach, were audio-recorded, and lasted at least 90 minutes. The first interviews were conducted following enrollment (on average15 months post-injury; range 4 – 36 months), and the second interviews took place following completion of all of the first interviews, when the investigators surmised that parent experiential themes were saturated (~ 27 months post-injury).

The interview guide used in the original study included global questions (e.g., 'Tell me about when you arrived in the emergency room') and became more probing based on parents' responses. The first interviews focused on the period from the child's injury up to the interview. The second interviews gathered continued accounts of the family's experiences after the first interview and also included member checking [13]. All audio-recordings were transcribed verbatim and the transcripts were checked against the recordings for fidelity. The first author also kept extensive field notes, which included observations, notes, and comments used to contextualize the interview data.

To help the co-investigators on this secondary analysis understand the broad context of parents/family's experiences in the original study, the first author created a summary of each family's overall post-injury experience. The summary included an overview of the circumstances of the child's injury, a summary of the family's acute care and rehabilitation experiences, and a summary of the family's community reintegration experiences (as reported by the parents). This was done so that each parent's linguistic and paralinguistic responses were always considered within the family's broader social and historical context [30-32].

Data analysis

Parents' prognostic metacommunications were examined using the method of discourse analysis, which fits with the qualitative framework used for this analysis, ethnography of speaking [33-37]. Ethnography of speaking is guided by speech codes theory and is a well-accepted interpretive empirical framework for discovering how culture (attitudes, beliefs, notions, and expectations) can shape a person's talk with others, or an individual's interpretation of another's talk with him or her (in this case parents interpretation of provider prognostic talk). In contrast with critical discourse analysis, discourse analysis within the framework of ethnography of speaking takes a non-judgmental stance. The aim is to discover and understand parents' interpretations from their point of view, not to criticize the parents or any providers described in the prognostic encounters.

We used an adaption of the S-P-E-A-K-I-N-G framework originally described by Hymes [38, 39], which attends to some specific human and social factors known to influence talk encounters or the interpretation of talk encounters. Our adaptation of the S-P-E-A-K-I-N-G framework included parents' descriptions and perceptions of: a) the **S**etting (time, physical space, and psychological or cultural context of talk; **P**articipants Identities: the perceived resources of all speakers and the listeners in each conversation; **E**nds: the personal or social results anticipated from talk; **A**ct Means: the chosen words employed and how they were structured; **K**ey: the demeanor or emphasis employed in speech; **I**nstrumentalities: the modes or style of the talk; **N**orms of Interaction: cultural and societal expectations and the participants' reactions or actions; and **G**enre: the type of speech (e.g., emotionally narrative story, poetry, or argument) used by the parent which also gives clues to parents' intended meaning (e.g., people argue when they feel disadvantaged or misunderstood).

An underlying assumption of ethnography of speaking is that people intentionally or unintentionally structure their metacommunications based on their cultural influences on that phenomenon [34-37]. According to speech codes theory, the ways in which parents interpreted health care providers' prognostic talk would be based on the social systems parents are exposed to (societal, ethnic, gender, educational, occupational, moral, and spiritual to name a few) regarding parenting a severely injured child and regarding delivering information to help parents in early acute care. Social factors shape parents' culture about what it means to be 'a good parent' in a relationship with his or her child and what it means to be a 'caring' or 'supportive' health care provider [36, 37]. The ways that parents described and discussed each of his or her early acute care prognostic encounters provided direct and indirect information about parents' attitudes, beliefs, notions, and expectations, as individuals or as a group.

Parents' metacommunications describing their prognostic encounters in the early acute care period were considered in this analysis. Digital recordings of interviews and investigator field notes were used to supplement the transcripts further for this analysis. The paralinguistic detail added included: pauses; particular tones associated with the words used (e.g., sarcasm, anger, humor, imitating or mocking the way something was said); major voice intonation changes, which placed emphasis on particular words or phrases; and other utterances or gestures (e.g., balking, hissing, laughter, demonstrations). These para-linguistic factors added meaning to parents' choice of words and helped the investigators gain a deeper understanding of what parents were trying to persuade the interviewer to understand from his or her perspective [34-37].

Throughout the analysis, the two research questions asked were: 1) what do the parents' metacommunications tell us about how they interpreted providers' prognostic talk? and/or, 2) what are their expectations for prognostic talk in this context? The two primary coders (the first and third authors) are healthcare researchers with qualitative research experience and training in ethnography of speaking. Analysis of the data proceeded as follows: a) the two primary coders read and re-read the parent transcripts as a whole to gain a sense of parents' overall experiences in early acute care; b) coders then read the transcripts line by line, using discourse analysis and the S-P-E-A-K-I-N-G framework [34-37], paying attention to individual words (why that word?), the meaning of individual or groups of words (what might they be trying to do with these words, this way?), and other verbal and non-verbal factors which also lent meaning to what the parents were trying to express; c) coders independently coded each transcript; d) coders then met after coding 2-3 transcripts to discuss their conclusions, using the parent's own narratives as the primary source to resolve any coding disagreements; e) a final summary of coding conclusions was created for each family using parents' narrative data to support coders' consensus; and then, f) the experiential summary, interview transcript, and the final coding consensus (comprising an audit trail) were sent to the last author, who acted as a peer reviewer. Methodological peer review increased rigor by allowing outside feedback on use of the method and alternative coding conclusions or theory to be considered in the final product. After this methodological peer review was completed, individual cases (each family) were compared to all others cases in order to develop themes related to the prognostic encounters in early acute care that parents seemed to be reacting positively and negatively to.

