Parents' Experiences Following Children's Moderate to Severe Traumatic Brain Injury: A Clash of Cultures

Cecelia I. Roscigno[1] and **Kristen M. Swanson**[2]
[1]College of Nursing, University of Illinois at Chicago, Chicago, IL, USA

[2]School of Nursing, University of North Carolina, Chapel Hill, Chapel Hill, North Carolina, USA

Abstract

Little is understood about parents' experiences following children's moderate to severe traumatic brain injury (TBI). Using descriptive phenomenology we explored common experiences of parents whose children were diagnosed with moderate to severe TBI. Parents from across the United States (N = 42 from 37 families) participated in two semistructured interviews (~ 90 minutes and 12–15 months apart) in the first five years following children's TBI. First interviews were in person. Second interviews, done in person or by phone, facilitated updating parents' experiences and garnering their critique of the descriptive model. Parent themes were: (a) grateful to still have my child; (b) grieving for the child I knew; (c) running on nerves; and (d) grappling to get what your child and family need. Parents reported cultural barriers because of others' misunderstandings. More qualitative inquiry is needed to understand how the knowledge, attitudes, beliefs, and expectations of others (culture) influence parents' interactions and the family's adjustment and well-being.

Keywords

brain injury; children, disability; culture/ cultural competence; disability/ disabled persons; lived experience; parenting; phenomenology; quality of life; research, qualitative; trauma

More than 600,000 children under the age of 21 years sustain a traumatic brain injury (TBI) in the United States each year. Children under five years and adolescents who are 15 – 19 years of age comprise two of the three age groups who are most at risk for sustaining a TBI (Langlois, Rutland-Brown, & Thomas, 2006). The early injury severity of TBI is often defined according to the Glasgow Coma Scale (GCS) score, a global neurologic measure evaluating eye opening, motor, and verbal responses to various levels of stimuli (Teasdale & Jennett, 1974). The GCS has a potential score of 3 – 15, with moderate TBI ranging from nine to twelve and severe TBI ranging from three to eight. A heterogeneous cluster of short or long-term physical, cognitive, emotional, behavioral, or social impairments are commonly reported following moderate to severe TBI, which can affect children's development, socialization, and progression towards independence (Eker et al., 2000; Ommaya, Goldsmith, & Thibault, 2002).

Parents' sometimes play a significant role in providing long-term support following children's moderate to severe TBI even into young adulthood, when parents would typically be stepping back from managing their child's life (Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2005). An underlying assumption is that the majority of parents' stressors in managing, adjusting to, and supporting the children's condition post TBI is from their impairments and/or the parents' or the families' style of coping (Ben & McColl, 2004; Gan, Campbell, Gemeinhardt, & Mcfadden, 2006; Hawley, Ward, Magnay, & Long, 2003; Kreutzer, Marwwitz, & Kepler, 1992; Rivara et al., 1992; Wade et al., 2003; Wade et al., 2006). Little is known, however, about the collective range of things that parents have to manage, adjust to, or support.

Although the individual child's changes and the personal and family styles of coping are also contributors to adjustment, management, and support of children's TBI, a deeper understanding is needed of the factors within the individual, their family, and their broader community and culture, which parents encounter following their child's injury (Bronfenbrenner, 1977; Knafl & Deatrick, 2003). Of the qualitative investigations evaluating parents experiences published to date, the samples have been small and derived from local or regional sites; hence, transferability of those findings might be limited to the settings and communities from which those samples were drawn (Aitken, Mele, & Barrett, 2004; Bond, Draeger, Mandleco, & Donnelly, 2003; Chilsholm & Bruce, 2001; Kao & Stuifenbergen, 2004; Smith & Testani-Dufour, 2002; Ward, Shum, Dick, McKinlay, & Baker-Tweney, 2004; Wongvatunyu & Porter, 2005).

Developing family-centered care programs has become a key priority for health care in the United States, and it requires input from family members of those with traumatic brain injury (Conway et al., 2006; Institute of Medicine, 2001). The purpose of this investigation was to describe the common experiences of a sample of English speaking parents from across the United States following their respective child's moderate to severe TBI. A broader understanding of parents' experiences and expectations following children's moderate to severe TBI and their interpretation of the social factors including attitudes, beliefs, notions, and expectations influencing these experiences (i.e., cultural components) is needed to evaluate the relevancy of our current practices, services, and existing theories (Philipsen, 1997).

Methods

Design

Ethical approval was received at an independent clinical site, the local University (covering two additional clinical sites), an independent third clinical site, and another University when the first author transferred to a new institution. We used a descriptive phenomenological approach to gain a subjective understanding of the experiences of a socially varied group of parents whose children were no more than five years post TBI. Parents were enrolled and first interviewed between 4 months and 3 years post injury, and followed up with a second interview 12–15 months later. The original aim of interviewing parents in the investigation was to describe how well parents approximated their children's experiences and to understand the children's experiences within the context of parents' experiences because parents are often used as a proxy for the child's perspective. After hearing the stories of the first three parents, however, it became apparent to the authors that parents' accounts of factors affecting life quality and their management of their child's condition are not fully appreciated or accounted for in our extant theories.

