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How Healthcare Provider Talk with Parents of Children Following Severe Traumatic Brain Injury is Perceived in Early Acute Care

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Abstract

Healthcare provider talk with parents in early acute care following children's severe traumatic brain injury (TBI) affects parents' orientations to these locales, but this connection has been minimally studied. This lack of attention to this topic in previous research may reflect providers' and researchers' views that these locales are generally neutral or supportive to parents' subsequent needs. This secondary analysis used data from a larger descriptive phenomenological study (2005 – 2007) with parents of children following moderate to severe TBI recruited from across the United States. Parents of children with severe TBI consistently had strong negative responses to the early acute care talk processes they experienced with providers, while parents of children with moderate TBI did not. Transcript data were independently coded using discourse analysis in the framework of ethnography of speaking. The purpose was to understand the linguistic and paralinguistic talk factors parents used in their meta-communications that could give a preliminary understanding of their cultural expectations for early acute care talk in these settings. Final participants included 27 parents of children with severe TBI from 23 families. We found the human constructed talk factors that parents reacted to were: a) access to the child, which is where information was; b) regular discussions with key personnel; c) updated information that is explained; d) differing expectations for talk in this context; and, e) perceived parental involvement in decisions. We found that the organization and nature of providers' talk with parents was perceived by parents to positively or negatively shape their early acute care identities in these locales, which influenced how they viewed these locales as places that either supported them and decreased their workload or discounted them and increased their workload for getting what they needed.

Early acute care (from initial hospital admission to discharge into rehabilitation care) of children following severe traumatic brain injury (TBI) requires extensive talking with parents to inform them and involve them in decision-making for the child. Parents' lack of

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knowledge about TBI means they need healthcare providers (henceforth referred to as providers) to thoroughly explain the child's injuries, treatments, secondary responses to injuries and treatments, and the range of potential outcome trajectories for the child (Jee, Shepherd, Boyles, Marsh, Thomas, & Ross, 2012; Madrigal, Carroll, Hexem, Faerber, Morrison, & Feudtner, 2012).

The precipitating hospital factors that can complicate ideal communication in early acute care settings includes: a) the intersection of high technology and complex medical conditions, which encourages providers to prioritize technical skills and minimize interpersonal skills (Jee et al., 2012); b) minimal communication instruction given to providers to prepare them for managing their own and others' emotions (Gillotti, Thompson, & McNeelis, 2002); c) the multiple and divergent disciplinary roles involved in the care of the child and family, and the lack of organizational structure to promote respectful interdisciplinary communication that results in a unified message to the family (Boos, Okah, Swinton, Wolff, & Haney, 2010; Institute of Medicine, 2001); and d) providers' attempts to protect themselves from chronic exposures to encounters where they may believe there is no 'good outcome' or 'good news' to give the family (Meadors & Lamson, 2008; Roscigno et al., 2012). In addition, the family's cognitive, emotional, and behavioral states following the child's injury make their processing information and learning particularly difficult and time consuming. Parents may become overwhelmed or hampered by medical jargon, the amount of new information they must process quickly, the descriptions of procedures that seem barbaric (i.e., drilling holes in the skull or taking a bone flap out of the skull and freezing it), or they may react emotionally to discussions of negative possible outcomes (Jee et al., 2012; Ularntinon, Bernard, Wren, St. John, Horwitz, & Shaw, 2010). Taken together, perceptions of provider talk with parents following children's traumatic brain injury becomes a critical human factor that can strongly shape how parents frame the caring or uncaring nature of the locales where such talk experiences occurred.

BACKGROUND

Early acute care settings have physical characteristics that define their use (high use of technology), but they also have human cultural characteristics that define and shape how these settings are used and experienced (e.g., outsiders must get permission to enter or stay). Gustafson (2001) explained that a particular setting, such as an early acute care unit, takes on meaning to parents and families as the unit is experienced physically, psychologically, spiritually, and culturally. That unit is also influenced by the broader social context in which it is situated (e.g., the unit within the hospital and the hospital within a community, state, and country). How parents and families experience the space's physical, social, psychological, and cultural characteristics related to the care of the child and the care of the family directly and indirectly shape how the parents and families identify with these units as *places*.

Due to advances in early medical care, more children are surviving TBI in recent years and children's long-term outcomes are heterogeneous and based on a number of injury, medical, and social factors (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012). Culturally competent, effective, and timely talk with parents is known to be a critical factor in building trusting relationships with families (DeLemos et al., 2010). It involves creating mechanisms by which all providers and the family can be knowledgeable of, and have input into, the plan of care. It also involves creating a means for provider disagreements to be discussed away from the family, so that a unified message is given to parents that shows respect between all providers (Gordon et al., 2009; Hoonakker et al., 2008). Given the minimal research on this topic with this population, and the problems translating research knowledge into practice (Institute of Medicine, 2001), early acute care providers may still lack a complete

understanding of how their talk processes or policies can trickle down to affect parents' perceptions of the caring or helpful nature of early acute care units. Parents' retrospective orientations to their early acute care talk experiences are important because they give insight into how they perceive involvement in their child's care, what information they needed, and how they coped with various encounters both initially and long-term (Bronner, Peek, Knoester, Bos, Last, & Grootenhuis, 2010; Revenson & Lepore, 2012; Ularntinon et al., 2010).