Our methodological approach and results also shared with a pediatric neurosurgeon (second author) who works with this population on a regular basis. Neurosurgeons are one of the key physicians on the early acute care team caring for children following severe TBI. Depending on the institutional intensive care practise model [40], neurosurgeons often play a key role in communications with parents about diagnosis, test interpretations, treatment decisions, and prognosis. Our primary purpose was to position the parents' point of view on this topic in the forefront. Yet, we also wanted to ensure that a clinical representative had the opportunity to assess our analysis and contribute to the discussion, so that the final conclusions would be relevant to early acute care clinical practise.

In order to protect parent and provider identities and decrease the perception of passing judgment, we have removed all identifying information, including the sub-disciplines involved in specific encounters. We were concerned that identifying sub-disciplines in specific examples might lead the reader to believe that the particular behaviour described occurred only in that sub-discipline. It was more difficult to always remove disciplinary references because this changed context, and therefore, meaning might be misconstrued. Each example presented, however, should be considered as one example of behaviour(s) found not only within one discipline or sub-discipline, but reported to occur in some providers across the disciplines of medicine and nursing. We recognize that different providers have different levels of expertise and prognostic roles, but parents viewed all early acute providers as having more knowledge and expertise than they had with severe TBI. Parents expected a minimum level of emotional intelligence by all providers in how to discuss prognostic related information with parents in early acute care. Our objective in this manuscript was not to make any one provider group appear particularly good or bad at discussing prognostic-laden information with parents. Instead, we wanted to illustrate how the presentation of prognostic information might be interpreted differently by parents than any providers in early acute care might intend.

Results

Participants in the final analysis included 27 parents from 23 families who came from 9 states and were cared for at 14 different early acute care locations in the USA. The relevant injury and demographic information on the participants is presented in table 1. We use the terms child and children to refer to the child's relationship to his or her parent(s), not the child's developmental maturity. Several of the children were at the time of interviews young adults. Parents' conceptualizations of hope were embedded in their discussions of what they experienced in early acute care. In general, parents expressed: the injustice of providers over emphasizing negative medical certainty (predicting a negative child or family prognosis with certainty); the hubris of providers failing to discuss all information needed to make informed decisions; and the fallacy of dismissing a parent's hope as being indicative that he or she had no sense of the gravity of his or her child's condition.

Parents expressed initial ambivalence, in early acute care, regarding his or her negative reactions to provider prognostic encounters. Parents were grateful to providers for saving their child's life and they did not want to offend providers. When parents perceived that the family was immersed in a setting where negative medical certainty for children with severe TBI was a given truth, it took parents time to gain confidence that their own beliefs, which contrasted with the negative medical certainty, might also be well-founded.

We present the six themes of cultural clashes, related to early acute care prognostic encounters with providers that parents of children with severe TBI commonly expressed. Then within each of these themes, we present the varying ways parents described clashes. At least one narrative example is presented to demonstrate some of the linguistic and paralinguistic persuasive strategies that parents used to position their perspective on prognostic encounters. Underlining of words within the examples is used to convey the emphasis that parents placed on those particular words. This was important to also pass on to the reader because it is one of the multiple strategies people use to persuade a listener, and the investigators in this analysis also used this information to come to their final conclusions.

The delivery of the prognosis could disadvantage parents

Parents felt that healthcare providers forgot how a parent's response to his or her child's injuries left the parent physically, cognitively, and emotionally vulnerable to being able to receive and synthesize information and prognosis in early acute care. Parents also felt that some providers were desensitized to how the early acute care setting, the system of care, and the multiplicity of providers also disadvantaged parents. Timely, clear, and unbiased information helped parents to cope and make decisions. Parents assumed that healthcare providers were aware of parents' learning needs, given their family's circumstances. Parents expected all providers to work together and use anticipatory guidance to facilitate parent learning. Parents were at times, however, left to interpret medical language and figure out how to navigate the complex acute care systems. Such oversights inherently disadvantaged parents in attaining, processing, and utilizing information:

> They don't take into consideration the fact that when you hear 'brain bleed', [raises voice intonation] you shut down and you don't hear anything else for the next 35 minutes…..They give it to you, [raises voice] bam, bam, bam and if you miss it, [spoken without concern] 'Sorry about your luck!' And when you have 15 doctors working on 1 child, you get [sarcastic tone and raises intonation] 15 different views … .When the [lead physician] is doing rotation, nobody told us you get like 30 seconds of his time. You don't get a half hour, you can't ask 35 questions. [emphasized in tone] We learned very early on, [following said very abruptly] have 2 questions on paper, be at the door when he walks in the room, follow him to the bed, you know, 'This is what I need to know today, tell me this', [slows down] and it worked, you know, because you get about a minute and a half and [sarcastic tone and raised intonation] you better get those questions in and you'd better be paying attention. So, you know, they miss that as professionals. I think, they miss the fact that you're [raises intonation] not hearing everything and even if you hear it, you may not know what it means … . I didn't know what a CFS [sic CSF; cerebrospinal fluid] leak was. They just assumed I should know. (Parent 26)

When language and explanations were vague, unclear, and did not prepare parents for all possibilities, including negative physiologic responses or negative outcomes, parents were caught off guard. A lack of information could cause a parent to be uncertain about what to expect (i.e., vulnerable). Parents wanted to glean from providers' expertise and experience: "I wanted the guy that shot from the hip and told me true and honest. It's just, for me that was more comforting. I didn't want to try to second guess and read between the lines" (Parent 3). Parents also wanted explanations of what was being done to maximize his or her child's outcome, which required ongoing and in-depth explanations from all providers involved.