Husserl (1982) addressed such instances where an investigator might change the focus of their inquiry by remaining open-minded to the phenomenon under investigation, "one must

have the courage to accept what is really to be seen in the phenomenon precisely as it presents itself, rather than interpreting it away" (p. 257). This approach is in contrast to the linear method that many investigators might take when learning about health care phenomena. Bracketing or consciously striving to set aside apriori knowledge is an important tenet of descriptive phenomenology that distinguishes it from some of the other qualitative methods.

Descriptive phenomenology emphasizes uncovering knowledge about human experiences from the participants alone. Bracketing encourages the investigator to become aware of their apriori knowledge and biases. The investigator must constantly reflect on how these factors could potentially bias interpretations, and take measures, to suspend premature conclusions. Bracketing strategies include prolonged engagement with participants, deep reflections on interpretations of the data, debriefing with peers that have experience with the methodology or population under investigation, and seeking the critique of informants as to the veracity of the investigator's interpretations (Husserl, 1965; Gearing, 2004). The participants are considered the experts on the phenomenon of interest being studied. Thus, parents' narratives were used as the primary source of data in this investigation (Husserl, 1965).

Sample

Forty-two parents, from 37 families were recruited from across the United States from 2005 through 2007. Several recruitment methods were used: personal solicitation at a children's hospital in Northwestern United States; national advertisement on two TBI related websites; posters placed in public locations; classified advertisements; and in the final stages a more targeted approach using mailed invitations to participants in a regional southeastern brain and spinal cord injury program and a northwestern hospital's pediatric trauma registry. Recruitment was primarily aimed at recruiting a diverse group of children. We believed that a sample reflecting diversity in the children would also result in a diverse group of parents with varied experiences.

To be included, children needed to be: (a) 6 – 18 years of age at time of injury; (b) categorized with moderate to severe TBI by GCS Score [obtained via referring clinician ($n = 17$), trauma registry scores as screened by the PI ($n = 3$), parents copies of medical reports voluntarily shared ($n = 15$), or unsubstantiated parental report ($n = 4$)]; (c) able to participate in an interview process, (d) within 4 months to 3 years post injury at the time the parents were enrolled; (e) still dependent on parent(s)/guardian(s); (f) conversant in English; (g) able to assent or consent to participation, as appropriate; and (h) living with at least one parent or legal guardian who was willing to be interviewed separately. Children were excluded if they had an additional diagnosis of spinal cord injury or significant developmental impairment prior to injury. Recruitment continued until themes were saturated and the sample reflected reasonable diversity in social demographic variables.

Procedures

Once parents expressed interest in the study, arrangements were made for a phone appointment, which allowed the investigator to explain the study's purpose, procedures, and answer questions. Verbal consent was obtained over the phone. Prior to the start of any interviews, written informed consent was obtained. Parents completed a questionnaire that focused on family/child demographics, circumstances surrounding the child's injuries, and the child's acute care and rehabilitation history. Parents participated in two semi-structured tape-recorded interviews, which lasted at least 90 minutes and took place 12 to 15 months apart.

All parents were interviewed by the same investigator in a private location of their choosing, so as not to be overheard by the child or other family members. Interviews began with an opening question: "Tell me the first thing you remember surrounding the circumstances of your child's injury"? Follow-up questions included: "Tell me about getting to the hospital"; "Tell me about your time in the Emergency room or ICU"; "Tell me about the rehabilitation hospital or outpatient experience"; and "Tell me about when you first returned home"? Parents were encouraged to elaborate on their stories with probes such as: "Tell me more about that"; "How did that feel?"; "Why was that important to you?" Interviews were tape-recorded and transcribed verbatim. Transcripts were checked by Roscigno against the recordings for fidelity. She kept extensive field notes which included observations while in the family's presence, notes taken during phone conversations, or comments freely offered by families after the tape recorder was turned off. All data were de-identified to protect the confidentiality of participants and others.

Second interviews took place over the phone or in person. Second interviews had a dual purpose: (a) to gather accounts of parents' experiences since the time of the first interview and (b) soliciting feedback on our preliminary model of those experiences. The initial model was then revised based on the collective feedback garnered in the second interviews. Using this system of member checks to refine our initial model enhanced the trustworthiness and credibility of findings (Bradbury-Jones, Irvine, & Sambrook, 2010). The parents from each family were given an honorarium of $50.00 for each of the two interviews they participated in. Parent's responses to open-ended interview questions were the primary source of data.

Analysis

Transcripts were hand-coded and analyzed using the descriptive phenomenological framework (Collaizi, 1978). To assure rigor in the analysis process and screen for potential bias or premature foreclosure on findings, the PI consulted several times with two colleagues, one an expert in phenomenological methods and the other a counselor who worked with children and families following TBI. By subjecting individual transcripts to review and drafts of the emerging model to critique, the trustworthiness and credibility of the investigator's interview techniques, data fidelity, and analysis process were enhanced (Ryan-Nicholls & Will, 2009). The final model of themes contained emphasis on the socio-cultural factors that influenced parents' and families' experiences over time and how parents reconciled the responses of others to their predicament. We believe that using a longitudinal descriptive phenomenologic approach provides much deeper insight into those factors parents' found important to their experiences than would have ever been possible had the study been designed based on extant theories or a cross sectional approach (Guba & Lincoln, 1989; Husserl, 1965).