In a larger investigation using descriptive phenomenology to explore 42 parents' overall experiences following children's moderate to severe TBI (37 families), Roscigno & Swanson (2011) noticed strong language tones and detailed provocative stories in the *meta-communications* (talk about talk) of parents of children following severe TBI. These parents often felt constrained and misunderstood during the process of receiving early acute care. This was in contrast to the experiences of parents of children with moderate TBI, who most often felt understood, but gave vague specifics about what was good or helpful when probed. Overall differences in the tone, detail, and genre of each group's meta-communications signaled that there was something different about each group's subjective orientations to the early acute care talk experiences and places. We reasoned that exploration of the talk about talk from parents of children diagnosed with severe TBI, including the language parents used and their corresponding behaviors, would provide important preliminary information to improving care delivered in these settings. The aim was to explore and discover what parents were trying to tell us explicitly and implicitly about the talk in these settings. Cummins, Curtis, Diez-Roux, and Macintyre (2007) claimed after conducting a synthesis of published literature, that the findings from the research they synthesized has shown causal relationships linking people's orientation of settings (i.e., place) to their health. The inductive approach we took is a critical first step to acknowledging parents complete talk needs in order to create future family-centered places that are sensitive to their perspective and experiences.

METHODS

Ethical approval for this secondary analysis was obtained from the University of Illinois, Chicago; and the University of North Carolina, Chapel Hill, as well as two clinical recruitment sites, which are not identified to protect the identities of all systems of care described by parents. Written informed consent was obtained from all participants. Transcript data were de-identified. A copy of this manuscript has been shared with the involved parents, for whom contact information was still current ($n = 20$ of 23 families). We did not have permission, however, to interview parents for feedback.

Participants

In the original study, forty-two parents from thirty-seven families were recruited from across the United States from 2005 through 2007. Recruitment strategies included: personal solicitation at a northwestern children's hospital; advertisement on two TBI related websites; local advertisements; and mailed invitations to targeted participants in a regional southeastern brain and spinal cord injury program and a northwestern hospital's trauma registry. Recruitment was aimed at enrolling a diverse group of children, which we believed would then reflect a diverse group of parents with varied experiences.

Inclusion criteria of children were that they: (a) were 6 – 18 years of age at injury; (b) diagnosed with moderate to severe TBI; (c) had no other neurologic impairment; (d) had the ability to consent/assent and participate in an interview; (e) were within 4 – 36 months of their injury; (f) dependent on their parent/guardian; (g) were conversant in English; and, (h) at least one parent/guardian who was also willing to be interviewed separately. Recruitment

continued until the sample reflected reasonable diversity in child's injury severities and family social demographics, and the themes of both children's and parents' experiences were saturated.

Since parents of children with moderate TBI gave vague specifics about why talk in early acute care met their expectations, they were not included as comparisons. The transcripts from the 29 parents of children with severe TBI were initially evaluated to make sure they met our inclusion criteria: (a) discussed in detail their talk with providers in the early acute care period; and, (b) discussed the meaning they interpreted (cognitively, emotionally, or behaviorally). Two families were excluded because of a lack of sufficient detail, but both parents were in agreement with the other parents' appraisals of what was important for early acute care talk discussed in second interviews.

Data Collection and Preparation

All families were interviewed initially in-person by the first author. Second interviews were done by phone ($n = 19$ families) or in person ($n = 3$ families), and one parent declined to participate in the second interview. The investigator had prolonged engagement with families at the first interviews, beyond the interview (Patton, 2002). Thus, the investigator believed that phone interviews would still meet the aims of the second interviews if parents wished this method.

Both interviews used a semi-structured approach, were audio-recorded, and lasted at least 90 minutes. The first interviews were conducted at enrollment (4 – 36 months post injury; $M = 15$ months). Second interviews took place upon completion of all first interviews (12 – 15 months after first interviews; $M = 27$ months post-injury). The first interviews focused on injury circumstances and subsequent parent/family experiences. Second interviews gathered accounts of experiences after the first interview and also collected feedback on the author's synthesis.