A dominant negative prognostic culture was perceived to influence provider talk

The negatives of the child's condition were at times perceived to be emphasized and re-emphasized to parents via linguistic and behavioural approaches during early acute care. Parents described the use of extreme case formulations by some providers said with authority to position the provider's belief that the child would likely have the worst possible outcome (e.g., 'Your child will always' or 'Your child will never'), or to reflect the provider's concern for giving the parent optimism (e.g., 'I don't want to give you false hope'). Those providers were referred to across parents in a variety of pejorative terms such as 'the grim reaper', 'Dr. Doom and Gloom', and 'the one who almost made my husband pass out'. Parents used their own linguistic devices throughout their narratives to convey to the interviewer the cultural and psychological milieu perceived by various types of prognostic encounters. Negative medical certainty encounters or discounting parents' attempts to be positive were believed to be contrary to creating a caring or family-centred environment for parents:

> Some [providers] don't give you much hope and don't think that much else you do is going to help, one way or another. It's like [I say], Okay, well, you can think

> what you want, but I'm going to do everything I can and don't take my [the parent's] hope away. (chuckles) … . The medical field didn't see the bigger picture….. I always say, I'm amazed that [providers] go to school for so many years and know so little….That's why God gave us parents, is because they're supposed to be our advocates… [the team was saying] that, 'He is never going to walk or talk again', 'He might have to have that feeding tube forever' … .I really thought maybe they have to have the, kind of like the lawyers, they have to have the good guy and the bad guy… or maybe for legal reasons they can't say, 'Your son's going to be okay'. They have to give you the worst picture, 'cause I thought it was weird how bad they [portrayed it]. It's like, why say anything? How weird of them! I don't know, it's like, I think for anybody's mental health …saying that kind of stuff isn't good. It's really weird (Parent 7).

Parent 7 used trivializing words and statements in her talk ('you can think what you want', 'the medical field didn't see the bigger picture', 'they go to school for so many years and know so little', 'how weird of them', and 'It's really weird'). She also used negative adjectives ('bad guy' or 'worst picture') and extreme case formulations to describe the providers' actions ('never going to walk or talk again'). She contrasted her actions by using possibility language ('I'm going to do everything I can') and uses 'God' to describe a higher authority associating parents to children (to be the child's advocate). Her generalization ('anybody's mental health') is used to illustrate the effects of negative medical certainty when given with authority. The two coders interpreted from her entire story that it was not that she was asking to be given a false sense of the child's prognosis. Instead, she came to believe over time that some providers in this context would not or could not tell parents anything positive ('they can't say'), and that some early acute care providers were not comfortable with parents' expressions of hope ('don't take my hope away'). This mother (and other parents) believed that a negative provider culture surrounding the meaning of surviving severe TBI caused some providers' to position the worst case scenario in his or her talk instead of explaining all possibilities and considering parents' needs.

In some locales, a negative prognostic culture related to severe TBI was described as so palpable that parents noticed how some providers who wanted to express any optimism to parents had to do it privately or they risked admonishment by peers. These observations influenced parents' perceptions of the rules of prognostic talk in early acute care settings:

> [As my son was beginning to emerge from his coma] I had a man [on the team] say, 'Your son is going to be just fine, get some of those DVD stories, let him listen to them, get him Nintendo games, blah, blah, blah'. And I thought, that was good, but then they took him off our case. Isn't that interesting? Because they said 'he was too positive'. I guess, I thought, well I liked hearing that and then he was gone (Parent 31).

Parents encountered several different disciplines involved in the child's care and at various points in the providers' career trajectories. Each had different roles, brought different information, and at times had different perspectives:

> You know, what they [one group of physicians] said was, 'On their scale of 1 to 10, 10 being brain dead, she was a 9. The only thing left intact was her brain stem.' And looking at … .her x-rays, it looked like a target where somebody had blasted it with a shotgun. This was all black (points to her own cerebral cortexes), and there were spots everywhere, everywhere, where the shearing was. But I mean, she was, there was really hardly anything left…when [one physician] said, 'You really, maybe just turn off the machine', on the [date], 8 days after her accident. They said, 'You know, basically be kind, she's never going to be any more than a vegetable'. The person that came in the next day was [another physician on another team]. He

> said, 'I don't want you to do anything yet. I don't want you to make a final decision. I can't read a crystal [ball], I don't know' … .He said, 'Please, we don't have to pull [the plug] and say stop'. He goes 'But we do have a DNR [do not resuscitate] on her' … .[Then a nurse] said, 'If she's meant to go, she'll go. That's just the way life [works] and that's how God is' (Parent 3).

Because the initial team of providers explained the information forming their prognostic beliefs ('there was really hardly anything left [of her cortexes according to the scans they showed me]'), coders interpreted that Parent 3 perceived the provider meant well ("he wasn't doing it spitefully"). This mother realized the initial provider was preparing her for a highly probable outcome based on the daughter's imaging scans. Alternatively, she perceived a particular decision she was expected to make when they said 'be kind' and her daughter would 'never …be any more than a vegetable'. In the second interview, this same mother illustrates that she was not ready to make a final decision at that point (8 days post-injury):

> It was devastating. It was horrendous … I mean there wasn't any way I was going to be pulling the plug that night. I mean and make that kind of a decision at that point. I left and I thought, okay, I've got to go back the next day and put on my brightest, yellowest, happiest sweater … . The [other physician] coming in the next day and saying 'let's wait and see', and 'have some hope', was helpful.

Parent 3 attempted to counteract what she perceived as tacit pressure from one group of providers and discusses her beliefs about her moral obligation to wait. She counteracts any perceived negativity by reframing to the positive ('go back the next day and put on my brightest, yellowest, happiest sweater' and describes the provider who said 'let's wait and see' as helpful), which was similar to what other parent reactions. Divergent prognostic perspectives between team members left parents trying to decipher why perspectives were different, thereby immersing parents in differing ideologies or politics at times. Parents then had to worry about making the wrong decision or offending some providers.