Results

The final sample consisted of 42 parents from 37 families. Families came from 13 of the 50 United States, with the majority coming from across Washington State ($n = 15$) and Florida ($n = 11$). One parent of an adult child initially gave verbal consent to participate, but later that parent declined to be interviewed and one parent was reporting on the experiences of two siblings. Although 38 families participated in the overall study, the parent data is derived from 37 families. Participants consisted of: mothers ($n = 29$); fathers ($n = 3$); both parents ($n = 5$). Despite several targeted attempts to recruit a sample with racial and ethnic diversity, the final sample was primarily White ($n = 39$) and Non-hispanic ($n = 38$), but parents were diverse in many other sociodemographic factors. The injury severities of the children of participating parents were: severe TBI ($n = 29$ parents) and moderate TBI ($n = 13$ parents). Days spent in intensive care ranged between $1 - 60$ days ($M = 15$; SD = 14; $Mdn = 10$), whereas days spent receiving in-patient rehabilitation was reported as: none ($n = $

7); 1 to 6 ($n = 4$); 7 to 14 ($n = 4$); 14 to 21 ($n = 7$); 21 to 28 ($n = 2$); and > 28 ($n = 13$). The parent make-up of families was reported as: single parent ($n = 11$); two-parent ($n = 25$); non-biologic parent ($n = 1$). The family living settings were reported as: suburban ($n = 17$); rural ($n = 13$); and urban ($n = 7$). Parents' total family annual incomes were reported as: < \$20,000 ($n = 7$); \$20,000 to < \$40,000 ($n = 10$); \$40,000 to < \$60,000 ($n = 5$); \$60,000 to < \$ 80,000 ($n = 5$); \$80,000 to < \$100,000 ($n = 5$); and > \$100,000 ($n = 5$). The children's ages ranged from 8 – 20 years of age at their first interview ($M = 15.5$; SD = 3.4; $Mdn = 16.6$).

First interviews with parents were conducted between 4 to 36 months following the child's TBI ($M = 15$; SD = 10; $Mdn = 12.5$). Parents from 33 families participated in second interviews, which were conducted 20 to 48 months post-TBI ($M = 27$; SD = 9; $Mdn = 26$). Second interviews were often much longer (~120 minutes) because parents found they had a lot to reflect on and share at this later time point. A total of seven parents were lost to follow-up and 1 parent declined to be interviewed a second time because of a belief that the interview would stir up too many bad emotions. Of the seven families lost to follow-up in the second interviews, six had children categorized with moderate TBI and had reported that life was pretty much back to baseline at the time of their first and only interview. These families might not have been compelled to continue in the study because they thought their participation was no longer relevant.

Experiential Model

Four main parent themes were found: (a) grateful to still have my child; (b) grieving for the child I knew; (c) running on nerves; and (d) grappling to get what your child and family need. These themes, depicted in Table 1, summarize those experiences parents reported as most salient to their lives during the first five years after their children survived a moderate to severe TBI. The four themes illustrate commonalities in parents' reactions to their children's injuries and any perceived barriers or supports they experienced. The subsequent subthemes illustrate the differing ways those themes were expressed. Narrative exemplars for the subthemes are provided in the text and, where appropriate, more than one example illustrates the differences between parents either because of the child's injury severity, development, passage of time, or some other identified factor.

Grateful to still have my child—Whereas parents were well aware of the seriousness of their child's circumstances, they focused on any positive aspects of their child's health condition both initially and over time, as their child began to emerge from the coma. By focusing on the positive, parents believed they could muster the energy needed to maintain a vigil at their child's bedside, make decisions, and interact with the health care team, family, and friends.

They are alive: Initially parents focused on the fact that their child was still alive and had even some small chance to survive the injury:

> We get into the ER [emergency] room … [my child was] still on the spine board, with the neck brace, already has the ventilator tube in, and the first thing I do when I see that, is I look over to see if it's working, you know? Is [my child] still being ventilated, you know? And when I saw it was still working, I just went, "Okay. [she's] still alive."

Seeing glimpses of the child I knew: Later, as the child was progressing through the later stages of coma, parents focused on behaviors that gave them glimpses of the child's personality they knew. These same behaviors were typically seen as random or meaningless to health care providers, but they gave parents hopeful evidence that the child they knew was emerging from the coma:

> [My son] asked for a calculator. … And otherwise he was not, you know, nothing made sense. [Up until that point] like he wasn't speaking, he was non-verbal. And we said, what do you mean and he said he needed to work logarithms. So he was a math nut, so we knew that that part [of his brain] maybe was still working.

Grieving for the child I knew—Parents expressed sorrow for the child they once knew. Their grief was often compounded by their perceptions that the only conversations many providers would enter into were those that assured parents understood the gravity of their child's medical condition and future. Parents appreciated the need for the facts and negative possibilities, but they also longed for conversations where "the facts" could be interspersed with recognition for any positive things occurring that might be grounds for hope in their child's and family's future.

I did not know what to expect: Parents felt suspended in their confusion and sadness and yearned to understand more about TBI, especially what was going on with their child. Beyond TV shows where actors miraculously awoke from a coma, most parents had no frame of reference for TBI. They wanted one-on-one conversations in which medical terminology, parent education pamphlets, procedures, and recovery were explained to them by a nurse or physician who took the time to assess their understanding and answer their questions:

> She had bleeding from the brain; swelling of the brain she was in a coma, at that time … had so many fractures that they just didn't know where to begin yet. So, after a couple of days-I kept thinking, "She's just going to wake up, just like on TV [television]."