Data Analysis

Discourse analysis within the framework of ethnography of speaking (ES) was used to analyze transcript data (Philipsen & Coutu, 2005; Philipsen, Coutu, & Covarrubias, 2005). ES is a well-accepted empirical framework for discovering how culture (attitudes, beliefs, notions, and expectations) shapes talk or the interpretation of others' talk. Here we use the word 'talk' to describe language used, behavioral interactions, and the overall organization of talk. This also included talk that was described as expected by parents, but missing. ES takes a non-judgmental approach (e.g., discovering and understanding), not criticizing talk participants. ES uses the S-P-E-A-K-I-N-G framework first described by Hymes (1972) and subsequently developed as described in Philipsen and Coutu (2005). It points investigators to particulars known to affect how talk is structured for a purpose or how the interpretation of another's talk is based on our cultural influences (Philipsen & Coutu, 2005).

We used an adaptation of Hyme's framework presented in Table 1. Parents' meta-communications provided us with direct and indirect information about their beliefs, expectations, meanings, and responses. According to speech codes theory, interpretation of talk is based on cultural influences that people are exposed to (societal, ethnic, gender, educational, occupational, and spiritual) and the local situations within which the encounter takes place. By starting to understand how parents talk about early acute care talk, we can better judge the utility of various communicative processes and policies according to parents' needs (Philipsen et al., 2005).

Only transcript data describing the early acute care experiences was considered. Digital recordings of interviews, and field data were used to supplement the transcripts with

contextual information that was important for this analysis (Patton, 2002). This included *paralinguistic* features such as pauses, particular tones associated with words used (e.g., sarcasm, anger, humor, imitating or mocking the verbal and non-verbal ways something was said), major voice intonation changes by parents emphasizing particular words or phrases, and other utterances (sounds indicating emotional expressions, demonstrations, or gestures).

The two primary coders (C.R. (PI of original study) and T.S.), read a summary of each family's overall experiences and the entire transcript of their acute care experiences to first gain a sense of the family's broader experiences (Potter, 2004). They then read the transcripts line by line, paying attention to parents' use of individual words, word groups, and verbal and nonverbal factors, which together lent meaning to what parents were trying to convey in their meta-communications. The two research questions asked of the data were: a) what are the parents trying to do with their talk when they describe these experiences; and, b) what do their actions in their own talk about talk in the early acute care period tell us? These questions fit with the methodology guiding this analysis (Philipsen & Coutu, 2005; Philipsen et al., 2005; Potter, 2004).

Coders independently coded each transcript and then met after every 2–3 transcripts to discuss their impressions. Transcript data, field notes, and summaries were used as primary sources to discuss any disagreements in coding. All data was then shared with the methods expert (G. P.), who acted as a methodology peer reviewer. Final coding summaries were compared and contrasted to develop commonalities of how parents used their own talk to react to early acute care talk experiences, in order to understand their culture. Our analytic approach and our final summary were then shared with a clinical peer reviewer (G. G.) to ensure fair portrayal of clinical providers, that our examples were not extreme cases, and to consider his clinical recommendations (Patton, 2002).

RESULTS

Final participants were 27 parents from 23 families. They came from 9 states and were cared for at 14 different acute care locations in the United States. Parent participants from each family included only mothers ($n = 18$), only fathers ($n = 1$), or both parents ($n = 8$ from 4 families). Parents were primarily Caucasian and non-Hispanic (92%). Family yearly incomes were reported as: < \$20,000 ($n = 3$); \$20,000 to < \$60,000 ($n = 8$); \$60,000 to < 100,000 ($n = 8$); or > \$100,000 ($n = 4$). Marital status in families was reported as single ($n = 7$) or married ($n = 16$). Children's acute care hospitalizations ranged between 3 and 60 days, ($M = 21.5$). The injured children's ages ranged from 12 to 20 years of age at enrollment. Thus, we use the terms child/children to refer to their relationship to their parent(s) and not their maturity.

Parents most commonly used the following talk strategies from the S-P-E-A-K-I-N-G Framework in their meta-communications regarding early acute care: strong negative tones in their speech; words with derogatory meanings; increased voice inflections on individual words, phrases, or sentences that they wanted the interviewer to note; non-verbal behaviors (gestures, mimicry, demonstrations) to emphasize barriers; emotionally laden stories, arguments, and extreme case formulations ("they never", "they always"), which positioned their moral perspectives regarding their experiences (Edwards, 2000).

By treating parents' language and corresponding paralinguistic behaviors as our first object of this analysis we could attend to how the nature of provider talk was culturally perceived to construct parents' early acute care identities. We could then also demonstrate the ways parents used their own talk to situate their cultural perspectives. Finally, we were then able to discern, across parents, the common talk factors (physical, psychological, cultural, and

political) that they believed shaped their identities in the early acute care period: a) physical access to the child, which is where information was; b) regular discussions with key personnel; c) updated information that was explained; d) differing expectations for talk in this context; and, e) parental involvement in decisions. Our approach differentiated this analysis from a simple thematic analysis, where interview data (talk) is only viewed as an index of experience (Philipsen et al., 2005; Potter, 2004).