Truth-telling involves acknowledging all possibilities

Parents wanted honest information, including negative possibilities, but they also argued that providers should acknowledge uncertainty in early predictions of outcomes following severe TBI:

> Father: [We asked one physician] 'What would you see, in our case that would give us hope'? And he said, 'Nothing'. He said, 'I don't see her', [pause] he said, 'I don't think that there's any hope; she's not going to come out of this'. I mean, it was pretty much a hundred percent, and that was kind of weird.
>
> Mother: He wasn't, he was kind of a, I think he's a good [physician], but he just didn't have a real good bedside manner; just didn't know how to deal with those things. Father: …I always wondered, like, it made me think, you know, everybody has their flaws … .And his must be, 'I'm not going to give them any false hope', you know? But I thought, the reality is, there has to be cases that do survive it, you know and ours [is a case that did and she's doing well].
>
> Mother: It means they're minimal.
>
> Father: So I'm hoping someday I can meet him and just say, 'Hey, just want you to know, so if this ever happens again, you might be able to tell people that you do know of a case where it looked like there was no hope', and I think there's some logic behind [being cautious], you know, you don't want everybody to think it's all going to work out, either. But that was very devastating, and <u>obviously it wasn't correct</u>! (Parents 14; see table 2)

When the providers used extreme case formulations, as in this case, without explaining and balancing prognostic factors and scientific limitations, providers created a frightening psychological environment for these parents that initially impaired them ('that was very devastating') and other parents. The persuasive word choices were perceived as biased and caused these parents and others to lose respect for the emotional intelligence skills ('bedside manner') of the providers who used them instead of explaining the range of possible outcomes.

Hubris created a negative medical certainty

Three families reported that acute care providers went beyond a provider's expected role of explaining medical prognosis following severe TBI, to also predict social responses. These families questioned the morality of including this information, "They told us that's the first thing you can expect; that he [her boyfriend] will not stick around … .[questioning tone] But he's been there for her the whole time" (Parents 14). In addition, when providers refused to acknowledge their own actions resulting in a faulty prognostication (n = 2 families), the parents noted that such avoidance permanently fractured trust:

> When he told me that her brain stem was dying, and that her chances, and his exact words, 'Her chances are zero to none' … .I called the family in …there was like 150 people …because we all thought she was going to die. The doctor was standing there and he finally turned around to the nurse and he said, 'Did we give her such and such'?. [They had given her dilating eye drops] before we took her down [for the CT scan] and the nurse goes, 'Well, yeah, you ordered it'. And he goes, 'Oh, well that explains it'. He wasn't looking at her brainstem [when he made the prediction]; he was going by her, the dilation in her eyes [which he thought meant her brain had herniated]. [In an angry tone] Well the drug he gave her dilated her eyes. And so, he was just so matter of fact. He never apologized. Never said, 'I'm so sorry that I put you through this'. 'I'm so sorry that I said that'. He forgot that he had ordered the drug that dilated her eyes. And here I was, you know, my whole family, everybody was crying and thinking she was going to die, [they] were only giving her like a day to live … .To me the least he could have done was apologize. And he was so insensitive that he couldn't even apologize. (Parent 22)

Parent 22 tells an emotionally laden story to make her case that providers should be clinically knowledgeable ('He forgot that he had ordered the drug that dilated her eyes'). She illustrates that if a provider makes a mistake, they should be sensitive to how that error constructs the family's emotional vulnerability ('my whole family, everybody was crying and thinking she was going to die'). She positions her view that in order to do no further psychological harm to the family, a provider should take responsibility for his or her mistake ('the least he could have done was apologize'), explain what happened, and express regret for putting the family through a frightening experience. When this provider or others did not apologize to the family, it left the family with a sense that their experience and feelings did not matter ('he was so insensitive that he couldn't even apologize') to those providers in that setting.

Effects of negative medical certainty on the parent-provider relationship

Parents considered the negative prognostic information given them, but if it was not perceived as balanced, then parents discounted the provider's communication skills and ignored his or her advice. They sought out other credible authorities (in or outside the team or place):

> [Our provider] he had told us that she was, you know, 'Going to be in a coma forever' …We probably ought to be looking for her for a place [for her] to stay'

> … .So when he told me that [without explaining] I said, ‘Okay, well this guy is an idiot’, because I’m going to ask him to explain to me what was wrong and show me the MRI’s and do all this stuff and tell me [why he thinks that]. I called his office to make that appointment and he wouldn’t do it. He wanted to do it in the hospital. Okay, so I had [him come and talk to us], um, he just, he didn’t have enough answers for the questions [I had]. He didn’t bring the MRI’s. So we got copies of her MRI’s and I made an appointment with another [provider] outside the hospital … . He was very honest … .[He said] ‘You could have a very small brain injury, a small [brain injury] and have it make immense issues, or you can have a very large one that doesn’t matter at all. It just depends on where it is and what it is’ … . [Then] he said, ‘Well, it’s bad!’ He said, ‘Really bad!’ and then he went on to say, ‘She’s 17, we don’t know, you know. For somebody to tell you she will forever be in a coma or for somebody to tell you that she’s going to be in a vegetative state [it] is just the wrong thing. Statistically, probably true, but the fact is at her age, you don’t know how her brain is going to rewire itself. You don’t know how it’s going to heal … .There is nobody on earth that can tell you how far she’s going to come, if she’ll be totally just as able as she was [before]. She needs to wake up’. And he said, ‘Until she wakes up from her coma, we won’t know’. And he said, ‘There’s no reason to give up hope’. And he looked at me … .He looked at me and he said, ‘This is going to be a bad year’! [But I said], ‘That’s okay, we can deal with that’! (Parent 34)

It wasn’t that Parent 34 or other parents would not pay attention to negative possibilities, but that parents also gave close attention to how information was framed (‘going to be in a coma forever’) and what information was discounted or left out (‘he didn’t have enough answers for the questions [I had]. He didn’t bring the MRI’s’). What information was included or excluded gave parents a sense of the veracity of information being provided to them (’well this guy is an idiot’).