Longing for the child I knew: Some parents, particularly those whose children survived a severe TBI, were still periodically grieving, during their second interviews. They attributed their prolonged sadness to the realization that some of the changes they were witnessing in their child were likely permanent and their recognition that their child and family would chronically face the negative attitudes of some others:

> My child before the wreck she was active, very popular in school. She was a volleyball player. … She had so many plans, you know, she had scholarships. … She wanted to play Olympic volleyball. … I see her now and I look at her now and I remember what she was like before.

Parents of children with a moderate TBI, however, found that their children's recovery trajectories were not so far off from their expectations. Because their children acted like themselves much sooner, parents were able to move through their grieving more quickly. In fact, some children with moderate TBI displayed an early level of awareness that reassured parents their child as they knew them had returned and their long-term impairments seemed minor:

> The day they were moving him from intensive care to the [hospital] for rehab [rehabilitation]. … [h]e woke up that morning and I was sleeping in the little parent bed and he woke up, and he just looks at me, and he said, "Mommy, I'm sorry I wasn't careful."

Adjusting my expectations of my child: As time progressed, parents realized they had to potentially amend their expectations for their child's recovery. Providing parents the appropriate time and space to grieve and adjust their expectations was expressed as important to parents, but not always recognized as necessary or supported by some health care providers:

> You have to accept it. Doesn't mean that you agree with it, but you have to accept it. Just so you can survive and move on. … It was mainly just time and just reinforcing how happy I was to still have my daughter.

Running on Nerves—Running on nerves was the most prevalent theme throughout parents' narratives. It described the multiple internal and external sources of stress that parents had to continuously counter.

<u>**Going on autopilot:**</u> The physiological and psychological response of parents to their children's injury and the circumstances they encountered often caused parents to forgo caring for their own needs, so that they could be present and available for the child's potential or actual needs:

> I had a broken humerus; the radial nerve was severed. My lungs were bruised. … I was in extreme pain … with an arm splint, and the arm wasn't even set. … The bone, the nerves, the muscle, all that was–kept moving back and forth. Oh, yeah– I was in extreme pain. … "You're not treating me; get me out of here. I need to be with my [child]." Because I knew, the way everybody was acting, [my child's] injuries were severe. They thought [my child] was dying. … I knew I just had to get there, because I just–I just felt that pull.

> You're just whipped, you know; you have nothing left; you are on such survival—I mean I wore the same clothes … nothing mattered. People finally would say, "Well, honey, you probably should take a shower." … It'd been like four or five days; you just don't care.

<u>**They thought I knew what they meant:**</u> During the acute care period, parents described times when there were breakdowns in communication regarding the meaning of a TBI, confusions caused by the language used by health care professionals, and differences in values pertaining to their child's future opportunities. Few providers took the time to educate them oneon-one, using language they could understand, and verifying whether or not the parents actually understood all of the information that they were receiving:

> They throw words at you, like the aphasia and the other one that starts with a "d" [dysphasia] and they tell you, you know, here's, here's what the prognosis is and then you go look those things up and … you always get the impression all the time that they're in such a hurry. There must just be billions of people that they have to see and they've got to rush to the next person. It makes you feel like you don't really, you shouldn't really ask any questions, because they're not welcome, because they're just too busy.

When providers took the time to explain things in words parents could understand, verified that they understood what was explained, and were willing to re-explain if necessary, parents appraised them as caring individuals because they believed these behaviors showed an understanding of their experiences and needs. These providers were reported to stand out among others (see working with those who care).

<u>**Using all of your resources:**</u> As time went on, many parents believed that they could no longer rely on professionals to be their sole source of information. Parents began using the internet, reading various books, talking to other parents of children with TBI, and contacting friends–or even friends of friends–who had various types of expertise. Parents were sometimes skeptical about the veracity of the information that some providers gave to them because they believed that some providers were premature in deciding various opportunities or resources were not warranted for their child. At times, parents viewed the information

provided to them as somewhat biased and only focused from a medical or statistical perspective. Parents of children with severe TBI often suspected that some providers were failing to consider their child as a complete person, or that they dismissed their child as a "lesser person" now:

> They said [that] she'd need a nursing home for the rest of her life, and [they] were strongly encouraging us to put in a trach[eostomy]. For them it's kind of an "easy fix." And we were thinking, "We don't know if that's what we need." And so we started talking to everybody.

> You have to be their advocate, because no one else is going to be. … I read everything I could get my hands on, on brain injury and children, and [the] brain, and learning, and, you know–for me–that was healing to me.