Exemplars are presented to highlight the defining features from parents' culture and to demonstrate some of the ways that parents used their own talk to position their perspective above the perspective they perceived from others, and justify their reactions, which to outsiders might be viewed as abnormal. To protect parent and provider identities, we used pseudonyms for parents and removed references to particular provider disciplines. Underlining of words in the exemplars indicates that the parent(s) placed emphasis on those words through tone and/or inflection. A positive talk example demonstrates how attending to the talk factors that the other parents discussed negatively drastically changed the two parents' meta-communications, appraisals of people and place, and their involvement in care.

Access to Information

Parents who experienced any limitation to full visitation attempted to illustrate how organizational controls of access to the setting, where care of the child occurred, immediately constrained their role as a parent. Physician-parent encounters were described as most often not deliberate; they were perceived to be structured for providers' daily schedules and the goals of the organization. If the parent was not at the child's bedside when providers came by, they were disadvantaged to get updated information, ask questions, and fully participate in on-going decision-making as Brenda noted:

But I mean we got, and as vicious as this sounds, and as probably hardworking as those ladies are down at the desk, the volunteers, we just called them the Nazis. I mean they just, "No, you can't get up there." We were just, by the time we left [hospital name], I mean it was just to the point that I was ready to scream a fit, and even other people would say, you know, "Well, you can try, but they won't let you in"....[So one time] the Nazis at the desk looked at me and said, "Where are you going?" I said, "I'm going upstairs and deliver these chocolates," and it was a basket...[they said] "No problem, go ahead." Well I brought chocolates every bloody day after that. "...I went upstairs. The lady behind the voice [unit call box] said, "What are you here for?" And I said, "I'm here to deliver the chocolates" and she said, [in a lighter tone] "Oh, come on in."

Brenda uses strong derogatory words, emphasis in tone on particular words, and an illustrative story to show how the experience constrained her as a parent until she found a way to overcome the human constructed barriers of that place.

Regular Discussions with Key Personnel

Children's health status could change often and quickly in early acute care. Some nurses were not aware of updated plans, so parents needed time with key physicians to have the information explained and get questions answered. Lisa noted such needs could not be met during the time allotted during physician rounds or quick checks on the patient:

I think I saw him [her doctor] twice and that was just by chance, because I was in the room with her, sleeping in the room with her when he made his rounds. Other than that I never saw him, so I would have to ask the nurses, did the doctors make their rounds? What did the doctors say? What are they going to do?.... The doctors

were like, you know, they were too busy to stop and talk to you. They were too busy to explain things to you.

Parents perceived physicians to be the primary decision-makers on the health care team, and therefore, parents expected periodic one-on-one conversations with them, regardless of the other providers who provided information. When regular physician-parent talk did not occur, parents most often perceived this as intentional avoidance (too busy) or that the physicians were not trained to develop relationships (unskilled) as illustrated here and in subsequent parent quotes. This left parents feeling unimportant for decision input. Parents expressed the tensions of working within the hospital system to get the information they needed. Some parents were more aggressive in their approaches to counter barriers, by not restricting talk to the child's bedside or waiting for provider talk to come to them. Karen's talk reveals that she also shaped the parent-provider talk process by making the place and interactions conform to her family's needs for fuller explanations and discussions about decisions:

I would literally stand in the hallway by the doctors' elevator every day so that I would catch the guy going in, and then I walked him back to the elevator every morning, because their time, it's just so hard to get any time with these guys. And I appreciate that [they are busy], but I still needed answers... That's why you got to be there all the time because if you're not there all the time, you're missing half of those people that came through to see your kid. And make decisions about your kid.

Parents spent more time with bedside nurses than any other providers. In many cases nurses helped parents overcome information barriers by explaining, updating, or negotiating for meetings with physicians as Lisa reported, "the nurses got us back on track". Conversely, at times nurses contributed to information barriers by not being knowledgeable or comfortable to explain the child's plan of care in detail as Cindy revealed, "She said you'll have to ask your doctor", or they did not advocate for parent-physician meetings. Thus, nurses were reported as important mediators to parents' understanding because they were able to witness parents' distress and confusion and had the ability to intervene in the talk processes or policies that might be creating barriers.