The very locations where prognostic talk occurred also mattered to parents. Negative prognostic talk that occurred at the child’s bedside, while the child was in a coma, could upset family members:

> I was talking real positive stuff, and then the [provider], she said [mimics a sweet tone], ‘Ma’am? Who were you talking to’? and I said [in an uncertain tone], ‘Well, the surgeons and stuff’. She said [in a sweet questioning tone], ‘What did they tell you’? And I said [in an uncertain tone], ‘Well they said, you know, he lived; he made it through the surgery and everything’. And she goes [mimics a sweet tone], ‘Honey’, she goes, ‘He made it through this surgery’, she goes, ‘This doesn’t mean, [pause] you know [pause]’. And I looked at her, and I said [in a firm tone], ‘Don’t talk like that, I do not want my son’, because I know in comas they can hear things, and I said, [firm tone] ‘I do not want him to hear any of this. It has to be all positive. If you have anything negative to say or anything like that, we must go out in the hallway. And all the [other providers], everybody that comes in, we are all to speak out in the hallway’. [Tone changes to a lighter tone] and all of a sudden you just become strong, because now you realize you’re fighting for a life! You know? (Parent 20)

Parent 20 believed that conversations might still be heard by the child, even if the child was in a coma, as did other parents. Parents worried that such a psychological setting might affect the child’s will to live (’I do not want him to hear any of this’). Parents recognized that providers did not intend to be insensitive by talking at the bedside, but they noted that providers were probably desensitized to how families saw the child’s room as a healing space (’we are all to speak out in the hallway’). Parents believed it was the family’s role to also secure a safe psychological space for the child (’fighting for a life’).

Parents needed to think and act positively as a part of their role

Parents described their need to acknowledge uncertainty about the child’s future so that they could maintain a positive outlook for the family. The alternative was to be swallowed up in grief and despair:

> And I think what they [providers] probably don’t see …when the parent sees their kid often as bad as [our daughter], and one day we counted nineteen tubes in and out, it’s like, it’s ‘Okay, I’m really not in denial’. You know? I think their [providers’] concern is that there’s some kind of denial going on [in parents]. What they don’t understand is [that] it’s absolutely impossible for the parent to have denial …the maternal or paternal instinct is natural and you’re going to want the best [for your child], but you can’t help but feel and see the worst. So, I think their [providers’] thought, at least this is how I was figuring it, is that they can’t see how a full acceptance of how sick they are [the child] can exist at the same time as [parents’] hope … . People understand it when they say it’s bad. You don’t have to <u>beat them over the head</u> … .What is better is to say, ‘Here are all the options and all the things that, you know [we could think about]’, to broaden it, [because] to just keep them <u>locked up</u> in this <u>cage of absolute horror</u> is simply not helpful [for parents]. (Parent 6)

Parent 6 illustrated, as other parents did, the various ways they tried to counteract expressions of negative medical certainty. Although parents believed most providers meant to be caring in prognostic encounters, parents could not accept the logic behind provider beliefs (’there’s some kind of denial going on [in parents]’; ‘they can’t see how a full acceptance of how sick they are [the child] can exist at the same time as [parents’] hope’). Parents perceived that such beliefs drove particular provider actions as Parent 6 conveys (’beat them over the head’; ‘keep them locked up in this cage of absolute horror’). Parent 6 argued for all parents in this situation that they are not out of touch with reality, but trying to find ways to maintain a drive so they could care for their family and make the best decisions.

Outcomes could differ from providers’ early negative predictions

Parents described particular verbal and non-verbal provider behaviors which parents perceived as attempts to halt further more complex discussions including the ambiguity of predicting the child’s long-term future and value. Parents underrated the credibility of those providers perceived to be unable to allow discussions of all information. These providers’ actions were described across parents as ‘strange’, ‘weird’, ‘insensitive’, or ‘interesting’, and those providers were appraised to have skills that equated with ‘no bedside manner’. In most of these cases (14 out of 16 families who reported negative prognostic encounters), the child’s outcome was reported as significantly better than what parents perceived had been predicted in early acute care (table 2). Parents’ hindsight caused them to emphasize the immediate and long-term emotional impact of what they perceived as unbalanced early acute care prognostic encounters throughout their metacommunications.

Parents came to believe that the family’s early positive coping strategies, persistence, and creative solutions played some role in their child’s improved outcome. Parents said they pushed for different considerations in early acute care (respecting the child’s complete self), they noticed symptoms in the child that needed preventative strategies when providers were not present or astute (seizures or brain storming), they noted that heavy medications might also explain a child’s neurologic unresponsiveness, or they stalled the withdrawal of life support or treatments when they believed such options were too premature. Even the two parents whose child's outcomes were closer to what they had been told in early acute care (see * in Table 2) argued that negative prognostic talk given with certainty and authority in the early acute care period was not helpful to a family's coping and decision-making (see Parent 7 narrative also):

> The best way is just to be straight up honest, you know, and to the point. 'This is what has happened [to your child]. This is what is going to take place. This is what you need to expect'. You know, 'later on down the road things may improve, things may not improve' … .But, you know, they're [providers], they don't know [everything]. (Parent 32)

Parents included in this analysis expressed a variety of emotions, from questioning, to frustration, to extreme indignation, at the way they felt managed at times by the negative culture created by some provider's words, non-verbal behaviors, actions or inactions. Parents argued that early acute care providers should see parents as the best advocate for the child, not as someone whose viewpoint needed to be managed or changed.