<u>You have to keep pressing those that should be helping you:</u> Parents of children with severe TBI were most likely to assert that they had to have a strong backbone and stand up to the "experts" or "gatekeepers" to get the care and services that their family needed and they believed their child deserved. Although conflicts occurred around differing issues (procedures, hope, resources), in differing locations (ICU, rehabilitation, classroom, or community) with differing providers (physicians, nurses, therapists, educators, or others) cultural clashes were a commonly reported source of stress for parents:

> Once she went to the floor, the brain surgeon wasn't involved. I mean, he did his surgery, he's done; check the wound, "O.K.!" So it was like nobody was following her brain. …She wasn't waking up– we're coming up on a month–and they said, … "There's nothing else to do now. We need to put her in a SNF [skilled nursing facility]." And that's when we were kind of like. … "Well, why isn't–what have you done to her brain? I mean, what can be done?"–You know? We were like, "Oh, you don't have a neurologist, huh?" … We said, "We're not discharging our daughter to a SNF until you have a neurologist get on the team and figure out what's going on." So, they pulled one in. That was the worst day of our lives, besides the [day of the] accident. He was so negative, and so it's like, "Well, you know, it's been a month. She's not waking up, so I doubt if we're going to have a child that wakes up. We're going to have such little brain function; we're talking about probably a vegetative state." And we said, "Well, she's on a lot of meds. You think maybe she's not waking up because she's on so many meds?" And he looked, and he goes, "Well, she is on a lot of meds. Well, we could back her off." … So as soon as they took her off that, we had some wakeful times.

> [His teachers were always telling him], "You're faking it," or, "You're just looking for an excuse not to do something," or "You're just lazy," so, he's taken quite a bit of ridicule … [they were] going to fail him out of the fourth grade, or retain him in the fourth grade. …What he did do was correct. … He just can't do it as fast as they want him to do it.… I felt like it was going to be really detrimental … [to his] self-esteem, being one. It's just going to help reassure him that he's a failure.

<u>Others in the community do not understand about TBI:</u> Parents were oftentimes unprepared to handle the variety of problems and clashes of culture that occurred prior to discharge and once they went home. Many continued to have newer and more complex social issues to deal with, solve, and attempt to overcome in their community. Whereas parents did receive some support from providers, friends, co-workers, and family, they clarified that most could not endure along with them. Parents believed that others did not truly understand what it is like to parent a child following TBI or appreciate how the social

environment also shapes their family's experiences. The issues they faced were not transient but ongoing:

> Holding a regular job is, you know, almost impossible without losing it because your boss goes at some point, okay, you know, "You can't keep walking out every … couple of days, because you've got to go up to the school". … They were good with me in the first year, but as it went on, they were less willing to cooperate.

Grappling to Get What My Child and Family Need—Parent's reported that their bonds to their child are what they reported gave them the strength to become an advocate for their child, to protect the child's whole person, and to provide their child with the best possible future.

You cannot give up on your child: Parents reported that, too often, others whom they had entrusted to care for their child's needs were willing to give up, or they were too narrowly focused on how to help their child:

> Our love for our daughter just filled us with strength, because, it was unbearable, but knowing that it was up to us to preserve her future gave me tremendous strength. People said, "I don't know how you do it." It's like, "[I] didn't feel I had a choice." And I think that's what it was, is that it was, like this is my calling at this point, and this is what I will be doing.

At odds with others: Parents longed for interactions with providers that were "human to human" and considerate of their experiences and perspective as opposed to interactions and information that they often believed was based only on certain kinds of evidence:

> The first thing he said, "I'm Dr. [name].… The first thing I want to let you know is many children and adults die from the type of injury she suffered." So, I'm like going, that's not what I want to hear. And I just walked away. First of all, at 1:30 in the morning, [that approach] doesn't help! Then for that to be the first thing that came out of his mouth! I just thought his bedside manner sucked.… I walked away because I was overwhelmed.

Parents of children with severe TBI reported being even more vulnerable to how some health care providers interacted with them and how they were able to participate in the process:

> I don't know how you ever teach humanity, to understand that you actually can impact the future and progress and recovery of your patient, if you hook up with their family members…. When they [health care providers] are able to communicate, it does make a difference. We sought, aggressively, support from the medical profession for our daughter. We didn't get it willingly, but we sought it assertively, and we did get it from certain people. From others, we never did…. [They should know that parents] actually aren't sitting there, waiting for you to fix their people. They actually often want to be part of the process of bringing their loved one to health.

Working with those who care: Interactions with providers were not always negative. Parents also reported some professionals that showed compassion, caring, and really tried to be supportive to the parents' needs in whatever ways they could. "The teacher she has—I mean, they treated her really good, really good. People understand in the school that a big accident happened and what we went through."

He [the neurosurgeon] said, "We're going to have you guys work with us." And I think that's something that [hospital] did that was really good, was in almost every stage of care, they would give us jobs. So they were like, "Do this,"….But then they would teach us what they were looking for.

Architect of the positive for your child: When families returned to their communities, parents construed early on, that they had to monitor and sometimes manipulate the many layered environments within which their children interacted. Parents were aware that many others lacked knowledge about TBI and were consequently insensitive to their children's supportive needs at times:

I've become extremely protective, and very watchful, and I'm aware of, I watch people's faces when they look at him and talk to him. I try to steer things in a certain direction…. I do go at great lengths to try to make things positive around him, and if there is [a] negative, you take a lot of time trying to explain, not explain it away, but explain people and emotions and forgiveness [to my child] and things like that.

The child's stage of development also influenced how parents' implemented being the architect of the positive:

[Because of my daughter's age] I felt like I needed to step back and let this professional work with her to teach her to be a self-advocate, because that's what she needs to go forward and be successful and have a sense of confidence … her confidence has taken a real hit in this whole experience.