Talk with parents was not always cohesive between all providers involved. When providers were reported as disagreeing amongst each other and some providers shared these disagreements with parents in a covert way, they inspired parents' confidence in positioning their family goals, but they also increased parents' uncertainty and distrust of the other providers as Joan and Marc reported:

So, then we heard from [providers group B] again...[they said] "We overheard the [provider group A] planning to do an intervention on you guys. And they're going to convince you to move her out of here, and to put in the trache[ostomy] and the permanent feeding tube. And we don't think it's necessary. We don't see any reason to give up on her at this point"... So [later], we [parents] got cornered by the [provider group A]...[After they told us what they thought, we told them all about our daughter and we said] "So, what we're telling you is that we want you to preserve as much of that as possible, and not to give up on her." They then said, [mimics one provider's tone in a derogatory way] "Oh, oh, well, we want that too." And then I said, [stated in a matter of fact tone] "So, we aren't going to consider a tracheotomy until at least day ten."

Such talk encounters meant parents had to navigate between differing ideologies and politics expressed between providers, which added to parent stress and distress because parents

needed to be allies with all providers who cared for their child as Joan and Marc explained, “We were quite clear that we needed to make friends with everybody”.

Updated Information that is *Explained*

The way parents used words to describe the information sharing they experienced (i.e., they tell you, they told me, he/she said) in the context of their stories revealed that parents often felt that information was in fact provided, but not *explained* to them, or the encounter did not solicit parent input. Parents needed the language to be simple, free of medical jargon, and not so vague as to prevent them from understanding all the implications; further they needed all of the health issues and details specific to their child discussed. When parents perceived that reasonable explanations were not given, they noted that their lack of knowledge and feelings of disempowerment were constructed by the talk processes within these settings as Susan explains:

I realized that they were not telling me everything...maybe in the ICU they don't, maybe they don't want to tell you everything, because they don't know how it ultimately will end up. I was in the dark for a long time...[My daughter started posturing] and I said, “What’s wrong with her? What’s wrong with her?”....”Why is she doing that?”.... they just made me leave the room...they just kept saying...” We’re trying to rule things out” there was so much going on...it was so stressful...they pretty much knew what she had, but they were just ruling all these other things out...for days I was just in the dark. Nobody ever said [here’s why we are doing the tests], and when I found out, I was really upset. I was like, “Why didn’t you just tell me that [you thought she had a stroke] to begin with?”

Vague language or a lack of timely sharing and explaining left parents confused and uninformed, increased their uncertainty, and subsequently left them disadvantaged to fully participate in informed decision-making. As illustrated by Susan, she didn’t understand what had occurred until several days later when her child had been transferred from that setting and someone finally explained what had happened. This late revelation made Susan feel that the early acute care place did not value her capabilities should she be fully informed. She argued that the providers in this place did not understand that they played a role in shaping her helplessness.

Differing Expectations for Talk in this Context

When provider talk did not meet parents’ expectations, it triggered parents’ deep reflections on the social norms of talk in such contexts where parents were disadvantaged and needed timely, explanatory, and supportive talk. Parents presented cases showing that their vulnerability often reflected a lack of consideration by some providers for the culturally insensitive experiences created by the timing and prioritizing of talk important to the provider or hospital over talk important to the family as illustrated by Joyce:

[After the surgery] first thing [the doctor] he did not tell me was, “You’re daughter’s doing fine,” he goes, “What kind of insurance do you have?” I was blown away at that point. I said, “How is she?” [mimics doctor in an aloof manner] “Oh, she’s fine, da-da-da-da-da,” you know, but, “ Who do you go through? We need your insurance information.” I’m like, “ Right now, I could care less about insurance” ... So I was very blown away by that...and I said, “So, if you would’ve known my daughter had this insurance,” because I told them what it was, and he was like, [mimics physician huffing and rolling eyes]... And I said, “So, if I, if you would’ve known what kind of insurance my daughter would’ve had before,” I said, “would you have done a half-assed job?” And I walked away. I was pissed. I was very upset.

While this provider may have wanted to know their insurance information in order to calculate care options, this parent needed to believe that the values and feelings of the family, particularly the continued worth of the child (i.e., caring), were prioritized and respected by all providers throughout their talk. Thus, parents argued and demonstrated that providers' who prioritize other needs, over parents' caring needs, will likely be viewed as detached and should expect that a parent might react emotionally, without their response being abnormal to the context.

Parental Involvement in Decisions

Many parents did not perceive that they were actively involved in a shared decision-making process and instead often felt a decision had essentially been formulated by providers and was then presented to them without exploration of additional options. Parents often felt that the way information was presented was prioritized towards moving the child along to a long-term facility and this realization exposed the power differential, especially related to decisions that impacted options for outcome. Parents felt that some providers were detached from the implications of important decisions for the family. Parents often described such conversations with physicians as occurring "on the go", when physicians briefly stated their ideas while on rounds, without fully discussing it with the parents, asking and considering their input, and offering them other options to also consider. Parents gained insight over time into the politics of how talk was organized in early acute care processes related to severe TBI as illustrated by parents from two separate families, Barbara and then Joan and Marc:

They were going to do whatever they wanted. Like I said, I had to fight.... And not only did they put [a feeding tube] in, but they put it in in such a way... it was permanent...and she only used it for a week...."Why are you putting this in?".... She was still in the hospital...she had not been formally accepted into rehab, so they were preparing her.... Wherever she was going to go, they wanted her to have a trach[ostomy], and they wanted her to be on a feeding tube. They felt like she was going to be, from what I can gather now, she was going to be the worst case that they saw....[We interpreted they just wanted] to get her out of [the] ICU, we don't care where she goes, but before she leaves ICU, she's going to have these two things put in her.... Who are you? You don't really have much of a say on matters.