Table 2 gives examples of one of the significant negative medical certainty prognostic encounters that each of the 16 families reported were made to them. These 16 families perceived that no corresponding discussions of uncertainty occurred, while the other 7 families reported discussions of prognostic uncertainty in early acute care. Narratives in table 2 were shortened, but used to present varying examples of how negative medical certainty was perceived by parents to be expressed by some providers. Alongside these prognostic examples are parent and child reports of the child's ecological outcomes (social and interactional) at second interviews. Parents felt that broader long-term prognostic considerations were needed by early acute care providers related to children's severe TBI. Parents argued that despite the possibility of residual impairments in the child's functioning following severe TBI, children and families can still have meaningful lives, if appropriately supported. Parents did not want to minimize the child's new needs, but they believed that early acute care providers should carefully consider what their actions meant to families.

Discussion

Prognostic encounters with various healthcare providers gave parents insights into the cultures and politics that governed the healthcare environment (the place), and therefore shaped parents' involvement in decision-making for his or her child. Parents perceived that a culture (medical) that focuses on impairment and the economic value of a person to his or her community played a role in shaping providers' actions in prognostic encounters. Negative medical certainty encounters were reported as shaping parents' early feelings that the family's perspective was not being heard and they had to 'fight' or 'stand their ground', which are battle metaphors and inconsistent with a supportive environment for shared decision-making.

Mattingly [24] has explained that medical settings can be cultural borderlands because of the differences in attitudes, beliefs, notions and expectations revealed and emphasized when providers and parents discuss the child's care and future [41, 42]. Thorne [43] noted that cultural clashes affect the family-provider relationship and lead family members to develop a guarded alliance with providers. Family members may surmise that providers' actions with the family are also influenced by broader cultural and political systems (e.g., science, limited healthcare resources, and beliefs about the value of persons with disabilities). Such family beliefs can shape any interpersonal communications in which prognosis is discussed [23, 37, 44, 45].

Parents were very grateful for the child's medical care, but felt that formal and informal prognostic talk at times created a frightening or threatening psychological environment by overtly or tacitly emphasizing a very negative future for the child and family. Parents felt that when providers framed the information discussed to the worst case, such actions delegitimized parents' efforts to consider other information important to the family (e.g., the parent-child relationship and moral obligation). Negatively perceived encounters with providers were reported by parents as having both immediate and long-term physiological (fight or flight) and psychological effects on parents [46]. Parents recognized that providers were strongly influenced by a bio-medical view of quality of life related to disability [47, 48], but they needed providers to also consider providers' moral obligation to fully inform parents [49-52]. Parents gravitated to providers who could allow the required time and attention needed to explain or re-explain balanced information with empathy to parents. Even professionals promoting the use of imaging or clinical indicators to help providers decipher early predictors of prognosis warn of the limitations of our current knowledge [41, 42, 53]. Others have researched the complexities of provider-family encounters and the affects of stranger uncertainty (how will the other react) when discussing the prognosis of severe TBI [27]. This analysis gives more details into the specific prognostic factors that parents used to shape their interpretations.

Parents who reported no negative medical certainty encounters (n = 7) initially described these prognostic encounters as uncomfortable, but later realized that a provider's recognition of ambiguity allowed a small possibility to remain optimistic. Parents described their optimism as either their child's outcome would be better than expected or the family would adjust to the prognosis. Prognostic uncertainty eventually became a safe psychological space for parents, but they still needed to be updated on the child's condition and involved in on-going collaborative decision-making. In contrast, negative medical certainty was always described as fearful, threatening, debilitating, or traumatizing to parents. Parents who experienced negative medical certainty expressed worry for how other parents might cope with these encounters if they didn't have the same personal or social resources as they believed they had.

When credible authorities (practitioners), stress negative medical certainty in prognostic talk they can, at least, temporarily paralyze parent's ability to cope because the negative psychological environment created engulfs parents in confusion, disorganization, and/or grief [18, 20, 54]. While parents in this study initially reported similar physical, cognitive, and emotional reactions to providers' expressions of negative medical certainty in the early acute care period, parents subsequently rejected the authority of such expressions and how it shaped parent resources. Parents subsequently attempted to overcome feelings of helplessness by using positive reframing, anger, blocking, ignoring, arguing, or avoiding providers they found distressing. Parents searched for providers who would help them understand and consider all information.

While providers may be quick to judge such parent coping strategies as maladaptive, Frankl [55] cautioned against pathologizing parent reactions because 'an abnormal reaction to an abnormal situation is normal behavior' and should be expected (p. 38). Understanding context is critical to making judgments about coping strategies [56, 57]. Boss [58] has called for providers to become more comfortable with the ambiguity of prognosis and meaning in such clinical situations. Boss emphasizes that providers should support families' efforts to build on their resilience; recognizing that these families are both immersed in grief and making efforts to move forward.

Parents' arguments for the right way to communicate centred on 1) autonomy for the family to make an informed decision that included their values and goals, because the final decision would affect them; and 2) an understanding that parents' have a moral and social responsibility to act in his or her child's best interests, despite the potential outcome [59]. Parents' metacommunications revealed their cultural beliefs of what it meant to them to be a 'good parent' in this situation by a) not giving up quickly; b) considering all information (interconnectedness of a family) that could affect a parent's decision; and c) the parent's responsibility to fight for the best possible future life quality for his or her child as others have reported [21, 60, 61].

Parents believed that some providers focused only on the optimism he or she expressed while ignoring his or her expressions of co-existing fear and concern [21, 22, 24]. Extreme case formulations were then perceived to be used pre-emptively by those providers to cease broader discussions of prognosis [62]. Parents needed to remain optimistic for the family, until the evidence was overwhelming that optimism was not warranted. Extreme case formulations or statements such as 'I don't want to give you false hope' sent the explicit or implicit message to parents that strategies toward family resilience were not legitimate considerations following severe TBI in early acute care.