What about the rest of my family's needs: Parents discussed the effect that a child's brain injury, and others' reactions to his or her brain injury, had on the entire family. Parents' energy was primarily consumed in caring for and advocating for the child with the TBI, often leaving less time to talk about his or her feelings as a parent, focus on their couple relationship, or always attend to the complete needs of the siblings in the household. Parents often discussed how the family issues (couple reactions and role changes, financial, employment issues, and dealing with the psychological needs of siblings) as a whole were not dealt with during the acute care phase or when they returned home, so they believed that care was not in fact "family-centered":

We'd been at the hospital all day and you know how husbands and wives do, I just went into the bathroom. Little did I know he was in the tub sobbing like a baby and I sat down on the toilet and I said, "Do you want to talk?" and he said, "No, get out. I don't. I don't want to talk now, I don't want to talk ever," and he never has. But I felt so shut out as a wife, like it was a side of my husband that I'd never seen and it scared me, because, you know when you can't get in, you know when you feel shut out like that, you know that part of your marriage has died. When you can't connect in a time of grief like that, there's just no way that things are going to be whole.

[Her brother is] nine, you know. And the thing is, with my kids, they have all been really close…. Then we came home…. I was like, "What do I do? What do I tell him?" So I said—I just explained to him, "[Your sister] had an accident, and she has, like, a sore inside of her brain," and I said, "So sometimes she doesn't remember things, how to do things that she used to be able, used to know how to do." I said, "So we just have to kind of help her to remember how to do them" ….They went to play this game, and she wasn't playing it right, I mean, just totally wasn't playing it right…. I didn't hear him say it, but [she] said, "Mom, [brother's name] said that…. I'm brain damaged," … "and that's why I'm not playing this game right."

Searching for a community: Parents were also frustrated because no support groups were available in the communities, which were geared for children and their families. Parents longed to connect with other families that have been through this because they believed they would understand and be helpful to them in ways that others could not. Most parents actively searched, and some even attended an existing adult TBI support group, but then they realized that it was not a good fit for them, "It's so much more difficult for people to understand what it's like to have a child with a brain injury that stems from an accident…. It's sudden. And it affects you for the rest of your life."

Discussion

Parents' narratives illustrated a variety of triumphs, changes, losses, and their experiences with supports and barriers during the first five years following their children's injuries. Almost immediately, parents were thrust into a multiplicity of roles: student; medical decision-maker; ancillary caregiver; researcher; psychologist; advocate for their child and family; and teacher/interpreter for family, friends, and the community at large. As Patterson and McCubbin (1983) have described in their theory of family stress and adaptation, from the ICU to their neighborhoods, this group of parents' realities were framed by how they defined their child's injury and its implications. Parents, however, reported that their early definition was also positively or negatively constructed by their early interactions with health care providers and the community. The family's environment was also framed by the resources available to them (knowledge, private insurance coverage, family income, community support and services) and the pile-up of new and existing demands on each family (positive or negative life events involving the child with TBI or other family members, which require great time and attention).

Many parents did not accept any early negative constructions of their child's injury severity and its meaning. They believed that it was too early to predict outcomes and continued to persist to provide opportunities to maximize their child's capacity. These parents did so, however, believing that they were without adequate support or even facing opposition from those they expected to be caring and supportive. This perception of being alone in their quest to help their child added to their stress via a perception of a pile up of demands.

Particularly parents of children with severe TBI were often stretched to their maximum countering how others defined their child following their injury along with the pile-up of new demands in their lives trying to create supportive environments that met their child's particular needs. Many of the families had few resources given to them (knowledge, community services to access, or support groups) to assist them in countering the new stressors in their lives. These parents persisted and pursued to get what they needed without much or any support. In general, parents often encountered others who did not understand their experiences, and therefore did not understand the parents' perspective of advocating and hoping. Parents found that many who worked with this population needed a better understanding of what it is like for many children with moderate to severe TBI and their families to deal with the health care system; care for their whole family, live in their neighborhoods, work with the schools, engage in community activities, and rub up against differing cultural beliefs about TBI (Bronfenbrenner, 1979). Many parents found that not only was the relationship with their child changed, but as Bronfenbrenner's model suggests, the very ecology of their existence was altered, at least temporarily, by their child's TBI.

Parents believed that people who work with children with TBI do not realize the socio-cultural factors that influence everyday life and its meaning for families following TBI. They reported many misinformed responses ranging from ignorance to pity to fear, which can serve to disable children's capacity to fully participate in society and create barriers for

the parents to help their child in relevant ways that would give them a meaningful life. In an attempt to dismantle a world dismissive of their child, advocating parents oftentimes became disillusioned and likewise felt dismissed by others as being over-reactive, too sensitive, or difficult to deal with.

Cultures shape the way people interpret, respond to, and judge each other's actions and words (Philipsen, 1997; Philipsen & Coutu, 2005). Physicians and nurses brought to the acute care situation an understanding of the pathophysiology and likely bio-medical outcomes given the extent of injury. Parents brought a deep knowledge of their child and expectations for a full and rich life with their son or daughter. As more time progressed, parents began to see how many providers' beliefs and recommendations were often shaped by a biomedical culture and this culture clashed with their own. Sometimes there were some providers who understood the parents' culture and parents felt a deep appreciation. When providers took time to explain what was going on, listen to parents' expectations and explanations, and express their mutual goal to do all that was possible to help their child and family, parents felt cared for and trusted their child and family was in a supportive environment.