They kind of had their minds made up about what, what was what. They'd come around, they'd look at [our daughter] for a couple of minutes, maybe not that much, and if we're lucky enough to be there, they'll tell us something. [One physician said] "You should consider the possibility of a nursing home... where she could receive the best care." And this is like we're still reeling, 'cause it's only day 5 or so...[We said] "You're just here giving us this information and we're imploding" ... "Do you have any idea the weight of the words you're throwing out here?" Because [that team of providers] they were so strident about the...severity of her injury, in part because it was great science for them. But we weren't interested in great science...their bedside manner sucks.... To have him come and drop a huge weight and go, plus, they have no ability to process it with us. You know, I mean they're really not very skilled [so we complained to the nursing care coordinator and attending physician because we were upset].

Parents reported they first tried to modify the situation by asking providers to include them and consider broader information, and by positively reframing how they (parents) viewed their present situation. Parents often described that their positive reframing approaches were not fully understood or respected by providers in these settings and they did not feel entirely included in a dialogue related to decisions. Then parents discussed moving to emotional forms of coping (anger, blocking, ignoring, demanding), because they felt disadvantaged,

avoided, or discounted. Parents felt they had to work harder to navigate such places, and at least initially, these experiences constrained their coping. Over time, however, most parents used their personal and social resources to overcome barriers at a cost of their physical, psychological, and spiritual well-being.

A Positive Talk Example

The following exemplar conveys John and Lindsey's positive talk experience: And we were met by the [physician] ...a really nice guy...and he basically sat us down and said..."This is serious. It's more than my capabilities.... And he wanted to reassure us that—it would take a long time, we wouldn't know anything, and they would tell us something as soon as they knew something.... He said, "We won't know anything about his response or his injuries until he comes out of surgery," and he said, "I think it's four or five hours before we're going to know anything" And he probably came out around eleven or so, and [he] sat down and told us what they had done. He is a very kind person, he is very detail oriented.... So then we got to go in ICU—[another physician] came back. And he said, "What we're going to do is we're going to have you guys work with us".... So they were like, "Do this," and then they would explain...but then they would teach us what they were looking for.... Seemed like they wanted our [help]....[Our physician in the ICU] I called him "The gnome", because he kind of kept just appearing [laughter] But then it kind of transitioned to the ICU nurses, and they did a good job.... in terms of explaining things, what they're doing, how they're doing it.... and that helped.... just to know what's going on, and accommodating us; saying, "Yeah, you can sleep here," and "Oh, by the way, here's some towels, and here's some blankets," and that kind of stuff. Just to ease our mind that we could be there.

Such talk strategies: invited the parents' participation by giving them full and ongoing access to information; helped them understand the diagnosis, treatments, and recovery responses by explaining and inviting talk; decreased their stress and distress by diminishing their workload to get information; showed respect for their family values toward helping the child; and built John and Lindsey's trust in all providers by showing them that their complete needs and well-being mattered to all people in this place.

DISCUSSION

The approach of this analysis did not attempt to provide an objective account of early acute care provider-parent talk. We recognized that parents' orientations to such talk experiences could, however, provide important new contextual and cultural insights (Philipsen & Coutu, 2005; Revenson & Lepore, 2012). Parents described talk processes that were perceived to be designed to meet the medical needs of the child and the organizational needs of providers, units, third party payers, or hospitals. Parents' wanted providers to understand that many early acute care talk experiences were not supportive to their information or involvement needs.