Snyder [63] and Snyder and Rand [64] have argued against equating hope with delusions or denial. They argue that people with high hope tend to have better outcomes in the goals they attempt to attain, because these individuals use strategic, modified, and repeated efforts to attain his or her goals. Persons with hope tend to generate more effective routes to attain their goals, especially under constrained circumstances. Such persons can also adjust their notions of hope as new information is received. Parents understood that some things were out of their control. Parents made strong cases for the moral injustice of what they experienced and the need for providers in these settings to think about parents' hope in early acute care differently [62, 65, 66]. Parents needed reasonable time and space to consider and adjust to negative possibilities. Mattingly [24, p. 6] explains that hope is located in highly situated practises (emotions, thoughts, and actions) of parents 'creating, or trying to create, lives worth living even in the midst of suffering, even with [the possibility of] no happy ending in sight …it [hope] also involves the struggle [of parents trying] to forge new communities of care that span clinical and familial worlds.'

Clinical implications

Swanson [67] has pointed out that an essential component of caring for others is the fundamental value of maintaining belief, which she defines as the faith that people have the 'capacity to make it through [potentially negative] events and transitions and face a future with [positive] meaning' (p. 354). When healthcare providers maintain belief in a parent's ability to make the right decisions for his or her family, this value shapes the substance and character of other caring behaviours: a) learning what it is like to be in the parent's skin, at this time, and in this context (knowing); b) listening and making appropriate emotional expressions to parents (being with); c) anticipating and doing for the parent/family those things that they would do for themselves if they knew how or were able (doing for); and, d) reasonably facilitating the family's capacity to be involved as they wish (enabling).

By maintaining belief in the family, the provider empathizes with the parent(s), but also knows that with adequate and relevant support (being with, doing for, and enabling), the family will be able to get through this situation and find positive meaning from decisions that fit their family values. It is human nature for persons to search for positive meaning in their attempts to cope, problem-solve, and move forward from distressing situations in order to have a life worth living [21, 22, 24, 58, 60, 68]. In fact, a positive cognitive and psychological approach is used in coping interventions delivered to families, such as the intervention McMillan et al. [69] developed. Parents can adjust his or her hope as new information presents.

A unified and balanced depiction of the child's prognosis in early acute care creates a cultural and psychological environment that decreases parents' workload and distress [49-52]. By discussing how the medical perspective may limit consideration of things that might be important to parents (spirituality, religion, culture, ethics, or other personal factors), providers leave room for a parent-provider dialog, which engages parents in shared decision-making [70]. This approach clarifies misunderstandings on either side (parent or provider), which minimizes ideologies or power differentials and supports convergence of provider-parent understanding [71].

Providers should also consider the physiologic and psychological family factors that limit parents' ability to learn in this context. Hearing about procedures that seemed barbaric to parents (e.g., drill holes in the child's head, place a wire inside the child's brain tissue, or remove a portion of the child's skull or brain), the stress of the child's tenuous health condition, competing family factors, and parents' lack of self-care, are all factors that can impair parents' processing of information (written or verbal). Information needs should be individualized, communicated in more than one way (demonstrations, video, pictures, written, drawings, or participation), and may need to be re-explained (Swanson's doing for and enabling) [67]. Involving parents in decision-making, as much as each family desires, allows the parents to feel that they have lived up to the codes for being a 'good parent' in this context [21, 60, 61].

Limitations

This approach did not attempt to provide an objective account of the prognostic statements actually made to parents. Parents' perceptions of providers' prognostic encounters can provide important preliminary insights [36, 37]. It might be argued that the parents who volunteered were motivated to participate because of particularly negative acute care experiences, and these experiences may not be representative of other parents. Alternatively, recruitment in the original study was primarily aimed at understanding children's experiences. We originally recruited parents to understand the context of children's early experiences, but later realized from parents' interviews that their perspective was not fully appreciated. The first author and parents were unaware that negative prognostic encounters would end up being a secondary analysis.

Recollections of the early acute care prognostic encounters may have been biased by parents' hindsight of the child's later outcome. Another consideration is that as parents gained more experience as an advocate for his or her child, each parent also gained deeper insights into parent-provider resources shaping those early prognostic encounters. If we had interviewed parents during the early acute care period, their subjective appraisals might not have been as deeply reflective because of their stress, grief, and trauma.

While we did not formally return to the parents for member feedback on this final interpretation, the primary investigator's summary of hope and prognosis was discussed in the second interviews. In fact, some narratives were explained in more detail during the member feedback portion of second interviews. Our interpretations of prognostic encounters came from parent descriptions alone which were repeated across parents (saturation). The sample, however, was not diverse in ethnicity or language, and the original study recruited only parents whose child survived his or her severe TBI. Parents of children who were excluded from participating (e.g., the child died or was too cognitively impaired to participate in an interview or the parents chose not to participate) might have differing viewpoints.

The knowledge gained from this analysis provides important preliminary insight into how prognostic communications can be perceived, and may help to explain or even legitimize the reactions and responses of some parents in the acute care setting following severe TBI [56, 57]. Qualitative research is not intended to be generalized. Instead this analysis presents early acute care contextual information related to parent-provider discussions of the child's prognosis that explain an alternative perspective (parents) from what providers may believe to be important.

Research implications

Future studies should prospectively explore the situational, clinical, and interpretive factors that are important for parents and providers involved in the care of children with TBI. Capturing formal prognostic conversations via video-recording would allow parents' and providers' verbal and non-verbal behaviours to be understood [72]. By supplementing the video-recordings of prognostic encounters with parent and provider cognitive appraisals, a deeper understanding of how culture shapes each participant's role in the encounters would be elucidated [36, 37].

Conclusion

Providers' experience with death following severe TBI may also influence them to orient their prognostic talk with parents towards the worst case. Limited exposure to children's long-term outcomes following severe TBI may cause early acute care providers' to believe that all children with severe TBI remain in a persistent vegetative state, a minimally conscious state, or have severe disabilities (e. g., a poor life quality). Children's outcomes are quite variable and influenced by many medical and social factors. While providers may reason that emphasizing and re-emphasizing the negatives of the child's condition is necessary to prepare parents, parents in this study illustrated that balanced information and parent inclusion in shared decision-making was what the family needed in early acute care.