Parents of children with moderate TBI most often had their early expectations met with receiving encouraging information and being involved in the care of their child during the acute care phase. They reported more attitudinal barriers when they returned to their community. Parents of children with severe TBI, however, often reported that early acute care information about the injury was not always user friendly, and was negatively framed. They frequently found it difficult to get relevant and user-friendly information about their child's health status, treatments, and plans of care on a just in time basis. Parents oftentimes believed their perspective was not considered or valued in decision-making. Previous investigators have also reported that the nature of information sharing and a lack of relevant resources in acute care settings is perceived to create stress for families and add to their demands (Aitken et al., 2004; Bond et al., 2003; Clark et al., 2008; Duff, 2006; Foster & Tilse, 2003; Smith & Testani-Dufour, 2002).

There were multiple occasions when parents realized a cultural clash with providers of services in the hospital or community. For instance, the culture of medical care focuses on prevention of secondary brain injury and restoring functional ability while emphasizing limitations because of impairments. Parents looked for evidence of the child's abilities or strengths and focused on creating a supportive environment where their child could thrive to the best of his or her capabilities. When in the ICU and at their most vulnerable, parents expected others to be honest about all possibilities, however, they wanted physicians and nurses to acknowledge uncertainty in their ability to precisely predict long-term outcomes following severe TBI, so they expected them to not take their hope away.

Parents questioned why anyone would ever want to destroy their drive to help their child. They particularly doubted those few providers who outright told them their child would not have a good outcome with such certainty in the ICU, especially because they believed there were many factors influencing outcome. They also later realized the providers were incorrect in their predictions and this added to their stress because they feared for other parents who might believe what they are told. A recently published investigation also found that parents believe they must be the bearers of hope for their child (Keene, Reder, & Serwint, 2009).

Parents had to rely on others to care for their child following TBI. From the ICU, through rehabilitation, and back into the community parents of children with severe TBI often encountered negative attitudes regarding the value of investing resources to keep their child

alive, to minimize their child's impairments, or to preserve their child's rights to a meaningful life. Parents oftentimes believed that they were expected to listen to the experts (particularly health care personnel and teachers) rather than provide their knowledge and input regarding their own child. In the classroom and out in their communities, parents were particularly disturbed about the tendencies of some to judge their child's behavior as willfully lazy, rude, or manipulative. Over time, some parents witnessed their child's needs not being attended to, or believed they were being judged as over-reactive. They then felt abandoned from those they expected to be caring for their child and family, and feared for their child's future and the world their child had to navigate.

Parents' perception of their capacity to provide care and advocate for their child were very much related to their earliest interactions with the health care and school systems. Knafl and Deatrick (2003) found that the family's management of their child's chronic illness was influenced by their understanding of the illness, perceptions about their child's abilities, assessment of the work it takes to manage the child's condition, and the extent to which parents experienced the child's illness as foreground or background to the family's life. For parents in this study, perceptions of the TBI and the way the world would accept their child went back to the earliest interactions during the acute care phase. The very nature of how the injury and its likely outcome were introduced influenced parents' outlook on whether they were sharing their child's uncertain future in a supportive versus adversarial environment. Parents believed they were expected to make many decisions early on, yet most parents had no prior knowledge about the physiology of TBI, its treatments, or expected recovery trajectories. Many reported that they were given handouts, pamphlets, and books about TBI in general, yet parents said they longed for one-on-one conversations explaining such complicated information and discussing with them what was going on for their child in specifically; they wanted providers to listen to their input.

According to cognitive load theory, people learn better when they can build from existing knowledge and experiences or they are guided through any new learning activities by someone with experience (Kirschner, Sweller & Clark, 2006). Parents of children with severe TBI most often reported they had to learn a great deal of complicated information in a relatively short amount of time, all while experiencing a fight or flight response to their child's tenuous health condition, and with minimal expert guidance. Without assistance to process the pile up of complicated information, parents found it more difficult to process, retain, and synthesize it (Kirschner et al., 2006). They were forced to discern this information on their own, which added to their load and stress. The few parents who reported that providers were patient and taught them one-on-one using lay terms, answering questions, and were willing to explain things more than once, reported that they greatly appreciated this assistance and were able to understand and retain information. Parents needed to understand their child's care and all possibilities because they felt responsible to act in their child's best interests.

Parents believed they had an immense responsibility to make every reasonable attempt to provide the best future opportunities for their child. When hospitals, schools, and the community do not respond to the parents' and family's needs, the child's needs might become foreground to the parents' life. There is a growing body of literature accumulating that demonstrates how socio-cultural factors influence care decisions and create disparities or barriers for families following TBI.