Thorne (1993) described the relational effect of culturally bound and insensitive medical talk in hospitals. Much like we found in the stories of our parents, she noted that families present with a *naïve trust* towards providers. Parents in this study came with an expectation that all providers in this setting will know about, and be empathetic to, their informational and involvement needs. Parents expressed expectations in their talk that providers' knowledge would be reflected in regular and repeated dialogues that are sensitive and respectful to parents' lack of knowledge, their current physical and psychological condition, their family values, and their ongoing informational needs specific to their child's condition. Otherwise, parents transitioned to *disenchantment* with their providers; where they realize

“the anticipated help will not be provided for them in the way that they had expected” (Thorne, p. 87). Like Thorne described, disenchantment then led many parents to take on a *guarded alliance* with key personnel. Parents recognized that providers were also part of larger cultural systems (medicine, science, etc.), which at times meant they had differing values that clashed with parents’ values (Roscigno & Swanson, 2011). In addition to what Thorne described, we found that parents who experienced human constructed talk barriers in early acute care did whatever they could in order to maneuver these barriers by becoming *self-reliant* to get what they needed. Yet, this self-reliance created an additional workload for parents to get the information and involvement that they wanted, while treading carefully to minimize offending or alienating any involved providers (*a balancing act*). The construction of barriers, additional work, and the need to balance how they were perceived by providers, in order to get what they needed, shaped these locales as physically taxing, frightening, or at times even threatening places to parents. Kearns and Gessler (1998) pointed out that notions such as health and healthcare are products of a particular society in a particular place and time. Societal notions of pediatric health and healthcare have broadened in recent times to include not only the expectation of providing for the physical well-being of the hospitalized child, but also the physical, psychological, cultural, and spiritual well-being of the child and family members (through patient and family-centered care and shared decision-making) (Conway et al., 2006; Gillotti et al., 2002; Institute of Medicine, 2001). Parent identities have changed in recent times, and many parents now want to take a more active and shared role in healthcare decisions (Coulter, 2002; Madrigal et al., 2012; Ularntinon et al., 2010). Thus, we can assume that parents in this analysis were evaluating their early acute care talk encounters in the context of these expectations (Ong, De Haes, Hoos, & Lammes, 1995).

Kearns and Gessler (1998) described their synthesis of therapeutic places as spaces that provide mechanisms for persons to experience physical, mental, and spiritual healing; giving them feelings of warmth, an identity, and a sense of rootedness or authenticity. Therapeutic places also commonly incorporate the familiar and provide daily routines, are sensitive to individuals’ cultural beliefs, and create an atmosphere in which social detachment and social disparities are minimized (p. 8). Being sensitive to parents’ cultural beliefs in this particular case would involve not only recognizing ethnic, geographic, spiritual or family beliefs, but also recognizing that parents come with a sense of what it means to be a ‘good parent’ in such situations (a parent culture) (Philipsen et al., 2005; Roscigno & Swanson, 2011). Parents wanted to be actively informed and involved in care and decisions for their child.

Connecting With Parents through Talk

Access to the child was a spatial and psychological disparity that differentiated parents’ talk experiences by promoting or constraining their proximity to ongoing information about their child and influencing parents’ participation in decision-making [as discussed in Ularntinon et al., 2010]. Regular dialog with parents helps to establish and sustain an effective working relationship, in which trust is at the core (creating interpersonal warmth, rootedness and an identity in the problem) (Jee et al., 2012; Ong et al., 1995). These parents needed information to be explained in language they could understand and respond to (preventing a medical culture language disparity). Bourhis, Roth, and MacQueen (1989) found that physicians often believe they explain information in language lay persons can understand, but others disagree. These authors noted that when one tries to speak in the language of the other, it promotes interpersonal harmony, limits social detachment, and decreases the stranger uncertainty often inherent in unfamiliar encounters [as Berger, 2005 described]. Disorganized, insensitive, and irregular talk across providers led parents to conclude negative assumptions about the intentions behind such behaviors [as Berger, 2005 described]. Negative assumptions then constrained parents’ perceptions of collaborative

strategies available to them for shared decision-making, which limited their sense of available choices for their responses.

Talk Factors Leading to Disenchantment

We found when the talk of health care providers' was perceived to prioritize provider or organizational beliefs or needs over the family's needs, parents perceived that the providers were detached, insensitive, and uncaring to their plight, which was reflected in parents' tone of language, choice of words, the types of stories they told, and their subsequent responses. Providers' ability to emotionally connect with a parent, in a time of such vulnerability, is considered one of the most important traits expected by society (Coulter, 2002; Ong et al., 1995).

The multiplicity of disciplines that play a role in talking with parents, shaping parents' meaning and responses, has been minimized (Bourhis et al., 1989; Cummins et al., 2007; Revenson & Lepore, 2012). We found that parents were at times caught between differing individual or disciplinary viewpoints related to the meaning of the child's current condition and possible treatment decisions. Parents' stories illustrated that poor interdisciplinary communication can hinder future talk between parents and all providers, because it at times creates covert alliances with some providers and plays a role in creating distrust of other providers.