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Table 1

Child injury and family social demographics.

Demographic Characteristics of Families Represented (n = 27 parents) from 23 Families			
Variable	***n***	***M* (SD)**	**Range**
Parent Participants			
Mothers alone	18		
Fathers alone	1		
Both Parents	4		
Marital Status of Families			
Married	16		
Single Parent	7		
Child's Age at first Interview (years)	23	16(2)	12-20
Time Since Child's Injury at First Interview (months)		16(11)	4 - 36
Child's Mechanism of Injury			
Motor Vehicle	12		
Pedestrian	3		
Sports/Recreational	6		
Recreational Vehicle	2		
Child's Intensive Care Unit Days	23	21.5 (15)	3 - 60
Family Social Living Setting			
Suburban	9		
Rural	10		
Urban	4		
Family Reported Income (dollars/year)			
< $20 000	3		
$20 000 to <40 000	7		
$40 000 to <60 000	1		
$60 000 to <80 000	4		
$80 000 to <100 000	4		
≥ $100 000	4		

Table 2

Parents’ reports of significant negative prognostic statements made with no discussions of uncertainty and the parent and child’s reports of child’s outcome at second interviews. Parents whose child’s later outcome was close to early predictions*.

Parent Contested Early Prognostications of Varying Types of Negative Medical Certainty 16 of the 23 families of children with severe TBI	
Negative Medical Certainty Prognostications as Reported by Parents	**Parent/Child Reported Ecological Outcomes by Second Interviews**
“On their scale of one to ten—ten being brain dead—she was a nine.” and said “You really, maybe just turn off the machine,” on the [date], eight days after her accident, they said, “You know, basically be kind, she’s never going to be any more than a vegetable.” (Parent 3)	Independent in all ADLs, living independently, some cognitive impairment, but attending a four year university with a “B” average. Active socially.
“Would need a nursing home for the rest of her life” (Parents 6)	Independent in all ADLs, living with parents but independent for age, some cognitive impairment, but graduated high school and about to start at a community college. Active socially and engaged to be married.
*“Never walk or talk again” and “should consider a nursing home” (Parent 7)	Independent in all ADLs. Walking and talking. Living with parents and requires their assistance due to judgment and behavioral issues, attending specialized high school and working a part-time job.
“Well, he beat the odds here [living to this point], but now we’re facing pneumonia, and blood clots, and we have many more hoops to go through.”” Kept stressing only the negatives and that was frightening.” (Parent 11)	Independent in ADLs, graduated high school, worked over summer and then living independently at Community College several miles from parents’ home with some assistance, working part-time.
“We’re talking about probably a vegetative state”. … “need to find a nursing home.” (Parent 12)	Some motor, cognitive, and behavior impairment, but performs ADLs independently. Lives at home with parents (age appropriate). Attending high school. Active socially. Writing poetry and stories.
“I don’t think that there’s any hope; she’s not going to come out of this [coma].” (Parents 14)	Independent in all ADLs, living independently. Some cognitive impairment and emotional issues, but attending vocational school. Planning her wedding.
“You do know that she may not wake up. If she does, she will be a vegetable.” (Parent 16)	Some motor and cognitive impairment, but independent in all ADLs and about to graduate from high school. She has fewer friends, but describes them as closer. Serves on a community board.
“The [daughter] that you knew is no longer with us. She’ll be a different person.” “That was devastating. …because they can’t tell you what she’ll be like… so I was so scared.” (Parent 18)	Independent with ADLs. Living at home with parent (age appropriate). Attending high school with specialized classes. She has fewer friends, but reports closer relationships.
“‘Some people pray, pray, pray that their child will live [but] we’ve seen people come back with their children ‘and I can’t remember what she said, but she implied it was almost better to just let them go and let them die.” (Parent 20)	Independent with ADLs. Living at home with parent (age appropriate). Some cognitive and motor impairment, but attending high school, active socially.
“He just matter of fact said, ‘she’ll never be normal again.’” (Parent 22)	Independent with ADLs. Some memory and judgment impairment. Living at home (age appropriate). Attending high school. Has fewer close friends, but “better relationships”.
[Conflicting accounts from different providers] “He’s going to have no injury” and “He’s going to be severely injured” “We were confused and scared for a while.” (Parent 27)	Hearing and mild memory impairment, but graduated high school and attending University with “B” average. Active socially
“Outcome would be quite bleak.” (Parents 28)	Independent with ADLs. Living with family (age appropriate). Graduated high school. Applying to colleges.
They “came in and had the grim faces. … [Asked] “He’s not talking? [then would say] “Hmmm.” [They had] The look of dim and grim all the time [when they evaluated him], which frightened us.” (Parent 31)	Independent with ADLs. Cognitive impairment. Graduated from high school and attending University. Living at University with some assistance.
*“I should never expect to ever see him transition back into a school setting at all.” “There may never be any chance of him ever walking again. …in a wheelchair for the rest of his life.” (Parent 32)	Dependent in ADLs. Wheelchair bound. Significant cognitive impairment. Seizures. Homebound for schooling. Lost all friends, but closer to family.
“Going to be in a coma forever” ((Parent 34)	Independent in ADLs. Cognitive impairment, but living independently

Parent Contested Early Prognostications of Varying Types of Negative Medical Certainty
16 of the 23 families of children with severe TBI

	at school, attending a four year University. Active socially.
"What you see now, that could be all you're ever going to have." [Did not discuss uncertainty]. (Parent 37)	Independent with ADLs. Living at home with parent (age appropriate). Cognitive impairment, attending high school and taking honors/advanced placement classes. Active socially.

ADLs = activities of daily living.