For instance, third party payers play a formidable role in care decisions, which can trump the individual's actual needs (Chan et al., 2001; Hoffman et al., 2003; Tilford et al., 2005). Differing beliefs about the factors affecting children's disabilities result in unmet needs (Glang et al., 2008; Gfroerer, Wade, & Wu, 2008; Prigatano & Gray, 2007; Sharp, Bye,

Llewellyn, & Cusick, 2006; Slomine et al., 2006; Smith & Smith, 2000). A lack of relevant community support to help with meaningful social reintegration is commonly reported (Aitken et al., 2004; Armstrong & Kerns, 2002; Clark et al., 2008; Hart et al., 2006; Hawley, 2003; Jumisko, Lexell, & Söderberg, 2007; Leith, Phillips, & Sample, 2004; Wehman, Targett, West, & Kregel, 2005; Wongvatunyu & Porter, 2005). As time goes on, Wade et al. (2006) pointed out that social barriers exert more influence on outcome for people with severe TBI than injury severity. At the broader cultural level, public misperceptions about TBI have been shown to influence how individuals are allowed to be involved in meaningful social activities following their TBI (Aitken et al., 2004; Crothers, Linden, & Kennedy, 2007; Gfroerer et al., 2008; Jumisko et al., 2007; Pierce & Hanks, 2006; Prigatano & Gupta, 2006; Swift & Wilson, 2001; Winstanley, Simpson, Tate, & Myles, 2006). The accumulation of existing evidence and the stories these families provided make a strong argument for broader socio-cultural sources of disparities and stress on the parents and family. The sources of stress reach beyond the child's injury or impairments.

Limitations

These findings were derived from a sample that was limited in racial, ethnic, and language diversity; hence, caution should be used when applying findings. Given that this was a self-selected sample, some might argue that findings were more biased toward families with strong opinions or very negative experiences to convey. Parents' stated that their motivation for participating was to help other parents in the future.

Many parents' narratives from this investigation and the synthesis of existing literature, point to inconsistencies between health care and societal responses and the support needed by children and their families following TBI. Parents in this investigation believed that most people attributed their child's limitations to the TBI alone. They, however, concluded that their child's abilities and disabilities were the net result of the injury and the way others made sense of and responded to their child and family. Many parents in this study suggested that providers, researchers, and policy makers need to explore the extent to which disability is a label hoisted on a child that results in a constructed social reaction. Parents called for research that incorporates input from the children and parents who deal with the impairments and the socio-cultural supports or barriers on a daily basis.

Implications

Parents' narratives highlight that a better understanding of the attitudes, beliefs, notions, and expectations (culture) of others is needed because these factors can have both immediate and long-term negative implications on the interactions with the child, parents, and the family as a whole.

Conclusion

More qualitative research, with the families' input is needed to explore, describe, and define the ecological factors that influence their lives following children's moderate to severe TBI. Clinical and social programs that provide services for this population should consider the family members as primary sources of data to drive knowledge about their experiences, how these experiences affect adjustment, and to evaluate the relevancy of services intended to assist them.

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Biographies

Cecelia I. Roscigno, PhD, RN, CNRN, is a postdoctoral fellow in the Department of Women, Children, & Family Health Science at the University of Illinois at Chicago College of Nursing, Illinois, USA.

Kristen M. Swanson, PhD, RN, FAAN, is the Dean and alumni distinguished professor at the University of North Carolina School of Nursing in Chapel Hill, North Carolina, USA.

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Table 1

Parents' Four Major Themes and Subthemes of Experiences

Four Major Themes and Subthemes	Inductively Derived Definitions
Grateful to Still Have My Child	Parents focused on any positive signs to get through what was perceived as a threatening situation.
They are alive	Parents focused on the child still being alive as positive motivator.
Seeing glimpses of the child I knew	Parents focused on indicators of child's old self as positive motivators.
Grieving For the Child I Knew	Parents grieved actual or potential changes in their child, but needed time to process and adjust.
I didn't know what to expect	Parents have no models or experience to go by to understand coma, TBI, treatments, or recovery possibilities.
Longing for the child I knew	Parents described the grieving process they experienced because of actual or anticipated changes in their child. While grieving, however, they were also moving forward.
Adjusting my expectations of my child	Parents could transition and accept the circumstances, but needed support and time.
Running on Nerves	Parents' described their physiologic, psychological, and emotional responses to their child's injuries and the new demands placed on their family.
Going on autopilot	Parents' described their physiologic and psychological response to their child's life being threatened.
They thought I knew what they meant	Providers often used language parents did not understand, and assumed parents had prior knowledge of the meaning of having a TBI.
Using all of your resources	Parents often needed more information than they were getting and needed to know that others were considering their family; otherwise, parents searched elsewhere their information or ceased asking for help.
You have to keep pressing those helping you	Others' attitudes about TBI were the hardest to change, but parents had to advocate for their child.
You need a deeper level of support than many can give	Some people tried to be supportive, but they typically could not endure along with the parents.
Others in the community do not understand about TBI	Parents had to teach the community about TBI, or their child and family suffered the consequences.
Grappling to Get What Your Child and Family Need	Parents' experienced cultural barriers when attempting to get what their child and family needed.
You cannot give up on your child	Parents felt they have to be the ones to fight to preserve opportunities for the child.
At odds with others	The differing factors that parents and some others perceived influenced their child's outcome and future opportunities. Parents perceived that at times these differing beliefs also influenced how they were treated.
Working with those who care	Working with people that don't "get it" took too much energy, so parents gravitated to those who displayed caring and understanding.
Architect of the positive for your child	Parents attempted to create and maintain healing social environments for their children.
What about the rest of my family's needs	The family was affected by child's TBI, but this was typically not addressed in acute care or social policies.
Searching for a community	Parents searched for other families (in support groups) who would understand, but they were typically not available for children with TBI.