Information that was difficult to get, or perceived as biased, created a power differential that increased parent uncertainty about their role in decision-making and how future talk with providers would be affected. Collins, Drew, Watt and Entwistle (2005) and Karnieli-Miller and Eisikovits (2009) have illustrated how provider talk can be structured in such a way as to position the authority of medical and statistical probabilities, while minimizing the importance of other information important to the family (religious, spiritual, cultural, etc.). Philipsen et al., (2005) explained that when a provider structures their talk in such a way, they may or may not be doing it intentionally and the action may instead stem from cultural beliefs related to the talk topic, which the individual takes for granted as everyone's viewpoint. We have tried to show the impact of various talk behaviors as perceived by parents, so that providers can begin considering the situational and organizational factors that may be driving talk interactions with parents of children following severe TBI in early acute care places.

Limitations

This study was a secondary analysis and we were unable to re-interview the parents to confirm our final interpretations. Our interpretation, however, came from parents' thick descriptions illustrating how the context shaped their identities and expectations. This study, however, included only parents whose child survived severe TBI; other parents whose child died, or those who chose not to participate, might have differing viewpoints. We would caution that the findings from this analysis are not meant to be generalized. They instead provide a preliminary understanding of how early acute care talk processes and policies can influence meaning and behaviors following severe TBI. This topic should be explored further in a prospective study that controls for any selection bias. While recall is most often seen only as a limitation, we found that as parents gained experience over time, they also gained insight into their early experiences and responses. Parents' deeper insight helped them to reflect on talk factors that they believed were important to shaping their experiences, meanings, and responses. Parents might not have been completely aware of these patterns while they were immersed in events. Due to the small and homogenous sample, along with the secondary nature of this analysis, we were unable to discern obvious influences of family

demographics to explain our findings. Without reporting the demographic descriptors, however, questions might be raised about how representative the sample was.

Clinical and Research Implications

This study emphasized the need for regular, intentional, and dialogical conversations with parents about the child's current condition, treatments, and future care options. Policies and procedures related to talking with parents that prioritize organizational or provider needs is perceived by parents to limit them in being fully informed and involved in decision-making, which shapes their orientation to these places. The long-term impact of making the parent work harder to be fully informed and involved in early decisions was evident by parents' emotional behaviors during these interviews related to negative experiences (crying, red in the face, emotionally laden stories, or anger) an average of more than 2 years after the injury.

In this study, we only present the parents' appraisals, but since healthcare providers are meant to serve the needs of families, parents' appraisals are especially important. Future studies should attempt to uncover the attitudes, beliefs, notions, and expectations of talk from all the various types of participants (parents and all providers). Our analysis gives preliminary evidence to help with the design of future communication studies evaluating talk in early acute care. A larger and diverse sample with more detailed demographics might give further insights into social and cultural factors also affecting talk and the interpretation of talk (e.g., ages, education, employment history; healthcare discipline, experience, communication training, and any significant cultural affiliations or experience with disability).

We found preliminary evidence that talk with parents in early acute care was perceived to construct their identities and meaning positively or negatively. Basso (1996), an ethnographer, similarly studied subjective orientations to settings in stories of Western Apaches that were handed down through generations. He recognized that the Western Apache orientations to the settings, described within their stories, were not only to give listeners a description of the locale. Their approach was also done to help bring listeners back in time, so that they could understand what the events meant to those who had been there in that space and time, as we tried to do here. Basso coined the term describing this process of attending to how others orient to a setting as 'place-making.' He described place-making as "...not only a means of reviving former times but also of revising them, a means of exploring not merely how things might have been but also how, just possibly, they might have been different from what others have supposed" (p. 6). Basso points out that anyone can be a place-maker by being curious and asking: "What happened here? Who was involved? What was it like for them? [and], Why should it matter to us" (p. 5)?

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Research highlights

- Provider talk with parents following children's brain injury has not been explored.
- We used a novel approach, ethnography of speaking (ES), to understand the effects.
- ES attended to linguistic and paralinguistic features of parents' talk about talk.
- Acute care places often increased parents' workload, constructing their identities.
- Talk plays a role in parent understanding, involvement, and references to locales.

Table 1

Variables of interest when using the methodology of ethnography of speaking as adapted from Hymes (1972) and Philipsen and Coutu (2005).

S-P-E-A-K-I-N-G FRAMEWORK	
Variable of Interest	Description
S: Setting or scene	Time, physical, psychological or cultural context of talk.
P: Participant's identities	Perceived resources of the speakers and the listeners involved.
E: Ends	Personal or social results anticipated from one's own talk or another's talk.
A: Act sequence and act topic	The chosen words employed and how they are structured for an action.
K: Key or tone	The demeanor or emphasis employed in talk.
I: Instrumentalities	The modes or style of the talk (i.e., formal, informal, specific to a group).
N: Norms of interaction	The cultural and societal expectations of the interaction and the participants' reactions or actions.
G: Genre	The type of talk act or event (i.e., emotionally laden narrative story, description, argument), which tells meaning in and of itself (e.g., people argue when they feel misunderstood or disadvantaged).